



Scottish Stoma Forum

Specialist Nurse and Patient Survey 2023 Briefing





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1. Executive Summary

To better understand and prioritise the needs of patients living with or awaiting stoma surgery in Scotland, the Scottish Stoma Forum sought to scope the experiences and views of both stoma patients and the specialist nurses who care for them.

The nurse survey respondents indicated their concerns over the pressure they are under in terms of delivering a full service to all their patients. This was due to the reduction in band 6 and above specialists and the continued challenges they face in maintaining contact with patients particularly in rural areas. Additional comments covered the urgent need for succession planning and that Health Boards must ensure local stoma forums are in place and active, to facilitate decision making to improve patient care.

The largest ever survey of Scottish stoma patients shows that, overall, most respondents reported some degree of satisfaction with the support and services they had received.

However, some of the presented data and, many of the patient views demonstrated extremely concerning gaps in service and the resulting negative impacts on the lives of ostomates.

The SSF have laid out four key recommendations that should be addressed:

1. Scottish Government should direct health boards to implement all recommendations from the 2016 and 2020 national stoma care reviews and have active oversight of progress in this area. Central to this is the delivery of equitable stoma care services across the country with a Once for Scotland Approach. This must also include the establishment of local fora in all health board areas involving patient representation.
2. Patients should be given the opportunity for an annual review with a Band 6 or above specialist nurse to achieve positive patient outcomes as a result of evidence based assessment of their needs. This review would consider patient choice of the most appropriate product or service, including potential referral for further specialist support e.g., physiotherapist, dietitian, psychological support.
3. Immediate steps should be taken to improve the dispensing of stoma care prescriptions. Patients have highlighted challenges, in some cases, of getting their prescription to their dispenser of choice due to the lack of electronic prescribing and communication.
4. The Scottish Government should investigate opportunities to address patient information and support gaps including financial and other assistance to relevant patient groups. The overwhelming majority of patients reported they had no contact with a patient group, charity or other stoma patients. They also highlighted the need for pre and post-operative information, peer support and specialist assistance with mental health challenges and a sense of isolation.



2. The Scottish Stoma Forum

The Scottish Stoma Forum was formed in 2007 to ensure the services provided to Scottish stoma patients are maintained at the highest possible level and reflect the diversity, demographics and geography of Scotland.

SSF has a broad membership made up of patient groups, medical & nursing healthcare professionals, industry bodies (British Healthcare Trades Association & Community Pharmacy Scotland). It also works collaboratively with NSS NHS National Procurement and the Scottish Government on key initiatives and activities when required.

Living with a stoma

There are many reasons why someone may require a stoma. Common reasons include bowel cancer, bladder cancer, inflammatory bowel disease (Crohn's Disease or Ulcerative Colitis), diverticulitis or an obstruction to the bladder or bowel. A stoma can be temporary or permanent depending on the cause. A stoma operation can be planned or unplanned emergency. Living with a stoma has a significant impact physically, practically, and psychologically.

The journey for each stoma patient (ostomate) will be very individual and the support provided by a range of healthcare professionals and partners can determine that experience. Stoma care specialist nurses, surgeons, product suppliers, pharmacists, stoma support groups and GPs are key providers of that support.

The lived experience of ostomates influences the work undertaken by SSF to improve services for this growing patient group:

Patient experience statements

After an emergency colostomy I have had very little medical follow up in the 11 months since. I had to insist on seeing the surgeon, have had two GP appointments – both at my request, minimal stoma nurse support and only discovered the existence of a support group by chance. Not told about it by stoma nurse. Now find it invaluable for filling in all the gaps.

I feel like it's been very difficult to access help from the stoma nurses. Each time I ask for something it feels like I'm bothering them or when I ask for a product it always is declined due to money. I feel as though I can't ring up and have improvised most of the time or relied on samples as we cannot receive some products in Scotland.

I was left to myself with aftercare. Probably because I was very ill at the beginning. However, when I got home, I did not get enough information, therefore, ended up with a hernia. My fault, doing too much. I was given a bag and told where to order them from. This was pretty much my aftercare. I don't feel this is enough.



Stoma care in Scotland: what we know

- **Number of Scottish patients living with a stoma has increased:**
Overall, there are 19,993* stoma patients in Scotland. Patient Numbers are increasing by approximately 3% per annum.
- **Increasing demand and cost on the NHS in Scotland**
Based on the Health Board values, costs equate to c. £1,787 per patient **

UK average patient value equates to £2,098 (17% higher than Scotland average) **

Previous NHS Scotland and Scottish Government stoma care reviews

In recent years NHS Scotland has conducted two important reports into stoma care services and costs.

- Stoma Appliance Service in the Community: Stoma Care Quality and Cost Effectiveness Review 2015 published in February 2016 2016 Report
- National Stoma Quality Improvement Group 2020 2020 NSQIG Report

The **2016 Review** made 26 recommendations including, that:

- Scottish Government continue to work with the Scottish Stoma Forum as a reference group on policy and service provision.
- NHS Board Strategic Plans give proper recognition to stoma care services.
- Designated leads for stoma care services are identified.
- Succession planning and continuity of stoma care services are informed by formal assessment of capacity/ demand by NHS Boards



The **2020 National Stoma Quality Improvement Group** was asked to build on and take forward the findings of the 2016 Review to ensure resources are allocated for maximum clinical and financial value.

The NSQIG made 14 recommendations that it hoped would “provide a clear pathway to an improved and consistent ‘Once for Scotland’ model”; a national approach to stoma care to end variation in practice and bring down escalating costs. Recommendations included:

- NHS boards to review future stoma nurse workforce requirements in line with CNOD Transforming Roles Programme
- Scope how NHS Education Scotland can work with the Scottish Stoma Nurse Forum to develop a framework of educational and clinical preparation requirements for stoma care nurses in line with the NES Career Development Framework and CNOD Transforming Roles Programme. This should include a review of the current industry and the Association of Stoma Clinical Nurses supported education and CPD provision.

The journey for each stoma patient (ostomate) will be very individual and the support provided by a range of healthcare professionals and partners can determine that experience.

3. SSF: Our concerns

- The 2016 and 2020 report recommendations have not been taken forward
- A lack of official current data on WTE specialist stoma nurse workforce numbers
- A reported reduction in stoma specialist nursing support
- A lack of NHS led educational courses to enable specialist nurses to enter stoma care and to support workforce planning activity across NHS boards for the future professional requirements to support this patient group.

In the light of these continuing concerns, SSF sought to scope the experiences and views of people living with stomas and the clinicians who care for them, to better understand and prioritise the needs of patients living with or awaiting stoma surgery in Scotland.

The ambition was to identify key themes arising from the data which could then be shared with our partners to inform and support the development of patient services as well as with key political decision makers.

SSF commissioned a survey of stoma patients and specialist nurses funded by ASCN (Association of Stoma Care Nurses) and managed by an independent body (Client Focused Evaluation Program).



The ambition was to identify key themes arising from the data which could then be shared with our partners to inform and support the development of patient services.

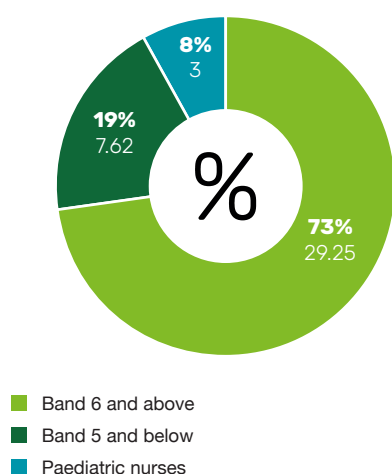
4. Specialist Nurse survey

Stoma specialist services increasingly stretched

The NHS Scotland workforce survey has not been completed since 2018 and SSF does not believe this is now an accurate reflection of the actual resources in place. A 2023 Survey by the Scottish Stoma nurse group showed 39.2 WTE nurses in Scotland for stoma care.

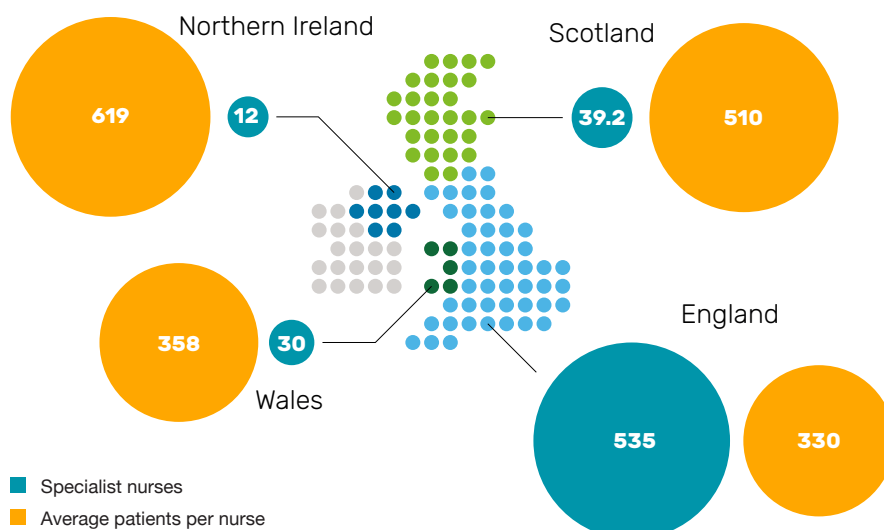
The 19,993* patients in Scotland are supported by 39.25 Stoma specialists. As illustrated by the chart below only 29.25 of these specialists are band 6 and above (this excludes the 3 Paediatric nurses). There is an ongoing trend of those nurses who have retired being replaced with lower band colleagues, this has an impact on patient care as these more junior nurses do not always have the knowledge and skills of the more qualified nurses.

Nurse resources across Scotland



Source: Scottish Stoma nurse group survey.

Patients to WTE nurse comparison



Source: UK information.

Patients need more support in the community

Patients are discharged to the community much earlier than previously however specialist nurses are spending more of their time in hospital and less in the community. This chart gives a comparison of the estimated nurses and patients in the four UK nations and clearly shows the disparity between Scotland and the other nations in terms of patients per nurse.

The survey was sent to all Health Board nurses across Scotland during Nov 22 – March 23

7 Health Boards & 11 nurses responded out of a total of 14 boards – a 50% return.

Key outputs

Are you able to see all your patients for an annual review either face to face or remotely within a 12-month period?

The response to this question was an emphatic **No** from all the HB's (7 health boards).

Some of the key statements were:

- Not enough time to see all patients.
- Due to rural geographical area, there would not be enough time. Some patients are well established in their stoma care management and do not wish to see me.
- X Health board do not employ stoma nurse specialists as such, these are colorectal nurse specialists who have stoma care as part of their role, they also provide care and support for colorectal cancer patients, patients with bowel dysfunction and run the bowel



screening programme within NHS X so difficult to answer. Due to the way we collect our data we would have to apply to our audit team for numbers, this is available but takes time in a priority queue.

- Inadequate resource time/clinic space.
- We follow up new stoma patients for the first year, thereafter patients can self-refer if required to be seen with any issues/problems. We don't have the resources to see patients yearly on an ongoing basis.
- No capacity in service including clinic allocation to carry this out.

These responses indicate there are real pressures on time, resources, and the capacity of the current service and the nurses do not believe they are able to support patients fully, particularly in more rural areas.

Q. How satisfied are you with the current arrangements for provision of stoma care to your patients in your health board?

- 1** Very dissatisfied
- 2** Dissatisfied
- 1** Neither dissatisfied nor satisfied
- 3** Satisfied

Key points from the nurses who responded:

We are currently trying to encourage patients to come to a weekly clinic for review as this will help with time and travel for the nurse. Due to distances the nurse must travel within our area, it is time consuming and then limits the time spent on patients in the hospital setting needing trained.

If we had more time and resources to see patients/more clinic space we could spend more time attending to the holistic needs of the ostomist, using our specialist knowledge in stoma care. We could also devote more time to the development of the service and be more involved in the research aspect of our roles, as well as our own personal development.

Lack of staff to manage increasing workload of patients. Patients not getting enough valuable time spent with them. Increasing demands from hospital.

We have a very inexperienced team due to lack of succession planning following retirements and maternity leave but have a complex caseload both in hospital and community and the bulk of the complex workload falls to the only experienced nurse who is also the band 7 so time for service development and review does not happen. We are continually firefighting.

I personally feel undervalued and most of the time left holding the service together. There is an overall shortage of staff everywhere, but experienced staff are getting thinner on the ground and see the colorectal service as struggling whilst other specialties are able to get extra staff, but we are not.

Due to the reduction in staff over the last few years satellite clinics have been disbanded and therefore patients do not always have access to clinic within their own locality. This is something we hope to address in the near future.

Lack of support from management to develop service. Lack of management support for appropriate banding of staff.

Summary

As can be seen from the data and the nurses' statements there are concerns over the care available to patients and the significant challenges in reviewing patients at least annually. The issues around banding levels have been highlighted as well as the lack of succession planning and focus on the stoma service from HB Management teams.

This situation is causing increasing pressure on specialist nurses and the patients they care for. As a result, a range of urgent actions are required at both national and health board level. The evidence from the specialist nurses survey suggests that the 2016 and 2020 report recommendations have not been implemented in a Once for Scotland manner.

5. The Patient Survey: What we learned

The online patient survey was launched in November 2022, and with nearly 1,000 respondents, it is the largest survey of patients ever conducted in Scotland:

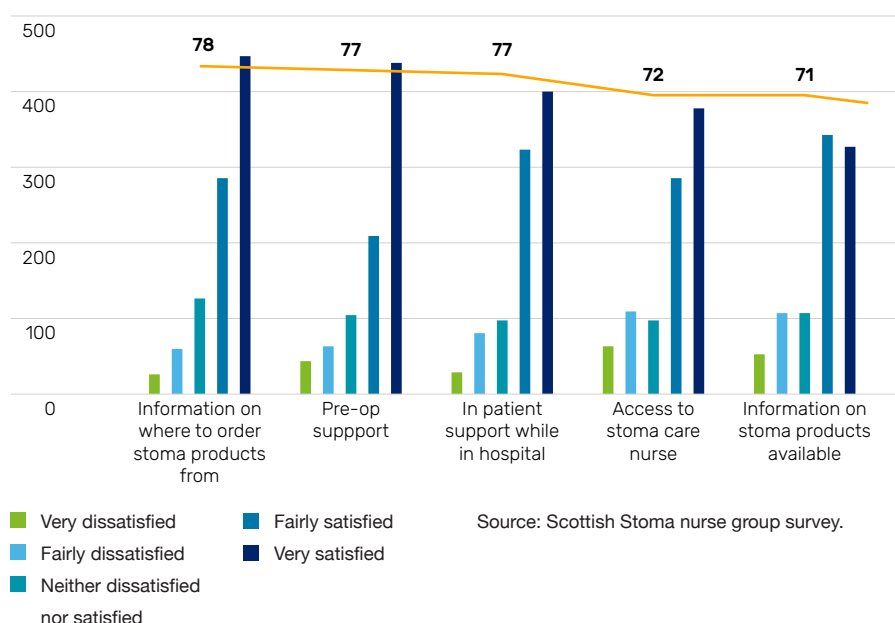
- 964 patients responded
- 83% of respondents were 55 years or older
- 49% of respondents had colostomies, 38% had ileostomies and 13% had urostomies
- Most patients had their surgery over 12 months ago (87%)

Patients were asked to rate and comment on a range of areas of support that may have been available to them.

The Patient Survey results showed that, overall, most respondents reported some degree of satisfaction with the support and services they had received. However, some of the data and, particularly, many of the patient views demonstrate extremely concerning gaps in service and the resulting negative impacts on the lives of ostomates.

The following summary highlights the key themes emerging from the data. The examples of patient experience statements included below illustrate the lived experience around these themes.

How satisfied or dissatisfied are you with each of the following areas of support? (Number of patients)



Areas of support: Satisfaction ratings

68% or more of respondents were fairly or very satisfied with information relating to the range and supply of stoma products, pre-op and inpatient support and access to a stoma care nurse.

Most patients were fairly or very satisfied with most areas of support they might need in their patient journey.

However, there were 18% very or fairly dissatisfied with their access to a stoma care nurse and 16% to information on available stoma products.

Patient experience statements:

Emergency stoma, very well supported by hospital, stoma nurse, colostomy UK and Respond

I am very grateful that I have a direct number for my stoma nurse and seeing the surgeon once a year is a good support. My stoma supplies company (DAC name) are also excellent and always easy to get hold of.

I had emergency surgery and didn't get a lot of help with after care and felt that it had and still does have a huge impact on my mental health and physical health.

5. The Patient Survey: What we learned

(DAC) always very helpful as is my stoma clinic at Victoria Hospital Kirkcaldy Fife – nothing too much trouble – a truly great service when you wake up in hospital and find you now have a stoma! – great care during my hospital stay and since discharge.

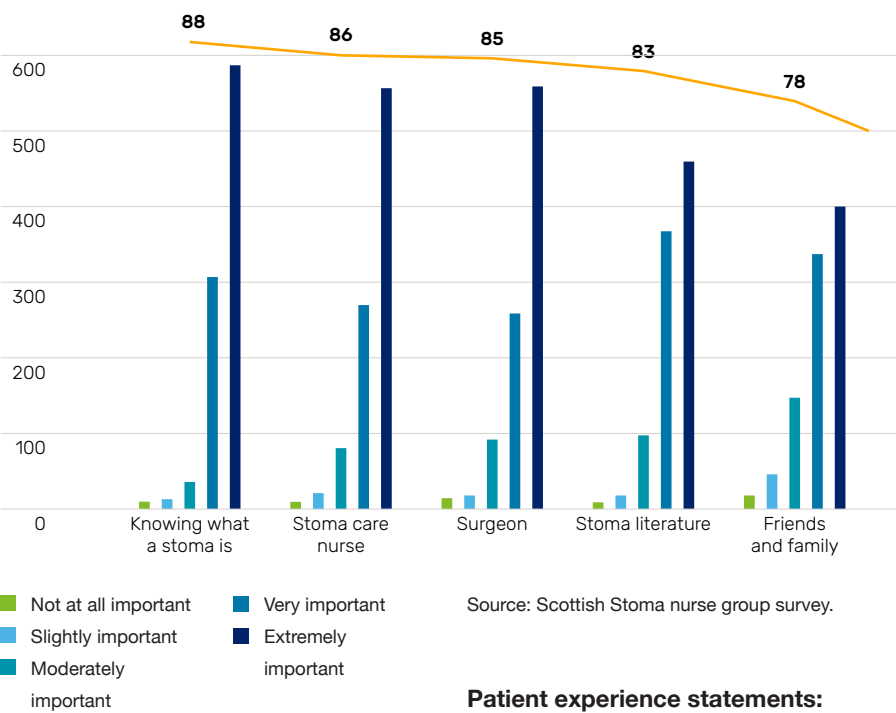
(Having) Access to anyone. Consultant. Stoma nurse. Anyone would be a start. Seen once by consultant. Six months after operation for irreversible stoma. No contact with anyone since.

A good stoma nurse makes the difference on how you cope.

It would have been very helpful to have been given details of stoma products available to help me manage my stoma and also online forums, etc., I had to source all of these myself. I understand that not all products are suitable for everyone but even just to be aware that there are products available for you to try which can help support you and make life a bit easier would have been very helpful.

I feel I get a good service in Aberdeenshire. I have a direct line to access either a stoma nurse or IBD nurse if I start to have any problems. I had my surgery 15 years ago and occasionally need support. Especially after having my children, I found my shape had changed and I experienced a lot of leaks which the stoma nurse helped to resolve.

Thinking about before and after your stoma surgery. How important are each of the following areas of support to you? (Number of patients)



Areas of support: Importance ratings

The support of surgeons (85% of respondents) and stoma care nurses (84% of respondents) was viewed as very or extremely important.

While knowing about stomas was felt to be important, patients rated support from clinical and nursing staff extremely highly.

Patient experience statements:

I found the support given in hospital after surgery very poor. Very little information was given on what had actually been done during my emergency surgery. Was not given information on the range of stoma products available. Was given no information on diet and was given no psychological help. I felt extremely lost and lonely and very worried about how I would cope with two stomas.

I have had great care from all members of the NHS and stoma care nurses since last year (2022), but I would like to see more options for better urostomy bags and their designs, as well as a better way to use a night bag.

My stoma nurse is my first point of contact, and she is fantastic.

I keep very well informed about 'all things ostomy' (new products, medical intervention, research, etc.) but this is all down to me. I feel concerned for those who don't find internet research, speaking out, etc., as easy as I do.

Living with a stoma is an ongoing challenge which impacts on patients' daily lives. A significant majority of patients were concerned about specialist support. 24% were fairly/very dissatisfied with psychological support and 30% of respondents fairly/very dissatisfied with specialist support e.g., sex therapist, physiotherapist, occupational therapist, dietician.

Of these areas of support, which ONE could be improved the most?

	Responses	%
Advice on living with stoma	177	18%
Specialist support (e.g. sex therapist, physiotherapist, occupational therapist, dietician)	144	15%
Access to stoma care nurse	131	14%
Access to local stoma support group	119	12%
Psychological support	100	10%

Patient experience statements:

Dietician would be an advantage. As I've had two obstructions since surgery in 2009, the first I spoke with a dietician was 2022. Dos and don'ts are so very important as well as meal prep ideas.

I would very much like access to a stoma care nurse, a stoma group in my area, diet advice, hernia advice and to meet others who have a stoma. In Tayside there is almost no help or advice available and anyone with a stoma is left more or less to cope on their own.

Mental health (support) would help, as this condition is very isolating and lonely.

Personally, I feel I'm still struggling with dealing with my stoma (operation 2019). Silly things but important to me (i.e., still have difficulty traveling and eating out).

Physiotherapists are absolutely crucial in telling you how to manage your stomach muscles and how to exercise safely. Also support garment suppliers must gain more knowledge about hernia support and prevention.

There are no contacts re support local groups, or exercise, or relationships, or diet, or mental health, or travel – a large void following surgery in any of these areas. Struggling.

I didn't know the problems I would have with intimacy so feel this is extremely important.

You're fitted with this stoma told how to put it on and clean it. And you're left to get on with it no one to talk to that have the same issue as you – it's very lonely.

Nobody discusses the person as a whole – stoma conversations are limited to stoma function. Impact on the person (work, sexuality, social) is not brought up or is quickly dismissed. There are missed opportunities to introduce coping mechanisms, humour and normalcy of the stoma experience.

The role of Stoma Care Nurses

The survey questioned ostomates who were at various stages of treatment. Some had surgery recently while others have lived with their stoma for several years. Stoma care nurses have a critical role to play in supporting patients and other members of the NHS workforce engaging with ostomates.

74% of respondents reported having access to a stoma care nurse at some point in their treatment. 15% said they didn't have access and a further 10% didn't know.

When asked how often face to face reviews with a stoma care nurse should take place, 41% of respondents said once every year, 24% stated once every 6 months, with 12% suggesting this should be every 3 months.

However, when asked about their last face-to-face review of their stoma, 44% of respondents said this took place over 1 year ago. A further 19% said they had never had a face-to-face review.

5. The Patient Survey: What we learned



When did you last have a Face-to-face review about your stoma?

	Responses	%
Less than 3 months	136	14%
3-5 months ago	90	9%
6-12 months ago	123	13%
More than a year ago	423	44%
Never	185	19%

62% of patients said their last face to face review was with a hospital stoma care nurse while only 3 % reported this taking place with a NHS community nurse.

Patient experience statements:

My stoma nurse is very, very, good, she is easy to contact and able to provide good support by phone or email where required. She allows me to be independent and make contact outside of scheduled appointments easily to provide advice and guidance – that means the frequency of face-to-face appointments can be longer in between without worry to me.

Not had a review or seen a stoma nurse for at least 3-4 years.

Access to a stoma nurse through an online forum or at the end of a helpline would be great. Sometimes I have questions my GP can't answer but I don't want to go through the hospital ER to speak to someone.

(Need) Face-to-face meetings with a stoma nurse. More advice on stoma products which help with emptying stoma bag with dense output. Much more about diet, things to avoid, which exercises are advisable, etc.

Apart from a brief 30 minute (very good) appointment with the stoma nurse prior to my surgery I received no further support in terms of what to expect. The stoma nurse is too stretched and really just wants to ensure the patient is well and the bags fit. I have had to personally seek online support but am still clueless about exercise/possibility of hernia and how to deal with these.

Before my first year was up I had support but now I find it very difficult to get access/support for my stoma. Nine years on but I still feel I need someone to turn to now and then.

Feel very alone sometimes and no one ever really explained how much it would affect me mentally. Folk – i.e., GPs, stoma nurses, etc., – are so busy I hate to call them, so I don't.

Stoma care nurse should be proactive about contact and regular reviews. It's too easy to be passive (as I am) and put up with issues, not realising that they can be easily solved. Picking up the phone can be difficult.

Other Supports

While 18% of respondents said that advice on living with a stoma could be improved, the overwhelming majority of patients were not reaching out to organisations and support groups for assistance.

- 81% had no contact with a national patient organisation or charity.
- 75% had no contact with other stoma patients.
- 95% had no contact with a local stoma support group.

Patient experience statements:

(Needed) A support group with other stoma people – it is very hard being alone and thinking you are the only one with a stoma.

Most of my questions, information, hints and tips, I have learned online from support groups, especially Colostomy UK. They have provided leaflets/information about travelling abroad, exercise, getting back to work, radar keys, psychological effects, etc.

(Needed) Local support group and guidance on products available and what products are available on prescription, e.g., support garments.

Received emergency operation – no warning – no post-op info – still not 100% acceptance of new lifestyle – would like to join support group to enhance self help.

I was not mentally prepared. It would have been beneficial to have spoken to someone living with a stoma before my operation. And to have heard about the self-help group before my operation. I found it 12 months post operation. Psychological help would also have been good. I felt very alone.

Initially it is very important to have access to other people who have a stoma, it helps to normalise your condition. I think ostomates should be consulted more about their experience of using products, to improve upon the products available.

Stoma Care Products: Advice, Information and Supply

With regards the comments below about how a patient accesses their next prescription: Today all prescriptions are generated via a paper prescription via the patients GP surgery or other prescriber. There have been many examples of delays in the prescription being written and the postal service taking up to two weeks to deliver the post to the dispenser, which causes the patients anxiety worrying they might run out of their appliances, leading to quality of life issues.

Respondents comments:

77% rated the importance of receiving information about stoma products before their surgery as very or extremely important

24% stated it was the single most important type of information to receive before surgery

87% rated receiving information after surgery about stoma products and how to get supplies as very/extremely important

29% identified information about stoma products as the most important information following surgery

96% of patients in the survey obtained their stoma care supplies from a Dispensing Appliance Contractor:

86% felt the product supplier to be very/extremely important to their stoma management

77% valued contact with the supplier "very much"

How important do you consider your product supplier(s) to be in the management of your stoma?

	Responses	%
Not at all important	18	2%
Slightly important	23	2%
Moderately important	87	9%
Very important	388	40%
Extremely important	444	46%
Blank	4	0%

Patient experience statements:

(DAC name) are fantastic, extremely reliable, brilliant communication and all staff are lovely. My stoma nurses are not very active in overseeing my care, it has been roughly three years since I last seen them in clinic, and I have had surgery to make my stoma permanent during this time.

Very surprised in this day and age of technology that GP posts prescription! This is in Fife. Certainly not good for mental health.

Stoma suppliers such as (DAC name) have an important role in making it easier for the patient when supplies are delayed, e.g., chasing GP prescriptions (I've had to do this myself quite a few times despite my mentioning I have just a few days of supplies left, without help).

5. The Patient Survey: What we learned

I find it bewildering that the NHS Scotland do not appear to be able to provide prescriptions by email to my preferred provider (DAC name) The delays in prescriptions being processed can cause anxiety and worry about the number of products I have left at that time.

In Scotland the GP has to post my prescription to my stoma supplier, this can take over three weeks at times. Why can't my prescription be emailed through as soon as requested to save delays in delivery.

NHS Scotland must set up the electronic prescription system that NHS England has – using the post for sending and receiving prescriptions during strikes has caused various delays, lost prescriptions, and added to my stress and anxiety.

I would like to not to have to fight for products. It is damaging to mental health when items are not approved like odour neutralizers, particularly in Scotland we are no longer allowed support underwear, prevention is cheaper than cure I have not seen any cost benefit analysis to justify removal of such an important product. I would like to see the removal of a postcode lottery of our access to products. We are reasonable adults we can keep costs down in many ways work with patients for better policies for GPs and health boards. Stoma nurses are often referred to as the people who stop us getting products. Surely, they should be our advocates and care givers unequivocally first.



I have (found) (DAC name) to be fantastic and helpful. If I've needed a product at short notice they have sorted samples out for me quickly. I also find having my bags pre-cut by them much easier. I'd be lost without them.

There should be more support given to people before and after they get a stoma. There should be access to supplies we need for free and not based on what NHS areas offer. Support wear should be free as well to everyone and cut down on more ops due to hernias. Living with a stoma is hard, we shouldn't have to fight for supplies we need, they should be free and not limited. More support for people should be available.

I also have to voice my opinion in paying for stoma support underwear they are so expensive, so I am making do with what I have.

Patient Survey conclusions

- The Patient Survey is a patient view of Scottish stoma care highlighting the views and experiences of almost 1000 patients with a stoma across Scotland.
- Patients conveyed strong messages about the need for more regular reviews from a stoma care nurse.
- Patients valued the practical role that product suppliers (DACs) play in the management of patients' stomas on an everyday basis.
- Where patients experience a lack of contact with health professionals and a wider sense of isolation, everyday living and the consequences of having a stoma can be extremely challenging both physically and mentally.

6. Scottish Stoma Forum recommendations and suggested actions

1. Scottish Government should direct health boards to implement all recommendations from the 2016 and 2020 national stoma care reviews and have active oversight of progress in this area. Central to this is the delivery of equitable stoma care services across the country with a Once for Scotland Approach. This must also include the establishment of local fora in all health board areas involving patient representation.
 - Action: Health boards should assess their stoma care services and undertake workforce planning to ensure adequate numbers of specialist nurses to support the number of ostomates in their area. Scottish Government and Health Boards, together, should urgently address the ongoing deficiency of relevant workforce data.
2. Patients should be given the opportunity for an annual review with a Band 6 or above specialist nurse to achieve positive patient outcomes as a result of evidence based assessment of their needs. This review would consider patient choice of the most appropriate product or service, including potential referral for further specialist support e.g., physiotherapist, dietitian, psychological support.
 - Action: A full analysis should be conducted of the patients within each Health Board, they should be contacted for a review and clinics should be set up or virtual consultations should be carried out.
3. Immediate steps should be taken to improve the dispensing of stoma care prescriptions. Patients have highlighted challenges, in some cases, of getting their prescription to their dispenser of choice due to the lack of electronic prescribing and communication.
 - a. Action: The Digital Prescribing and Dispensing Pathways programme, <https://www.nss.nhs.scot/national-programmes/digital-prescribing-and-dispensing-pathways/about-the-digital-prescribing-and-dispensing-pathways-programme/> roll out should be accelerated to deliver improved patient satisfaction and dispensing efficiencies. The Chief Pharmaceutical Officer should ensure:
 - All dispensers, particularly dispensing appliance contractors, are included in all relevant DPDP working groups
 - The technology required for serial prescribing and the future paperless dispensing model meets the needs of stoma patients and their prescribers
4. The Scottish Government should investigate opportunities to address patient information and support gaps including financial and other assistance to relevant patient groups. The overwhelming majority of patients reported they had no contact with a patient group, charity or other stoma patients. They also highlighted the need for pre and post-operative information, peer support and specialist assistance with mental health challenges and a sense of isolation.
 - a. Action: In addition, a centralised repository of relevant information should be created for patients to access, with signposting to the relevant local and national patient groups and charities, industry suppliers and dispensers. SSF would welcome the opportunity to partner with National Education Scotland and others in the development of such a Scottish stoma information point.



Abbreviations

ASCN	Association of Stoma Care Nurses
BHTA	British Healthcare Trades Association
CNOD	Chief Nursing Officers Directorate
DAC	Dispensing Appliance Contractor
GP	General Practitioner
HB	Health Board
IBD	Irritable Bowel Disease
NES	National Education Scotland
NSQIG	National Stoma Quality Improvement Group
SSF	Scottish Stoma Forum
WTE	Whole Time Equivalent



Scottish Stoma Forum
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