Dietary advice and management for people with an ileostomy

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Abstract

Background: Ileostomy formation is a common surgical procedure. Complications include high output and obstruction for which dietary management is common but not clearly defined.

Aim: To explore dietary advice and modifications for ileostomy management through investigation of the current evidence and experiences of people with an ileostomy, and healthcare professionals (HCPs).

Methods: 1) A systematic scoping review of the evidence for dietary management in people with an ileostomy, following JBI methodology. Experimental, observational, and qualitative studies were included, as well as published expert opinion from the last decade. 2) An online survey asking adults with an ileostomy about dietary advice they received and would have preferred to receive. 3) A qualitative study involving in-depth interviews with hospital-based HCPs; analysed thematically using the framework method.

Results: The review found an abundance of literature, particularly expert opinion, on dietary management for people with an ileostomy. However, this literature was highly heterogenous in terms of dietary strategies and outcomes reported. Of 291 survey respondents, 90 did not receive dietary advice; however, 82 (91%) of these would have liked advice. >1/3 of respondents experienced anxiety, confusion, and frustration relating to their diet. Stoma nurses were the most common source of dietary advice. Qualitative findings revealed differences in understanding, priorities and framing of dietary advice between professions which may contribute to conflicting information. Inter-disciplinary working increased HCP confidence in, and consistency of, dietary advice to patients with an ileostomy but varied between hospitals.

Conclusion: People with an ileostomy need better dietary advice. This could reduce anxiety and physical complications, improving quality of life and reducing burden on the NHS. To achieve this, high quality research evaluating dietary management and provision of dietary advice for people with an ileostomy is a priority to inform best practice. Findings from this thesis will inform future development of relevant and realistic dietary interventions.

299 words

Dedication and Acknowledgements

The last four years have been an incredible journey and one I could not have completed without the support of a great number of people.

I am very grateful to the NIHR Bristol Biomedical Research Centre (BRC) for providing the opportunity and funding to enable me to pursue a change in direction for my dietetic career, into the world of research. Also, for the opportunity to conduct research on a topic that has always been of great interest to me and one I had seen a clear need for in clinical practice. The Nutrition Theme of the BRC has been a fantastic place to do my PhD; the support and wisdom of this group of multidisciplinary researchers, and my cohort of PhD students, has been invaluable.

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This thesis is for all of those I have mentioned here and for all of the healthcare professionals and patients doing their best to manage gastrointestinal disease and surgery during the COVID-19 pandemic.

Author's Declaration

I declare that the work in this dissertation was carried out in accordance with the requirements of the University's *Regulations and Code of Practice for Research Degree Programmes* and that it has not been submitted for any other academic award. Except where indicated by specific reference in the text, the work is the candidate's own work. Work done in collaboration with, or with the assistance of, others, is indicated as such. Any views expressed in the dissertation are those of the author.

SIGNED: [redacted] DATE: 29/09/21

Alexandra Mitchell

CONTENTS

List of Tables and Figures

Peer-reviewed publications arising from this PhD thesis

Original research articles

Publication 1

Mitchell A, Perry R, England C, Searle A and Atkinson C., 2019. Dietary management in people with an ileostomy: a scoping review protocol. *JBI Database of Systematic Reviews and Implementation Reports*, 17(2), p.129-136.

Author contributions: AM conceptualised the review. AM, RP, CA, CE, and AS contributed to design and search strategy. AM drafted the full manuscript. CA and CE provided feedback on the manuscript. All authors read and approved the final manuscript.

Publication 2

Mitchell, A., England, C. and Atkinson, C., 2020. Provision of dietary advice for people with an ileostomy: a survey in the UK and Ireland. *Colorectal Disease*, 22(12), p.2222-2231.

Author contributions: AM, CA, and CE conceptualised the study. AM designed the online survey. CA and CE provided feedback on the survey design. AM analysed the data and drafted the full manuscript. CA and CE provided feedback on the manuscript. All authors read and approved the final manuscript.

Publication 3

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Conference proceedings

Mitchell, A., England, C. and Atkinson, C., 2020. A survey of dietary advice for people with an ileostomy. *Clinical Nutrition ESPEN*, 40, p.593.

- Poster presentation at ESPEN conference, online, September 2020.

Abbreviations and acronyms commonly used in this thesis

ACPGBI	Association of Coloproctology of Great Britain and Ireland
AKI	acute kidney injury
ASCN	Association for Stoma Care Nurses
BDA	British Dietetic Association
CCUK	Crohn's and Colitis UK
CPD	continuing professional development
ESPEN	European Society for Parenteral and Enteral Nutrition
FAP	familial adenomatous polyposis
FODMAPs	fermentable oligosaccharides, disaccharides, monosaccharides, and polyols
GI	gastrointestinal
GP	general practitioner
HCP	healthcare professional
HOS	high-output stoma
IA	Ileostomy and Internal Pouch Association
IBD	inflammatory bowel disease
JBI	Joanna Briggs Institute
MDT	multidisciplinary team
MU	monomeric units
NHS	National Health Service
NIHR	National Institute for Health Research
NSP	non-starch polysaccharides
ORS	oral rehydration solution

PPI	patient and public involvement
QoL	quality of life
RCT	randomised controlled trial
RO	resistant oligosaccharides
SCFA	short-chain fatty acid
UC	ulcerative colitis
UK	United Kingdom
USA	United States of America
WHO	World Health Organization
WOCN	Wound, Ostomy and Continence Nurses

1 INTRODUCTION

1.1 BACKGROUND AND RATIONALE

Several thousand people have a stoma placed every year in the UK, with colostomies and ileostomies being most common (Elliston et al., 2019). Gastrointestinal (GI) stomas alter bowel function and in turn may influence dietary choices. People with an ileostomy are more susceptible to diet-related problems than people with a colostomy due to having a shorter functioning GI tract (Robertson et al., 2005). Ileostomy formation is a life changing operation, which can increase quality of life (QoL) for some, e.g., people with severe inflammatory bowel disease (IBD), but also have negative consequences that people may then have to live with for many years (Morris and Leach, 2017, Petersén and Carlsson, 2021, Jansen et al., 2015). Common complications among people with an ileostomy include high stoma output and blockage (Paquette et al., 2013, Thygeson, 2021). These complications can have serious consequences in terms of physical health and QoL. Wind and odour are also common problems (de Oliveira et al., 2018, Leong et al., 1994). People with an ileostomy frequently modify their diet and report that dietary implications of their ileostomy affect daily life (Davidson, 2016, Jansen et al., 2015, Morris and Leach, 2015).

Although people have been studying dietary effects on ileostomy function since the 1970s, the research is far from comprehensive or conclusive, likely due to the complexities of isolating effects of specific dietary components, and GI differences between individuals with ileostomy. As such, there are still issues with unclear and unhelpful dietary advice being provided to people with an ileostomy. This can be a significant source of stress and confusion and prevent optimal stoma management (Morris and Leach, 2015).

Currently, there is a lack of high-quality research, and no systematic reviews have previously been conducted, evaluating the effectiveness of dietary advice and management in people with an ileostomy (Mitchell et al., 2019). The published literature provides an abundance of expert opinion articles making recommendations for dietary management of ileostomies based primarily on clinical experience (Burch, 2011a, Baker and Greening, 2009, Cronin, 2013, Burch, 2008, Medlin, 2012). However, despite many commonalities in the dietary advice advocated within expert opinion, there are also variations which can lead to confusion and frustration. This is likely complicated by the issue that certain dietary factors may be

problematic for some but pose little or no difficulty for others (de Oliveira et al., 2018), suggesting a need for individually tailored dietary advice.

Several studies, and work with our patient and public involvement (PPI) group and clinicians, suggest that diet-related advice and management is an area of priority for people with an ileostomy (Persson et al., 2005, Beeken et al., 2019, Morris and Leach, 2015, Hubbard et al., 2017, Jansen et al., 2015). However, dietary intervention for people with an ileostomy is complex in many ways (see Chapter 2.12). Firstly, the patient group is heterogeneous in terms of, for example, underlying conditions and co-morbidities (Chapter 2.3), access to health services/health professionals, psychological response to disease and surgery, age, ethnicity, and socioeconomic background (Hubbard et al., 2017, Beeken et al., 2019, Jansen et al., 2015). Secondly, outcomes relevant to ileostomy management are numerous and variable in terms of timescale (short- vs medium-term; Chapter 2.5). Thirdly, there are many potential confounding and mediating factors in the causal relationship between dietary intervention and ileostomy management (Chapter 2.9). For example, physical and psychological differences within the patient group. Fourthly, there are several potential routes for implementation of a dietary intervention for people with an ileostomy (Chapter 2.10). For example, different healthcare professionals (HCP) across acute and/or community settings. Additionally, barriers to change in dietary advice provision, from the healthcare provider perspective, and dietary habits, from the patient perspective, may be considerable. Finally, such an intervention needs to be adaptable across different service models.

In order to inform clinical practice, high-quality studies are needed investigating the effectiveness of dietary interventions for people with an ileostomy. To develop feasible dietary interventions for ileostomy management it is first necessary to understand the current landscape of evidence for, and provision of, dietary advice to people with an ileostomy. There is a need to understand what is known about dietary management for people with an ileostomy. In terms of provision of advice in practice, this involves knowing what and how dietary advice is provided, by whom, and whether this meets the needs of patients. We need to know more about the extent of variation existing in dietary advice provision for people with an ileostomy, and identify whether variations are systematic, for example by health profession, i.e., dietitian, stoma/colorectal/IBD specialist nurse, surgeon, or location, i.e., NHS Trust or geographical region. Furthermore, if dietary advice differs, it is also important to explore the perspectives and understanding of the HCPs providing the advice, to unpick why it differs. Additionally, a better understanding is required of what dietary changes people

make following ileostomy surgery and how this may be influenced by advice from multiple sources, alongside other factors such as symptoms, medication, and psychological wellbeing.

1.2 AIM AND RESEARCH QUESTIONS

The aim of this thesis is to explore dietary advice and modifications for ileostomy management through consideration of previous research, current evidence, and experiences of people with an ileostomy and healthcare professionals. This will inform theory relating to the provision of dietary advice and management for people with an ileostomy by addressing the following research questions:

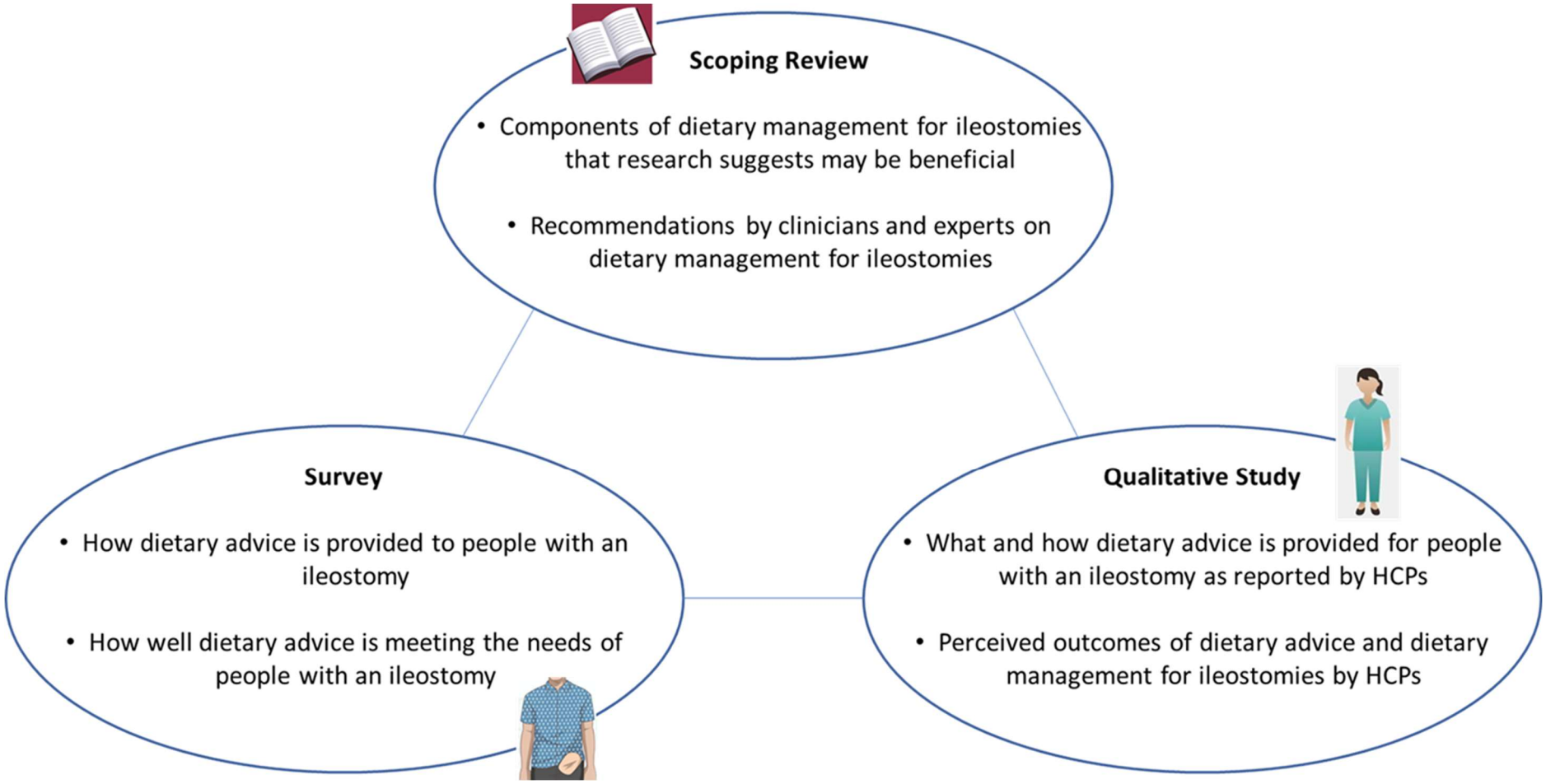
1. What published evidence is there for oral dietary management in people with an ileostomy?
2. What dietary advice is provided to people with a new ileostomy, and why?
3. How is dietary advice being provided to people with an ileostomy?

1.3 OVERVIEW OF STUDIES

I set out to achieve this overarching aim through a series of three studies (Figure 1.3.1).

Study 1: A systematic scoping review of the evidence for oral dietary management in people with an ileostomy.

The systematic scoping review maps the evidence for dietary management and advice in people with an ileostomy and identifies gaps in the evidence base. Components of dietary modification suggested by research and clinical expertise to be of potential benefit for people living with ileostomies are identified. The review also considers how, and by whom, dietary advice has been provided in previous studies and in clinical practice.



HCP, healthcare professional

Figure 1.3.1 Studies contributing to the thesis

Study 2: An online survey exploring the extent to which people with an ileostomy receive the dietary advice they require.

The online survey provides findings from a large, heterogenous sample of people with an ileostomy across the UK and Ireland. This survey identifies whether issues with dietary advice for people with an ileostomy that had been highlighted anecdotally and in small qualitative studies, such as provision of conflicting advice, are widespread across multiple demographics and conditions. Results include the prevalence of dietary advice from different sources, identifying common sources and modes of advice. The survey also investigates attitudes and preferences of people with an ileostomy regarding provision of dietary advice.

Study 3: A qualitative study to investigate current practice from the perspectives of those who provide dietary advice to people with an ileostomy.

In the qualitative study, in-depth semi-structured interviews with different HCPs, including stoma nurses, dietitians, and surgeons, explore the perspectives of the key HCPs who deliver dietary advice to people with an ileostomy; including what dietary advice they provide, and how, when, and why they provide it. Key providers of dietary advice to people with an ileostomy were identified within the acute care setting across three NHS sites in England. This study investigates the attitudes of these HCPs towards dietary advice for people with an ileostomy, and their understanding of the evidence base. Similarities and differences between professions and sites are explored. This study will provide an understanding of what current care looks like, relating to provision of dietary advice for people with an ileostomy, and how and why it might vary between individuals, professions, or institutions. This will highlight potential facilitators and barriers to implementing changes to improve provision of dietary advice and dietary management for people with an ileostomy.

1.4 THESIS OVERVIEW

This thesis aims to explore dietary advice and modifications for ileostomy management through the investigation of previous research, current evidence, and the experiences of people with an ileostomy and the HCPs who provide care for them. In this first chapter, the rationale for the thesis and contributing studies has been described, and overarching research questions for the thesis presented.

Chapter 2 describes and critiques the background literature to explain why dietary advice and management is important for people with an ileostomy, and considerations relating to provision of dietary advice. Chapters 3, 4 and 5 describe and discuss the methods and findings from each of the three studies that I conducted. In Chapter 6, a discussion is presented of how, in synthesis, the three studies contribute to answering the overarching research questions of the thesis, concluding with reflections on the implications of the thesis findings for future research and clinical practice.

Together, the findings from the series of studies included in this thesis will fill gaps in knowledge relating to 1) the nature and extent of the evidence base for dietary management in people with an ileostomy, 2) provision and need for dietary advice from the perspective of adults with an ileostomy, 3) current practice from the viewpoints of HCPs providing dietary advice to adults with an ileostomy. The new knowledge generated will enable priorities for future research to be established and inform the design of future dietary interventions and studies. It will also help clinicians to reflect on their current practice and identify ways that provision of dietary advice to people with an ileostomy might be improved.

2 BACKGROUND

2.1 CHAPTER INTRODUCTION

Dietary advice and management for people with an ileostomy incorporates the multiple components of dietary intervention, i.e., what advice is provided, how it is provided and in what context, along with how this advice is received by patients, and their diet-related behaviours and outcomes associated with these behaviours.

In this chapter, I explain the main terms and concepts relevant to the thesis and discuss the supporting literature. This includes explanation of what an ileostomy is, who may have an ileostomy and why, and how quality of life (QoL) may be impacted in people with an ileostomy. I then go on to discuss ileostomy problems and complications that may be affected by diet, dietary modifications made by people with an ileostomy, and studies that have investigated effects of dietary modification in people with an ileostomy. Potential mechanisms for a causal effect of diet modification on ileostomy outcomes are examined. Finally, I look at other factors that may influence the effectiveness of dietary interventions for people with an ileostomy. This includes factors such as ongoing disease and effects of other GI surgery and, also, how dietary advice is provided i.e., by whom, in what setting and what communication style? Implications of the complexity of dietary interventions are discussed. The chapter ends with a brief summary and consideration of the implications from the background literature discussed for the thesis.

2.2 WHAT IS AN ILEOSTOMY?

2.2.1 The gastrointestinal tract

The gastrointestinal (GI) tract consists of all the connected hollow organs of the digestive system; starting with the mouth where food is taken into the body, through to the anus where waste products are excreted in faeces. The GI tract includes the following organs in order: mouth, oesophagus, stomach, small intestine (duodenum, jejunum, and ileum), large intestine (caecum, colon, rectum), and anus. Figure 2.2.1.1 shows where different nutrients are absorbed along the GI tract. The majority of macro- and micro-nutrients are absorbed in the duodenum, jejunum, and proximal ileum. However, bile acids and vitamin B12 are absorbed in the terminal ileum, and the colon is the main site for absorption of sodium chloride,

potassium, and water. The colon is also where some fibre is digested by the microbiome (gut bacteria), producing short-chain fatty acids and gas.

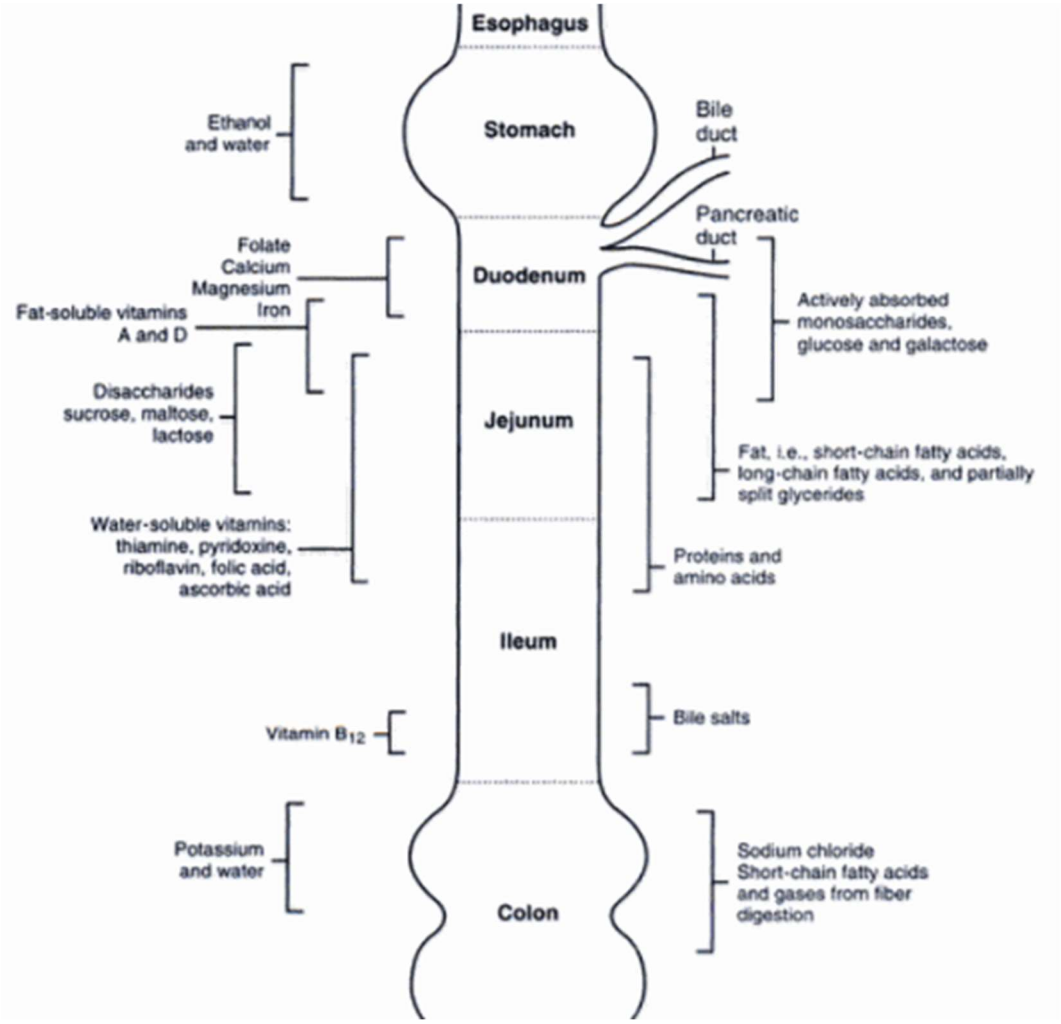


Figure 2.2.1.1 Sites of nutrient absorption in the gastrointestinal tract

(Image source: https://epomedicine.com)

The small intestine has its own less extensive but more transient microbiota composition than that of the large intestine, likely due to high sensitivity to dietary changes (El Aidy et al., 2015, Ruan et al., 2020). Streptococcus and Veillonella are consistently found in the small intestine reflecting the primary function of the small intestine microbiome to metabolise ingested simple carbohydrates (sugars). Streptococci ferment carbohydrate producing lactic acid which in turn is likely to be fermented by Veillonella (El Aidy et al., 2015).

Parts of the small and large intestines in situ can be seen in Figure 2.2.1.2. The length of the small and large intestines varies considerably between individual adults. However, the

proportions of component parts are approximately as follows. The duodenum is only 20-25cm long, while the jejunum is ~2.5m and the ileum ~3m. The small intestine joins to the large intestine where the ileum connects to the caecum at the ileocecal junction. The large intestine (caecum, colon, and rectum) totals ~1.5-2m. Overall length of intestine is increased in men, younger adults, and those with higher body weight (Hounnou et al., 2002).

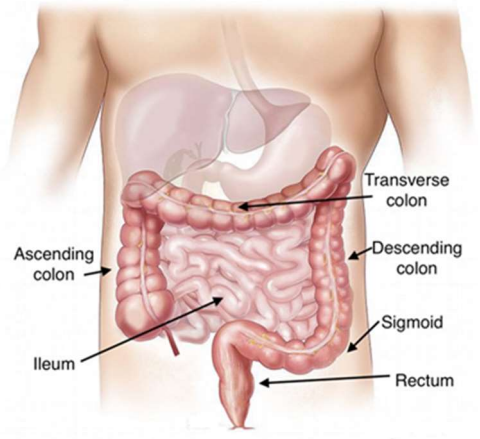


Figure 2.2.1.2 Diagram of small and large intestine

(Image source: www.woundreference.com)

2.2.2 **Intestinal output stomas**

A GI output stoma is a surgical opening in the abdomen where the end of the functioning GI tract is brought out to the surface for removal of waste products. Stomas formed low down the GI tract, from the colon (large intestine), are known as colostomies. If the stoma is formed high up in the GI tract, from the jejunum, this is called a jejunostomy. An ileostomy is a stoma formed from the ileum.

People with a colostomy still have some functioning colon, which is the primary location for fluid and electrolyte absorption (See Figure 2.2.1.1 above). They also have all of their small intestine intact for digestion and absorption of nutrients (unless they have had additional surgery to remove sections – resections – of small intestine). As a result their risk of dehydration and malnutrition is low (Arenas Villafranca et al., 2015).

When a stoma is created from the small intestine, such as a jejunostomy or ileostomy, the person no longer has a functioning colon. A person with a jejunostomy usually has less than 2 metres of small intestine remaining for digestion and absorption, and short bowel syndrome (SBS) is likely to occur (Mountford et al., 2014). SBS is a common cause of intestinal failure

and is characterised by a high, watery output and malabsorption of fluid, electrolytes (e.g., sodium, magnesium, potassium), and nutrients. Intravenous (IV) fluids and/or nutrition (parenteral nutrition, PN) are usually required to supplement or replace oral intake (Parrish and DiBaise, 2017). High-output stoma (described in detail in section 2.5) due to intestinal failure also occurs in some people with ileostomy (Baker and Greening, 2009). This thesis is concerned specifically with ileostomies since oral dietary management is most relevant for this group due to the greater risk of complications and malnutrition than with a colostomy but low likelihood of requiring artificial nutrition, as is common with a jejunostomy.

2.2.3 **Brooke ileostomy**

There are two types of Brooke ileostomy: loop ileostomy and end ileostomy, as shown below in Figure 2.2.3.1.

Figure 2.2.3.1 Loop ileostomy (left) and end ileostomy (right)

(Image source: www.salts.co.uk)

A loop ileostomy is created when part of the ileum is pulled out through the abdomen forming a loop which is then divided into two adjoined stomas. The higher stoma is the ileostomy, formed from the end of the functioning GI tract. This type of ileostomy is often temporary, for example, where the GI tract needs time to rest and heal such as after major surgery. At a later date, once the lower section of GI tract has healed, the two stomas can be freed from the abdominal wall and re-joined (Phang et al., 1999).

An end ileostomy is created when the end of the functioning ileum is brought out through the abdomen as a single stoma, while any remaining detached lower section of GI tract is sewn up and left inside the abdomen and no longer has a function. End ileostomies are often permanent, usually following removal of the entire colon, but can sometimes be reversed by re-opening the detached lower section of GI tract and re-joining it with the ileum after the end is freed from the abdominal wall (Ho et al., 1995, Fonkalsrud et al., 2000). This is sometimes

done as an alternative to a temporary diverting loop ileostomy due to the fact that an end ileostomy can be formed more easily to extend further beyond the abdominal wall making it easier to manage (particularly preferable if the ileostomy may be required for an extended period of time) and possibly the only option in some patients with obesity (Fonkalsrud et al., 2000).

Faecal matter is expelled from loop and end ileostomies but is not controlled. An external pouch (stoma bag) is worn, attached to the skin surrounding the stoma, to collect faecal waste (Figure 2.2.3.2). The stoma bag requires regular emptying, usually 4-10 times per day, and should be changed 2 to 3 times per week. Ileostomy output should be a porridge like consistency but can be liquid (Black, 1997). Depending on the length and adaptation of the remaining small intestine, ileostomy output will contain digestive enzymes along with nutrients that have not been fully digested and absorbed (Medlin, 2012, Higham and Read, 1990, Nightingale and Woodward, 2006). High or watery ileostomy output and excessive gas production are common issues and can cause problems such as leakage (where stoma output escapes from the stoma bag), ballooning (where the stoma bag bulges with gas) and skin irritation (sore skin around the stoma). Complications that can be related to or managed by diet are discussed in more detail in section 2.5.

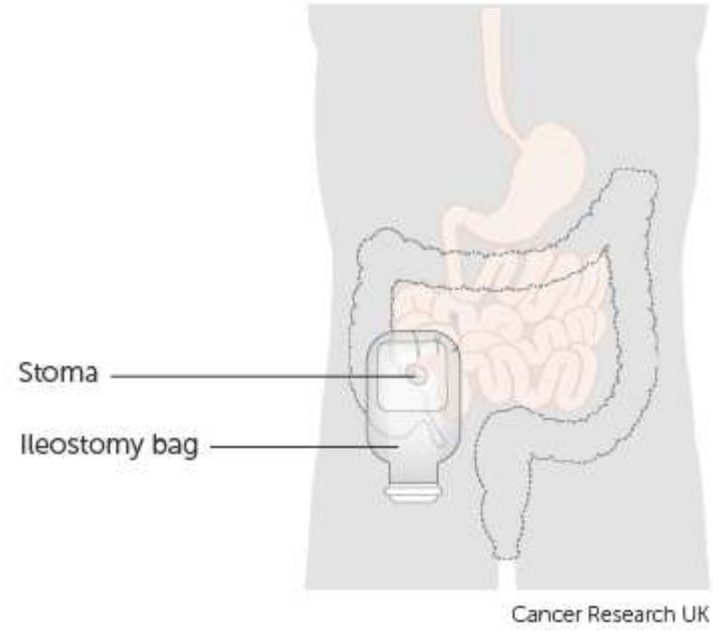


Figure 2.2.3.2 Ileostomy with stoma bag

(Image source: www.cancerresearchuk.org)

2.2.4 **Continent ileostomy (Koch pouch)**

An alternative to the end ileostomy is a continent ileostomy (also known as a Koch pouch). This procedure involves creating an internal reservoir and valve from the ileum (Beck, 2008). Faecal matter collects in the internal reservoir and requires manual emptying several times a day using a catheter (soft tube). This type of ileostomy does not require an external pouch to be worn.

The Koch pouch operation was superseded (although not entirely replaced) by the ileo-anal pouch, in the 1980s (Kirkegaard et al., 1990). Surgery to create an ileo-anal pouch (ileal pouch-anal anastomosis, IPAA) aims to retain normal function of the anus and prevent the need for a permanent ileostomy. An internal pouch is created from the end of the ileum and joined to the anus, after removal of the colon and rectum.

This thesis relates specifically to Brooke ileostomies and not continent ileostomies. This is due to the current rarity of continent ileostomies in the UK and some differences in management and complications between Brooke ileostomies and continent ileostomies, for example, drainage into a stoma bag versus manual drainage via a catheter, valve problems and pouchitis with continent ileostomy (Beck, 2008).

2.2.5 **Consequences of resection of the small intestine**

In addition to lacking a functioning colon, people with an ileostomy have varying lengths of functioning small intestine above the ileostomy depending on their previous history of small intestinal surgery. People with a history of disease in the small intestine e.g., Crohn's disease, are more likely to have had previous resections of the small intestine. This may, in turn, result in differences in susceptibility to complications.

People with an ileostomy are at risk of dehydration and malnutrition (Messaris et al., 2012). Following ileostomy formation, the ileum adapts to improve its ability to absorb fluid and electrolytes (Cisler and Buchman, 2015). However, the extent of adaptation depends on the individual, the length of small intestine remaining, and the duration of time since surgery. Excess fluid and electrolyte losses can manifest as liquid and/or high-volume stoma output (Goodey and Colman, 2016). This not only increases risk of dehydration and electrolyte disturbances but can impact on activities of daily living and QoL (Jansen et al., 2015). Effects of having a stoma on QoL are discussed in section 2.4 and ileostomy complications that can be affected by diet are discussed in detail in section 2.5.

2.3 WHO HAS AN ILEOSTOMY?

2.3.1 Reasons for ileostomy formation

Annually in the UK, >21,000 people have surgery to form a stoma i.e., an intestinal stoma (e.g. ileostomy or colostomy) or urostomy (Elliston et al., 2019). Stomas of the GI tract are created when part of the intestine needs to be removed, and/or rested to promote healing, due to disease, surgery or injury (National Health Service, 2019).

There are many reasons why a person may require an ileostomy. Common conditions requiring ileostomy formation are Crohn's disease, ulcerative colitis, and colorectal cancer (Messaris et al., 2012). Other conditions that may require ileostomy formation include Familial Adenomatous Polyposis (FAP), trauma/perforation of the colon and/or ileum, bowel obstruction, necrotizing fasciitis, and diverticulitis (Pine and Stevenson, 2014).

2.3.2 Inflammatory bowel disease

Crohn's disease and ulcerative colitis are types of inflammatory bowel disease (IBD). Severe flare-ups of inflammation cause pain, malabsorption, and diarrhoea, and in the long-term can lead to malnutrition, fistula (an abnormal opening connecting to another organ/space), scarring (strictures) and bowel obstruction (Veauthier and Hornecker, 2018). Crohn's disease can affect anywhere along the GI tract while ulcerative colitis only affects the colon and rectum, and inflammation is continuous along the intestine tract from the rectum. Where IBD cannot be appropriately controlled with medication, surgery may be considered to remove and/or rest the diseased part(s) of the intestine. This may result in the formation of a stoma.

2.3.3 Colorectal cancer and other bowel disease

In colorectal cancer, surgery is carried out to remove the cancerous tumour(s) from the colon and/or rectum. The surgery required depends on the location and size of the tumour. If the whole colon needs to be removed, then a total colectomy is performed, and an ileostomy formed. If a hemi-colectomy is required and only part of the colon removed, an ileostomy is sometimes formed as part of this surgery (Hanna et al., 2015). If lower bowel is still in situ, then the ileostomy may only be needed while this heals from the surgery. Colostomies are also common in people with colorectal cancer.

FAP is a hereditary disease, causing benign growths (polyps) in the colon. Although the growths are initially benign, there is a very high risk that at least one will become cancerous; therefore, people with FAP are commonly recommended to have preventative surgery to

remove their colon (Vasen et al., 2008). Preventative or curative surgery may involve formation of an ileo-anal pouch or lower anterior resection, with temporary ileostomy, or formation of a permanent ileostomy. Other bowel disease, such as diverticulitis or necrotizing fasciitis, may cause bowel obstruction (due to inflammatory stricture) or severe infection requiring colectomy and ileostomy formation (Pine and Stevenson, 2014).

2.3.4 Temporary or permanent ileostomy

If the colon must be totally or partially removed (total or partial colectomy), a permanent or temporary ileostomy may be required, respectively (Pine and Stevenson, 2014). A temporary (de-functioning) ileostomy is formed at the same time as partial colectomy is performed to protect the new anastomosis(es) while it heals. Later, the ileostomy is reversed, and the colon re-joined to the functioning GI tract. Temporary ileostomies are usually in situ for a few months, and sometimes longer, prior to reversal (Neuman et al., 2011).

2.4 QUALITY OF LIFE IN PEOPLE WITH AN ILEOSTOMY

2.4.1 Impact of stoma on quality of life

Ileostomy formation is a major surgical procedure with long-term implications for body image, activities of daily living, work and social life (Petersén and Carlsson, 2021). Focus groups conducted with participants with colostomy or ileostomy highlighted how having a stoma increased uncertainty around body (bowel and sexual) function and appearance. People with a temporary stoma spoke of 'putting life on hold', while those with a permanent stoma managed the uncertainty by changing their perspective as well as how they went about particular activities. These adjustments helped increase their feelings of control and confidence (Petersén and Carlsson, 2021).

A study in Germany showed that Global and GI QoL were significantly impaired in a large sample of people with permanent ileostomy (82% IBD, 7% colorectal cancer) compared to the general population (Schiergens et al., 2017). Of the 1434 respondents to the cross-sectional survey, 63% reported that stoma-related complications affected their QoL. Associations between vitamin B12, iron, and zinc deficiency and reduced QoL were also found.

Global and stoma-specific QoL have been assessed in a longitudinal study of 60 colorectal cancer patients who underwent surgery that included formation of a temporary diverting loop

ileostomy (Neuman et al., 2011). Global QoL was good and comparable to that of the general population. Results from the stoma quality of life (SQOL) questionnaire showed higher overall QoL compared to the broader population of people with a stoma included in the SQOL validation study (Baxter et al., 2006). This suggests that a temporary ileostomy may have less impact on QoL than a permanent stoma. Exploratory analysis of individual items included in the SQOL questionnaire indicated that common difficulties faced by colorectal cancer patients with a temporary ileostomy were sexual activity, concerns about leakage, discomfort in clothing and concerns relating to appearance. The findings from the focus groups study described above suggest these common difficulties are similar for people with a permanent stoma (Petersén and Carlsson, 2021).

2.4.2 **Quality of life with a stoma in IBD and cancer patients**

A mixed-methods study compared QoL in cancer and non-cancer patients with a stoma (ileostomy or colostomy) (Jansen et al., 2015). The study recruited participants from the Dutch Ostomy Association (n=668) to complete a generic and a specific QoL questionnaire and answer free text questions. Non-cancer patients, including people with IBD, commonly reported being relieved of symptoms such as diarrhoea, and being able to participate in more activities that involved leaving the house following stoma formation. In contrast, cancer patients with a stoma did not describe any positive influences on daily life within their 10 most common reported themes. This shows how stoma formation may impact cancer and IBD patients differently, both physically and psychologically, due to their different health experiences and condition or treatment-related symptoms. Interestingly, the quantitative data from this study, when adjusted for confounders, showed that cancer patients with a stoma had a better global QoL compared to non-cancer patients with a stoma, except in the mental health domain. Stoma-specific QoL was also higher in cancer patients but the difference between groups was small (61.7 versus 59.7, p=0.04). It is important to note that the majority of participants in the non-cancer group had an ileostomy (63%) while in the cancer group most participants had a colostomy (74%).

These findings support the theory that for cancer patients having a stoma is unlikely to lead to any positive change in their daily life, while for IBD patients having a stoma may improve their ability to carry out daily activities compared to when they were living with IBD. For example, IBD causes diarrhoea and increased urgency which can make leaving the house very difficult and is highly anxiety provoking (Lönnfors et al., 2014). People with a recent

colorectal cancer diagnosis may not have had severe symptoms prior to surgery and stoma formation.

QoL before and after ileostomy creation has been investigated in a recent qualitative study (Morris and Leach, 2017). In-depth interviews were conducted with 10 people with an ileostomy and themes identified using interpretative phenomenological analysis. Two major themes were reported: 1) being controlled by Crohn's, and 2) transition to a new life with an ileostomy. These themes reflect the severity of the impact Crohn's disease can have on daily activities and QoL, and the improvements in QoL that ileostomy formation can provide by reducing GI symptoms and increasing ability to carry out daily activities. Participants spoke of how ileostomy formation enabled them to regain control in their life that previously had been taken from them by the Crohn's disease.

IBD patients are more likely to have an ileostomy formed while cancer patients are more likely to have a colostomy. Ileostomy output is looser than that from a colostomy and there is a much greater risk of high output and dehydration. Therefore, although IBD patients are more likely to see an improvement in QoL following stoma formation, their daily functioning and health may still be affected to a greater degree than cancer patients. For cancer patients, QoL may be lower for those with an ileostomy, compared to colostomy, due to looser output and greater risk of high output and other complications e.g., leakage, pain, blockage, or obstruction.

In the mixed-methods study, a list of top 10 factors impacting daily life were identified using content analysis. For cancer patients, impact on sexual relationships was a common issue, but not for non-cancer patients. Diet was highlighted as one of the top 10 factors impacting daily life for both groups, along with fatigue, leakage, pain, bowel complaints, clothing, physical functioning and difficulty performing daily activities (Jansen et al., 2015).

2.4.3 **Diet-related aspects of quality of life with a stoma**

In a small qualitative, phenomenological study where six people with Crohn's Disease and ileostomy were interviewed, participants reported receiving dietary advice from dietitians and nurses (Morris and Leach, 2015). The findings suggested that there was variation in advice between and within professions. Participants expressed cautiousness when eating out due to concerns about the effects on their stoma. These concerns about eating in public were reflected by people with a stoma in another qualitative study using similar methods to explore the experiences of people with colorectal cancer after surgery (Burden et al., 2016).

Participants in both qualitative studies identified ‘trial and error’ as informing their dietary choices (Burden et al., 2016, Morris and Leach, 2015). Furthermore, a qualitative study of people undergoing colorectal surgery within an Enhanced Recovery After Surgery (ERAS) programme reported that those with a stoma found managing their diet challenging and were confused by contradictory dietary advice they received (Short et al., 2016).

In summary, ileostomy formation is a life changing surgery affecting body image and function. For some people, such as those with IBD, bowel function may be better controlled after ileostomy formation, leading to an improvement in some aspects of QoL. However, for other people, such as those requiring ileostomy formation to treat colorectal cancer, bowel function may be more difficult to manage compared to prior to surgery and is likely to impact on QoL. Diet is an important factor affecting daily life for people with a stoma (ileostomy or colostomy) due to its effects on stoma function (Jansen et al., 2015). Contradictory advice on diet may contribute to confusion and difficulty with managing their diet for people with an ileostomy.

2.5 DIET-RELATED OUTCOMES IN ILEOSTOMY MANAGEMENT

Management of GI output stomas aims to prevent or treat complications and problems including high-output, loose output, blockage/obstruction, wind, and odour. Components of ileostomy management can include medication, e.g., Loperamide to slow GI transit, fluid management including oral isotonic fluids and oral rehydration solutions (ORS) as well as IV fluids for acute dehydration, and dietary management such as a low fibre diet to reduce stoma output and risk of blockage (Mountford et al., 2014, Cronin, 2013).

Table 2.5.1 describes common ileostomy problems and complications that may be prevented and/or treated with appropriate dietary management.

Table 2.5.1 Ileostomy problems and complications that may be affected by diet or resolved with dietary management

Problem	Definition	Causes	Consequences
High-output stoma	A high volume of output from the ileostomy ≥ ~1500ml / 24 hours (definitions vary between 1000-2000ml / 24 hours)	▪ Intermittent bowel obstruction ▪ Crohn's disease ▪ Short bowel syndrome ▪ Malabsorption disorders ▪ Intra-abdominal sepsis ▪ Enteritis ▪ Prokinetic medications ▪ Withdrawal from steroids	▪ Leakage ▪ Dehydration ▪ Electrolyte abnormalities ▪ Acute kidney injury (AKI) ▪ Malnutrition
Dehydration	Fluid losses exceed fluid absorbed by the body	▪ High-output stoma ▪ Malabsorption ▪ Insufficient fluid intake to replace additional losses e.g., vomit, sweat	▪ Electrolyte abnormalities ▪ Acute kidney injury (AKI)
Electrolyte abnormalities	Abnormally high or low blood serum levels of sodium, potassium, magnesium, phosphate, or calcium	▪ High-output stoma ▪ Malabsorption ▪ Dehydration ▪ Insufficient intake to replace additional losses e.g., vomit, sweat	▪ Seizures ▪ Irregular heartbeat *If abnormalities become severe:* ▪ Coma ▪ Cardiac arrest
Acute kidney injury (AKI)	Sudden onset of kidney damage and impaired kidney function If treated effectively, kidney function can return to baseline function	▪ Dehydration ▪ Kidney stones ▪ Sepsis ▪ Ischaemia	▪ Electrolyte abnormalities *If severe:* ▪ Chronic kidney failure ▪ Seizure ▪ Coma
Blockage/obstruction	Partial or total blockage of the stoma or small intestine	▪ Stomal stenosis (narrowing at the stoma site) ▪ Stricture (narrowing due to swelling or scarring) of the small intestine ▪ Adhesions (areas of scar tissue that stick together) of the small intestine	▪ Abdominal pain ▪ Vomiting ▪ Constipation and diarrhoea ▪ Dehydration ▪ Damage to small intestine
Gas and odour	Excessive gas production from the small intestine Bad smelling gas and/or output from the stoma	▪ Consumption of certain foods or drinks ▪ Enteritis	▪ Leakage ▪ Abdominal pain

Information in this table was informed by the following articles: (Delrio and Conzo, 2008, Ahmad et al., 2019, Bellomo et al., 2012, Rassam and Counsell, 2005)

High-output stoma (HOS) has not been consistently defined but is usually considered as an output greater than 1-2 litres per day (Goodey and Colman, 2016, Medlin, 2012, Mountford et al., 2014). High and/or loose stoma output are common problems for people with an ileostomy, particularly in the days or weeks immediately following surgery (Baker and Greening, 2009, Burch, 2011a, Baker et al., 2011). This is due to the absence of the large bowel which, as described in section 2.2, is normally where most fluid and electrolytes, i.e., sodium and potassium, are absorbed. The remaining bowel will adapt to improve absorption, but how well this happens varies between individuals and depends on the length of bowel remaining intact after surgery (Baker and Greening, 2009). High or loose output may contribute to leakage from the stoma. In a survey of 256 people with a stoma living in Ireland (of which 197 had an ileostomy), 86 (35%) reported leakage to be a moderate or severe problem for them (Davidson, 2016).

Potential consequences of uncontrolled high output include dehydration, acute kidney injury (AKI), and malnutrition (Medlin, 2012, Arenas Villafranca et al., 2015). Severe complications, including persistent high-output or obstruction, may require hospital admission for treatment including IV fluids, electrolyte replacement, and, in some cases, further surgery (Burch, 2011a, Arenas Villafranca et al., 2015). After ileostomy formation, 60-day readmission with dehydration ranges from 7.3%-14.1% (Liu et al., 2021), and in a study from the USA, all-cause 30-day readmission was 30% (Justiniano et al., 2018). Stoma-related complications can be a considerable burden in terms of QoL, time and resources to both the individual and to healthcare systems such as the NHS (Kwiatt and Kawata, 2013).

Although wind and odour are natural consequences of GI function, the increased social implications in people with a stoma, e.g., ballooning of the stoma bag or leakage, can have a negative psychological impact and effect on QoL (Nugent et al., 1999). Half of respondents to the survey of people with a stoma conducted in Ireland reported gas/wind to be a moderate or severe problem for them (Davidson, 2016).

Dietary advice is commonly provided as an important component of stoma management (Burch, 2011a). People with an ileostomy may be advised to restrict fibre intake to prevent blockage and high-output (Burch, 2011a, Burch, 2017, Arenas Villafranca et al., 2015), and to add salt to their meals to replace losses in their stoma output (Cronin, 2013, Arenas Villafranca et al., 2015). Fluid restriction and ORS may be used to manage high output (Goodey and Colman, 2016, Arenas Villafranca et al., 2015). White starchy carbohydrates,

for example rice, pasta and bread, and gelatine-containing sweets, for example marshmallows and jelly sweets, are recommended to thicken stoma output (Burch, 2011a, Cronin, 2013). Additionally, it is often advised to avoid specific foods and drinks to control wind and odour from the stoma (Burch, 2011a, Piras and Hurley, 2011). This type of dietary advice is recommended and reported extensively within expert opinion literature, particularly the nursing literature.

2.6 EVIDENCE OF DIETARY MODIFICATION IN PEOPLE WITH AN ILEOSTOMY

Several observational studies have described dietary advice and modification experienced by people with a stoma including those with an ileostomy. Questionnaires have been used to provide data specifically relating to people with an ileostomy in the UK, but none recently (Thomson et al., 1970, Bingham et al., 1982). The most recent cross-sectional study of dietary modifications in people with an ileostomy was conducted in Brazil and published in 2018 (de Oliveira et al., 2018).

A survey of people with a stoma in Ireland, most of whom were approached as members of the Ileostomy Association (IA), found that, of 256 respondents (197 with ileostomy), 141 (55%) had adjusted their diet, 69 (27.6%) avoided eating vegetables, 80 (32%) avoided fruit, and 125 (49.6%) avoided fizzy drinks due to their stoma (Davidson, 2016). Similarly, in a survey of people with a stoma, distributed through ostomy support groups in the USA, 117 out of 174 respondents with an ileostomy (67.2%) reported that their stoma affected what they eat (Richbourg, 2012).

Three observational studies have investigated potential associations between diet and ileostomy symptoms. A large study of 952 IA members in 1970 asked participants to identify if they associated certain problems with their ileostomy with individual foods and drinks listed in a questionnaire (Thomson et al., 1970). Many items were reported to affect ileostomy function by some participants, with onion, fish, rhubarb, and alcohol appearing to affect the greatest proportion of people with an ileostomy. For example, 165 participants (23.2%) associated alcohol, and 236 participants (33.4%) associated rhubarb, with watery output; 13-39% of participants associated onions with watery flow, flatulence, pain, and odour; 28-38% associated fish with odour. However, the authors of that study concluded that people with an ileostomy should not remove any specific food from their diet unless they had

found it to be repeatedly problematic. This conclusion was based on the finding that no specific food or drink was identified as problematic by a majority of respondents.

Another study recruiting IA members carried out interviews with 79 participants (Bingham et al., 1982). These were structured interviews where participants were asked about the effect of 200 food items on ileostomy function. Of the 79 participants, 39 also completed 7-day weighed food and drink diaries to provide full dietary assessment. A healthy control group of similar size provided comparison of dietary intake. Analysis of food diaries found that participants with an ileostomy consumed less fruit and vegetables compared to healthy controls (206g/d v 303g/d). In contrast to the previous study (Thomson et al., 1970), several foods were reported by a majority of people with an ileostomy to adversely affect ileostomy function: nuts; pips, pith, seeds, skin of fruit and tomatoes; onions; beetroot; lettuce; raw cabbage and carrot; peas; sweetcorn; mushrooms; raisins, currants, sultanas (Bingham et al., 1982). In addition, reported salt and fluid intake was significantly higher in participants with an ileostomy compared to healthy controls.

More recently, a cross-sectional study of dietary intake and food avoidance, using questionnaires, was carried out with a sample of 103 people with a stoma (40 ileostomy; 63 colostomy) in Brazil (de Oliveira et al., 2018). In that study, only a relatively small proportion of people with an ileostomy or colostomy reported avoidance of any one particular food for a specific reason related to their stoma (≤ 20% due to high output; ≤ 30% due to gas or odour). Vegetables were the most commonly reported foods to be avoided by people with an ileostomy for any stoma-related reason, but dairy foods were slightly more likely to be avoided due to increased output (dairy, n=7 (17.5%); fruit, n=6 (15%); vegetables, n=5 (12.5%)).

The findings from these observational studies show that dietary modification and avoidance of certain foods are common amongst people with an ileostomy although the specific dietary modifications vary hugely between individuals. High fibre fruits and vegetables are most commonly reported to adversely affect ileostomy function and be avoided by people with an ileostomy.

2.7 EVIDENCE OF CAUSAL ASSOCIATION BETWEEN DIET AND ILEOSTOMY FUNCTION

Although dietary management is commonly used in clinical practice for people with a stoma and, as seen in section 2.6, people with an ileostomy frequently modify their diet; there is a scarcity of evidence to inform the dietary advice given (Baker, 2015). Research on dietary management for people with an ileostomy is limited and there are no large-scale, high-quality randomised controlled trials (RCTs) (Mitchell et al., 2019). Practice is informed, in the main, by clinical experience and a small number of cross-sectional studies (Baker, 2015). Some specific components of dietary management, such as oral rehydration solutions (ORS), marshmallows, and low fibre diet, have been tested in small-scale experimental studies (Clarebrough et al., 2015, Chalkia et al., 2016, Arenas Villafranca et al., 2015, Mogos et al., 2015), but these studies are heterogenous and low-quality.

For example, despite ileostomy patients being commonly advised to consume marshmallows, only two studies, one of which was a small pilot study, have investigated the use of marshmallows to thicken and reduce ileostomy output (Clarebrough et al., 2015, Donoghue et al., 2009). Both studies investigated the effect of consuming three marshmallows three times a day for one week. Although the pilot study reported a clinically significant reduction in output with marshmallow consumption (1863ml/day versus 1476ml/day), there were only eight participants and it was not powered to detect a difference in output (Donoghue et al., 2009). Following this, Clarebrough et al. (2015) carried out a randomised crossover trial including twenty-eight people with an ileostomy which found a statistically significant reduction in output. Although this was a small sample, a sample size calculation suggested that this study was adequately powered. However, individual response to the intervention was highly variable and median reduction was only 75ml per day (95% confidence interval, 23-678). Ileostomy output was measured by the participants themselves which may have introduced bias due to individual error potentially influenced by pre-conceptions of the effectiveness of the intervention. Most participants in this study did not have HOS (median output without marshmallows was 742ml/day), limiting generalisability of the findings to people with a high output. Also, both studies only investigated the effect of marshmallow consumption for 1 week, therefore the effect on output over a longer period of time is still unknown.

Arenas Villafranca et al. (2015) conducted a prospective, cohort study with 43 ileostomy and colostomy patients to identify incidence of early and late HOS following surgery, and to

investigate the use of a protocol (including fluid, dietary, and medical management) for management of HOS. Early HOS was defined as a stoma output ≥1500ml for two consecutive days within 3 weeks of stoma formation. Late HOS was defined as a stoma output ≥1500ml for two consecutive days at least 3 weeks after stoma formation. Seven (16%) of the cohort were identified with early HOS, and six (14%) with late HOS. All of the patients with early HOS had an ileostomy, as did five of the six with late HOS (the other had a colostomy). Five of the seven patients with early HOS received medication, i.e., Loperamide, and dietary advice to reduce output, as per the clinical protocol, and their HOS resolved following this intervention (Arenas Villafranca et al., 2015). Dietary advice included in the protocol was to restrict oral fluid intake to 500-1000ml per day, avoid fluid intake during meals, increase salt intake in food, and avoid insoluble fibre. Although the HOS resolved following intervention, as there was no control group it cannot be ruled out that the HOS would have resolved in the same period without intervention. Furthermore, because the intervention involved both medical and dietary management, it is not possible to identify how much, if any, each component of the protocol contributed to the resolution of the HOS. In addition, the very small numbers involved prevent generalisable conclusions from being drawn from this study alone.

2.8 POTENTIAL MECHANISMS FOR DIETARY EFFECTS ON ILEOSTOMY FUNCTION AND MANAGEMENT

2.8.1 High output ileostomy

When a patient has high output (see Table 2.5.1 above), dietary management aims to slow intestinal transit time and thicken output. Most patients will have a high output in the immediate period following surgery to form an ileostomy. Based on normal intestinal fluid transport (Figure 2.8.1.1), an ileostomy output of 1-1.5L per day is expected and has been observed (Rowe and Schiller, 2020). However, usually, the ileum adapts over the days and weeks following surgery and output reduces to <1L per day. The terminal ileum has the greatest capacity for adaptation of the intestinal mucosa (inner wall); therefore, the greater the length of distal ileum resected, the increased risk of poor adaptation and impaired recovery of GI absorptive capacity. Patients with larger ileal resection are more likely to have ongoing problems with high output due to malabsorption. Fibre and fluid modification are common components of dietary management used to slow transit time and reduce fluid losses. Fat and

some artificial sweeteners may reduce absorption and have a laxative effect. Possible mechanisms for a causal relationship between diet and stoma output are discussed below.

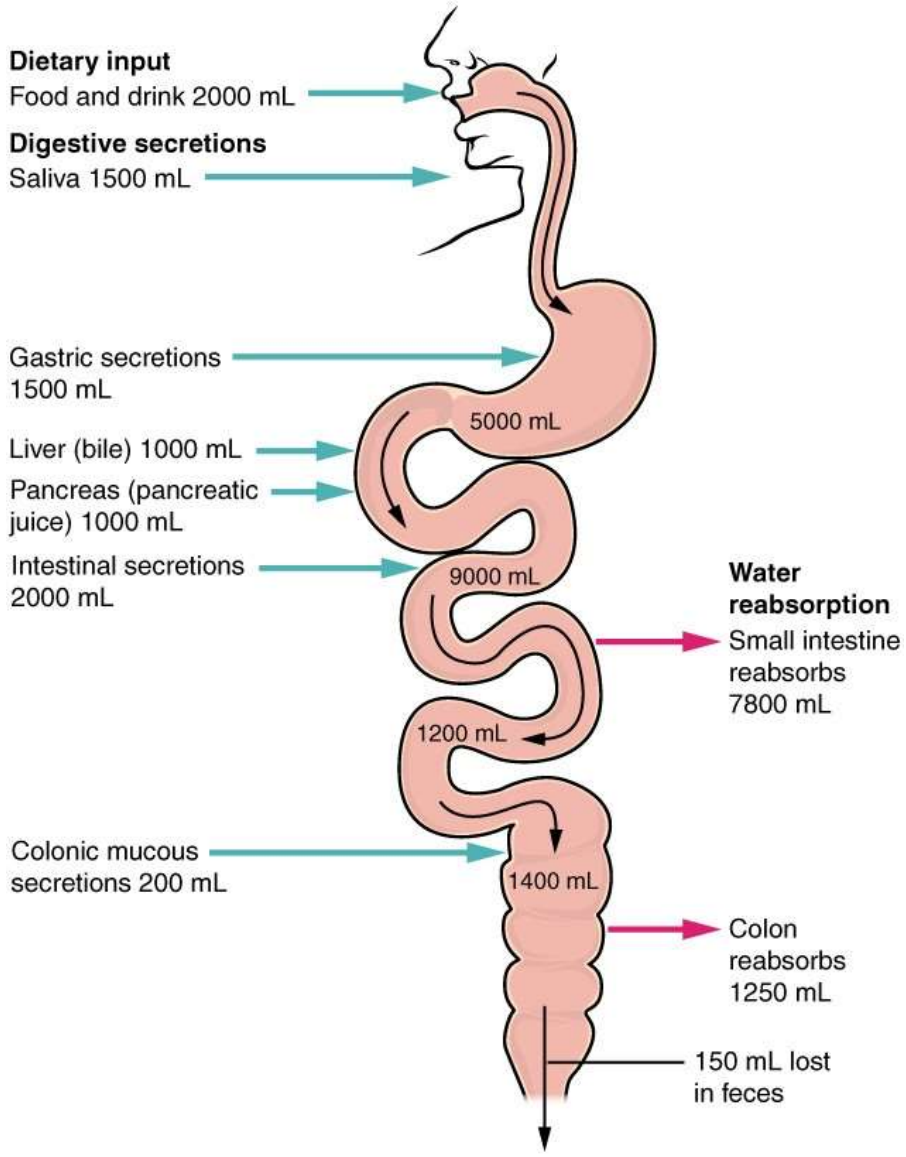
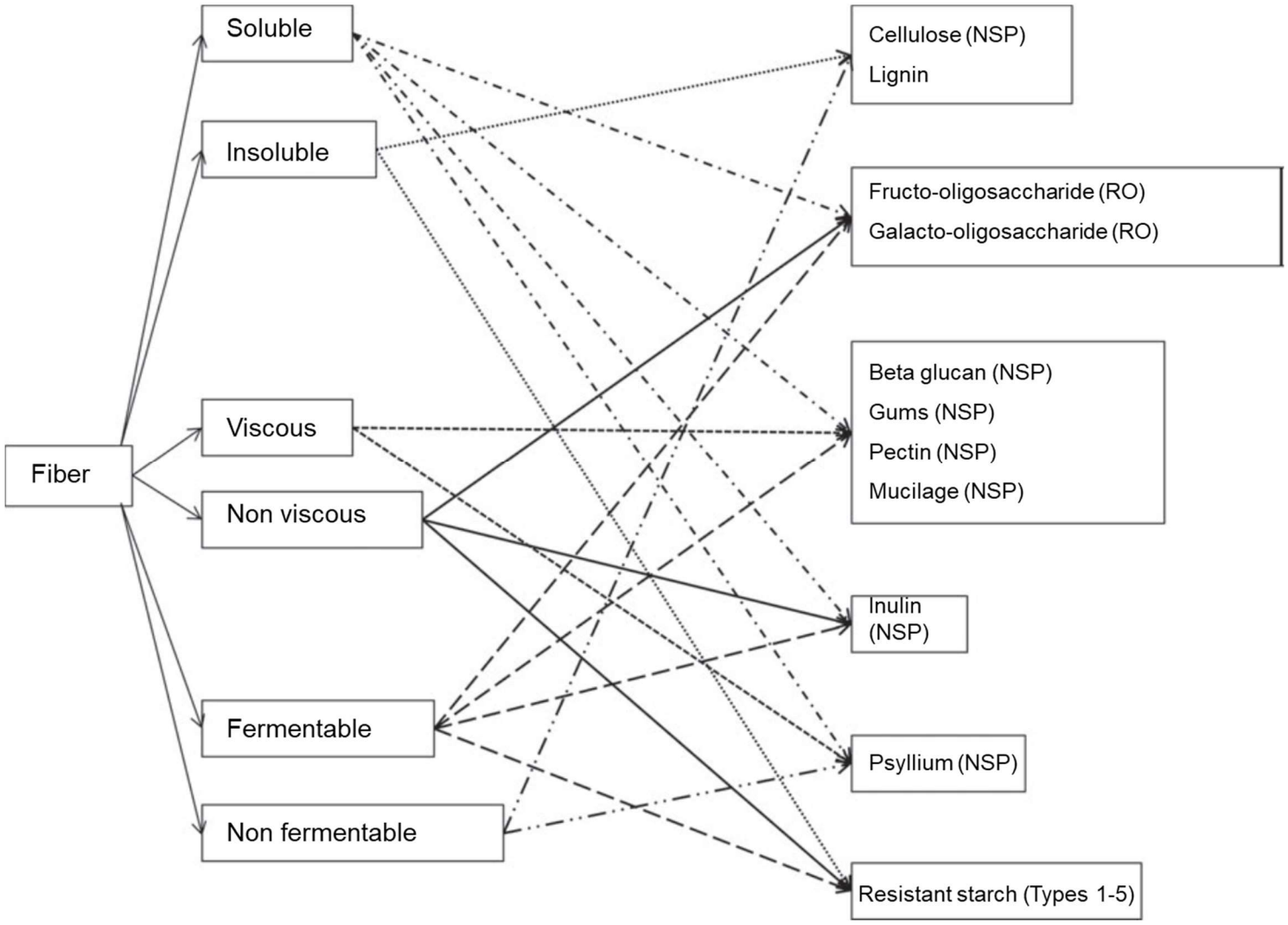


Figure 2.8.1.1 Digestive secretions and fluid absorption

(Image source: Anatomy & Physiology. Provided by: OpenStax CNX. Located at: http://cnx.org/contents/14fb4ad7-39a1-4eee-ab6e-3ef2482e3e22@8.25.)

2.8.2 **Fibre**

Fibre is plant-derived carbohydrate that humans are unable to digest (O'Grady et al., 2019). Fibre is not all the same, having various physiological effects, and can be categorised in several ways (Figure 2.8.2.1). Most commonly in the past, fibre has been divided into two types based on its solubility: insoluble and soluble.



NSP, non-starch polysaccharide (MU ≥10)

RO, resistant oligosaccharides (MU 3-9)

MU, monomeric units

Figure 2.8.2.1 Fibre sub-types by solubility, viscosity, and fermentability. Adapted from O'Grady et al. (2019)

Insoluble fibre maintains its physical structure which stimulates the gut mucosa to increase secretions and peristalsis thereby reducing transit time. Soluble fibre is defined by its ability to dissolve in water. This solubility enables the fibre to create a gel with viscous consistency; however, not all soluble fibre is viscous. Soluble fibres that are also highly fermentable, e.g., inulin, are rapidly fermented once they dissolve and therefore non-viscous (O'Grady et al., 2019). It is the viscosity that determines the effect of the fibre on consistency and nutrient absorption and is therefore a key property to consider when considering fibre intake. Viscous fibre acts as a thickener and may delay gastric emptying and increase transit time (Mudgil and Barak, 2013). It is for this reason that soluble fibres, such as psyllium and guar gum, are sometimes recommended for people with an ileostomy who have loose, high output (Rowe and Schiller, 2020). However, variations in viscosity and fermentability of different soluble fibres may require advice to focus on specific sub-types of fibre rather than recommendations to increase soluble fibre.

The following studies investigated psyllium and guar gum specifically. In one study where a treatment group (n=20) were prescribed 7g psyllium fibre per day and compared to controls (n=18), ileostomy output was significantly reduced in the treatment group (-322ml/d vs -95ml/d i.e. ~1 bag less per day in the treatment group vs controls) (Crocetti et al., 2014). In a separate study investigating the effect of guar gum (15g per day for 5 days) using a randomised crossover design (n=5), no significant difference in transit time was seen (although mean transit time was reduced with guar gum i.e. 8.6 hrs vs 11.9 hrs), and viscosity of ileostomy output reduced despite guar gum being a viscous fibre (Higham and Read, 1992). Fat absorption also reduced with ingestion of guar gum, and protein, sodium and water losses increased, coinciding with an increase in output volume. The second study had only a very small sample size of five participants limiting the strength of these findings.

The authors of the second study described above expressed surprise that the viscosity of ileostomy output was reduced with guar gum ingestion (Higham and Read, 1992); however, this finding makes sense in the context of the knowledge that gums, although viscous, are also fermentable. This would explain both the lack of viscosity seen in the ileostomy output as well as reduced nutritional absorption which may have been caused by increased viscosity in the proximal small intestine (prior to significant fermentation) impairing the contact of nutrients with pancreatic secretions and the intestinal epithelium (Higham and Read, 1992). Another possible explanation, offered by the authors of that study, was that an increase in

digestive secretions, due to delayed nutrient absorption, diluted and altered the consistency of the guar gum mixture thereby reducing its potential to thicken output.

In recent years, the fermentability of fibre has been identified as an important property particularly for the management of irritable bowel syndrome (IBS) and potentially for other bowel disorders (Algera et al., 2019). Resistant oligosaccharides are small and soluble making them highly fermentable (O'Grady et al., 2019). The fermentation process releases energy from the previously undigested carbohydrate (fibre) and produces short-chain fatty acids (SCFAs) and carbon dioxide (CO_2) (Bernalier-Donadille, 2010). Therefore, consuming more fermentable fibre will increase gas production. As such, reducing intake of fermentable fibre could be beneficial for people with an ileostomy who are having problems with excessive gas production.

One study used magnetic resonance imaging (MRI) to investigate the effect of lettuce and rhubarb on intestinal water content (Major et al., 2017). A randomised crossover trial was conducted in 15 adult participants without bowel disorders. Three meals were tested one week apart: 1) white bread and butter 2) cooked rhubarb and lactose free cream 3) lettuce with mayonnaise. Small bowel water content reduced after the bread meal and increased after the rhubarb and lettuce meals ($p<0.01$ for change from baseline over 0-3 hours). The increase was greater from rhubarb than lettuce. This study demonstrates how different foods and meals differently effect small bowel water content which can be measured using MRI. This has implications for dietary management of ileostomy output; however, it cannot be determined from this study which are the active components of the meals tested. The rhubarb and lettuce meals had a higher insoluble fibre content but also contained over twice as much fat as the comparison bread meal. The authors suggested that chemicals in plants (e.g., rhein in rhubarb and lactucins in lettuce) designed to deter animals may stimulate intestinal secretions. Another important consideration is whether effects in people with an ileostomy and/or active bowel disorders may differ to those in people with a healthy intact GI tract, since it is known that the small intestine adapts after total colectomy and ileostomy formation.

A further consideration for fibre modification to manage GI transit time and stool/output consistency is the shape and size of the fibre consumed. In an earlier randomised crossover trial, Lewis and Heaton (1999) compared the effects of consuming bran like flakes versus small granules in 18 healthy participants. Inert plastic particles were used to investigate the

effect of particle shape alone on transit time and stool form and water content. Flakes caused a significant decrease in transit time and increase in stool form and weight. Granules did not cause significant change in transit time; however, stool form and weight did increase. No difference in stool water content was seen with consumption of flakes or granules. The findings from this study support the theory that the size and shape of particles consumed, irrespective of viscosity or fermentability, affects the stimulation of the small intestine and thus transit time. This has implications for ileostomy management in identifying the need to consider not just what foods are consumed but also the form in which they are consumed. For example, it is possible that while raw vegetables may increase output, finely chopped and well-cooked vegetables may not be problematic.

2.8.3 **Sugar alcohols (sweeteners)**

Sugar alcohols are low digestible carbohydrates and, although natural, are commonly used as food additives as a sweetener, thickener and/or bulking agent (Grembecka, 2015). They act as prebiotics, undergoing fermentation by gut bacteria (intestinal microbiome), and are well known to cause GI symptoms including flatulence and bloating as well as having a laxative effect when consumed in excessive quantity. For people with an ileostomy who are prone to high output and/or excessive gas, they may be more sensitive to these effects following ingestion of foods or drinks containing sugar alcohols.

2.8.4 **Fluids**

Ileostomy output and consistency will also be affected by oral fluid intake and absorption. The volume and composition of fluid consumed determine how much fluid is absorbed and how much is lost in ileostomy output. A key characteristic of fluids is their osmolarity. The osmolarity of a fluid is a measure of the number of particles dissolved in 1L of water. Prior to intestinal absorption, fluid volume and composition, mainly energy density and to a lesser extent osmolarity, affect rate of gastric emptying into the small intestine (Leiper, 2015). Once the stomach contents have been delivered into the small intestine, absorption or secretion of fluid and electrolytes across the intestinal wall begins immediately to establish osmotic equilibrium (Figure 2.8.4.1). Sodium and glucose/fructose passively assist absorption of water from the intestine; however, the degree of absorption depends on the concentration of sodium and glucose in the fluid relative to the cells and blood (osmotic gradient). Exactly how these factors affect water absorption varies between different sections of the intestine due to differences in anatomical structure (Shi and Passe, 2010).

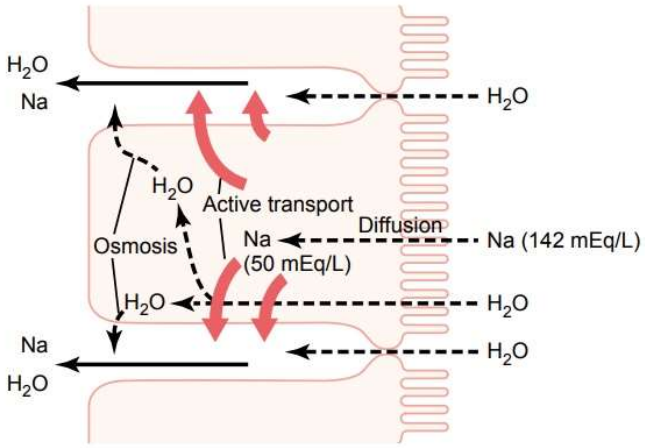


Figure 2.8.4.1 Water and sodium absorption in the small intestine

(Image source: https://www.brainkart.com/article/Absorption-in-the-Small-Intestine_19860/)

Based on this knowledge of the physiology of nutrient absorption in the GI tract, oral rehydration solutions (ORS) were developed to optimise fluid and electrolyte absorption in diarrhoeal illness (Sentongo, 2004). Findings from many studies led to the proposal of a set of criteria for ideal ORS formulation: 1) glucose concentration <160mmol/l 2) carbohydrate and sodium concentration approximately equimolar 3) similar osmolarity to plasma (isotonic). In people with a jejunostomy (shorter length of small intestine compared to those with ileostomy), ORS with a sodium concentration of 90-120 mmol/l has been demonstrated to achieve positive sodium balance (Nightingale et al., 1992). Several variations on this ORS formulation have been used in practice to manage high output in patients with an ileostomy or jejunostomy, with generally favourable results (Arenas Villafranca et al., 2015, Culkin et al., 2021).

2.8.5 **Fat**

It was previously hypothesised that a high fat diet would slow transit time and thereby increase nutrient absorption. This hypothesis was based on observations that patients with coeliac disease or cystic fibrosis had a slower transit time when they had steatorrhoea (fat in their stool indicating fat malabsorption). A randomised crossover trial (n=8) was conducted to investigate the effect of fat ingestion on ileostomy output (Higham and Read, 1990). The findings of this study did not, however, provide support for the authors' hypothesis. Instead, results showed that protein and fluid output increased on the high fat diet (160g, provided for one day) compared to the low-fat diet (22g, provided for one day). It was suggested this may

be due to increased pancreaticobiliary secretions stimulated by the increase in fatty acids present in the lumen of the small intestine. As shown in Figure 2.8.1.1 above, pancreaticobiliary secretions (pancreatic juices) contribute a large volume of fluid into the small intestine which may contribute to watery and high output in people whose GI absorption is insufficient to accommodate higher volumes of secretions. This was just one small study in people with less than 10cm terminal ileum resected and as such it is unclear how fat modification may or may not affect ileostomy management in general.

In people with more than 100cm of resected small intestine, bile acid deficiency may occur due to high losses, leading to fat malabsorption and steatorrhoea (Rowe and Schiller, 2020). In such cases a lower fat diet or bile acid supplementation may be required.

2.8.6 **Obstruction**

Phytobezoars are a mass of undigested food in the GI tract, usually made up of fibrous plant material i.e., insoluble fibre. As a primary cause of bowel obstruction (see Table 2.5.1 above), they are rare (<4%); however, many case reports have been published (Bedioui et al., 2008, Serrano and Tupesis, 2013). In patients with intestinal stricture or adhesions, phytobezoar may be a secondary cause of small bowel obstruction and the incidence of this may be higher (Taylan et al., 2010). Risk factors for mechanical small bowel obstruction due to phytobezoar include a high fibre diet, poor mastication, previous bowel surgery, decreased GI motility, and GI hyposecretion.

2.8.7 **Summary of mechanisms**

Evidence for causal associations between diet and ileostomy function or complications, although limited, is strengthened by evidence-based physiological mechanisms which support these associations underpinning the dietary advice provided in practice. Fibre and sugar alcohols affect transit time, chyme (semi-digested stomach contents released from the stomach into the small intestine) and output consistency (viscosity), and gas production (fermentation) through physical and microbial reactions. Sodium and glucose have a well-established role in fluid transport across the wall of the intestine and thereby affect hydration. Fat may affect transit time and GI secretions, potentially contributing to fluid losses. Faster transit contributes to malabsorption of nutrients due to reduced contact time, firstly, with digestive enzymes that break down nutrients and, secondly, with intestinal villi (protrusions that line the inner wall of the small intestine increasing surface area) where nutrients are absorbed (El Aidy et al., 2015).

2.9 MEDIATING AND CONFOUNDING FACTORS IN THE EFFECTS OF DIETARY INTERVENTION ON ILEOSTOMY MANAGEMENT

Some studies have investigated diet in people with a stoma including participants with an ileostomy or a colostomy (and sometimes urostomy) without differentiating and acknowledging differences between stoma type (Floruta, 2001, Davidson, 2016). There is considerable variation in underlying and ongoing disease as well as in length of functioning intestine remaining for digestion and absorption with different types of stomas, as explained in section 2.2; however, the implications of these fundamental differences for stoma complications and dietary management are sometimes not considered.

Mediating factors are variables such as patient characteristics that influence a causal relationship such as that between diet and ileostomy function. Confounding factors are those factors associated with both variables in an apparent causal relationship which may be a stronger contributor to the outcome variable than the one investigated but, due to the close association with the causal variable, makes the variable under investigation appear to have a greater causal role than it plays in reality. Underlying condition, other GI surgery, and medication are key factors that may play a mediating or confounding role in the effect of diet on ileostomy function and management. These are discussed below.

2.9.1 Underlying disease and intestinal capacity

Even within a sample of people with an ileostomy, there can be large differences in the amount of functioning small intestine they have. Crohn's disease can affect any part of the GI tract and therefore people with severe Crohn's disease may require resections to either or both the small and large intestine. In contrast, ulcerative colitis specifically affects the large intestine only. People with colorectal cancer are also unlikely to have either disease affecting the GI tract or need for GI surgery proximal to an ileostomy. Therefore, patients requiring ileostomy formation due to ulcerative colitis or colorectal cancer usually have lower risk of malabsorption and associated complications such as high output than those with a background of Crohn's disease who may have significantly reduced functional length of small intestine or ongoing inflammation in places (Seifarth et al., 2021).

A recent systematic review and meta-analysis investigated risk factors for hospital readmission with dehydration after ileostomy formation (Liu et al., 2021). Data were pooled from ten studies (27,089 patients) for 29 potential risk factors. A pre-operative diagnosis of colorectal cancer was associated with lower risk compared to other diagnoses. Unexpectedly,

IBD diagnosis was not associated with increased risk for hospital readmission with dehydration after ileostomy formation in the meta-analysis. As both types of IBD were analysed as one group, this may have been due to differences between patients with Crohn's disease and ulcerative colitis, as discussed in the previous paragraph. However, surprisingly, this explanation was not considered by the authors of the meta-analysis in their discussion. They did suggest that this finding may be a consequence of substantial heterogeneity of outcome for IBD patients in the included studies. If patients with a pre-operative diagnosis of Crohn's disease have substantially different outcomes in terms of complications related to high output compared to patients with ulcerative colitis, this heterogeneity is to be expected.

In one retrospective analysis of people with a loop ileostomy, Vergara-Fernández et al. (2019) found ulcerative colitis to be an independent predictor of complications related to high-output stoma. However, the small number of patients with ulcerative colitis (n=11/102) reduces the strength of this finding. In that study, 55% (6/11) of patients with ulcerative colitis had complications that had been defined as related to high output i.e., presenting to the emergency department, or readmitted, with dehydration and electrolyte disturbances, or acute renal failure, in conjunction with output >1.5L/24h. In contrast, it was shown in another study that patients who had a loop ileostomy following surgery for ulcerative colitis had a lower rate of only 11% (8/71) for readmissions due to high output related complications (Park et al., 2018). However, in the second study, a higher cut-point was used to define high output i.e., >2L/24h which is likely to explain some of the difference observed.

Seifarth et al. (2021) conducted their retrospective analysis on a sample of 296 patients with either diverting ileostomy, end ileostomy, or anastomotic stomata with at least part ileum. This sample included patients with a diagnosis of Crohn's disease (n=64), ulcerative colitis (n=99), or cancer (n=73). In this study, a multivariate logistic regression was performed and the following independent risk factors for high-output stoma (>1L/24h for >3 days) were identified: Crohn's disease, surgical procedure (right-sided colectomy, separate ileostomy, small bowel resection), and older age. The fact that Crohn's disease but not ulcerative colitis was found to be a risk factor supports the explanation suggested above for the lack of association between IBD diagnosis and readmission for dehydration after ileostomy formation in the recent meta-analysis (Liu et al., 2021). The variation in definition of high output stoma makes comparison of results between studies difficult and is a weakness of the meta-analysis.

An additional consideration, particularly for patients with Crohn's disease, is that if multiple resections of the small intestine have been performed, they will have anastomoses where remaining intestine has been re-joined, increasing likelihood of strictures (narrowing) due to inflammation or scarring. Strictures due to scarring may also be present where inflammation due to active Crohn's disease has previously occurred and caused long-term damage to the wall of the intestine (Lowe et al., 2020). Patients with strictures are at higher risk of small bowel obstruction, including mechanical obstruction due to food bolus, and more likely to require surgery due to obstruction. Multiple resections of the small intestine are therefore an independent risk factor for complications that may benefit from dietary management and should be considered as a potential mediating or confounding factor when investigating associations between diet and ileostomy function.

2.9.2 **Medical management**

Antimotility medications are commonly prescribed for patients with an ileostomy to manage high output (Rowe and Schiller, 2020). Loperamide is usually used as the first-line medication, with codeine phosphate commonly added if loperamide alone is insufficient. Loperamide and codeine are opioid receptor agonists that act on intestinal receptors to reduce activity of the smooth muscle in the intestinal wall. Anti-secretory medications are also often prescribed for management of high output stoma. Proton-pump inhibitors suppress gastric acid secretions and can be effective in managing high output where hypersecretion of acid is a contributing factor (Rowe and Schiller, 2020). Octreotide is less commonly prescribed to reduce intestinal secretions in the management of high output.

Loperamide and codeine are started at a low dose and gradually increased as required. The timing of when medication is commenced, and dosage increased, depends on experience, capability, and capacity of the medical or surgical team responsible for the patient's care as well as the availability and content of a local protocol. In addition, the timing of medication changes relative to fluid and dietary management can vary considerably from patient to patient making it extremely difficult to identify the effective components of treatment and their relative contributions. Several studies have evaluated the effectiveness of protocols that combine multiple components for ileostomy management, including dietary modifications (Arenas Villafranca et al., 2015, Nagle et al., 2012). While these protocols seem to improve management and reduce complications, the effectiveness of the included dietary components remains unclear as it is not possible to disentangle the effects.

The factors described above may increase or decrease the risk of problems and complications in people with an ileostomy which in turn will affect the potential impact of dietary management. It is therefore important that these factors are taken into consideration when designing and evaluating dietary interventions for people with an ileostomy.

2.10 SITUATION AND CONTEXT OF DIETARY INTERVENTIONS FOR PEOPLE WITH AN ILEOSTOMY

In the previous sections, I have considered evidence for a causal association between diet and outcomes relating to ileostomy function; firstly, by looking at experimental studies investigating effects of dietary modification; secondly, looking at plausible mechanisms for a causal association; and thirdly, considering additional factors that may have a mediating or confounding effect in dietary management for people with an ileostomy. However, to establish effective dietary management, it is important not only to understand how dietary components affect outcomes but also to understand how the context (e.g., source and setting) and process (e.g., communication and service provision) of dietary advice provision affects patients' diet-related behaviours and outcomes. These aspects of dietary advice are considered in this and the following section (2.10 and 2.11).

It has previously been reported that people with a stoma were often not satisfied with the dietary advice they received, and that the advice was insufficient, inconsistent, and could be conflicting (Morris and Leach, 2015, Persson et al., 2005). There are many discrepancies and inconsistencies between expert opinion articles on the dietary advice proposed for stoma management, and it is likely these are representative of differences in practice between individual clinicians and healthcare professions (Morris and Leach, 2015); for example, one article suggests that, to reduce risk of blockage, all fruit, except for bananas, should be avoided immediately after ileostomy surgery and gradually re-introduced (Burch, 2011a), while another advises that soft fruit without skins can be consumed (Cronin, 2013).

There are many healthcare professionals (HCP) and other sources who may provide dietary advice to individuals with a stoma. These include stoma nurses, dietitians, surgeons, gastroenterologists, other specialist nurses, and support groups and associations such as the Ileostomy and Internal Pouch Association (Burch, 2011a, Morris and Leach, 2015, IA, 2020). As such, people with an ileostomy may have several opportunities to receive advice for

dietary management but this is likely to come with an increased risk of advice being inconsistent and conflicting.

Interventions evaluated in some of the more recent research literature have focused on the provision of standardised advice for ileostomy management, specifically or including dietary advice, in an inpatient hospital setting (Arenas Villafranca et al., 2015, Nagle et al., 2012, Mogos et al., 2015, Mukhopadhyay et al., 2015). The aim of these interventions was to reduce the incidence and/or severity of complications following ileostomy formation. The profession of the person providing the dietary advice in intervention studies was often not reported. Where it was reported, dietary advice was most commonly provided by a dietitian or nutritionist.

Controlled experimental studies investigating the immediate effect of consuming a specific food or diet have been more commonly conducted in patients with established ileostomy in a community or outpatient setting, usually in participants' own homes (Kramer, 1987, Berghouse et al., 1984, Barrett et al., 2010, Clarebrough et al., 2015).

2.11 COMMUNICATION AND DECISION MAKING IN HEALTHCARE SETTINGS

2.11.1 Communication style

Traditionally in healthcare, a paternalistic style of communication and decision-making has been used by HCPs in patient consultations (Redsell and Buck, 2009). This style of communication involves the HCP deciding on the course of action and treatment the patients should follow and telling them what they should do. In recent decades, an information giving approach has become more popular and accepted. Using this approach, the HCP provides the patient with information on the options available but does not advise them on which option to take or engage at all in the decision-making process. The information giving model aims to empower patients to take ownership of their health and to respect patient autonomy.

A third model for communication in healthcare consultations, shared decision making, has been developed and promoted to overcome the limitations of the paternalistic and information-giving approaches (Charles et al., 1997). The paternalistic style fails to account for the patient's social and personal background which influence their priorities and ability to follow the plan recommended by the HCP (Redsell and Buck, 2009). The information giving approach assumes that, after receiving the information provided by the HCP, the patient has

sufficient knowledge and self-efficacy to make their own decision. This is often not the case, and some patients prefer to be recommended a specific treatment by a person with professional expertise i.e., the HCP (Deber et al., 2007, Buck, 2009).

2.11.2 **Shared decision-making**

Shared decision making is a more complex approach requiring additional communication skills from the HCP. The contrast with the traditional paternalistic style of communication between HCP and patient makes shared decision making challenging (Redsell and Buck, 2009). It has been identified, based on qualitative research with HCPs and their patients, that inter- and intra-patient preferences exist with regard to communication style (Buck, 2009). A patient's preference and need may change over time and be different depending on their stage of illness. Therefore, for HCPs to effectively implement shared decision making, they themselves must seek out further information including the preferred role for their patient in the decision-making process at that time, a holistic understanding of their patient, and evidence-based knowledge of available treatment options (Redsell and Buck, 2009). They must then use this knowledge to tailor the provision of information to their patient, check understanding and response, and collaborate with their patient to agree a goal (Elwyn et al., 2000, Lawless et al., 2021).

2.11.3 **Patient-centred care**

Shared decision making epitomises the principles of patient-centred care. Healthcare services such as the NHS aspire to provide patient-centred care which is thought to improve quality and efficiency of care (Richards et al., 2015). The World Health Organisation (WHO) has defined person-centred care as *"care approaches and practices that see the person as whole with many levels of needs and goals, with these needs coming from their own personal social determinants of health" p.49* (World Health Organization, 2015). A systematic review of the literature that included a definition of patient-centredness identified 15 dimensions of patient-centredness (Scholl et al., 2014) thus highlighting the complexities of implementing and evaluating this model of care. The dimensions identified in the systematic review were grouped at three different levels. Principles identified were 'essential characteristics of the clinician', 'clinician-patient relationship', 'patient as a unique person', and 'biopsychosocial perspective'. Enablers were 'clinician-patient communication', 'integration of medical and non-medical care', 'teamwork and teambuilding', 'access to care', and 'coordination and continuity of care'. Activities were 'patient information', 'patient involvement in care',

‘involvement of family and friends’, ‘patient empowerment’, ‘physical support’, and ‘emotional support’ (Scholl et al., 2014).

A systematic, integrative (mixed methods) review of the literature relating to patient-centred care specifically in dietetics identified six themes: ‘establishing a positive dietitian-patient relationship’, ‘displaying humanistic behaviours’, ‘using effective communication skills’, ‘individualising and adapting care’, ‘redistributing power to the patient’, and ‘lacking time for patient-centred care practices’ (Sladdin et al., 2017). These themes were identified through a rigorous review process and meta-synthesis of data from included qualitative and quantitative studies. Unsurprisingly, five of the six themes map closely onto dimensions of patient-centredness identified by Scholl et al. (2014) i.e. ‘clinician-patient relationship’, ‘characteristics of the clinician’, ‘clinician-patient communication’, ‘patient as a unique person’, and ‘patient empowerment’. The sixth theme, lack of time for patient-centred care, highlights the main barrier perceived by dietitians (Sladdin et al., 2017). Interestingly, time was not identified as an enabler of patient-centred care in Scholl et al.’s systematic review (Scholl et al., 2014).

Studies investigating an association between length of consultation and patient-centredness do suggest that, overall, longer consultations are positively associated with patient-centredness, but this association may not be strong and other factors may have greater influence. For example, in a U.S. study of outpatient consultations at an HIV clinic, a weak association was shown between patient-centredness and visit length (Laws et al., 2011); however, it was suggested that long consultations also reflected inefficient use of time, thereby leading the authors to recommend that dialogue quality should be the main focus in achieving patient-centred consultations. In this study, length of consultation ranged from just under two minutes to 45 minutes with a median length of 15 minutes. In a large-scale study of GPs, conducted in England, increased consultation length was associated with greater patient-centredness (Orton and Pereira Gray, 2016). Longer consultations were also more common with female than male patients.

Interventions where HCPs communicated empathy or positive expectations of outcome have demonstrated a small benefit to patients across a range of psychological and physical outcomes, compared to usual care (Howick et al., 2018). Many of the empathy interventions were delivered in consultations allocated additional time compared to standard care. In a study where 752 participants were presented with a hypothetical scenario where they were

the recipient of advice giving from a friend, the advice was perceived as higher quality when 1. emotional support and 2. problem inquiry and analysis were provided prior to advice giving (Feng, 2009). The sequence of emotional support prior to problem inquiry and analysis was important but the author was keen to suggest that although emotional support should be provided first, this does not mean that it should not continue to be provided at a later stage as required.

Combining formats for advice provision, e.g., verbal and written, and actively engaging the patient in the process, e.g., encouraging active response and checking understanding, are likely to improve patient recall of information provided during consultation with an HCP (Richard et al., 2017, Webber et al., 2001, Watson and McKinstry, 2009).

In addition to characteristics of one-to-one clinician-patient consultations, characteristics of access to and coordination of care were identified as enablers in the systematic review identifying dimensions of patient-centred care (Scholl et al., 2014). An umbrella review of integrated care interventions of different types suggests that well-coordinated and integrated care can improve patient QoL, particularly for those with chronic conditions (Flanagan et al., 2017). Although findings from Shaw et al. (2020) were not conclusive due to a lack of high-quality evidence, their systematic review and meta-analysis of 14 studies (1 RCT) supported a conclusion that multi-disciplinary team (MDT) involvement for patients undergoing surgery is associated with reduced hospital length of stay and reduced inpatient mortality.

In summary, the theory and research described above support the idea that dietary interventions provided in a healthcare setting are more likely to be effective if they are delivered within a context of patient-centred care and if the HCP delivering the intervention actively involves the patient in shared decision-making. This emphasizes the importance of considering how dietary advice is provided as well as what dietary advice is provided when evaluating the quality of dietary advice patients receive or the effectiveness of dietary interventions.

2.12 COMPLEX INTERVENTIONS

2.12.1 Dietary interventions are complex

When reviewing studies that have conducted dietary interventions, when evaluating provision of dietary advice in practice, and when designing and conducting novel dietary interventions, it is important to consider the fact that dietary interventions are complex. This means that they present additional challenges in their design and evaluation.

Complex interventions can be defined as those interventions that are designed to act in a complex system (Rickles, 2009). A complex system is non-linear and dynamic (Rickles et al., 2007). Describing a system as dynamic suggests that it evolves over time. It is important to consider that complex differs from complicated. A complex system is one with many component parts that interact in multiple different ways. Although a complicated system also has many component parts, these interact in a formulaic way making the effect on outcome of any change in a component variable highly predictable.

2.12.2 Establishing causality in complex interventions

Randomised controlled trials (RCTs) are seen as the gold standard method for primary research to establish causality. The premise for this is that randomisation removes bias by equating all differences between the control and intervention group except for intervention-related differences. This can be checked for known potential confounding differences for example age and gender. However, it is not possible to check for unknown potential confounding differences. Also, although randomisation within a large sample may often produce similar age and gender between groups i.e., non-significant difference, we cannot know that a very small difference may not lead to an exponentially large difference in outcome within a complex system where causal mechanisms are not all known (Rickles, 2009). Observational studies aiming to minimise bias through adjustment for known confounders succumb to the same flaw when evaluating complex interventions.

A key difficulty in identifying causality in complex systems is the interaction between causal mechanisms i.e., these mechanisms are not distinct (Rickles, 2009). This means that by adjusting a variable in one causal mechanism you may change not only the outcome specified in the causal mechanism but also other variables and outcomes in other causal mechanisms. As such, you cannot be sure how much, if any, of the change in outcome was due to the change in the target variable or another variable within a separate causal mechanism that was

also influenced by the target variable. Another fundamental problem of assessing causality of a complex intervention is that complex interventions do not just change the target variable but also influence 'nearby' variables (spillover) which may or may not be visible (Rickles, 2009).

2.12.3 **Randomised controlled trials versus realist evaluation**

The MRC (Medical Research Council) model of the development and evaluation process for complex interventions and realist evaluation provide alternative approaches to designing and evaluating effectiveness of complex interventions. The MRC model is based on the principle that RCTs provide the strongest evidence for the effectiveness of a complex intervention by preventing selection bias and controlling potential effects of confounders (Craig et al., 2008). In contrast, realist evaluation developed from a belief that complex interventions cannot be fully isolated or kept constant (Pawson and Tilley, 2004).

Key differences between these two models are that in an RCT, evaluation of outcome and process are kept separate, with outcome evaluation being the essential component, and a primary outcome identified *a priori* to define the threshold for effectiveness. In realist evaluation, no single outcome measure is used to define effectiveness, and all outputs (intermediate implementation targets) and outcomes (targeted behaviours) are considered essential to the evaluation (Pawson and Tilley, 2004). Realist evaluation is characterised by the use of realist explanation where outcomes are considered as the consequences of the interaction between underlying mechanism (theory of a process) and context (Pawson and Tilley, 1997). In contrast to the successionist model of causation (i.e., a linear relationship between cause and effect) that underpins RCT methodology, realist explanation is based on a generative model of causation. Factors at all levels of social reality are acknowledged to influence outcomes via mechanisms and contexts and therefore realist evaluation collects data at the individual, interpersonal, institution, and infra-structure level (Pawson and Tilley, 2004).

Despite fundamental differences in ontology and epistemology, these two approaches do have several similarities in their guidance for how a complex intervention should be developed and evaluated (Pawson and Tilley, 2004, Craig et al., 2008). Both include the following stages: 1. Identify relevant evidence base and theory 2. Development 3. Implementation 4. Evaluation. Use of both quantitative and qualitative research methods is recommended in the MRC model and realist evaluation; although quantitative results are usually given greater weight in RCTs, with the evaluation of effectiveness focussing on quantitative measures, and qualitative data

more likely to be collected as part of the process evaluation. Both approaches may include subgroup analyses to gain a more nuanced understanding of the effectiveness of the complex intervention.

2.13 SUMMARY AND IMPLICATIONS

There are many different bowel surgeries and several types of GI stoma. Each has their own specific impacts on individuals and nuances of management. Ileostomy formation is a common procedure when surgery is required for the treatment of IBD or colorectal cancer. Diet-related complications such as high output, obstruction and malnutrition are commonly experienced amongst people with an ileostomy due to the complete removal or defunctioning of the large intestine; sometimes in addition to significant resection of the small intestine, in those with Crohn's disease. These complications can negatively affect QoL due to physical, psychological, and social impacts. High fibre foods have been associated with these complications and unpleasant symptoms such as wind and odour. Findings from in vivo studies investigating effects of specific nutrients on digestion provide support for associations between diet and ileostomy function. For example, fibre, fat, and sweeteners (sugar alcohols) have been shown to affect intestinal transit and digestion. Fluid composition is important to manage increased fluid losses particularly in the early post-operative period after ileostomy formation.

Dietary advice may be presented to people with an ileostomy in a range of contexts and formats. What advice is provided, when and where, how and by whom will all affect the patient's understanding, beliefs and feelings related to their diet and ileostomy management which in turn will influence diet-related behaviours. Changing dietary advice provision and management requires complex interventions which present unique challenges in their design and evaluation.

The concepts and literature described in this chapter have informed the development of the overall aim and research questions for this thesis, and the three studies conducted to achieve this aim. The aim of this thesis is reiterated below.

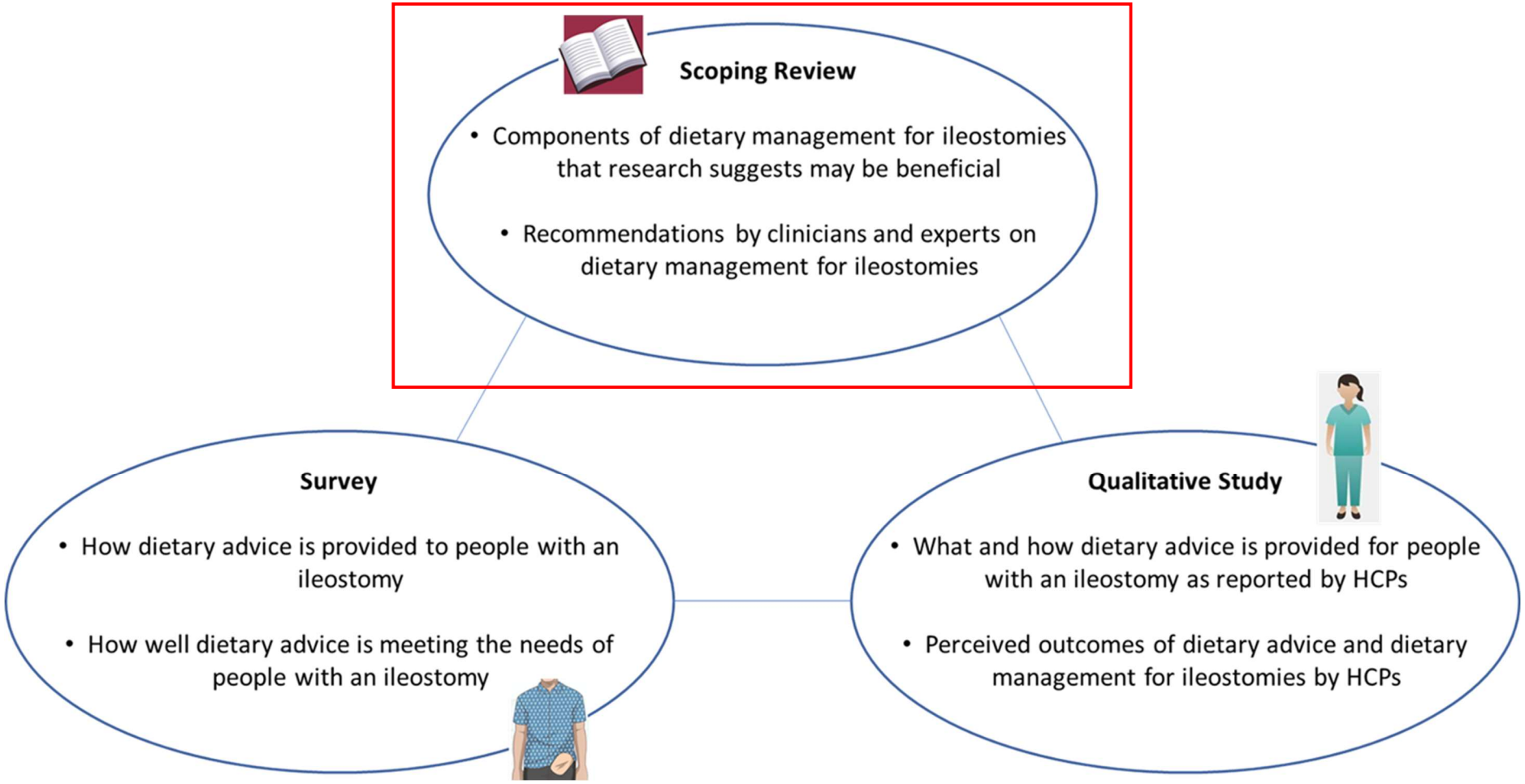
Aim: To explore dietary advice and modifications for ileostomy management through consideration of previous research, current evidence, and experiences of people with an ileostomy and healthcare professionals.

To achieve this aim, the following research questions will be addressed:

1. What published evidence is there for oral dietary management in people with an ileostomy? *(Study 1)*
2. What dietary advice is provided to people with a new ileostomy, and why? *(Studies 1, 2 & 3)*
3. How is dietary advice being provided to people with an ileostomy? *(Studies 2 & 3)*

This chapter has provided an overview of the topic for this thesis. The following chapters build on this knowledge, presenting the three studies conducted to achieve this aim and discussing how the study findings fill gaps in the literature and in clinical practice.

STUDY 1. Dietary management for people with an ileostomy: a systematic scoping review



3 STUDY 1 – DIETARY MANAGEMENT FOR PEOPLE WITH AN ILEOSTOMY: A SYSTEMATIC SCOPING REVIEW

3.1 CHAPTER INTRODUCTION

Study 1 addresses the first, and contributes to answering the second, of the questions posed to achieve the overall thesis aim - What published evidence is there for oral dietary management in people with an ileostomy? What dietary advice is provided to people with a new ileostomy, and why?

People with an ileostomy potentially have much to gain, in terms of quality of life (QoL), physical function and health, from managing their diet. It is therefore necessary to identify and understand the available evidence to inform clinical practice, and to identify areas where additional knowledge is needed.

A preliminary search for existing reviews relating to dietary management of stomas did not identify any systematic reviews or scoping reviews. The following databases were searched: Joanna Briggs Institute Database of Systematic Reviews and Implementation Reports (JBISRIR), PROSPERO, Cochrane Database of Systematic Reviews (CDSR), MEDLINE, and CINAHL. Preliminary literature searches also indicated a paucity of research investigating dietary management of stomas, with considerable heterogeneity amongst available studies. The lack of high quality, homogenous research evidence on diet among people with an ileostomy meant that it was not going to be possible to conduct a meaningful systematic review of effectiveness of dietary modifications. As such, I proposed the present scoping review as the first study to contribute to this thesis. The objective of this scoping review was to identify and map the evidence for oral dietary management of ileostomies. This review highlights gaps in the literature that need addressing to inform ileostomy management in clinical practice and identifies dietary strategies and outcomes requiring investigation in future studies.

The journal manuscript reporting the results of this scoping review is published in full in 'JBI Evidence Synthesis' (Mitchell et al., 2021). To reduce repetition with other chapters in the thesis, this chapter includes the methods and findings of the published scoping review.

3.2 REVIEW QUESTIONS

Primary question:

What oral dietary strategies for managing ileostomies in humans have been reported?

Secondary questions:

- What types of evidence have considered oral dietary strategies for managing ileostomies?
- What aspects of ileostomy management, for example stoma output or flatulence, are the oral dietary strategies considered to affect?
- What sources do people with an ileostomy receive dietary advice from?

3.3 INCLUSION CRITERIA

Participants

This review included evidence in people with an ileostomy. There are several conditions that may require ileostomy formation, most commonly Crohn's disease, ulcerative colitis, colorectal cancer, and familial adenomatous polyposis (Richbourg, 2012). Articles were not restricted to people with a specific condition as common advice for dietary management of ileostomies is provided irrespective of underlying condition (Burch, 2011a). In practice, dietary management for an underlying condition may need to be integrated with dietary management for the ileostomy (Morris and Leach, 2015).

Evidence relating to people with a colostomy or jejunostomy were excluded from this review. This is due to differences in complications and management with different types of gastrointestinal (GI) stoma. People with an ileostomy have greater risk of complications, such as high-output, dehydration, and blockage, than people with colostomy (Baker et al., 2011, Ng et al., 2013). There is therefore a greater requirement for, and differences in, oral dietary management of complications in people with an ileostomy compared to those with colostomy (Burch, 2011a, Baker et al., 2011, Ng et al., 2013). People with a jejunostomy have short bowel syndrome (SBS) characterised by severe malabsorption which often requires restriction of oral intake and parenteral nutrition support (Mountford et al., 2014).

Age or sex was not restricted as these factors have not been identified to affect dietary strategies used for ileostomy management. However, articles relating to babies not yet fully

weaned were excluded as dietary management in this group differs considerably. Animal studies were also excluded.

Concept

The concept for this review was oral dietary management of ileostomies. This included modification of the usual foods and drinks a person consumes to manage complications and nutritional consequences associated with the ileostomy. Examples identified in the protocol for this review were: fibre modification; low residue diets; reintroduction diets; added salt; low fat diet; probiotics and/or prebiotics; increased low fibre starchy carbohydrates; regular intake of gelatine-containing sweets; specific food/drink avoidance such as onions, nuts, and fizzy drinks; high energy and/or protein diet; oral nutritional supplement drinks (Mitchell et al., 2019). Only evidence relating to oral diet was included. Artificial nutrition support (enteral and parenteral nutrition) is a separate concept and was therefore excluded.

Outcomes were ileostomy complications, such as high-output, loose/watery output, blockage, wind, odour, malnutrition, and dehydration, that may be managed through modification of oral diet (McDonough, 2013).

During the screening process, it was identified that additional criteria for inclusion/exclusion were needed beyond those in the protocol (Mitchell et al., 2019). The need for adding post-hoc exclusion criteria is expected in scoping reviews as, by their nature, the variety and extent of related evidence only becomes known through carrying out the review process (Arksey and O'Malley, 2005). After agreement by reviewers, the following exclusion criteria were added and applied to the screening process as evidence relating to these concepts did not specifically help to answer the research questions:

- People with an ileostomy used as subjects for the purpose of investigating digestion of specific foods in the small intestine.
- Sodium balance studies not looking at stoma management outcomes.
- Nitrogen balance studies.
- Articles/studies where the purpose was to consider management of SBS, not ileostomies specifically.
- Single nutrient supplements.
- Elemental diet.

- Dietary modification to prevent or treat conditions associated with ileostomy complications. For example, renal calculi.
- Dietary management relevant only to a specific subgroup of people with an ileostomy. For example, marathon runners or palliative patients.

The decision was made to exclude articles focusing on dietary management in SBS and/or intestinal failure because these conditions commonly occur in people with jejunostomy but more rarely in people with ileostomy, require specific management, and often require supplementary IV fluids and/or parenteral nutrition (Mountford et al., 2014). Furthermore, although oral rehydration solutions (ORS) and fluid management protocols were initially given as examples for inclusion within the review (Mitchell et al., 2019), subsequently studies that focused on these aspects were excluded. Strict fluid management including use of ORS in combination with medication such as loperamide and codeine is key to management of SBS and intestinal failure. Similar medical management is also common for high output stoma (HOS); however, there is a clear distinction between this and general fluid advice for stoma management e.g., limiting caffeinated, fizzy, and alcoholic drinks (which were included in the review).

Context

All settings were included as dietary advice provided in one setting may be relevant to ileostomy management, and continue to be followed, in another setting. For example, dietary advice provided in hospital may be followed after discharge (Short et al., 2016).

There was no restriction on date stated in the protocol (Mitchell et al., 2019); however, during the screening process, the decision was made by reviewers to limit expert opinion articles to the last 10 years. Therefore, expert opinion articles published before 2008 were excluded from this review. This decision was made for the following reasons: 1) the large number of expert opinion articles identified; 2) contemporary expert opinion articles are likely to be most relevant in terms of current advice being given in clinical practice; 3) to prevent excessive repetition.

There was no restriction by country or language, to enable the full extent of the evidence to be mapped.

Types of studies

All types of original research, quantitative and qualitative designs, were included. Reviews, including narrative reviews and expert opinion articles termed as reviews, were also included. The only text and opinion-based evidence included was expert opinion. Inclusion criteria included consensus guidelines in peer-reviewed publications. Guidelines and documents disseminated by associations, societies or institutions were excluded as they are not usually peer-reviewed publications or research.

3.4 METHODS

This review was conducted following the Joanna Briggs Institute (JBI) methodology for systematic scoping reviews (Peters et al., 2015). The protocol was published a priori (Mitchell et al., 2019). I chose to follow the JBI methodology for systematic scoping reviews as this provides a rigorous, standardised, and transparent process for conducting and reporting scoping reviews (Peters et al., 2015). The JBI scoping review methodology builds on earlier work to improve the quality and relevance of scoping reviews (Arksey and O'Malley, 2005).

Search strategy

The search strategy was designed to find all published and unpublished research studies along with published reviews of the literature, consensus guidelines, and expert opinion articles relevant to the topic of dietary management in people with an ileostomy. Following JBI guidance, a three-step search strategy was performed (Peters et al., 2015). In step 1, an initial limited search of MEDLINE and CINAHL was carried out followed by analysis of the text words contained in the title and abstract, and of the index terms used to describe the article. Identified keywords and index terms were included in the full search strategy. In step 2, the full search strategy was performed in each of the specified databases. Appendix I contains the full search strategy for MEDLINE. This search strategy was tailored to each database. Searches were carried out first in 2018 and updated in August 2019. In step 3, reference lists of all included articles were screened to identify additional relevant articles. The final list of included articles was checked for completeness by subject experts. No date limitation was included in the search strategy; however, expert opinion articles were only included if published in the 10 years prior to first full search in 2018 (2008-2019), as discussed above.

Databases searched: MEDLINE, Embase, and AMED via Ovid, CINAHL via EBSCO, Web of Science, CDSR, and JBI Database of Systematic Reviews and Implementation Reports (JBISRIR). Trial registers searched: ClinicalTrials.gov, WHO ICTRP, and Cochrane Central Register of Controlled Trials. Databases searched for unpublished studies: OpenGrey, EThOS, ProQuest – Nursing and Allied Health Source Dissertations, Google Scholar.

Study selection

Records returned from the database searches were collated using EndNote X9 (Clarivate Analytics, PA, USA) and duplicates removed. Two independent reviewers screened all titles and abstracts, assessing against the inclusion/exclusion criteria. Articles failing to meet the criteria for inclusion were discarded and full texts for all remaining articles acquired. Full texts were then assessed in detail against the inclusion/exclusion criteria by two independent reviewers. Full text articles not meeting criteria for inclusion were excluded. Full texts excluded with reasons for exclusion are detailed in Appendix II. Any disagreements between reviewers were resolved through discussion, and where necessary a third reviewer was involved. Where something was unclear that affected the decision of whether to include a study, authors were contacted for clarification.

Data extraction

Data were extracted from included studies, consensus guidelines, and expert opinion articles into an electronic charting form based on the draft form detailed in the protocol (Mitchell et al., 2019). The charting form was piloted by two reviewers and some changes made to improve consistency. An outline of the final charting form used for data extraction can be found in Appendix III. Data extraction was carried out by two independent reviewers. Any disagreements arising between reviewers were resolved through discussion or with a third reviewer.

Data synthesis

Summaries of all included studies and articles are presented in tables according to study design or article type. This was done to differentiate between levels of evidence since experimental studies can suggest causality, observational studies can indicate associations, and expert opinion articles suggest common views in clinical practice. Data synthesis of dietary strategies and associated outcomes is presented as a tabular and narrative summary.

3.5 RESULTS

3.5.1 Article inclusion

Database searches of published literature and registered trials returned 8,055 results (Appendix I). An additional 427 records were identified from other sources. After removal of duplicates, 5,687 records were screened. After title and abstract screening, 195 records were retrieved for full text screening of which 118 were excluded for not meeting inclusion criteria (Appendix II). An additional 14 eligible articles were identified through hand searches of reference lists of included articles, resulting in a total of 91 included studies and expert opinion articles. Figure 3.5.1.1 shows the PRISMA flow diagram of the search results and selection process (Moher et al., 2009).

Data were extracted from 31 individual research studies and 44 expert opinion articles, including two reporting guidelines based on expert consensus (Prinz et al., 2015, Wound Ostomy Continence Nurses Society Guideline Development Task Force, 2018), and were included in the data synthesis reported in the results (characteristics and findings/recommendations for individual studies and expert opinion articles/guidelines are in Appendix IV). In addition, seven records presented data from a study reported in another included article (Arenas Villafranca et al., 2014b, Arenas Villafranca et al., 2014a, Barrett et al., 2009, Bingham et al., 1977, Gaffney et al., 1986, Morris and Leach, 2009, Kennedy, 1981), two were related to reported expert opinion articles (McGlade, 2018, Cronin, 2012), and six were review articles (Baker, 2015, Buckman and Heise, 2010, Gibson, 2011, McNeil, 1984, Willcutts and Touger-Decker, 2013, Young, 2016). Reference lists from review articles were included in hand searches. One in-progress registered trial was identified, which aims to investigate physiological effects of probiotic dairy drinks in adults with established ileostomy (Troost, 2016).

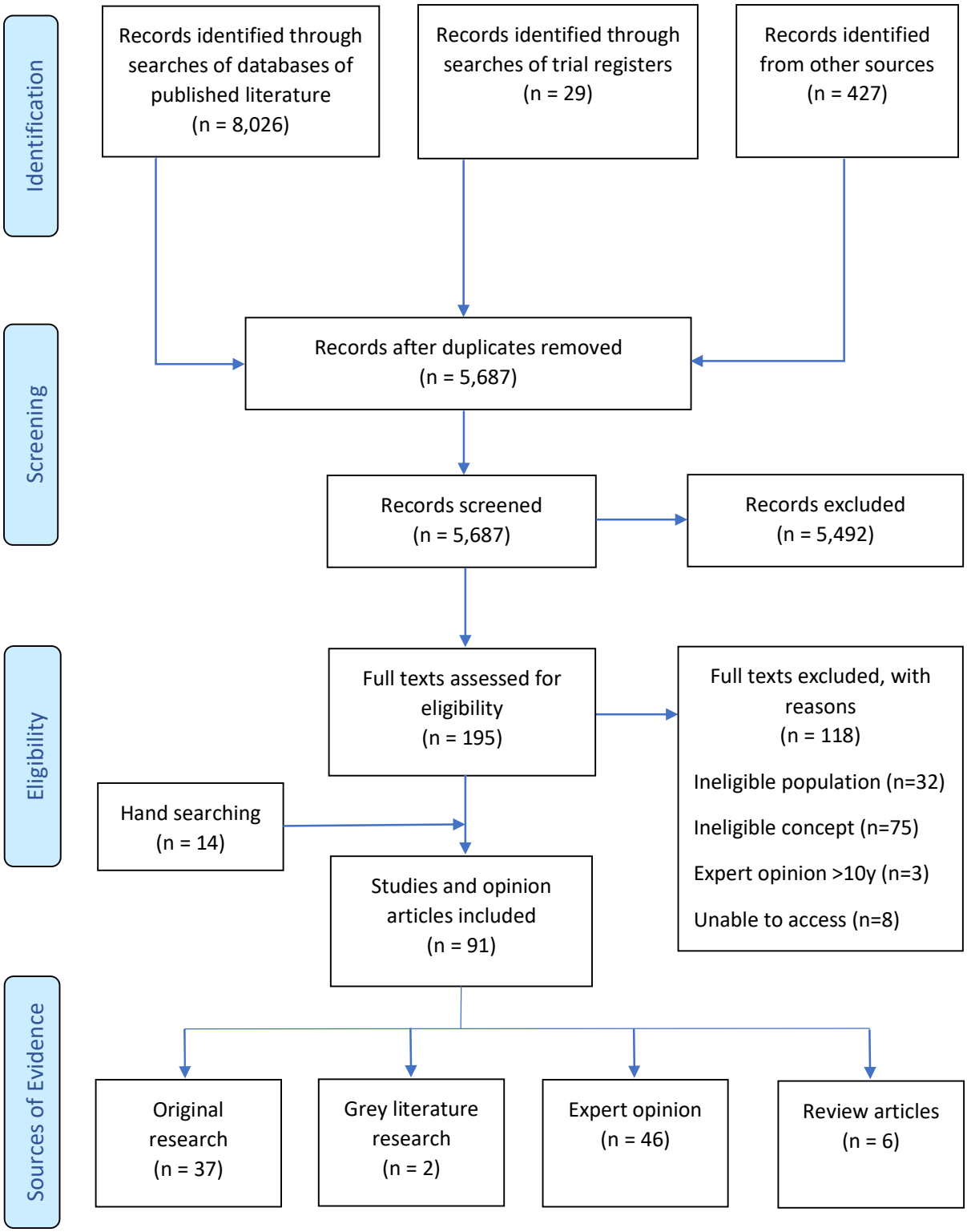


Figure 3.5.1.1 Flow diagram of search results (Moher et al., 2009)

3.5.2 **Characteristics of studies/articles**

Characteristics of the 31 eligible research studies are summarised in Table 3.5.2.1. Eleven were experimental (four crossover randomised controlled trials (RCT) (Barrett et al., 2010, Berghouse et al., 1984, Clarebrough et al., 2015, Higham and Read, 1990), six non-randomised crossover trials (Donoghue et al., 2009, Kramer, 1987, Kramer et al., 1962, Andersson et al., 1974, Gaffney et al., 1987a, Gaffney et al., 1987b), and one non-randomised controlled trial (Mogos et al., 2015)), three used a pre-post design (evaluating a new protocol or process of patient education and support) (Arenas Villafranca et al., 2015, Mukhopadhyay et al., 2015, Nagle et al., 2012), thirteen were observational (12 cross-sectional (Biermann et al., 1966, Bingham et al., 1982, Brydolf and Segesten, 1994, Daly and Brooke, 1967, Gazzard et al., 1978, Kennedy et al., 1982, Matras et al., 2005, McDonald and Fazio, 1988, de Oliveira et al., 2018, Richbourg, 2012, Thomson et al., 1970, Wilson, 1964), one longitudinal (Roy et al., 1970)), and four were qualitative (Kelly, 1991, Kittscha, 2011, Morris and Leach, 2015, Morris and Leach, 2016). Most were from the UK (11 studies), USA (7 studies), and Australia (6 studies). People with ileostomy due to Crohn's disease or ulcerative colitis were the populations most frequently studied, followed by people with ileostomy due to colorectal cancer. Most expert opinion articles/guidelines were from the UK (23 articles) and USA (15 articles). Specialist nurses (including stoma nurses) contributed to two-thirds of them (29/44; 66%), and dietitians to a smaller proportion (5/44; 11%).

Table 3.5.2.1 Overview of study characteristics

Study design	Number and characteristics of studies	Populations included	Dietary modifications/components reported	Outcomes reported relating to ileostomy management
Experimental studies				
RCT (cross-over design)	4 studies published between 1984 and 2015 Number of participants = range 8-28 2 Australia, 2 UK	Crohn's, UC, colorectal cancer, FAP, bowel obstruction, ischemic bowel	• High v low FODMAP • High refined cereals + sucrose v high unrefined cereals + low sucrose • High v low fat • Marshmallows	1. Volume/weight of stoma output 2. Consistency of stoma output 3. Transit time 4. Abdominal pain
Non-randomised controlled trials	1 study published in 2015 Number of participants = 43 Romania	Not reported	• Low fibre diet v standard care	1. Volume of stoma output 2. Obstruction of stoma 3. Flatulence + odour
Non-randomised controlled trials (cross-over design)	6 studies published between 1962 and 2009 Number of participants = range 1-8 2 Australia, 2 USA, 1 Sweden, 1 UK	Crohn's ± gall bladder disease, UC (condition not reported in all studies)	• High fat v low fat • High fibre v low fibre • Marshmallows • >35 specific foods/drinks including grapes, raw peaches, raisins, strawberries, bananas, baked beans, prune juice, beer, cooked cabbage, corn, water	1. Volume/weight of stoma output 2. Consistency of stoma output 3. Gas 4. Odour 5. Food visible in output
Pre-post studies				
Pre-post intervention design	3 studies published between 2012 and 2015 Number of participants = range 43-203 1 India, 1 Spain, 1 USA	Crohn's, IBD, colorectal cancer, diverticulitis, trauma, ileal perforation, obstruction, gangrenous gut, iatrogenic ileal injury	• Low fibre, low insoluble fibre, low caffeine, high salt • Avoid specific drinks e.g., alcohol + fruit juice, avoid/limit specific foods/drinks if cause problem • Avoid fluids with meals, avoid eating late in day, small + frequent meals, chew well	1. Volume of stoma output 2. Consistency of stoma output 3. Obstruction/ileus 4. Dehydration

Observational studies				
Longitudinal	1 study published in 1970 Number of participants = 344 USA	Crohn's, UC, colorectal cancer, aganglionic megacolon	• Dairy products, nuts, popcorn, fruit, vegetables	1. Diarrhoea 2. Obstruction
Cross-sectional	12 studies published between 1964 and 2018 Number of participants = range 11-952 5 UK, 3 USA, 1 Australia, 1 Brazil, 1 Poland, 1 Sweden	Crohn's, UC, FAP, cancer, c-difficile, radiation damage, ischemia, spina bifida, neurogenic bowel, bowel perforation/kink	• Low fibre, low residue, high fat, high salt, ↑ fluid intake, alcohol • Beans, onion, cabbage, parsley, spinach, lettuce, beer, beetroot, peas, fizzy drinks, nuts, carrot, corn, fruit, seeds/skin/pith, veg., fish, cheese, egg, spice, shellfish, pickles, popcorn, bran, dairy products, meat, cereal, potato, legumes, celery, rhubarb, mushrooms, pineapple, oranges • Avoid/limit eating late in day, small meals, chew well	1. Volume of stoma output 2. Consistency of stoma output 3. Output flow 4. Leakage 5. Obstruction 6. Pain 7. Flatulence 8. Odour 9. Food visible in output
Qualitative studies				
Interviews	4 studies published between 1991 and 2016 Number of participants = range 6-45 3 UK, 1 Australia	Crohn's, UC, cancer	• Low fibre, low fat • Oranges, onion, curry, nuts, fruit, whole meal bread, banana, baked beans, vegetable stalks, apple skin, grapefruit pith, milk, beansprouts, lettuce • Small + frequent meals, chew well, limit intake when out	1. Consistency of stoma output 2. Blockage 3. Pain 4. Flatulence

Abbreviations: FAP, familial adenomatous polyposis; FODMAP, fermentable oligosaccharides, disaccharides, monosaccharides, and polyols; IBD, inflammatory bowel disease; RCT, randomised controlled trial; UC, ulcerative colitis; UK, United Kingdom; USA, United States of America; ↑, increase; +, and.

3.5.3 **Overview of dietary modifications for management of ileostomy-related problems**

Dietary modifications associated with ileostomy-related problems in research studies are presented in tables in the following sections of Chapter 3.5. The large range of oral dietary modifications reported were grouped into three types of dietary strategy: 1) nutrient modifications 2) foods and drinks 3) eating-related behaviours. All reported nutrient modifications and eating-related behaviours are shown in the tables. However, due to the large number of individual foods and drinks reported across studies, only those reported in more than one study are included in the tables (a full list of all individual foods and drinks reported across studies is provided in Appendix V). Time frames covered by the studies included the initial post-operative healing period (most pre-post and qualitative studies, and some experimental studies) and beyond the initial 6 to 10-week healing period (most observational studies, and some experimental studies). Expert opinion articles recommended a wide range of dietary modifications for ileostomy management in both the initial post-operative healing period and beyond (Appendix V).

The number of nutrient modifications, individual foods and drinks, and eating-related behaviours reported to be associated with aspects of ileostomy management varied considerably across the different study types. In experimental studies (n=11), nine nutrient modifications and 34 individual foods and drinks were investigated, but no eating-related behaviours. In pre-post studies (n=3), ten nutrient modifications, 80 foods and drinks, and 11 eating-related behaviours were investigated. In observational studies (n=13), eight nutrient modifications, 94 foods and drinks, and five eating-related behaviours were reported.

In qualitative studies (n=4), two nutrient modifications, 17 foods and drinks, and one eating-related behaviour were reported. In expert opinion articles/guidelines (n=44), 51 nutrient modifications, 339 foods and drinks, and 23 eating-related behaviours were suggested to have either positive or negative consequences for ileostomy management.

3.5.4 **Volume and consistency of stoma output**

Nutrient modifications suggested to reduce volume of stoma output in experimental studies were low fibre (Mogos et al., 2015, Gaffney et al., 1987a, Gaffney et al., 1987b), low fat (Higham and Read, 1990), low Fermentable Oligosaccharides, Disaccharides, Monosaccharides, And Polyols (FODMAP) (Barrett et al., 2010), high refined carbohydrate (Berghouse et al., 1984), and restricted fluid intake (Kramer, 1987) (Table 3.5.4.1). A low

FODMAP diet was also shown to thicken output consistency in one study (Barrett et al., 2010). One observational study reported increased output volume with a high fat diet (de Oliveira et al., 2018), and a pre-post study also suggested high fat to be associated with loose, watery output (Nagle et al., 2012). Alcohol was suggested to increase output in two pre-post studies (Nagle et al., 2012, Arenas Villafranca et al., 2015), and was associated with increased loose, watery output in one observational study (Thomson et al., 1970).

Table 3.5.4.1 (part 1 of 2) Dietary modifications affecting volume of stoma output

Dietary component (n studies)	**Type of study (+/-)**
Volume of stoma output	
Nutrient modifications	
Low fibre (1)	Experimental (+)
High fat (2)	Experimental (-) Observational (-)
Low fat (1)	Experimental (+)
High FODMAP (1)	Experimental (-)
Low FODMAP (1)	Experimental (+)
High refined carbohydrate + high sucrose (1)	Experimental (+)
High unrefined carbohydrate + low sucrose (1)	Experimental (-)
Decrease fluid intake (1)	Experimental (+)
Alcohol (3)	Pre-post (-) Observational (-)
Foods and drinks[*]	
Marshmallows (2)	Experimental (+)
Beans (2)	Observational (-)
Baked beans (2)	Experimental (-)
Beer (2)	Experimental (+) Observational (-)
Beetroot (2)	Observational (-)
Cabbage, cooked/unspecified (3)	Experimental (-) Pre-post (-) Observational (-)
Cereal (2)	Observational (-)
Fruit, raw/unspecified (2)	Pre-post (-) Observational (-)
Milk (2)	Experimental (neutral) Pre-post (-)
Mushroom (2)	Observational (-)
Onion (2)	Observational (-)
Peach, raw/unspecified (2)	Experimental (-) Observational (-)
Prune juice (2)	Experimental (-)
Raisins (2)	Experimental (-) Pre-post (-)
Vegetables, green leafy or raw/unspecified (2)	Pre-post (-) Observational (-)
Eating-related behaviours	
Consume more in day/less in evening (2)	Pre-post (+)
Consume fluids with meals (1)	Pre-post (-)

FODMAP, fermentable oligosaccharides, disaccharides, monosaccharides, and polyols;
+ = positive consequence of dietary component for associated ileostomy-related problem;
- = negative consequence of dietary component for associated ileostomy-related problem;
[*] Only includes foods and drinks reported in >1 study.

Table 3.5.4.1 (part 2 of 2) Dietary modifications affecting consistency of stoma output

Consistency of stoma output	
Nutrient modifications	
Fibre (1)	Qualitative (-)
High fat (1)	Pre-post (-)
High FODMAP (1)	Experimental (-)
Low FODMAP (1)	Experimental (+)
Added sugar (1)	Pre-post (-)
Alcohol (1)	Observational (-)
Foods and drinks[*]	
Marshmallows (3)	Experimental (+/neutral) Pre-post (+)
Banana (3)	Pre-post (+) Qualitative (-)
Cereal (2)	Observational (-)
Cheese (2)	Pre-post (+) Observational (-)
Dairy products (3)	Pre-post (-) Observational (-)
Fish, fried/grilled/boiled/unspecified (3)	Pre-post (-) Observational (-)
Fruit, raw/unspecified (5)	Pre-post (+) Observational (-) Qualitative (-)
Milk (2)	Pre-post (-) Observational (-)
Onion (3)	Observational (-) Qualitative (-)
Potato (4)	Pre-post (+) Observational (-)
Rice (2)	Pre-post (+)
Spice (2)	Pre-post (-) Observational (-)
Toast (2)	Pre-post (+)

FODMAP, fermentable oligosaccharides, disaccharides, monosaccharides, and polyols;
+ = positive consequence of dietary component for associated ileostomy-related problem;
- = negative consequence of dietary component for associated ileostomy-related problem;
[*] Only includes foods and drinks reported in >1 study.

In terms of individual foods and drinks, 32 were tested in experimental studies where output volume was reported (22 made no difference, eight had a negative effect, and two had a positive effect; Appendix V). In pre-post studies, people were advised to avoid/limit 13 foods and drinks to reduce output volume, and 27 foods and drinks were suggested to alter output consistency. In observational studies, 33 foods and drinks were reported to increase output volume, and 40 were associated with loose, watery output. Across all studies, 23 of the foods and drinks were associated with output volume and/or consistency in more than one study (Table 3.5.4.1). Most were fruit, vegetables, and dairy products and intake was adversely associated with output volume/consistency, although there was suggestion of a beneficial effect of marshmallows. However, some conflicting evidence between different study types was observed (e.g., beer, banana, cheese, fruit, and potato were associated with both beneficial and adverse changes in stoma output; Table 3.5.4.1). The proportion of participants

within studies that reported associations between specific foods/drinks and output, however, was highly variable and mostly <50% (see Appendix IV for key findings by study).

For dietary behaviours, some pre-post studies advised eating more in the daytime and less in the evening to manage stoma output (Nagle et al., 2012, Mukhopadhyay et al., 2015), but consuming fluids with meals (during the initial post-operative period) was suggested to increase output volume (Arenas Villafranca et al., 2015) (Table 3.5.4.1).

In expert opinion articles and guidelines, over 30 nutrient modifications were reported to have positive or negative consequences for stoma output volume, and 20 for output consistency (Appendix V). The most common advice was that alcohol increases volume of output (eight articles) (Rudoni and Russell, 2016, Bracey and Mortensen, 2015, Bradshaw and Collins, 2008, Gondal and Trivedi, 2013, Fleming and Mortensen, 2011, Pachocka and Urbanik, 2016, McDonough, 2013, Hanachi et al., 2012) and causes loose, watery output (seven articles) (Pachocka and Urbanik, 2016, St-Cyr and Gilbert, 2011, Fleming and Mortensen, 2011, Burch, 2011a, Burch, 2008, Bracey and Mortensen, 2015, Burch, 2011b). It was also frequently reported that caffeine causes high and/or loose, watery output (six articles) (Rudoni and Russell, 2016, Bracey and Mortensen, 2015, Fleming and Mortensen, 2011, Pachocka and Urbanik, 2016, McDonough, 2013, St-Cyr and Gilbert, 2011), while low fibre, and high starch, diets were reported to prevent or help to resolve this (five (O'Connor and Dehavillande, 2016, Burch, 2017, Gabe and Slater, 2013, Slater, 2012, Dizer et al., 2011) and eight (Slater, 2012, Fulham, 2008b, Gondal and Trivedi, 2013, Goodey and Colman, 2016, Berti-Hearn and Elliott, 2019, Wound Ostomy Continence Nurses Society Guideline Development Task Force, 2018, Gabe and Slater, 2013, Cremen and Lee, 2016) articles respectively). However, there was conflicting advice on whether a high fibre diet was beneficial or detrimental for managing high and/or loose, watery output (two reported it as beneficial (Kwiatt and Kawata, 2013, Martin and Vogel, 2012), four as detrimental (Burch, 2017, Fulham, 2008b, Gondal and Trivedi, 2013, Burch, 2011a)). Insoluble fibre was suggested to have a negative consequence while soluble fibre was recommended as positive, in two articles (Collins and Sulewski, 2011, Pachocka and Urbanik, 2016). High fat and high sugar diets were reported to have negative consequences for stoma output, in three articles respectively (Kwiatt and Kawata, 2013, Hanachi et al., 2012, Gondal and Trivedi, 2013, McDonough, 2013, Martin and Vogel, 2012). Advice to reduce hypotonic fluids to reduce stoma output was common and consistent across five articles (Gondal and Trivedi, 2013, Goodey and Colman, 2016, Slater, 2012, McDonough, 2013, Wound Ostomy Continence

Nurses Society Guideline Development Task Force, 2018). Less frequently, advice extended to also reduce hypertonic fluids (McDonough, 2013, Wound Ostomy Continence Nurses Society Guideline Development Task Force, 2018). Isotonic/rehydration drinks were recommended in three articles (O'Connor and Dehavillande, 2016, Rudoni and Russell, 2016, Goodey and Colman, 2016), and three provided general advice to decrease fluid intake if high and/or loose, watery output occurred (Pachocka and Urbanik, 2016, Stankiewicz et al., 2019, Martin and Vogel, 2012). Three articles recommended the consumption of fluids between, rather than with, meals to prevent high volume of stoma output (Goodey and Colman, 2016, Fulham, 2008b, McDonough, 2013). Small, frequent meals were also recommended in several articles to manage stoma output (Akbulut, 2011, Gondal and Trivedi, 2013, Berti-Hearn and Elliott, 2019, Collins and Sulewski, 2011).

Over 100 specific foods and drinks were reported in expert opinion articles and guidelines in relation to volume and consistency of stoma output (Appendix V). Refined, starchy carbohydrate foods and gelatine-containing sweets were commonly reported to be beneficial for management of stoma output. Common types of foods and drinks reported to be detrimental were fruits, vegetables, wholegrain foods, fried and spicy foods, along with caffeinated and fizzy drinks.

3.5.5 **Dehydration**

Findings in relation to dehydration include only dietary advice/modifications provided to people with an ileostomy in general. As stated in the methods, studies/articles where the concept was fluid management for an acute/severe problem in people with an ileostomy (e.g., high output requiring hospital admission), were not included in this review.

Very few research studies reported on dietary management of dehydration in this context. One observational study suggested that increasing fluid intake was beneficial (Brydolf and Segesten, 1994) and one pre-post study that consuming adequate fluid in line with standard recommendations for healthy individuals and rehydration fluids were beneficial (Nagle et al., 2012) (Table 3.5.5.1).

Table 3.5.5.1 Dietary modifications affecting dehydration

Dietary component (n studies)	Type of study (+/-)
Dehydration	
Nutrient modifications	
Rehydration fluid (1)	Pre-post (+)
Normal fluid intake (1)	Pre-post (+)
Increase fluid intake (1)	Observational (+)

+ = positive consequence of dietary component for associated ileostomy-related problem;
- = negative consequence of dietary component for associated ileostomy-related problem.

In expert opinion articles/guidelines, 14 nutrient modifications were advised to manage dehydration (Appendix V). The most common advice was to ensure adequate fluid intake in line with standard recommendations for healthy individuals (seven articles) (Bak, 2008, Burch, 2011b, Black, 2009a, Fulham, 2008a, Fulham, 2008b, Berti-Hearn and Elliott, 2019, Kirkland-Kyhn et al., 2018), consume higher amounts of salt/sodium (13 articles) (Kirkland-Kyhn et al., 2018, Burch, 2011b, Burch, 2011a, Stankiewicz et al., 2019, Berti-Hearn and Elliott, 2019, Fulham, 2008b, Burch, 2008, Cronin, 2013, St-Cyr and Gilbert, 2011, Dizer et al., 2011, Bradshaw and Collins, 2008, Burch, 2013, McDonough, 2013), and consume isotonic/rehydration fluids (10 articles) (Stankiewicz et al., 2019, Rudoni and Russell, 2016, Burch, 2008, Cronin, 2013, Gabe and Slater, 2013, Gondal and Trivedi, 2013, Pachocka and Urbanik, 2016, Kirkland-Kyhn et al., 2018, Hanachi et al., 2012, Kwiatt and Kawata, 2013). Other advice was to increase fluid intake (four studies) (Burch, 2011a, Pachocka and Urbanik, 2016, McDonough, 2013, Dizer et al., 2011), and to limit or avoid caffeine (three articles) (Rudoni and Russell, 2016, Fulham, 2008b, Kirkland-Kyhn et al., 2018) and alcohol (one article) (Rudoni and Russell, 2016). Hypertonic fluids or excessive amounts of hypotonic fluids were reported to contribute to dehydration, as was consumption of fluids with meals (one article each) (Cronin, 2013, Kwiatt and Kawata, 2013, Stankiewicz et al., 2019). High sugar drinks (three articles) (Rudoni and Russell, 2016, Stankiewicz et al., 2019, Kirkland-Kyhn et al., 2018) and a diet high in sugar or fat (one article) (Kwiatt and Kawata, 2013) were reported to negatively affect hydration. A high potassium diet was advised to be beneficial with regard to dehydration (two articles) (St-Cyr and Gilbert, 2011, Berti-Hearn and Elliott, 2019). The advice regarding fibre was unclear with a low fibre diet advised to be beneficial in one article (Burch, 2008) and conflicting recommendations between two articles on whether a high fibre diet was advisable (Kirkland-Kyhn et al., 2018, Stankiewicz et al., 2019).

Thirty-one specific foods and drinks and consumption of five specific fluids in excessive quantity were reported in expert opinion articles/guidelines in relation to dehydration with an ileostomy (Appendix V). Two articles suggested that increasing water intake was beneficial (Kirkland-Kyhn et al., 2018, Collins and Sulewski, 2011), while two advised that water, particularly in excessive amounts, had a negative effect (Stankiewicz et al., 2019, Kwiatt and Kawata, 2013). There was also contradictory advice between articles on consumption of fruit juice (Rudoni and Russell, 2016, Stankiewicz et al., 2019, Kwiatt and Kawata, 2013). Coffee (Pachocka and Urbanik, 2016, Stankiewicz et al., 2019, Kwiatt and Kawata, 2013, Rudoni and Russell, 2016) and diet drinks (Fulham, 2008b, Dizer et al., 2011) were reported to be detrimental, while milk and squash were recommended (Rudoni and Russell, 2016, St-Cyr and Gilbert, 2011).

3.5.6 **Flatulence and odour**

A high fibre diet increased flatulence (Gaffney et al., 1987a), while a low fibre diet reduced flatulence and odour (Mogos et al., 2015, Gaffney et al., 1987b) in experimental studies (Table 3.5.6.1). A pre-post study suggested that alcohol was associated with increased flatulence and odour (Nagle et al., 2012), and this association was also reported in an observational study (Thomson et al., 1970).

No individual foods and drinks were reported in experimental studies in relation to flatulence or odour as outcomes. In pre-post studies, 21 foods and drinks were suggested to increase flatulence, and 27 to affect odour (20 increased, seven reduced odour). In observational studies, forty-two foods and drinks were associated with increased flatulence, and 37 with odour (three of which were reported to be beneficial) (Appendix V). Across all studies, 17 of the foods and drinks were associated with flatulence and/or odour in more than one study (Table 3.5.6.1). Common foods and drinks reported to increase flatulence and odour were fibrous vegetables, beans, animal products, and fizzy drinks.

In pre-post studies, patients were advised that eating quickly and chewing gum increases flatulence (Mukhopadhyay et al., 2015, Nagle et al., 2012) (Table 3.5.6.1). No other studies mentioned eating-related behaviours in relation to flatulence or odour.

Table 3.5.6.1 Dietary modifications affecting flatulence and odour

Dietary component (n studies)	Type of study (+/-)
Flatulence	
Nutrient modifications	
High fibre (1)	Experimental (-)
Low fibre (2)	Experimental (+)
Alcohol (2)	Pre-post (-) Observational (-)
Foods and drinks[*]	
Beans (2)	Pre-post (-) Observational (-)
Beer (2)	Pre-post (-) Observational (-)
Cabbage (3)	Pre-post (-) Observational (-)
Cauliflower (2)	Pre-post (-) Observational (-)
Cucumber (2)	Pre-post (-) Observational (-)
Dairy products (2)	Pre-post (-) Observational (-)
Egg (3)	Pre-post (-) Observational (-)
Fish, boiled/grilled/fried/unspecified (2)	Pre-post (-) Observational (-)
Fizzy drinks (4)	Pre-post (-) Observational (-)
Fruit (2)	Observational (-)
Onion (4)	Pre-post (-) Observational (-)
Peanuts (2)	Pre-post (-) Observational (-)
Peas (2)	Observational (-)
Eating-related behaviours	
Chewing gum (2)	Pre-post (-)
Eat fast (1)	Pre-post (-)
Odour	
Nutrient modifications	
Low fibre (1)	Experimental (+)
Alcohol (2)	Pre-post (-) Observational (-)
Foods and drinks[*]	
Beans (4)	Pre-post (-) Observational (-)
Cabbage (3)	Pre-post (-) Observational (-)
Cheese, strong/unspecified (2)	Pre-post (-) Observational (-)
Egg (4)	Pre-post (-) Observational (-)
Fish, boiled/grilled/fried/unspecified (4)	Pre-post (-) Observational (-)
Lettuce (2)	Observational (+/-)
Meat (2)	Pre-post (-) Observational (-)
Onion (5)	Pre-post (-) Observational (-)
Parsley (2)	Pre-post (+) Observational (+)

+ = positive consequence of dietary component for associated ileostomy-related problem;
- = negative consequence of dietary component for associated ileostomy-related problem;
[*] Only includes foods and drinks reported in >1 study.

In expert opinion articles/guidelines, alcohol was reported to increase flatulence in three articles (Schreiber, 2016, Zeigler and Min, 2017, Pachocka and Urbanik, 2016). One article suggested that a high fat diet increases flatulence and odour (Bradshaw and Collins, 2008), and another that a high fibre diet increases flatulence (Fulham, 2008b). A vegetarian diet was also reported to increase flatulence in one article (Hall, 2018). Fifty-five foods and drinks (some only if consumed in excessive quantity) were reported to increase flatulence, and 13 to reduce flatulence (Appendix V). Thirty-eight foods and drinks were reported to increase odour, and 21 to reduce odour. Types of foods and drinks reported to increase flatulence and/or odour were most commonly fibrous vegetables, beans, animal products, and fizzy drinks.

Eating-related behaviours suggested to increase flatulence were chewing gum (eight articles) (Bradshaw and Collins, 2008, Cronin, 2013, Collins and Sulewski, 2011, Zeigler and Min, 2017, St-Cyr and Gilbert, 2011, Pachocka and Urbanik, 2016, McDonough, 2013, Dizer et al., 2011), drinking through a straw (five articles) (St-Cyr and Gilbert, 2011, Collins and Sulewski, 2011, Zeigler and Min, 2017, McDonough, 2013, Dizer et al., 2011), talking while eating (three articles) (Dizer et al., 2011, Cronin, 2013, Collins and Sulewski, 2011), drinking quickly/gulping (Cronin, 2013), rushing meals (Dizer et al., 2011), eating with mouth open (St-Cyr and Gilbert, 2011), sucking sweets (St-Cyr and Gilbert, 2011), and infrequent meals (McDonough, 2013) (one article each).

Small, frequent, and regular meals were recommended to reduce flatulence (Akbulut, 2011, Collins and Sulewski, 2011, Dizer et al., 2011, Kirkland-Kyhn et al., 2018, Hall, 2017), as well as chewing well (Hall, 2017). Gradual reintroduction of foods after surgery was also suggested as a strategy to manage flatulence and odour in one article (Berti-Hearn and Elliott, 2019).

3.5.7 **Blockage**

In experimental studies, a low fibre diet reduced risk of blockage in the initial post-operative healing period (Mogos et al., 2015) (Table 3.5.7.1). In one pre-post study, avoiding high intakes of insoluble fibre prevented blockage (Arenas Villafranca et al., 2015). Another suggested that consuming fluids between meals reduced risk of blockage (Mukhopadhyay et al., 2015). A high fibre or high residue diet was associated with increased risk of blockage in observational studies (Gazzard et al., 1978, Roy et al., 1970), and this association was also reported in two qualitative studies (Kelly, 1991, Kittscha, 2011).

Table 3.5.7.1 Dietary modifications affecting blockage

Dietary component (n studies)	Type of study (+/-)
Blockage	
Nutrient modifications	
High residue (1)	Observational (-)
High fibre (3)	Observational (-) Qualitative (-)
Low fibre (1)	Experimental (+)
High insoluble fibre (1)	Pre-post (-)
Foods and drinks[*]	
Apple skin (3)	Pre-post (-) Observational (-) Qualitative (-)
Bran (2)	Experimental (-) Observational (-)
Nuts (4)	Pre-post (-) Observational (-) Qualitative (-)
Orange, pith/unspecified (2)	Pre-post (-) Observational (-)
Popcorn (2)	Pre-post (-) Observational (-)
Sweetcorn (2)	Pre-post (-) Observational (-)
Eating-related behaviours	
Consume fluids between meals (1)	Pre-post (+)

+ = positive consequence of dietary component for associated ileostomy-related problem;
- = negative consequence of dietary component for associated ileostomy-related problem;
[*] Only includes foods and drinks reported in >1 study.

No foods and drinks were tested in experimental studies in relation to blockage, but in one study, All-bran caused obstruction resulting in discontinuation of testing (Kramer, 1987). Patients were advised to be cautious with 16 individual foods in one pre-post study due to risk of blockage (Nagle et al., 2012). Nine foods and drinks in observational studies, and four in qualitative studies, were associated with blockage (Appendix V). Across all studies, six foods were reported in more than one study to be associated with blockage or obstruction and were those high in insoluble fibre i.e., fruits, vegetables, nuts, and wholegrains (Table 3.5.7.1).

In expert opinion articles/guidelines, a diet high in fibre (Burch, 2011a, Black, 2009a, Fulham, 2008b, Deitz and Gates, 2010, Burch, 2015, Black, 2009b, St-Cyr and Gilbert, 2011, Berti-Hearn and Elliott, 2019) or specifically insoluble fibre (McDonough, 2013, Wound Ostomy Continence Nurses Society Guideline Development Task Force, 2018) was commonly reported to increase risk of blockage (eight and two articles, respectively). Recommendations to prevent blockage were to ensure adequate fluid intake in line with guidance for healthy individuals (four articles) (Akbulut, 2011, Bak, 2008, Berti-Hearn and Elliott, 2019, Kirkland-Kyhn et al., 2018) or increase fluid intake (two articles) (Schreiber,

2016, Wound Ostomy Continence Nurses Society Guideline Development Task Force, 2018), and to follow a low fibre diet during the initial post-operative healing period (one article) (St-Cyr and Gilbert, 2011). Eighty foods were reported to increase risk of blockage (Appendix V). Types of foods commonly reported to increase risk were those high in insoluble fibre including fruits, vegetables, nuts, and wholegrains. By far the most common eating-related behaviour recommended to reduce risk of blockage was to chew well (17 articles) (Bak, 2008, Burch, 2008, Burch, 2011a, Burch, 2011b, Collins and Sulewski, 2011, Schreiber, 2016, Zeigler and Min, 2017, Burch, 2015, Burch, 2013, McDonough, 2013, Berti-Hearn and Elliott, 2019, Kirkland-Kyhn et al., 2018, Burch, 2019, Dizer et al., 2011, Dorman, 2009, Fulham, 2008b, Fulham, 2008a). Other behavioural advice reported was to reintroduce foods gradually (Burch, 2011a, McDonough, 2013), cook food until soft (Berti-Hearn and Elliott, 2019), and to consume small, frequent meals, avoiding large portions (Dorman, 2009, Kirkland-Kyhn et al., 2018).

3.5.8 **Malnutrition and malabsorption**

In one experimental study, a low fibre diet reduced malnutrition during the initial post-operative healing period (Mogos et al., 2015) (Table 3.5.8.1). In another, corn was visible in the stoma output, showing it had not been digested (Kramer et al., 1962). Fourteen foods were reported in observational studies to be visible in stoma output (Appendix V) but only nuts were reported in more than one study (Bingham et al., 1982, McDonald and Fazio, 1988) (Table 3.5.8.1).

Table 3.5.8.1 Dietary modifications affecting malnutrition and malabsorption (food visible in output)

Dietary component (n studies)	**Type of study (+/-)**
Malnutrition/Malabsorption	
Nutrient modifications	
Low fibre (1)	Experimental (+)
Foods and drinks[*]	
Nuts (2)	Observational (-)

+ = positive consequence of dietary component for associated ileostomy-related problem;
- = negative consequence of dietary component for associated ileostomy-related problem;
[*] Only includes foods and drinks reported in >1 study.

Dietary advice for malnutrition was uncommon in expert opinion articles/guidelines; however, a diet high in energy (Slater, 2012), protein (Fulham, 2008b), calcium (Fulham, 2008b), vitamin B12 (Akbulut, 2011), and salt (Collins and Sulewski, 2011) was recommended to prevent or treat malnutrition (Appendix V). Low fat sources of protein were advised (Akbulut, 2011), and supplement use recommended in the initial post-operative

period (Fulham, 2008b). The following were reported to contribute to malnutrition: high sugar, high soluble fibre, excessive consumption of hypotonic or hypertonic fluids, alcohol, and caffeine (McDonough, 2013). Snacks between meals were recommended in two articles to prevent malnutrition (Collins and Sulewski, 2011, Fulham, 2008b). Three foods (corn, nuts, and vegetables) were reported to be visible in stoma output, but only in one article (Martin and Vogel, 2012) (Appendix V).

3.5.9 **Pain and leakage**

In an experimental study, participants in the high and low FODMAP intervention groups reported pain while on the diet (Barrett et al., 2010). Alcohol was also associated with pain in one observational study (Thomson et al., 1970) (Table 3.5.9.1).

Thirty-three foods and drinks were associated with pain in observational studies, and three in qualitative studies (Appendix V), but only nuts and skins were reported in more than one study to be associated with pain (Kennedy et al., 1982, Daly and Brooke, 1967) (Table 3.5.9.1).

Leakage was only reported as an outcome associated with diet in two observational studies. High fat and fluids (de Oliveira et al., 2018), consuming most of daily intake in the evening (Daly and Brooke, 1967) (Table 3.5.9.1), and four foods high in insoluble fibre (de Oliveira et al., 2018), were associated with leakage (Appendix V).

Table 3.5.9.1 Dietary modifications affecting pain and leakage

Dietary component (n studies)	**Type of study (+/-)**
Pain	
Nutrient modifications	
High FODMAP (1)	Experimental (-)
Low FODMAP (1)	Experimental (-)
Alcohol (1)	Observational (-)
Foods and drinks[*]	
Skins e.g. fruit skin (2)	Observational (-)
Nuts/peanuts (3)	Observational (-) Qualitative (-)
Leakage	
Nutrient modifications	
High fat (1)	Observational (-)
Fluids (1)	Observational (-)
Eating-related behaviours	
Consume less in day/more in evening (1)	Observational (-)

FODMAP, fermentable oligosaccharides, disaccharides, monosaccharides, and polyols;
+ = positive consequence of dietary component for associated ileostomy-related problem;
- = negative consequence of dietary component for associated ileostomy-related problem;
[*] Only includes foods and drinks reported in >1 study.

In expert opinion articles and guidelines, only pulses and green vegetables were reported to cause pain (Hall, 2018), and none for leakage (Appendix V). No specific nutrients or eating-related behaviours were reported in relation to either pain or leakage.

3.5.10 **Unspecified outcomes**

Certain nutrient modifications (e.g., low fibre, high salt), foods/drinks (e.g., beans, fizzy drinks, fruit, nuts, vegetables), and eating-related behaviours (e.g., chew well, small frequent meals) also reported within the outcomes sections above were suggested to be associated with ileostomy management but the specific outcome(s) they related to (e.g., high stoma output or blockage) was not identified. A full list of these nutrient modifications and eating-related behaviours that were reported in research studies, along with individual foods and drinks reported in more than one study (n=16), are presented in Table 3.5.10.1.

Details of all foods and drinks reported without specified outcome are included in Appendix V as well as dietary modifications reported in expert opinion articles/guidelines.

Table 3.5.10.1. Dietary modifications affecting unspecified outcomes

Dietary component (n studies)	Type of study (+/-)
Unspecified outcomes	
Nutrient modifications	
High fibre (1)	Observational (-)
Low fibre (1)	Pre-post (+)
High fat (3)	Pre-post (-) Observational (+/-)
High sodium (1)	Pre-post (+)
High potassium (1)	Pre-post (+)
High salt (1)	Observational (+)
Increase fluid intake (2)	Observational (+)
Foods and drinks[*]	
Banana (2)	Observational (-) Qualitative (-)
Beans (2)	Pre-post (-) Observational (-)
Cabbage (2)	Observational (-)
Carrot (2)	Observational (-)
Coconut (2)	Observational (-)
Corn (2)	Observational (-)
Egg (2)	Observational (-)
Fizzy drink (2)	Pre-post (-) Observational (-)
Fruit, raw/seeds/skin/unspecified (5)	Per-post (-) Observational (-)
Lettuce (3)	Observational (-) Qualitative (-)
Mushroom (2)	Observational (-)
Nuts (3)	Observational (-)
Onion (2)	Observational (-)
Orange (2)	Observational (-)
Peas (2)	Observational (-)
Pineapple (2)	Observational (-)
Popcorn (2)	Observational (-)
Potato (2)	Observational (+/-)
Spice (2)	Observational (-)
Vegetables, raw/unspecified (3)	Pre-post (-) Observational (-)
Eating-related behaviours	
Reintroduce foods gradually (1)	Pre-post (+)
Chew well (4)	Pre-post (+) Observational (+)
Chewing gum (1)	Pre-post (-)
Drink with a straw (1)	Pre-post (-)
Eat fast (1)	Pre-post (-)
Consume more in day/less in evening (1)	Observational (+)
Consume less when out (1)	Observational (+)
Small, frequent meals (3)	Pre-post (+) Qualitative (+)
Reduced size and frequency of meals (1)	Observational (+)
Small portions (1)	Observational (+)
Small bites (1)	Pre-post (+)

+ = positive consequence of dietary component for associated ileostomy-related problem;
- = negative consequence of dietary component for associated ileostomy-related problem;
[*] Only includes foods and drinks reported in >1 study.

3.6 DISCUSSION

3.6.1 Overview of key findings

This is the first review to systematically and comprehensively search and synthesize the literature relating to oral dietary strategies for ileostomy management. A large range of oral dietary strategies have been reported which could be grouped into three types of dietary strategy: 1) nutrient modifications 2) foods and drinks 3) eating-related behaviours. The research evidence for most dietary strategies came primarily from observational studies, nearly all of which were cross-sectional and relied on participant self-report. Ten outcomes relating to ileostomy management were identified in relation to these dietary strategies: volume and consistency of stoma output, dehydration, flatulence, odour, blockage, pain, malnutrition, food visible in output, and leakage.

Quality assessment of studies was not included as part of the scoping review. Heterogeneity of studies in terms of dietary strategies reported and outcomes measured prevented the possibility of providing evidence-based recommendations for practice. Only four RCTs had been published (each investigating a different dietary strategy) and all had small sample sizes, the largest being 28 participants (Barrett et al., 2010, Berghouse et al., 1984, Clarebrough et al., 2015, Higham and Read, 1990). None of the 11 experimental studies (including non-RCTs) had a sample size over 50, and over half had less than 10 participants. This limitation in sample size meant that the majority were under powered and had poor generalizability of findings. Pre-post studies included a combination of dietary strategies in the intervention. The benefit of this is that it represents real-world practice; however, it is impossible to determine which components of the intervention contributed to its effectiveness. In observational studies, the reliance on self-report of diet and ileostomy-related outcomes is a common weakness. Integral to this, specifically in the context of the aims of this review, is the inability to determine from the findings whether reported associations between specific dietary strategies/components and a particular outcome were based on practical experience of the participant or advice they received and followed. Inclusion of qualitative studies helped ensure the full range of potential dietary strategies for ileostomy management was mapped. However, due to the nature of the included qualitative studies, little insight can be gained into the effectiveness of any dietary strategy reported, or how widely it is used.

In research studies, approximately 20 nutrient modifications, over 100 individual foods and drinks, and approximately 15 eating-related behaviours were reported for the dietary

management of ileostomies, with an even greater number in expert opinion articles. The most common nutrient modifications across research studies and expert opinion were fibre, fat, and alcohol. Across most outcomes and articles, low fibre and low fat were suggested to be beneficial, while alcohol was detrimental. Other nutrient associations frequently reported in expert opinion (but with minimal attention in research studies), included negative consequences of caffeinated drinks and positive consequences of white, starchy carbohydrates on stoma output. Eating-related behaviours were infrequently reported in research studies and, where they were, this was usually as part of a multi-component intervention in pre-post studies, or occasionally in observational studies, and usually not associated with a specific outcome. As expected, the issues commonly addressed were the same as those that caused difficulty for large numbers of people with an ileostomy in the survey (Study 2), namely very loose or watery stoma output, wind or gas, high volume of stoma output, and increased odour from stoma bag (Mitchell et al., 2020). Volume and consistency of stoma output were the outcomes most commonly reported across all study types, but it is likely that there was some overlap in the findings related to these outcomes as volume (over a short time period) usually increases when output is more loose and watery. Flatulence and odour were also common outcomes in observational studies. Other overlaps in findings may occur. For example, volume and consistency of output, and amount of gas produced (flatulence), will also contribute to the risk of leakage, and pain may be caused by wind or blockage.

The scoping review search found a large amount of expert opinion published in the last 10 years. Despite limited research evidence for any one dietary strategy, this abundance of expert opinion reflects the common provision of dietary advice for people with an ileostomy in clinical practice; highlighted in the survey of people with an ileostomy in the UK and Ireland (Mitchell et al., 2020) which is presented in Chapter 5 (Study 2). In line with results from the survey showing a high prevalence of conflicting dietary advice, there was considerable variation in the oral dietary strategies recommended by expert opinion for ileostomy management. Lists of foods and drinks that could cause a specific negative outcome, e.g., high output, were often reported without guidance on whether people with an ileostomy should limit, avoid completely, or cautiously consume and only avoid if problematic, these foods and drinks. Other articles did acknowledge individual differences in tolerating certain foods and drinks, suggesting a gradual trial and error approach following ileostomy surgery. This approach is supported by findings from observational studies where

many individual foods and drinks were reported by some to be problematic; however, most people with an ileostomy could tolerate the same foods and drinks well. In some studies, a small number of foods were reported as problematic by a high proportion of people with an ileostomy, but most were problematic to <50% (Bingham et al., 1982, Gazzard et al., 1978, McDonald and Fazio, 1988, de Oliveira et al., 2018, Richbourg, 2012, Thomson et al., 1970). Many of the foods and drinks reported to be problematic for ileostomy management are those known to have varying levels of negative GI consequences, e.g. causing wind or diarrhoea, in the general population (Staudacher and Whelan, 2017). For example, beans and onions are known gas-producing foods. Therefore, educating people with an ileostomy, and all healthcare professionals who provide dietary advice, to have a basic understanding of digestion by-products could aid dietary management.

Underlying active disease of the functioning GI tract, for example Crohn's disease, is a potential confounding factor when considering the effect of diet on outcomes relating to ileostomy management (McDonald and Fazio, 1988). People with an ileostomy who also have active disease and/or have had other surgery to their small intestine, such as inflammation or resection resulting in anastomoses or stricture, have a greater physiological propensity to experience consequences of dietary intake on ileostomy management (Fulham, 2008b). In addition to these factors, whether a certain food is problematic is likely to vary depending on the quantity and frequency of consumption, how the food has been prepared (e.g. vegetables that have been very well cooked until soft have been suggested to be better tolerated), how well the person chews the food, and what it is consumed with (Berti-Hearn and Elliott, 2019, Dorman, 2009). Most information about how a food was prepared and consumed is unknown and/or unreported in studies. Furthermore, in observational studies, it is often unclear whether a participant who reports avoiding a specific food or drink does so because they have been advised of the potential adverse consequence or because they have personally experienced a problem.

3.6.2 **Strengths and limitations**

Strengths of this scoping review include development and publication of an a priori search strategy and protocol (Mitchell et al., 2019). Inclusion of contemporary published expert opinion in addition to research studies enabled us to report findings that can inform discussion around clinical practice. Specifically, our results show the extent of, and variation in, dietary advice for people with an ileostomy that, in recent years, clinical experts have

believed to be beneficial, and promoted. By presenting this information from clinical practice alongside a synthesis of the research evidence, the extent to which research findings inform and are reflected in the dietary advice provided to people with an ileostomy can be seen. Understanding current perspectives and behaviours in clinical practice also helps to inform priorities for future research. Another strength of this review was that a multidisciplinary team of reviewers was involved at all stages of the review process providing diversity of clinical and methodological perspectives.

There are also some limitations. Due to the sheer number of individual foods and drinks reported across studies, only those reported in more than one study were presented within the main tables. This may suggest that these foods/drinks were definitively associated with outcomes, but as discussed above the evidence was not clear cut for most foods. Another limitation that readers should keep in mind is that this review did not include acute fluid management or dietary management in people with short bowel syndrome. There is a large body of literature in this area which lends itself to a separate review since these findings and recommendations are not appropriate for inclusion within general dietary advice for people with an ileostomy.

There were a small number of full texts we were unable to access for screening (Appendix II), but these were generally expert opinion articles or articles published a long time ago. In addition, some foreign language articles may have been missed due to use of all English search terms. However, we did include eligible foreign language articles from our database searches. Since the purpose of this scoping review was to map the evidence available to inform dietary management for people with an ileostomy, the small amount of evidence that we were unable to access is unlikely to have added much to the findings or meaningfully changed the conclusions.

3.6.3 **Recommendations for future research**

This review suggests that fibre modification plays a key role in dietary management for people with an ileostomy and highlights a need for research into relative contributions of soluble and insoluble fibre (in the diet overall and in specific foods or meals) to outcomes relating to ileostomy management, when adjusting overall fibre intake.

Observational studies have shown large variation in the extent and components of dietary strategies used by people with an ileostomy. Inter-individual factors contribute to differences in response to specific dietary strategies. As such, there is a need for future research to

investigate individual risk of problems with ileostomy management and how this could be measured, and to test associations with diet in groups with different level of risk i.e., low versus moderate versus high risk.

Longitudinal studies investigating associations between well-defined dietary strategies and outcomes related to ileostomy management are needed, particularly RCTs, to improve understanding of causality. For example, a better understanding is needed of whether dietary strategies to prevent adverse outcomes for ileostomy management are effective in the short- and/or long-term following ileostomy surgery, and whether the same or different dietary strategies are effective in managing/resolving common issues when they arise. Future studies should include larger sample sizes, justified by sample size calculations, and ideally be powered for subgroup analyses, for example to compare participants with extensive small bowel resection versus those with ileostomy only.

Future research should combine quantitative assessment of adherence to dietary strategies, and clinical and QoL outcomes, with a qualitative approach to understanding attitudes and determinants relating to dietary management of ileostomies. This represents a current gap in the literature and is essential to inform implementation of effective provision of dietary advice to people with an ileostomy.

3.6.4 **Conclusion**

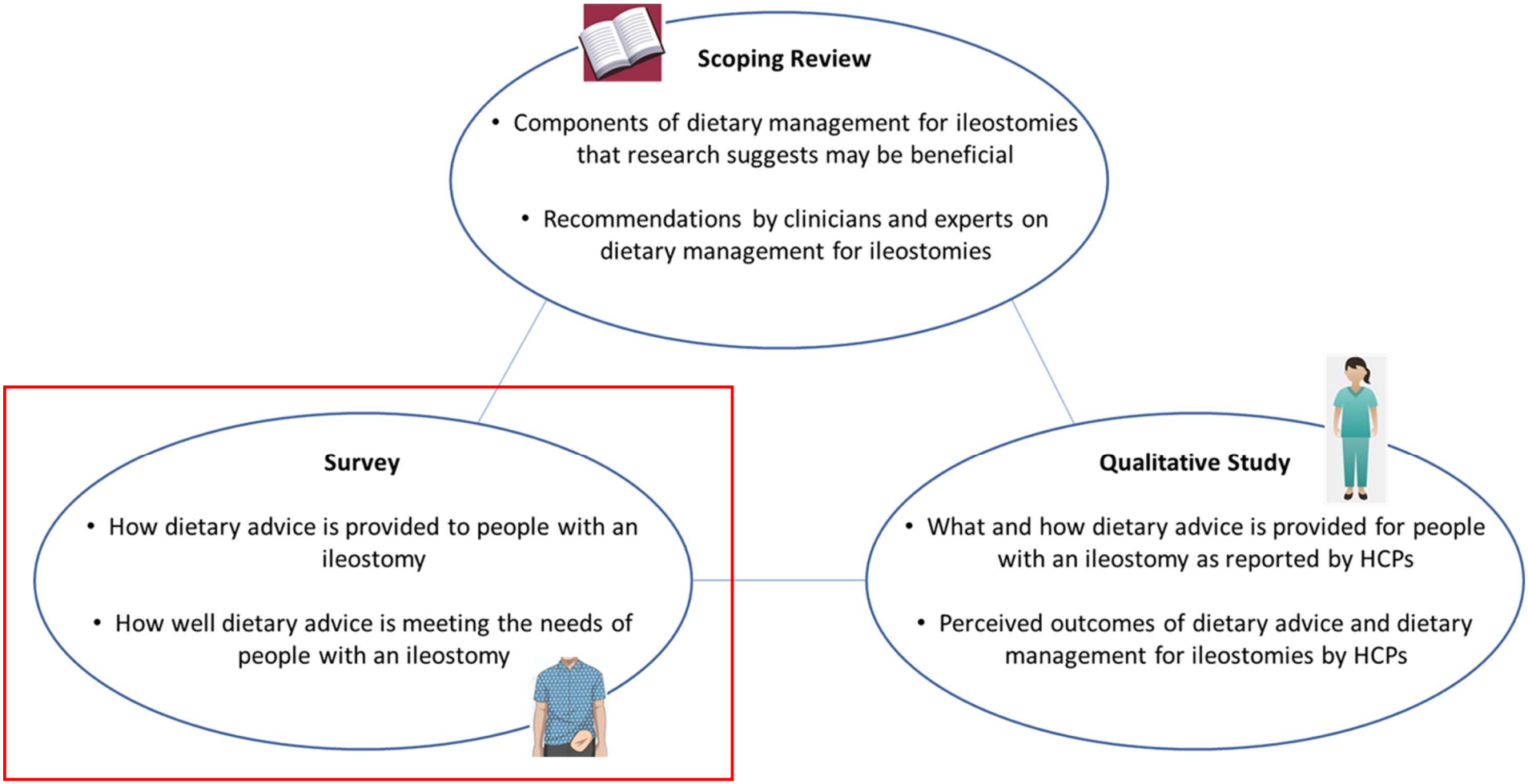
This review has shown that there is an abundance of literature reporting on dietary management for people with an ileostomy. However, this literature is highly heterogenous in terms of the dietary strategies and outcomes reported. The quantity of expert opinion far outweighed the number of research studies, and it is likely that most dietary advice provided in practice is based on expert opinion with some supported by limited research. As demonstrated by the variation in advice between expert opinion articles published in the last decade, the lack of a robust evidence-base to inform advice may lead to it being inadequate, inconsistent, and often conflicting. Dietary advice may also be overly restrictive without strong evidence to support the need for this. Acknowledgement by healthcare professionals of the uncertainty in dietary advice for ileostomy management and potential for individual differences in response to diet is important to increase understanding and trust.

3.7 IMPLICATIONS FOR THESIS

Study 1 explores and describes how there is inadequate research evidence to establish effectiveness of dietary management, and therefore to determine best practice and advice, for people with an ileostomy. Overall, the range of current evidence summarised in this scoping review confirms that adapting diet for ileostomy management is likely to be beneficial for many people; however, the many different dietary strategies/modifications reported in research studies, along with considerable variation in advice reported in expert opinion articles, shows that there is still a long way to go in identifying the best dietary advice for people with an ileostomy, and if/how this advice should be adapted to the individual.

In addition to identifying the available evidence that should under-pin clinical practice, we need to further understand how dietary advice is provided and perceived in current practice. This will allow us to consider ways in which this aspect of care might be improved for people with an ileostomy. To start to address these gaps in knowledge, I designed and conducted two further studies. Firstly, an online survey to identify if and how people with a new ileostomy received dietary advice, and their attitudes towards this advice. Secondly, a qualitative study involving interviews with healthcare professionals in which they share their perspectives on the dietary advice they provide to people with an ileostomy. The methods and findings of these studies are described in the next two chapters.

STUDY 2. Provision of dietary advice for people with an ileostomy: a survey in the UK and Ireland



4 STUDY 2 – PROVISION OF DIETARY ADVICE FOR PEOPLE WITH AN ILEOSTOMY: A SURVEY IN THE UK & IRELAND

4.1 CHAPTER INTRODUCTION

Study 2 contributes to answering the second and third questions posed to address the overall thesis aim - What dietary advice is provided to people with a new ileostomy, and why? How is dietary advice being provided to people with an ileostomy?

It had been suggested that current provision of dietary advice for people with an ileostomy fails to meet patient need. For example, a qualitative study in 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 (Morris and Leach, 2015). In a Swedish survey of ostomy patients' perceptions of quality of care, 95% of ileostomists believed information on diet was important; however, 36% (14/39) said information received was not satisfactory (Persson et al., 2005). 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 (Beeken et al., 2019). Of those who received dietary advice, 82% found this useful. However, in the last study, results were not reported separately by stoma type. These studies suggest that dietary advice is not always provided to people undergoing ileostomy formation and where it is dietary advice may often be unsatisfactory.

No previous studies have comprehensively described attitudes to dietary advice or established the range of sources from which dietary advice was received for people living with an ileostomy. Study 2, an online survey, was designed to provide a more detailed and large-scale picture of dietary advice provision in the UK and Ireland from the perspective of people living with an ileostomy. This knowledge is important to better understand the issues relating to provision of dietary advice for people with an ileostomy. The aims of this study were to explore 1) the proportion of ileostomists who received dietary advice for ileostomy management; 2) source(s) of advice; 3) attitudes towards advice; and 4) perceived need for dietary advice.

This chapter includes the methods and findings of the online survey which have been published in the journal 'Colorectal Disease' (Mitchell et al., 2020). Some further details

have been added to the text from the journal article in this chapter for the thesis. The chapter concludes with consideration of the implications of this study for the thesis.

4.2 METHODS

Patient and public involvement

The important contribution that patients and members of the public can make to ensuring that research is relevant and well-designed is now widely acknowledged by health researchers and funding bodies (Robinson, 2014). The lived experience of patients and carers gives them a very different perspective on receiving care and participating in research compared to clinicians and researchers. This perspective can provide unique insights into what is important to patients and how studies can be conducted to encourage participation and reduce drop-out.

To harness the knowledge and experience of people who have had an ileostomy, to inform and develop the research for this thesis, I worked with stoma nurses to convene a patient and public involvement (PPI) group. I developed an information sheet and provided invitation letters for the stoma nurses to send out to their patients who had had ileostomy surgery within the past year. Letters were sent out with a compliment slip from the stoma nurses to show patients that their stoma nurse was aware of and supported the proposed research. It was hoped that this would encourage patients to respond to the letter and volunteer to be involved in the PPI group. Sixteen people with an ileostomy were invited to join the PPI group and, of these, five responded to say they would like to be involved.

The role of the PPI group was to advise on aspects of planning and implementation of studies in dietary management of ileostomies. An initial meeting was held in March 2018. Members own experiences were discussed, and it was highlighted that there were many limitations in the dietary advice they received for their ileostomy. I used a consultation approach to ask for their views on the proposed research to ensure the relevance of the research questions, aims and objectives (INVOLVE, 2012).

Questionnaire design and development

An online multiple-choice survey was developed in collaboration with healthcare professionals (HCP) and members of the PPI group. A draft questionnaire was created 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 the PPI group took part in cognitive interviews (with AM) to assess and increase face validity of the questions (Drennan, 2003). Using this method, PPI members spoke out loud their thoughts while completing the survey, and probing questions were used to gain further insight. As well as cognitive interviews, PPI members were asked for their views on the relevance of the questions and if there were any other important aspects they felt were not captured. Based on the cognitive interviews with the first two PPI members, 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 (see Appendix VI). In the cognitive interview with the third PPI member, the updated survey was used and only a few minor changes were made after this.

Recruitment and data collection

Online Surveys (https://www.onlinesurveys.ac.uk) was used to administer the cross-sectional survey. An outline of the survey structure and questions with multiple-choice answers can be seen in Appendix VII. The survey link was available on the websites of the Ileostomy and Internal Pouch Association (IA; 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 ≥16 years and currently living with an ileostomy. Responses from outside the UK and Ireland were excluded. Ireland was included as the IA covers the UK and Ireland and was a main collaborator in disseminating the survey and reaching relevant groups for recruitment.

The first page of the online survey 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, or opt out of completing the survey, prior to submission.

Data analysis

A convenience sample anonymously responded to the survey. Responses were downloaded to SPSS v24.0 (IBM, 2016) 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. It is conceivable that responses may differ according to length of time since having a stoma placed. Therefore, a post-hoc comparison is presented between those who had been living with an ileostomy for <6 months versus >10 years.

Ethics

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) (Eysenbach, 2004).

4.3 RESULTS

4.3.1 **Respondent characteristics**

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 for analysis. Demographics and clinical characteristics of included respondents are shown in Table 4.3.1.1.

Most of the respondents were female (72.5%), age 45-74 years (64.9%), had an ileostomy due to ulcerative colitis (37.8%), and had an ileostomy for either >10 years (23.7%) or <6 months (21.3%).

Table 4.3.1.1 Respondent characteristics (n=291)

	n (%)
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	
Southeast England	54 (18.6)
Southwest England	42 (14.4)
Scotland	26 (8.9)
West Midlands	25 (8.6)
East Midlands	24 (8.2)
Northwest England	24 (8.2)
London	23 (7.9)
East of England	18 (6.2)
Wales	17 (5.8)
Yorkshire and Humber	17 (5.8)
Northeast 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 to 2 years	46 (15.8)
3 to 5 years	48 (16.5)
6 to 10 years	37 (12.7)
Over 10 years	69 (23.7)
Elective v emergency surgery	
Elective	159 (54.6)
Emergency	125 (43.0)
Not sure	7 (2.4)
Permanent v 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)

4.3.2 **Ileostomy-related problems**

Table 4.3.2.1 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.

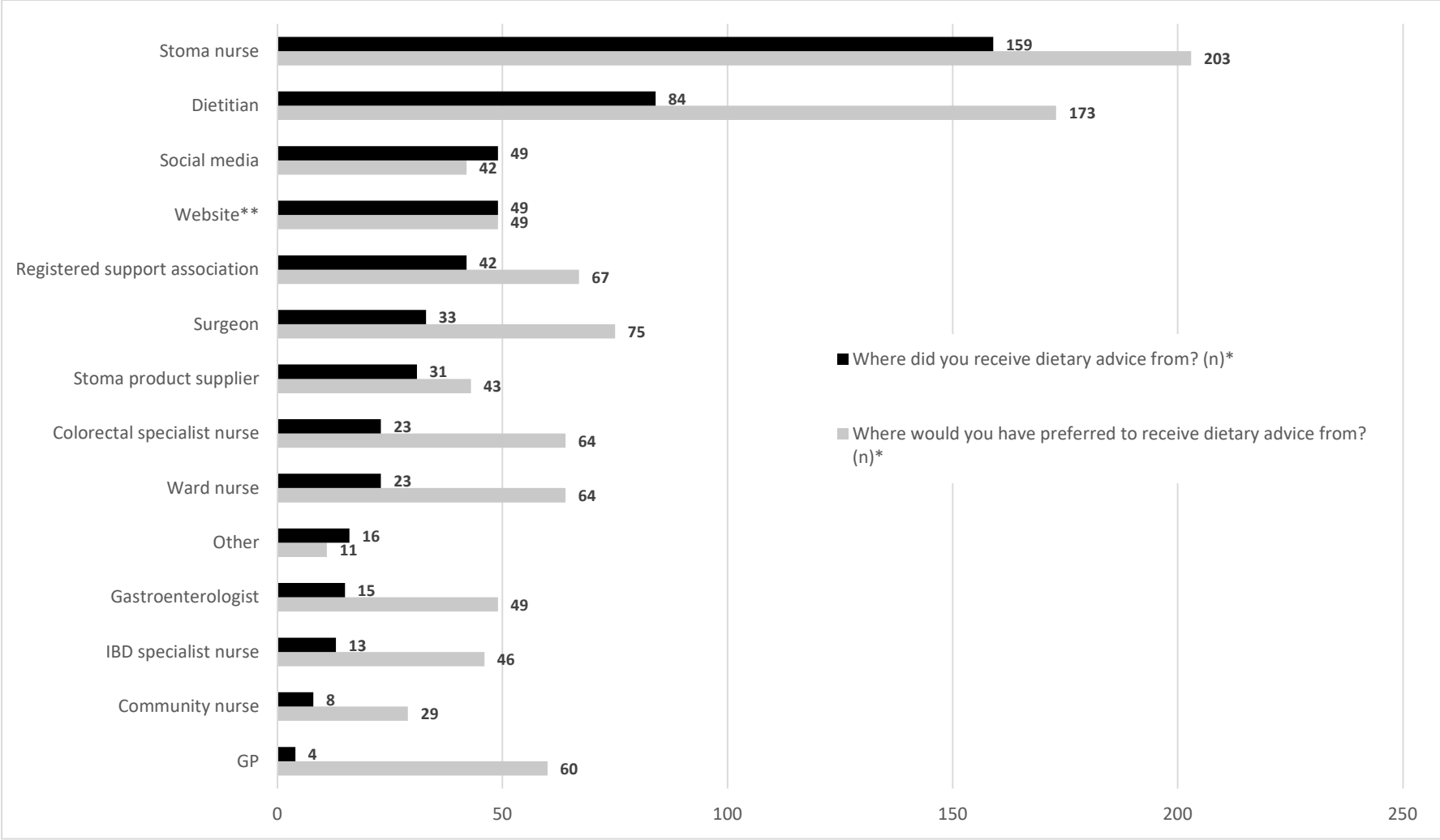
Table 4.3.2.1 Ileostomy-related problems

Since having an ileostomy, have any of the following caused you difficulties?	**n (%)**
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)

4.3.3 **Provision of dietary advice**

Two hundred and one of the 291 respondents (69.1%) received dietary advice for their ileostomy either from a HCP or the internet. Of 90 who did not receive dietary advice, 82 (91.1%) would have liked to.

Figure 4.3.3.1 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. Of those reporting to have received advice from a website, social media, or a registered support association e.g., IA, 92-95% sought out diet advice from these sources.



* 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. IBD, inflammatory bowel disease; GP, general practitioner.

Figure 4.3.3.1. Sources of dietary advice for people with an ileostomy

Table 4.3.3.1 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%, 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 (≤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 (~58%).

Table 4.3.3.2 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 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. 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. Most did not receive advice on weight management (146 of 201, 72.6%). Of those who did, 36 (65.5%) were advised to gain weight, six (10.9%) to lose weight, and 13 (23.6%) to maintain their weight.

Table 4.3.3.1 Format of dietary advice for people with an ileostomy

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

*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. IBD, inflammatory bowel disease; GP, general practitioner.

Table 4.3.3.2 Timing of dietary advice for people with an ileostomy

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

*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. IBD, inflammatory bowel disease; GP, general practitioner.

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 (Figure 4.3.3.2). 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 4.3.3.3). 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.

Table 4.3.3.3 Questions relating to patient satisfaction with dietary advice (n=201)

	Extremely n (%)	**Fairly** n (%)	**Slightly** n (%)	**Not at all** n (%)
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)

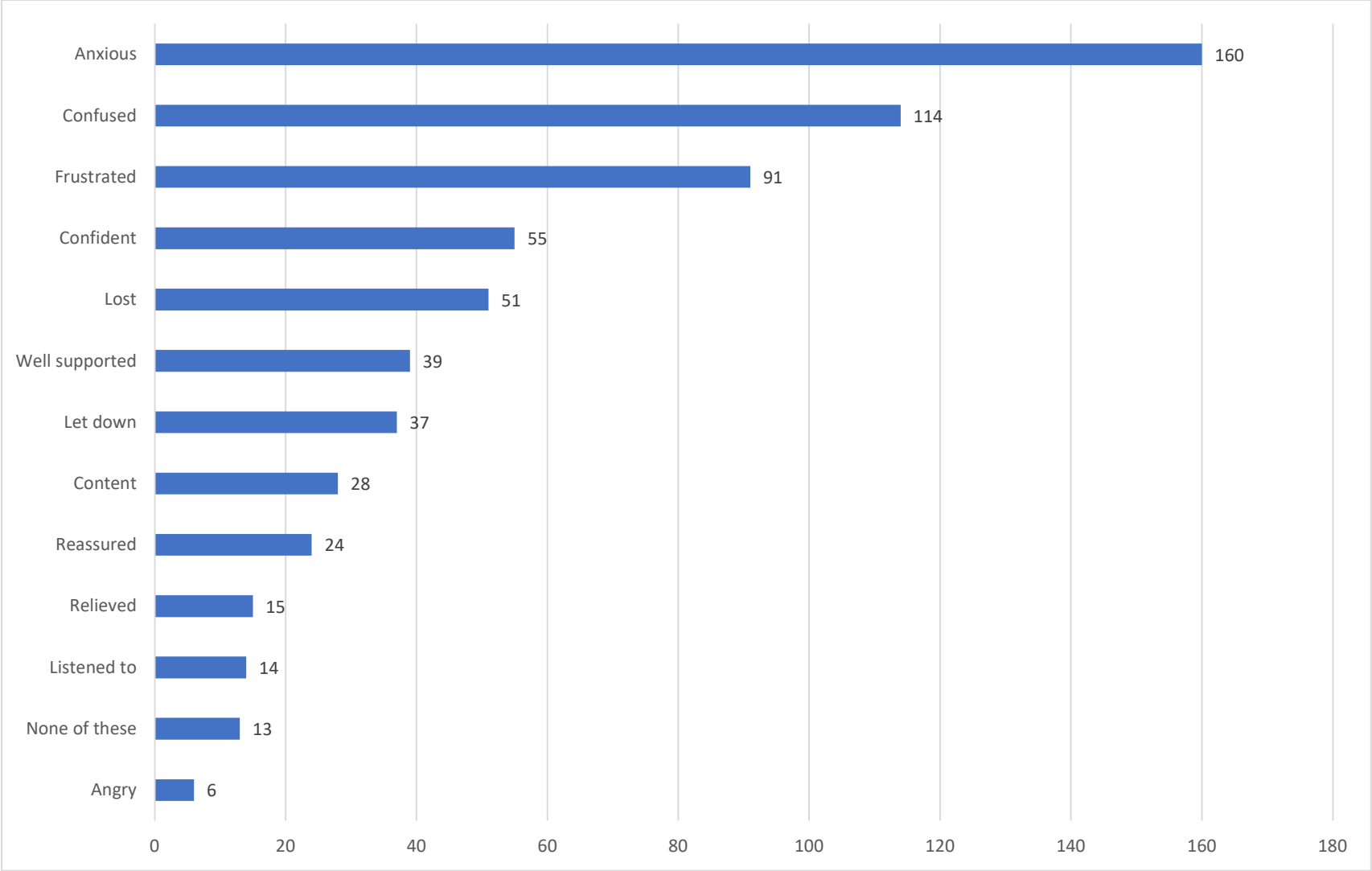


Figure 4.3.3.2 How did/do you feel about managing your diet with a new ileostomy? Select up to 3 options.

4.3.4 **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.

4.3.5 **Subgroup analysis**

Table 4.3.5.1 shows results of interest from the post-hoc subgroup analysis comparing respondents with an ileostomy for less than six months (Group 1; n = 62) and respondents with an ileostomy for more than ten years (Group 2; n = 69). More people in group 1 than group 2 reported receiving any dietary advice (79.0% v 52.2%), and they were more likely to report receiving dietary advice from a stoma nurse (71.0% v 31.9%) and via social media (21.0% v 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 received advice on how to prepare certain foods (71.4% v 30.6%). Nearly all respondents 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% v 77.8%).

Table 4.3.5.1 Comparison of respondents with ileostomy <6 months versus >10 years

	Group 1 **Ileostomy < 6 months**	**Group 2** **Ileostomy > 10 years**
Number of respondents (% of total respondents)	62 (21.3)	69 (23.7)
Number who received dietary advice (%)	49 (79.0)	36 (52.2)
Number who received dietary advice from a stoma nurse (%)	44 (71.0)	22 (31.9)
Number who received dietary advice via social media (%)	13 (21.0)	6 (8.7)
Number who received conflicting dietary advice (% of respondents who received dietary advice)	32 (65.3)	20 (55.6)
Number who received advice on how to prepare certain foods (% of respondents who received dietary advice)	35 (71.4)	11 (30.6)
Number who made changes to their diet based on advice received (% of respondents who received dietary advice)	47 (95.9)	28 (77.8)

4.4 DISCUSSION

4.4.1 Overview of key findings

This study highlights 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 wanted it. A recent UK-based study of people with an output stoma of any type reported similar findings (Beeken et al., 2019), 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. These findings support those from the Swedish survey of ostomy patients' perceptions of quality of care which highlighted that dietary advice was important to people with an ileostomy (95%) but over a third found the advice they received to be unsatisfactory (Persson et al., 2005).

There was 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 (Morris and Leach, 2015) and dissatisfaction with preoperative advice regarding appropriate dietary choices for people with a stoma (Short et al., 2016). It is 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, as highlighted in Study 1 (Baker, 2015, Mitchell et al., 2021). Provision of appropriate advice is also complicated by individual variation due to differences in length and health of functioning intestine, sometimes in addition to independent co-morbidities such as diabetes (Fulham, 2008b, Medlin, 2012).

The most common problems experienced by survey respondents were loose and high output (86.6% and 62.5% respectively) and gas (70.8%). Only 1.7% had no difficulties due to any of the following: loose or high output, gas, odour, pain, or blockage. 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. A previous survey carried out in the USA found that, out of 174 respondents with an ileostomy, 67.2% reported their dietary choices were affected by having an ileostomy (Richbourg, 2012). In a recent cross-sectional study conducted in Brazil, 32.5% of participants with an ileostomy reported that they avoided specific foods due to fear of increased output, 27.5% due to increased odour, and 40.0% due to increased gas (de

Oliveira et al., 2018). These and other studies investigating whether having an ileostomy affects dietary choices have shown that the type and extent of dietary modification is variable (Richbourg, 2012, Bingham et al., 1982, Thomson et al., 1970, de Oliveira et al., 2018). Foods most commonly avoided are nuts, types of vegetables and fruits (particularly if raw), corn and legumes (Richbourg, 2012, de Oliveira et al., 2018). However, some people with an ileostomy are able to continue a normal diet without apparent adverse consequence (Richbourg, 2012).

4.4.2 **Strengths and limitations**

A strength of this study is that it is the first study 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. Another key strength was the use of cognitive interviews and collaboration with a wide range of stakeholders when designing the questionnaire (Drennan, 2003). This increased face validity, reducing risk of respondents misinterpreting questions and responses, and ensured questions were relevant and comprehensive.

This study also has some limitations. Although there was engagement 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 female, whereas Hospital Episodes Statistics (HES) suggest that ~47% of ileostomies are in females (NHS digital, 2018). Over-representation of women is common in studies where surveys are the primary data collection method (Smith, 2008). An additional limitation is that self-selection bias may have resulted in responders with more ileostomy-related problems than non-responders, and who were perhaps therefore more interested in diet and diet-related issues.

A wide range of ages were represented, although there were fewer responses in the 16-24 years age group, reflecting the smaller proportion of ileostomy surgeries performed in this age range (NHS digital, 2018). Older adults ≥75 years were under-represented, perhaps due to social media as the primary mode of survey distribution (NHS digital, 2018). All regions of Great Britain were well represented; however, small numbers of respondents from Northern Ireland and the Republic of Ireland may limit generalisability to these countries. Similarly, it was not possible to look at regional variations due to the small group numbers if responses were broken down by region.

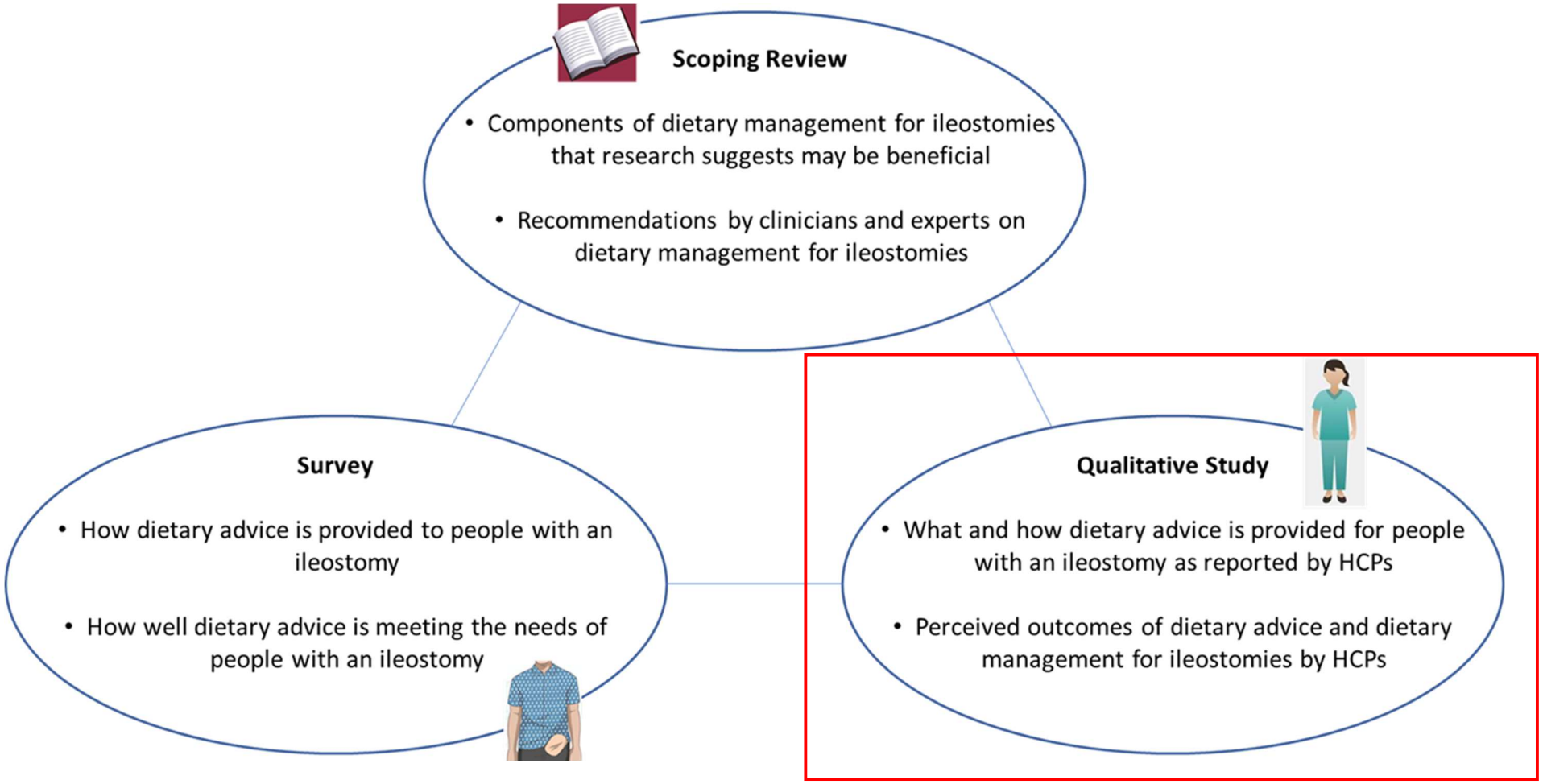
4.4.3 Conclusion

The findings of this survey suggest that there is an unmet need for high quality dietary advice among people who undergo ileostomy surgery. Diet-related complications and difficulties as well as anxiety about managing diet with a new ileostomy are 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 available to all patients undergoing ileostomy formation and be clear and consistent between HCPs to alleviate concerns and improve stoma management.

4.5 IMPLICATIONS FOR THESIS

Studies 1 and 2 have shown that diet can affect ileostomy symptoms and complications in many ways and that dietary advice is a priority for people with an ileostomy. Together, the findings from these studies demonstrate a need for improvement in quality and consistency of dietary advice and management for people with an ileostomy. A key component of this is the need for high quality research, particularly intervention trials, to inform and develop best practice in the provision of dietary advice to people with an ileostomy. Both studies have confirmed that many HCPs provide dietary advice to people with an ileostomy, with variable advice being based on a combination of expert opinions and inadequate research evidence. Therefore, to develop future interventions with high applicability to real-world contexts, we first need to understand 1) what current care looks like in terms of provision of dietary advice for people with an ileostomy 2) knowledge and beliefs of HCPs involved in providing advice 3) potential facilitators and barriers to providing effective dietary advice for people with an ileostomy in practice. My final thesis study, a qualitative study utilising in-depth interviews with HCPs, was devised to address these gaps in knowledge.

STUDY 3. Healthcare professionals' perspectives on the dietary advice they provide to people with an ileostomy: a framework analysis of in-depth interviews



5 STUDY 3 - HEALTHCARE PROFESSIONALS' PERSPECTIVES ON THE DIETARY ADVICE THEY PROVIDE TO PEOPLE WITH AN ILEOSTOMY: A FRAMEWORK ANALYSIS OF IN-DEPTH INTERVIEWS

5.1 CHAPTER INTRODUCTION

Study 3 contributes further to answering the second and third questions posed to address the overall thesis aim - What dietary advice is provided to people with a new ileostomy, and why? How is dietary advice being provided to people with an ileostomy?

Studies 1 and 2 have demonstrated that dietary advice and management for people with an ileostomy is an important issue for patients, and an area of clinical practice that frequently does not meet the needs of this population. Findings show that dietary advice may be provided from many different sources, including a range of healthcare professionals (HCP), and is highly variable in extent and content, often being perceived as conflicting by recipients. Limited evidence suggests that various dietary modifications/strategies are potentially beneficial to some or all people with an ileostomy; however, the evidence base is not sufficient to be conclusive regarding which are the most effective and acceptable dietary strategies.

Following on from these findings, there is a need to develop and test well informed dietary interventions for people with an ileostomy. These interventions need to be based on an understanding of current practice, attitudes of stakeholders, and potential facilitators and barriers to providing effective dietary advice for people with an ileostomy. To address these previously undescribed aspects, I designed a qualitative study to explore these issues with HCPs who currently provide this advice. This study is the final study contribution to the thesis and is presented in this chapter from development and data collection to analysis and interpretation. The chapter concludes with an evaluation of the implications of Study 3 for the thesis.

5.2 METHODS

5.2.1 Aim and objectives

The aim of this study was to investigate the perspectives of healthcare professionals relating to provision of dietary advice to people with an ileostomy.

Six objectives were included in the research proposal:

1. Identify types of dietary advice that may be provided to people with an ileostomy.
2. Identify similarities and/or differences between healthcare professions in their perceptions of dietary advice provided to people with an ileostomy.
3. Identify similarities and/or differences between healthcare professionals at different NHS trusts in their perceptions of dietary advice provided to people with an ileostomy
4. Explore rationale for provision of certain types of dietary advice to people with an ileostomy.
5. Identify healthcare professionals' perceptions of the efficacy of dietary advice for ileostomy management.
6. Identify healthcare professionals' awareness and attitudes to research into dietary management of ileostomies.

5.2.2 Research questions

1) What dietary advice is provided to people with an ileostomy, and how and when is it provided?

2) What factors influence the dietary advice provided to people with an ileostomy?

3) What are the determinants of effective dietary management?

5.2.3 Methodology

A pragmatic approach was taken in designing this study. A key principle of pragmatism that informed the study design was consideration for practical consequences (Johnson and Onwuegbuzie, 2004). Due to the lack of previous investigation on this topic and the complex, social interactions involved in provision of dietary advice to people with an ileostomy, qualitative research methods were considered to be best placed to provide the detailed description and understanding required (Pope and Mays, 1995). As such, this study employed thematic analysis of semi-structured interviews using the Framework approach (Ritchie et al., 2013).

Health services involve complex, multi-level processes; therefore, pragmatic use of both quantitative and qualitative methods is particularly suited to research in this area (Fetters et al., 2013). The quantitative survey conducted in Study 2 provides data on common features of, and attitudes towards, dietary advice provision for people with an ileostomy. However, the interactive process of the provision of dietary advice by a HCP to a patient, in the context of multiple interactions between HCPs and patients, is clearly a complex one that cannot be fully described and understood using quantitative methods alone (Pope and Mays, 1995). In the study presented in this chapter, qualitative methods enabled detailed description of the practices and beliefs of HCPs relating to provision of dietary advice to people with an ileostomy. This description is required to inform the development of future interventions and experimental studies investigating associations between diet and ileostomy management.

5.2.4 **Study design**

Semi-structured interviews were used to explore HCPs' perspectives on dietary advice for management of an ileostomy.

Patient and public involvement

A group of people (n=5) with a new ileostomy in the past year volunteered to be members of a patient and public involvement (PPI) group and were involved in planning and developing this study. This was the same group who were involved in the development of the survey for Study 2. Details of how members of the PPI group were recruited are described in the previous chapter (Chapter 4.2).

A consultation approach was used initially to ask for the group's views on the proposed study to ensure the relevance of the research questions, aims and objectives (INVOLVE, 2012). A meeting was held with three available members who highlighted many limitations in the dietary advice they received after ileostomy formation. All felt that carrying out interviews with HCPs who provide dietary advice to people with an ileostomy, e.g., stoma nurses, surgeons, and dietitians, was an important avenue for research. They reported receiving some dietary advice for their ileostomy from a stoma nurse and surgeon, although all expressed frustration with the overall lack of advice they received. They also reported that some of the advice (verbal and publications) they received was conflicting. These accounts from PPI members reflect findings from previous interviews and surveys conducted with people with an ileostomy (Morris and Leach, 2015, Persson et al., 2005).

The PPI group also contributed to the development of the interview topic guide by highlighting relevant issues for exploration during the consultation meeting and commenting on a draft version (see Appendix VI). As the study participants were to be HCPs, the public contributors were not involved in other aspects of the study design or study implementation.

Study sites

HCPs from three NHS hospitals in England were recruited and interviewed. Sites were chosen to include a combination of large, specialist teaching hospitals and a smaller, district hospital. It was necessary to recruit participants from several sites for two reasons. Firstly, to achieve a sufficient sample size. Secondly, it was considered that participants of the same profession working at the same hospital may provide similar dietary advice due to working closely together and using the same patient-facing publications (online or printed resources). Therefore, it was essential to interview HCPs of the same profession across different sites to meet the second and third study objectives (see section 5.2.1 above).

Eligibility criteria

HCPs who provide dietary advice to adults with an ileostomy as part of their role were eligible to be recruited for this study.

Sampling

A combined purposive and snowballing sampling strategy was employed to identify and recruit the key providers of dietary advice to people with an ileostomy at each site. Purposive sampling is where participants with certain characteristics or experiences are intentionally recruited to ensure a range of viewpoints are included (Ritchie et al., 2013). Snowball sampling involves asking participants to identify other relevant people to approach as further potential participants (Ritchie et al., 2013).

In this study, purposive sampling was used to recruit a representative breadth and depth of HCPs in terms of profession and location, for the purpose of achieving the study aims and objectives. Onwuegbuzie and Leech (2007) recommend including at least three cases from each subgroup (e.g., dietitians) for comparison between subgroups when using qualitative methods and interviews. A quota was set of a minimum of five of the following HCPs who were considered to be the key providers of dietary advice to people with an ileostomy: stoma nurses, dietitians, surgeons, and gastroenterologists.

Ethics and recruitment

This study was approved by the Health Research Authority (HRA) and University of Bristol Faculty Research Ethics Committee in October 2018 (Reference number 74881). The study was also accepted on to the National Institute for Health Research (NIHR) Portfolio (https://www.nihr.ac.uk/researchers/collaborations-services-and-support-for-your-research/run-your-study/crn-portfolio.html).

Local collaborators were identified at three study sites (for the purpose of confidentiality, sites will remain anonymous within this thesis), and confirmation of capacity and capability gained from the site Research and Development (R&D) departments. These local collaborators helped to identify relevant HCPs at their site who were then approached to establish interest in study involvement and to further identify eligible participants in line with eligibility criteria and the sampling design.

Recruitment began in December 2018. The first participant was consented and interviewed in January 2019. Recruitment and interviews were conducted over an 8-month period with the final interview being completed in August 2019.

Consent

All potential participants were provided with a participant information sheet explaining the purpose of the study, what they would be asked to do as a participant, how the information they provide would be used and anonymised, and their right to withdraw from the study at any stage up until 72 hours after the interview (Appendix VIII). After 72 hours, the interview may have been transcribed and withdrawing the data from the study after transcription could have been difficult, for example if ideas had started to be generated from the data. Where possible, participant information sheets were provided at least 24 hours prior to the interview to give eligible HCPs time to consider whether they wanted to participate. In situations where it was not possible to provide the information sheet at least 24 hours in advance and the person was confident that they did wish to participate without additional time for consideration, exceptions to this were made. Prior to starting each interview, the interviewer checked that the participant had read and understood the information provided and asked the participant to sign a consent form (Appendix IX).

Data protection and confidentiality

All study sites were assigned a site study number and all participants allocated a pseudonym identifying their profession and site number e.g., DT-S1-01, which relates to dietitian, site number one, participant number one. Site numbers and participant pseudonyms were used to anonymise all data reported from the study. Interview notes and transcripts were anonymised using pseudonyms.

Due to the relevance to the research aims, characteristics of the study site and the professional occupation of all participants are reported in association with the qualitative data acquired through interviews. Although participants were allocated pseudonyms, it may be possible for some participants to be identified by some readers from the data reported. All participants were informed of this risk as part of the consent process. Due to the nature of the topic being researched which is not sensitive, this did not have an impact on participant recruitment and was judged to be a low-level risk for participants.

Interviews were recorded on an encrypted digital device and transferred to a secure University of Bristol server with password protection. Only members of the research team and identified individuals at a University of Bristol approved transcribing service had access to the interview recordings via a password. Electronic documents containing participant or site data such as transcripts, interview notes, or details of participant allocation to pseudonyms were stored on a secure University of Bristol server with password protection. Paper documents containing participant or site data were stored at the University of Bristol or NHS premises in a locked facility.

Anonymised data will be stored for up to 20 years on the University of Bristol's online Research Data Storage Facility. In accordance with the University's policy for sharing of anonymised research data, participants were asked for their consent to make the anonymised interview transcripts available, on request and following approval, to other researchers for whom this data may help facilitate the answering of their research question.

Data collection

Face-to-face in-depth, semi-structured interviews were carried out with all participants (all interviews were conducted by AM). A topic guide was used to ensure topics relevant to the research questions were covered and also to encourage participants to identify and explore

concepts important to them (Figure 5.2.4.1). As such, participants were asked questions based on the topic guide with additional prompts and questions depending on their responses.

The topic guide was developed based on the clinical experience of members of the research team, concepts suggested in the literature, and the experiences and advice of members of the PPI group (see above) and stakeholders (see Appendix VI). Questions in the topic guide were matched to the study objectives. The topic guide was piloted on the first two participants. After this, it was reviewed by AM and AS, but no further amendments were deemed to be required. Further into the interview process, an additional question was identified that was relevant to some participants but not others. Going forward, this question was asked when deemed appropriate. The question was 'Do you think this approach/practice is typical for your profession?'.

It was anticipated that each interview would last approximately 30-60 minutes. All interviews were audio-recorded and transcribed verbatim by a University of Bristol approved transcription service. Interview transcripts and notes were anonymised prior to analysis.

One participant at each site was asked to provide details on specific site characteristics, i.e., type of hospital (teaching or district general or community etc) and estimated number of initial ileostomy formations carried out annually, for context to aid analysis of the interviews. Copies of publications (printed or online) providing dietary advice to people with an ileostomy that were used at each site were also requested.

Data analysis

Before and while carrying out the interviews and analysis, I engaged in reflexivity by documenting and reflecting on my values, biases, and potential influences as a dietitian who had recently worked in clinical practice and previously provided dietary advice to people with an ileostomy as part of my professional role (Creswell, 2007). This is discussed in further detail in section 5.4.2.

Interview data were analysed using the Framework Method of thematic analysis following a combined inductive and deductive approach (Gale et al., 2013). The analysis process followed was as described by Ritchie et al. (2013) (Figure 5.2.4.2). Initially, transcripts were coded inductively to generate categories and sub-categories for the framework matrix. Once transcripts were coded and charted into the framework matrix, thematic analysis was conducted deductively to identify key themes relevant to the research questions.

Topic Guide for Interviews with Healthcare Professionals

Introduction

- Introduce self
- Check participant has read and understood information sheet
- Explain process for the interview and that it will be audio-recorded
- Gain consent

Advice provided to people with an ileostomy

- How does the provision of dietary advice to people with an ileostomy fit into your role?
    - How long has this been part of your role?
- How much of a priority is providing dietary advice to people with an ileostomy?
- What dietary advice do you give to people with an ileostomy?
    - Does this vary? If so, what influences this? E.g. patient condition (Crohn's/Diabetes Mellitus), symptoms, over/under-weight, patient characteristics, time.
    - When and how is this advice provided? E.g. Before/straight after surgery, after discharge; verbal, printed, online.
- What informs the dietary advice provided? E.g. research evidence, training, clinical experience.
- What is/are your main priority/priorities when providing dietary advice to people with an ileostomy?
- How effective do you believe dietary advice for ileostomies to be?
- How well do you find patients adhere to the dietary advice provided for ileostomies?
    - What do you consider to be the barriers to adherence?
- What issues do ileostomy patients and/or their family/carers report relating to diet?
- Are you aware of specific websites or support groups that patients may be referred to?
- How does dietary management fit in with medical management of ileostomies?

Other healthcare professionals who provide dietary advice to people with an ileostomy

- Who do you think is the main provider of dietary advice to people with an ileostomy?
- Which other healthcare professionals provide dietary advice to people with an ileostomy?
    - Who else is important to interview?
- Are you aware of dietary advice provided by other healthcare professionals to people with an ileostomy?
    - [If applicable] Do you have a view on why there are differences?
- Overall, how sufficient do you feel the advice and support is that people with an ileostomy receive regarding dietary management?

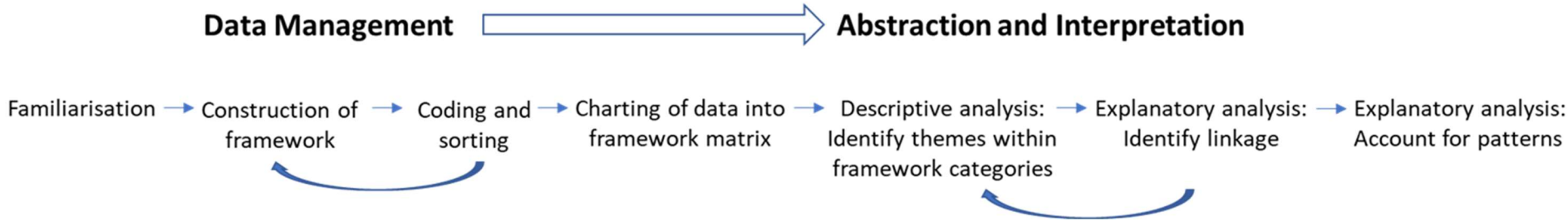
Evidence for dietary management of ileostomies

- To what extent are you aware of the current evidence for dietary management of ileostomies?
- Do you believe that research into dietary management of ileostomies is needed?
    - If so, what is the most important research question to be addressed?

Conclusion

- Summary of points discussed in the interview
- Is there anything else relevant to the topic that you would like to talk about/think we have missed?

Figure 5.2.4.1 Interview topic guide



Adapted from Ritchie et al. (2013)

Figure 5.2.4.2 Framework analysis process

Initially, three transcripts were independently coded by AM and AS, then discussion took place to reach consensus on the coding framework. The codes were grouped into categories and sub-categories that formed the organisational structure for the framework matrix. AM then coded and charted (summarised by code/sub-category) data from all interview transcripts. A sub-set of the interview data was independently coded, and charting checked, by AS who is experienced in qualitative and framework analysis. Details of all steps taken in this process are shown in Table 5.2.4.1. NVivo (QSR International Pty Ltd, Victoria, Australia) was used to organise the data during the analysis process.

The completed framework matrix was used to carry out descriptive and explanatory thematic analysis considering potential influences of professional role and institutional setting. Findings were compared and discussed between AM and AS until consensus was reached. Involving two researchers with different disciplinary backgrounds, i.e., a dietitian with a clinical background in acute care (AM) and a psychologist with a background in health psychology (AS), in the analysis process was done to reduce bias in the interpretation of data from the interview transcripts and to provide a broader perspective enabling more in-depth analysis.

Table 5.2.4.1 Stages of the framework analysis process

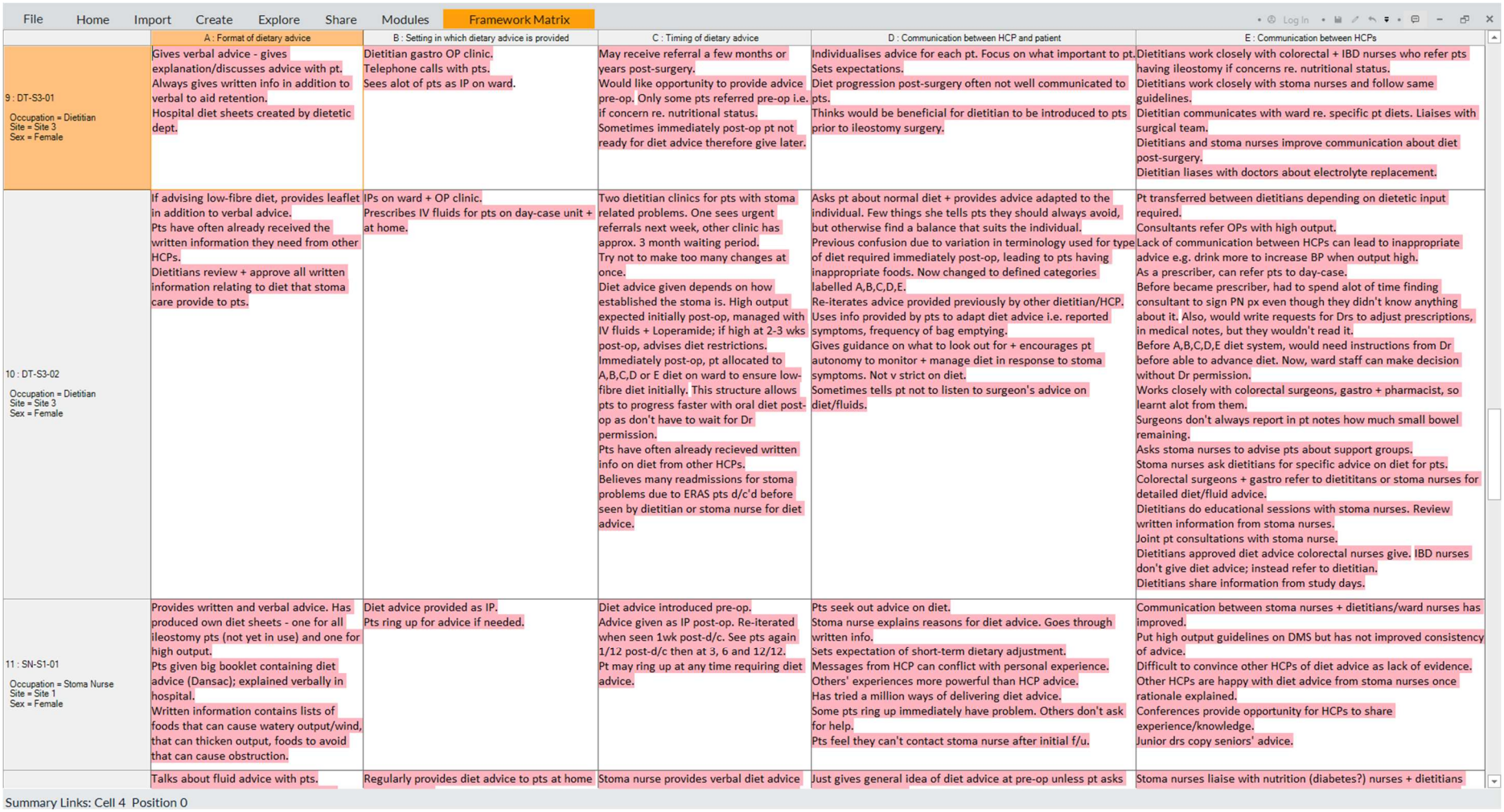
Data management
1. AM and AS independently carried out preliminary coding of three transcripts (from multiple professions and sites) on paper. 2. AM and AS met to discuss preliminary coding and agree on categories and sub-categories to develop a Framework matrix. 3. AM created initial version of the Framework matrix. 4. AS reviewed and agreed initial version of the Framework matrix. 5. AM and AS independently coded one of the initial three transcripts based on the matrix categories, using NVivo. 6. AM and AS met to discuss/resolve differences in matrix coding based on the first transcript. 7. AM and AS independently coded the second transcript based on the matrix categories and clarification on their application from discussion at the previous meeting. 8. AM and AS met to discuss/resolve differences in matrix coding. 9. AM and AS independently coded the third transcript based on the matrix categories and clarification on their application from discussion at the previous meeting. 10. AM and AS met to discuss and resolve differences in matrix coding. 11. AM completed matrix summaries for two of the coded transcripts. 12. AM and AS met to check agreement with summaries and discuss minor changes to the matrix prior to further coding and completion of the matrix for other cases. Identified that summaries needed to be more condensed/concise to provide appropriate overview. 13. AM revised initial two matrix summaries and completed a third. 14. AM and AS met to further review summaries and matrix coding structure. Agreed summaries now at appropriate level. Agreed two sets of two matrix categories to be merged. Therefore, further coding adjusted accordingly. 'Training' and 'Guidelines' combined into 'Formal guidance'. 'Reasons for following diet advice' and 'Barriers to following diet advice' combined into 'Factors influencing adherence to diet advice'. 15. AM coded and completed matrix summaries for a further three transcripts. 16. After a break to complete other studies, AM coded four further transcripts and started to complete matrix summaries for these. 17. At this stage, it became apparent that the scale of proposed analysis was not possible to complete within remaining PhD timeframe. Options were discussed between AM, AS, CA and CE. Decision made that analysis for PhD thesis should be limited to the main providers of diet advice i.e., stoma nurses, dietitians, and colorectal surgeons. Analysis to be extended after PhD completed to include other professionals interviewed. 18. AS checked another completed matrix summary and suggested to reduce use of quotes as they took up unnecessary space (links to transcript text ensure quotes are easily identified). 19. AM coded and completed matrix summaries for the remaining transcripts to be included in the PhD thesis analysis. AS checked two more of these but no changes were required.

Data analysis (abstraction and interpretation)

1. AM and AS independently reviewed the framework matrices to start identifying themes and concepts relevant to answering the research questions.
2. AM and AS met to compare, discuss, and develop initial ideas for themes.
3. AM and AS further reviewed the data using the framework matrices.
4. AM created a schematic model of dietary advice provision based on concepts identified in the interview data.
5. AM and AS met again to compare, discuss, and further develop themes.
6. AM created initial list of themes to be included in the results.
7. AS reviewed the themes and then AM revised the list of themes based on suggestions from AS.
8. Final themes were agreed between AM and AS.

5.2.5 **Worked example of framework analysis**

Once a transcript had been coded, all extracts related to each code were reviewed separately, and summaries of the content were written and added to the framework matrix. This process was repeated for each transcript. Figure 5.2.5.1 shows an extract from the framework matrix. Coded sections of the transcript that a summary statement was based on were linked in NVivo to the relevant text in the framework matrix. This was done to ensure that all summaries were grounded in the raw data and to enable relevant quotes to be quickly identified when writing up the results. An example of this is demonstrated in Figure 5.2.5.2. In this example, the circled summary statement in the framework matrix is linked to the transcript text highlighted in yellow.



File Home Import Create Explore Share Modules Framework Matrix

	A : Format of dietary advice	B : Setting in which dietary advice is provided	C : Timing of dietary advice	D : Communication between HCP and patient	E : Communication between HCPs
9 : DT-S3-01 Occupation = Dietitian Site = Site 3 Sex = Female	Gives verbal advice - gives explanation/discusses advice with pt. Always gives written info in addition to verbal to aid retention. Hospital diet sheets created by dietetic dept.	Dietitian gastro OP clinic. Telephone calls with pts. Sees alot of pts as IP on ward.	May receive referral a few months or years post-surgery. Would like opportunity to provide advice pre-op. Only some pts referred pre-op i.e. if concern re. nutritional status. Sometimes immediately post-op pt not ready for diet advice therefore give later.	Individualises advice for each pt. Focus on what important to pt. Sets expectations. Diet progression post-surgery often not well communicated to pts. Thinks would be beneficial for dietitian to be introduced to pts prior to ileostomy surgery.	Dietitians work closely with colorectal + IBD nurses who refer pts having ileostomy if concerns re. nutritional status. Dietitians work closely with stoma nurses and follow same guidelines. Dietitian communicates with ward re. specific pt diets. Liaises with surgical team. Dietitians and stoma nurses improve communication about diet post-surgery. Dietitian liases with doctors about electrolyte replacement.
10 : DT-S3-02 Occupation = Dietitian Site = Site 3 Sex = Female	If advising low-fibre diet, provides leaflet in addition to verbal advice. Pts have often already received the written information they need from other HCPs. Dietitians review + approve all written information relating to diet that stoma care provide to pts.	IPs on ward + OP clinic. Prescribes IV fluids for pts on day-case unit + at home.	Two dietitian clinics for pts with stoma related problems. One sees urgent referrals next week, other clinic has approx. 3 month waiting period. Try not to make too many changes at once. Diet advice given depends on how established the stoma is. High output expected initially post-op, managed with IV fluids + Loperamide; if high at 2-3 wks post-op, advises diet restrictions. Immediately post-op, pt allocated to A,B,C,D or E diet on ward to ensure low-fibre diet initially. This structure allows pts to progress faster with oral diet post-op as don't have to wait for Dr permission. Pts have often already recieved written info on diet from other HCPs. Believes many readmissions for stoma problems due to ERAS pts d/c'd before seen by dietitian or stoma nurse for diet advice.	Asks pt about normal diet + provides advice adapted to the individual. Few things she tells pts they should always avoid, but otherwise find a balance that suits the individual. Previous confusion due to variation in terminology used for type of diet required immediately post-op, leading to pts having inappropriate foods. Now changed to defined categories labelled A,B,C,D,E. Re-iterates advice provided previously by other dietitian/HCP. Uses info provided by pts to adapt diet advice i.e. reported symptoms, frequency of bag emptying. Gives guidance on what to look out for + encourages pt autonomy to monitor + manage diet in response to stoma symptoms. Not v strict on diet. Sometimes tells pt not to listen to surgeon's advice on diet/fluids.	Pt transferred between dietitians depending on dietetic input required. Consultants refer OPs with high output. Lack of communication between HCPs can lead to inappropriate advice e.g. drink more to increase BP when output high. As a prescriber, can refer pts to day-case. Before became prescriber, had to spend alot of time finding consultant to sign PN px even though they didn't know anything about it. Also, would write requests for Drs to adjust prescriptions, in medical notes, but they wouldn't read it. Before A,B,C,D,E diet system, would need instructions from Dr before able to advance diet. Now, ward staff can make decision without Dr permission. Works closely with colorectal surgeons, gastro + pharmacist, so learnt alot from them. Surgeons don't always report in pt notes how much small bowel remaining. Asks stoma nurses to advise pts about support groups. Stoma nurses ask dietitians for specific advice on diet for pts. Colorectal surgeons + gastro refer to dietititans or stoma nurses for detailed diet/fluid advice. Dietitians do educational sessions with stoma nurses. Review written information from stoma nurses. Joint pt consultations with stoma nurse. Dietitians approved diet advice colorectal nurses give. IBD nurses don't give diet advice; instead refer to dietitian. Dietitians share information from study days.
11 : SN-S1-01 Occupation = Stoma Nurse Site = Site 1 Sex = Female	Provides written and verbal advice. Has produced own diet sheets - one for all ileostomy pts (not yet in use) and one for high output. Pts given big booklet containing diet advice (Dansac); explained verbally in hospital. Written information contains lists of foods that can cause watery output/wind, that can thicken output, foods to avoid that can cause obstruction.	Diet advice provided as IP. Pts ring up for advice if needed.	Diet advice introduced pre-op. Advice given as IP post-op. Re-iterated when seen 1wk post-d/c. See pts again 1/12 post-d/c then at 3, 6 and 12/12. Pt may ring up at any time requiring diet advice.	Pts seek out advice on diet. Stoma nurse explains reasons for diet advice. Goes through written info. Sets expectation of short-term dietary adjustment. Messages from HCP can conflict with personal experience. Others' experiences more powerful than HCP advice. Has tried a million ways of delivering diet advice. Some pts ring up immediately have problem. Others don't ask for help. Pts feel they can't contact stoma nurse after initial f/u.	Communication between stoma nurses + dietitians/ward nurses has improved. Put high output guidelines on DMS but has not improved consistency of advice. Difficult to convince other HCPs of diet advice as lack of evidence. Other HCPs are happy with diet advice from stoma nurses once rationale explained. Conferences provide opportunity for HCPs to share experience/knowledge. Junior drs copy seniors' advice.
	Talks about fluid advice with pts.	Regularly provides diet advice to pts at home	Stoma nurse provides verbal diet advice	Just gives general idea of diet advice at pre-op unless pt asks	Stoma nurses liaise with nutrition (diabetes?) nurses + dietitians

Summary Links: Cell 4 Position 0

Figure 5.2.5.1 Example extract from the framework matrix

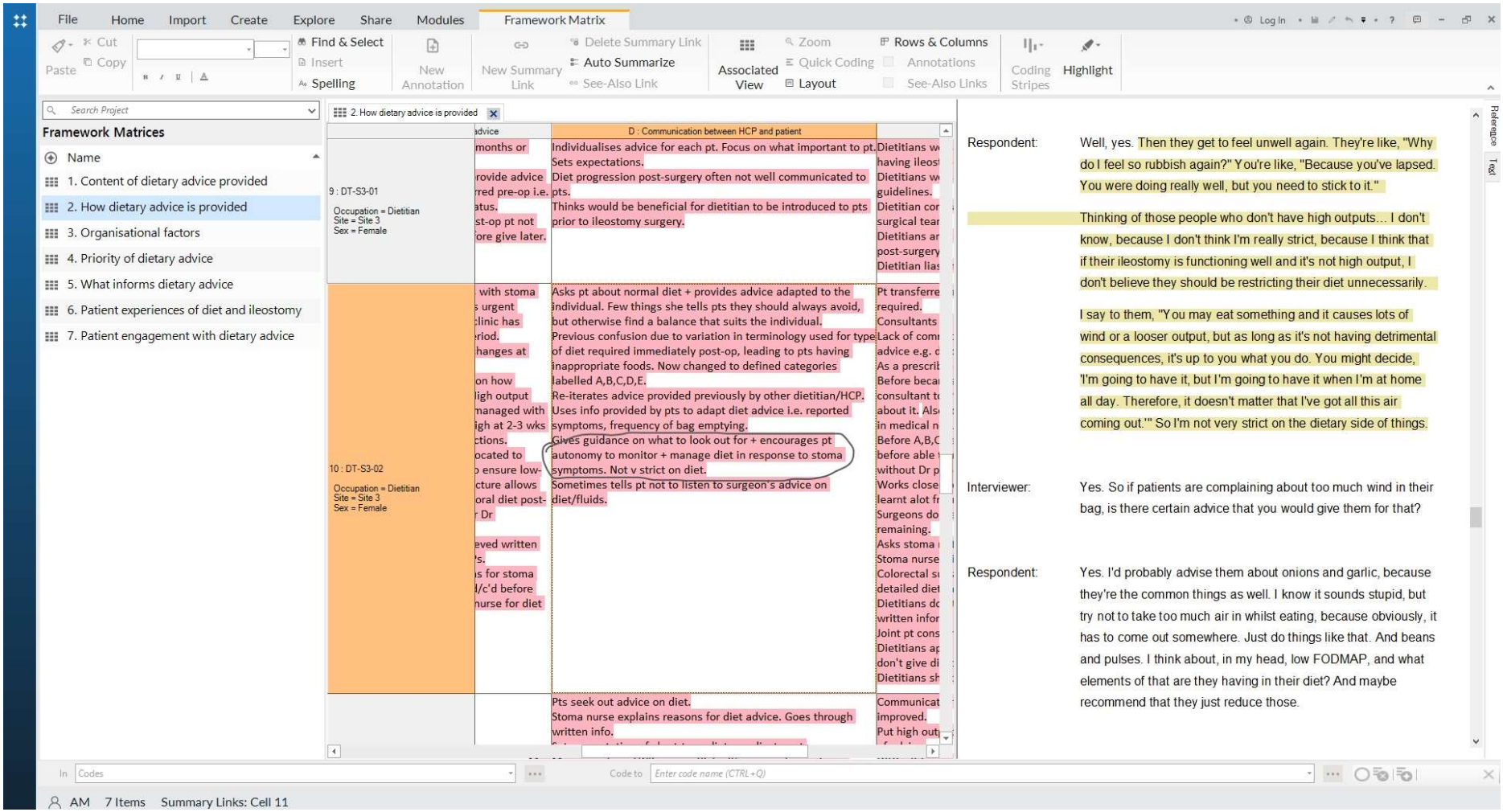


Figure 5.2.5.2. Example of how transcript text is linked to summaries in the framework matrix

5.3 RESULTS

5.3.1 Participants

Twenty-one HCPs were recruited across three study sites (hospitals). Site characteristics reported by one participant from each site are shown in Table 5.3.1.1.

Table 5.3.1.1 Site characteristics

	Type of hospital	**Approximate number of surgeries for initial ileostomy formation per year**
Site 1	Teaching	54 (2017)
Site 2	District general	60 (year not available)
Site 3	Teaching	94 (2018)

Face-to-face interviews were conducted with five stoma nurses, five dietitians, five colorectal surgeons, four colorectal specialist nurses, one IBD specialist nurse, and one gastroenterologist. Interview length ranged from 12 to 67 minutes with a mean length of 39 minutes.

5.3.2 Framework matrix

Coding and development of the framework matrix elicited seven categories and 28 sub-categories relevant to the six objectives (Table 5.3.2.1; Figure 5.3.2.1). This process highlighted the extent and breadth of in-depth data gathered relevant to each objective.

In Study 2 (Chapter 4), stoma nurses, dietitians and surgeons were the most common and important HCP sources of dietary advice for people with an ileostomy according to survey respondents. In addition, the scoping review in Study 1 (Chapter 3) showed these HCPs, particularly stoma nurses, were publishing expert opinion pieces on the subject. Based on these findings, and time constraints on the size of project possible to be completed within the timeframe remaining for the PhD, it was decided by AM, supervisors (CA, AS and CE), and JB (qualitative researcher and examiner for AM's annual review) that the analysis for this thesis should focus solely on the perspectives of stoma nurses, dietitians, and colorectal surgeons. The following results and discussion for Study 3 are based on analysis of the 15 interviews conducted with stoma nurses (5), dietitians (5), and colorectal surgeons (5) across the three study sites.

Table 5.3.2.1 Framework matrix structure

Categories	Sub-categories (codes)
1. Content of dietary advice provided	1.a Advice on diet 1.b Advice on fluids 1.c Medical management of the ileostomy 1.d Adaptation of advice for co-morbidities 1.e Adaptation of advice for dietary preferences
2. How dietary advice is provided	2.a Format of dietary advice 2.b Setting in which dietary advice is provided 2.c Timing of dietary advice 2.d Communication between HCP and patient 2.e Communication between HCPs
3. Organisational factors	3.a Role identity * 3.b Role conflict # 3.c NHS resources and priorities
4. Priority of dietary advice	4.a Priority for patient 4.b Priority for participant 4.c Priority within patient's care 4.d HCP confidence in dietary advice
5. What informs dietary advice	5.a Clinical experience 5.b Formal guidance 5.c Awareness of research
6. Patient experiences of diet and ileostomy	6.a Diet-related problems with ileostomy 6.b Impact on day-to-day life 6.c Conflicting information 6.d Online advice and support 6.e Experience-based learning with diet +
7. Patient engagement with dietary advice	7.a Patient understanding of dietary advice 7.b Patient attitudes to dietary advice 7.c Factors influencing adherence to diet advice

HCP, healthcare professional; *e.g., what is expected/possible within professional role; #e.g., where other professions undermine advice given, +e.g., individual patient trial and error to identify links between diet and symptoms

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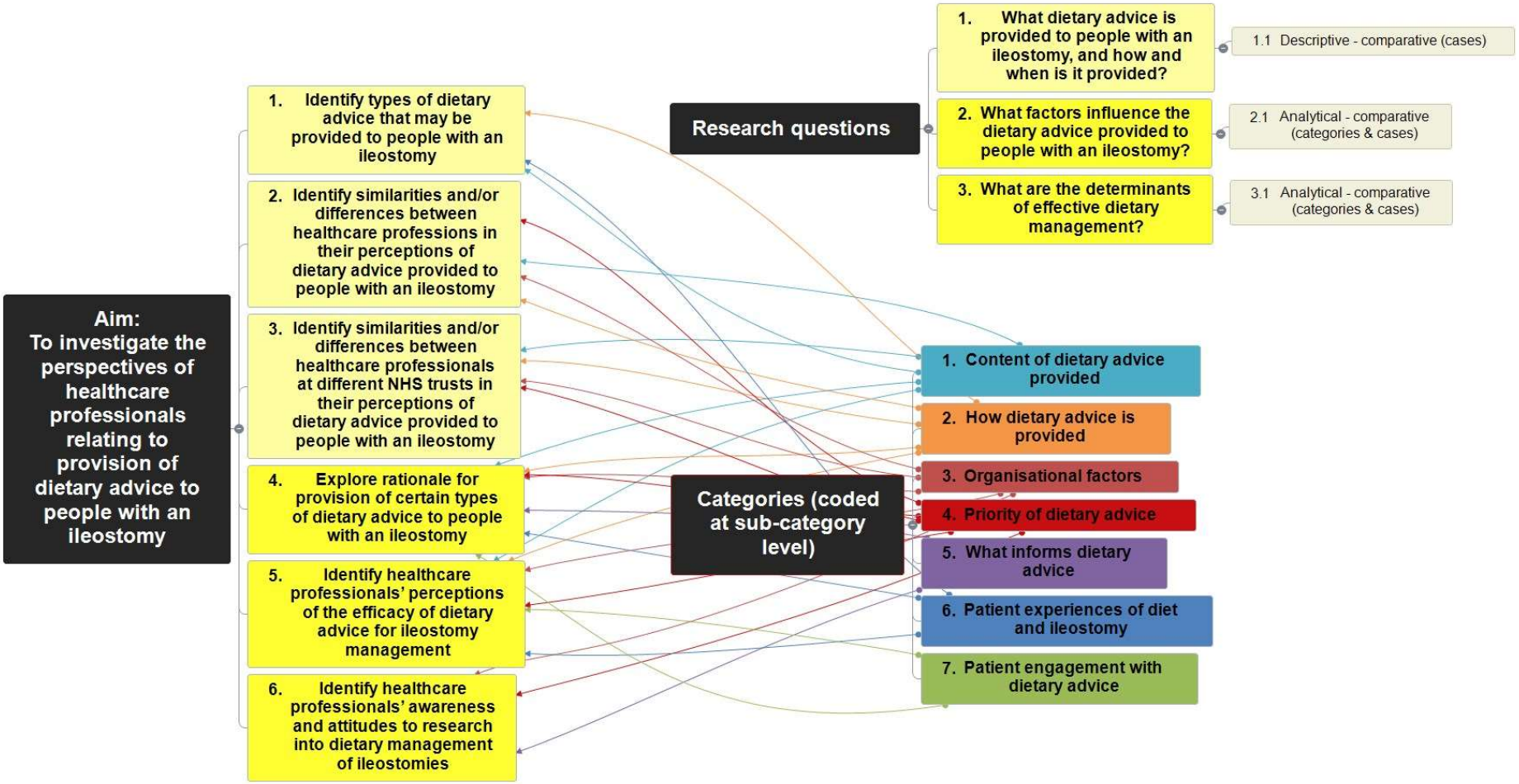

Figure 5.3.2.1 Framework categories and research questions mapped to study objectives

5.3.3 **Key themes**

Descriptive and analytical analysis of the framework matrices resulted in the identification of eight key themes related to the research questions for this study (Table 5.3.3.1). 'Foods to include and exclude' and 'Role of fibre' were the main topics of dietary advice provided by HCPs to patients with an ileostomy. 'Healthcare professionals' role identity and role expectations' were key to what and how dietary advice was provided. The dietary advice provided appeared to be strongly influenced by the 'Comparative value of personal experience and research'. 'Consensus and consistency' in delivering dietary advice were commonly spoken about as important factors affecting the quality of dietary advice and management patients received. Patient experience of receiving dietary advice, as reported by the HCPs providing it, was reliant on 'Team working and coherence' between HCPs and the patient's family and support network. Components of a 'Patient-centred care' pathway included managing patient expectations, communication style, condition-specific care, and adaptation of dietary advice based on patient co-morbidities and preferences. A common goal of dietary advice and education, for HCPs, was 'Patient self-management'.

The results of the framework analysis are presented below by theme, with supporting quotes from the data. Results presented include comparative findings from analysis focussed on profession and site-specific attitudes and behaviours.

Table 5.3.3.1 Theme development

Themes	Sub-themes	Codes	
1. Foods to include and exclude	• Problematic foods • Marshmallows and jelly babies • Other foods that thicken output	1.a Advice on diet 2.a Format of dietary advice 6.a Diet-related problems with ileostomy	
2. Role of fibre	• Timing and re-introduction • Unclear role of soluble fibre	1.a Advice on diet 1.c Timing of dietary advice	
3. HCP role identity and role expectations	• Stoma nurse main provider of diet advice • Dietitians as specialists • Surgeons as co-ordinators of care	3.a Role identity 3.b Role conflict 3.c NHS resources and priorities	4.b Priority for participant 4.c Priority within patient's care
4. Comparative value of personal experience and research	• In-role learning • Awareness and utilisation of research	4.d HCP confidence in dietary advice 5.a Clinical experience 5.b Formal guidance	5.c Awareness of research
5. Consensus and consistency	• Lack of consensus guidelines • Mixed messages	2.d Communication between HCP and patient 2.e Communication between HCPs 3.b Role conflict 4.b Priority for participant 4.d HCP confidence in dietary advice	5.b Formal guidance 5.c Awareness of research 6.c Conflicting information 6.d Online advice and support
6. Team working and coherence	• Communication and relationships within the MDT • Formal and social support	2.d Communication between HCP and patient 2.e Communication between HCPs 3.c NHS resources and priorities	7.c Factors influencing adherence to diet advice
7. Patient-centred care pathway	• Patient expectations • Contrasting communication • Patient journey (clinical condition) • Adaptation of dietary advice for comorbidities and patient preferences	1.d Adaptation of advice for co-morbidities 1.e Adaptation of advice for dietary preferences 2.a Format of dietary advice 2.b Setting in which dietary advice is provided 2.c Timing of dietary advice	2.d Communication between HCP and patient 3.c NHS resources and priorities 4.a Priority for patient 7.b Patient attitudes to dietary advice
8. Patient self-management	• Understanding of dietary advice • Output management affects daily life • Obsession with diet • Trial and error • Autonomy	6.a Diet-related problems with ileostomy 6.b Impact on day-to-day life 6.e Experience-based learning with diet 7.a Patient understanding of dietary advice 7.b Patient attitudes to dietary advice	7.c Factors influencing adherence to diet advice

5.3.4 **Theme 1: Foods to include and exclude**

Specific foods that are high in insoluble fibre, e.g., nuts, dried fruit, and brassicas, were identified as having the potential to cause an intestinal or stomal blockage or obstruction. Surgeons would advise patients on a small number of specific foods that they should avoid for this reason. However, the food(s) focussed on varied between surgeons providing the advice.

"From the obstruction point of view, I think historically patients have come back to me and said, 'Yes, your advice really helped,' which was, 'If you're going to have an apple, peel it, don't eat the skin. If you're going to have a grape, peel it. Don't eat orange segments. Don't eat fruit cake because the dried fruit will just swell and that could block if you've got a narrowing at the site of the stoma'." (Surgeon; site 1)

"Then in terms of actual what sort of food they should think of and avoid, the first thing I'll always say is peanuts or nut generally, in terms of avoiding obstruction." (Surgeon; site 3)

"Anything from the brassica family were they broccoli, brussels sprouts. cauliflower, cabbage; those with real dense fibrous stems to them, it's a common story that we hear. At that point it's 'well you don't have a colon anymore' (in most cases). 'You don't necessarily need a high fibre diet and avoiding those types of vegetables which are known precipitating factors for your bowel obstructions can be advantageous to you'." (Surgeon; site 3)

Stoma care booklets provided to patients by stoma nurses included lists of foods that may cause specific problems e.g., high output or obstruction.

"On one side it has got listed all the foods that you can eat that…that are good for you, and, at the top, foods that will help thicken an output, so the ileostomy, for pointing to those. And in the middle section, at the top part, will be foods that you can eat but you might need to be a bit more cautious about, and then at the bottom might be some foods that we say, 'be very cautious about to start off with, when you are first starting to eat'." (Stoma nurse; site 3)

"But we are quite adamant about particular kinds of foods, based on our experience with patients, that tend to be more problematic, so very, very high residue, like nuts and seeds. We give them a list of foods that can cause blockages and things like that." (Stoma nurse; site 1)

Despite variation between booklets, these lists are viewed by some HCPs and patients as authoritative instructions to avoid potentially problematic foods and drinks listed. Some

patients avoid all items listed obsessively due to a fear of causing or exacerbating unpleasant symptoms and complications.

"Yes, because again, just looking from one table of what to eat and what not to eat, from one booklet to another trust booklet, actually, it is quite different. Some people are allowed iceberg lettuce; other people aren't. So, it's like, 'Well, which one can you do?' Some people are allowed asparagus tips; other people aren't. So, again, if people say, 'Oh, am I allowed asparagus tips?' I'm like, 'Well, I don't know. It depends which booklet you follow'." (Dietitian; site 2)

"Obsessed with food actually. There's lots of patients I see in my clinic who are absolutely obsessed because somebody's given them a list. Absolutely obsessed with it and get quite emotional about it, because obviously food…" (Stoma nurse; site 2)

HCPs perceive that they are making patients aware of potentially problematic foods and drinks and believe other HCPs and information sources, such as those online, are responsible for installing the belief in many patients that they need to strictly avoid these foods, and thus follow a restrictive diet, long-term.

"Further down the line, I usually go down the route of highlighting to patients that certain foods may be more likely to increase stoma output, but also encourage them to try and eat as freely as they can and avoid foods that are problematic for them. Rather than going down a route of saying that, these foods will categorically cause you problems and should be categorically avoided, although I know a lot of people do." (Dietitian; site 1)

"Like I said, if they've come out of area they come in and they have a big, long list of what they can't eat. Not what they can but what they can't eat." (Stoma nurse; site 2)

Stoma nurses and dietitians advised patients to eat specific foods to thicken their ileostomy output e.g., marshmallows or Jelly Babies, and white (low fibre) starchy foods.

"There are certain foods that we can eat to try and thicken the output of it, like your marshmallows, Jelly Babies and such like…" (Dietitian; site 1)

"We talk a lot about white foods and nursery food and the sort of things, you know, that may thicken up outputs, the usual things, even though there's no real evidence around marshmallows, jelly babies, and…you know, those." (Stoma nurse; site 3)

Use of marshmallows to thicken output appeared controversial. One surgeon believed in this advice based on findings from a research study he believed to be well conducted while one of the stoma nurses (site 1) did not recommend marshmallows due to own experience of lack of benefit.

"I was the handling editor for a randomised control trial of marshmallows impact on ileostomy output so there are some good quality studies out there." (Surgeon; site 3)

5.3.5 **Theme 2: Role of fibre**

All HCPs agreed that patients should follow a low-fibre diet during the early post-operative phase of recovery for ileostomy formation, particularly if output was watery/high, which it commonly is initially. However, terminology for the diet being advised was used interchangeably within and between participant interviews i.e., low fibre or low residue.

"Initially, if I'm involved in the period soon after their surgery when they've recently had their stoma formed off and they do have quite a high output, it might be just discussing with them to try and completely avoid fibre in their diet." (Dietitian; site 1)

"I would say for the majority, they will have very watery faecal output, which continues to not thicken up for some weeks, and in that instance, I will advise patients to eat a low fibre, low residue diet." (Stoma nurse; site 1)

Dietitians advised avoiding a high fibre diet to manage high output. Within this, reducing insoluble fibre was key. Dietitians and stoma nurses also gave advice on how to reduce risk associated with eating foods high in insoluble fibre i.e., chew well, eat slowly, and consume in small amounts.

"The main thing that I talk about is fibre and the different types of fibre, so breaking that down into soluble and insoluble, and obviously what that means for the patient, what foods it is found in. Because obviously soluble fibre can be a good way of slowing things down in the gut. Thinking about carbohydrates, fruits, vegetables, so the food groups that tend to have fibre in them." (Dietitian; site 3)

"I just say, 'If you're very well controlled, eat normally as much as you can. Cut things small. Chew very, very well'." (Stoma nurse; site 2)

There was agreement between HCPs that patients should only need to follow a strict low fibre diet short-term, and that, in the medium to long-term, high-fibre foods should be gradually reintroduced to enable patients to consume a more typical healthy, balanced diet.

"…long term, they should be able to eat and drink again quite normally, depending on how their bowel copes with the amount of fibre in their food and fluids. They will always need to pay attention to it. Hopefully, it shouldn't be too restrictive, but there's an interim period where you do need to be quite strict and really reduce, particularly, the fibre content of food…" (Dietitian; site 2)

"I think here we're quite specific about low residue diet, certainly post-operatively, so we talk a lot about what they should… we feel they should eat after their surgery and then we're saying, 'Within a few weeks, then you'll start to build up your diet and add different things into it'; but we're still quite low residue focused, but what we really want is for everyone to get back to normal; try and eat as normally as possible." (Stoma nurse; site 3)

5.3.6 **Theme 3: Healthcare professionals' role identity and role expectations**

Role identity and expectations were defined by participants within and between professions. Stoma nurses were identified amongst all HCPs to be the main provider of dietary advice to patients with an ileostomy due to the fact that their role involves them seeing all patients with an ileostomy and giving basic diet advice relating to the ileostomy.

"The stoma nurses because they are seeing everybody. We are only getting the further patients who are having problems with it. Whereas the stoma nurses are seeing everybody." (Dietitian; site 3)

"Me, I would say, because I see all of them. A dietitian wouldn't get involved in the normal, run of the mill, not playing up ileostomy… Yes, me, probably, the stoma nurse." (Stoma nurse; site 2)

Dietitians were seen as the experts in diet and nutrition but, despite this, were not the main providers of dietary advice to patients with an ileostomy due to limited staffing resource and only being referred patients with complications requiring dietary management, for example, high output stoma.

"If it was a high stoma, so in other words, more proximal to the small bowel, I think we would be thinking of getting dietitian advice for that in hospital. Again, I would default to the dietitian to come and advise on what might be more beneficial for them." (Surgeon; site 1)

"Our dietitian numbers are somewhat thin on the ground. We'd love more. They'd probably love more; but their expertise is probably concentrated at the moment towards our intestinal failure service and the TPN side of things rather than sitting down with ostomates per se." (Surgeon; site 3)

Provision of dietary advice to patients with an ileostomy was seen to be only a very small part of the colorectal surgeon's role; and, in the most part, on an ad-hoc basis. Beyond the scope of the surgery for ileostomy formation, surgeons saw their role more as someone who co-ordinates patient care, rather than being the providers.

"I would always get a stoma nurse if I felt there were problems directly due to diet and stoma function. I would get the stoma nurses to discuss. I think they have more time and often can see the patients at a more leisurely pace, in a setting that is probably not in a ward or a [surgical] clinic but in the stoma nurse department and therefore I think that is more beneficial to the patients." (Surgeon; site 1)

"It may be that I am a bit more of a coordinator but I'm not going to be able to give as good advice probably as a dietitian or a stoma care practitioner… If they're running into problems, I'll get as many people involved as possible because I don't know everything." (Surgeon; site 3)

The IBD-specialist surgeons saw themselves as having a greater interest and knowledge of dietary management compared to general or cancer-specialist colorectal surgeons. They explained this as a function of the nature of IBD which, as a condition, often requires significant dietary management, and a close working relationship between the gastroenterologist and surgeon in the care of IBD patients.

"I think, in terms of the IBD specialist within colorectal surgery, I think we're probably… much higher up in terms of the knowledge and awareness of nutrition. Whereas I think the jobbing colorectal surgeon who's doing cancer stuff, I would not be surprised if it's lower down their list. That's not saying I know more than anyone else, it's just saying I think that group of surgeons who are IBD specialists probably are more aware of the nutritional side of things. We do a lot more work with the gastroenterologists and so you're going to rub off,

aren't you? In terms of what they do and what you do. I think we know more." (Surgeon; site 1)

5.3.7 **Theme 4: Comparative value of personal experience and research**

For all HCPs, clinical experience and professional training, both formal and informal, were the main sources of knowledge and understanding that informed their provision of dietary advice.

"My own experience and probably anecdotal, so from my experience that I have picked up, from others and from myself with my own patients. Is it based on my reading of any evidence? No." (Surgeon; site 1)

"I've, over years, I think, just built it up. Definitely experience…" (Dietitian; site 3)

"It is from the dietitian in the hospital. It is chatting and working closely with them and the nutrition team and hearing what they recommend." (Stoma nurse; site 3)

"I suppose, for me, personally... I worked in London up until a few years back, so I've been on study days at [Institution] and things. That was my first big exposure to stomas, intestinal failure, etc., and had training and everything there. So [Name], a dietitian there... We've kept in touch a bit and when I started working here. I emailed her for some advice about a particular patient that was really tricky; and asking for up-to-date patient-information booklets, and just seeing what was out there." (Dietitian; site 2)

In the case of one surgeon who had personal experience of a family member with a stoma, this was also a primary influence.

"Actually, for me, seeing the impact on somebody personally and knowing what he did, and a few little tips and tricks because he had a stoma for a while. It was quite useful because that's not the sort of clinical, surgical thing that you concentrate on. It is quite useful to see a little bit of that. Also, it's useful I think for the patients to show that I've got a bit of insight even though I've not had a stoma myself." (Surgeon; site 3)

It was commonly acknowledged that there was a reliance on own and colleagues' clinical experience to inform practice. Reasons given for this were:

1) a lack of time for continuing professional development (CPD) activities such as keeping up to date with published literature or participating in research and audit (sites 2 and 3).

"But I haven't got much time for CPD, and therefore, I'll just rely on experience and what I think works, and then what I hear." (Dietitian; site 3)

"I think it's about time, you know, sitting down and looking at the evidence around it, but also, I don't think I would change practice if my nutritional team and my dietitian were doing what they were doing, I would go by what they were doing…" (Stoma nurse; site 3)

2) lack of evidence-base (all sites).

"…there isn't really the research." (Stoma nurse; site 1)

"…[The]evidence base for much of the dietary advice is relatively low quality, I think it's fair to say anyway, and as a consequence it's difficult to correct someone else's lived experience of a disease when we don't truly know a lot of the time anyway." (Surgeon; site 3)

Confidence in awareness of relevant research varied between and within professions. There was a general impression that research on the topic of dietary management for people with an ileostomy was limited and that there was no recent or strong evidence that had implications for practice.

"I feel I'm reasonably well aware. I don't think there's a huge amount of evidence out there, it hasn't changed that much over the years." (Dietitian; site 1)

"The actually latest, current stuff, I couldn't tell you, but I do know that when I've been on study days and it's all been discussed, nothing new has necessarily come out, as such." (Dietitian; site 3)

"Probably not very aware at all actually, no, because I think we just crack on with our job. I don't think I look at what evidence is out there. I tend to speak to the nutritional team and say, 'Right, what would you suggest?' And I expect them to be up to date with it all and then tell me, disseminate that information, you know." (Stoma nurse; site 3)

Most HCPs interviewed showed a desire for more research to provide better evidence to support or change practice. Some expressed concern at an absence of knowledge relating to potential long-term effects of dietary modification for ileostomy management.

"I have been in this role for only about 10 months now, so I do feel like a big component of it is passing on knowledge, which is, I think, good knowledge; but wanting to have more evidence based… information to sort of back up everything." (Stoma nurse; site 1)

"Well, at the end of the day, is there safe dietary with nutritional advice to patients with ileostomies that can improve their quality of life living with a stoma? The idea is me going around saying, 'You've got to cut out things like nuts and dried fruit and you can't have anything with piths and skins. Watch all those fibrous foods like lettuce, cabbage and sprouts and don't have new potatoes unless you peel them.' Actually, what I am doing, is that maybe some patients on that advice are saying, 'Right, I'm having no fresh fruit and veg'? And that can't be healthy either because they're probably going to miss out on certain nutritional requirements that would be forming a healthy diet." (Surgeon; site 1)

There was individual variation, associated with self-confidence in the dietary advice HCPs provided, as to whether the benefit of additional research would be to 1) justify and expand their provision of dietary advice to patients with an ileostomy, or 2) increase confidence in the effectiveness of dietary advice for these patients, or 3) improve their own ability to provide good advice.

"So, I kind of think, actually, in these types of patients, I feel like, as dietitians, we are probably the experts. Therefore, trying to prove that, actually, the advice that we're giving can reduce length of stay or admissions to hospital and can improve biochemistry, blah, blah, blah- I think just to help promote what we do and put it out there is probably the biggest priority." (Dietitian; site 3)

"I don't know the evidence and therefore I don't know whether 1) There is evidence, 2) Whether the evidence is good and 3) Whether the evidence actually benefits patients; I don't know… any evidence, as long as it's validated and appropriate, is good and can guide patients or clinicians or healthcare professionals to either say, 'There isn't any advice that needs to be given,' or, 'There is advice that needs to be given.' Any research is good as long as it's well undertaken and well-constructed and validated, whether it shows there is benefit for dietary advice or not." (Surgeon; site 1)

"I think it will be beneficial for the patient. I think we'll be more confident in the way we give the information, therefore, as in anything, those patients probably will be more accepting of that because they want us to say… 'Have this, don't have that' and 'This is good, this is what you need to do'; but we're not. We're quite wishy washy and… obviously some patients will need one type of diet or another… but if we had some more research around what was more effective then I think that would help us; And what nutrients are required…" (Stoma nurse; site 3)

5.3.8 **Theme 5: Consensus and consistency**

Consensus and consistency in delivering dietary advice was identified as important by HCPs; however, there was an awareness that this often was not achieved. The way dietary advice was presented differently between HCPs, influenced by differing priorities of each profession, as well as conflicting anecdotal advice from informal sources such as family and online forums, demonstrated how patients receive mixed messages.

"…it's when we've got a clear plan, because we all need to be saying the same thing…" (Dietitian; site 2)

"I think it's very difficult for patients if they receive contradictory advice. So, for instance, if one healthcare professional is giving them very stringent advice and a list of absolute no-go foods, and someone else is saying, 'Well, actually try this and see what happens'. That advice can be very confusing for patients and can leave the patient quite unsure as to what they should or shouldn't be doing in relation to it, so I think that's tricky." (Dietitian; site 1)

"The surgeons, their priority might be more towards trying to gear the patient towards discharge, getting them home, independence and that sort of thing. Stoma nurses are very much wanting to get the patient independent with managing their stoma bags. Dietitians are trying to, hopefully, educate the patient and get their stoma output under control.
We shouldn't be too often in conflict with what our priorities are, but there might be slightly different emphasis given in the advice. The stoma nurses might be wanting the output to be reduced more so the patient can be more independent. While we might be trying to get the patient a bit better hydrated or thinking about their nutritional status more. It's a slightly different emphasis on why we're trying to change the diet." (Dietitian; site 1)

"So, the classic thing I suppose is degree of oral fluid intake and the high output stoma, and the confusion that exists surrounding what they can and can't drink. There's a lot of confusing advice about whether they should increase their fluid intake, what that fluid should be; And the concept surrounding the paradoxical increase in ileostomy output that may occur if you're drinking pure water is one which is often difficult for some people to grasp. It's quite poorly understood. There's a lot of well-meaning incorrect advice given both from family, friends, often healthcare professionals too and certainly on internet fora where people say, 'Don't get dehydrated, make sure you drink plenty of water'. I mean, you see that all the time." (Surgeon; site 3)

Consistency and consensus within dietary advice provided, between HCPs, varied by site. Closer multi-disciplinary working was perceived to facilitate better consensus and consistency.

"…then they go to the dietitians and say, "What do you think? Do you want any input in this? What else would you say?" So, we don't do it just on our own. It's usually with everybody else." (Stoma nurse; site 3)

"I've made contact with some of the… dietitians and I've sent through the advice that I would give patients and I said, 'Please could you just have a look at this and sign this off?' And I never heard anything. And yet I know… that might be somebody who would go in and say, 'You must eat your five portions of [fruit and vegetables]'." (Stoma nurse; site 1)

In addition to inter-disciplinary and inter-individual variation and contradictions, one HCP was aware that a general lack of clarity on dietary management for ileostomies meant that some advice she as an individual HCP provided to patients could at times appear contradictory.

"'If you really, really want some peanuts… then eat them [in] small amounts, not all at once, and have some fluid' which is the opposite of what I'd say. You see you're always contradicting yourself I feel with this, with ileostomy advice, because you're saying, 'Well drink a bit of water with that. And oh, don't eat and drink at the same time.' There's that contradiction all the time." (Stoma nurse; site 3)

Absence of published evidence-based guidelines meant that local and profession-specific guidelines, although limited, were relied upon to provide some consistency and reference for practice.

"In terms of actual sort of evidence-based guidelines, NICE guidelines, anything in relation to that, then I'd struggle to give you an example I think." (Dietitian; site 1)

"Obviously dietitians, like [Name], I work with here. We work quite closely together, especially with patients with high output. We've come up with… the high-output protocol that we've written. I wrote it. Then I gave it to [Name] to pass to her superior. She's agreed with it, so it's out on the wards. It's in the doctors' [shared computer] drive. So, we all follow that protocol for high output." (Stoma nurse; site 2)

"I mean we do have ASCN guidelines, the National Stoma Care Organisation…, and there is information that we give based on high output and diet information in regard to that… That's not even a great deal. It's more in regard to problematic stomas, you know, high output. It would be in regard to that rather than generally." (Stoma nurse; site 1)

5.3.9 **Theme 6: Team working and coherence**

Dietitians and stoma nurses had a close working relationship at two of the three sites (2 and 3). They each valued the expertise and input the other profession provided, and prioritised good communication to share knowledge and optimise patient care.

"We do get a lot of advice from our dietitians. We work really closely with them and if we feel that somebody is struggling, even with the information, … - they haven't got a high output stoma, they've got a normal functioning ileostomy - we do tend to get the dietitians involved, even in the hospital, so that they give guidance and then we're talking about the same thing because we really want to be driven by what they're saying as well. You know, make sure we are giving the right advice to these people." (Stoma nurse; site 3)

"We also work quite closely, I suppose, with… the Stoma team and they often will see them, or they'd come up into the Stoma Department for a quick review. I know, a couple of times, I've popped along there as well just to catch up with a patient and see how they're getting on to save having to make another appointment, especially if it's someone that has been quite complicated." (Dietitian; site 2)

In contrast, there seemed to be a lack of collaboration between dietitians and stoma nurses at one site.

"Now, obviously the dietitians and the nutritionists have an understanding, but perhaps not quite such an understanding as we do. So, I can see why you would think somebody telling you not to eat fruit vegetables and to only eat white bread, would be an anathema to most nutritionists. So, …better communication with them, between us and them, has improved things; the ward nurses… again, better communication with them and better training of them… is helping a little bit; but still… patients… get advice from everybody." (Stoma nurse; site 1)

"…the advice we give I think is closely in correlation to what they would be told by surgeons when they are talking about that pre-operatively and post-operatively, and through dietitians

who go and see them. I mean we are not collaborating all the time together, but it's sort of consistent on what we all say to them." (Stoma nurse; site 1)

Condition-specific MDTs facilitated cross-disciplinary learning and collaborative patient care.

"Certainly from the stoma care nurses and the cancer nurse specialists, we often see patients jointly together in outpatient clinics but particularly when you're planning surgical intervention and when you're seeing patients in the post-operative setting you get familiar with the generic advice that tends to get given about, particularly if their large bowel is out of circuit because they've got a de-functioning loop ileostomy, the avoidance of high-fibre diet, those type of things, which the cancer nurse specialists tend to go through with the patients. You know, you have some understanding." (Surgeon; site 3)

"…we see a lot of people with Crohn's Disease who have not got a stoma and they're coming to the gastroenterologist; saying, 'Should you operate on this stricture? Should you operate on this Crohn's?' We would try our best to avoid surgery, so I would want to make sure that they've had an elemental diet or seen the dietitian to try and remove anything that might be precipitating their obstructive Crohn's problems beforehand." (Surgeon; site 1)

HCPs believed that patients' support networks, e.g., family, had potential to either help or hinder dietary management. Whether a particular social network was deemed by the HCP to be positive or negative ultimately depended on whether members' beliefs relating to diet, health and stoma management aligned with their own beliefs.

"…it's very powerful sometimes for patients to hear things from people who seem to have a similar experience. That seems much more powerful than a health professional telling you, so it can have a much bigger effect and a much bigger impact… and then we go in and go, 'No, actually, what you said wasn't right'; …you don't always know what they've been told as well… So, inside them, they can often be conflicted, and that's hard." (Stoma nurse; site 1)

"Sometimes, [the patient] can be really motivated, very interested in it, and just want to do whatever they can; they're really engaged, and with a supportive family and the family bringing them in Jelly Babies, marshmallows, cheese biscuits and extra salt to sprinkle on their food or just doing everything that they can." (Dietitian; site 2)

It was highlighted that at some points in the patient care pathway, routes of communication between HCPs, and between patient and HCPs, were weakened or severed, leaving some patients need for dietary advice and support unmet.

"…a higher level of follow-up from dietetic services for these patients a little bit further down the line would probably improve the situation. I think the input they have access to at certain points of their treatment is pretty adequate, but I think at certain points they go into windows of time where if they're having difficulty, they possibly don't have quite so much access to it. That is largely dictated by what services are funded at different points of patients' pathways. I think the greatest gap is probably between inpatient and outpatient services." (Dietitian; site 1)

"…the patients that are six months out and they think, 'Well, my stoma nurse is busy,' or 'She doesn't want to see me now. She only saw me at the beginning,' and 'I don't really know who to go to,' and 'So I'll got to my GP,' and the GP gives the… healthy plate advice…" (Stoma nurse; site 1)

"There could probably be a little bit more getting in touch with people a bit more frequently because we tend to only do it for the people who have real major problems. The people who don't complain tend to probably just tick along. Occasionally I'll see people after a few months and [they] say, 'Yes, I'm still having this problem.' We leave it to the patients to get in touch with us... We probably don't leave the door ajar enough if that makes sense." (Surgeon; site 3)

5.3.10 **Theme 7: Patient-centred care pathway**

Several stoma nurses and surgeons spoke of trying to manage patient expectations and provide reassurance with the information they provided pre-operatively. They didn't want to worry patients too much, but most thought patients should be made aware that their diet would be affected to some extent, at least in the short-term, after ileostomy formation.

"I give them no dietary advice; unless they say, 'Am I going to be able to eat and drink afterwards?' and I say, 'You should be able to eat and drink normally,' knowing that that's perhaps not quite true because if they have problems, they might have to modify their diet. I almost don't worry them with, 'Oh no, you're going to need to cut out all of that'. I just don't tell them anything. If they do ask, I say, 'After a while you'll be able to eat and drink

normally and we'll see how it goes,' but I don't know how much advice is given about diet before a planned ileostomy or colostomy." (Surgeon; site 1)

"So, in general when I am talking to a patient before surgery, I try to reassure them that, although they might make some dietary changes, it is about actually their diet fitting in with their life and their stoma, and it is all about having a normal life really. And just to reassure them that they might have to make some changes, but it is an adjustment and not a complete change to their diet." (Stoma nurse; site 3)

"I have to say with most ileostomy patients, or patients I know are going to have an ileostomy, proactively I will tell them they will need to make a short-term adjustment to their dietary intake that we will review as they go along." (Stoma nurse; site 1)

Communication styles used by HCPs with their patients were sometimes contrasting. Commonly, advice was communicated to patients in a way akin to a traditional paternalistic approach (described in Chapter 2.11.1), with the HCP informing the patient of what they should or should not eat and drink. However, several HCPs spoke of coming up with a compromise with patients particularly in relation to fluid restrictions and oral rehydration solutions suggesting an element of shared decision-making (see Chapter 2.11.2).

"If I give them the advice, I expect them to take it. That said, I know that they won't always and that there is often a compromise position because often patients who are on fluid restriction have all sorts of things that they can't and can eat, exclusions, this, that and the other. They moan about it a lot, so you have to find a way to talk them through and some of them will say, 'Well, I can't do that all the time.' You know that they aren't fulfilling the whole diet because it's unpalatable. So, on that sort of thing, you often have to just compromise a little bit." (Surgeon; site 1)

"...people do really struggle... with not being allowed to drink very much; especially if their IV fluid management isn't, maybe, quite as good as it needs to be. They can often feel so thirsty and quite distressed by that, especially when it's hot like it is now... So, it depends on the patient and our negotiating skills with them, I suppose, as well and how we implement it..." (Dietitian; site 2)

Another common approach used by HCPs was more aligned with the information giving model (see Chapter 2.11.1), where information on possible consequences of eating certain foods was provided but the decision of what to consume was left up to the patient.

"Because I don't do the list thing, I just say, "Be aware of what you're eating and drinking. Just be aware of it." ... My patients go, 'I had mushy peas and they weren't for me, because they came out of my ileostomy,' and things like that. Then I go, 'Okay. Either, you know it's that, so when you eat it next time you know it's that or avoid it. It's entirely up to you.' Dietary wise, patients will always come in because they feel restricted in their diet, and then I tell them otherwise. And I always say to the patients they're in charge. They don't need to come in; because I'm not in charge. If they have a problem they come to me, but they're in charge of their diet. They're in charge of their stoma and their output and things like that. You try and give them back control." (Stoma nurse; site 2)

"I think that if their ileostomy is functioning well and it's not high output, I don't believe they should be restricting their diet unnecessarily. I say to them, 'You may eat something, and it causes lots of wind or a looser output, but as long as it's not having detrimental consequences, it's up to you what you do. You might decide, I'm going to have it, but I'm going to have it when I'm at home all day. Therefore, it doesn't matter that I've got all this air coming out.' So, I'm not very strict on the dietary side of things." (Dietitian; site 3)

Some HCPs expressed concern that patients might be overloaded with information during the peri-operative period. At site 1, elective patients were given a very large amount of written information on all topics, prior to ileostomy formation.

"We often find that what they were told in the hospital, they've totally forgotten. What they were told pre-operatively, they remember quite a bit, and on the home visit… I think it's finding out when we're telling them their advice, when is the right time to tell it, and we find that six weeks' time it's really good to reiterate that and they'll often say, 'I definitely cannot have anything that you're telling me about I could have now,' like vegetables or anything, 'I can't have any of that.' And that's because all they remember is the low residue diet we've talked to them about. They don't remember about adding anything else in, you know, just trying to build up their diet… I keep thinking, is it because we're giving too much information at certain times? So, I'm trying to think about when we're giving the information. But a lot of that as well is depending on how the stoma's functioning." (Stoma nurse; site 3)

"They would be given it [the stoma care booklet containing diet advice] pre-op, and they are given about 50 other pieces of documentation to carry…" (Stoma nurse; site 1)

Patients come to have an ileostomy formation for many different reasons, due to a range of conditions, and in a variety of circumstances. IBD and cancer patients were identified as two

specific groups who were under the care of different MDTs and followed differing care pathways.

"I'm sure that my colleagues who do much more IBD specific specialist surgery will have the relationship with their IBD nurse specialist that I have with the cancer nurse specialist and the stoma care nurses." (Surgeon; site 3)

"I would say it doesn't help from the fact that the ileostomy services are probably going to come under the dietetic surgical service in hospital and then when they go home, they're going to split up into two different camps. The colorectal surgery patients or the colorectal cancer patients and the IBD patients, and there's different dietetic services that support both of them and neither one of them has the ability to see patients quite as quickly as some other areas. So, I think probably the answer to closing that gap [between inpatient and outpatient services] would be to have more of a dedicated service for patients with ileostomies that have the ability to offer support within that window of time. It could be in the form of telephone support." (Dietitian; site 1)

Differences in needs and experiences with dietary management between IBD and cancer patients were recognised by several HCPs.

"I suppose it depends on the previous experience of patients. A lot of patients that I see with colitis who have had diarrhoea will know the sort of foods that give them diarrhoea and therefore principles of it, although not exactly the same, are kind of there already. In those sorts of situations, it will be, 'Well what's different to what you're having at the moment?' The same with the patients who have a pouch, who have a temporary stoma. For the people who go from nothing to having a stoma, you'll probably be a bit more prescriptive because they're going from a situation where they just don't really know what's going on, it's completely foreign. They may want some more guidance I guess so I'll probably be a bit more prescriptive in those sorts of situations." (Surgeon; site 3)

"... say if they have got Crohn's Disease or there is inflammation or if there is stricturing, then that would change their long-term dietary recommendations." (Dietitian; site 3)

Additionally, there was an awareness that patients with an ileostomy sometimes had co-morbidities, not related to their ileostomy formation, that required dietary management (e.g., diabetes), and that these patients required specialist and adapted dietary advice.

"Some of our patients that come in who are diabetic… we are talking about having a really high stodgy, starchy diet, and they are like, 'Whoa. This is nothing I've ever been told before.' Then we know that we can also coordinate and liaise with nutrition [diabetes?] nurses and dietitians who can… offer a little more input on that side as well, on… what's appropriate long-term." (Stoma nurse; site 1)

Dietitians commonly spoke of how they adapted dietary advice to patient preferences and lifestyle. There was also some mention of this amongst stoma nurses. Specifically, vegetarians and people who usually ate a high fibre diet were identified as requiring additional reassurance and explanation of the dietary advice provided due to the contrast to their usual diet and conflict with their beliefs relating to a healthy diet.

"Looking at their diet and what they normally have, and how they might need to adapt that. But, also, I think it is always good to give them an idea of what they can progress onto. So, say for example one patient I had recently… she liked to have a really high fibre diet. She was vegetarian/vegan, so therefore she was having… very high fibre content… She was very upset about the idea of not having a high fibre [diet]. But, when we explained and discussed what fibre is and how it affects the bowel, and that actually once her gut had completely healed and everything had slowed and settled basically, then she would be able to slowly start phasing those sorts of fibre back in. So, it is individualising it for each patient on what it means for them. On the other extreme, for some patients, they might have a really low fibre diet anyway, in which case thinking about introducing some suitable forms of fibre at some point in the future is the advice." (Dietitian; site 3)

"I think there is a good chunk of people who they are very, very healthy. That's a very important part of their life, as it should be, and they want to eat the foods that they've always been told or have always been educated about being healthy. They tend to maybe eat those more fibrous foods or more residue foods. But I mean, the thing is, again, we are not telling people it's a complete no to that. It's about finding out how these foods work with them as individuals. For someone, having nuts and seeds might not do anything to them. Then somebody else, it causes severe problems. It's really about testing the waters." (Stoma nurse; site 1)

5.3.11 **Theme 8: Patient self-management**

HCPs believed that dietary management was more effective in patients who gained a better knowledge and understanding of diet. Those with a permanent ileostomy were perceived to

seek out more information and support and take ownership of their stoma management while those with temporary ileostomy tended to be less engaged and have less understanding of dietary management.

"I think a little bit further down the line, probably the patient having an understanding of how diet impacts on them; Either in the form of specific dietary advice or more as a method of facilitated learning for that patient, to being able to identify what effect diet is having in relation to their output, is probably more important further down the line and ultimately certainly has the potential to have a massive impact on that person's quality of life and their ability to nourish themselves." (Dietitian; site 1)

"Those who have de-functioning loop ileostomies as part of their cancer resections perhaps don't quite appreciate the differences [in how foods affect them]. Those who are younger, have got permanent end ileostomies, it's a more long-term thing, it is going to be their life. There isn't going to be any change. They tend to be much more well-versed. The differences in generations between them as well. So, younger patients [are] much more active on social media, support groups, online, tend to have got much more information out there and to be more well informed; are more likely to be part of patient support groups like Crohn's and Colitis UK. They really buy in to things, take ownership of their disease state in quite a different way because they know that they are like that for longer, whereas the patients with the loop ileostomies are…always sold as being a temporary measure. There's not quite perhaps that same impact…" (Surgeon; site 3)

However, patients readmitted with obstruction sometimes knew they had eaten something specific that had caused it and reported to have eaten it knowing the risk.

"The ones who probably have the best concept are the repeat offenders who come in with multiple episodes of bowel obstruction. They know what sets it off, they still eat it anyway because sometimes you just can't help yourself and then they come in and they go 'I know…'" (Surgeon; site 3)

A lack of understanding of basic dietary principles, such as 'what is fibre?', was thought to be a barrier to good dietary management in some patients.

"I suspect the general understanding, within the populous, of dietary advice generally - what's a high fibre fruit, vegetable, that type of thing - I think it's probably very poorly

understood. So, I suspect, for many patients, they get given some advice but are bamboozled by it. I don't think it probably helps many." (Surgeon; site 3)

Many patients were perceived to be obsessed with their diet due to high anxiety about possible consequences, such as high output and blockage, and insufficient understanding of how best to manage their diet. In particular, lists of foods associated with symptoms and complications were often interpreted as lists of foods that should always be avoided. This meant that some patients had a very restrictive diet, often unnecessarily.

"Yes, the other thing… is just making sure that in amongst all that information we give, and even though there are some restrictions, ensuring that we are giving them enough information to make sure that they are receiving the right nutrition and enough nutrition right after surgery, because it can become quite a point of obsession, I think, sometimes by ileostomy patients in particular… they are so restricted in what they can eat that they are missing out on some of the essential nutrition they should be receiving, because they are so worried about what they should and should not be having." (Stoma nurse; site 1)

HCPs were aware that patients with an ileostomy commonly had a need for self-determination in terms of both the diet they consumed and their stoma output and management.

"I mean, there are some things, you know, patients are resistant to. This is a horrible thing to have to manage. I get that… it's really difficult for people… but, eventually, even the most challenging stomas can be managed; but somehow the 'what I put in my body and comes out' thing is still… And is that partly that they're sort of trying to have their own self-determination?... 'I will eat what I want!'" (Stoma nurse; site 1)

"In that sort of situation people want to take ownership of their ongoing treatment and feel that they're not diseased anymore. This is normal for them and therefore they need to be in charge of it." (Surgeon; site 3)

"… sometimes it is just snippets of information that people can take at a time, whereas when I see somebody in clinic, then they are good to go and they just want all of the information and they are like, 'Right, I want to get on with my life. I want to get back to work. I have got kids… I just want to lead a normal life.'" (Dietitian; site 3)

Poorly controlled stoma output and dietary restrictions have many negative consequences on daily life for people with an ileostomy. Most HCPs believed that patients needed to find a

personal balance that worked for them, through controlled experience-based learning. This belief informed how they provided dietary advice, providing general principles and guidance on gradual reintroduction of higher fibre and other potentially problematic foods, to promote patient autonomy with dietary management.

"I think the wind and the bloating and leakages are massive problems for some people. I think if some people are having lots of wind because of the foods that they're eating, it actually tends to be more of an image problem that they have. Because again, of course, the bag blows up with air, and they can't hide the fact that they have a bag, which I think they struggle with." (Dietitian; site 3)

"There are the social issues as well, not being able to enjoy a complete meal in the same way as they used to and joining in family meals. Sometimes they're just having to eat a completely different meal to the people they're with." (Dietitian; site 1)

"…when they come back to clinic maybe after six weeks, a couple of months, they've had a chance to get over the operation… get a feel for the personality of their stoma. A lot of people give them names and see what their vagaries are, what time they work and those sorts of things so that they can then start adapting their diet and bringing things in a little bit more. It's amazing how often people I see six months down the line saying, 'I've not tried having alcohol yet because I've been told not to.' I say, 'Well you've just got to get that nice balance. If everything is okay, feed things in but do it quasi scientifically, so try one thing at a time. If you want to have a pint of beer, have that but don't have a curry as well… because otherwise you don't know which is the one that set you off or not…a food diary is still not a bad thing so that you can look back at it and see what's affected you.'" (Surgeon; site 3)

"What I'm trying to do all the time is… give [patients] enough information so that they understand why I'm telling them this, so that they can start to make those adjustments themselves, so they can think. So, one of the things I might say is that they keep a food diary… And they correlate in one column what they've eaten and then they might look at a column of what their output from their stoma… And that you might look to sort of six to eight hours after you've eaten… so that would correlate like that. I don't know how many patients do that but for me it's about reminding them that there is a link between what they're putting in their body and what will come into the bag." (Stoma nurse; site 1)

5.4 DISCUSSION

5.4.1 Overview of key findings

Eight key themes were identified from the 15 in-depth interviews with stoma nurses, dietitians, and colorectal surgeons, using a rigorous framework analysis process. Content of dietary advice was described across two themes: 'Foods to include and exclude' includes problematic foods and foods that thicken output; 'Role of fibre' includes advice on fibre in the short- and long-term, re-introduction, and relevance of soluble fibre. How and when dietary advice was provided, the factors influencing advice provided, and determinants of effective dietary management were all incorporated within the other six themes: 'HCP role identity and role expectations' presents stoma nurses as the main provider of dietary advice, dietitians as experts, and surgeons as co-ordinators of care; 'Comparative value of personal experience and research' includes role-related experience and learning, and awareness and utilisation of research; 'Consensus and consistency' includes mixed messaging and a lack of consensus guidelines to inform practice; 'Team working and coherence' includes communication and relationships within the multi-disciplinary team as well as perceptions by HCPs of patients' social support (formal and informal); 'Patient-centred care pathway' focusses on the overall dietary and nutritional care received by individual patients including adaptation of advice and support; 'Patient self-management' includes patient understanding and attitudes, and the importance of experiential learning and self-determination.

5.4.2 Reflexivity

As a dietitian who has provided advice to patients with an ileostomy in the past and worked closely with specialist dietitians who work a lot with people with an ileostomy, I was aware of having preconceptions based on my training and clinical experience relating to the topics to be covered in the study interviews. Based on my own clinical experience, I held the beliefs that 1) there are differences between healthcare professions in their approach to providing dietary advice for ileostomy management 2) there are institutional differences in the dietary advice provided to people with an ileostomy, particularly within a profession. The second belief is based on my experience that HCPs learn from and often receive supervision from senior colleagues.

I wrote the following statement in a reflexive research journal prior to conducting the study interviews. I did this to identify potential biases I might have that I needed to actively work to

ensure they 1) were not conveyed in my communication with participants, and 2) did not lead me to misinterpret the data.

"It is my belief that, in general, stoma nurses provide very specific general advice such as a list of foods to avoid to prevent blockage and avoid high output. They may also provide additional advice to patients with problematic management such as encouraging rehydration drinks and extra salt to those with high output.

Dietitians are trained to have a holistic and patient-centred approach to the provision of dietary advice which I believe makes the advice they provide more tailored to the individual. Also, the dietitian will place more importance on preventing unnecessary dietary restrictions that may increase risk of malnutrition in a vulnerable group.

Stoma nurses and dietitians often have access to published patient literature including advice on diet for ileostomy management. The verbal advice that they provide to patients is likely to be guided and in line with local literature they provide to their patients which they may or may not have been involved in writing.

Gastroenterologists are often the lead member of a multidisciplinary nutrition team. In my experience, they are more likely to see patients with severe management problems associated with their ileostomy and are likely to focus their advice on fluid management alongside medical management.

It is my experience that surgeons who perform ileostomy surgery may or may not give advice on diet to people with an ileostomy. If they do, this can often be related to specific foods that patients should avoid to reduce risk of blockage or general advice such as following a healthy, balanced diet.

Some healthcare professionals may tell patients with an ileostomy to ignore dietary advice from other sources."

I considered how I needed to ask questions relating to the advice each HCP provides and their views on dietary advice provided by other HCPs in a way that would not be leading towards the type of response I anticipated. I also considered how I must pay attention to my own body language to ensure that I remained neutral and did not indicate validation, surprise, or disagreement with what a participant was saying.

I hoped and anticipated that the involvement of a second researcher, with a different disciplinary background, at all stages of the data analysis process would help to identify and challenge any unconscious bias in my interpretations to ensure the findings would be a true reflection of the participants' narratives.

The fact that the interviewer was known to be a dietitian I believe helped encourage participation and develop rapport with participants. I got the impression that participants felt that I understood and could relate to their experiences which made them feel more comfortable talking openly. However, this may also have been a limitation in some situations where some participant responses came across as somewhat defensive as if I might be judging them or they had something to prove. I explained at the start of the interview that the aim wasn't to test them but to understand what was happening in practice and why, but this may not have been sufficient to entirely remove any concerns about professional image or being judged. From the interviewer's perspective, more experienced/senior HCPs seemed more open to talking about their own gaps in knowledge and understanding, and weaknesses in the service they were a part of.

5.4.3 **Research question 1: What dietary advice is provided to people with an ileostomy, and how and when is it provided?**

Specific foods were often highlighted as being particularly problematic to people with an ileostomy. However, which ones were advised to patients as presenting a very high risk, and to be avoided, varied by HCP. Often, highlighting high risk foods was the extent of the dietary advice provided by surgeons. Stoma nurses commonly provided patients with booklets containing lists of foods associated with different symptoms and complications. Of these, some were highlighted to patients as particularly high risk. Dietitians focussed more on a low-fibre diet which included educating patients on high fibre foods to avoid and suitable low fibre alternatives but placed less emphasis on labelling a small number of specific foods as high risk. One reason for this could be that dietitians tended to be referred patients requiring assistance with managing high output, while the specific foods highlighted to patients by surgeons and stoma nurses, in general, tended to be those thought to increase risk of obstruction (Taylan et al., 2010). Another reason could be that dietitians are trained to provide a whole diet approach (British Dietetic Association, 2021).

All HCPs agreed that patients should follow a low-fibre diet initially during the post-operative period. However, the terms 'low-fibre' and 'low residue' were used

interchangeably by participants despite implied differences, difficulties in defining a low residue diet, and a lack of research on low residue diets (Vanhauwaert et al., 2015). Insoluble fibre was explicitly and non-explicitly identified by HCPs as the key dietary component to reduce. However, the role and required modification of soluble fibre was less clear. This is in keeping with a lack of clarity on the role of soluble fibre for ileostomy management in the literature (Arenas Villafranca et al., 2015). As well as educating patients on high and low fibre foods, dietitians and stoma nurses provided advice on how to reduce the risk associated with consuming high-fibre foods i.e., chew well, eat slowly and in small amounts.

Stoma nurses, and sometimes surgeons, provided limited dietary advice pre-operatively. They expressed a desire to avoid giving patients another thing to worry about and aimed to be reassuring while acknowledging that the patient might need to make some dietary changes. However, booklets containing dietary advice in the form of lists of problematic foods were often given to patients along with other pre-operative information. This potential contrast in information at a time when patients may be overloaded with information may add to patient anxiety or disengagement. Post-operatively, the surgical team (consultant surgeon and their team of surgeons/doctors), and to some extent stoma nurses, acted as gatekeepers to determine which patients received specialist advice from a dietitian. Dietetic input was reliant on other MDT members acknowledging and valuing dietitians' expertise, and availability of dietetic resource.

The interviews highlighted discrepancies in the advice HCPs reported to provide versus their experiences with some patients and colleagues regarding dietary advice provision. It was recommended that high-fibre foods be reintroduced gradually with the aim being for patients to return to a more balanced and normal diet long-term. No HCP described advising patients to follow a very restrictive diet long-term; however, there were several reports of patients who had followed a strict diet much longer than necessary, believing this was required. It may be that the HCPs, particularly stoma nurses and surgeons, who agreed to participate in this study had a greater interest in diet and nutrition which might have manifested as better knowledge and communication of diet advice than their colleagues. Other factors that may contribute to this phenomenon are gaps in patient care meaning that patients miss out on follow-up advice, and mixed messages from online sources.

5.4.4 **Research question 2: What factors influence the dietary advice provided to people with an ileostomy?**

Professional role was a key factor in determining the dietary advice provided to patients with an ileostomy. Different professions felt they had different responsibilities in terms of providing dietary advice and they also had differing priorities. Surgeons were very aware of the consequences of obstruction and therefore focussed on dietary advice relating to preventing obstruction. In contrast, dietitians were commonly asked for input with patients with a high-output stoma; therefore, their advice usually centred around reducing output, and ensuring nutritional sufficiency.

Dietitians and stoma nurses received some formal training on dietary management of ileostomies and gained additional knowledge from study days. The strongest influence on the dietary advice all HCPs provided was experiential learning through their own and colleagues experiences within their clinical role. Where individuals and professions worked more closely together, there was greater sharing of knowledge and learning which facilitated increased consistency and consensus in the dietary advice provided by the MDT.

No formal MDT was in place for people undergoing stoma or ileostomy formation. The surgeon and stoma nurse were always involved in these patients' care but did not formally discuss or agree planned care. Referral to other HCPs was made as and when additional expertise was required. A systematic review of MDT co-management of surgical patients suggests that patient co-management between surgical and medical consultants in conjunction with wider MDT involvement can improve clinical outcomes (Shaw et al., 2020). MDT interventions included an MDT meeting, most often daily and sometimes weekly. MDT meetings provide a regular opportunity for team members to discuss all aspects of a patient's care and treatment plan. One mechanism through which formal MDTs may improve patient outcomes is by increasing consensus and consistency of care and advice provided to patients.

Although patients with an ileostomy were not all under one formal MDT, some may be under a condition-specific MDT such as IBD or colorectal cancer. However, due to the condition focus and lack of stoma nurse involvement (within the formal MDT), stoma management is unlikely to be a priority for discussion and this aspect of patient care may gain little benefit from the MDT. There are also patients with an ileostomy that fall outside of the remit of IBD and cancer MDTs.

The lack of published consensus guidelines on dietary management for ileostomies or stomas, which was highlighted in Study 1 (Chapter 3) (Mitchell et al., 2021), contributed to inconsistency and lack of clarity in the dietary advice provided to patients. However, where locally agreed guidelines/protocols, e.g., for management of high-output stoma, were in use, these were seen to have improved practice.

HCPs relied on experiential learning due to a lack of time for structured activities for knowledge acquisition, such as research or audit or reviewing literature. Although there was variation in how confident individual HCPs were in their awareness of relevant research, most HCPs correctly believed there was a lack of research evidence to inform or support the dietary advice provided for ileostomy management.

5.4.5 **Research question 3: What are the determinants of effective dietary management?**

Communication and understanding of advice were deemed key to effective dietary management. Mixed messages caused confusion, and limited patient understanding and confidence in the dietary advice they received. In the peri-operative period, patients are given a large amount of information by a variety of HCPs at a time when they are under considerable stress and unwell and/or recovering from major surgery. These findings are supported by those previously reported in a qualitative study of patients undergoing colorectal surgery within an Enhanced Recovery After Surgery (ERAS) programme which found that patients can be presented with an overwhelming amount of written information pre-operatively (Short et al., 2016).

How information is provided needs to be adapted to take account of the patient's capacity and desire, in the immediate context, to engage with new information (Redsell and Buck, 2009). Several HCPs expressed an awareness of this and adjusted the amount and format of dietary advice accordingly. For example, providing small amounts of information using a paternalistic communication style immediately post-surgery, then moving to more of an information giving or shared decision-making approach later in the recovery process. Some HCPs also spoke of tailoring dietary advice to the individual in terms of the patient's prior knowledge and beliefs, dietary preferences, and co-morbidities.

The complexity of some of the dietary advice impacted on patient understanding. Some HCPs expressed concern that understanding of advice in relation to fibre intake was commonly poor due a lack of knowledge amongst the general public about what fibre is and where it is found.

Fluid advice for high output was a common example of when patients received conflicting information. As one surgeon highlighted, advice to drink less water when dehydrated and thirsty due to high output is counterintuitive and the reasoning behind it a difficult concept for many patients, and potentially some HCPs, to understand.

In a quasi-experimental trial, Webber et al. (2001) showed that combining written and verbal information, checking understanding, and repeating and emphasising key points improved patient recall of information provided. Stoma nurses and dietitians used a combination of written and verbal advice, and often checked current understanding and repeated advice at different time points.

Consistency of dietary advice intersects with concordance of health beliefs between patient, HCPs, and family and social support networks in determining behaviours. HCPs perceived similarity in beliefs between HCPs and patients regarding priorities for dietary management of the ileostomy i.e., avoiding blockage and reducing risk and consequences of high output. Many HCPs and patients shared the belief that dietary management needed to fit in with the patient's lifestyle. However, there appeared to be inconsistency in the assessment of risk associated with aspects of diet and potential consequences and complications, between patients and HCPs and other members of patients' family and support networks.

HCPs suggested several factors that determine patients' behaviour in response to receiving inconsistent messages. Firstly, there was a perception amongst other HCPs that any advice provided by the surgeon tended to carry a lot of weight with patients even if brief or non-specific. Surgeons should be aware of the power their position provides them and acknowledge to themselves and their patients where other members of the MDT have greater expertise, being careful to ensure that any advice they give aligns with their colleague(s). The surgeons in this study acknowledged that they were not the experts on dietary management and often referred to the dietitian or stoma nurse for input. However, they still provided some diet advice themselves while lacking awareness of what dietary advice those HCPs they referred to were providing. Secondly, anecdotal peer experience could undermine HCP advice. This is likely due to an increased feeling of relatedness with peers and may be less likely to occur where the HCP has developed a good rapport with the patient, listened to and addressed their concerns, and checked understanding (Street et al., 2008). Thirdly, patients were more likely to follow advice that fits with their beliefs and lifestyle. It is therefore important for HCPs to take the time to understand key aspects of their patient's beliefs and

lifestyle to tailor dietary advice to the individual and implement shared decision making where appropriate.

For some individuals and situations, HCPs felt that a more paternalistic communication style was preferred by the patient because they lacked relevant knowledge and understanding at that time to interpret information and make informed decisions about their diet. For some patients, and in other circumstances e.g., after discharge from hospital, HCPs perceived a strong desire for self-determination among patients and for them to be in control of decisions about their diet. This self-determination manifested as a spectrum of behaviours, from choosing to ignore advice and eat what they want, to strictly avoiding all foods and drinks associated with increased risk of symptoms and complications. Diet is a fundamental part of daily life and HCPs were aware of the important role diet played for people with an ileostomy as something affecting their health and stoma function that they could control.

Patients often asked HCPs for more dietary advice to increase their self-efficacy (via increased knowledge and understanding) in managing their diet and ileostomy. This suggests these patients have positive outcome expectancies for dietary management of their ileostomy. Behaviour-specific efficacy is a strong determinant of health behaviours in those who place high value on their health, while the health locus of control construct has little influence on behaviour (Norman, 1995, AbuSabha and Achterberg, 1997). As such, patients who ask for dietary advice, and receive what they need, are likely to have increased self-efficacy and are more likely to make diet-related behaviour changes.

In addition, in the current study, HCPs believed that patients with an expectation that their ileostomy was temporary lacked ownership of their stoma management. In contrast, patients with a permanent ileostomy were perceived to want to take ownership. This may be due to greater acceptance amongst patients who have an expectation that this change in their anatomy is how their body functions now and will do for the rest of their life.

Surgeons and dietitians identified differences between IBD and colorectal cancer patients undergoing ileostomy formation, influencing the level of diet and fluid advice and management required. Patients with Crohn's disease are more likely to need intense management and dietetic input due to extensive small bowel resection (Parrish and DiBaise, 2017). However, they are also likely to have increased awareness and understanding of diet and GI symptoms based on their prior experience of living with a GI disorder.

Understanding the patient as a unique person with individual needs, in terms of both what advice they require and how they require it to be given at that particular point in time, coordination of care, patient involvement in care, and patient empowerment are key components of patient-centred care (Scholl et al., 2014, Redsell and Buck, 2009). In this study, some aspects of these components were apparent, as described in this section above, but overall, how dietary care was provided to patients with an ileostomy fell short of being fully and consistently patient-centred.

5.4.6 **Strengths and limitations**

Strengths of this study include the involvement of public contributors and stakeholders, i.e., HCPs, in the development and refinement of the interview topic guide. Interviews were all conducted face-to-face at the participant's place of work and by the same researcher. This ensured that interviews were convenient to participants, and in a place that was comfortable and familiar to them. Face-to-face interviews facilitated development of rapport between the interviewer and participants and enabled the interviewer to respond to body language in addition to verbal cues. Having all interviews conducted by the same researcher provided consistency.

Interview data collected was in-depth and comprehensive. Probing questions were used to follow-up relevant details related to questions in the topic guide. I believe that having experience of working in the clinical setting being discussed was beneficial to the interviewer's understanding of participant responses and ability to quickly identify appropriate probing questions to ask.

The analysis process used to interpret the interview transcripts was a strength of this study. Data was analysed using a rigorous framework approach to thematic analysis. Codes (Framework sub-categories and categories) were generated inductively from the interview transcripts followed by deductive thematic analysis of the framework to identify key themes that answered the three pre-determined research questions. The coding framework and framework matrices were developed by consensus of two researchers, one who had conducted the interviews and was a dietitian with clinical experience; the other was a psychologist with expertise in qualitative research methods and health services research. Having multi-disciplinary perspectives in the analysis process was a key strength in this study as it enabled initial beliefs and interpretations from the interview data to be challenged leading to a deeper understanding of the data and interpretation of findings.

Coding and charting of the interview transcripts were systematic and comprehensive. Data were well organised within the framework matrices by code (category) and case (participant), and summaries clearly linked to raw data in the transcripts. As such, the analysis process was thorough and transparent, increasing validity of the study findings.

A limitation of this study is that the three sites where the HCP interviews were conducted were all in the same region of England – the South-West. However, sites included a mix of different size hospitals and a combination of teaching and district hospitals. Although the limited regional representation in the sample did not allow for the identification of regional differences, this did mean that inter-site differences were more clearly attributable to the institutional structure than if regional differences had also been at play between the three sites. Examples of institutional differences between included sites were ways of working with other professions and size of department which influenced opportunities for peer support and learning. Ideally a greater number of sites from a wider range of regions would have been included, but this was not practical for this PhD study.

It was anticipated that a large teaching hospital would carry out more surgeries annually than a small district hospital. As such, within the site characteristics data collected, the responses for annual number of initial ileostomy surgeries did not fit the expected pattern, with more surgeries carried out at the district general hospital (site 2: n=60) than one of the large teaching hospitals (site 1: n= 54). This led me to question whether some figures included all ileostomy procedures whereas others included just initial formations.

As described above, the findings in this thesis are the results from the analysis of 15 interviews conducted with dietitians, stoma nurses and colorectal surgeons (across three hospital sites) who have been identified as the main providers of dietary advice to people with an ileostomy (Mitchell et al., 2020). The findings reported provide valuable insights into the provision of dietary advice by these main providers. However, other HCPs are also known to give some dietary advice to people with an ileostomy, and six further interviews with colorectal nurses (n=4), an IBD nurse and a gastroenterologist were also conducted to provide a wider and more complete picture. Unfortunately, due to time constraints of the PhD, this additional perspective and understanding was not able to be included as part of this thesis. The additional data will, however, be analysed and included in publication of the study findings at a later date.

5.4.7 **Implications for practice**

Two main areas for practice are highlighted in the findings from this study. Firstly, the importance of consistency and consensus in the provision of dietary advice to people with an ileostomy. This is difficult when several HCPs are responsible for providing diet advice and there is a lack of strong evidence and consensus guidelines for dietary management in people with an ileostomy.

Currently, at least at the NHS hospitals where participants in this study were based, a formal MDT for patients with a stoma does not exist. Integrating a stoma MDT with existing IBD and cancer MDTs may be difficult to achieve but could provide considerable benefit in terms of coordination of care, and the clarity, consistency and comprehensiveness of dietary advice provided. Having a formal MDT improves communication between HCPs and would increase HCPs knowledge and understanding of individual patients enabling a more holistic and tailored approach to the provision of dietary advice.

Secondly, HCPs caring for patients with an ileostomy should consider how they can be more 'patient-centred' in their provision of dietary advice. Advice giving should be adapted in terms of communication style and content to the patient's need at a specific point in time. HCPs should be aware of what else is going on for the patient that may affect their ability to positively engage with dietary advice. For example, the risk of information overload pre-operatively, feeling unwell and vulnerable post-surgery while recovering in hospital, practical and emotional support from significant others, or the need for autonomy over their long-term health and well-being.

Patients with an ileostomy should be encouraged to ask questions about their diet. Advice given should be tailored to patients' beliefs. This shows respect for the patient as an individual and is likely to reduce resistance to dietary changes and increase understanding. Checking patient understanding and repeating advice at different time points is likely to improve patient recall of information provided.

HCPs should be aware of power dynamics at play. For example, surgeons should acknowledge that their position may influence patients to follow their advice above that of other HCPs even on topics that are not their speciality, such as diet. If surgeons were to highlight to their patients that other HCPs have greater knowledge about diet and check that any advice they give is consistent with that provided by dietitians and stoma nurses, this could compensate for the effect of this power dynamic.

5.4.8 **Conclusions**

Provision of dietary advice to patients with an ileostomy was strongly determined by the profession of the HCP providing the advice, through their role identity, training, and clinical experiences. The institution (hospital) where the HCP worked also had some influence although this was less prominent. Institutional differences centred around the structure and relationships within the MDT. Closer team working improved consistency of dietary advice. Insufficient research evidence and lack of published consensus to inform practice contributed to mixed messages and reduced confidence in the provision of dietary advice by HCPs.

Due to the nature of ileostomy formation involving long-term change to the patient's body and requiring daily management, HCPs and patients were motivated to promote self-management and self-determination of diet. Individual differences between patients meant that experiential learning was key, and encouraged, in a controlled way, by HCPs. However, the lack of 'one size fits all' guidance proves a struggle for some patients, particularly those with high anxiety around risk of complications.

The findings from this study provide a detailed picture and new in-depth understanding of the provision of dietary advice to people with an ileostomy within the NHS. This research will help HCPs working with patients with an ileostomy to understand potential pitfalls as well as components of good practice, to inform their practice with the potential to improve how patients receive dietary advice for ileostomy management.

5.5 IMPLICATIONS FOR THESIS

Studies 1 and 2 showed that considerable variation exists in the provision of dietary advice to people with an ileostomy both in terms of what advice is provided and by whom. Study 1 highlighted large gaps in the research evidence for dietary management in people with an ileostomy and suggested that much of the advice provided in practice is based on expert opinion. The findings from Study 3 support these conclusions by showing that the HCPs providing dietary advice for ileostomy management are primarily informed by clinical experience and training, and mostly believe there to be a lack of research to support practice.

Study 3 adds extensive detail and understanding to some of the findings from the survey in Study 2. For example, Study 2 showed that stoma nurses are the main provider of dietary advice for ileostomy management, and this was confirmed in the qualitative findings from Study 3. In addition, the qualitative data provides us with an understanding of why stoma

nurses are the main provider and how surgeons, dietitians and stoma nurses view each other's role in provision of dietary advice to patients with an ileostomy.

In Study 2, results from the survey suggested that people with an ileostomy often receive advice that appears to them to be conflicting. Findings from Study 3 start to explain how and why this is happening, beyond the issue highlighted in Study 1 that research evidence to inform practice is lacking and largely inconclusive. The qualitative results show how differing levels of HCP understanding, priorities and framing of dietary advice along with contrasting communication styles from different professions contributes to mixed messages and lack of consistency.

Study 3 fills a previous gap in knowledge around what the provision of dietary advice to patients with an ileostomy looks like in current practice, from the HCP's perspective; knowledge and beliefs of HCPs, relating to dietary advice for ileostomy management; and facilitators and barriers to effective dietary advice and management for patients with an ileostomy.

This study completes the series of three studies that make up this thesis. Study 1 described the research landscape and gaps in evidence informing dietary management for people with an ileostomy. Study 2 identified the extent to which dietary advice is not meeting the needs of people with an ileostomy. Study 3 describes what and how dietary advice is being provided to patients with an ileostomy within the NHS and provides some explanation and understanding as to why.

In the next and final chapter of the thesis, findings from all three studies will be discussed as a whole in more detail, and within the context of other literature. Implications for practice and future research will be suggested before presenting my final conclusions.

6 DISCUSSION

6.1 CHAPTER INTRODUCTION

The thesis concludes in this final chapter with discussion of how key findings from the three studies presented in chapters 3-5 answer the research questions that were posed to achieve the overarching aim set out in Chapter 1. Methodological strengths and weaknesses of the research conducted are considered. Following this discussion of the study findings, implications for practice and recommendations for future research are presented. Finally, a theoretical model is proposed, based on findings from the research conducted, to provide a framework for future development of dietary interventions for people with an ileostomy. The chapter, and thesis, ends with my final conclusions.

6.2 KEY FINDINGS

6.2.1 **Research question 1: What evidence is there for oral dietary management in people with an ileostomy?**

Dietary management is believed, by healthcare professionals (HCP) and patients, to be beneficial for those with an ileostomy and dietary advice to facilitate this is commonly, if not consistently, provided in practice. This is apparent in the extent of expert opinion articles (identified in Study 1) that provide recommendations for dietary management for people with an ileostomy, statistics from the survey reported in Study 2 and other published surveys (Beeken et al., 2019, Persson et al., 2005), and qualitative findings reporting the experiences, attitudes, and beliefs of HCPs (Study 3) and people with an ileostomy (Morris and Leach, 2015).

In Study 1, research and published expert opinion literature relating to oral dietary management for people with an ileostomy was, for the first time, systematically identified and described, using JBI scoping review methodology (Peters et al., 2015). Findings from the review showed that a large range of dietary strategies have been reported in the literature, all of which can be categorised within one of the following three groups: 1) nutrient modifications 2) foods and drinks 3) eating-related behaviours, i.e., how food and drink was consumed such as timing and preparation.

Most of the research evidence for dietary management and ileostomies comes from cross-sectional observational studies; although a handful of small, controlled trials investigating individual dietary modifications, and pre-post studies evaluating combined dietary interventions have also been conducted. Research studies have associated ten outcomes for ileostomy management with diet: volume and consistency of stoma output, dehydration, flatulence, odour, blockage, pain, malnutrition, food visible in output (maldigestion), and leakage. Stoma output volume and consistency were the most reported outcomes. In Study 2, survey responses from 291 people with an ileostomy in the UK and Ireland provided further evidence that loose/watery output, high output, gas, odour, pain, and blockage are common difficulties for people with an ileostomy (43-87%) and that dietary advice and management are thought to be beneficial and are important to people with an ileostomy.

From the scoping review, it was found that approximately 20 nutrient modifications, over 100 individual foods and drinks, and approximately 15 eating-related behaviours have been reported, across research studies, for the dietary management of ileostomies. These numbers were even higher within the expert opinion literature. Low-fibre and low-fat diets were the most common nutrient modifications suggested to have a beneficial effect on ileostomy outcomes.

Although negative effects of caffeinated drinks and benefits of white, starchy carbohydrates on stoma output were well documented within expert opinion literature, there was minimal research evidence to support or refute the validity of this advice. Marshmallows (and other gelatine-containing sweets) have also been recommended within expert opinion literature to thicken stoma output. Two small studies (one a pilot study) were found to have investigated the effect of marshmallows on ileostomy output; however, although suggestive that for some people there may be a benefit, the results were inconclusive due to high inter-participant variation and most participants having a normal output volume (not high-output stoma) at baseline (Clarebrough et al., 2015, Donoghue et al., 2009). Eating-related behaviours such as chewing food well were again well documented within expert opinion but were rarely the subject of investigation in research studies.

Overall, this thesis has shown that although there is an abundance of literature reporting on dietary management for people with an ileostomy, expert opinion articles far outweigh original research articles and the studies that have been conducted are highly heterogenous in terms of dietary strategies and outcomes investigated. In addition, much of the research

evidence on this topic is far from current and used small samples that were underpowered to show differences in outcomes. The variation in the recommendations published in expert opinion articles highlights a lack of consensus on the optimal oral dietary management for people with an ileostomy.

6.2.2 **Research question 2: What dietary advice is provided to people with a new ileostomy and why?**

In the survey conducted for this thesis (Study 2) and in another recent survey of people with a stoma (Beeken et al., 2019), provision of dietary advice for ileostomy management was shown to be common but not universal (approximately 30% had never received any dietary advice). Most people who did not receive any dietary advice would have liked to receive this (>90% in the survey for Study 2), suggesting an unmet need for wider support with dietary management. In addition, Study 2 has provided further insight into the experiences of dietary advice and management for people with an ileostomy. There was a high prevalence of conflicting information (62% of those who received some dietary advice) and respondents identified anxiety, confusion, and frustration as the most common feelings (positive and negative) associated with managing their diet with a new ileostomy. These findings add support for the case that dietary advice needs to improve to provide people undergoing ileostomy formation with the guidance and support they require.

Study 2 adds to the existing literature by providing a quantitative description of the types of dietary advice received by people with an ileostomy living in the UK. Most people (approximately 90%) who received dietary advice relating to their ileostomy were advised about adding or removing specific foods in their diet, over half were advised how to prepare certain foods, and over three-quarters were advised how to eat certain foods, e.g., chew well. Only about one-quarter received advice on weight management, and this was mostly advice to gain weight.

Qualitative findings from in-depth interviews with HCPs (Study 3) have provided novel insights into HCPs perspectives on dietary management of ileostomies in practice, and their knowledge and beliefs relating to the evidence-base for this. HCPs commonly gave advice to include or exclude specific foods; however, which foods were included in the advice varied between professions and individuals. Surgeons' advice was often limited to the signposting of high-risk foods, particularly those they believed to increase risk of blockage. Foods mentioned were high in fibre such as nuts, brassicas, and skins/pith.

Advice from stoma nurses and dietitians focussed on a low fibre or low residue diet immediately post-surgery for ileostomy formation. However, stoma nurses' advice tended to be centred around printed patient information that included lists of foods that may cause problems (high output, blockage, wind/odour) for people with an ileostomy, while dietitians centred their advice around educating patients on high fibre foods (particularly those high in insoluble fibre) to limit or avoid initially and low fibre substitutions; the priority being to manage high output. In addition to providing advice on high and low fibre foods, stoma nurses and dietitians also advised on how to reduce risk when eating higher fibre foods i.e., chew well, eat slowly and in small amounts. These findings were in keeping with the recommendations for dietary management in people with an ileostomy published in the expert opinion literature described in Study 1. The HCP participants in Study 3 agreed that a strict low fibre diet was only required in the short-term and that, within a few weeks, patients should be able to gradually reintroduce fibre into their diet.

Foods commonly recommended in expert opinion articles to thicken output, such as white, starchy carbohydrates and marshmallows, were also mentioned to be a component of the diet advice provided by several HCPs in the qualitative study presented in this thesis (Study 3). However, there was variation in confidence in advising marshmallows for this purpose. One surgeon believed that the evidence to support this advice was good; one stoma nurse mentioned that they commonly gave this advice despite a lack of evidence; another stoma nurse at a different site highlighted that she didn't recommend marshmallows to her patients with an ileostomy as in her experience she had not found them to be beneficial.

The dietary advice provided to patients with an ileostomy was strongly influenced by professional role identity and experiences, training, and engagement with research. Stoma nurses viewed themselves, and were viewed by other HCPs, as the main providers of dietary advice to patients with an ileostomy, despite dietitians being acknowledged as the experts. This was because stoma nurses see all patients undergoing ileostomy formation while only those patients with certain complications, e.g., high output, are referred to the dietitian. From these role identities and resources, it follows that stoma nurses look to provide a general overview of dietary management while dietitians provide more in-depth, tailored dietary advice to the patients they see. Provision of dietary advice was perceived to be on the periphery of the surgeon's role and therefore they did not assume much responsibility for dietary advice and management. Surgeons' priorities were to prevent obstruction and not to add to patients' worry by overloading them with additional information.

For all HCPs, practice was informed for the most part by clinical experience. The reliance on experiential learning was explained to be due to a lack of strong research evidence to inform practice in this area, and a lack of time for CPD and research-related activities. Personal experiences and beliefs also influenced the advice provided and explained some of the intra-profession variation observed.

6.2.3 **Research question 3: How is dietary advice being provided to people with an ileostomy?**

People with an ileostomy receive dietary advice from many different sources. Results from the survey in Study 2 show that stoma nurses are the most likely source of dietary advice for people with an ileostomy (55% of all respondents), followed by dietitians (29%). Many people received advice from more than one source. Other sources of dietary advice were online sources such as social media, websites, and registered support associations e.g., IA, as well as stoma product suppliers. These findings from the survey fit with the narratives described by the HCP participants in Study 3.

Dietary advice was provided verbally, most commonly; but written/printed format was also frequently used by certain health professions (dietitians and specialist nurses), and often HCPs used a combination of the two. Survey respondents showed a preference to receive more dietary advice in printed format and from the dietitian, in addition to, rather than instead of, advice from their stoma nurse. As regards timing of dietary advice provision, advice may be provided pre-operatively, during inpatient stay post-operatively, or after discharge from hospital. However, survey respondents reported that most dietary advice was provided during hospital admission, although they would have liked to receive more advice before surgery and ileostomy formation.

In Study 3, similarities and differences were described between hospitals in how HCPs worked together and how this influenced the provision of dietary advice to people with an ileostomy. Commonly, disease-specific specialist nurses, i.e., colorectal and IBD nurses, worked closely with the surgeons and would see patients together in outpatient clinics. In some cases, dietitians and stoma nurses worked collaboratively, sharing knowledge and co-developing resources. Where this happened, provision of dietary advice was more likely to be consistent. In contrast, where a lack of collaboration and coherence of knowledge and beliefs between HCPs exists, this likely contributes to mixed, and potentially conflicting, messages being received by the patient.

Patient care pathways varied between site and between conditions e.g., cancer patients followed a different pathway to those with IBD. This led to differences in patient access to HCPs and dietary advice. After discharge from hospital, patients have less contact with HCPs and there is greater responsibility placed on the patient to communicate if they have problems and/or require additional advice and support. Limited dietetic resources meant that access to dietary advice from a dietitian was not available when needed in some cases and situations (particularly for outpatients).

As formal MDTs and patient care pathways exist only for some conditions, and not specifically for patients who have stoma surgery or an ileostomy, this leads to inconsistencies in access to and provision of care including provision of dietary advice. As such, for patients undergoing ileostomy formation, increased involvement, coordination, and collaboration of the wider MDT, including stoma nurses and dietitians, has potential to improve dietary management and QoL.

Many of the HCPs interviewed for this thesis acknowledged differences in the needs and experiences of patients with an ileostomy relating to their underlying condition (these were discussed in Chapter 1), and described tailoring dietary advice based on these. Adapting advice and communication to the individual is central to the principles of patient-centredness (Scholl et al., 2014).

Communication is an important component of provision of dietary advice which was explored in Study 3. The way HCPs communicated with patients with an ileostomy about dietary management varied from a paternalistic style, to more of an information giving approach where patients were encouraged to make their own decisions from the information provided, to a more collaborative approach between HCP and patient that contained elements of shared decision-making (Redsell and Buck, 2009). However, none of the HCPs in the study appeared to use a comprehensive shared decision-making approach which is fundamental to providing truly patient-centred care (discussed in Chapter 2.11). This lack of patient-centredness, alongside barriers to access within patient care pathways, could in part explain why people with an ileostomy are often unsatisfied with the dietary advice they receive.

6.3 STRENGTHS AND LIMITATIONS

Strengths

A strength of the research conducted for this thesis is the originality and relevance of the research questions addressed by the three studies. The topic of dietary management for people with an ileostomy is an historically under-researched area of clinical practice. No previous reviews have systematically searched and synthesised the existing literature (Mitchell et al., 2019). Although it had been suggested anecdotally that people with an ileostomy often received insufficient and/or conflicting advice, prior to the survey conducted for this thesis, the extent and characteristics of this problem, particularly within the UK, had not been investigated. Additionally, the qualitative research conducted with HCPs is the first to provide in-depth analysis and appraisal of current clinical practice and context relating to dietary management for people with an ileostomy.

The studies contributing to this thesis used a range of research methods to appropriately address different aspects of the overarching thesis aim. Scoping review methodology was used to identify and synthesise descriptively the research previously conducted and what the published literature suggests about dietary management for people with an ileostomy. An online survey was used to reach a large and broad sample of the population of people in the UK and Ireland who have an ileostomy, to identify and quantitatively describe similarities and differences in if, when and how dietary advice is received and to provide a quantitative overview of patient attitudes to dietary advice. In-depth interviews and framework analysis were used to elicit the complexities of HCP views, understanding and practices relating to the provision of dietary advice to people with an ileostomy, through qualitative data analysis.

This mixed methods approach is pragmatic and is commonly used in health services research. It acknowledges the advantages and disadvantages of different methods, using multiple research methods to combine the benefits and different perspectives of each included method and address limitations through triangulation of findings (O'Cathain et al., 2007). Triangulation refers to the process of conducting separate quantitative and qualitative research and analysis followed by a comparison of results considering the extent of alignment and where results from one method compliment those derived using another method (O'Cathain et al., 2010). Taking a mixed methods approach to this thesis has yielded findings and interpretations of greater breadth and depth than could have been achieved employing either quantitative or qualitative methods alone.

Another aspect of this thesis that has enabled me to provide in-depth answers to my overarching research questions is the inclusion of multiple perspectives on dietary advice and management for people with an ileostomy from both people with an ileostomy and the HCPs who care for and provide dietary advice to these patients. It was important to include both these perspectives as the lived experience of the same situation e.g., a patient consultation where dietary advice is provided, can be very different based on the role 'played' in the situation described.

The rigorous application of transparent and well documented methods in the studies conducted for this thesis is a key strength. For each of the methods used in the three studies, I completed reading and official training produced and led by experts in these methods.

In Study 1, the JBI guidelines for conducting a systematic scoping review of the evidence in relation to oral dietary management in people with an ileostomy were closely followed (Peters et al., 2015). The protocol for the scoping review was published *a priori* and amendments that needed to be made during the process of conducting the review were clearly described with justification, in Chapter 3 and in the published journal article reporting the results of the review (Mitchell et al., 2019, Mitchell et al., 2021). Results from the search and screening process were clearly reported following PRISMA and JBI guidelines (Moher et al., 2009, Peters et al., 2015). Search strategies, details of the full text articles that were screened and excluded, and the form used for data extraction from included studies and articles have all been published for full transparency (Mitchell et al., 2021).

In Study 2, stakeholders, including public contributors, were involved in the design of the survey. Cognitive interviews with people with an ileostomy were conducted as part of the development process, as recommended for questionnaire design, to increase face validity (Drennan, 2003). Stakeholders, i.e., clinicians and people with an ileostomy, were also involved in the development of the interview topic guide used in Study 3. HCPs from different disciplines, and public contributors, reviewed an initial draft of the interview topic guide and changes were made based on their feedback and suggestions, to ensure that interview questions were relevant and comprehensive. As such, PPI and multi-disciplinary stakeholder involvement ensured that different relevant perspectives and priorities were considered and used to strengthen the study designs used for this thesis.

Interview transcripts from Study 3 were analysed using the Framework Method of thematic analysis. Data were analysed systematically through rigorous application of a coding

framework and the charting of data into the framework matrix by case and category. All of the summaries included in the framework matrix were linked, using NVivo software, to raw data in the interview transcripts to ensure that all results were thoroughly grounded in data and for transparency. Development of the coding framework and interpretative analysis were iteratively conducted by two researchers from different disciplines – one from dietetics and the other from psychology. Multidisciplinary perspectives enhanced this thesis by providing broader and more in-depth understanding and interpretation. It also helped to minimise the introduction of unconscious bias in the interpretation of data.

Limitations

A limitation of the scoping review is that the searches were conducted in 2019 and therefore more recent publications are not included. Also, due to the heterogeneity of the dietary components and the breadth of literature included in the review, quality assessment of studies was not conducted. For reasons such as these, quality assessment is not usually included in scoping reviews. Quality assessment is an essential component of systematic reviews of effectiveness, to identify the strength of the findings and therefore the level of confidence that may be placed in recommendations for practice that are based on these. However, scoping reviews are not designed to evaluate effectiveness, instead their purpose is to describe and provide an overview of the current body of literature relating to the topic.

A key limitation of the online survey is that there may be a lack of diversity in the sample of people who responded to the survey which was posted on the websites of the Ileostomy and Internal Pouch Association (IA) and Crohn's and Colitis UK (CCUK) and shared via social media (mainly Twitter). It was identified that older people >75 years were underrepresented in the sample of respondents, likely due to the digital medium used for recruitment. Unfortunately, this is a commonly under-served group in clinical research (National Institute for Health Research, 2020). Initially, it was planned to recruit people with an ileostomy to complete the survey via email to IA members, in addition to recruitment via the IA and CCUK websites and related social media platforms. However, unfortunately, at the time of the study, the IA were undergoing an organisational restructure between the umbrella and regional groups which meant they were not in a position to facilitate this alternative means of recruitment. Characteristics such as ethnicity, socio-economic status and level of education were not collected for the survey and therefore it is not known which groups were well represented or underrepresented in the responses and results. This has implications for the

potential generalisability of the survey findings which may not represent the experiences and attitudes of marginalised groups. With hindsight, it would have been beneficial to include a wider range of demographic questions. However, when designing the questionnaire, the priority was brevity and to include only the most important and relevant questions, to reduce burden on respondents.

There was also a lack of diversity in the group of people who responded to the invitation to be involved in PPI for this research. Invitations were sent out via stoma nurses, and potential public contributors were made aware that they would be paid for their time, to encourage a wide range of people to be involved. However, more needs to be done to overcome the barriers some groups face to participating in research; for example, language and literacy barriers, lack of interest and trust in research, limited access to technology (National Institute for Health Research, 2020).

People from across the UK were represented in the results from the online survey of dietary advice for people with an ileostomy. However, due to the nature of qualitative methods (involving in-depth data and interpretative analysis), it was only practical to include a small number of sites within one region of the UK (Southwest) to conduct the HCP interviews. Therefore, any regional variations in training and practice would not have been picked up. Since the NHS is a UK wide organisation and HCPs from the same profession in the UK would all have been required to complete regulated training and examinations to meet the standards of the same regulatory bodies, it is anticipated that regional variations within the UK would be small.

6.4 IMPLICATIONS FOR PRACTICE

Many studies and articles included in the scoping review (Study 1) reported on a low fibre diet, and others a low residue diet. However, variation in terminology around fibre and residue is confusing due to a lack of clarity in definitions (Vanhauwaert et al., 2015). It is particularly difficult to define a low residue diet since some GI residue is produced by all foods. As the majority of GI residue is produced by foods containing fibre, and fibre content, unlike GI residue, can be measured, it would seem prudent for future clinical research and practice to follow the recommendations made by Vanhauwaert et al. (2015), in their review of low residue and low fibre diets, to redefine the low residue diet as a low fibre diet. In the scoping review, and the review by Vanhauwaert et al. (2015), there was considerable

variation between studies in the quantitative definition of a low fibre diet or meal. Therefore, clinicians need to be aware of how low fibre was defined in different studies when using research to inform advice on a low fibre diet for patients, including those with an ileostomy. Vanhauwaert et al. (2015) recommend that a low fibre diet be defined as a diet containing ≤10g fibre/day.

Dietary advice is important to people with an ileostomy as described in the online survey (Study 2). From a clinical point of view, appropriate dietary advice is particularly important 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 (Chan et al., 2019, Arenas Villafranca et al., 2015). 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 (Rowe and Schiller, 2020). Appropriate patient follow-up and support is needed, and dietary advice should be reviewed and adapted over time.

The online survey showed that stoma nurses are the HCPs who most frequently provide dietary advice to people with an ileostomy, followed by dietitians and colorectal surgeons (Mitchell et al., 2020). This is reflected in the scoping review findings where the expert opinion literature was predominantly written by stoma nurses (Mitchell et al., 2021). Stoma nurses are specialists in stoma management, including ileostomies, while dietitians are specialists in clinical nutrition and providing individualised dietary advice. Results from the survey suggest that people with an ileostomy want more dietary advice from a dietitian, in addition to advice from their stoma nurse (Mitchell et al., 2020). It is therefore important for stoma nurses and dietitians to work together to provide the most relevant and consistent dietary advice. Multidisciplinary working with other HCPs who provide care to people with an ileostomy, i.e., colorectal surgeons and IBD/colorectal specialist nurses, is likely to further improve patient experience and outcomes. HCPs working with people with an ileostomy should work to ensure that dietary advice is fully embedded within care pathways.

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 (Bracey and Mortensen, 2015), for example if there is a specific problem such as high output (Slater, 2012). This practice was described by the HCPs interviewed in the qualitative study (Study 3) and is unlikely to change dramatically, at least in the near future, as NHS dietetics services do not have

sufficient resources to provide advice to all people with an ileostomy. Multidisciplinary working is essential to establish 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 locally 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. Acknowledgement by HCPs of the uncertainty in dietary advice for ileostomy management and potential for individual differences in response to diet is also important to increase understanding and trust.

Alternatively, this could be achieved on a national level if professional (e.g., Association of Coloproctology of Great Britain and Ireland or Association of Stoma Care Nurses) and patient organisations (e.g., IA) work together with the British Dietetic Association (BDA) to develop such guidance. It could then be made accessible not only to stoma nurses, surgeons, and people with an ileostomy, but also to GPs 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 survey respondents who received dietary advice were at least fairly satisfied with the advice, but there is still much room for improvement (Mitchell et al., 2020).

Quality, and appropriate personalisation, of dietary advice could be improved if all HCPs who support people with an ileostomy were to undertake appropriate training, assessment and continuing professional development (CPD). 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.

6.5 FUTURE RESEARCH

Patient and public involvement (PPI) should underpin future research to ensure we answer salient research questions, design studies that are practical for participants, and produce findings that inform clinical practice. Additionally, further research with under-served groups of people with an ileostomy is needed to understand similarities and differences in their experiences of and attitudes towards dietary advice and management compared to those highlighted by respondents to the online survey in Study 2.

Findings from this thesis provide support for fibre modification having an important role in dietary management for people with an ileostomy. Evidence included in the scoping review (Study 1) consistently suggested that insoluble fibre is associated with negative outcomes such as blockage and high or loose output in people with an ileostomy (Mitchell et al., 2021). The role of soluble fibre in ileostomy management is less clear; although some sources have reported it to be beneficial (Higham and Read, 1992, Collins and Sulewski, 2011, Pachocka and Urbanik, 2016, Crocetti et al., 2014). In several previous studies investigating high versus low fibre diets in people with an ileostomy, the relative contributions of soluble and insoluble fibre to total intake have not been reported (Mogos et al., 2015, Gaffney et al., 1987a, Gaffney et al., 1987b). Future studies investigating the role of fibre must report the relative contributions of different fibre types to enable conclusions to be drawn as to whether findings are due to total fibre intake, or more specifically the amount of insoluble or soluble fibre consumed. It is therefore important that future studies differentiate between insoluble and soluble fibre (in the diet overall or in specific foods/meals), or group different fibres by other key characteristics such as viscosity or fermentability.

The heterogeneity of GI history among people with an ileostomy combined with the complexities of dietary intake, described in Chapter 1, makes designing research studies to investigate associations between individual foods or drinks and ileostomy-related problems difficult, particularly with respect to establishing generalisable findings to inform dietary advice. Despite the complexities, priority must be given to high quality research studies investigating associations between diet and ileostomy management since people with an ileostomy report a clear need for better, more consistent support (Persson et al., 2005, Morris and Leach, 2015, Beeken et al., 2019, Mitchell et al., 2020).

Longitudinal studies investigating associations between well-defined dietary strategies and outcomes related to ileostomy management are needed, particularly RCTs, to improve understanding of causality. For example, we need to better understand whether dietary strategies to prevent adverse outcomes for ileostomy management are effective in the short- and/or long-term following ileostomy surgery, and whether the same, or different, dietary strategies are effective in managing/resolving common issues when they arise. A potential intervention study might provide standardised dietary information immediately following ileostomy formation, with follow-up sessions during the six months post-surgery to monitor intake and GI symptoms, and provide tailored dietary advice based on the individual patient experience. Future studies should include larger sample sizes, justified by sample size

calculations, and ideally be powered for subgroup analyses, for example to compare participants with extensive small bowel resection versus those with ileostomy only.

Observational studies have shown large variation in the extent and components of dietary strategies used by people with an ileostomy. Inter-individual factors contribute to differences in response to specific dietary strategies. As such, there is a need for future research to investigate individual risk of problems with ileostomy management and how this could be measured, and to test associations with diet in groups with different level of risk i.e., low versus moderate versus high risk.

Future research should include quantitative assessment of adherence to dietary strategies and clinical and QoL outcomes, alongside a qualitative approach to understanding participant attitudes, barriers, and facilitators to dietary management of ileostomies. This represents a current gap in the literature and is essential to inform implementation of effective provision of dietary advice to people with an ileostomy.

6.6 THEORETICAL CONSIDERATIONS

The aim of this thesis was to explore dietary advice and modifications for ileostomy management for the purpose of informing theory relating to the provision of dietary advice and management for people with an ileostomy. This knowledge was required to identify if, where and how the provision of dietary advice may be improved for people with an ileostomy. As such, the exploratory research presented in this thesis is hypothesis generating and further research to test hypotheses resulting from the findings of this thesis is required as the next step in advancing knowledge and understanding of this topic.

As discussed in Chapter 1 (1.11), providing dietary advice in a healthcare setting, such as within the NHS, is a complex intervention with many factors contributing to how the patient experiences such an intervention and determining their response and outcomes pertaining to this. Inductive analysis of the in-depth qualitative data collected in Study 3 from interviews with HCPs, led to the identification of such factors and suggested how they link together to determine how dietary advice is provided to and experienced by people with an ileostomy. This is represented in the model presented in Figure 6.6.1.

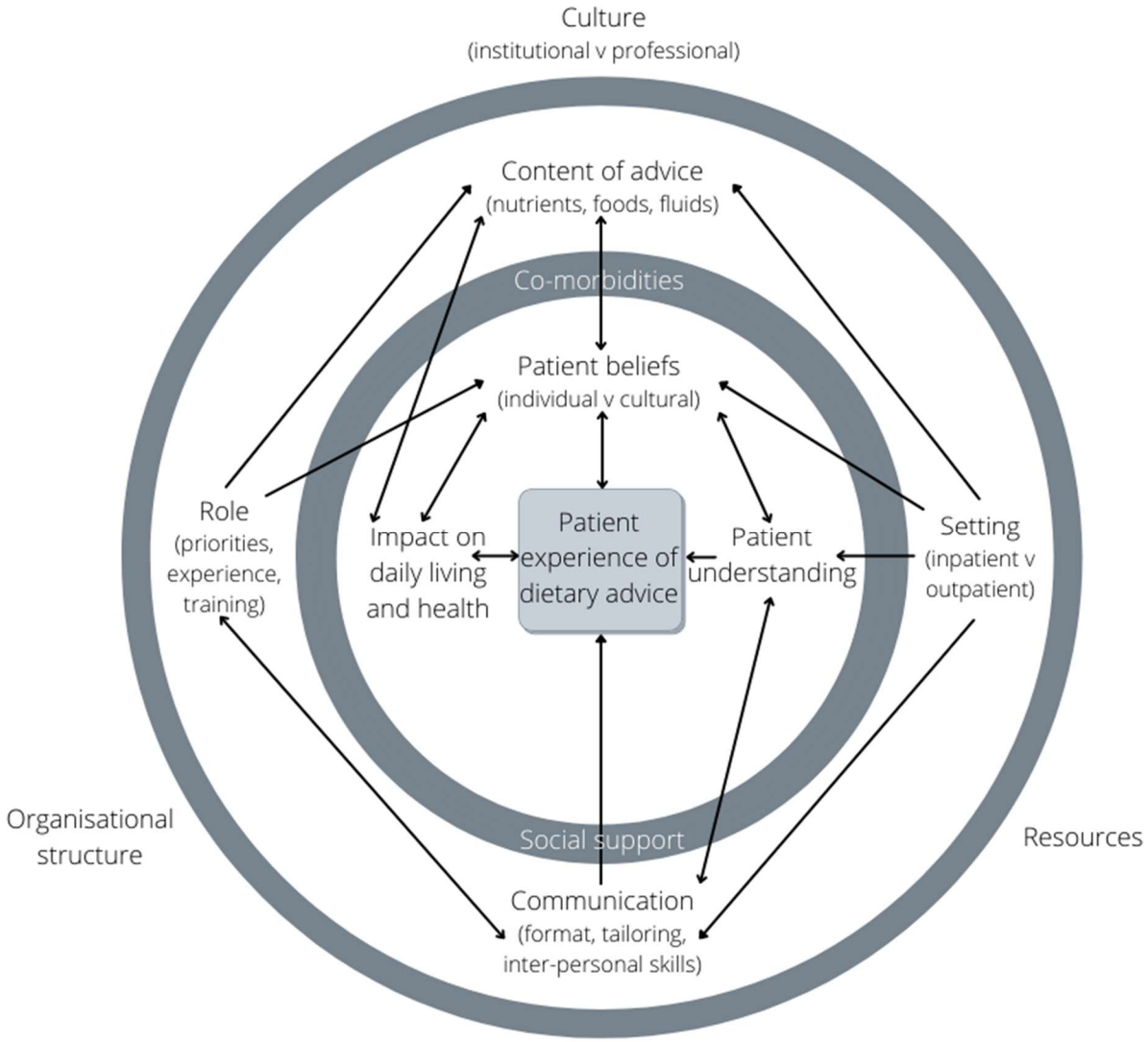

Figure 6.6.1 Model of determinants for the patient experience of receiving dietary advice (derived from this thesis)

Factors at the institutional level (outer layer) are institutional and professional culture, organisational structure, and human and physical resources. Factors associated with the HCP providing the advice (middle ring) are the HCP's role, the content of the dietary advice they are providing, how they communicate with their patient, and the setting in which they provide the advice. Factors personal to the patient receiving the advice, i.e., social support and co-morbidities, mediate individual cognitive factors (inner circle), i.e., patient beliefs and understanding, which, in conjunction with the impact of their ileostomy and diet-related behaviours on their daily life and health, determine the patient experience of dietary advice.

Findings from Study 1, the scoping review of evidence for dietary management in people with an ileostomy, inform knowledge relating to the following factors identified as determinants of the patient experience of dietary advice in the model presented: content of advice, impact on daily living and health, and, to a lesser extent, co-morbidities, HCP role, communication, and setting. Findings from Study 2, the survey of people with an ileostomy about the dietary advice they received, inform knowledge on HCP role (who provided advice), communication (format of advice), setting, content of advice, co-morbidities, patient beliefs (whether dietary management is or could be effective), patient understanding, and impact on daily living and health. Findings from Study 3 provide in-depth description and explanation of key themes relating to all of the determinants in the model.

This thesis describes the need for better dietary interventions for people with an ileostomy and identifies specific areas for improvement. Together, findings from each of the three studies and the theoretical model proposed provide the knowledge and understanding needed to develop, implement, and evaluate new targeted interventions.

6.7 THESIS CONCLUSIONS

This thesis aimed to address gaps in knowledge regarding what evidence there is for oral dietary management in people with an ileostomy, what dietary advice is provided to people requiring surgery and ileostomy formation, and why and how this advice is, or is not, provided. Three studies were conducted using mixed methods to answer the research questions posed to achieve this aim. Findings from these studies have led me to the following conclusions.

Current practice relating to dietary management and the provision of dietary advice to people with an ileostomy is based mostly on expert opinion with limited research to support some aspects e.g., fibre modification (Study 1). Provision of dietary advice to people with an ileostomy is common but by no means universal across the UK (Study 2). Advice comes from a wide range of sources, with stoma nurses being the main source of advice and other common sources being dietitians, surgeons, and online sources. One person may receive dietary advice from multiple sources and often advice is inconsistent or may appear contradictory. Differences in HCP understanding, priorities and framing of dietary advice, in addition to contrasting communication styles, contribute to mixed messages and lack of consistency (Study 3). Closer MDT working increases confidence in and consistency of dietary advice to patients with an ileostomy but varies between hospitals.

High quality research evaluating dietary interventions for people with an ileostomy is a priority to establish evidence for best practice in dietary management and provision of dietary advice. The findings from this thesis will inform future development of relevant and realistic dietary interventions to fulfil this. This thesis also provides information and recommendations, based on the study findings, that HCPs caring for patients with an ileostomy may reflect on to identify potential areas for improvement in their practice.

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Appendix I

Search strategy

Ovid (MEDLINE, Embase, AMED)

1. Ileostomy/
2. Ostomy/
3. ostom*.tw.
4. stoma.tw.
5. ileostom*.tw.
6. 1 or 2 or 3 or 4 or 5
7. Diet/
8. nutrition*.tw.
9. diet*.tw.
10. Diet, Fat-Restricted/
11. Dietary Fiber/
12. (fibre or fiber).tw.
13. Prebiotics/
14. Probiotics/
15. (probiotic* or prebiotic*).tw.
16. (food or eat* or drink*).tw.
17. Eating/
18. Drinking/
19. fluid*.tw.
20. Sodium/
21. sodium.tw.
22. Salts/
23. salt.tw.
24. Rehydration Solutions/
25. ("oral rehydration therap*" or "rehydration solution*").tw.
26. Electrolytes/
27. electrolyte*.tw.
28. Dietary Supplements/
29. supplement drink*.tw.
30. oral nutrition support.tw.
31. sip feed*.tw.
32. 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31
33. 6 and 32
34. Animals/ not Humans/
35. exp Animals, Laboratory/
36. exp Animal Experimentation/
37. Models, Animal/
38. Rodentia/
39. (rat* or mouse or mice).ti.
40. 34 or 35 or 36 or 37 or 38 or 39
41. 33 not 40

Database searched	Number of records returned Date of search – 25/1/18	Number of records returned Date of search – 29/8/19
	Search not restricted by date	*Publication date: Jan 2017-Sept 2019*
MEDLINE	1829	239
EMBASE	3018	591
AMED	11	1
CINAHL	1242	390
Cochrane database of systematic reviews	193	134
Web of Science	948	152
Sub-total	**7241**	**1507**
Sub-total after repeat records due to search overlap removed	**7241**	**747**
Sub-total after duplicates removed	**4609**	**584**
		Search not restricted by date
JBISRIR		38
ClinicalTrials.gov		5
WHO ICTRP		24
ProQuest		254
OpenGrey		21
EThOS		52
Google Scholar		100
Sub-total		**494**
Total records screened	**4609**	**1078**

Appendix II

Table of excluded full texts

	Reference	Reason
1	Adaba F, Vaizey CJ, Warusavitarne J. Management of Intestinal Failure: The High-Output Enterostomy and Enterocutaneous Fistula. Clinics in colon and rectal surgery. 2017;30(3):215-22.	Purpose to consider management of intestinal failure/short bowel syndrome, not ileostomies specifically
2	Adams K. Helping older patients to adapt to stomas using an enhanced recovery programme. British Journal of Community Nursing. 2019;24(5):224-8.	Not specific to ileostomy and no specific diet advice
3	Anaraki F, Vafaie M, Behboo R, Maghsoodi N, Esmaeilpour S, Safaee A. Clinical profile and post-operative lifestyle changes in cancer and non-cancer patients with ostomy. Gastroenterology and Hepatology from Bed to Bench. 2012;5(SUPPL.1):S26-S30.	Does not consider types of dietary modification
4	Appleton ND, Corris A, Edwards C, Kenyon A, Walsh CJ. Outpatient fluid and electrolyte management for patients with high output stomas and enterocutaneous fistulae. British Journal of Surgery. 2013;100:86-7.	Intravenous hydration and supplementation
5	Aslam MN, Naqi SA, Shoaib S. Management of high output stomas in our setup. Pakistan Journal of Medical and Health Sciences. 2010;4(4):526-30.	Artificial nutrition
6	Avila HCB, Neves IAP, Vargas PIT, Bento PFS, Esteves TS, Vieira, MHM. [The person with an ostomy: alterations in self-care and adaptation strategies]. Nursing: Revista de Formacao Continua em Enfermagem. 2008;18:24-30.	Full text unobtainable
7	Awad RW, el-Gohary TM, Skilton JS, Elder JB. Life quality and psychological morbidity with an ileostomy. The British journal of surgery. 1993;80(2):252-53.	No details of dietary modification
8	Azizah NO, Yunos M, Choen S, Keng V. Effects of stoma creation on quality of life. World Council of Enterostomal Therapists Journal. 1998;18(1):26-7.	Full text unobtainable
9	Baker M, Greening L. Practical management to reduce and treat complications of high-output stomas...sixth article in the series. Gastrointestinal Nursing. 2009;7(6):10-7.	Focus on jejunostomies and short bowel
10	Baker ML, Williams RN, Nightingale JMD. Causes and management of a high-output stoma. Colorectal Disease. 2011;13(2):191-7.	Focus on high output stoma/fluid management including parenteral/intravenous fluids. No detail specific to ileostomy
11	Baschet C, Taurinya D. [Dietary problems of colon or rectum surgical patients]. Soins: Chirurgie Generale et Specialisee. 1982;11:41-9.	Full text unobtainable

12	Batas R. Rehabilitation of ostomy patients -- nutrition and clothing issues. Obzornik Zdravstvene Nege. 2009;43(4):269-75.	Graphs of results with English titles showing results presented for all stoma types and not separately
13	Bird A, Wilson K, Bertinara A, Amos L. Educating patients in stoma care. Gastrointestinal Nursing. 2019;17(3):18-22.	General stoma, nothing specific to ileostomy
14	Bodemar G, Sjodahl R. Rice and glucose oral rehydration solutions in patients with high ileostoma fluid output. Lancet (London, England). 1992;340(8823):862.	Focus on oral rehydration solution
15	Brevinge H. 1993. Ileostomy output, sodium homeostasis and working capacity : a study in patients with conventional or reservoir ileostomy	Does not consider diet modification for ileostomy management
16	Brown C, Gibson P, Hart A, Kaplan G, Hautamaki E, Flood E, et al. Long-term impacts of colectomy surgery among ulcerative colitis patients study (LOCUS): The final analysis. Journal of Crohn's and Colitis. 2013;7(SUPPL.1):S190.	No specific ileostomy group and does not consider types of dietary modification
17	Burch J, and Taylor C. Patients' need for nursing telephone follow-up after enhanced recovery. Gastrointestinal Nursing. 2012;10(4):51-58.	Not related to dietary modification for ileostomy management
18	Burch J. Nutrition for people with stomas 1: overview of issues. Nursing times. 2008;104(48):24-5.	Does not consider dietary modification for stoma management
19	Burden ST, Stamataki Z, Hill J, Molasiotis A, Todd C. An exploration of food and the lived experience of individuals after treatment for colorectal cancer using a phenomenological approach. Journal of Human Nutrition & Dietetics. 2016;29(2):137-45.	Does not specify type of stoma
20	Camilleri M, Prather C M, Evans MA, Andresen-Reid ML. Balance studies and polymeric glucose solution to optimize therapy after massive intestinal resection. Mayo Clinic Proceedings. 1992;67(8):755-760.	Short bowel syndrome
21	Chalkia A, Migdanis A, Koukoulis G, Mamaloudis I, Migdanis I, Malisiova E, et al. The effect of isotonic drinks on electrolyte abnormalities of ileostomy patients: Preliminary results. Clinical nutrition ESPEN. 2016;13:e57-e8.	Focus on oral rehydration solution
22	Chia CLK, Tai YS, Tan KY. A preliminary study of the use of oral rehydration salts in decreasing ileostomy output. Techniques in Coloproctology. 2017;21(7):587-8.	Focus on oral rehydration solution
23	Chrobak A. Educational role of a nurse in medical care of patients with outer intestinal stoma. Polski merkuriusz lekarski : organ Polskiego Towarzystwa Lekarskiego. 2009;26(155):579-81.	No mention of ileostomy
24	Clarke AM, Chirnside A, Hill GL, Pope G, Stewart MK. Chronic dehydration and sodium depletion in patients with established ileostomies. Lancet. 1967;2(7519):740-3.	Sodium and fluid balance study not looking at stoma management

25	Codina Cazador A, Olivet Pujol F, Farres Coll R, Ruiz Feliu B, Font Pascual J, Fernandez Gutierrez F. Analysis of the quality of life in patients after pelvic pouch operation. Revista espanola de enfermedades digestivas : organo oficial de la Sociedad Espanola de Patologia Digestiva. 1998;90(9):646-54.	Does not consider types of dietary modification
26	Cohen A, Lee DY, Long MD, Kappelman M, Martin CF, Kinneer PM, et al. Dietary patterns and self-reported associations of diet with symptoms of inflammatory bowel disease. Gastroenterology. 2012;142(5 SUPPL.1):S256.	Results for ileostomies not reported separately to all ostomies
27	Cohen AB, Lee D, Long MD, Kappelman MD, Martin CF, Sandler RS, et al. Dietary patterns and self-reported associations of diet with symptoms of inflammatory bowel disease. Digestive Diseases and Sciences. 2013;58(5):1322-8.	Results for ileostomies not reported separately to all ostomies
28	Cooper JC. 1987. Nutritional status and ileostomy function following proctocolectomy for inflammatory bowel disease.	Looks at nutritional status but not diet to manage ileostomy
29	Cuyle P-J, Engelen A, Moons V, Tollens T, Carton S. Lanreotide in the prevention and management of high-output ileostomy after colorectal cancer surgery. Journal of drug assessment. 2018;7(1):28-33.	Focus on oral rehydration solution/fluid management and drug therapy; Dietary recommendations mentioned but no details provided
30	Davidson F. Quality of life, wellbeing and care needs of Irish ostomates. British journal of nursing (Mark Allen Publishing). 2016;25(17):S4-S12.	Results for ileostomy and colostomy pts reported together; No separate analysis; However, 77% of sample had an ileostomy
31	De Coster A. Water, water everywhere but not a drop to drink? British Journal of Community Nursing. 2017;22(8):369-.	Not about ileostomies
32	Deeny P and McCrea H. Stoma care: the patient's perspective. Journal of Advanced Nursing. 1991;16(1):39-46.	No details of diet modification
33	Feinberg SM, McLeod RS, Cohen Z. Complications of loop ileostomy. The American Journal of Surgery. 1987;153(1): 102-7.	Not diet - apart from 1 mention in comment which is not a result of the study
34	Fernandez De Bustos A, Creus Costas G, Pujol Gebelli J, Virgili Casas N, Pita Merce AM. Per os early nutrition for colorectal pathology susceptible of laparoscopy-assisted surgery. Nutricion Hospitalaria. 2006;21(2):173-8.	Only 2 ileostomy pts in sample with no separate results. Purpose of study was to test protocol for early oral nutrition re: tolerance
35	Ferreira-Aparicio FE, Gutierrez-Vega R, Galvez-Molina Y, Ontiveros-Nevares P, Athie-Gutierrez C, Montalvo-Jave EE. Diverticular disease of the small bowel. Case Reports in Gastroenterology. 2012;6(3):668-76.	Not dietary management for ileostomy
36	Ferrie S, Bloomfield-Stone S. Nutrition to promote wound healing in the stoma patient. World Council of Enterostomal Therapists Journal. 2010;30(2):10-3.	Advice for wound healing, not specific to ileostomies

37	Fisher AV, Campbell-Flohr SA, Sell L, Osterhaus E, Acher AW, Leahy-Gross K, et al. Adaptation and Implementation of a Transitional Care Protocol for Patients Undergoing Complex Abdominal Surgery. Joint Commission journal on quality and patient safety. 2018;44(12):741-50.	No specific dietary advice described (and not clear whether ileostomy patients were involved)
38	Floruta CV. Dietary choices of people with ostomies. Journal of wound, ostomy, and continence nursing : official publication of The Wound, Ostomy and Continence Nurses Society / WOCN. 2001;28(1):28-31.	Ileostomy sub-group not analyzed separately
39	Forbes A. Crohn's disease: Rehabilitation after resection. Digestive Diseases. 2014;32(4):395-8.	Short bowel syndrome
40	Fuchssteiner H, Nigl K, Mayer A, Kristensen B, Platzer R, Brunner B, et al. Nutrition and IBD-consensus of the austrian working group of IBD (inflammatory bowel diseases) of the OGGH. Zeitschrift fur Gastroenterologie. 2014;52(4):376-86.	No details of dietary modification for ileostomy management
41	Fulham J. Improving the nutritional status of colorectal surgical and stoma patients. British journal of nursing (Mark Allen Publishing). 2004;13(12):702-8.	Expert opinion outside of inclusion date
42	Gabe S. Managing high-output stomas: module 2 of 3. British Journal of Nursing. 2013;22(15S):S18-20.	Short bowel syndrome
43	Galmiche JP, Mue E, Geffroy PY. Dietetic problems posed by digestive tract stomas. Revue du Praticien. 1978;28(20):1531-2.	Expert opinion outside of inclusion date
44	Giunchi F, Balbi B, Giulianini G, Cacciaguerra G. Cholelithiasis and urolithiasis in ileostomy patients. The Italian journal of surgical sciences. 1989;19(1):37-40.	Dietary modification to prevent conditions associated with ileostomy complications i.e. cholelithiasis and urolithiasis
45	Giunchi F, Cacciaguerra G, Borlotti ML, Pasini A, Giulianini G. Bowel movement and diet in patients with stomas. The British journal of surgery. 1988;75(7):722.	Only 10/100 participants had ileostomy and no subgroup analysis relating to dietary intake was included
46	Glazer, KB. Nutrition guide for people with ostomies. Coping with Cancer. 2009;23(2):27.	Full text unobtainable
47	Gooszen AW, Geelkerken RH, Hermans J, Lagaay MB, Gooszen HG. Quality of life with a temporary stoma: Ileostomy vs. colostomy. Diseases of the Colon and Rectum. 2000;43(5):650-5.	No details of dietary modification
48	Gooszen AW, Geelkerken RH, Hermans J, Lagaay MB, Gooszen HG. Temporary decompression after colorectal surgery: Randomized comparison of loop ileostomy and loop colostomy. British Journal of Surgery. 1998;85(1):76-9.	No details of dietary modification
49	Gordon J. 2009. Partners' Experience of Living with a Person Who Has Undergone Colostomy or Ileostomy Surgery: A Phenomenological Study	No mention of diet/nutrition/food

50	Grahn SW, Lowry AC, Osborne MC, Melton GB, Gaertner WB, Vogler SA, et al. System-Wide Improvement for Transitions After Ileostomy Surgery: Can Intensive Monitoring of Protocol Compliance Decrease Readmissions? A Randomized Trial. Diseases of the colon and rectum. 2019;62(3):363-70.	No specific dietary advice described
51	Grant M, McMullen CK, Altschuler A, Mohler MJ, Hornbrook MC, Herrinton LJ, et al. Gender differences in quality of life among long-term colorectal cancer survivors with ostomies. Oncology Nursing Forum. 2011;38(5):587-96.	Type of stoma not identified
52	Haalboom JRE, Poen H, Struyvenberg A. The effect of changes in dietary sodium content on complaints and clinical parameters of volume depletion in patients with a permanent ileostomy. Zeitschrift fur Gastroenterologie. 1987;25(3):168-74.	Sodium balance
53	Hassink EA, Rieu PN, Severijnen RS, Brugman-Boezeman AT, Festen C. Adults born with high anorectal atresia - How do they manage? Diseases of the Colon and Rectum. 1996;39(6):695-9.	Does not report results separately for ileostomy sub-group and does not report details of dietary modification
54	Herrick D. 2019. Elderly Partners' Lived Experience of Bladder and or Colorectal Cancer Diagnosis Living with an Ostomy	Lack of information on diet for ileostomy management
55	Hidalgo Dóniga C, Caso Maestro Ó, Pérez Torres JB, García Manzanares ME. Aplicación de la terapia de vacío en el tratamiento de la dehiscencia completa de inserción mucocutánea del estoma. Gerokomos. 2018;29(3):145-7.	Ileostomy case study but no details of dietary modification
56	Hoedjes M, De Kruif A, Mols F, Bours M, Beijer S, Winkels R, et al. An exploration of needs and preferences for dietary support in colorectal cancer survivors: A mixed-methods study. PLoS ONE. 2017;12(12):e0189178.	Not ileostomy specific and no specific dietary management details
57	Jansen F, van Uden-Kraan CF, Braakman JA, van Keizerswaard 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. Supportive care in cancer : official journal of the Multinational Association of Supportive Care in Cancer. 2015;23(6):1689-97.	No details of dietary modifications and ileostomy pts not reported separately
58	Kara B, Aslan FE. Stomalı Bireylerin Evde İlk Gün Deneyimlerinin İncelenmesi. Turkish Journal of Colorectal Disease. 2017;27(4):117-25.	Type of stoma not specified, and no mention of diet/food
59	Kelly D. Patients with colorectal cancer expressed a loss of adulthood related to a loss of professional and sexual identity, dignity, privacy, independence, and ability to socialise. Evidence Based Nursing. 2004;7(4):126.	Commentary on qualitative study identifying disruption of eating habits as component of loss of ability to socialize (Rozmovits & Ziebland, 2004)
60	Kenyon A, Corris A, Wilson K, Merriman A, Neithercutt D, Walsh C. Outpatient fluid and electrolyte management for patients with high output stomas and enterocutaneous fistulae. A nutrition nurse led service. Proceedings of the Nutrition Society. 2010;69(OCE7).	Fluid management; high output stoma - unclear if jejunostomy or ileostomy

61	Ko CY, Rusin LC, Schoetz Jr DJ, Coller JA, Murray JJ, Roberts PL, et al. Using quality of life scores to help determine treatment: Is restoring bowel continuity better than an ostomy? Colorectal Disease. 2002;4(1):41-7.	No details of how participants modified their diet
62	Kohler LW, Pemberton JH, Zinsmeister AR, Kelly KA. Quality of life after proctocolectomy: A comparison of Brooke ileostomy, Kock pouch, and ileal pouch-anal anastomosis. Gastroenterology. 1991;101(3):679-84.	No details of dietary modification
63	Krokowicz L, Bobkiewicz A, Borejsza-Wysocki M, Kuczynska B, Lisowska A, Skowronska-Piekarska U, et al. A Prospective, Descriptive Study to Assess the Effect of Dietary and Pharmacological Strategies to Manage Constipation in Patients with a Stoma. Ostomy/wound management. 2015;61(12):14-22.	Study results not relevant as all but 1 participant with colostomy and not reported separately
64	Krouse RS, Wendel CS, Demark-Wahnefried W, Bulkley JE, McMullen CK, Grant M, et al. Dietary modifications of rectal cancer survivors to improve bowel function symptoms. Cancer Research. 2015;75(15 SUPPL.1).	No distinction made between ileostomy/colostomy
65	Kvasnovsky CL, Bjarnason I, Papagrigoriadis S. What colorectal surgeons should know about probiotics: A review. Colorectal Disease. 2015;17(10):840-8.	Use of probiotics in people currently with ileostomy not included
66	Livia de Oliveira A, Loures Mendes L, Pereira Netto M, Goncalves Leite IC. Cross-cultural Adaptation and Validation of the Stoma Quality of Life Questionnaire for Patients with a Colostomy or Ileostomy in Brazil: A Cross-sectional Study. Ostomy/wound management. 2017;63(5):34-41.	No details of dietary modification
67	Lopes MGF, De-Freitas LA, Martins TCP, Mosca ERT, Silva AASC, De-Souza DA. Specialized Oral Diet Improved Clinical Outcome of a Patient with Severe Intestinal Insufficiency in a Late Postoperative Period: A Case Report in Clinical Nutrition. Journal of the Academy of Nutrition & Dietetics. 2016;116(8):1243,50-9,50.	Case study - not standard management for ileostomy (case had severe intestinal insufficiency)
68	Mallappa S, Gabe S, Phillips R, Robertson MD, Clark SK. How safe and effective is oral rehydration therapy in correcting the metabolic disturbances post-colectomy in patients with familial adenomatous polyposis? United European Gastroenterology Journal. 2014;2(1 SUPPL.1):A84.	Focus on oral rehydration solution, and ileostomy pts not analyzed separately from other post-colectomy pts
69	Martin K. 1994. Enterostomal therapy nursing interventions and social adjustment of patients following ostomy surgery	No mention of ileostomy or diet
70	Matarese LE, Seidner DL, Steiger E, Fazio V. Practical guide to intestinal rehabilitation for postresection intestinal failure: A case study. Nutrition in Clinical Practice. 2005;20(5):551-8.	Short bowel syndrome
71	McDonald A. Orchestrating the management of patients with high-output stomas. British Journal of Nursing. 2014;23(12):645-9.	Short bowel syndrome
72	McLeod RS, Fazio VW. Quality of life with the continent ileostomy. World Journal of Surgery. 1984;8(1):90-5.	No details of dietary modification

73	McMullen C, Altschuler A, Wendel C, Grant M, Hornbrook M, Bulkley J, et al. Long-term rectal cancer survivors with anastomosis and ostomy report similar life challenges. Psycho-Oncology. 2013;22(SUPPL.2):118-9.	No details of dietary modification. Participants were colorectal cancer patients with anastomosis but compared to similar analysis in ostomy patients (not clear if ileostomy/colostomy)
74	Medlin S. Nutritional and fluid requirements: High-output stomas. British Journal of Nursing. 2012;21(6 SUPPL.):S22-S5.	Short bowel syndrome
75	Mohil RS, Narayan N, Sreenivas S, Singh N, Bansal A, Singh GJ. Challenges of managing emergency ileostomy: nutrition - a neglected aspect. ISRN Emergency Medicine. Volume 2012, Article ID 968023, 6 pages	Not diet modification for ileostomy management or to counteract nutritional consequences of ileostomy
76	Mohr L. 2015. Adolescent perspectives following ostomy surgery: A grounded theory study	No details of diet/nutrition/food
77	Moraes JT, Melo AFF, Araujo C, Das Gracas Santiago Faria R, Ferreira NR, Belo VS. Anthropometric and dietetic evaluation of people with ileostomies. Arquivos de Gastroenterologia. 2019;56(1):34-40.	Does not give details of dietary modification for ileostomy
78	Mountford CG, Manas DM, Thompson NP. A practical approach to the management of high-output stoma. Frontline Gastroenterology. 2014;5(3):203-7.	Short bowel syndrome
79	Nieves CB-dL, Diaz CC, Celdran-Manas M, Morales-Asencio JM, Hernandez-Zambrano SM, Hueso-Montoro C. Ostomy patients' perception of the health care received. Revista latino-americana de enfermagem. 2017;25:e2961.	No details of dietary modification. Unable to differentiate results from pts with ileostomy
80	Nikitin AM, Bondarev IA. [Problems with ileostomies (review of the literature). Khirurgiia. 1984;8:140-4.	Full text unobtainable
81	North J, Osborne W. ASCN UK Guideline: parastomal hernias. British Journal of Nursing. 2017;26(22):S6-S13.	No details of dietary modification for ileostomy
82	Padilla L. 2013. Transitioning with an Ostomy: The Experience of Patients with Cancer following Hospital Discharge	Only 1 participant with ileostomy (no details of diet modification for this participant)
83	Parker BM. Ileoanal teaching tools: developing a tool to meet a specific need. Ostomy and Wound Management. 1994;40(4):65-73.	Full text unobtainable
84	Perche JP, Mauletti A, Dobez AG. Diet of stoma patients. Soins Chirurgie. 1981(5-6):59-60.	Expert opinion outside of inclusion date
85	Perry-Woodford ZL. Quality of life following ileoanal pouch failure. British Journal of Nursing. 2013;22(16 SUPPL):S23-8.	No details of dietary modification
86	Pittman J. 2011. Ostomy complications and associated risk factors: Development and testing of two instruments	Looks at nutritional status but not diet modifications
87	Price A, Allen L, Atwood T. Healthcare practitioners help ostomy patients adjust nutritionally. Ostomy and Wound Management. 1989;24:30-41.	Full text unobtainable

88	Raza A, Tan S, Iqbal A, Goldstein L, Vidyasagar S, Yin L, et al. Potential use of an oral non-glucose amino acid-based fluid for preventing dehydration in patients with ileostomy. Diseases of the Colon & Rectum. 2016;59(5):E124-5.	Focus on oral rehydration solution, and mouse study
89	Robinson PN, Pearl D, Vokes L, Pratt J, Stapely C, Trebble T. Audit of enteral and parenteral management in post-operative intestinal failure in a district general hospital. Gut. 2011;60(SUPPL.1):A98.	Short bowel syndrome; nutrition support is artificial nutrition and focus on oral rehydration solution
90	Saunders DR, Saunders MD, Sillery JK. Beneficial effects of glucose polymer and an H2-receptor blocker in a patient with a proximal ileostomy. American Journal of Gastroenterology. 1989;84(2):192-4.	Focus on oral rehydration solution and fluid management
91	Savard J. 2008. Adolescents' and young adults' lived experience of living with IBD and an ostomy	Unclear which participants had ileostomy; no details of diet modification for ileostomy
92	Scarpa M, Barollo M, Polese L, Keighley MRB. Quality of life in patients with an ileostomy. Minerva Chirurgica. 2004;59(1):23-9.	No details of dietary modification
93	Schiergens TS, Hoffmann V, Schobel TN, Englert GH, Kreis ME, Thasler WE, et al. Long-term Quality of Life of Patients with Permanent End Ileostomy: Results of a Nationwide Cross-Sectional Survey. Diseases of the Colon and Rectum. 2017;60(1):51-60.	Does not consider dietary modification
94	Schmidt CM, Wiesenauer CA, Sitzmann JV. Long-term effects on diet after proctocolectomy for ulcerative colitis. American Journal of Surgery. 2008;195(3):353-7.	Unclear timepoint of assessment post-surgery therefore unable to distinguish those with ileostomy as most had IPAA with temporary ileostomy
95	Shaffy, Kaur S, Das K, Gupta R. Physical, nutritional and sexual problems experienced by the patients with colostomy/ileostomy: a qualitative study. Nursing and Midwifery Research Journal. 2012;8(3):210-22.	Not specified which results relate to ileostomy rather than colostomy
96	Silva DG, Bezerra ALQ, Siqueira KM, Paranaguá TTB, Barbosa MA. Influence of dietary habits in the social reintegration of a group of people with ostomy. Revista Eletronica de Enfermagem. 2010;12(1):56-62.	Discusses ostomies in general (colostomies and ileostomies combined) and no mention of diet specifically in relation to ileostomy
97	Simon A. Management of patients with stomas. Revue de l'infirmiere. 2016;(217):25-7.	Full text unobtainable
98	Sinclair LG. 2004. Stories of young adults with permanent ileostomies	Lack of information on diet for ileostomy management

99	Sinha A, Goyal H, Singh S, Rana SP. Quality of life of ostomates with the selected factors in a selected hospital of Delhi with a view to develop guidelines for the health professionals. Indian Journal of Palliative Care. 2009; 15(2):111-14.	No details of diet modification
100	Smith L, Boland L. High output stomas: ensuring safe discharge from hospital to home. British Journal of Nursing. 2013:S14-8.	Focus primarily on ileostomy pts with short bowel syndrome
101	Staruchowicz L, Taylor A. Effectiveness of follow-up care provided by stoma care nurses: a systematic review protocol. 2012;JBI Database of Systematic Reviews and Implementation Reports 10(14):1-9	Nothing of relevance in protocol; Review findings do not appear to have been published
102	Stokes AL, Tice S, Follett S, Paskey D, Abraham L, Bealer C, et al. Institution of a Preoperative Stoma Education Group Class Decreases Rate of Peristomal Complications in New Stoma Patients. Journal of Wound, Ostomy & Continence Nursing. 2017;44(4):363-7.	No details of dietary advice provided; diet advice was provided to participants as part of a multi-faceted education intervention
103	Stryker SJ, Pemberton JH, Zinsmeister AR. Long-term results of ileostomy in older patients. Diseases of the Colon & Rectum. 1985;28(10):844-846	No details of diet modification
104	Sun V, Grant M, McMullen CK, Altschuler A, Mohler MJ, Hornbrook MC, et al. Surviving colorectal cancer: Long-term, persistent ostomy-specific concerns and adaptations. Journal of Wound, Ostomy and Continence Nursing. 2013;40(1):61-72.	Qualitative study not differentiating ileostomies from colostomies ("ileostomy" not in text)
105	Sun V, Grant M, Wendel CS, McMullen CK, Bulkley JE, Altschuler A, et al. Dietary and behavioral adjustments to control bowel function by long-term colorectal cancer survivors. Journal of Clinical Oncology. 2014;32(3 SUPPL. 1).	Mixed methods study not differentiating ileostomies from colostomies ("ileostomy" not in text)
106	Sun V, Grant M, Wendel CS, McMullen CK, Bulkley JE, Altschuler A, et al. Dietary and Behavioral Adjustments to Manage Bowel Dysfunction After Surgery in Long-Term Colorectal Cancer Survivors. Annals of Surgical Oncology. 2015;22(13):4317-24.	Mixed methods study not differentiating ileostomies from colostomies ("ileostomy" not in text)
107	Sun V, Wendel C, Grant M, Bulkley JE, McMullen CK, Hornbrook MC, et al. Behavioral adjustments, supplements, and medications to manage bowel dysfunction in rectal cancer survivors. Journal of Clinical Oncology. 2017;35(5 Supplement 1).	Results for ileostomy pts not reported separately to all rectal cancer survivors
108	Thorpe G. 2012. An existential phenomenological exploration of the experience of living with a new stoma	Lack of information on diet for ileostomy management
109	Ward K, Murray B, Feighery C. Salt-losing ileostomy diarrhoea: Long-term treatment with a glucose electrolyte solution. Gut. 1981;22(10):T8.	Focus on oral rehydration solution
110	Ward K, Murray B, Neale G, Weir DG. Treatment of salt losing ileostomy diarrhoea with an oral glucose polymer electrolyte solution. Irish Journal of Medical Science. 1984;153(2):77-8.	Focus on oral rehydration solution

111	Wells M, Anderson AS, Caswell S, Craig K, Connaghan J, MacAskill S, et al. Using the patient generated index (PGI) to elicit quality of life priorities in patients following curative treatment for colorectal cancer: Experience from two lifestyle intervention development studies. European Journal of Cancer, Supplement. 2009;7(2-3):232.	Does not consider dietary modification
112	Williams J. Flatus, odour and the ostomist: coping strategies and interventions. British Journal of Nursing. 2008;17(2):S10-4.	Advice appears to be for colostomies rather than ileostomies
113	Williams JM. 2016. A qualitative exploration of the transmission of knowledge and skills by specialist stoma care nurses to facilitate the needs of patients adapting to a newly formed stoma	No details of diet modification for ileostomy
114	Wright SM, Noon MJ, Greenough WB. Oral Rehydration Therapy and Feeding Replaces Total Parenteral Nutrition: A Clinical Vignette. Journal of General Internal Medicine. 2016;31(2):255-7.	Focus on oral rehydration solution
115	Xinxuan C, Liwen B, Mingxiu Z. Management of stoma among colorectal cancer patients in a surgical ward: a best practice implementation project. JBI Database of Systematic Reviews and Implementation Reports. 2014;12(4): 533-47	Not ileostomies
116	Yang R, Yang HR, Cai WD. Effect of team support training on rehabilitation of stoma patients with rectal cancer. World Chinese Journal of Digestology. 2015;23(7):1196-201.	Only includes colostomy patients, not ileostomy
117	Youngman K. 2015. The impact of a temporary stoma on an individual's self-concept	Unknown which results relevant to ileostomy
118	Zoeller S. Case Study of Ulcerative Colitis and Ileostomy: Highlighting the Nutrition Quality of Life Tool. Support Line. 2016;38(4):16-23.	Does not consider dietary modification; brief reference to patient increasing fluid and salt only

Appendix III

Final charting form (outline of database)

Record no.	*Automatically generated*
Reviewer	*Automatically recorded*
Date reviewed	*Day/month/year*
Author/s	*Free text*
Author/s profession/s	Number of stoma nurses Number of specialist nurses (specialism: *free text*) Number of dietitians Number of gastroenterologists Number of colorectal surgeons Number of medical doctors – other (specialism: *free text*) Number of medical doctors – unspecified Number of surgeons – other (specialism: *free text*) Number of surgeons – unspecified Number of non-clinical academics Number of others (specified profession: *free text*) Not specified
Year of publication	*Select year*
Journal/Source	*Free text*
Publication type	Journal article Conference abstract Other abstract Book Thesis Other (specified: *free text*)
Evidence type	Original research – experimental Original research – observational Original research - qualitative Consensus guidelines Review Expert opinion
Design	RCT – crossover RCT – parallel arms Quasi-experimental – single arm Quasi-experimental – non-randomised trial (no control) Quasi-experimental – non-randomised trial (with control) Cross-sectional Cohort study Case-control study Case study/case series Qualitative - interviews Qualitative – focus groups Systematic review Narrative review Other (specified: *free text*) Not applicable
Country	*Select country*
Inclusion criteria	*Free text*
Exclusion criteria	*Free text*

Setting	Hospital – inpatient Hospital – outpatient Community – clinic Community – care home Community – home Other (specified: *free text*) Not specified
Total sample size in analysis	*Number (no decimal)*
Total number of males in analysis	*Number (no decimal)*
Total number of females in analysis	*Number (no decimal)*
Number in control group in analysis	*Number (no decimal)*
Number of males in control group in analysis	*Number (no decimal)*
Number of females in control group in analysis	*Number (no decimal)*
Number in intervention group in analysis	*Number (no decimal)*
Number of males in intervention group in analysis	*Number (no decimal)*
Number of females in intervention group in analysis	*Number (no decimal)*
Total number recruited	*Number (no decimal)*
Total number of dropouts	*Number (no decimal)*
Total number recruited into control group	*Number (no decimal)*
Total number of dropouts in control group	*Number (no decimal)*
Total number recruited into intervention group	*Number (no decimal)*
Total number of dropouts in intervention group	*Number (no decimal)*
Condition requiring ileostomy (Original research articles only)	Crohn's disease Ulcerative colitis Colorectal cancer Other cancer Trauma Functional bowel disorder Familial adenomatous polyposis (FAP) IBD unspecified Other (condition specified: *free text*) Not specified
Age group (Original research articles only)	Children Adults Young adults Older adults Not specified

Other participant characteristics	*Free text*
How is dietary advice provided to patients? (Original research articles only)	Verbal Printed Online Other (specified: *free text*) Not specified
Who provides dietary advice to patients? (Original research articles only)	Stoma nurse Specialist nurse – other (specified: *free text*) Ward nurse Community nurse Nurse - unspecified Dietitian Gastroenterologist Colorectal surgeon Medical doctor – other (specified: *free text*) Medical doctor – unspecified Surgeon – other (specified: *free text*) Surgeon – unspecified Other (specified: *free text*) Not specified
When is dietary advice provided to patients?	First 1-2 weeks post-surgery Within first 2 months post-surgery After first 2 months post-surgery Not specified
Type of dietary management – provide details in Key findings/ Recommendations	Low fibre High fibre Low residue Low insoluble fibre High insoluble fibre Low soluble fibre High soluble fibre High white starchy carbohydrate Low sugar High fat Low fat High protein Low protein High energy Supplement drinks (high energy and protein) Low caffeine High salt Avoid specific irritant foods and/or drinks Avoid specific irritant foods and/or drinks only if problematic for individual Consume gelatine containing sweets Healthy, balanced diet as per Eatwell Guide Normal diet Avoid/Limit eating late in day Reduce meal size Increase volume of fluids consumed Reduce volume of fluids consumed

	Increase frequency of meals Chew well Other (specified: *free text*)			
Details of dietary intervention	*Free text*			
Outcomes Table	**Symptom** Stoma output – volume Stoma output – consistency Flatulence Odour Leakage Blockage or obstruction of small bowel/ stoma Pain in small bowel/stoma Thirst Dehydration Malnutrition Other – please specify Not specified	**Food/ nutrient/ behaviour** *(free text)*	**Timeframe** Post-operative After healing period e.g. 8-12 weeks Both Not specified	**Positive/ negative impact** Positive affect Negative affect Not known Neutral
Key findings and/or recommendations relating to concept i.e. oral dietary modifications for outcomes directly relevant to stoma management e.g. low residue diet to prevent blockage, NOT QOL	*Free text*			
Conflicts of interest/funding	*Free text*			
Comments	*Free text*			

Appendix IV

Characteristics of included studies and expert opinion

Table of Experimental Studies

Author, year country	Sample characteristics	Dietary Intervention	Outcomes	Key Findings
Randomized controlled trials - crossover design				
Barrett et al, 2010 Australia	n=10 (4 male) Crohn's; UC Adults: mean age 55y (range 31-78) Time with ileostomy: mean 14y (range 1-33)	• High FODMAP and low FODMAP diet for 4 days each (all food provided; participants blinded) • Washout period at least 2 weeks • Setting: own home • Profession providing dietary intervention: not specified	1. Weight/volume of stoma output 2. Consistency of stoma output 3. Abdominal pain	1. Baseline mean stoma output 757g/d (range 500-1015). Mean stoma output ↓ with low FODMAP diet (409g/d, SE 65) v high FODMAP diet (504g/d, SE 51, p=0.01). • Volume of stoma output ↓ 95ml/d (28-161) with low FODMAP diet. 2. Consistency of stoma output perceived (VAS 0-10) as thicker with low FODMAP diet (2.3, 0.9-3.7, v 4.8, 3.5-6.1, p=0.005). 3. Moderate-to-severe abdominal pain experienced by 4 and 2 participants on low and high FODMAP diets, respectively.
Berghouse et al, 1984 UK	n=10 (6 male) Crohn's; UC Adults: average age in Crohn's group (n=5) 44y (range 22-68y), average age in UC group (n=5) 50y (range 32-70y)	• Diet A: high in refined cereals + sucrose; Diet B: high in unrefined cereals + low sucrose, for 2 weeks each ● Washout period of 1 week • Setting: own home + hospital research setting • Profession providing dietary intervention: dietitian (verbal + printed advice)	1. Weight/volume of stoma output	1. Mean wet weight of stoma output ↑ on diet B v diet A (238g, SD 90, v 162g, SD 79, p<0.02) • Mean dry weight of stoma output ↑ on diet B v diet A (24g, SD 7, v 15g, SD 7, p<0.01).
Clarebrough et al., 2015 Australia	n=28 (17 male) Colorectal cancer; FAP; IBD; bowel obstruction; ischemic bowel Adults: median age 66y (range 33-82) Ileostomy ≥3 months	• 3 marshmallows (14.5g per serving) 3x/day for 5 days • Washout period of 2 days • Setting: own home • Profession providing dietary intervention: not specified	1. Volume of stoma output 2. Consistency of stoma output	1. Median stoma output for control period 742ml/d (range 353-2600ml). • Median stoma output for intervention period not reported. • Median ↓ in stoma output 75ml/d (95%CI: 23-678, p=0.0054) during intervention period v control period. 2. 20/28 had ↓ in stoma output with marshmallow intervention + reported thicker output. 18 reported noticeable ↓ in stoma output.
Higham & Read, 1990 UK	n=8 (3 male) Crohn's; UC Adults	• Low fat (22g/d) and high fat (160g/day) diet for 1 day each (all food provided) • Washout period of 1 week • Setting: not specified • Profession providing dietary intervention: not specified	1. Weight/volume of stoma output 2. Transit time	1. Mean stoma output ↓ with low fat diet (397g v 532g). 2. No significant difference in transit time.

Author, year country	Sample characteristics	Dietary Intervention	Outcomes	Key Findings
Non-randomized controlled trials				
Mogos et al., 2015 Romania	n=43 (32 male): 21 intervention, 22 control Condition not specified Adults: mean age control 57.9y ±8.6y, mean age intervention 58.1y ±8.8y	• Intervention: Low fiber diet prescribed by nutrition specialist • Control: Summary diet advice provided by surgeon • Setting: hospital inpatient • Profession providing dietary intervention: nutrition specialist	1. High stoma output 2. Obstruction of stoma 3. Flatulence + odor	1. ↓ incidence of high stoma output with intervention (21% v 97%, p<0.01). 2. ↓ incidence of stoma obstruction with intervention (1% v 49%, p<0.01) 3. ↓ incidence of flatulence + unpleasant odors with intervention (16% vs 99%, p<0.01).
Non-randomized controlled trials - crossover design				
Donoghue et al., 2009 (conference abstract; pilot study) UK	n=8 Condition not specified Age group not specified	• Intervention: 3 marshmallows 3x/day for 1 week • 1-week control prior to intervention • Setting: not specified • Profession providing dietary intervention: not specified	1. Volume of stoma output 2. Consistency of stoma output	1. ↓ volume of stoma output with marshmallow consumption (1,476ml/d v 1,863ml/d, p=0.0068). 2. No significant difference in consistency of stoma output.
Kramer, 1987 USA	n=7 (2 male) UC Adults: age 27-68y	• 35 foods/drinks tested for 3 days each by 3-6 participants • 3-day control period prior to each test period • Setting: own home • Profession providing dietary intervention: nutritionist	1. Weight of stoma output	1. Significant ↑ in weight of stoma output with grapes, raw peaches, raisins, strawberries, bananas, baked beans, prune juice. • Small but significant ↓ in weight of stoma output with beer. • Additional consumption of 1300-1400g/d water above approx. average consumption of 1500g/d did not significantly alter weight of stoma output. • Non-significant ↓ in weight of stoma output with fluid restriction of 250-500g/d water only.
Kramer et al., 1962 USA	n=7 (1 male) UC Adults: mean age 38y (range 27-68)	• Following foods/drinks tested for 3 days each: milk, water, orange juice, prune juice, fried food, pork, baked beans, cooked cabbage, corn, dark rye bread, carbonated beverages, black pepper (test foods provided) • 3-day control period before each test period • Setting: own home • Profession providing dietary intervention: not specified	1. Weight/volume of stoma output 2. Food visible in effluent	1. ↑ weight of stoma output with: 200g/d prune juice (mean 2205g/72h v 1448g/72h, p=0.001), 200g/d cooked cabbage (mean 1868g/72h v 1438g/72h, p=0.02). • The following foods/drinks did not alter stoma output: milk, orange juice, fried food, pork, corn, rye bread, carbonated beverages, black pepper. • Additional water (1292-1420g/d above control intake) did not significantly alter stoma output. 2. Large quantity of corn hulls observed in effluent.

Author, year country	Sample characteristics	Dietary Intervention	Outcomes	Key Findings
Andersson et al., 1974 Sweden	1 participant (male) with ileostomy Crohn's + gall bladder disease Adult: age 33y	• High fat diet (100g/d) for 2-4 four-day periods. Later, low fat diet (40g/d) for 4-6 four-day periods (all food provided) • Setting: metabolic ward • Profession providing dietary intervention: not specified	1. Consistency of stoma output	1. No difference in stoma output consistency between high- + low-fat diets. • Consistency remained watery.
Gaffney et al., 1987 Australia	n=3 Condition not specified Adults	• Test meal on 3 separate days (test meals provided): low fiber (0.7g), medium fiber (3.2g), high fiber (13.5g) • Setting: not specified • Profession providing dietary intervention: not specified	1. Weight of stoma output 2. Volume of gas	1. ↑ weight of stoma output with ↑ dietary fiber. 2. ↑ gas with ↑ dietary fiber ($p<0.05$).
Gaffney et al., 1987 (conference abstract) Australia	n=8 Condition not specified Adults	• High fiber dinner (10g fiber) on 3 separate days, low fiber dinner (1g fiber) on 1 day (test meals provided) • Washout period of 1 week between each test diet day • Setting: not specified • Profession providing dietary intervention: not specified	1. Volume of fermentation gases 2. Odor	1. ↓ volume of fermentation gases with low fiber meal (90ml v 391ml) 2. No significant difference in odor between high and low fiber meals.

Note: Only outcomes related to ileostomy symptoms/management are reported; Setting = setting where intervention carried out.

Table of Longitudinal Studies

Author, year country	Sample characteristics	Sources of diet advice	Dietary Modification	Outcomes	Key Findings
Pre-post studies					
Arenas Villafranca et al., 2015 Spain	n=43 (26 male) 47% ileostomy, 53% colostomy IBD; colorectal cancer; benign pathologies Adults: median age 66y (IQR 58-73)	• 3-phase standard protocol including pharmacological + nutritional guidance • Setting: hospital inpatient	Low insoluble fiber; low caffeine; high salt; avoid specific drinks i.e. alcohol, fruit juice; avoid fluids with meals	1. Early HOS - onset + resolution 2. Late HOS onset + resolution	1. 7 ileostomy patients had early HOS. • Protocol applied to 5/7 early HOS patients. HOS resolved in phase 1 for 4/5, in phase 2 for 1/5. 2. 6 patients (5 with ileostomy) had late HOS. • Protocol applied to 2/6 late HOS patients. HOS resolved in phase 1 for 2/2.
Mukhopadhyay et al., 2015 India	n=60 (36 male) Crohn's; trauma; ileal perforation; obstruction; gangrenous gut; iatrogenic ileal injury Adults: mean age 45y (range 20-60y)	• Each patient had individualized diet chart • Setting: hospital inpatient	Avoid specific drinks; avoid specific foods/drinks if cause problem; avoid eating late in the day; ↓ meal size; ↑ meal frequency; chew well; fluids between meals	1. Volume of stoma output 2. Consistency of stoma output	1. Stoma output ↑ from day 1 to day 7 on oral intake (mean 122cc/24h v 900cc/24h, p<0.001) + ↓ from day 7 to 3 months on oral intake (mean 900cc/24h v 615cc/24h, p<0.001). 2. Consistency of output thickened between day 7 and 3 months.
Nagle et al., 2012 USA	n=203 (102 male); 42 intervention (21 male), 161 control (81 male) Permanent or temporary ileostomy Diverticulitis; IBD; colorectal cancer Adults: mean age intervention 50.9y, mean age control 50.8y	• Intervention: standardized patient education provided peri-operatively by stoma nurse + ward nurse (verbal + printed diet advice) • Control: standard care including education on low residue diet • Setting: hospital inpatient	Low fiber; avoid/limit specific foods/drinks if cause problem; ↓ meal size; ↑ meal frequency; chew well; largest meal in middle of day; normal diet	1. Readmission due to diarrhea + dehydration 2. Readmission due to obstruction/ ileus	1. ↓ readmission due to dehydration alone, and with any other complication, from 15.5% to 0% (p=0.02). 2. ↓ readmission for small bowel obstruction/ileus, from 9.3% to 4.7% (p>0.05). Overall, ↓ in 30-day post-discharge readmission rate for new ileostomies following intervention, from 35.4% to 21.4%.

Author, year country	Sample characteristics	Sources of diet advice	Dietary Modification	Outcomes	Key Findings
Observational studies					
Roy et al., 1970 USA	n=344 (193 male) Crohn's; UC; colorectal cancer; aganglionic megacolon Permanent ileostomy Adults and adolescents: age range 10-70+y Time with ileostomy: Mean 7.6y	Not specified	Avoid specific foods/drinks if cause problem; normal diet	1. Diarrhea 2. Obstruction	226 (66%) patients followed normal diet without restrictions at follow-up. 5 followed strict dietary modifications to control ileostomy function. 1. 4 reported dairy caused diarrhea. 2. 93 made minor dietary modifications i.e. avoiding nuts, popcorn, specific fruit + vegetables high in fiber, seeds, or acid. • Partial obstruction due to 'undigested coarse foods' reported by a few patients.

Note: Only outcomes related to ileostomy symptoms/management are reported; Setting = setting where intervention carried out.

Table of Cross-sectional Studies

Author, year country	Sample characteristics	Sources of diet advice	Dietary Modification	Outcomes	Key Findings
Cross-sectional studies - surveys/questionnaires/structured interviews					
Biermann et al., 1966 USA	n=107 respondents with ileostomy Condition not specified Adults	Not specified	Avoid specific foods; consume specific foods	1. Odor	1. Most respondents did not think diet important other than to control odor. • Foods commonly avoided to ↓ odor: beans, onions, foods in cabbage family. • Foods commonly consumed to ↓ odor: parsley, spinach, lettuce. 61% of physicians did not advise a special diet for ileostomy patients.
Bingham et al., 1982 UK	n=79 ileostomy group; n=70 control group Crohn's; UC Adults: mean age 50y Sub-group: n=37 (17 male) completed full dietary assessment; n=37 matched controls Mean age 50y (range 21-75) Time with ileostomy: mean 9.9y (range 0.5-34)	Not specified	Low fiber; high salt; ↑ fluid intake; avoid specific foods if causing problem; avoid/limit eating late in day	1. Volume of stoma output 2. ↑ flow 3. Flatulence 4. Odor 5. Food identifiable in effluent •	Percentage of people with ileostomy avoiding or modifying intake: 1. ↑ output: beer 25%. 2. ↑ flow: onion 50-75%; beetroot 30%. 3. Flatulence: onion 50-75%; peas 50%; carbonated drinks 40-45%. 4. Odor: onion 50-75%. 5. Identifiable in effluent: nuts 70-90%; pips, pith, seeds, skin of fruit and tomatoes 50-85%; lettuce 50%; raw cabbage + carrot 50-75%; peas 50%; sweetcorn 75%. No cereal, animal product or drink negatively affected >50% of people with ileostomy who had tried them. Diet assessment of ileostomy group v controls: ○ ↑ fluid intake in ileostomy group (1643 v 1508g/d). Total water intake from food and fluids not significantly different. ○ ↑ intake of table salt ($p<0.001$) + drinks ($p<0.01$) in ileostomy group. ○ ↑ energy + water intake with ↑ length of ileal resection ($p<0.01$). ○ ↓ fruit + vegetable intake in ileostomy group (206 v 303g/d). ○ More people with ileostomy than controls ate the following foods: cornflakes, Special K, Rice Krispies, puffed wheat, Shredded Wheat, Weetabix, Hovis, tinned spaghetti, corn flour, blancmange, sago, tapioca, semolina, instant potato, cocoa. ○ Fewer people with ileostomy than controls ate the following foods/drinks: All-bran, potato skin, tomato, fruit, raw carrot, cabbage, celery, peach, leek, onion, spring greens, runner beans, lettuce, cucumber, watercress, radish, sweetcorn, asparagus, broccoli, mushroom, pickled onion, pickles, spices, garlic, plum, rhubarb, redcurrants, gooseberries, blackberries, raspberries, strawberries, grapefruit, orange/orange pith, raisins, prunes, jam with seeds, walnuts, almonds, alcoholic spirits.

Author, year country	Sample characteristics	Sources of diet advice	Dietary Modification	Outcomes	Key Findings
Brydolf & Segesten, 1994 Sweden	n=11 8 conventional ileostomy, 3 continent ileostomy UC Adolescents + adults	Not specified	↑ fluid intake; avoid specific foods if cause problem	None relating to ileostomy symptoms/ management	↑ fluid intake in participants with conventional ileostomy
Daly & Brooke, 1967 UK	n=100 (38 male) UC Adults: age between 20-80y Time with ileostomy: majority 5-10y, none <5y	Not specified	Avoid specific foods if cause problem; normal diet; avoid eating late in the day	1. Leakage 2. Pain	Diet was unrestricted in 83%. 1. Most avoided eating meals late in the day due to risk of leakage overnight. 2. 17% restricted diet due to pain associated with nuts, fruit skins + certain vegetables.
Gazzard et al., 1978 UK	n=50 (14 male) Crohn's; UC Adults: mean age 32y (range 19-64) Time with ileostomy: ≥6 months	Not specified	Low residue diet; avoid specific foods if cause problem	1. Watery output 2. Obstruction 3. Flatulence 4. Odor	Foods associated with symptom by n/50 participants: 1. Watery output: green vegetables 9, fruit 6, fish 3, fizzy drinks or beer 3, onion 2, cheese 2, egg 1, spices 1 2. Obstruction: 10 avoided high residue foods e.g. nuts 3. Flatus: fizzy drinks or beer 32, green vegetables 16, onion 6, egg 3, spices 2, cheese 1, fruit 1. 4. Odor: fish 17, egg 13, cheese 7, onion 6, green vegetables 3, spices 3.

Author, year country	Sample characteristics	Sources of diet advice	Dietary Modification	Outcomes	Key Findings
Kennedy et al., 1982 UK	n=90 (51 male): 51 ileostomy group (28 male), 39 matched controls (23 male) Crohn's; UC Adults: UC group mean age 48y (range 23-80); Crohn's group mean age 46y (range 27-74); controls mean age 49y (range 26-77) Time with ileostomy: UC group mean 5.5y (range 1-15); Crohn's group mean 5y (range 1-11)	Not specified	Normal diet; high salt; ↑ fluid intake; avoid specific foods if cause problem; chew well	1. Discomfort / Obstruction	1. 59% of people with ileostomy avoided ≥1 food e.g. nuts, skins, pips due to discomfort or obstruction of stoma. Dietary intake of people with ileostomy vs controls was similar apart from people with ileostomy had ↑ intake of fluid + salt.
Matras et al., 2005 Poland	n=45 (17 male); 23 cases (8 male), 22 control (9 male) UC; FAP Adults: Cases age 31-68y, Controls age 22-64y Time with ileostomy: 1-13y	Not specified	↑ fluid intake; ↓ meal size	None relating to ileostomy symptoms/ management	Following differences for ileostomy group v controls: ○ ↓ portion size of all foods, bread, cheese, potato (all $p<0.05$) ○ ↑ portion size of fats ($p<0.05$) ○ ↑ frequency of consumption of milk, soup, potato, fruit, fluid (all $p<0.05$).

Author, year country	Sample characteristics	Sources of diet advice	Dietary Modification	Outcomes	Key Findings
McDonald & Fazio, 1988 USA	n=98: 37 Crohn's with ileostomy, 34 Crohn's without stoma, 27 controls Crohn's Adults: Crohn's with ileostomy group mean age 37y; Crohn's without stoma group mean age 35y; controls mean age 35y	Physician; surgeon; dietitian; nurses; other patients; family members; pamphlets (verbal + printed) •	Avoid specific foods i.e. nuts and skin; avoid specific foods if cause problem	1. Diarrhea 2. Visible in output 3. Obstruction	Percentage of ileostomy group reporting problem with the following foods (↑ v control group, p<0.01): 1. Diarrhea: raw fruit 57%, shellfish 50%. 2. Visible in output: nuts 69%. Unspecified outcome: corn 79%, fizzy drinks 57%, lettuce 52%, pickles/gherkin 27%. • Obstruction experienced with the following foods: popcorn, sweetcorn, lasagna, orange pith, apple skin, bran. 76% (28/37) of ileostomy group received diet advice from a physician or surgeon vs 82% (28/34) of Crohn's without stoma group. 63% (23/37) of ileostomy group received diet advice from a dietitian vs 26% (9/34) of Crohn's without stoma group (p=0.003). ○ Most common advice was "eat what you can". ○ People with ileostomy advised to avoid nuts + skin.
de Oliveira et al., 2018 Brazil	n=103: 40 with ileostomy, 63 with colostomy Condition not specified Adults: mean age 60y (range 25-94) Time with stoma: range 1-360 months Time with ileostomy: 58% >1y Time with colostomy: 67% >1y	Not specified	Avoid specific foods/drinks if cause problem	1. ↑ output 2. Leakage 3. Constipation 4. Flatulence 5. Odor	Results for ileostomy group: 1. 13 (33%) avoid certain foods due to ↑ output: dairy (n=7), fruit (n=6), vegetables (n=5), fatty food (n=2), beans, meat, cereal (all n=1). 2. 8 (20%) avoid certain foods due to appliance leakage: leafy vegetables, fruit (both n=2), nuts, fatty sauces, beverages (coffee/alcohol), corn, flatulent foods (all n=1). More people with ileostomy v colostomy avoiding foods due to concern about leakage (20% v 5%, p=0.035). 3. 3 (8%) avoid certain foods due to constipation: cereal (n=3), fruit (n=2), potato (n=1). 4. 16 (40%) avoid certain foods due to flatulence: vegetables (n=11), legumes (n=6), soft drink (n=4), egg, dairy, fruit (all n=2), peanuts (n=1). 5. 11 (28%) avoid certain foods due to odor: vegetables (n=8), egg (n=4), meat (n=2), beans (n=1).

Author, year country	Sample characteristics	Sources of diet advice	Dietary Modification	Outcomes	Key Findings
Richbourg, 2012 USA	n=174 Crohn's; UC; FAP; cancer; c. diff; radiation damage; ischemia; spina bifida; neurogenic bowel; bowel perforation; kink in colon Adults: mean age 59y (range 22-94) Time with ileostomy: mean 15y (range 1-56)	Not specified	Low fiber; avoid specific foods if cause problem; avoid/limit eating late in day; ↓ meal size; ↓ meal frequency; chew well; limit intake when travelling/ socializing	1. Pain	67% (n=117) modified their dietary choices due to their ileostomy. 1. 'Some foods are painful' Foods avoided (reason not known): nuts (27%), popcorn (17.8%), corn (13.2%), raw vegetables (8.6%), skins/casings (7.5%), celery (6.9%), raw fruit (5.7%), beans (5.2%). Many other foods listed as avoided by <5% of study population.
Thomson et al., 1970 UK	n=952 (329 male) Condition not specified Adults: range 10-79y (IQR 40-59) 75% had ileostomy for 1-10y	Not specified	Not specified	1. Watery flow 2. "Upset timing of bag filling" 3. Pain 4. Flatulence 5. Odor	Food/drink most commonly associated with: 1. Watery flow: rhubarb (33%); alcohol (23%). 2. "Upset timing of bag filling": rhubarb (9%); mushrooms (8%). 3. Pain: onion (13%); pineapple (12%), mushrooms (10%). 4. Flatulence: peas (24%); onion (23%); beans (22%). 5. Odor: onion (39%); white fish (30%).
Wilson, 1964 Australia	n=98 (93 adults of which 43 male) Permanent ileostomy for UC Adults: mean age 41y Time with ileostomy: mean 3.75y	Not specified	Avoid specific foods if cause problem; high salt	None reported	○ 65/98 avoided some food(s). ○ Most commonly avoided: cabbage, nuts, onion, spinach, fish, peas, pineapple, coconut, fatty foods, stews, spiced/highly seasoned foods, oranges, fruit (particularly fruit skin or seeds), carrot, mushroom, egg. ○ Condiments + spices were avoided sometimes. ○ 56/98 participants added extra salt in their diet.

Note: Only outcomes related to ileostomy symptoms/management are reported

Table of Qualitative Studies

Author, year country	Sample characteristics	Sources of diet advice	Dietary Modification	Key Findings
Qualitative studies - interviews				
Kelly, 1991 UK	n=45 (15 male) UC Adults: mean age 42y Time with ileostomy: median 1-5y	Not specified	Avoid/limit specific foods if cause problem	Foods associated with / causing • Loose output: oranges, onion. • Blockage: certain high fiber foods (some people are careful with their diet to avoid this; others take a chance). • Pain: curry, nuts.
Kittscha, 2011 (thesis) Australia	n=6 (4 male) Crohn's, cancer Adults Time since discharge from hospital after ileostomy: 1 + 4 weeks	• Dietitian (verbal + printed advice) • Setting: hospital inpatient	Low fiber; normal diet; ↓ meal size; ↑ meal frequency; chew well	• Risk of blockage with high fiber foods during first few weeks after ileostomy formation – advice from dietitian. Advised to puree asparagus and other vegetables.
Morris & Leach, 2015 UK	n=6 (2 male) Crohn's Adults: mean age 52.2y Time with ileostomy: mean 18.8y	• Dietitian, stoma nurse (verbal + printed advice) • Setting: hospital inpatient	Low fiber; low fat; healthy, balanced diet; limit intake when eating out	Foods associated with / causing • Negative effect on stoma output consistency: fruit, whole meal bread, fibrous foods, banana. • Positive effect on consistency: baked beans. • Blockage: nuts, vegetable stalks, apple skins, grapefruit pith. • GI pain: milk. • Flatulence: beansprouts Some foods people were advised to avoid were not problematic e.g. spicy foods, baked beans.
Morris & Leach, 2016 (abstract) UK	n=10 (4 male) Crohn's Adults: mean age 52.2y	• Dietitian • Setting: not specified	Avoid specific foods if cause problem	Exclude specific foods after experience of adverse reaction e.g. lettuce.

Setting = setting where diet advice is provided.

Table of Expert Consensus Guidelines

Author, year country	Author/s profession	Sources of diet advice	Dietary Modification	Dietary Recommendations
Goldberg et al., 2018 (Wound, Ostomy and Continence Nurses Society) USA	Stoma nurse; colorectal surgeon; urologist; surgeon	• Healthcare providers; stoma nurse • Setting: hospital inpatient	Low insoluble fiber; high salt; avoid specific drinks; ↑ fluid intake	**Immediate post-operative period:** ↓ hypertonic fluids; ↓ hypotonic fluids; high sodium diet; include complex starches; avoid high sugar drinks including juices. • If stomal stenosis, ↓ insoluble fiber + ↑ fluid intake to soften stool.
Prinz et al., 2015 (Wound, Ostomy and Continence Nurses Society) USA	Stoma nurse	• Clinicians providing ileostomy care • Setting: hospital inpatient	Low residue; ↓ meal size; ↑ frequency of meals; chew well	**Immediate post-operative period:** low residue diet may be indicated (due to bowel edema); consider small, frequent meals; adequate fluid intake. • Thickens output: banana, rice, applesauce, peanut butter, soda crackers, pasta, bread, marshmallows, cheese. • Blockage may be caused by high fiber foods: stringy + fibrous foods e.g. celery + asparagus, foods with nondigestible fibrous peel e.g. apple + corn, raw cabbage, dried fruits, nuts, popcorn, meats with casings, mushroom, coconut, foods with large seeds. • ○ Chew food well (to optimize digestion/ absorption).

Table of Expert Opinion Articles

Author, year country	Author/s profession	Sources of diet advice	Dietary Modification	Dietary Recommendations
Akbulut, 2011 Turkey	Not specified	• Doctor, dietitian, nutrition nurse • Setting: not specified	Low fiber; low insoluble fiber; low residue; high white starchy carbohydrates; low sugar; low fat; high protein; high energy; balanced diet; ↓ meal size; ↑ meal frequency; chew well	**Immediate post-operative period:** high energy, high protein diet, low insoluble fiber. Apples (pectin) + oatmeal (oligosaccharides) may be beneficial to reintroduce first after 4 weeks low fiber diet. **6-8 weeks post-surgery:** add one new food at a time; consume a varied diet; eat regularly (skipping meals ↑ output and flatulence); small frequent meals may be beneficial; chew food thoroughly; cutting up food to bite size pieces may ↑ tolerance. **After bowel adaptation,** 6 small meals/day. Lactose-restricted + oxalate restricted diet may be required for extended period. • If osmotic diarrhea: ↓ simple + ↑ complex carbohydrates. • If strictures: avoid popcorn, nuts, seeds, mushrooms, celery, fruit + vegetable skins, + chew thoroughly. • ↓ odor: spinach, parsley (avoid excess due to oxalate content). • ○ Avoid alcohol + caffeine (small amounts may be permitted). ○ Consuming fluids between meals rather than with meals may be beneficial. ○ Consume low fat protein sources e.g. lean meats, egg white.
Bak, 2008 USA	Stoma nurse	• Nurse (verbal) • Setting: hospital inpatient	Normal diet; chew well	**After ileostomy formation,** progress back to normal diet. Reintroduce foods one at a time to determine tolerance. Introduce high fiber foods slowly. Food tolerance prior to ileostomy should be same after ileostomy • To prevent blockage: chew foods well + drink plenty of fluids. • Gas-forming foods include onions, hard-boiled eggs, spicy foods, fish, dried beans, carbonated drinks, beer. ○ Drink a glass of water each time pouch emptied to replace fluids. ○ If not on fluid restriction, consume 64oz fluid/day.

Author, year country	Author/s profession	Sources of diet advice	Dietary Modification	Dietary Recommendations
Berti-Hearn & Elliott, 2019 USA	Stoma nurse; nurse	• Stoma nurse; home care clinicians • Setting: community - home/care home	Low fiber; high salt; high potassium; avoid specific foods; avoid/limit specific foods if cause problem; ↑ meal frequency; chew well	**Immediate post-operative period:** avoid raw fruit and vegetables. Slowly introduce fiber, cooked fruit + vegetables one at a time. • To prevent watery output, eat every 3-4 hours. • May thicken output: yoghurt, cheese, peanut butter, starchy foods. • To prevent blockage, avoid high fiber, stringy foods e.g. nuts, corn, celery, asparagus, popcorn, coconut, mushroom, cabbage. ○ Chew food well; cook food until soft. ○ Consume at least 2L fluid/day. ○ ↑ foods high in sodium + potassium.
Black, 2009a UK	Stoma nurse	• Not specified • Setting: care home	Low fiber; high salt	• Blockage may be caused by high fiber foods/skins. ○ Add salt to diet.
Black, 2009b UK	Consultant nurse in coloproctology	• Stoma nurse • Setting: not specified	Avoid specific foods	• High fiber diet may cause obstruction. • To prevent obstruction, avoid celery, sweetcorn, dried fruit, nuts, coconut.
Bracey & Mortensen, 2015 UK	Colorectal surgeon	Not specified	Avoid/limit specific foods/drinks if cause problem	• ↑/loosen output: beans, beer, caffeinated beverages, chocolate, leafy green vegetables, raw fruit + vegetables, spicy food, whole meal foods, cereal, alcohol, citrus fruit + juice. • ↓/thicken output: applesauce, banana, boiled rice, cheese, smooth peanut butter, tapioca, white bread, potato, suet pudding, pasta. • May cause obstruction: mushroom, sweetcorn, potato skin, nuts, tomato skin, raw fruit skin, celery strings. • ↑ flatulence: beer, carbonated beverages, dried beans + peas, milk/milk products, onions, cabbage, broccoli, sprouts.

Author, year country	Author/s profession	Sources of diet advice	Dietary Modification	Dietary Recommendations
Bradshaw & Collins, 2008 UK	Stoma nurse	• Community nurse • Setting: community	Low fiber; high salt; avoid specific foods/drinks if cause problem; healthy, balanced diet	No set rules for diet modification. Individuals will respond differently. Most people with ileostomy should follow a normal, healthy balanced diet. Try all foods + only avoid a food if frequently causing undesirable symptoms. • May cause loose output: high fiber foods, alcoholic drinks, apple juice, coffee, dairy, green leafy vegetables, baked beans, liquorice, chocolate, tomatoes, prune juice, spiced foods, sorbitol. • Thickens output: potato, white rice, banana, stewed apple, smooth peanut butter, bread, cream crackers, marshmallows, Jelly Babies, crisps. • Constipation relief: cooked fruit + vegetables, fresh fruit, fruit juice, water. • Prevents dehydration: add extra teaspoon of salt to food daily. • May cause obstruction: mushrooms, dried fruit, sweetcorn, coconut, orange pith, nuts, popcorn, tough fruit + vegetable skins, celery, Chinese vegetables, peas. • ↑ flatus + odor: asparagus, apples, beer, cabbage, broccoli, brussels sprouts, cauliflower, cucumber, dried peas + beans, eggs, fatty foods, onions, turnips, dairy products, chewing gum, carbonated drinks, garlic, fish. • ↓ odor: parsley, cranberry juice, yoghurt, orange juice.
Burch, 2008 UK	Enhanced recovery facilitator	• Not specified • Setting: hospital inpatient	Low fiber; high white starchy carbohydrates; high salt; avoid specific foods; avoid/limit specific foods/drinks if cause problem; healthy, balanced diet; ↓ meal size; ↑ meal frequency; chew well	**Immediate post-operative period:** oral fluids should be encouraged, + food chewed well. Food should be consumed little + often. **First 6 weeks post-ileostomy:** avoid nuts, raw vegetables, salad, peas, sweetcorn, mushrooms to prevent blockage. Then reintroduce in small, well-chewed portions. **After 6-8 weeks,** when ileostomy function settles, try new foods. Low fiber diet including white bread + pasta. Added salt may not be needed in long term if diet contains some salty or processed food. • • If high output, consume salty foods + low fiber diet, restrict oral fluids for 1/2-1hr before + after meals. • Loose stools may be caused by alcohol therefore consume in moderation. • To ↓ risk of blockage, consume fruit + vegetables but chew well. Removing skins, seeds + pips may be beneficial, or use tinned or well-cooked fruit + vegetables.

Author, year country	Author/s profession	Sources of diet advice	Dietary Modification	Dietary Recommendations
Burch, 2011a UK	Enhanced recovery nurse	• Stoma nurse; community nurse; dietitian • Setting: community	Low fiber; high white starchy carbohydrates; high salt; avoid specific foods/drinks if cause problem; healthy, balanced diet; ↓ meal size; ↑ meal frequency; chew well	**First few weeks after ileostomy formation:** chew all foods well, avoid fruit initially (except banana), gradually introduce fiber into diet starting with cooked fruit. • Loose output may be caused by spicy foods, alcohol. • Thickens output: white bread, white rice, potato, white pasta, biscuits, sponge cake, white crackers, banana. Small snack e.g. plain biscuit with mid-morning + afternoon drink may be beneficial. • To prevent dehydration: slightly ↑ salt intake unless diet already high in salt. • May cause blockage: hard foods e.g. nuts; fibrous foods e.g. fruit skin; sweetcorn; dried fruit, salad; poorly chewed food.
Burch, 2011b UK	Enhanced recovery nurse	• Stoma nurse; community nurse • Setting: hospital inpatient, community	Low fiber; high salt; avoid specific foods if cause problem; normal diet; healthy, balanced diet; ↓ meal size; ↑ meal frequency; chew well	**In general,** can eat + drink normal diet. However, **in first few months,** high fiber diet/foods may cause problems. ○ Chew food well. ○ Add little bit of salt to meals daily unless diet already high in salt. ○ Eating little + often may be better tolerated. ○ Ensure balanced diet to aid healing. • • Loose output may be caused by alcohol, high fiber foods. • Blockage may be caused by poorly chewed food.
Burch, 2013 UK	Enhanced recovery nurse	• Nurse • Setting: not specified	High salt; avoid/limit specific foods if cause problem; chew well	**If recently formed stoma,** chew food carefully to prevent blockage. High fiber foods may not be well tolerated. • To prevent dehydration, add salt to diet if not already high in salt
Burch, 2015 UK	Enhanced recovery nurse	• Community nurse • Setting: community	Avoid specific foods post-surgery then only if cause problem; chew well	**First few weeks/months post-surgery:** avoid high fiber foods. **After first few weeks:** only avoid if produce unacceptable symptoms. • Blockage may be caused by sweetcorn, other high fiber foods. • Chew food well, especially sweetcorn + high fiber foods, to prevent blockage.
Burch, 2017 UK	GI specialist nurse	• Stoma nurse; nurse • Setting: hospital inpatient + outpatient	Low fiber; high salt; normal diet	**In general,** can eat + drink normal diet. • ↑/loose output: brown bread, high fiber diet. • ↑ salt intake to replace losses in loose output. • ↓/thicken output: white bread, low fiber diet.

Author, year country	Author/s profession	Sources of diet advice	Dietary Modification	Dietary Recommendations
Burch, 2019 UK	GI specialist nurse	• Healthcare provider in nursing/ residential home • Setting: care home	Avoid/limit specific foods if cause problem; chew well	• Check individual reactions to different foods. • Output can be thickened by replacing brown/whole meal bread with white bread. • To ↓ risk of blockage, chew food well. • Blockage may be caused by foods that are hard to chew e.g. mushroom, sweetcorn, fruit + vegetable skin. • Do not avoid all fruit + vegetables. Root vegetables + cooked/stewed fruit generally cause less problems. • ○ Consume adequate fluid i.e. ~1.5L/day. ○ Small amount of salt daily (N.B. most diets contain sufficient salt without addition).
Collins & Sulewski, 2011 USA	Dietitian	• Dietitian; healthcare practitioners • Setting: not specified	Low insoluble fiber; high soluble fiber; high salt; high potassium; avoid specific foods if cause problem; ↓ meal size; ↑ fluid intake; ↑ meal frequency; chew well	Try new foods one at a time. Identify individual reactions to certain foods using a food diary. • ↑ loose output: apple juice, fried food, fructose-sweetened drinks, sugar-free candies. • ↓ loose output: applesauce, banana, peanut butter, toast. • If output high/watery, ↓ insoluble + ↑ soluble fiber. • May cause obstruction: apple peel, whole-kernel corn, dried fruit, nuts, popcorn. If not avoiding, chew these foods well. • ↑ flatulence + watery output with skipping meals. • May ↑ flatulence: carbonated beverages, beans, soy, cabbage, dairy products, nuts, onion, talking while eating; chewing gum; drinking with a straw, smoking. • ↑ odor: asparagus, broccoli, cabbage, egg, garlic. • ↓ odor: buttermilk, cranberry juice, yoghurt. • ○ Add extra teaspoon of salt to food daily. ○ Include high salt foods: broth, canned vegetables, soy sauce, tomato juice. ○ ↑ water intake. ○ Consume foods high in potassium: chicken, turkey, banana, cherries, potato. ○ Consume foods high in soluble fiber: applesauce, banana, tapioca, potato, oatmeal, white rice. ○ Consume small, frequent meals and snacks. •

Author, year country	Author/s profession	Sources of diet advice	Dietary Modification	Dietary Recommendations
Cremen & Lee, 2016 UK	Nurse	• Not specified • Setting: community care home	High white starchy carbohydrates; high salt; consume gelatin containing foods; healthy, balanced diet; ↑ fluid intake	○ Maintain balanced diet to prevent malnutrition associated with malabsorption. ○ ↑ fluid + salt may be required. • Thickens output: carbohydrates e.g. white bread + pasta, foods containing gelatin.
Cronin, 2013 UK	IBD specialist nurse	• Stoma nurse; ward nurse (verbal + printed) • Setting: hospital inpatient + outpatient	Low fiber; high salt; avoid specific foods/drinks; avoid/limit specific foods/drinks if cause problem; consume gelatin containing sweets	**10-12 weeks post-surgery:** some people can return to normal diet. Introduce new foods gradually. Fruits unlikely to cause a problem are soft ripened fruit + some tinned fruit, including pears, apples, raspberries, watermelon, honeydew melon, cantaloupe melon, banana, avocado, mango (without stringy bits), strawberries, grapes (without skin), nectarines (ripe + without skin, or tinned). Vegetables permitted as easily digested: green beans, marrow, courgette, okra, broccoli florets, herbs. • Thickens output: rice, bread, potato, crisps, pasta, noodles, carrots, parsnips, sweet potato, plantain, pumpkin, yams, marshmallows, gummy bears, fruit pastilles, American hard gums, jelly cubes, Jelly Babies, Percy Pigs, drinks containing thickeners, milkshake, frozen yoghurt. • To replace losses and prevent dehydration ↑ salt intake by adding salt to food or consuming salty foods e.g. salted crisps, pretzels, salted crackers, Marmite, salted rice cakes and salty cheese. • ↑ fluid + sodium losses can be caused by hypertonic fluids e.g. tea, coffee, carbonated drinks. • Blockage may be caused by foods containing indigestible cellulose: fruit skin, sweetcorn, garden peas, mushrooms, pineapple, onion, nuts, pine nuts, sunflower seeds, dried fruit, coconut, potato skin, pomegranate, celery, mange tout, radish, artichokes, asparagus, raw vegetables. Should be avoided (for at least 3 months after surgery). • Avoid to ↓ flatulence: talking while eating, gulping while eating, chewing gum, excessive fizzy drinks, drinking too quickly. • Limit to ↓ flatulence: beans (e.g. kidney, cannelloni, borlotti, soya, broad, green/brown, red lentils), peas (chickpeas, mushy peas). • ↓ odor: marshmallows.

Author, year country	Author/s profession	Sources of diet advice	Dietary Modification	Dietary Recommendations
Deitz & Gates, 2010 USA	Stoma nurse	• Nurse; healthcare provider • Setting: not specified	Healthy, balanced diet	**Up to 6 weeks post-surgery:** obstruction may be caused by high fiber foods, e.g. apple skin, nuts, raisins, due to intestinal edema. ○ Consume a well-balanced diet. • May ↑ flatulence: beer, carbonated drinks, dairy products. • May ↑ odor: eggs, cheese, fish.
Dizer et al., 2011 Turkey	Dietitian; nurse	• Stoma nurse; nurse; dietitian; doctor specializing in nutrition; pharmacist (verbal + printed) • Setting: hospital inpatient + outpatient	Low fiber; high fiber; high white, starchy carbohydrates; high salt; high potassium; avoid specific foods/drinks; avoid/limit specific foods/drinks if cause problem; normal diet; ↓ meal size; ↑ meal frequency; chew well; ↑ fluid intake	• If diarrhea: 1.↓ fiber intake 2.Consume the following to thicken output - white rice, tomato, mashed potato, apple, applesauce, peach, quince, banana, carrot, porridge, pasta, noodles, yoghurt, yoghurt soup, Tarhana soup 3.↓ output vol. by ↓ - dry beans, wholegrains, milk, whole meal bread, biscuits, pastries, fruits, vegetables, meat + chicken broth, fried foods, oily foods, spicy foods 4.↑ fluid intake. • Consume foods high in potassium + salt to replace losses. • Add 1 tablespoon of salt to meals daily. • If constipation: 1.Include some fiber 2.Avoid fruits with seeds, apple/orange/tomato peel, celery, corn, cabbage, nuts, walnuts, peas, mushroom, green salad, leaf wrap 3.Consume small portions + chew well 4.↑ fluid intake 5.Eat high fiber foods e.g. wholegrains, fruit, vegetables. • May ↑ gas: peas, cauliflower, red cabbage, onion, broccoli, corn, turnip juice, broad beans, white cabbage, pepper, radish, brussels sprouts. • ↑ odor: fish, egg, onion, garlic, green vegetables, cucumber, asparagus, celery, cauliflower, cheese, cabbage, dry beans. • ↓ odor: fresh parsley, yoghurt, cranberry juice, peppermint. ○ Avoid specific foods based on personal experience. ○ Small, frequent meals + snacks. Last snack before bed. ○ Eat slowly + chew well. ○ ↑ fluid intake, particularly during summer. ○ Avoid meat + chicken broth. ○ Do not roast food. ○ Include the following in meals + snacks: potato, rice, unripe apple/banana, whole-wheat, rye, village bread. Diet plan included which indicates long list of foods + drinks that should be avoided in addition to the above advice.

Author, year country	Author/s profession	Sources of diet advice	Dietary Modification	Dietary Recommendations
Dorman, 2009 USA	Advanced practice nurse	• Nurse; surgeon • Setting: hospital inpatient	Low fiber; avoid specific foods if cause a problem; healthy, balanced diet; chew well	**Immediately post-surgery:** follow a low fiber diet. ○ Consume a healthy, balanced diet. • Thickens output: applesauce, pretzels, bananas, white rice, cheese, white toast, creamy peanut butter, yoghurt, noodles. • Obstruction may be caused by nuts, corn, popcorn, raw fruit + vegetables. • To prevent obstruction, chew high fiber foods carefully + avoid in large quantity. • May ↑ flatulence: beans, egg, beer, fish, broccoli, garlic, brussels sprouts, onion, carbonated drinks, spices, cabbage. • May ↑ odor: asparagus, egg, broccoli, fish, brussels sprouts, garlic, cabbage, onion, cauliflower, spices. • May ↓ odor: buttermilk, cranberry juice, parsley, yoghurt.
Fleming & Mortensen, 2011 UK	Colorectal surgeon	• Stoma nurse • Setting: not specified	Avoid/limit specific foods/drinks if cause problem	• May ↑/loosen output: beans, beer, caffeinated drinks, chocolate, leafy green vegetables, raw fruit + vegetables, spicy food, whole meal foods, cereal, alcohol, citrus fruit + juice. • May ↓/thicken output: applesauce, banana, boiled rice, cheese, smooth peanut butter, tapioca, white bread, potato, suet pudding, pasta. • May cause obstruction: mushroom, sweetcorn, potato skin, nuts, tomato skin, raw fruit skin, celery string. • May ↑ flatulence: beer, carbonated drinks, dried beans + peas, milk + milk products, onion, cabbage, broccoli, sprouts.

Author, year country	Author/s profession	Sources of diet advice	Dietary Modification	Dietary Recommendations
Fulham, 2008a UK	Stoma nurse	• Stoma nurse; ward nurse; dietitian (verbal) • Setting: hospital inpatient	Low fiber; high white starchy carbohydrates; supplement drinks; low caffeine; high salt; healthy, balanced diet; normal diet; ↑ meal frequency; chew well	**After surgery:** if appetite poor, nutritional supplement drinks + snacks can be beneficial. Sip supplements slowly as they can cause loose output. If signs of dehydration, consume fluids (not caffeinated or diet) + a salty snack e.g. crisps. Normal diet with considerations as follows: ○ Avoid drinking large volumes of fluid with meals. ○ To replace sodium losses, add an extra teaspoon of salt to food daily. • If high output, ↓ fiber intake. • Thickens output: potato, porridge, white rice, stewed apple, smooth peanut butter, just under-ripe banana, bread, crackers, crisps, marshmallows + Jelly Babies. • May cause obstruction: mushrooms, dried fruit, sweetcorn, coconut, nuts + seeds, popcorn, Chinese beansprouts, tough fruit + vegetable skins, orange pith, fibrous foods e.g. celery if not chewed thoroughly. • If ↑ flatulence, ↓ fiber intake.
Fulham, 2008b UK	Stoma nurse	• Nurse; ostomy associations (written) • Setting: hospital inpatient	Avoid specific foods if problem; healthy, balanced diet; chew well	• May cause blockage: sweetcorn, mushrooms, popcorn, coconut, nuts, beansprouts, dried fruit, tough fruit + vegetable skins. These foods may need to be avoided or chewed well.
Gabe & Slater, 2013 UK	Gastroenterologist; stoma nurse	• Stoma nurse; dietitian • Setting: hospital inpatient	Low fiber; high white starchy carbohydrates; high protein; high energy; supplement drinks; ↓ fluid intake	○ Protein, often provided in supplement drinks, improves healing. • To ↓ high stoma output a low fiber, high starch, high calorie diet is required. • Fluid restriction dependent on stoma output. Restrict hypotonic fluids to 500ml/d.

Author, year country	Author/s profession	Sources of diet advice	Dietary Modification	Dietary Recommendations
Gondal & Trivedi, 2013 USA	Doctor	• Surgeon; nutrition counsellor; nutritionist • Setting: hospital inpatient	Low fiber; high white starchy carbohydrates; low sugar; high salt; low caffeine; include specific foods; avoid specific foods/drinks	• ↑ stoma output: simple carbohydrates (e.g. honey, sugar, corn syrup, soda, chocolate, jam, jelly), sugar-free products containing sorbitol/mannitol/xylitol, caffeinated beverages (e.g. tea, coffee, cola), alcohol, fruit juice, dried fruit, frozen berries, coconut, high fiber foods (raw vegetables, corn, popcorn, potato skin, stir-fried vegetables, peas, beans, legumes, salad). • If stoma output ↑: • Avoid hypotonic fluids e.g. tea, coffee, alcohol, fruit juice. • Avoid high sugar foods. • Consume small, frequent meals. • ↑ starch + protein. • ↓ lactose to ↓ bloating + loose output. • Use salt liberally. • Include salty snacks like crackers, crisps, pretzels. • Avoid high fiber foods including skins. • Thickens/↓ stoma output: tapioca pudding, creamy peanut butter, almond butter, potato without skin, oatmeal, applesauce. Also, complex carbohydrates i.e. white pasta, white bread, grains, white rice, potato, fruits (apple, banana), vegetables without skin.
Goodey & Colman, 2016 UK	Stoma nurse	• Stoma nurse (verbal + printed) • Setting: hospital inpatient	High white starchy carbohydrates; avoid/limit specific foods/drinks; restrict hypotonic fluids; fluids separate to meals	• If stoma output ↑/watery: • Restrict hypotonic fluids e.g. tea, water, squash to ~1L/day. • ↑ starchy foods e.g. white bread, grain, white pasta, potatoes, root vegetables. • ↓ green leafy vegetables, fruit, fruit juice. • Avoid fluids within half an hour before/after a meal. • Consume 1L/day rehydration solution. • Avoid plain water. • ↓ tea/coffee. • Avoid carbonated drinks.
Hall, 2017 UK	Stoma nurse	• Stoma nurse • Setting: not specified	Avoid specific foods; avoid/limit specific foods if cause problem; ↓ meal size; chew well	○ Avoid sweetcorn + nuts. • • May ↑ flatulence: high intake of fruit, vegetables + pulses. • To ↓ flatulence: chew food well, avoid large meals, minimize amount of onion, mushrooms + green vegetables consumed at one meal. • Odor may be caused by fish.

Author, year country	Author/s profession	Sources of diet advice	Dietary Modification	Dietary Recommendations
Hall, 2018 UK	Stoma nurse	• Stoma nurse • Setting: not specified	Avoid specific foods/drinks; avoid/limit specific foods if cause problem; chew well	**Post-surgery:** start with plain food then gradually reintroduce other foods. ○ Avoid fizzy drinks. ○ Chew food well. ○ Chop + cook onions + mushrooms thoroughly. ○ Avoid sweetcorn + nuts. ○ Be cautious if eating skins. • Loose output +/or ↑ flatulence may be caused by vegetarian diets. • Flatulence, odor + pain may be caused by pulses + green vegetables.
Hanachi et al., 2012 France	Not specified	• Dietitian; nutritionist; doctor specializing in nutrition • Setting: not specified	Avoid/limit specific foods/drinks if cause problem; normal diet	**Particularly in first 1-2 months post-surgery**, consume ↑ volume of fluids + fluids containing salts. Low fiber diet or low-fat diet are unnecessary. Individual to adapt diet based on digestive symptoms + eating habits. • ↓ output: cheese, banana, blueberries, grapes, raisins, beetroot, cooked carrots, white bread, crackers, pasta, corn, white rice, potato, almonds, nuts, black tea, red wine, dark chocolate. • ↑ output: milk, fresh fruit, fruit juice, vegetables, prunes, grapes, cabbage, spinach, whole meal bread, wheat bran, oatmeal, fatty foods, flax seeds, alcoholic drinks, Coca Cola, beer, carbonated drinks, coffee, strong spices. • To prevent dehydration, consume solutions rich in bicarbonates. • ↓ odor + flatulence: yoghurt, cottage cheese, cranberries/cranberry juice, blueberries, spinach, parsley, fennel, anise/anise tea, cumin/cumin tea. • ↑ odor + flatulence: hard cheese, garlic, asparagus, artichoke, cabbage, mushroom, legumes, onion, turnip, salsify, some fish, grilled meat, processed meat, egg, beer, soft drinks, tea, coffee.

Author, year country	Author/s profession	Sources of diet advice	Dietary Modification	Dietary Recommendations
Kirkland-Kyhn et al., 2018 USA [Letter in response: McGlade, 2018]	Nurse	• Nurse (printed) • Setting: hospital inpatient	High fiber; high salt; avoid specific foods/drinks; avoid/limit specific foods if cause problem; healthy, balanced diet; normal diet; ↓ meal size; ↑ meal frequency; chew well	**~6-8wks post-surgery, after edema resolves:** transition from low-residue diet to normal diet. Introduce foods slowly. ○ Consume a balanced diet. • To help prevent watery output + flatulence, eat regularly. • To prevent dehydration: 1. Avoid high sugar drinks 2. ↑ water intake when drinking caffeinated drinks 3. Include high sodium + high fiber foods. [Letter in response to the article suggests that high fiber food should be avoided for 6-8 weeks after ileostomy surgery due to risk of blockage.] • If dehydrated, drink water mixed with electrolyte solution. • To prevent blockage: avoid foods that ↑ risk of blockage e.g. popcorn, mushroom, nuts; consume small, frequent meals; chew food well. • To prevent gas: avoid foods that produce gas e.g. beans, dairy products, onion.
Kwiatt & Kawata, 2013 USA	Colorectal surgeon	• Not specified • Setting: hospital inpatient	High fiber; low sugar; low fat	○ Avoid excessive consumption of hypotonic fluids e.g. water, fruit juice, soft drinks, tea, coffee. ○ Consume glucose-electrolyte solutions e.g. sports drinks. • • To prevent high output, ↓ intake of high fat + high sugar foods. • Thickens output: 20-30g/d fiber.
Martin & Vogel, 2012 USA	Colorectal surgeon	Not specified	Low fiber; high fiber; low sugar; low fat; low salt	**In first few months post-surgery,** consume low fiber diet due to small bowel edema. • • If high output, follow low sugar, low salt, low fat diet. A high fiber diet can be beneficial. • May ↓ output + thicken consistency: ↓ oral fluid intake. • May be visible in effluent: nuts, corn, other vegetables.

Author, year country	Author/s profession	Sources of diet advice	Dietary Modification	Dietary Recommendations
McDonough, 2013 USA	Dietitian	• Dietitian • Setting: hospital inpatient	Low fiber; low sugar; low caffeine; high salt; avoid/limit specific foods/drinks if cause problem; healthy, balanced diet; ↑ fluid intake; chew well; avoid fluids close to meals	**For 6-8 weeks post-surgery,** follow a low fiber diet. **After 6-8 weeks,** gradually return to a healthy, balanced diet. Reintroduce foods with high insoluble fiber one at a time to identify effect. • May cause ↑ output: high sugar intake, alcohol, caffeine, large amounts of hypertonic or hypotonic fluids. • Fiber does not need to be restricted but should not be excessive, to prevent ↑ output. • Consume fluids throughout the day with more between meals + less with meals to prevent ↑ stoma output. • To prevent dehydration: 500-750ml/day extra fluid; up to 1 extra teaspoon per day of sodium; further ↑ fluid + sodium intake if ↑ losses. • May thicken output: pasta, white bread, potato, cheese, white rice, marshmallow, pretzels, creamy peanut butter, applesauce, banana. • May cause obstruction: raw cabbage, Chinese vegetables, corn, raw celery, mushroom, coconut, apple peel, tomato, popcorn, dried fruit, nuts, grapes, orange, pineapple. • To prevent obstruction, chew food thoroughly. • May ↑ flatulence: chewing gum, drinking through a straw, carbonated drinks, long periods without eating, broccoli, garlic, onion, egg, fish, cabbage, brussels sprouts, legumes, cauliflower. • May ↑ odor: broccoli, garlic, onion, egg, fish, cabbage, brussels sprouts, asparagus, cauliflower, baked beans, strong cheese. • May ↓ odor: buttermilk, cranberry juice, orange juice, parsley, tomato juice, yoghurt, peppermint oil, spinach.
O'Connor & Dehavillande, 2016 UK	Dietitian	• Dietitian • Setting: hospital inpatient	Low fiber; low sugar; isotonic fluids	• If high output stoma, trial low fiber, low sugar diet + isotonic fluids.

Author, year country	Author/s profession	Sources of diet advice	Dietary Modification	Dietary Recommendations
Pachocka & Urbanik, 2016 Poland	Not specified	• Dietitian • Setting: hospital inpatient	Low insoluble fiber; high soluble fiber; low fat; high salt; high potassium; ↑ fluid intake; avoid/limit specific foods; avoid specific foods if cause problem; healthy, balanced diet; normal diet; ↓ meal size; ↑ meal frequency; chew well	**In post-operative period:** 1. Avoid/limit insoluble fiber 2. ↓ fat intake - avoid hard-to-digest animal fats 3. Avoid foods/drinks causing excessive gas production e.g. legumes, onion, cabbage, pear, leek, broad beans, broccoli, carbonated water 4. Avoid foods causing ↑ intestinal fermentation i.e. milk, honey, apple juice, pear, grapes 5. Avoid foods/drinks with laxative effect i.e. large amounts of coffee, beets, dried plum, hot spices 6. Consume foods high in soluble fiber. **For 6-8 weeks post-surgery:** avoid peas, nuts, corn, raw vegetables, mushrooms. ○ Reintroduce foods one at a time + try problematic foods twice with 2-day gap. ○ Small, frequent meals (4-6x/day). ○ Eat slowly + chew food well. ○ Drink between meals - still mineral water or electrolyte drinks/ diluted sports drinks are best. ○ ↑ fluid intake if consuming coffee or strong tea. ○ Prepare food using steaming, baking, stewing (without oil). Avoid frying, grilling, smoking, smoke-drying. • High, watery output prevented/managed by 1. limit insoluble fiber intake 2. ↑ soluble fiber. • Loose output can be caused by spicy + fried foods, alcohol, caffeinated drinks. • If mild diarrhea, 1. ↑ fluid intake to 2.5-3L water or rehydration solutions within 8-12 hours 2. consume white bread, cocoa, dried apple, banana, white rice, mint. • If stoma blockage experienced, ↓ or avoid difficult to digest foods e.g. celery, beans, cucumber, coconut, dried fruit, maize, cabbage, nuts, mushroom, green pepper. • Bloating foods to be avoided: animal fats, sweets, alcohol, spices, carbonated drinks, whole meal bread, thick groats.
Piras & Hurley, 2011 USA	Nurse	• Ward nurse; dietitian • Setting: hospital inpatient	Avoid/limit specific foods/drinks; chew well	○ Chew food well. ○ Avoid nuts, corn, popcorn. • ↓ odor-producing foods e.g. asparagus, cruciferous vegetables, eggs, spices. • ↓ gas-producing foods e.g. cruciferous vegetables, onion, carbonated drinks.

Author, year country	Author/s profession	Sources of diet advice	Dietary Modification	Dietary Recommendations
Rudoni & Russell, 2016 UK	Nurse	• Stoma care nurse; nurse • Setting: not specified	Avoid/limit specific drinks if cause problem; ↑ fluid intake; isotonic fluids	Advice for hydration especially during exercise: • Drinks that ↑ stoma output: strong coffee, alcohol, fizzy drinks, sugary drinks, strong fruit juice, caffeinated energy drinks, excessive amounts of plain water. • Recommended drinks for rehydration after exercise: milk, chocolate milkshake. • Recommend an electrolyte solution or hydration sports drink during + after exercise. Choose a sports drink with high sodium + potassium content + <4g glucose/100ml. • Avoid plain water during exercise. • Avoid sports drinks with high sugar content. • Consume a variety of drinks every day including squash, juice + electrolyte drinks. • Consume alcohol in moderation.
Schreiber, 2016 USA	Nurse	• Stoma care nurse; nurse • Setting: hospital inpatient	Avoid/limit specific foods/drinks if cause problem; ↑ fluid intake; chew well	**After initial period post-surgery,** few dietary restrictions. • ↑ risk of blockage: corn, celery, cabbage, nuts, popcorn, seeds. • Chew food well + ↑ fluid intake to prevent blockage. • ↑ gas: onion, broccoli, cruciferous vegetables, carbonated drinks, alcohol. • ↑ odor: onion, asparagus, cruciferous vegetables, egg, fish. • ↓ odor: yoghurt, parsley, buttermilk.
Slater, 2012 UK	Stoma nurse	• Dietitian • Setting: hospital inpatient	Low fiber; high white starchy carbohydrates; high protein; high energy; supplement drinks	↑ protein intake (often with supplement drinks) to improve healing. • May cause high output: high hypotonic fluid intake. • If high-output stoma, follow low fiber, high starch, high energy diet to ↓ output + replace nutritional losses.
Stankiewicz et al., 2019 Australia	Stoma nurse; dietitian	• Stoma nurse; dietitian; doctor • Setting: hospital inpatient + outpatient	Low fiber; avoid/limit non-isotonic drinks	Dietary aspects of protocol for management of high output: • Consume isotonic drinks. • Avoid tea, coffee, plain water, juices, high sugar drinks. • Avoid fluid intake with meals. • Temporary ↑ in salt intake. • Avoid high fiber foods.

Author, year country	Author/s profession	Sources of diet advice	Dietary Modification	Dietary Recommendations
St-Cyr & Gilbert, 2011 Canada	Stoma nurse	• Nurse; nutritionist • Setting: hospital inpatient + outpatient	Low fiber; high fiber; avoid specific foods; avoid specific foods if cause problem; high salt; high potassium; healthy, balanced diet; chew well	**Recommendations for post-operative period:** ○ Avoid high fiber foods including raw vegetables, nuts, seeds, + wholegrains for 6 weeks. ○ Eat slowly + chew well. ○ Reintroduce foods one at a time + record problematic foods. • To prevent dehydration: drink plenty; eat foods high in salt + potassium. **After post-operative healing period:** no dietary restrictions / healthy, balanced diet. • If loose output, consume plenty of fluids + high fiber foods that thicken output: • Thickens output: stewed apple, banana, cheese, marshmallow, pasta, noodles, buttermilk, creamy peanut butter, barley, white rice, tapioca, yoghurt, pretzel, chips, oat cereal, wholegrain cereal, potato, soda biscuits, white bread. • Softens output: alcohol, caffeinated drinks, fresh fruit, grape/apple/prune juice, prunes, green beans, spicy foods, fried food, spinach, sugary foods, chocolate, black liquorice, legumes. • May cause obstruction (avoid for 6 weeks then consume in moderation + chew well): sweetcorn, celery, Chinese vegetables, cabbage, grated coconut, raw pineapple, wholegrain cereals, potato peel, apple peel, peach skin, grape skin, dried apricot, dried banana, dried cranberries, raisins, peanuts, almonds, hazelnuts, cashews, melon seeds, pumpkin seeds, grape seeds, sausage, boloney sausage, pepperoni, salami, citrus fruit, beansprouts, mushroom, popcorn. • ↑ flatulence (foods/drinks): fizzy drinks, sparkling mineral water, beer, melon, cucumber, beans, pulses, peas, legumes, broccoli, cauliflower, brussels sprouts, Sauer kraut, sweet potato, turkey. • ↑ flatulence (behaviors): drinking with a straw, chewing gum, sucking sweets, eating with mouth open. • ↑ odor: fish, egg, onion, garlic, spicy food, cabbage, cauliflower, brussels sprouts, asparagus, broccoli, turnip, strong cheese.

Author, year country	Author/s profession	Sources of diet advice	Dietary Modification	Dietary Recommendations
Zeigler & Min, 2017 USA	Specialist nurse	• Stoma nurse; nurse • Setting: hospital inpatient + outpatient	Low fiber; avoid/limit specific foods/drinks if cause problem; normal diet; ↓ meal size; ↑ meal frequency; chew well	**For first 2 weeks post-surgery**: small, frequent meals + low fiber diet. **After first 2 weeks post-surgery:** most people can resume a normal diet. ○ Chew food thoroughly. • If loose output, the following may thicken output: applesauce, banana, rice, peanut butter, bread. • To avoid blockage: chew foods high in fiber thoroughly. • May ↑ flatulence: dairy products, onion, cabbage, broccoli, mushroom, beans, cucumber, alcohol. • To ↓ flatulence, avoid: carbonated drinks, drinking through a straw, chewing gum.

Abbreviations: C. diff, clostridium difficile; CI, confidence interval; d, day; FAP, familial adenomatous polyposis; FODMAP, fermentable oligo-, di-, mono-saccharides and polyols; g, grams; h, hour; HOS, high output stoma; IBD, inflammatory bowel disease; IQR, interquartile range; L, liters; ml, milliliters; oz, ounces; SD, standard deviation; SE, standard error; UC, ulcerative colitis; UK, United Kingdom; USA, United States of America; VAS, visual analogue scale; y, years; ↓, decrease; ↑, increase; +, and.

Appendix V

Tables of results

Abbreviations: CHO, carbohydrate; FODMAP, Fermentable Oligo-, Di-, Mono-saccharides And Polyols; RCT, randomized controlled trial; UK, United Kingdom; USA, United States of America.

31 research studies:

- 11 experimental – 4 RCTs, 4 non-randomized controlled trials, 3 trials without randomization or controls.
- 3 pre and post/single-arm studies (longitudinal cohorts)
- 1 longitudinal observational study (longitudinal cohort)
- 12 cross-sectional observational studies
- 4 qualitative studies

44 expert opinion articles:

- 2 expert consensus guidelines
- 42 opinion pieces

Number of research studies published by decade

Year of publication	Total research studies	Experimental studies	Pre-post studies	Observational studies	Qualitative studies
1961-1970	6	1	0	5	0
1971-1980	2	1	0	1	0
1981-1990	8	5	0	3	0
1991-2000	2	0	0	1	1
2001-2010	3	2	0	1	0
2011+	10	2	3	2	3

Number of research studies published by country

Country	Total research studies	Experimental studies	Pre and post studies	Observational studies	Qualitative studies
UK	11	3	0	5	3
USA	7	2	1	4	0
Australia	6	4	0	1	1
Sweden	2	1	0	1	0
Brazil	1	0	0	1	0
India	1	0	1	0	0
Poland	1	0	0	1	0
Romania	1	1	0	0	0
Spain	1	0	1	0	0

Number of expert opinion articles/guidelines published by country

Country	No. of expert opinion articles/guidelines
UK	23
USA	15
Turkey	2
Australia	1
Canada	1
France	1
Poland	1

Professions contributing as authors to expert opinion articles/guidelines

Profession	No. of expert opinion articles/guidelines	% of expert opinion articles/guidelines
Specialist nurse (including stoma nurses)	29	66
Nurse (no specialism specified)	7	16
Dietitian	5	11
Colorectal surgeon	5	11
Medical doctor (not specified as gastroenterologist)	4	9
Gastroenterologist	1	2
Surgeon (not specified as colorectal specialist)	1	2

Healthcare professionals reported in observational studies (n=1), pre-post studies (n=1) or qualitative studies (n=3) to be a provider of dietary advice to people with an ileostomy: stoma nurse, dietitian, colorectal surgeon, physician, ward nurse.

Nutrient modifications reported in experimental studies

1. Nutrient modifications associated with volume of stoma output

Nutrient modification	Number of articles	Positive (+) or negative (-) consequence	Timeframe of dietary modification
Decrease fluid intake	1	+	After healing
High fat	1	-	Not specified
Low fat	1	+	Not specified
High FODMAP	1	-	After healing
Low FODMAP	1	+	After healing
High refined CHO + high sucrose	1	+	After healing
High unrefined CHO + low sucrose	1	-	After healing
Low fiber	1	+	Post-operative

2. Nutrient modifications associated with consistency of stoma output

Nutrient modification	Number of articles	Positive (+) or negative (-) consequence	Timeframe of dietary modification
Loose, watery output			
Low FODMAP	1	+	After healing

3. Nutrient modifications associated with flatulence

Nutrient modification	Number of articles	Positive (+) or negative (-) consequence	Timeframe of dietary modification
High fiber	1	-	Not specified
Low fiber	2	+	Post-operative/ Not specified

4. Nutrient modifications associated with odor

Nutrient modification	Number of articles	Positive (+) or negative (-) consequence	Timeframe of dietary modification
Low fiber	1	+	Post-operative

5. Nutrient modifications associated with leakage – none

6. Nutrient modifications associated with blockage/obstruction

Nutrient modification	Number of articles	Positive (+) or negative (-) consequence	Timeframe of dietary modification
Low fiber	1	+	Post-operative

7. Nutrient modifications associated with pain in small intestine or stoma

Nutrient modification	Number of articles	Positive (+) or negative (-) consequence	Timeframe of dietary modification
High FODMAP	1	-	After healing
Low FODMAP	1	-	After healing

8. Nutrient modifications associated with food visible in output – none

9. Nutrient modifications associated with dehydration – none

10. Nutrient modifications associated with malnutrition

Nutrient modification	Number of articles	Positive (+) or negative (-) consequence	Timeframe of dietary modification
Low fiber	1	+	Post-operative

11. Nutrient modifications associated with unspecified symptoms/complications – none

Nutrient modifications reported in pre-post studies

1. Nutrient modifications associated with volume of stoma output

Nutrient modification	Number of articles	Positive (+) or negative (-) consequence	Timeframe of dietary modification
Alcohol	2	-	Post-operative/ Not specified

2. Nutrient modifications associated with consistency of stoma output

Nutrient modification	Number of articles	Positive (+) or negative (-) consequence	Timeframe of dietary modification
Loose, watery output			
High fat	1	-	Post-operative
Added sugar	1	-	Post-operative

3. Nutrient modifications associated with flatulence

Nutrient modification	Number of articles	Positive (+) or negative (-) consequence	Timeframe of dietary modification
Alcohol	1	-	Post-operative

4. Nutrient modifications associated with odor

Nutrient modification	Number of articles	Positive (+) or negative (-) consequence	Timeframe of dietary modification
Alcohol	1	-	Post-operative

5. Nutrient modifications associated with leakage - none

6. Nutrient modifications associated with blockage/obstruction

Nutrient modification	Number of articles	Positive (+) or negative (-) consequence	Timeframe of dietary modification
High insoluble fiber	1	-	Post-operative

7. Nutrient modifications associated with pain in small intestine or stoma - none

8. Nutrient modifications associated with food visible in output - none

9. Nutrient modifications associated with dehydration

Nutrient modification	Number of articles	Positive (+) or negative (-) consequence	Timeframe of dietary modification
Normal fluid intake	1	+	Post-operative
Rehydration fluid	1	+	Post-operative

10. Nutrient modifications associated with malnutrition - none

11. Nutrient modifications associated with unspecified symptoms/complications

Nutrient modification	Number of articles	Positive (+) or negative (-) consequence	Timeframe of dietary modification
Fat	1	-	Post-operative
Low fiber	1	+	Post-operative
High sodium	1	+	Post-operative
High potassium	1	+	Post-operative

Nutrient modifications reported in observational studies

1. Nutrient modifications associated with volume of stoma output

Nutrient modification	Number of articles	Positive (+) or negative (-) consequence	Timeframe of dietary modification
Alcohol	1	-	After healing
High fat	1	-	After healing

2. Nutrient modifications associated with consistency of stoma output

Nutrient modification	Number of articles	Positive (+) or negative (-) consequence	Timeframe of dietary modification
Loose, watery output			
Alcohol	1	-	After healing

3. Nutrient modifications associated with flatulence

Nutrient modification	Number of articles	Positive (+) or negative (-) consequence	Timeframe of dietary modification
Alcohol	1	-	After healing

4. Nutrient modifications associated with odor

Nutrient modification	Number of articles	Positive (+) or negative (-) consequence	Timeframe of dietary modification
Alcohol	1	-	After healing

5. Nutrient modifications associated with leakage

Nutrient modification	Number of articles	Positive (+) or negative (-) consequence	Timeframe of dietary modification
Fluids	1	-	After healing
High fat	1	-	After healing

6. Nutrient modifications associated with blockage/obstruction

Nutrient modification	Number of articles	Positive (+) or negative (-) consequence	Timeframe of dietary modification
High fiber	1	-	After healing
High residue	1	-	After healing

7. Nutrient modifications associated with pain in small intestine or stoma

Nutrient modification	Number of articles	Positive (+) or negative (-) consequence	Timeframe of dietary modification
Alcohol	1	-	After healing

8. Nutrient modifications associated with food visible in output – none

9. Nutrient modifications associated with dehydration

Nutrient modification	Number of articles	Positive (+) or negative (-) consequence	Timeframe of dietary modification
Increase fluid intake	1	+	After healing

10. Nutrient modifications associated with malnutrition – none

11. Nutrient modifications associated with unspecified symptoms/complications

Nutrient modification	Number of articles	Positive (+) or negative (-) consequence	Timeframe of dietary modification
Increase fluid intake	2	+	After healing
High fat	2	+/-	After healing
High fiber	1	-	After healing
High salt	1	+	After healing
Salt	1	+	After healing

Nutrient modifications reported in qualitative studies

1. Nutrient modifications associated with volume of stoma output – none

2. Nutrient modifications associated with consistency of stoma output

Nutrient modification	Number of articles	Positive (+) or negative (-) consequence	Timeframe of dietary modification
Loose, watery output			
Fiber	1	-	Not specified

3. Nutrient modifications associated with flatulence – none

4. Nutrient modifications associated with odor – none

5. Nutrient modifications associated with leakage – none

6. Nutrient modifications associated with blockage/obstruction

Nutrient modification	Number of articles	Positive (+) or negative (-) consequence	Timeframe of dietary modification
High fiber	2	-	Post-operative/ Not specified

7. Nutrient modifications associated with pain in small intestine or stoma – none

8. Nutrient modifications associated with food visible in output – none

9. Nutrient modifications associated with dehydration – none

10. Nutrient modifications associated with malnutrition – none

11. Nutrient modifications associated with unspecified symptoms/complications - none

Nutrient modifications reported in expert opinion articles/guidelines

1. Nutrient modifications associated with volume of stoma output

Nutrient modification	Number of articles	Positive (+) or negative (-) consequence	Timeframe of dietary modification
Alcohol	8	-	Post-operative/ After healing
Caffeine	5	-	Post-operative/ After healing
Complex CHO	1	+	Post-operative
Simple CHO	1	-	Not specified
Decrease simple CHO + increase complex CHO	1	+	After healing
Fructose-sweetened drinks	1	-	Not specified
High fat	3	-	Not specified
Low fat	1	+	Post-operative
High fiber	4	+/-	Post-operative/ Not specified
Low fiber	5	+	Post-operative/ After healing
High insoluble fiber	2	-	Post-operative/ After healing
High soluble fiber	1	+	Post-operative/ After healing
Soluble fiber	1	+	Not specified
High protein	1	+	Not specified
High sodium	1	+	Post-operative
Low salt	1	+	Post-operative
High starch	5	+	Post-operative/ After healing
High sugar	3	-	Not specified
Low sugar	2	+	Post-operative
High sugar drinks	2	-	Post-operative/ Not specified
Sugar	1	-	Not specified
Low lactose	1	+	Not specified
Decrease fluid intake	3	+	Post-operative/ After healing

Hypertonic fluid	1	-	Post-operative
Hypertonic fluid excess	1	-	Not specified
Hypotonic fluid	3	-	Post-operative/ After healing
Hypotonic fluid excess	2	-	Not specified
Isotonic fluid	1	+	Post-operative
Rehydration fluid	2	+	Post-operative/ After healing
Probiotics	1	+	Not specified
Mannitol	1	-	Not specified
Sorbitol	2	-	Not specified
Xylitol	1	-	Not specified

2. Nutrient modifications associated with consistency of stoma output

Nutrient modification	Number of articles	Positive (+) or negative (-) consequence	Timeframe of dietary modification
Loose, watery output			
Alcohol	7	-	Post-operative/ After healing
Caffeine	4	-	Post-operative/ After healing
High fat	1	-	Not specified
High fiber	3	+/-	Not specified/ After healing
Low fiber	2	+	Post-operative/ After healing
High insoluble fiber	2	-	Post-operative/ After healing
High soluble fiber	1	+	Post-operative/ After healing
Soluble fiber	1	+	Not specified
Carbohydrates	1	+	Post-operative/ After healing
High starch	1	+	Post-operative/ After healing
High sugar	1	-	Post-operative/ After healing
Decrease fluid intake	2	+	Post-operative/ After healing
Fructose-sweetened drinks	1	-	Not specified
Gelatine	2	+	Post-operative/ After healing
Thickener	1	+	Not specified
Vegetarian diet	1	-	Not specified
Supplements	1	-	Post-operative
Constipation			
Increase fluid intake	1	+	Post-operative/ After healing
High fiber	2	+	Post-operative/ After healing
Low fiber	1	-	Post-operative/ After healing

3. Nutrient modifications associated with flatulence

Nutrient modification	Number of articles	Positive (+) or negative (-) consequence	Timeframe of dietary modification
Alcohol	3	-	Post-operative/ After healing
High fat	1	-	Not specified
High fiber	1	-	Not specified
Probiotics	1	?	Not specified
Vegetarian diet	1	-	Not specified

4. Nutrient modifications associated with odor

Nutrient modification	Number of articles	Positive (+) or negative (-) consequence	Timeframe of dietary modification
High fat	1	-	Not specified

5. Nutrient modifications associated with leakage – none

6. Nutrient modifications associated with blockage/obstruction

Nutrient modification	Number of articles	Positive (+) or negative (-) consequence	Timeframe of dietary modification
Increase fluid intake	2	+	Post-operative/ After healing
Normal fluid intake	4	+	Post-operative/ After healing
High fiber	8	-	Post-operative/ After healing
Low fiber	1	+	Post-operative
High insoluble fiber	1	-	Post-operative
Insoluble fiber	1	-	Post-operative/ After healing

7. Nutrient modifications associated with pain in small intestine or stoma – none

8. Nutrient modifications associated with food visible in output – none

9. Nutrient modifications associated with dehydration

Nutrient modification	Number of articles	Positive (+) or negative (-) consequence	Timeframe of dietary modification
Alcohol	1	-	Not specified
Caffeine	3	-	Post-operative/ After healing
Increase fluid intake	4	+	Post-operative/ After healing
Normal fluid intake	8	+	Post-operative/ After healing
High fat	1	-	Not specified
High fiber	2	+/-	Post-operative/ After healing
Low fiber	1	+	Not specified
High potassium	2	+	Post-operative/ After healing
High sodium	2	+	Post-operative/

			After healing
High salt	6	+	Post-operative/ After healing
Salt	1	+	Not specified
Added salt	7	+	Post-operative/ After healing
High sugar	1	-	Not specified
High sugar drinks	3	-	Post-operative/ After healing
Hypertonic fluid	1	-	Not specified
Hypotonic fluid excess	1	-	Not specified
Isotonic fluid	1	+	Post-operative/ After healing
Rehydration fluid	12	+	Post-operative/ After healing

10. Nutrient modifications associated with malnutrition

Nutrient modification	Number of articles	Positive (+) or negative (-) consequence	Timeframe of dietary modification
Alcohol	1	-	Not specified
Caffeine	1	-	Not specified
Calcium	1	+	Not specified
High B12	1	+	Not specified
High energy	1	+	Not specified
High protein	1	+	Not specified
High soluble fiber	1	-	Not specified
High sugar	1	-	Not specified
Hypertonic fluid excess	1	-	Not specified
Hypotonic fluid excess	1	-	Not specified
Low fat sources of protein	1	+	Not specified
Salt	1	+	Not specified
Supplements	1	+	Post-operative

11. Nutrient modifications associated with unspecified symptoms/complications

Nutrient modification	Number of articles	Positive (+) or negative (-) consequence	Timeframe of dietary modification
Alcohol	2	-	Post-operative/ After healing
Caffeine	1	-	After healing
Animal fat	1	-	Post-operative/ After healing
Low fat	1	+	Post-operative
Increase fluid intake	1	+	Post-operative/ After healing
Normal fluid intake	1	+	Not specified
High fiber	1	-	Not specified
Low fiber	2	+	Post-operative
Low residue	2	+	Post-operative
High salt	1	+	Not specified
Added salt	2	+	Post-operative/ After healing
Rehydration fluid	2	+	Post-operative/ After healing

Specific foods/drinks reported in experimental studies

1. Foods and drinks associated with volume of stoma output

Food/drink	Number of articles	Positive (+) or negative (-) consequence	Timeframe of dietary modification
Apple juice	1	Neutral	After healing
Raw apple	1	Neutral	After healing
Baked beans	2	-	After healing
Banana	1	-	After healing
Beer	1	+	After healing
Cooked cabbage	1	-	After healing
Cantaloupe	1	Neutral	After healing
Cottage cheese	1	Neutral	After healing
Chilli	1	Neutral	After healing
Chocolate	1	Neutral	After healing
Cranberry juice	1	Neutral	After healing
Dates	1	Neutral	After healing
Fig juice	1	Neutral	After healing
Stewed fig	1	Neutral	After healing
Fizzy drink	1	Neutral	After healing
Fried food	1	Neutral	After healing
Grapes	1	-	After healing
Grape juice	1	Neutral	After healing
Marshmallows	2	+	After healing/ Not specified
Martini	1	Neutral	After healing
Milk	1	Neutral	After healing
Orange juice	1	Neutral	After healing
Raw peach	1	-	After healing
Peanut butter	1	Neutral	After healing
Black pepper	1	Neutral	After healing
Pork	1	Neutral	After healing
Prune juice	2	-	After healing
Raisins	1	-	After healing
Rye bread	1	Neutral	After healing
Strawberry	1	-	After healing
Watermelon	1	Neutral	After healing
Increase water	1	Neutral	After healing

2. Foods and drinks associated with consistency of stoma output

Food/drink	Number of articles	Positive (+) or negative (-) consequence	Timeframe of dietary modification
Loose, watery output			
Marshmallows	2	+/neutral	After healing/ Not specified

3. Foods and drinks associated with flatulence – none

4. Foods and drinks associated with odor – none

5. Foods and drinks associated with leakage – none

6. Foods and drinks associated with blockage/obstruction

Food/drink	Number of articles	Positive (+) or negative (-) consequence	Timeframe of dietary modification
All bran	1	-	After healing

7. Foods and drinks associated with pain in small intestine or stoma – none

8. Foods and drinks associated with food visible in output

Food/drink	Number of articles	Positive (+) or negative (-) consequence	Timeframe of dietary modification
Corn	1	-	After healing

9. Foods and drinks associated with dehydration – none

10. Foods and drinks associated with malnutrition – none

11. Foods and drinks associated with unspecified symptoms/complications – none

Specific foods/drinks reported in pre-post studies

1. Foods and drinks associated with volume of stoma output

Food/drink	Number of articles	Positive (+) or negative (-) consequence	Timeframe of dietary modification
Bran	1	-	Not specified
Cooked cabbage	1	-	Not specified
Coffee	1	-	Post-operative
Fresh fruit	1	-	Not specified
Fruit juice	1	-	Post-operative
Milk	1	-	Not specified
Prunes	1	-	Not specified
Raisins	1	-	Not specified
Spice	1	-	Not specified
Tea	1	-	Post-operative
Green leafy vegetables	1	-	Not specified
Raw vegetables	1	-	Not specified
Wholegrains	1	-	Not specified

2. Foods and drinks associated with consistency of stoma output

Food/drink	Number of articles	Positive (+) or negative (-) consequence	Timeframe of dietary modification
Loose, watery output			
Apple sauce	1	+	Post-operative/ After healing
Banana	2	+	Post-operative/ After healing
Cheese	1	+	Post-operative/ After healing
Coffee	1	+	Not specified
Dairy products	2	-	Post-operative
Fried fish	1	-	Post-operative
Cooked fruit	1	+	Not specified

Fresh fruit	1	+	Not specified
Grape juice	1	-	Post-operative
Hot drink	1	+	Not specified
Marshmallows	1	+	Not specified
Fried meat	1	-	Post-operative
Milk	1	-	Post-operative
Pasta	1	+	Post-operative/ After healing
Peanut butter	1	+	Not specified
Smooth peanut butter	1	+	Post-operative/ After healing
Potato	2	+	Post-operative/ After healing
Fried poultry	1	-	Post-operative
Prune juice	1	-	Post-operative
Rice	2	+	Post-operative/ After healing
Boiled rice	1	+	Not specified
Spice	1	-	Post-operative
Tapioca	1	+	Post-operative/ After healing
Toast	2	+	Post-operative/ After healing
Cooked vegetables	1	+	Not specified
Water	1	+	Not specified
Constipation			
Cooked fruit	1	+	Post-operative/ After healing
Fruit juice	1	+	Post-operative/ After healing
Cooked vegetables	1	+	Post-operative/ After healing

3. Foods and drinks associated with flatulence

Food/drink	**Number of articles**	**Positive (+) or negative (-) consequence**	**Timeframe of dietary modification**
Asparagus	1	-	Post-operative
Beans	2	-	Post-operative/ Not specified
Beer	1	-	Post-operative
Broccoli	1	-	Post-operative
Cabbage	1	-	Post-operative
Cauliflower	1	-	Post-operative
Corn	1	-	Post-operative
Cucumber	1	-	Not specified
Dairy products	1	-	Not specified
Egg	1	-	Post-operative
Fish	1	-	Post-operative
Fizzy drink	2	-	Post-operative/ After healing
Garlic	1	-	Post-operative
Leek	1	-	Post-operative
Milk	1	-	Not specified
Nuts	1	-	Not specified
Onion	1	-	Post-operative
Peanuts	1	-	Post-operative

Radish	1	-	Not specified
Soy	1	-	Not specified
Sprouts	1	-	Post-operative

4. Foods and drinks associated with odor

Food/drink	Number of articles	Positive (+) or negative (-) consequence	Timeframe of dietary modification
Asparagus	1	-	Post-operative
Baked beans	1	-	Not specified
Beans	1	-	Post-operative
Beer	1	-	Post-operative
Broccoli	1	-	Post-operative
Buttermilk	1	+	Post-operative/ After healing
Cabbage	1	-	Post-operative
Cauliflower	1	-	Post-operative
Strong cheese	1	-	Not specified
Corn	1	-	Post-operative
Cranberry juice	1	+	Post-operative/ After healing
Egg	2	-	Post-operative/ After healing
Fish	2	-	Post-operative/ After healing
Fizzy drink	1	-	Post-operative
Garlic	1	-	Post-operative
Kefir	1	+	Post-operative/ After healing
Leek	1	-	Post-operative
Meat	1	-	Post-operative/ After healing
Onion	1	-	Post-operative
Orange juice	1	+	Not specified
Parsley	1	+	Post-operative/ After healing
Peanut butter	1	-	Not specified
Peanuts	1	-	Post-operative
Poultry	1	-	Post-operative/ After healing
Sprouts	1	-	Post-operative
Tomato juice	1	+	Not specified
Yoghurt	1	+	Post-operative/ After healing

5. Foods and drinks associated with leakage - none

6. Foods and drinks associated with blockage/obstruction

Food/drink	Number of articles	Positive (+) or negative (-) consequence	Timeframe of dietary modification
Apple skin	1	-	Post-operative
Raw cabbage	1	-	Post-operative
Celery	1	-	Post-operative
Coconut	1	-	Post-operative
Coleslaw	1	-	Post-operative
Corn	1	-	Post-operative

Whole corn	1	-	Not specified
Dried fruit	1	-	Post-operative
Grapes	1	-	Post-operative
Mushroom	1	-	Not specified
Nuts	1	-	Post-operative
Orange	1	-	Not specified
Pineapple	1	-	Not specified
Popcorn	1	-	Not specified
Seeds	1	-	Not specified
Chinese vegetables	1	-	Not specified

7. Foods and drinks associated with pain in small intestine or stoma - none

8. Foods and drinks associated with food visible in output - none

9. Foods and drinks associated with dehydration - none

10. Foods and drinks associated with malnutrition - none

11. Foods and drinks associated with unspecified symptoms/complications

Food/drink	Number of articles	Positive (+) or negative (-) consequence	Timeframe of dietary modification
Beans	1	-	Post-operative
Fizzy drinks	1	-	Post-operative/ After healing
Raw fruit	1	-	Post-operative
Raw vegetables	1	-	Post-operative
Wholegrains	1	-	Post-operative

Specific foods/drinks reported in observational studies

1. Foods and drinks associated with volume of stoma output

Food/drink	Number of articles	Positive (+) or negative (-) consequence	Timeframe of dietary modification
Apple	1	-	After healing
Beans	2	-	After healing
Beer	1	-	After healing
Beetroot	2	-	After healing
Cabbage	1	-	After healing
Carrot	1	-	After healing
Cereal	2	-	After healing
Cucumber	1	-	After healing
Dairy products	1	-	After healing
Fried egg	1	-	After healing
Boiled fish	1	-	After healing
Fried fish	1	-	After healing
Grilled fish	1	-	After healing
Fizzy water	1	-	After healing
Fruit	1	-	After healing
Lettuce	1	-	After healing
Meat	1	-	After healing
Mince	1	-	After healing
Mushroom	2	-	After healing
Onion	2	-	After healing

Peach	1	-	After healing
Pear	1	-	After healing
Peas	1	-	After healing
Pineapple	1	-	After healing
Potatoes	1	-	After healing
New potatoes	1	-	After healing
Rhubarb	1	-	After healing
Sauces	1	-	After healing
Soup	1	-	After healing
Steak	1	-	After healing
Tomato	1	-	After healing
Turnip	1	-	After healing
Vegetables	1	-	After healing

2. Foods and drinks associated with consistency of stoma output

Food/drink	Number of articles	Positive (+) or negative (-) consequence	Timeframe of dietary modification
Loose, watery output			
Apple	1	-	After healing
Beans	1	-	After healing
Beer	1	-	After healing
Beetroot	1	-	After healing
Cabbage	1	-	After healing
Carrot	1	-	After healing
Cereal	2	-	After healing
Cheese	1	-	After healing
Cucumber	1	-	After healing
Dairy products	1	-	After healing
Egg	1	-	After healing
Fried egg	1	-	After healing
Fish	1	-	After healing
Boiled fish	1	-	After healing
Fried fish	1	-	After healing
Grilled fish	1	-	After healing
Fizzy drinks	1	-	After healing
Fizzy water	1	-	After healing
Fruit	2	-	After healing
Raw fruit	1	-	After healing
Lettuce	1	-	After healing
Milk	1	-	After healing
Mince	1	-	After healing
Mushroom	1	-	After healing
Onion	2	-	After healing
Peach	1	-	After healing
Pear	1	-	After healing
Peas	1	-	After healing
Pineapple	1	-	After healing
Potatoes	2	-	After healing
New potatoes	1	-	After healing
Rhubarb	1	-	After healing
Sauces	1	-	After healing
Shellfish	1	-	After healing
Soup	1	-	After healing
Spice	1	-	After healing
Steak	1	-	After healing
Tomato	1	-	After healing

Turnip	1	-	After healing
Green vegetables	1	-	After healing

3. Foods and drinks associated with flatulence

Food/drink	Number of articles	Positive (+) or negative (-) consequence	Timeframe of dietary modification
Apple	1	-	After healing
Baked beans	1	-	After healing
Beans	1	-	After healing
Beer	1	-	After healing
Beetroot	1	-	After healing
Cabbage	2	-	After healing
Carrot	1	-	After healing
Cauliflower	1	-	After healing
Cereal	1	-	After healing
Cheese	1	-	After healing
Cucumber	1	-	After healing
Dairy products	1	-	After healing
Egg	2	-	After healing
Fried egg	1	-	After healing
Boiled fish	1	-	After healing
Fried fish	1	-	After healing
Grilled fish	1	-	After healing
Fizzy drinks	2	-	After healing
Fizzy water	1	-	After healing
Fruit	2	-	After healing
Legumes	1	-	After healing
Lettuce	1	-	After healing
Mince	1	-	After healing
Mushroom	1	-	After healing
Onion	3	-	After healing
Peach	1	-	After healing
Peanuts	1	-	After healing
Pear	1	-	After healing
Peas	2	-	After healing
Pineapple	1	-	After healing
Potatoes	1	-	After healing
New potatoes	1	-	After healing
Rhubarb	1	-	After healing
Sauces	1	-	After healing
Soft drinks	1	-	After healing
Soup	1	-	After healing
Spice	1	-	After healing
Steak	1	-	After healing
Tomato	1	-	After healing
Turnip	1	-	After healing
Vegetables	1	-	After healing
Green vegetables	1	-	After healing

4. Foods and drinks associated with odor

Food/drink	Number of articles	Positive (+) or negative (-) consequence	Timeframe of dietary modification
Apple	1	-	After healing
Beans	3	-	After healing/

			Not specified
Beetroot	1	-	After healing
Cabbage	2	-	After healing/ Not specified
Carrot	1	-	After healing
Cereal	1	-	After healing
Cheese	1	-	After healing
Cucumber	1	-	After healing
Egg	2	-	After healing
Fried egg	1	-	After healing
Fish	1	-	After healing
Boiled fish	1	-	After healing
Fried fish	1	-	After healing
Grilled fish	1	-	After healing
Fizzy water	1	-	After healing
Lettuce	2	+/-	Not specified/ After healing
Meat	1	-	After healing
Mince	1	-	After healing
Mushroom	1	-	After healing
Onion	4	-	After healing/ Not specified
Parsley	1	+	Not specified
Peach	1	-	After healing
Pear	1	-	After healing
Peas	1	-	After healing
Pineapple	1	-	After healing
Potatoes	1	-	After healing
New potatoes	1	-	After healing
Rhubarb	1	-	After healing
Sauces	1	-	After healing
Soup	1	-	After healing
Spice	1	-	After healing
Spinach	1	+	Not specified
Steak	1	-	After healing
Tomato	1	-	After healing
Turnip	1	-	After healing
Vegetables	1	-	After healing
Green vegetables	1	-	After healing

5. Foods and drinks associated with leakage

Food/drink	Number of articles	Positive (+) or negative (-) consequence	Timeframe of dietary modification
Corn	1	-	After healing
Fruit	1	-	After healing
Nuts	1	-	After healing
Green leafy vegetables	1	-	After healing

6. Foods and drinks associated with blockage/obstruction

Food/drink	Number of articles	Positive (+) or negative (-) consequence	Timeframe of dietary modification
Apple skin	1	-	After healing
Bran	1	-	After healing
Lasagne	1	-	After healing

Nuts	2	-	After healing
Orange pith	1	-	After healing
Pips	1	-	After healing
Popcorn	1	-	After healing
Skins	1	-	After healing
Sweetcorn	1	-	After healing

7. Foods and drinks associated with pain in small intestine or stoma

Food/drink	Number of articles	Positive (+) or negative (-) consequence	Timeframe of dietary modification
Apple	1	-	After healing
Beans	1	-	After healing
Beetroot	1	-	After healing
Cabbage	1	-	After healing
Carrot	1	-	After healing
Cereal	1	-	After healing
Cucumber	1	-	After healing
Fried egg	1	-	After healing
Boiled fish	1	-	After healing
Fried fish	1	-	After healing
Grilled fish	1	-	After healing
Fizzy water	1	-	After healing
Fruit skin	1	-	After healing
Lettuce	1	-	After healing
Mince	1	-	After healing
Mushrooms	1	-	After healing
Nuts	2	-	After healing
Onion	1	-	After healing
Peach	1	-	After healing
Pear	1	-	After healing
Peas	1	-	After healing
Pineapple	1	-	After healing
Pips	1	-	After healing
Potatoes	1	-	After healing
New potatoes	1	-	After healing
Rhubarb	1	-	After healing
Sauces	1	-	After healing
Skin	1	-	After healing
Soup	1	-	After healing
Steak	1	-	After healing
Tomato	1	-	After healing
Turnip	1	-	After healing
Other vegetables	1	-	After healing

8. Foods and drinks associated with food visible in output

Food/drink	Number of articles	Positive (+) or negative (-) consequence	Timeframe of dietary modification
Raw cabbage	1	-	After healing
Raw carrot	1	-	After healing
Currants	1	-	After healing
Fruit pips	1	-	After healing
Fruit pith	1	-	After healing
Fruit skin	1	-	After healing
Lettuce	1	-	After healing

Mushrooms	1	-	After healing
Nuts	2	-	After healing
Peas	1	-	After healing
Raisins	1	-	After healing
Seeds	1	-	After healing
Sultanas	1	-	After healing
Sweetcorn	1	-	After healing

9. Foods and drinks associated with dehydration – none

10. Foods and drinks associated with malnutrition – none

11. Foods and drinks associated with unspecified symptoms/complications

Food/drink	Number of articles	Positive (+) or negative (-) consequence	Timeframe of dietary modification
Asparagus	1	-	After healing
Banana	1	-	After healing
Beans	1	-	After healing
Berries	1	-	After healing
Bread - small portion	1	+	After healing
Broccoli	1	-	After healing
Cabbage	2	-	After healing
Carrot	2	-	After healing
Cauliflower	1	-	After healing
Celery	1	-	After healing
Cereal	1	-	After healing
Cheese – small portion	1	+	After healing
Coconut	2	-	After healing
Condiments	1	-	After healing
Corn	2	-	After healing
Dairy products	1	-	After healing
Egg	2	-	After healing
Fish	1	-	After healing
Fizzy drinks	1	-	After healing
Fruit	3	-	After healing
Dried fruit	1	-	After healing
Raw fruit	1	-	After healing
Fruit seeds	1	-	After healing
Fruit skin	1	-	After healing
Garlic	1	-	After healing
Grapes	1	-	After healing
Ice-cream	1	-	After healing
Lettuce	2	-	After healing
Red meat	1	-	After healing
Melon	1	-	After healing
Milk	1	+	After healing
Mushrooms	2	-	After healing
Nuts	3	-	After healing
Onion	2	-	After healing
Orange	2	-	After healing
Parsley	1	-	After healing
Peach	1	-	After healing
Peanuts	1	-	After healing
Peas	2	-	After healing
Hot pepper	1	-	After healing
Pickles	1	-	After healing

Pineapple	2	-	After healing
Popcorn	2	-	After healing
Potatoes	2	+/-	After healing
Potato – small portion	1	+	After healing
Rice	1	-	After healing
Seeds	1	-	After healing
Shellfish	1	-	After healing
Skin	1	-	After healing
Soup	1	+	After healing
Spice	3	-	After healing
Spinach	1	-	After healing
Sprouts	1	-	After healing
Steak	1	-	After healing
Stew	1	-	After healing
Vegetables	2	-	After healing
Chinese vegetables	1	-	After healing
Raw vegetables	1	-	After healing

Specific foods/drinks reported in qualitative studies

1. Foods and drinks associated with volume of stoma output – none

2. Foods and drinks associated with consistency of stoma output

Food/drink	Number of articles	Positive (+) or negative (-) consequence	Timeframe of dietary modification
Loose, watery output			
Baked beans	1	+	Not specified
Banana	1	-	Not specified
Brown bread	1	-	Not specified
Fruit	1	-	Not specified
Onion	1	-	Post-operative
Orange	1	-	Post-operative

3. Foods and drinks associated with flatulence

Food/drink	Number of articles	Positive (+) or negative (-) consequence	Timeframe of dietary modification
Bean sprouts	1	-	Not specified

4. Foods and drinks associated with odor – none

5. Foods and drinks associated with leakage – none

6. Foods and drinks associated with blockage/obstruction

Food/drink	Number of articles	Positive (+) or negative (-) consequence	Timeframe of dietary modification
Apple skin	1	-	Post-operative
Grapefruit pith	1	-	Post-operative
Nuts	1	-	Post-operative
Pureed vegetables	1	+	Post-operative
Vegetable stalks	1	-	Post-operative

7. Foods and drinks associated with pain in small intestine or stoma

Food/drink	Number of articles	Positive (+) or negative (-) consequence	Timeframe of dietary modification
Curry	1	-	Not specified
Milk	1	-	Not specified
Peanuts	1	-	Not specified

8. Foods and drinks associated with food visible in output – none

9. Foods and drinks associated with dehydration – none

10. Foods and drinks associated with malnutrition – none

11. Foods and drinks associated with unspecified symptoms/complications

Food/drink	Number of articles	Positive (+) or negative (-) consequence	Timeframe of dietary modification
Banana	1	-	Not specified
Curry	1	-	After healing
Fried food	1	-	Post-operative
Lettuce	1	-	Not specified

Specific foods/drinks reported in expert opinion articles/guidelines

1. Foods and drinks associated with volume of stoma output

Food/drink	Number of articles	Positive (+) or negative (-) consequence	Timeframe of dietary modification
Almond butter	1	+	Not specified
Apple	2	+	Post-operative/ After healing
Dried apple	1	+	Post-operative/ After healing
Grated apple	1	+	Post-operative/ After healing
Apple juice	2	-	Not specified
Applesauce	6	+	Post-operative/ After healing
Baked beans	1	-	Not specified
Beans	4	-	Post-operative/ After healing
Banana	7	+	Post-operative/ After healing
Beer	3	-	Not specified
Beets	1	-	Post-operative
Frozen berries	1	-	Not specified
Biscuits	1	-	Post-operative/ After healing
Bran	3	-	Post-operative/ After healing
Brown bread	4	-	Post-operative/ After healing
White bread	6	+	Post-operative/ After healing
Broth (meat/chicken)	1	-	Post-operative/

			After healing
Cabbage	1	-	Not specified
Cooked cabbage	1	-	Post-operative/ After healing
Carrot	1	+	Post-operative/ After healing
Cooked carrot	1	+	Post-operative/ After healing
Cereal	2	-	Not specified
Cheese	2	+	Not specified
Chocolate	4	-	Not specified
Cocoa	1	+	Post-operative/ After healing
Coconut	1	-	Not specified
Coffee	4	-	Post-operative/ After healing
Excessive consumption of coffee	1	-	Post-operative
Strong coffee	1	-	Not specified
Cola	2	-	Not specified
Corn	1	-	Not specified
Corn syrup	1	-	Not specified
Dairy products	2	-	After healing/ Not specified
Fizzy drinks	3	-	Post-operative/ After healing
Flax seeds	1	-	Not specified
Fried food	3	-	Post-operative/ After healing
Fruit	2	-	Post-operative/ After healing
Citrus fruit	2	-	Not specified
Dried fruit	2	-	Post-operative/ After healing
Fresh fruit	2	-	Post-operative/ After healing
Raw fruit	2	-	Not specified
Fruit juice	4	+/-	Post-operative/ After healing
Fresh fruit juice	1	-	Not specified
Fruit juice pulp	1	-	Not specified
Strong fruit juice	1	-	Not specified
Fruit seeds	1	-	Post-operative/ After healing
Fruit skin	1	-	Post-operative/ After healing
Grapes	1	-	Not specified
Honey	1	-	Not specified
Jam	1	-	Not specified
Jelly	1	-	Not specified
Legumes	1	-	Not specified
Liquorice	1	-	Not specified
Milk	2	-	Post-operative/ After healing
Mint	1	+	Post-operative/ After healing
Molasses	1	-	Not specified
Noodles	1	+	Post-operative/ After healing

Oatmeal	3	+/-	Post-operative/ After healing
Oil	1	-	Post-operative/ After healing
Pasta	3	+	Post-operative/ After healing
White pasta	2	+	Post-operative/ After healing
Pastries	1	-	Post-operative/ After healing
Peach	1	+	Post-operative/ After healing
Peanut butter	2	+	Post-operative/ After healing
Smooth peanut butter	3	+	Not specified
Peas	1	-	Not specified
Dried plum	1	-	Post-operative
Popcorn	1	-	Not specified
Porridge	1	+	Post-operative/ After healing
Potatoes	4	+	Post-operative/ After healing
Mashed potato	1	+	Post-operative/ After healing
Potato skin	1	-	Not specified
Prunes	2	-	Post-operative/ After healing
Prune juice	1	-	Not specified
Pumpkin	1	+	Post-operative/ After healing
Quince	1	+	Post-operative/ After healing
Raisins	1	-	Post-operative/ After healing
Boiled rice	3	+	Post-operative/ After healing
Brown rice	1	-	Post-operative/ After healing
White rice	3	+	Post-operative/ After healing
Salad	1	-	Not specified
Skins	2	-	Not specified
Soda	1	-	Not specified
Spice	6	-	Post-operative/ After healing
Hot spice	2	-	Post-operative/ After healing
Spinach	1	-	Not specified
Squash	2	+/-	Post-operative/ After healing
Suet pudding	2	+	Not specified
Brown sugar	1	-	Not specified
Sugar free candy	1	-	Not specified
Tapioca	4	+	Post-operative/ After healing
Tarhana soup	1	+	Post-operative/ After healing
Tea	2	-	Post-operative/ After healing

Thick cereal	1	-	Post-operative/ After healing
Toast	2	+	Post-operative/ After healing
Tomato	2	+/-	Post-operative/ After healing
Vegetables	1	-	Post-operative/ After healing
Raw vegetables	4	-	Post-operative/ After healing
Fresh vegetables	2	-	Post-operative/ After healing
Fried vegetables	1	-	Not specified
Green, leafy vegetables	4	-	Post-operative/ After healing
Vegetables without skin	1	+	Not specified
Root vegetables	1	+	Post-operative/ After healing
Water	2	-	Post-operative/ After healing
Wheat	1	-	Post-operative/ After healing
Grains	2	+	Post-operative/ After healing
Wholegrains	4	-	Post-operative/ After healing
Wholegrain cereal	1	-	Post-operative/ After healing
Yoghurt	1	+	Post-operative/ After healing
Yoghurt soup	1	+	Post-operative/ After healing

2. Foods and drinks associated with consistency of stoma output

Food/drink	**Number of articles**	**Positive (+) or negative (-) consequence**	**Timeframe of dietary modification**
Loose, watery output			
Almonds	1	+	Not specified
American hard gums	1	+	Not specified
Apple	2	+	Post-operative/ After healing
Dried apple	1	+	Post-operative/ After healing
Grated apple	1	+	Post-operative/ After healing
Stewed apple	3	+	Post-operative/ After healing
Apple juice	2	-	Post-operative/ After healing
Applesauce	9	+	Post-operative/ After healing
Banana	14	+	Post-operative/ After healing
Under-ripe banana	1	+	Not specified
Barley	1	+	Post-operative/ After healing
Beans	2	-	Not specified

Green beans	1	-	Post-operative/ After healing
Beer	2	-	Not specified
Beetroot	1	+	Not specified
Biscuits	1	+	Not specified
Blueberries	1	+	Not specified
Bran	1	-	Post-operative/ After healing
Bread	6	+	Post-operative/ Not specified
Brown bread	3	-	Post-operative/ After healing
White bread	10	+	Post-operative/ After healing
Buttermilk	1	+	Post-operative/ After healing
Cooked cabbage	1	-	Post-operative/ After healing
Sponge cake	1	+	Not specified
Carrot	2	+	Post-operative/ After healing
Cooked carrot	2	+	Post-operative/ After healing
Cereal	2	-	Not specified
Cheese	8	+	Post-operative/ After healing
Chocolate	3	-	Post-operative/ After healing
Dark chocolate	1	+	Not specified
Cocoa	1	+	Post-operative/ After healing
Corn	1	+	Not specified
Crackers	7	+	Post-operative/ After healing
Crisps	4	+	Post-operative/ After healing
Fried food	3	-	Post-operative/ After healing
Citrus fruit	2	-	Not specified
Dried fruit	1	-	Post-operative/ After healing
Raw fruit	2	-	Not specified
Fresh fruit	2	-	Post-operative/ After healing
Fruit juice	1	-	Not specified
Fruit pastilles	1	+	Not specified
Fruit seeds	1	-	Post-operative/ After healing
Fruit skin	1	-	Post-operative/ After healing
Grapes	1	+	Not specified
Grape juice	1	-	Post-operative/ After healing
Gummy bears	1	+	Not specified
Jelly	1	+	Not specified
Jelly Babies	3	+	Not specified
Legumes	1	-	Post-operative/ After healing

Liquorice	1	-	Post-operative/ After healing
Marshmallows	6	+	Post-operative/ After healing
Milkshake	1	+	Not specified
Mint	1	+	Post-operative/ After healing
Noodles	4	+	Post-operative/ After healing
Nuts	1	+	Not specified
Oatmeal	3	+	Post-operative/ After healing
Parsnip	1	+	Not specified
Pasta	8	+	Post-operative/ After healing
White pasta	2	+	Post-operative/ After healing
Peach	1	+	Post-operative/ After healing
Peanut butter	5	+	Post-operative/ After healing
Smooth peanut butter	7	+	Post-operative/ After healing
Percy Pigs	1	+	Not specified
Plantain	1	+	Not specified
Porridge	2	+	Post-operative/ After healing
Potato	11	+	Post-operative/ After healing
Mashed potato	1	+	Post-operative/ After healing
Pretzel	3	+	Post-operative/ After healing
Prune	2	-	Post-operative/ After healing
Prune juice	1	-	Post-operative/ After healing
Pumpkin	2	+	Post-operative/ After healing
Quince	1	+	Post-operative/ After healing
Raisins	2	+/-	Post-operative/ After healing
Rice	4	+	Post-operative/ Not specified
Boiled rice	2	+	Not specified
Brown rice	1	-	Post-operative/ After healing
White rice	10	+	Post-operative/ After healing
Spice	5	-	Post-operative/ After healing
Hot spice	1	-	Post-operative/ After healing
Spinach	1	-	Post-operative/ After healing
Suet pudding	2	+	Not specified
Sugar free candy	1	-	Not specified
Sweet potato	1	+	Not specified

Tapioca	5	+	Post-operative/ After healing
Tarhana soup	1	+	Post-operative/ After healing
Black tea	1	+	Not specified
Thick cereal	1	-	Post-operative/ After healing
Toast	2	+	Post-operative/ After healing
White toast	1	+	Not specified
Tomato	1	+	Post-operative/ After healing
Fresh vegetables	1	-	Post-operative/ After healing
Green, leafy vegetables	2	-	Not specified
Vegetables without skin	1	+	Not specified
Raw vegetables	3	-	Post-operative/ After healing
Root vegetables	1	+	Not specified
Wheat	1	-	Post-operative/ After healing
Grains	1	+	Not specified
Wholegrains	2	-	Not specified
Wholegrain cereal	2	+/-	Post-operative/ After healing
Red wine	1	+	Not specified
Yam	1	+	Not specified
Yoghurt	4	+	Post-operative/ After healing
Frozen yoghurt	1	+	Not specified
Yoghurt soup	1	+	Post-operative/ After healing
Constipation			
Brown bread	1	+	Post-operative/ After healing
Buttermilk	1	+	Post-operative/ After healing
Coffee	1	+	Post-operative/ After healing
Cooked fruit	1	+	Post-operative/ After healing
Fresh fruit	2	+	Post-operative/ After healing
Fruit juice	1	+	Post-operative/ After healing
Vegetables	2	+	Post-operative/ After healing
Water	1	+	Post-operative/ After healing
Wholegrains	1	+	Post-operative/ After healing
Wholegrain cereal	1	+	Post-operative/ After healing
Yoghurt	1	+	Post-operative/ After healing

3. Foods and drinks associated with flatulence

Food/drink	Number of articles	Positive (+) or negative (-) consequence	Timeframe of dietary modification
Anise	1	+	Not specified
Anise tea	1	+	Not specified
Apple	1	-	Not specified
Apple juice	1	-	Post-operative
Artichoke	1	-	Not specified
Asparagus	2	-	Not specified
Beans	11	-	Post-operative/ After healing
Broad beans	2	-	Post-operative/ After healing
Beer	8	-	Post-operative/ After healing
Blueberries	1	+	Not specified
Broccoli	10	-	Post-operative/ After healing
Cabbage	9	-	Post-operative/ After healing
Red cabbage	1	-	Post-operative/ After healing
White cabbage	1	-	Post-operative/ After healing
Caraway	1	+	Not specified
Cauliflower	5	-	Post-operative/ After healing
Cottage cheese	1	+	Not specified
Hard cheese	1	-	Not specified
Coffee	1	-	Not specified
Corn	1	-	Post-operative/ After healing
Cranberry	1	+	Not specified
Cranberry juice	1	+	Not specified
Cucumber	4	-	Post-operative/ After healing
Cumin	1	+	Not specified
Cumin tea	1	+	Not specified
Dairy products	7	-	Post-operative/ After healing
Egg	4	-	Not specified
Hard-boiled egg	1	-	Not specified
Fennel	1	+	Not specified
Fish	5	-	Not specified
Fizzy drinks	12	-	Post-operative/ After healing
Fizzy water	2	-	Post-operative/ After healing
Excessive consumption of fruit	1	-	Not specified
Garlic	4	-	Not specified
Grapes	1	-	Post-operative
Honey	1	-	Post-operative
Leek	1	-	Post-operative
Legumes	3	-	Post-operative/ After healing

Limited total quantity of onion, mushroom + green vegetables at one meal	1	+	Not specified
Grilled meat	1	-	Not specified
Processed meat	1	-	Not specified
Melon	1	-	Post-operative/ After healing
Milk	2	-	Not specified
Mushrooms	2	-	Not specified
Nuts	2	-	Post-operative/ After healing
Onion	13	-	Post-operative/ After healing
Parsley	1	+	Not specified
Pear	1	-	Post-operative
Peas	3	-	Post-operative/ After healing
Pepper	1	-	Post-operative/ After healing
Pulses	2	-	Not specified
Excessive consumption of pulses	1	-	Not specified
Radish	2	-	Post-operative/ After healing
Salsify	1	-	Not specified
Sauerkraut	1	-	Post-operative/ After healing
Soft drinks	2	-	Post-operative/ After healing
Soy	2	-	Post-operative/ After healing
Spice	2	-	Not specified
Spinach	1	+	Not specified
Sprouts	7	-	Post-operative/ After healing
Sweet potato	1	-	Post-operative/ After healing
Tea	1	-	Not specified
Turkey	1	-	Post-operative/ After healing
Turnip	2	-	Not specified
Turnip juice	1	-	Post-operative/ After healing
Cruciferous vegetables	2	-	Not specified
Excessive consumption of vegetables	1	-	Not specified
Green vegetables	1	-	Not specified
Yoghurt	1	+	Not specified

4. Foods and drinks associated with odor

Food/drink	Number of articles	Positive (+) or negative (-) consequence	Timeframe of dietary modification
Anise	1	+	Not specified
Anise tea	1	+	Not specified
Apple	1	-	Not specified
Artichoke	1	-	Not specified
Asparagus	10	-	Post-operative/ After healing

Baked beans	1	-	Not specified
Beans	3	-	Post-operative/ After healing
Beer	1	-	Not specified
Blueberries	1	+	Not specified
Broccoli	6	-	Post-operative/ After healing
Butter	1	+	Post-operative/ After healing
Buttermilk	5	+	Post-operative/ After healing
Cabbage	7	-	Post-operative/ After healing
Caraway	1	+	Not specified
Cauliflower	6	-	Post-operative/ After healing
Celery	1	-	Post-operative/ After healing
Cheese	2	-	Post-operative/ After healing
Cottage cheese	1	+	Not specified
Hard cheese	1	-	Not specified
Rennet cheese	1	-	Post-operative/ After healing
Strong cheese	2	-	Post-operative/ After healing
Coffee	1	-	Not specified
Cranberry	2	+	Post-operative/ After healing
Cranberry juice	6	+	Post-operative/ After healing
Cucumber	2	-	Post-operative/ After healing
Cumin	1	+	Not specified
Cumin tea	1	+	Not specified
Dairy products	1	-	Not specified
Egg	11	-	Post-operative/ After healing
Fennel	1	+	Not specified
Fish	10	-	Post-operative/ After healing
Fizzy drink	1	-	Not specified
Garlic	8	-	Post-operative/ After healing
Leek	1	-	Post-operative/ After healing
Legumes	1	-	Not specified
Lettuce	1	+	Post-operative/ After healing
Marshmallow	1	+	Not specified
Grilled meat	1	-	Not specified
Processed meat	1	-	Not specified
Mushroom	1	-	Not specified
Onion	8	-	Post-operative/ After healing
Orange juice	2	+	Not specified
Parsley	7	+	Post-operative/ After healing

Fresh parsley	1	+	Post-operative/ After healing
Peanut butter	1	-	Post-operative/ After healing
Peppermint	2	+	Post-operative/ After healing
Pulses	1	-	Not specified
Salsify	1	-	Not specified
Sauerkraut	1	-	Post-operative/ After healing
Soft drink	1	-	Not specified
Spice	3	-	Post-operative/ After healing
Spinach	3	+	Not specified
Sprouts	5	-	Post-operative/ After healing
Tea	1	-	Not specified
Tomato juice	1	+	Not specified
Turnip	3	-	Post-operative/ After healing
Cruciferous vegetables	2	-	Not specified
Green vegetables	2	-	Post-operative/ After healing
Yoghurt	8	+	Post-operative/ After healing

5. Foods and drinks associated with leakage – none

6. Foods and drinks associated with blockage/obstruction

Food/drink	**Number of articles**	**Positive (+) or negative (-) consequence**	**Timeframe of dietary modification**
Almonds	1	-	Post-operative/ After healing
Apple	2	-	Post-operative/ After healing
Apple skin	5	-	Post-operative/ After healing
Dried apricot	1	-	Post-operative/ After healing
Artichoke	1	-	Post-operative/ After healing
Asparagus	3	-	Post-operative/ After healing
Dried banana	1	-	Post-operative/ After healing
Bean sprouts	4	-	Post-operative/ After healing
Beans	1	-	Post-operative/ After healing
Broad beans	1	-	Not specified
Soya beans	1	-	Not specified
Boloney sausage	1	-	Post-operative/ After healing
Cabbage	5	-	Post-operative/ After healing
Raw cabbage	3	-	Post-operative/ After healing

Celery	11	-	Post-operative/ After healing
Raw celery	1	-	Not specified
Coconut	9	-	Post-operative/ After healing
Grated coconut	1	-	Post-operative/ After healing
Corn	7	-	Post-operative/ After healing
Whole corn	1	-	Not specified
Popcorn	11	-	Post-operative/ After healing
Sweetcorn	12	-	Post-operative/ After healing
Dried cranberry	1	-	Post-operative/ After healing
Cucumber	1	-	Post-operative/ After healing
Dried fruit	12	-	Post-operative/ After healing
Citrus fruit	1	-	Post-operative/ After healing
Raw fruit	1	-	Not specified
Raw fruit skin	2	-	Not specified
Fruit seeds	1	-	Post-operative/ After healing
Fruit skin	6	-	Not specified
Fruit chewed well	1	+	After healing
Tinned/cooked fruit	1	+	After healing
Grapes	1	-	Not specified
Grape seeds	1	-	Post-operative/ After healing
Grape skin	2	-	Post-operative/ After healing
Hazelnuts	1	-	Post-operative/ After healing
Leaf wrap	1	-	Post-operative/ After healing
Meat casing	1	-	Not specified
Melon seeds	1	-	Post-operative/ After healing
Mushrooms	15	-	Post-operative/ After healing
Nuts	20	-	Post-operative/ After healing
Cashew nuts	1	-	Post-operative/ After healing
Peanuts	1	-	Post-operative/ After healing
Pine nuts	1	-	Post-operative/ After healing
Onion	1	-	Not specified
Orange	2	-	Post-operative/ After healing
Orange peel	1	-	Post-operative/ After healing
Orange pith	2	-	Not specified
Peach skin	1	-	Post-operative/ After healing

Peas	3	-	Post-operative/ After healing
Garden peas	1	-	Not specified
Mange tout peas	1	-	Post-operative/ After healing
Peel	1	-	Post-operative/ After healing
Pips	1	-	After healing
Green pepper	1	-	Post-operative/ After healing
Pepperoni	1	-	Post-operative/ After healing
Pineapple	3	-	Post-operative/ After healing
Raw pineapple	1	-	Post-operative/ After healing
Pomegranate	2	-	Post-operative/ After healing
Potato skin	4	-	Post-operative/ After healing
Pumpkin seeds	1	-	Post-operative/ After healing
Radish	1	-	Post-operative/ After healing
Raisins	2	-	Post-operative/ After healing
Raspberry	1	-	Post-operative/ After healing
Salad	2	-	Post-operative/ Not specified
Green salad	1	-	Post-operative/ After healing
Salami	1	-	Post-operative/ After healing
Sausage	1	-	Post-operative/ After healing
Seeds	4	-	Post-operative/ After healing
Large seeds	1	-	Not specified
Skins	2	-	After healing/ Not specified
Strawberry	1	-	Post-operative/ After healing
Sunflower seeds	1	-	Post-operative/ After healing
Tomato	1	-	Not specified
Tomato skin	3	-	Post-operative/ After healing
Chinese vegetables	4	-	Post-operative/ After healing
Raw vegetables	5	-	Post-operative/ After healing
Stringy vegetables	1	-	Not specified
Vegetables chewed well	1	+	After healing
Tinned/cooked vegetables	1	+	After healing
Vegetable skin	5	-	Not specified
Walnuts	1	-	Post-operative/ After healing

Wholegrains	1	-	Post-operative/ After healing
Wholegrain cereal	1	-	Post-operative/ After healing

7. Foods and drinks associated with pain in small intestine or stoma

Food/drink	Number of articles	Positive (+) or negative (-) consequence	Timeframe of dietary modification
Pulses	1	-	Not specified
Green vegetables	1	-	Not specified

8. Foods and drinks associated with food visible in output

Food/drink	Number of articles	Positive (+) or negative (-) consequence	Timeframe of dietary modification
Corn	1	-	Not specified
Nuts	1	-	Not specified
Other vegetables	1	-	Not specified

9. Foods and drinks associated with dehydration

Food/drink	Number of articles	Positive (+) or negative (-) consequence	Timeframe of dietary modification
Apricot	1	+	Post-operative
Banana	1	+	Post-operative
Banana (high potassium)	1	+	Post-operative/ After healing
Broth (high sodium)	1	+	Post-operative/ After healing
Coffee	2	-	Post-operative/ After healing
Excessive consumption of coffee	1	-	Not specified
Strong coffee	1	-	Not specified
Crisps	1	+	Post-operative/ After healing
Diet drinks	2	-	Post-operative/ After healing
Fizzy drinks	1	-	Not specified
Fruit juice	2	+/-	Post-operative/ After healing
Excessive consumption of fruit juice	1	-	Not specified
Strong fruit juice	1	-	Not specified
Marmite	1	+	Not specified
Milk	2	+	Post-operative/ Not specified
Orange juice	1	+	Post-operative
Potatoes	1	+	Post-operative
Potatoes (high potassium)	1	+	Post-operative/ After healing
Pretzels	1	+	Not specified
Salty ayran	1	+	Post-operative/ After healing
Salty cheese	1	+	Not specified
Salty crackers	1	+	Not specified
Salty crisps	1	+	Not specified
Salty rice cakes	1	+	Not specified

Salty soup	1	+	Post-operative/ After healing
Excessive consumption of soft drinks	1	-	Not specified
Spinach (high potassium)	1	+	Post-operative/ After healing
Squash	2	+	Post-operative/ Not specified
Tea	1	-	Post-operative/ After healing
Excessive consumption of tea	1	-	Not specified
Strong tea	1	-	Post-operative/ After healing
Tomato	1	+	Post-operative
Tomato (high sodium)	1	+	Post-operative/ After healing
Canned vegetables (high sodium)	1	+	Post-operative/ After healing
Water	1	-	Post-operative/ After healing
Excessive consumption of water	1	-	Not specified
Increase water	2	+	Post-operative/ After healing
Still mineral water	1	+	Post-operative/ After healing
Consume water equivalent to output volume	1	+	Not specified

10. Foods and drinks associated with malnutrition

Food/drink	Number of articles	Positive (+) or negative (-) consequence	Timeframe of dietary modification
Banana	1	+	Not specified
Broth	1	+	Not specified
Cherry	1	+	Not specified
Chicken	1	+	Not specified
Potatoes	1	+	Not specified
Soy sauce	1	+	Not specified
Tomato juice	1	+	Not specified
Turkey	1	+	Not specified
Canned vegetables	1	+	Not specified

11. Foods and drinks associated with unspecified symptoms/complications

Food/drink	Number of articles	Positive (+) or negative (-) consequence	Timeframe of dietary modification
Apple	1	+	Post-operative
Unripe apple	1	+	Post-operative/ After healing
Bacon	1	-	Post-operative
Unripe banana	1	+	Post-operative/ After healing
Beans	1	-	Post-operative/ After healing
Cured beef	1	-	Post-operative/ After healing
Berries – small amount	1	+	After healing
Boza	1	-	Post-operative/ After healing

Brown bread	1	-	Post-operative/ After healing
Rye bread	1	+	Post-operative/ After healing
Brines	1	-	Post-operative/ After healing
Meat broth	1	-	Post-operative/ After healing
Chicken broth	1	-	Post-operative/ After healing
Bulgar wheat	1	-	Post-operative/ After healing
Cake	1	-	Post-operative/ After healing
Boiled carrot	1	+	Post-operative
Cemen	1	-	Post-operative/ After healing
Chips	1	-	Post-operative/ After healing
Chocolate	2	-	Post-operative/ After healing
Coffee	1	-	Post-operative/ After healing
Compote	1	-	Post-operative/ After healing
Cooking oil	1	-	Post-operative
Corn	1	-	Not specified
Sweetcorn	2	-	Not specified
Cream	1	-	Post-operative/ After healing
Crisps	1	-	Post-operative/ After healing
Raw dried fruit	1	-	Post-operative/ After healing
Fried egg	1	-	Post-operative/ After healing
Pickled fish	1	-	Post-operative/ After healing
Fizzy drinks	2	-	Post-operative/ After healing
Plain foods	1	+	Post-operative
Fruit	2	-	Post-operative/ Not specified
Fruit juice	1	-	Post-operative/ After healing
Fruit skin	1	-	Post-operative
Raw fruit	2	-	Post-operative/ After healing
Raw fruit skin	1	-	Post-operative/ After healing
Cooked fruit – small amount	1	+	Post-operative
Garlic	1	-	Post-operative/ After healing
Grapes – small amount	1	+	After healing
Grape skin	1	-	Not specified
Grilled food	1	-	Post-operative/ After healing
Ice-cream	1	-	Post-operative/ After healing

Ketchup	1	-	Post-operative/ After healing
Lard	1	-	Post-operative
Legume soup	1	-	Post-operative/ After healing
Lemonade	1	-	Post-operative/ After healing
Stringy bits in mango	1	-	Not specified
Fried meat	1	-	Post-operative/ After healing
Roasted meat	1	-	Post-operative/ After healing
Milk	1	+	Post-operative/ After healing
Mushrooms	1	-	Post-operative
Mushrooms chopped and cooked well	1	+	Not specified
Mustard	1	-	Post-operative/ After healing
Nectarine skin	1	-	Not specified
Nuts	3	-	Not specified
Nuts – small portion	1	+	After healing
Oatmeal	1	+	Post-operative
Offal	1	-	Post-operative/ After healing
Olives	1	-	Post-operative/ After healing
Onion chopped and cooked well	1	+	Not specified
Pastries	1	-	Post-operative/ After healing
Peas	1	-	Post-operative
Pickles	1	-	Post-operative/ After healing
Popcorn	1	-	Not specified
Pork fat	1	-	Post-operative
Potatoes	2	+	Post-operative/ After healing
Potato flour	1	+	Post-operative
Rice	1	+	Post-operative/ After healing
Roasted foods	1	-	Post-operative/ After healing
Salami	1	-	Post-operative/ After healing
Salep	1	+	Post-operative/ After healing
Lemon salt	1	-	Post-operative/ After healing
Sausage	1	-	Post-operative/ After healing
Seasoned crackers	1	-	Post-operative/ After healing
Seasoned desserts	1	-	Post-operative/ After healing
Skin	1	-	Not specified
Smoked foods	1	-	Post-operative/ After healing
Soda water	1	-	Post-operative/ After healing

Packaged soup	1	-	Post-operative/ After healing
Spice	2	-	Post-operative/ After healing
Spicy tarhana	1	-	Post-operative/ After healing
Sucuk	1	-	Post-operative/ After healing
Sweet potato – small portion	1	+	After healing
Sweets	1	-	Post-operative/ After healing
Tahini havasi	1	-	Post-operative/ After healing
Strong tea	1	-	Post-operative/ After healing
Thick cereal	1	-	Post-operative/ After healing
Turkey	1	-	Post-operative/ After healing
Vegetables	2	-	Post-operative/ After healing
Vegetables – small portion	1	+	After healing
Cooked vegetables – small amount	1	+	Post-operative
Fried vegetables	1	-	Post-operative/ After healing
Raw vegetables	1	-	Post-operative
Vinegar	1	-	Post-operative/ After healing
Mineral water	1	-	Post-operative/ After healing
Split wheat	1	-	Post-operative/ After healing
Whole wheat	1	+	Post-operative/ After healing

Eating-related behaviors reported in experimental studies

1. Eating-related behaviors associated with volume of stoma output – none
2. Eating-related behaviors associated with consistency of stoma output – none
3. Eating-related behaviors associated with flatulence – none
4. Eating-related behaviors associated with odor – none
5. Eating-related behaviors associated with leakage – none
6. Eating-related behaviors associated with blockage/obstruction – none
7. Eating-related behaviors associated with pain in small intestine or stoma – none
8. Eating-related behaviors associated with food visible in output – none
9. Eating-related behaviors associated with dehydration – none
10. Eating-related behaviors associated with malnutrition – none
11. Eating-related behaviors associated with unspecified symptoms/complications – none

Eating-related behaviors reported in pre-post studies

1. Eating-related behaviors associated with volume of stoma output

Eating-related behaviors	Number of articles	Positive (+) or negative (-) consequence	Timeframe of dietary modification
Eat more in day/less in evening	2	+	Post-operative/ After healing
Consume fluids with meals	1	-	Post-operative

2. Eating-related behaviors associated with consistency of stoma output - none

3. Eating-related behaviors associated with flatulence

Eating-related behaviors	Number of articles	Positive (+) or negative (-) consequence	Timeframe of dietary modification
Eat quickly	1	-	Post-operative/ After healing
Chewing gum	2	-	Post-operative/ After healing

4. Eating-related behaviors associated with odor - none

5. Eating-related behaviors associated with leakage - none

6. Eating-related behaviors associated with blockage/obstruction

Eating-related behaviors	Number of articles	Positive (+) or negative (-) consequence	Timeframe of dietary modification
Consume fluids between meals	1	+	Post-operative/ After healing

7. Eating-related behaviors associated with pain in small intestine or stoma - none
8. Eating-related behaviors associated with food visible in output - none
9. Eating-related behaviors associated with dehydration - none
10. Eating-related behaviors associated with malnutrition - none
11. Eating-related behaviors associated with unspecified symptoms/complications

Eating-related behaviors	Number of articles	Positive (+) or negative (-) consequence	Timeframe of dietary modification
Chew well	2	+	Post-operative/ After healing
Chewing gum	1	-	Post-operative/ After healing
Drinking through a straw	1	-	Post-operative/ After healing
Eat quickly	1	-	Post-operative/ After healing
Frequent meals	1	+	Post-operative/ After healing
Reintroduce foods gradually	1	+	Post-operative/ After healing
Small bites	1	+	Post-operative/ After healing
Small, frequent meals	2	+	Post-operative/ After healing

Eating-related behaviors reported in observational studies

1. Eating-related behaviors associated with volume of stoma output – none
2. Eating-related behaviors associated with consistency of stoma output – none
3. Eating-related behaviors associated with flatulence – none
4. Eating-related behaviors associated with odor – none
5. Eating-related behaviors associated with leakage

Eating-related behaviors	Number of articles	Positive (+) or negative (-) consequence	Timeframe of dietary modification
Eat less in day/more in evening	1	-	After healing

6. Eating-related behaviors associated with blockage/obstruction – none
7. Eating-related behaviors associated with pain in small intestine or stoma – none
8. Eating-related behaviors associated with food visible in output – none
9. Eating-related behaviors associated with dehydration – none
10. Eating-related behaviors associated with malnutrition – none

11. Eating-related behaviors associated with unspecified symptoms/complications

Eating-related behaviors	Number of articles	Positive (+) or negative (-) consequence	Timeframe of dietary modification
Chew well	2	+	After healing
Consume less when out	1	+	After healing
Eat more in day/less in evening	1	+	After healing
Small portions	1	+	After healing
Small, frequent meals	1	Unknown	After healing

Eating-related behaviors reported in qualitative studies

1. Eating-related behaviors associated with volume of stoma output – none
2. Eating-related behaviors associated with consistency of stoma output – none
3. Eating-related behaviors associated with flatulence – none
4. Eating-related behaviors associated with odor – none
5. Eating-related behaviors associated with leakage – none
6. Eating-related behaviors associated with blockage/obstruction – none
7. Eating-related behaviors associated with pain in small intestine or stoma – none
8. Eating-related behaviors associated with food visible in output – none
9. Eating-related behaviors associated with dehydration – none
10. Eating-related behaviors associated with malnutrition – none
11. Eating-related behaviors associated with unspecified symptoms/complications

Eating-related behaviors	Number of articles	Positive (+) or negative (-) consequence	Timeframe of dietary modification
Small, frequent meals	1	+	Post-operative

Eating-related behaviors reported in expert opinion articles/guidelines

1. Eating-related behaviors associated with volume of stoma output

Eating-related behaviors	Number of articles	Positive (+) or negative (-) consequence	Timeframe of dietary modification
Consume fluids between meals	1	+	Post-operative/ After healing
Consume fluids with meals	2	-	Not specified
Small, frequent meals	1	+	After healing

2. Eating-related behaviors associated with consistency of stoma output

Eating-related behaviors	Number of articles	Positive (+) or negative (-) consequence	Timeframe of dietary modification
Loose, watery output			
Reintroduce foods gradually	1	+	Post-operative
Small portions	2	-/+	Post-operative/ After healing
Small, frequent meals	3	+	Post-operative/ After healing
Snack between meals	1	+	Not specified
Regular meals	1	+	Post-operative/ After healing
Constipation			
Chew well	1	+	Post-operative/ After healing
Eat slowly	1	+	Post-operative/ After healing

3. Eating-related behaviors associated with flatulence

Eating-related behaviors	Number of articles	Positive (+) or negative (-) consequence	Timeframe of dietary modification
Chew well	1	+	Not specified
Chewing gum	8	-	Post-operative/ After healing
Sucking sweets	1	-	Post-operative/ After healing
Drinking through a straw	5	-	Post-operative/ After healing
Drink quickly	1	-	Not specified
Gulping	1	-	Not specified
Eating with mouth open	1	-	Post-operative/ After healing
Talking while eating	3	-	Post-operative/ After healing
Reintroduce foods gradually	1	+	Post-operative
Rush meals	1	-	Post-operative/ After healing
Infrequent meals	1	-	Not specified
Regular meals	1	+	Post-operative/ After healing
Small, frequent meals	3	+	Post-operative/ After healing
Small portions	1	+	Not specified

4. Eating-related behaviors associated with odor

Eating-related behaviors	Number of articles	Positive (+) or negative (-) consequence	Timeframe of dietary modification
Chewing gum	1	-	Not specified
Reintroduce foods gradually	1	+	Post-operative

5. Eating-related behaviors associated with leakage – none

6. Eating-related behaviors associated with blockage/obstruction

Eating-related behaviors	Number of articles	Positive (+) or negative (-) consequence	Timeframe of dietary modification
Chew well	13	+	Post-operative/ After healing
Food chewed poorly	3	-	After healing/ Not specified
Cook food until soft	1	+	Post-operative/ After healing
Reintroduce foods gradually	2	+	After healing
Large portions	1	-	Not specified
Small, frequent meals	1	+	Post-operative/ After healing

7. Eating-related behaviors associated with pain in small intestine or stoma – none

8. Eating-related behaviors associated with food visible in output – none

9. Eating-related behaviors associated with dehydration

Eating-related behaviors	Number of articles	Positive (+) or negative (-) consequence	Timeframe of dietary modification
Consume fluids with meals	1	-	Post-operative/ After healing

10. Eating-related behaviors associated with malnutrition

Eating-related behaviors	Number of articles	Positive (+) or negative (-) consequence	Timeframe of dietary modification
Snack between meals	2	+	Post-operative/ Not specified

11. Eating-related behaviors associated with unspecified symptoms/complications

Eating-related behaviors	Number of articles	Positive (+) or negative (-) consequence	Timeframe of dietary modification
Chew well	6	+	Post-operative/ After healing
Eat slowly	2	+	Post-operative/ After healing
Consume fluids between meals	1	+	Post-operative/ After healing
Frequent meals	1	+	Post-operative/ After healing
Reintroduce food gradually	6	+	Post-operative/ After healing
Small, frequent meals	8	+	Post-operative/ After healing
Snack before bed	1	+	Post-operative/ After healing
Talking while eating	1	-	Post-operative/ After healing

Appendix VI

Record of changes made from stakeholder and PPI feedback

Online patient survey

PPI

- Wording and layout of several questions changed to increase clarity.
- Additional options provided for some questions e.g., 'social media' as separate source of dietary advice and 'ileostomy formation without small/large bowel resection' as a type of bowel surgery.
- Differentiate between elective and emergency surgery.
- Questions on preferences for dietary advice provision.
- Question on feelings associated with the dietary advice received.
- Question asking whether advice was sought or provided.
- Questions relating to symptoms.
- Question on support received with hospital meal choices.

Stakeholders

- Questions on bowel surgeries other than ileostomy. [IA and stoma patient]
- Options for type of bowel surgery. [colorectal surgeon]
- Question on advice for weight. [colorectal surgeon]
- Questions on type of dietary advice received: 'Were you given advice on changing the foods that you ate?'; 'Were you given advice on how you should prepare and/or eat certain foods?' [stoma nurse]

Interview topic guide

PPI

- Prompts re. influence of specific conditions to dietary advice for ileostomy i.e., Crohn's, diabetes mellitus, or need for weight management.
- Additional prompt: 'How is dietary advice provided? E.g., verbal/printed/online'
- Additional question: 'How much of a priority is providing dietary advice to people with an ileostomy?'
- Additional question: 'Overall, how sufficient do you feel the advice and support is that people with an ileostomy receive regarding dietary management?'

Stakeholders

- Additional question: 'How does dietary management fit in with medical management of ileostomies?' [dietitian]
- Additional prompts for stoma nurses and dietitians (HCPs who are generally non-prescribers): 'Do you advise on or prescribe relevant medications e.g., Loperamide?' [dietitian]
- Additional prompts relating to reasons for variation in dietary advice e.g., short bowel/vegetarian. [gastroenterologist]

Appendix VII

Survey of dietary advice for people with an ileostomy

p.1 Survey information for participants

Who is conducting this survey?
This survey is being carried out by researchers at the NIHR Bristol Biomedical Research Centre which is a collaboration between the University of Bristol and University Hospitals Bristol NHS Foundation Trust.
What is the survey about and why is it important?
The purpose of the survey is to investigate whether people with an ileostomy receive the dietary advice they require. The results of the survey may be used to develop dietary interventions for ileostomy management to be tested in future research studies and to increase awareness amongst healthcare providers.
What information are you collecting and how will it be used?
The survey will not ask you to provide any identifiable information. This means that **all responses are completely anonymous**. Combined results from all completed surveys will be reported in publications and presented to relevant audiences.
Should I complete this survey?
If you have an ileostomy and are 16 years old or above, you are eligible to complete the survey. Your responses will help to inform researchers and healthcare providers about the dietary advice provided to people with an ileostomy. It is your choice whether or not to complete the survey. The more responses we receive, the more informative the results will be.
How long will it take me to complete the survey?
The survey should only take about **5-10 minutes to complete**.

If you have read all of the information above and agree to take part in the survey, please click "Next" to begin the questions...

Please note that you will be able to go back and change your answers until you select "Finish" at the end of the survey. Once you press "Finish" your answers will be added to the results and it will not be possible to withdraw your responses at this point.

Please read each question, any additional information provided, and all possible answers carefully before selecting your answer(s).

p.2 Eligibility to complete the survey

1. What age are you?
   - Under 16
   - 16-24
   - 25-34
   - 35-44
   - 45-54
   - 55-64
   - 65-74
   - 75 or over

2. Do you currently have an ileostomy?

- Yes
- No

p.3 Demographics

3. Which region do you live in?

- South East England
- London
- North West England
- East of England
- West Midlands
- South West England
- Yorkshire and Humber
- East Midlands
- North East England
- Wales
- Scotland
- Northern Ireland
- Republic of Ireland
- Outside of the UK and Ireland

4. What gender are you?

- Female
- Male
- Other
- Prefer not to say

5. Are you a member of IA (The Ileostomy and Internal Pouch Association)?

- Yes
- No

p.4 Details of bowel surgeries

6. How long have you had an ileostomy?

- Less than 6 months
- 6 months up to 1 year
- 1 to 2 years
- 3 to 5 years
- 6 to 10 years
- Over 10 years

7. What was the reason for your ileostomy?

- Crohn's Disease
- Ulcerative Colitis

Cancer
Trauma
Functional bowel disorder e.g. constipation or diarrhoea not associated with any of the above conditions.
Other
I don't know

8. Was your ileostomy surgery elective or emergency surgery?
Elective (planned)
Emergency (unplanned)
Not sure

9. Is your ileostomy intended to be permanent or temporary?
Permanent
Temporary
Not sure

10. Have you had bowel surgery at any time other than when you had your ileostomy?
Yes
No
Not sure

p.5 Dietary advice for your ileostomy

11. Have you ever received advice on diet for your ileostomy (verbal, printed or online) from a healthcare professional (for example your doctor, stoma nurse or dietitian) or from the internet (including social media)?
Yes
No

a. Would you have liked to receive dietary advice for your ileostomy?
Yes
No
Not sure

b. Where did you receive this dietary advice from? Select all that apply. Please include dietary advice from all sources, including online and social media as well as from healthcare professionals.
Stoma nurse
Dietitian
Ward nurse
Surgeon
Gastroenterologist
Colorectal specialist nurse
IBD (Inflammatory Bowel Disease) specialist nurse

Community nurse
GP
Registered support association e.g. the ileostomy and internal pouch support group (IA)
Stoma product supplier
Website (NOT including that of registered support associations or stoma product suppliers)
Social media e.g. Facebook or Twitter etc.
Other

i. Please complete the table below to identify how and when you received dietary advice. Please include dietary advice from all sources, including online and social media as well as from healthcare professionals. Only complete the rows that are applicable to you e.g. if you gained advice from the stoma nurse, surgeon and social media, complete these rows and leave all other rows blank.

	How was the dietary advice provided? Select all that apply.	When was the dietary advice provided? Select all that apply.	Was this advice given to you or did you ask for it/seek it out?
Stoma nurse	Printed/verbal/online/other	Before surgery/after while in hospital/after discharge	Given/sought out/combination
Dietitian			
…			

c. Did you experience any conflicting advice on diet?
Yes
No

d. Thinking about all of the dietary advice that you received, including printed, online or verbal, did you receive any advice on changing types of foods that you ate? This includes adding or removing specific foods in your diet.
Yes
No

e. Thinking about all of the dietary advice that you received, including printed, online or verbal, did you receive advice on how you should prepare and/or eat certain foods? Select all that apply.
I was advised how to prepare certain foods. For example, boil carrots instead of eating them raw.
I was advised how to eat certain foods. For example, chew very well before swallowing.
I did not receive this type of advice.

f. Thinking about all of the dietary advice that you received, including printed, online or verbal, did you receive advice about your weight?
I was advised to lose weight.
I was advised to gain weight.
I was advised to maintain my current weight.
I did not receive any advice about my weight.

g. Thinking about all the dietary advice that you received, including printed, online or verbal, did the dietary advice make sense to you?
    Yes
    No
    Some of it

h. How confident were you in the dietary advice?
    Extremely
    Fairly
    Slightly
    Not at all

i. How useful was the dietary advice?
    Extremely
    Fairly
    Slightly
    Not at all

j. Did you make changes to your diet based on the dietary advice?
    Yes
    No

    i. Did the changes that you made to your diet help with managing your ileostomy?
        Yes
        No
        Not sure

k. How satisfied were you with the dietary advice?
    Extremely
    Fairly
    Slightly
    Not at all

12. Since having an ileostomy, have any of the following caused you difficulties? Select all that apply.
    Very loose or watery stoma output
    High volume of stoma output
    Wind or gas
    Increased odour (smell) from stoma bag
    Blockage or obstruction of the bowel or stoma
    Pain in your bowel or stoma
    None of the above

    a. Do you think that improved dietary advice could have prevented any of these issues?
        Definitely
        Possibly

Not sure
No

13. How did/do you feel about managing your diet with a new ileostomy? Select up to 3 answers that best describe how you felt/feel.
    Confident
    Anxious
    Well supported
    Let down
    Content
    Lost
    Listened to
    Confused
    Reassured
    Frustrated
    Relieved
    Angry
    None of the above

14. Please indicate, in the table below, how you would have preferred to receive dietary advice. Complete only for the sources you would have liked to receive advice from e.g. dietitian and GP. Leave blank if not applicable i.e. you feel that you received all the advice on diet that you needed.

	How would you have liked dietary advice to be provided? Select all that apply.	When would you have liked dietary advice to be provided? Select all that apply.
Stoma nurse	Printed/verbal/online/other	Before surgery/after surgery while in hospital/after discharge
Dietitian		
…		

15. While in hospital following your ileostomy surgery, did you receive support with your meal choices? Select all that apply.
    I was given a special menu
    I received verbal advice on making choices from the standard hospital menu
    I did not receive any support and did not need it
    I did not receive any support when I needed it
    I can't remember

    a. What support with meal choices in hospital would you have preferred to receive? Select all that apply.
        A special menu
        Verbal advice on choosing my meals
        The support I received was sufficient
        I did not need any support with my meal choices

p.6 Comments

16. Do you have any comments relating to the questions you have been asked in this survey?

p.7 Final page

The survey is complete! Thank you for taking the time to answer our questions.

Appendix VIII

Health professionals' perspectives on diet advice for ileostomies

Participant Information Sheet

We would like to invite you to take part in a research study. Before you decide whether or not to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with other healthcare professionals, relatives, or friends if you wish. Please do not hesitate to ask if anything is not clear or you would like more information.

What is this study about?

The purpose of this study is to understand what dietary advice healthcare professionals may provide to people with an ileostomy and why. This study is being carried out as part of a PhD on the dietary management of ileostomies.

Why have I been chosen?

You have been asked to take part in this study because you are a healthcare professional who provides advice on diet to people with an ileostomy as part of your role. This may only be a small part of your role, but we would still like to hear your views.

What will happen to me if I take part?

You will be asked to take part in an audio-recorded interview with a researcher. The interview will take place face-to-face on NHS or University of Bristol premises, or, if you prefer, over the telephone or internet. The interview will be audio-recorded on a password protected digital voice recorder. We expect interviews to last no longer than 60 minutes and may be shorter than this.

You may also be asked to provide details of some characteristics of your NHS trust to provide context for the interviews. Only one participant at each hospital will be asked to provide this information. If you are asked to provide this information but are not able to do so, you can still take part in the interview and another participant at your hospital will be asked to provide the contextual information.

Do I have to take part?

No, there is no obligation for you to take part in this study and you do not have to provide a reason for declining to take part if you prefer not to.

If you do decide to take part, you will be asked to give consent before the interview either by signing a consent form or formally agreeing over the phone/internet. You will be given, or sent, a copy of the consent form to keep. You will be free to withdraw completely from the study at any time before, during and up to 72 hours after the interview, and without giving a reason. After 72 hours, the interview will be transcribed, and it will not be possible to withdraw your data from the study.

Are there any disadvantages/risks in taking part in the study?

Taking part in this study may take up to 60 minutes of your time. We will try to make it as convenient for you as possible by arranging the interview at a time that suits you.

What are the benefits of taking part in the study?

We cannot say that you will benefit directly from taking part. However, the results of the study will help us to understand what, how and why dietary advice is provided to people with an ileostomy. This will help to inform the design of future studies related to ileostomy management.

What if something goes wrong?

This is an interview study and we do not expect anything to go wrong. If you are uncomfortable with anything during the interview, you can ask to pause or stop the interview at any point.

What will happen to the information I give to you?

The University of Bristol is the sponsor for this study based in the United Kingdom. We will be using information from you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. The NIHR Bristol Biomedical Research Centre, on behalf of the University of Bristol, will keep identifiable information about you for up to 3 years after the study has finished.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

You can find out more about how we use your information by contacting our Information Governance Manager at data-protection@bristol.ac.uk.

Personal information (name and contact details) will be stored in a locked research store and/or on a secure University of Bristol server with password protection for up to 3 years. If you want us to, we will use this information to keep you informed of the outcome of the study and may contact you about other research studies that you might be interested in.

Interview recordings will be deleted after transcription and checking. Interview transcripts will be made anonymous and stored on the University of Bristol's secure online Research Data Storage

Facility for up to 20 years. We are also asking for your permission to use your anonymous research data in future studies and to make it available to other researchers.

Will taking part in the study remain confidential?

All information collected in the course of the study will be kept strictly confidential. Although every effort will be made to anonymise all data, due to the need for us to report characteristics of the hospital at which you work and identify your profession for comparative purposes, there is a chance that someone might be able to identify you from this information.

The only situation in which non-anonymised information from the interview would be shared outside of the research team would be if you were to disclose sensitive information that indicated you might do serious harm to yourself or others. If this situation were to arise, an appropriate person of authority would be informed of the relevant information. The interview questions will not cover sensitive topics and therefore it is not anticipated that this situation will occur.

What will happen to the results of the research study?

Results from the research study, including anonymised quotes, may be published in medical journals, presented at conferences, and shared with support groups such as the Ileostomy and Internal Pouch Association (IA) and Bristol Ostomists Self Support Group, and with health professionals online, via social media and via magazines. The results will also be included in a PhD thesis on dietary management of ileostomies.

Who is organising and funding the study?

The study is organised and funded by the NIHR Bristol Biomedical Research Centre Nutrition Theme. The investigators conducting this study are Alexandra Mitchell (PhD Student), Dr Charlotte Atkinson, Dr Aidan Searle, and Dr Clare England from the University of Bristol.

Will there be money for travel expenses?

Yes, reasonable travel expenses will be covered.

Ethical approval

The study has been reviewed and approved by the NHS Health Research Authority and is sponsored by the University of Bristol. If you are concerned about any ethical issues, or you are concerned with how the study is being run, please contact the Research Governance team at the University of Bristol: research-governance@bristol.ac.uk

Who do I contact for further information?

Please phone (you may need to leave a message) or e-mail:

Alexandra Mitchell / Dr Charlotte Atkinson

alexandra.mitchell@bristol.ac.uk : 0117 3421883

charlotte.atkinson@bristol.ac.uk : 0117 3421766

Thank you for your time

Appendix IX

Participant Identification Number:

CONSENT FORM

Study: Health professionals' perspectives on diet advice for ileostomies

Name of Chief Investigator: Charlotte Atkinson

Please INITIAL the boxes

1. I confirm that I have read and understand the information sheet dated 17/10/18 (version 2) for the above study. ☐

2. I have had the opportunity to consider the information, ask questions if I wish and have had these answered satisfactorily. ☐

3. I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason and without my professional reputation or legal rights being affected. If I withdraw from the study more than 72 hours after the interview, I understand that any results, including direct quotes, that have been obtained by the study will be anonymised, kept and may be used in analysis. ☐

4. I consent to be interviewed about my experiences and views on providing dietary advice to people with an ileostomy and for the interview to be audio-recorded. ☐

5. I consent to the use of anonymised direct quotes in the write up of the project. ☐

6. I understand that the information collected about me will be used to support other research in the future and may be shared anonymously with other researchers. ☐

7. I agree to take part in the above study. ☐

Name of participant: _____

Signature of participant: _____

Date: _____

Name of person taking consent: _____

Signature of person taking consent: _____

Date: _____

Copies to: 1) Participant ☐ 2) Site file ☐