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ABSTRACT

Background: People with a stoma face many unique challenges. Leakage is a significant one but is not sufficiently discussed within the wider area of health and social care. Aims: This study aimed to articulate and achieve consensus on the problems experienced by people with a stoma, particularly leakage, in the hope of encouraging conversations among patients, clinicians and policymakers on how to solve them. Methods: Output from a modified Delphi panel, consisting of patient groups, was used to create a set of calls to action, with a particular focus on the issue of leakage. Findings: Leakage has a large impact on daily life and can cause both physical and mental health difficulties. Peer support and specialist care can be offer considerable benefits in dealing with these. Conclusions: There are significant unmet needs for equitable access to specialist stoma care and peer support, as well as information provision for non-specialist healthcare providers. The calls to action should be implemented.

Key words: Leakage ■ Stoma ■ Patient groups ■ Skin complications ■ Mental health

It is estimated that between 176 000 and 205 000 people in the UK live with a stoma, and around 21000 people have stoma surgery each year (Colostomy UK (CUK), 2021; NHS Digital, 2021). Surgery is performed to treat a range of conditions, including but not limited to bowel and bladder cancer and inflammatory bowel disease. While the formation of a stoma is a life-saving procedure for many, it poses considerable challenges (Bladder and Bowel UK, 2020).

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Leakage is a predominant problem and is a constant worry for many people with a stoma (Claessens et al, 2015; Porrett et al, 2021). It commonly leads to peristomal skin complications— incidence has been reported to be as high as 75% (Salvadalena et al, 2020)—may be associated with redness, irritation and pain, and can affect the adhesion of a stoma appliance. The possibility of unpleasant odour and noise means people with a stoma may face additional unique social anxieties following their surgery, with intimate relationships and body image particularly affected (Cardoso et al, 2015). In some cases, post-surgery anxiety can lead to a person isolating themselves from social situations (Claessens et al, 2015).

These psychological aspects of leakage are typically more apparent to people with a stoma than the link between leakage and peristomal skin complications (Down et al, 2021). Many people with a stoma worry that taking time off work or extra breaks during the working day will affect their ability to keep or progress in their job (Bayar et al, 2021).

Although stoma care in the UK is generally of a high standard when compared to other countries, with several specialist charities providing additional practical and emotional support, there is still wide variation across the country in both the provision of care and how it is funded (Association of Stoma Care Nurses UK, 2021). A lack of access to high-quality stoma care makes managing stoma-related complications more difficult, especially for those who have just had surgery. Evidence has also shown that, as well as improving patient outcomes, specialist nurses can deliver greater service efficiencies and cost-efficiency savings (Carter, 2020).

Aims

The aim of this research is to clearly articulate and achieve consensus on the difficulties faced by people with a stoma, particularly that of leakage. Ultimately, this research seeks to inform and develop a call to action for carers, community support organisations, payers, healthcare providers (both specialist and non-specialist) and policymakers.

Methods

This research used a modified Delphi method (Niederberger and Spranger, 2020), using the output from several small discussion subgroups to create consensus on a call to action, with a particular focus on the issue of leakage (*Figure 1*). The defining feature of the Delphi process is that in each round participants are provided with aggregated feedback from the previous round, with a consensus eventually achieved through this repeated process (Niederberger and Spranger, 2020).

In August 2021, a search of stoma-related literature was conducted using PubMed and Embase to generate statements that could be used as discussion points in the subgroups. The chosen statements were derived from the most frequently referenced literature. These were then categorised into 16 themes, split into sections:

Product and fit (*Table 1*)
- Product and supporting products
- Body shape changes
- Skin conditions

Relationships (*Table 2*)
- Telling people
- Family and friends

Mental health and support (*Table 3*)
- Feelings, emotions and mental wellbeing
- Physical contact with others
- Support (before and after surgery)

Confidence (*Table 4*)
- Body image and clothes
- Noises and smells
- Self-care

Daily life (*Table 5*)
- Diet, sleep and exercise
- Information
- Ongoing support

Out and about (*Table 6*)
- Work, travel and school
- Accessing facilities.

The UK's three main stoma charities—CUK, the Ileostomy and Internal Pouch Association (IA) and the Urostomy Association (UA)—were invited to participate, in an effort to bring together all parts of the UK stoma community. The final panel consisted of 12 people with a stoma (three with a colostomy, five with a urostomy and four with an ileostomy), who were aged between 26 and 75 years and had had their stoma for between 5 and 47 years, plus one carer.

Ethics

All the process complied with relevant laws and institutional guidelines. Informed consent was obtained from all participants and their privacy was ensured throughout the process. Participants were offered gift vouchers as a token of appreciation for their time. Neither the participants nor the charities received any payment or donations. Market research does not require ethical approval (British Healthcare Business Intelligence Association, 2022).

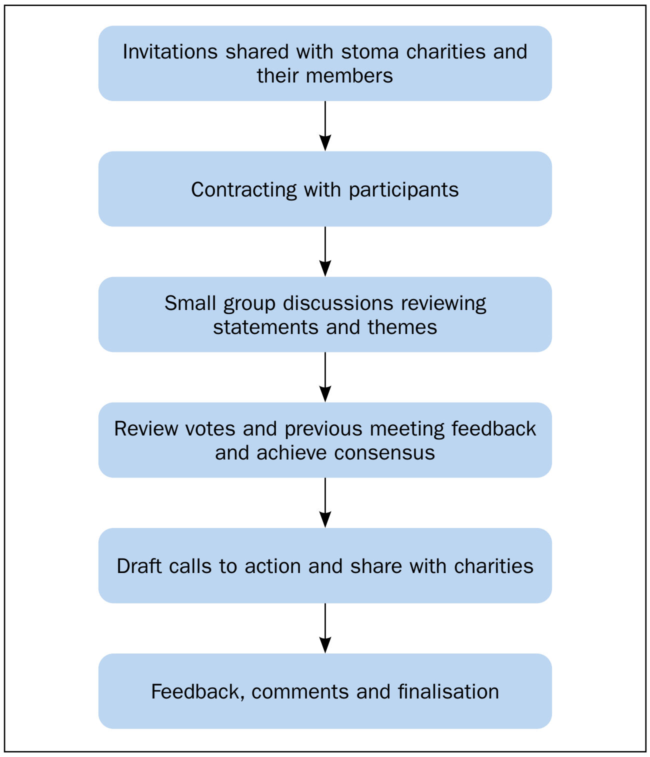

Figure 1. Method flowchart

Round 1

In the first stage, the panel was split into five groups of 2-4 participants, each consisting of people with the same type of stoma, plus one representative from one of the charities and, for two of the groups, a Coloplast observer (*Table 7*).

Meetings were took place in the form of video meetings on Microsoft Teams over the course of 4 days. Each meeting was facilitated by an experienced moderator (from Initiate Consultancy) to promote unbiased facilitation, ensure time keeping and achieve all statements being addressed. Each group gave feedback on which statements matched their own experiences, as well as providing additional comments on how they could be adjusted to be more accurate.

The groups agreed on a number between 1 and 4 (1 indicating full disagreement and 4 indicating full agreement) indicating their overall level of agreement with each statement.

The reported scores are not an average of the scores given by each member of the group: the methods employed involved each group discussing a statement and then agreeing, unanimously, on a single score. In a few cases, there was a

Table 7. Group participants

Group Number	Participants
Group 1	2 people with ileostomies, 1 IA representative, 1 Coloplast observer
Group 2	2 people with urostomies, 1 UA representative
Group 3	3 people with colostomies, 1 IA representative, 1 Coloplast observer
Group 4	2 people with urostomies
Group 5	2 people with ileostomies

Table 1. Product and fit

Statements from the literature	Group scores					
	1	2	3	4	5	Average
Product and supporting products						
'Confidence and security in attaining and maintaining a pouch seal, from the time of pouch system application to removal, that will not leak and cause urine or stool to drain out onto the skin and clothing, resulting in odour and soilage, are critical to successful patient self-management' (Colwell et al, 2019)	4	4	4	4	4	4
'When the pouch seal is inadequate, several additional problems may ensue such as excessive time committed to ostomy care, clothing damage, stigma and social embarrassment, and limited participation in interpersonal and social activities' (Colwell et al, 2019)	4	4	4	4	4	4
'Lack of access to stoma care nursing places patients at the greatest risk for developing peristomal skin complications. Without stoma care nursing, minor issues with stoma fitting can lead to hospitalization and more expensive treatment' (Kwiatt and Kawata, 2013)	3	3	3	3	4	3.2
Skin conditions						
'Skin irritation, leakage, and foul smell are the primary issues faced by patients' (Kwiatt and Kawata, 2013)	4	3	4	3	3	3.4
The consequence of leakage can be frequent peristomal skin complications that may cause redness, irritation, infection, and pain. 'Leakage from an ostomy appliance impairs peristomal skin integrity' (Porrett et al, 2021)	4	3	4	4	4	3.8
Body shape changes						
Over time, changes to ostomates' body shape can impact the fit of devices and has led to issues with leakage that have required changes to the product used. 'Assessing the patient's peristomal body and stoma profiles and utilizing the product type best suited to provide ultimate security and comfort is critical' (Colwell et al, 2019)	4	4	4	4	4	4

1=full disagreement, 4=full agreement. Number of respondents in groups 1–5: 2, 4, 3, 2 and 2 respectively

compromise where the group agreed to an average of their individual scores, which is why some scores have decimal numbers.

Any score of 3 or above was considered to represent agreement with a statement and these instances are coloured in green in the results tables. The average duration of each session was 1 hour.

Round 2

The moderator collated, aggregated and anonymised the findings from Round 1. At this stage, they drafted the calls to action, which were to be used in the next step in the process, Round 2. A consensus meeting was attended by IA, UA, Coloplast UK and Ireland, and the moderator. Both the findings and the call to action were presented and discussed and agreed upon. The consensus meeting lasted 1 hour and 30 minutes.

Round 3

The outputs from the consensus meeting were shared with all three stoma charities. Round 3 consensus meetings were held with IA, UA, CUK, Coloplast UK and Ireland, and the moderator.

Results

Round 1: results by theme

The scores given to the statements under the 'product and fit' theme were high overall, displaying the panel's widespread acknowledgement of the importance of properly fitting stoma products in avoiding leakage. Participants also found the idea that the effectiveness of stoma appliances is affected by changes in body shape to be very accurate.

The panel was in agreement that the statement from Kwiatt and Kawata (2013) regarding hospitalisation was exaggerated. Nevertheless, several participants recognised the skin-related problems caused by poorly fitting appliances, and one called for more dermatological care for people with a stoma.

Participants did not see telling others about their stoma-related experiences as a burden or worry; on the contrary, they preferred to focus on the therapeutic benefits that doing so could bring. The idea that a positive reaction from family and friends can be beneficial in helping people with a stoma to adjust to their new health status generated broad agreement.

Nevertheless, concerns around the impact a stoma could have on relationships still arose, with several respondents emphasising that those who have just undergone surgery might be worried about how they might be perceived by their family and friends. Participants said younger people were particularly affected by such concerns.

The panel was largely in agreement with statements regarding the effects of having a stoma on mental health. Participants in groups 1 and 4 reported that the majority of people with a stoma that they knew had experienced some kind of mental health problem (at least one from the list in

Table 2. Relationships

Statements from the literature	Group scores					
	1	2	3	4	5	Average
Telling people						
'Deciding to inform peers can present a harrowing conundrum, ostomates can agonize over how and when to tell others about their ostomy' (Nicholas et al, 2008)	3.5	3	1	2	2.5	2.4
Changes (physical, emotional, sociocultural and in exercise of sexuality) are linked 'to body image, the self-esteem and interpersonal relationships with the partner, family and friends, going beyond the visible with the emergence of fear, rejection, difficulty with new relationships, body shame, embarrassment by the collector equipment, fear of the sexual act causes damage to the stoma and it is difficult to talk about the condition' (Cardoso et al, 2015)	2.5	3	4	2	1.5	2.6
Family and friends						
Ostomates worry about how their stoma may affect relationships with family and friends (Dibley et al, 2018)	2	3	1	1	1	1.6
'Relationships, both sexual and non-sexual are impacted, with people frequently feeling that they smell, carry a stigma and are repugnant to others' (Grant et al, 2013)	3	3	1	3	2	2.4
'Acceptance of the stoma by family and friends can help the ostomate to positively adjust to their new stoma. The nurse can facilitate this by involving the family (as appropriate) in discussions' (Burch, 2014). 'Specialist nurses are well positioned to fulfil the need for long-term post-discharge care that empowers the patient with independence and a good quality of life' (Black, 2020)	2	4	4	4	4	3.6

1=full disagreement, 4=full agreement. Number of respondents in groups 1–5: 2, 4, 3, 2 and 2 respectively

the Ayaz-Alkaya (2019) statement).

There was also a consensus around the necessity of perioperative, long-term healthcare support care to alleviate mental health difficulties. Some participants objected to the suggestion that people with a stoma did not know where to access specialist care, but there was general agreement about the insufficient availability of such care, particularly during and after the COVID-19 pandemic.

Many participants mentioned they felt the statements represented more of an ambition for how care should be than how it actually is, particularly when asked about whether stoma nurses provide more services than just practical support. The two lower scores in response to the Porrett (1996) statement reflected this, as the groups did not feel stoma nurses were able to act as a life coach, given time and resource constraints.

Participants accepted that while people with a stoma did experience problems with leakage, noise and smell, they rejected the suggestion that these occurred daily—this point was made by several groups. Some participants noted these problems tended to be more prevalent shortly after surgery, with those who had had their stoma for a long time worrying about them less. The low scores recorded under the 'leakage, noise and smells' subheading can likely be attributed to this, as the panel was made up mostly of people who had had their stoma for a long time (a minimum of 5 and a maximum of 47 years).

All three statements provided to the panel regarding body image generated broad agreement. One participant mentioned they were familiar with the idea that those who were about to have surgery worry about how a stoma bag would impact their body image and choice of clothing because of their experience of manning a patient helpline.

There seemed to be a recognition that body image concerns generally diminish over time. Several participants were keen to place emphasis on their concerns surrounding the availability of holistic care as, if patients could access holistic care, this could help to assuage concerns about body image.

Some participants felt that Grant et al (2013) slightly overstated the degree to which daily self-care affected their lives, particularly as they became more experienced in dealing with stoma-related problems. There was considerable agreement with the idea that peer support and specialist nursing care improved quality of life, with one participant going as far as to say that such support could save lives. However, there was, again, a concern about care not being available, and two groups noted that the 'lifelong support' mentioned in the statement from Stott (2013) tended to come from charities rather than healthcare systems.

Participants were, in general, sceptical of the idea that dietary changes could help prevent leakage and the associated complications, instead placing emphasis on factors such as how well the stoma bag fitted. The dietary advice that the panel had received was extremely varied.

Although two groups took issue with the idea that engaging with other people with a stoma would reduce stigma, all participants agreed such engagement was important in other ways, such as in providing advice on how best to manage their stoma. Several participants mentioned the important role social media played in their ability to communicate with the

Table 3. Mental health and support

Statements from the literature	Group scores					
	1	2	3	4	5	Average
Feelings, emotions, and mental wellbeing						
'People with a stoma may experience mind health problems such as depression, anxiety, changes in body image, low self-esteem, sexual problems, denial, loneliness, hopelessness, and stigmatisation' (Ayaz-Alkaya, 2019)	4	3	3	3	4	3.4
'Leakage is a major concern for people who use a stoma appliance' (Nafees et al, 2018)	3	3	2	3	4	3
'Leakage can affect a person's physical and emotional well-being' (Nafees et al, 2018)	4	4	4	4	4	4
Physical contact with others						
'The creation of an ostomy can change the degree of control an individual has over their own bodily function, thus presenting difficulties for an individual to engage in social, work, and intimate relationships' (Grant et al, 2013)	3.5	2.5	2.5	4	3	3.1
Increasing familiarity and confidence, feeling in control of their stoma as soon as possible after surgery facilitates self-acceptance and body changes (Thorpe et al, 2016)	4	4	4	4	4	4
Healthcare support						
Perioperative and long-term support varies across the country. Help and advice from medical professionals and access to stoma care nurses is vital (Carter, 2020)	4	4	4	4	4	4
Ostomates are not always sure when and who to contact when problems occur, particularly soon after surgery once the immediate support has come to an end (Scottish Government, 2016)	1	4	2.5	4	4	3.1
Stoma nurses provide more than practical support—they are also important life coaches advising on all areas of life impacted when living with a stoma including, diet, exercise, social interactions, sex, travel, work and education (Porrett, 1996)	2	4	4	4	2	3.2
'The possible negative psychological outcomes and emotional issues arising from the stoma make it essential the provision of comprehensive patient care, with an interdisciplinary and specialized approach to the needs of patients and their families, with a view to full physical, emotional and social recovery towards rehabilitation' (Silva et al, 2017)	3	3	4	3	4	3.4

1=full disagreement, 4=full agreement. Number of respondents in groups 1–5: 2, 4, 3, 2 and 2 respectively

wider stoma community.

In addition, the provision of expert information was widely agreed upon to be crucial to adapting to living with a stoma.

The panel was broadly in agreement that stoma-related problems, particularly leakage, can have significant effects on social and professional life. One participant's problems with leakage stopped them from leaving the house, a reality that was echoed by other participants' knowledge of the experience of people with a stoma with whom they had previously communicated. There were several remarks about issues faced in working life, whether that be worrying about potential disciplinary action because of missed time or even being unable to work altogether. Awareness by employers of the impacts of the specific needs of people with a stoma can help to reduce the burden that stoma-related problems cause.

However, one point that came up in this theme is that people with a stoma often view their stoma surgery as changing their life in a positive as well as a negative way. This is because, although a stoma can have many complications, it is beneficial in alleviating the symptoms of whatever underlying disease the surgery was meant to treat. The lives of people with a stoma are therefore likely to be better after surgery (Petersén and Carlsson, 2021).

Round 1: uncategorised results

Participants frequently mentioned they preferred to be referred to as a 'person with a stoma', with the term 'patient' particularly resented. Similarly, many did not think having a stoma carried a 'stigma'.

Even though each group was composed of people with the same type of stoma, responses were remarkably homogenous, with several suggestions being echoed by those with all three types. Exceptions to this were primarily among those with a urostomy, who tended to worry less about a stoma bag affecting their day-to-day lives, but they also mentioned specific difficulties regarding a lack of product innovation and provision of specialist information.

After discussing the statements from the literature, participants were asked 'Considering our discussions today, do you think that leakage is a problem for the stoma community?' and 100% agreed. When asked to elaborate, responses varied, with some claiming leakage was constantly a worry for them and others stressing it was much more of a problem for people with newly formed stomas.

Table 4. Confidence

Statements from the literature	Group scores					
	1	2	3	4	5	Average
Leakage, noise and smells						
Ostomates have a daily concern with regards leakage, noise and smells that impacts day-to-day activity (Gautam and Poudel, 2016)	1.5	2	3.5	2	4	2.6
Leakage, smell and noise impacts my confidence in my daily life (Gautam and Poudel, 2016)	1.5	2.5	3	2	3.5	2.5
Body image						
Preoperatively patients worry about visibility of the bag, body image and impact on their choice of clothing (Dibley et al, 2018)	4	2.3	4	4	4	3.7
Following stoma surgery, people with a stoma worry about changes to their body image (Ayaz-Alkaya, 2019) Stomas negatively impact on body image (Sharpe et al, 2011)	2.5	3	4	3	4	3.3
Holistic care involving pre-and postoperative counselling, education and psychological support is important in coping with changes in my body (Noone, 2010)	4	3.5	4	4	4	3.9
Self-care						
‘The challenges of carrying out daily ostomy care involve equipment decisions and troubleshooting, cleaning, skin care, and getting used to wearing a pouch and always carrying an “emergency kit”. Daily routines of self-care is extensive’ (Grant et al, 2013) Finding ways to integrate these routines into lifestyle is important	3	3.5	2	4	3	3.1
Educational interventions and peer support programmes can be effective in empowering stoma patients to self-manage (Fearn et al, 2020)	3	4	4	4	4	3.8
Having access to preoperative and postoperative specialist nursing care, and ongoing lifelong support are important in my confidence in managing my stoma, to be able to lead full and active life (Stott et al, 2013)	2	4	3	4	3.5	3.3

1=full disagreement, 4=full agreement. Number of respondents in groups 1–5: 2, 4, 3, 2 and 2 respectively

Round 2

Upon reviewing the aggregated and anonymised feedback from the five Round 1 groups, participants in the consensus meeting reviewed and agreed a set of calls to action regarding stoma care, which are given below.

Healthcare provision

- The delivery of individualised and holistic care is fundamental for people living with a stoma
- Positive education is needed throughout the healthcare service to understand how stomas affect people
- To reduce the impact of leakage and its complications and improve quality of life, healthcare professionals need to have access to information regarding product innovations. This will enable them to provide the best holistic care for people with a stoma
- Stoma care nurses’ lifelong support and engagement is important to reduce leakage. Access to this specialist support should be consistent across the country
- Education covering the proper use of stoma appliances, lifestyle and mental health is important. Access to stoma care nurses is essential to receive this service
- People with a stoma should be offered an annual review that includes mental health, skin health, product choice, routines and self-care
- Primary care providers should not change stoma prescriptions without consultation with the person with a stoma
- People with a stoma should be offered care before and after surgery, and provided with ongoing lifelong support
- To reduce the impact of skin issues, people with a stoma need access to dermatology advice
- Psychological support is as important as physical healing: people with a stoma need access to mental health support.

Product

- Improve information for people with a stoma to understand products and innovations available.

Support

- Peer support saves lives. People with a stoma may benefit from engagement with others who have a stoma.

Daily life

- A stoma is a hidden condition; disabled toilet facilities should therefore be clean, spacious and accessible

Table 5. Daily life

Statements from the literature	Group scores					
	1	2	3	4	5	Average
Diet, sleep and exercise						
Nutritional and dietary advice can be an important factor when finding ways to prevent leakage and complications (de Oliveira et al, 2018)	1.5	1	1	3	3	1.9
Ongoing support						
‘Participation in activities with other stoma patients are influencing factors that protect patients against possible stigma’ (Yuan et al, 2018)	4	4	2	2	4	3.2
‘Interacting with others in similar situations and exchanging experiences, in demanding areas such as body image, sexuality and social activities could support patients in coping with their new life with a stoma’ (Petersén and Carlsson, 2021)	4	4	4	3	4	3.8
Information						
Ability to accept a stoma may be influenced by duration and quality of information, preparation and support (Dibley et al, 2018)	4	3.5	2.5	4	4	3.6
‘Education, marking, and discussion of expectations should be performed preoperatively’ (Kwiatt and Kawata, 2013)	4	4	3	4	3	3.6
‘A trained stoma professional should provide information on the care and management of stomas and on learning to live with a stoma. This information should include surgery and expectations (including leakage), in a way that it is understandable to the patient’ (National Institute for Health and Care Excellence, 2020)	4	4	4	4	2	3.6

1=full disagreement, 4=full agreement. Number of respondents in groups 1–5: 2, 4, 3, 2 and 2 respectively

- Employers need to be aware of and educated on how to support people with a stoma.

Round 3

The final set of calls to action were approved in collaboration with the three third-sector organisations via a series of video meetings on Microsoft Teams.

Limitations

The panel was composed primarily of people who were regularly involved with stoma charities—it is unlikely that the call to participate reached less-engaged people with a stoma. This is advantageous in the sense that many participants were able to speak on behalf of other people with a stoma with whom they had previously communicated, for example when manning phone lines, thus increasing the spectrum of views and experiences represented during discussions.

Nevertheless, it should be noted these participants are unlikely to be completely representative of the overall stoma community, as a certain degree of confidence and extroversion is required to actively participate in patient advocacy (this is also the reason that people who had recently undergone stoma surgery were not represented). Therefore, the possibility the results from this panel are understating the degree to which a stoma affects a person’s confidence must be considered.

A small number of respondents (13 in this study) is not out of the ordinary in the general context of Delphi panels (Niederberger and Spranger, 2020). The presence of an experienced independent research moderator facilitating these groups promoted discussion and mitigated the influence of opinions and gave all individuals the opportunity to express their views. As previously mentioned, many participants were able to draw upon extensive experience of communicating with and supporting other people with a stoma, and thus provide a wider range of insights than just their own.

Conclusions

By bringing together expert patient groups to form a consensus on the actions required to improve their stoma care, and by placing emphasis on the rarely discussed issue of leakage, this research forms a valuable addition to the existing literature.

The results of this research show that people with a stoma face unique and often significant physical and mental health difficulties in their day-to-day life, with leakage being both the cause of many of these and a particularly acute issue in itself.

They also show people with a stoma believe access to specialist stoma care and peer support are essential to dealing with these problems, and that there is a serious issue regarding the geographical variation of such care.

When presented with stimulus statements that described the role of stoma care nurses and the way access to specialist care helped people with a stoma, many participants felt the literature was putting forward a vision of how stoma care should be rather than describing how it actually is. The belief that expanding access to specialist stoma care would make a meaningful improvement to many people’s lives shone through clearly.

These conclusions inform the calls to action in this study:

Table 6. Out and about

Statements from the literature	Group scores					
	1	2	3	4	5	Average
Travel, work and school						
To improve quality of life for ostomates, it is important for people with a stoma, their 'family members and healthcare professionals to understand the practical and religious implications of stomas to support guidance and counselling' (Habib et al, 2020)	4	3	4	3	4	3.6
'Living with a stoma is life-changing for the patient, their relatives and care givers. This change also impacts on society as a whole as it may be associated with increased absence from work due to illness or the need to permanently reduce working hours or stop working, all of which are significant health-economic burdens.' (Martins et al, 2012)	4	3.5	1	3	2	2.7
Experience of leakage can be a primary reason for ostomates' withdrawal from physical, leisure and social activities (Colwell et al, 2019)	3	3.5	4	3	4	3.5
'Some ostomates may hesitate to go out socially because of fear of leakage and the inability to manage their stoma when outside of the home.' (Colwell, 2014) People with a stoma need access to toilets that are clean and spacious (Yamaguchi et al, 2018)	3	2	3	3	4	3

1=full disagreement, 4=full agreement. Number of respondents in groups 1–5: 2, 4, 3, 2, and 2 respectively

there is a significant unmet need for equitable access to specialist stoma care and peer support, as well as for additional information for non-specialist healthcare providers. **BJN**

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KEY POINTS

- While stoma surgery is a life-saving procedure for many, it poses both physical and psychological difficulties to people in their post-surgery lives.
- Access to specialist stoma care is highly variable across the health system. Non-specialist carers frequently have little understanding of what living with a stoma means and have limited access to appropriate information and education
- Expanding access to lifelong specialist stoma care, from pre-surgery education to regular check-ups after surgery, is key to reducing the impact of leakage and its complications have on people's lives

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CPD reflective questions

- Consider how the physical health difficulties leakage causes (such as peristomal skin complications, odour and noise) might lead to mental health/psycho-social challenges, such as anxiety or a lack of confidence
- Consider why participants might have placed such emphasis on specialist stoma care and peer support as a way of solving stoma-related problems
- Consider what can be done to avoid care discrepancies across the country and provide people with a stoma with adequate lifelong care
- Consider how future work and future improvements in stoma care pathways and policies could be more inclusive of people with a stoma, including those who are less engaged with the stoma community

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