

East of England Collaborative Procurement Hub
Integrated Care Team

StoMap Programme:

Ostomate Survey Report
2019



Author: Jill Kettle

Glossary

ASCN	Association of Stoma Care Nurses
AURs	Appliance User Reviews
BHTA	The British Healthcare Trades Association
CCGs	Clinical Commissioning Groups
DACs	Dispensing Appliance Contractors
DNA	Did Not Attend
Hub	East of England NHS Collaborative Procurement Hub
GP	General Practitioner
ICs	Integrated Care Systems
SCNs	Stoma Care Nurses
STPs	Sustainability Transformation Partnerships

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1. Executive Summary

The East of England NHS Collaborative Procurement Hub (the Hub) initiated 'StoMap', a programme of work to understand the stoma care market in the East of England region.

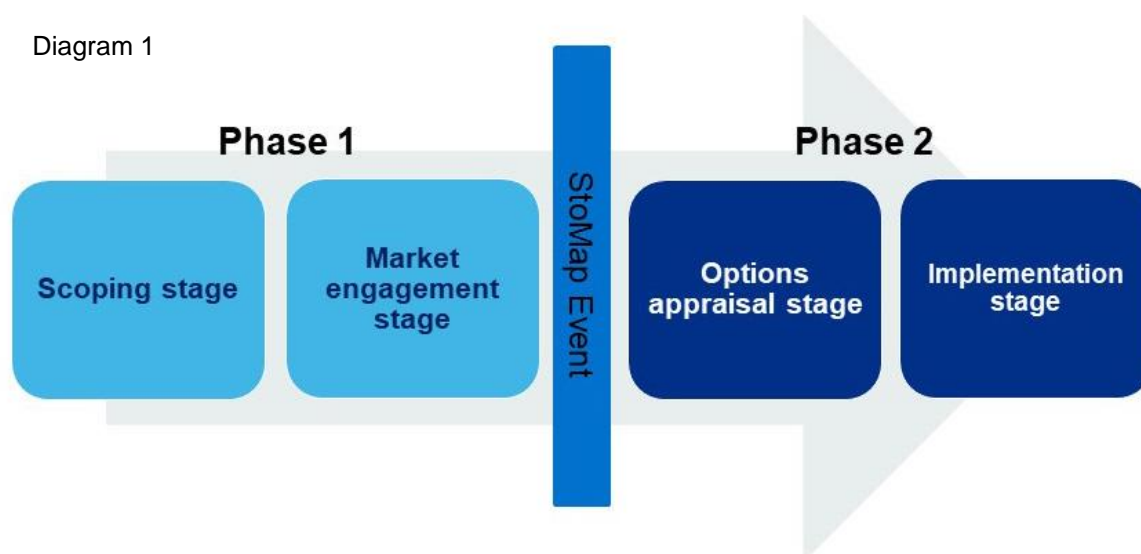
Stoma care is an identified priority market for Hub members and is aligned to the NHS Long Term Plan which has set out its ambition to review and restructure how we deliver healthcare to our nation's diverse population with a more sustainable approach over the forthcoming years.

The NHS Long Term Plan sets out its intentions of having a fully integrated community-based health care system for people to receive healthcare and support closer to home with support from local healthcare systems and local authorities.

Stoma services and products are also on the national NHS improvement agenda while NHS Supply Chain are also looking at the procurement of stoma products in order to improve the management of patients' ongoing stoma care and prescribing needs while reducing spend on stoma appliances.

The StoMap Programme will support the National Bladder and Bowel Health Project and ensure that the East of England service development is aligned to the national direction.

Diagram 1



For many people, undergoing stoma surgery can be a life changing process which may be as a result of a long-term health problem or as a result of an acute onset health problem or trauma; all of which require adjustments to lifestyle with support from suitably trained healthcare professionals.

As part of the scoping stage (Diagram 1) the Stoma Patient Survey was undertaken to engage with ostomates in the region to seek their views on their current stoma services. This information will also help to inform Phase 2 of the programme.

An Ostomate survey was compiled in May 2019 and developed in consultation with stoma care nurses, The British Healthcare Trades Association, patient ostomy associations, The Association of Stoma Care Nurses, manufacturers and clinical commissioning group medicines optimisation leads.

People who have stomas are referred to in this survey as patients while receiving hospital care and ostomates when they have been discharged to the community and have returned to daily living with their stoma.

2. Methodology

The survey was distributed via the SCNs, patient ostomy associations and the BHTA via the DACs. The SCNs were requested to ask ostomates to complete an online survey accessing SurveyMonkey and to give ostomates paper surveys where ostomates did not have access to the internet. The survey was also handed out to ostomates on two open days in the region and was posted on ostomy associations websites.

The survey closed on the 31st August 2019. Due to the survey being openly distributed we are not able to provide a response rate. The number of completed surveys is 160. Five more surveys were received after the survey had closed and therefore have not been included.

Nurse focus groups were set up with representation from the Essex Stoma Care Nurses Forum and the East Anglian Colo-rectal & Stoma Care Nurses Group to discuss the findings and to formulate recommendations in order to inform the StoMap Programme of work.

3. The aims and objectives of the Ostomate Survey

The overarching aims and objectives of the Ostomate Survey were to ensure that ostomates views form part of our baseline assessment of current service provision and;

- To map the current patient stoma service provision across the East of England region
- To explore the variation and access to products used in stoma care
- To inform the future strategy for integrated patient pathways
- To improve patient outcomes
- To reduce clinical risk

4. The Survey

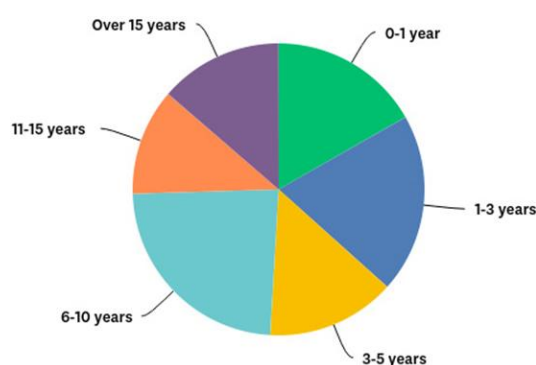
There were 40 questions in total with 160 responses. The questions have been divided into key themes.

a. Demography

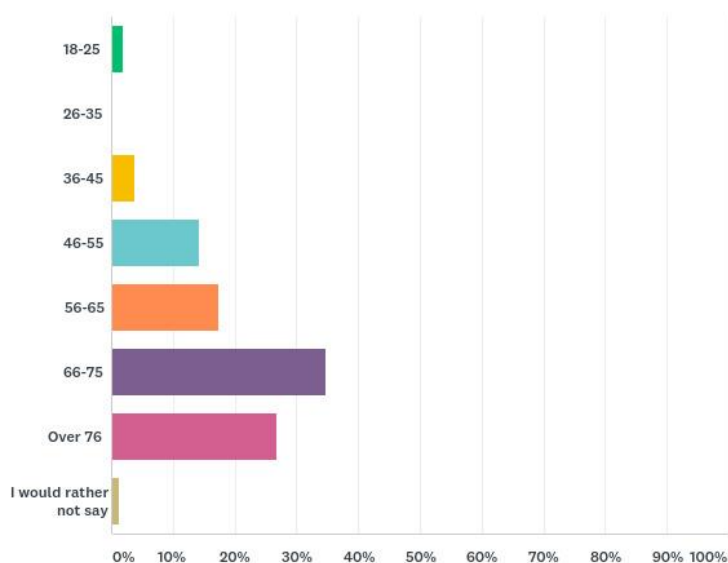
There was a total of 160 respondents and of those, 50% have been living with their stomas for less than 1-5 years while the remaining 50% have been living with a stoma for 6 years and above. This provided a viewpoint of how new ostomates rate the service alongside older service users across the region.

The ostomates who have had their stoma 0-1 year will still be adjusting to their new stoma and may experience problems such as sore skin etc. Evidence has shown that ostomates experience most problems in the first year following surgery while the newly formed stoma is going through a period of change.

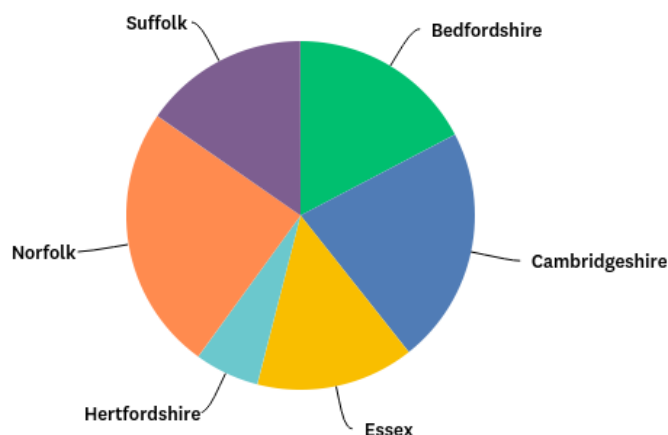
Q1 How long have you had a stoma?



Q2 Would you mind telling us which age category you fit in to?



Q3 In which county are you located?



The largest group of respondents were in the 56-75 and over 76 age range (78%) which is the national average age range for ostomates who have had stomas formed due to bowel disease being more prevalent in this age group. 11 of the respondents were aged between 18-45, which provided an insight into how young people with stomas are supported and what that age group expects from a stoma service.

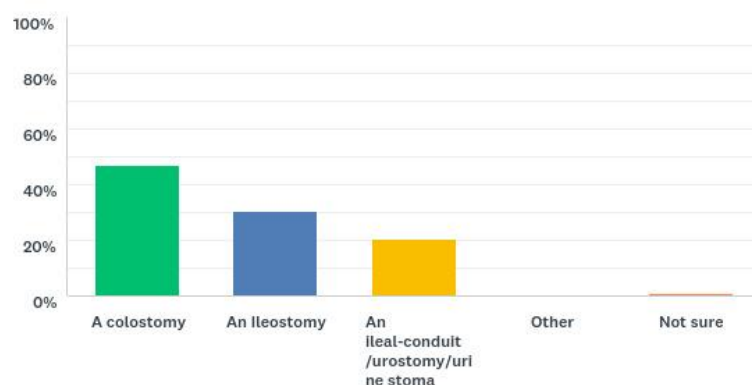
Respondents were spread across the region. This is particularly important for the region to ensure that the report is representative of age group, regional service differentiation, ostomate service satisfaction and the types of stoma formation across the region.

b. Types of stoma

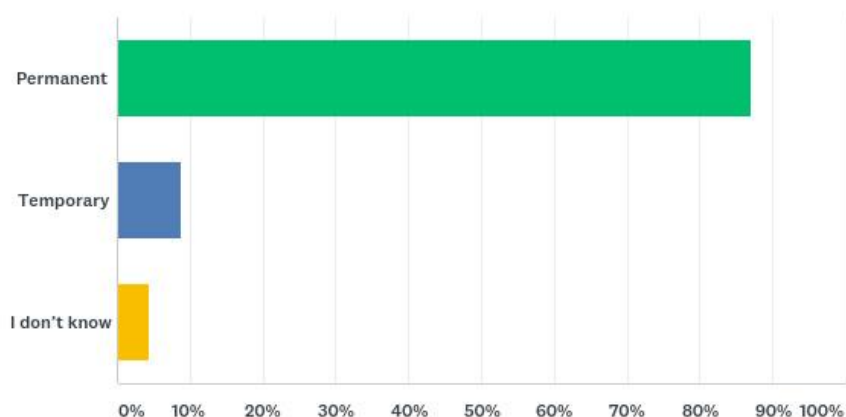
Some ostomates, following their chemotherapy and radiotherapy treatments prefer not to have their stoma reversed and it may not be known whether the stoma can be reversed following initial surgery.

Some ostomates can wait up to 15 months to have their stomas reversed. This may be due to ongoing treatment regimes.

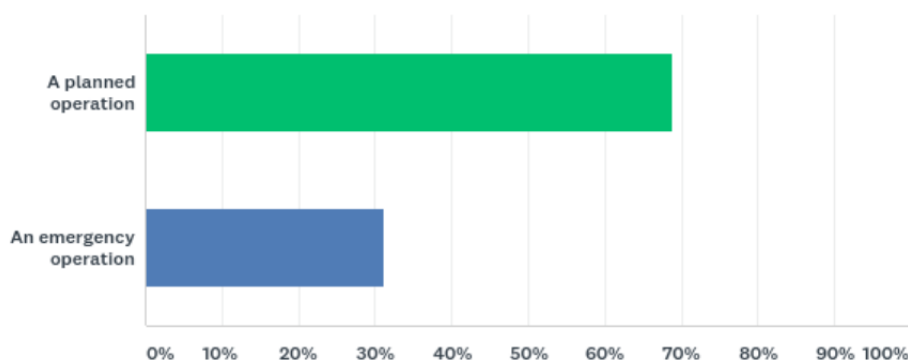
Q4 Do you have:



Q5 Is your stoma:



Q6 Did you have your stoma formed as:



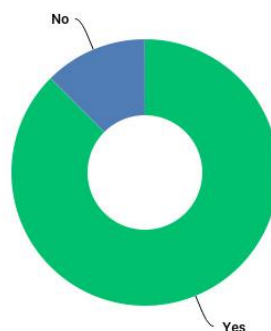
The majority of ostomates will require further long-term care and access to other services, such as psychological support and dietary advice.

70% of stoma operations were performed as a planned operation while 30% were performed as an emergency. The ostomates that have had their operation performed as an emergency can experience post-operative issues due to not having their stoma pre-operatively sited and counselling prior to surgery by the SCN. This may affect the type of products that they can use, and it is recognised that the stoma itself changes over a period of time post-operatively.

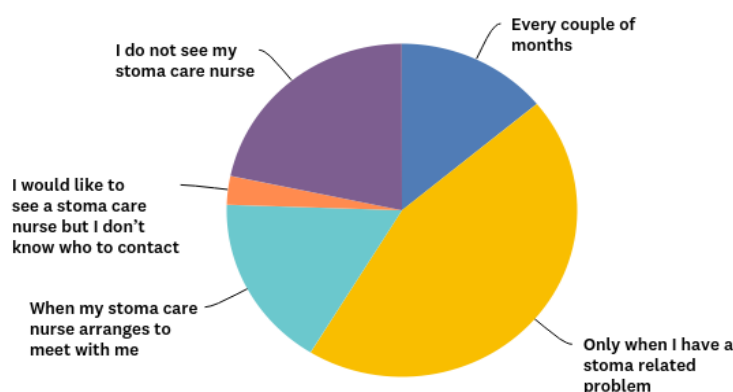
c. Stoma Care Team

The Hub Stoma Nurse survey showed that a high proportion of SCNs are approaching retirement age. 12% of ostomates surveyed did not know their SCN, this could be for a number of reasons, some of these patients may have had their operations privately, some may not have perceived issues with their stomas and therefore don't feel they need to see a SCN.

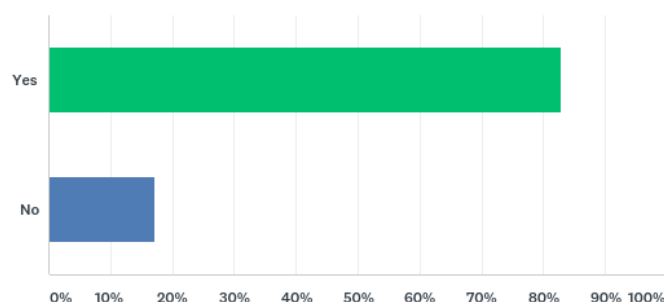
Q7 Do you know who your stoma nurse team is?



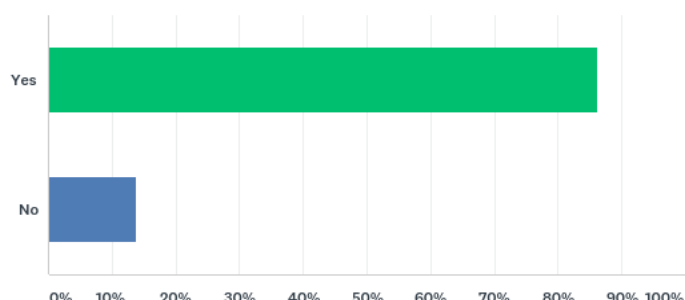
Q8 If yes, how often do you see your stoma nurse?



Q9 Is there a telephone messaging service where you can contact your stoma care nurse?



Q10 If no; would it be helpful to have a telephone messaging service?



There appears to be a variation in contacts with the SCN ranging from no visits to maybe monthly appointments. Where there are monthly appointments these may be at the ostomates request for support.

Nearly half of the ostomates only see an SCN when there is a perceived problem.

Some ostomates will persevere with their leakages and sore skin thinking this is normal but may require a review of their products to ensure a good fitting of an appropriate product.

There were 130 respondents who confirmed that they can contact their stoma team by a telephone answering service; the 27 respondents that do not have a telephone messaging service may be the same respondents who don't know who their stoma nursing team is, as all nurses confirmed that they do have a voicemail facility where patients can leave a message. However, some patients don't leave a message when they hear a voicemail message.

Some patients prefer to use email or texts in order to contact their SCNs (patients are requested to sign an Information Governance form to consent if they prefer email contact).

Addenbrookes Hospital have introduced an app called 'My Chart' which patients can access for their blood results, some medical notes and to track appointments although this has not been introduced to the stoma service yet.

d. Annual Clinical Review

Ostomates were asked whether they had an annual clinical review with their stoma care nurse.

There were 60% responses confirming that they have an annual review and 40% who do not have an annual review.

It is recommended that there should be an annual clinical review for all ostomates, and it is widely supported by the SCNs in the East of England region, although the SCNs noted that this is sometimes difficult due to capacity and staffing numbers.

Some patients who had had their stoma for many years may not want to have a review if they feel they are happy with their products. However, some ostomates are using 'legacy' products (products which are no longer manufactured as a mainstream item, but some

stock is maintained by the suppliers) and some patients may be experiencing ongoing problems which could be resolved by the SCN.

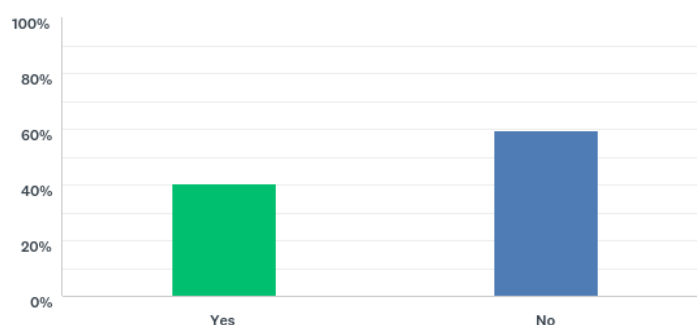
There appears to be a few patient pathway models in place regionally. There are examples of where SCNs review their patients in outpatient clinic biannually and do telephone follow ups annually. If there are problems identified on the phone call, the SCN will ask to see the patient face-to-face. Some SCNs will see their ostomates annually for clinical review while another nurse in the region does not do annual reviews at all due to a lack of capacity in staffing levels. 'What does good look like?' i.e. what is the ideal pathway? Are there the staffing resources available if an annual face-to-face review is required?

It would be useful to have clear clarification if the annual stoma review is a clinical review or Appliance User Review.

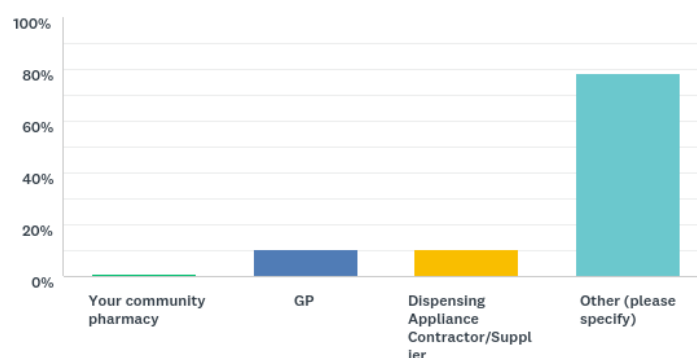
STPs will need to consider nursing capacity if an annual clinical review is to be accommodated in the patient pathway.

Within the survey ostomates may have confused their surgical follow up appointment with their consultant or colo-rectal nurse specialist as opposed to their stoma annual review with their SCN.

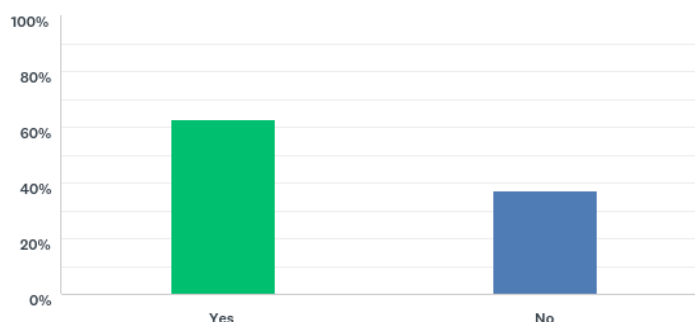
Q11 Do you have an annual stoma review with your stoma care nurse?



Q12 Do you have an annual stoma review with any other besides your stoma nurse?



Q13 If No, would you like an annual review?

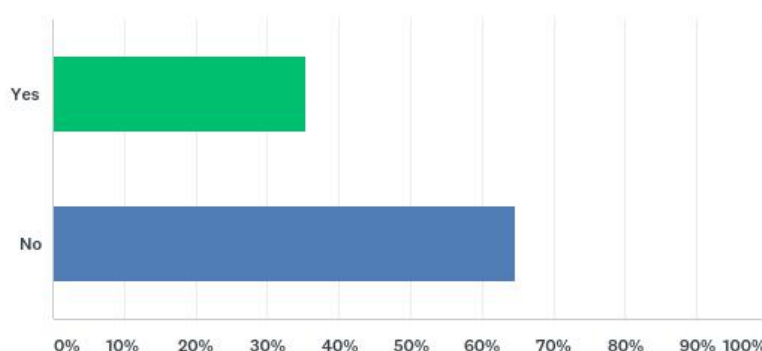


The SCNs suggested that only pouches should be demonstrated at Stoma Patient Open Days.

SCNs recommend an annual review, as they have noted that some patients experience problems with their stoma which can be rectified with a correctly fitted appliance and a review of their prescription products. However, not all ostomates would like an annual review (37%) and decline the appointment or DNA; these may be the ostomates that have had their stomas for a number of years and have adapted suitably to their lifestyle. However, the survey revealed that 63% of ostomates would like an annual review. SCNs ask whether an annual clinical review should be mandatory.

e. Stoma Support Groups

Q14 Do you attend a stoma patient support group?



There were 65% of responses from ostomates who do not attend a support group.

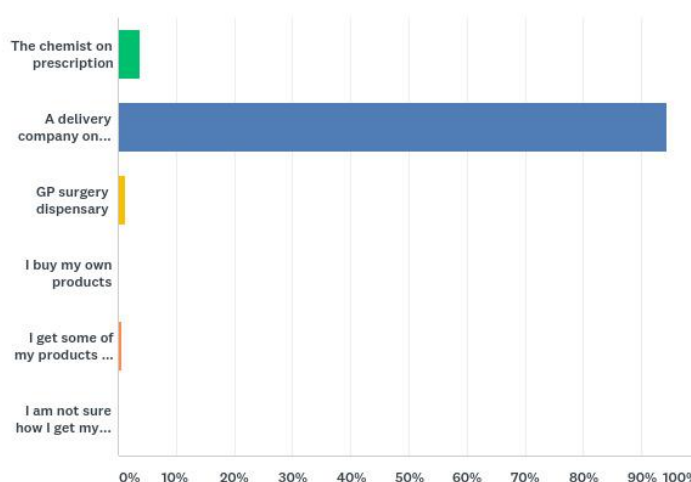
The support groups are usually ostomate led groups with nurses attending occasionally.

There are a few forums for ostomates on Facebook, Twitter and Instagram.

f. Products and Supply

The majority of ostomates (93%) obtain their stoma product supplies from a Dispensing Appliance Contractor.

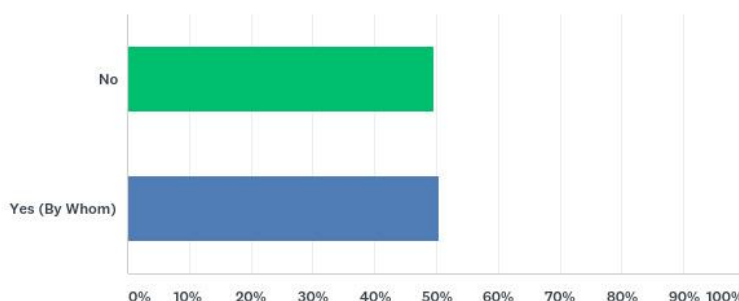
Q15 When you left hospital, where did you get your stoma products from?



Some nurses will order the ostomates prescription from a DAC post operatively on discharge from the acute hospital, while others will supply the patients with 2 weeks of products on discharge.

Prescriptions given on discharge should not exceed 2 weeks as the stoma itself goes through a period of change settling down after the operation. This prevents wastage of products no longer required.

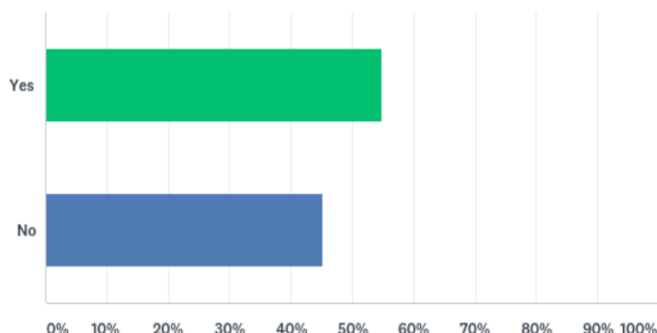
Q16 Were you made aware at the time of discharge, or subsequently, the multiple options to obtain your supplies:



Half of the respondents were made aware by their stoma nurse.

Not all hospitals have their own patient literature leaflets but may have manufacturers' leaflets.

Q17 Were you given a choice of where to obtain your stoma products? e.g. Delivery Appliance Company (delivered by a supplier to your home), GP surgery dispensary, Pharmacy

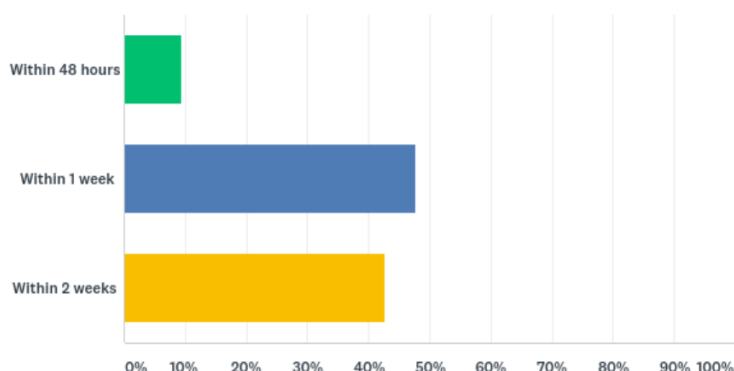


Half the respondents replied that they were not made aware of the multiple options to obtain their stoma supplies

However, 50% of respondents replied that they were made aware and this was by their SCN.

In the past, ostomates may have gone to their local community pharmacy to obtain their prescriptions but Dispensing Appliance Contractors have made the process of obtaining stoma products much easier for ostomates.

Q18 How quickly does your order take to arrive from requesting the prescription?

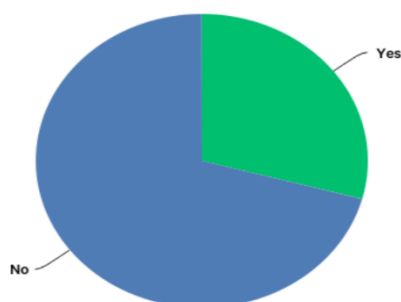


In the cases of obtaining products within 48hrs (10% of respondents), this may be where there is a Nurse Prescriber who has a centralised prescription service.

Within 2 weeks (48% responses) is an acceptable timeframe but a time frame of 1 week (or less) demonstrates excellent customer service.

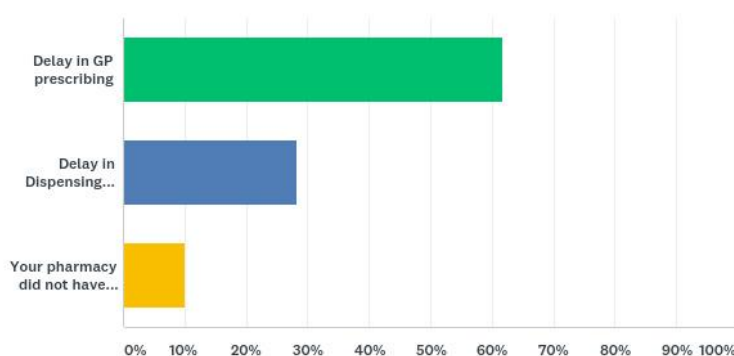
There were 42% of responses indicating that it takes 2 weeks to obtain their supplies. This can be dependable on the GP Practice dispensing the prescription in a timely manner and on the patient requesting the prescription within enough notice.

Q19 Do you ever experience delays outside of your expected delivery time frame?



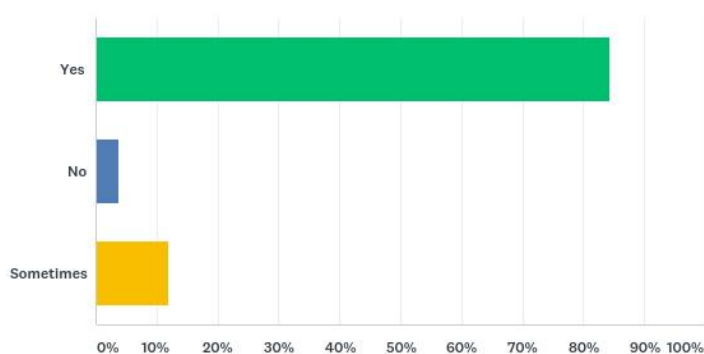
There were 30% of responses where there were delays which may have been due to the prescription being delayed from the GP (see next question). Stock in some cases may have been an issue.

Q20 If yes, what do you believe the delay was due to?



Respondents (61%) indicated that they believed that there was a delay in GP prescribing, 28% in DAC dispensing, which may have been as a result of a delay in obtaining the prescription, and the remaining 10% was due to stock being unavailable.

Q21 Are you satisfied with the range of products available?

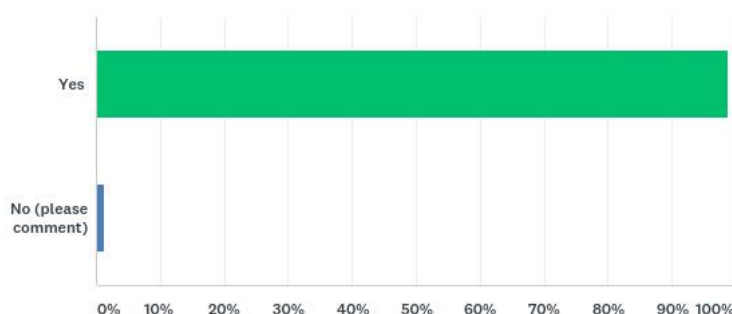


Most respondents (84%) were satisfied with the range of products while 4% were not and 12% were sometimes satisfied.

From the responses ostomates appear not to be aware of the different products available

An example was given by an SCN of a young female ostomate who had vanilla blush underwear on her repeat prescription (6 pairs a month, or 72 pairs per year) until the CCG-commissioned SCN intervened and changed the prescription. Another example was given of Cavilon sticks being given to a patient in hospital – they should not be required.

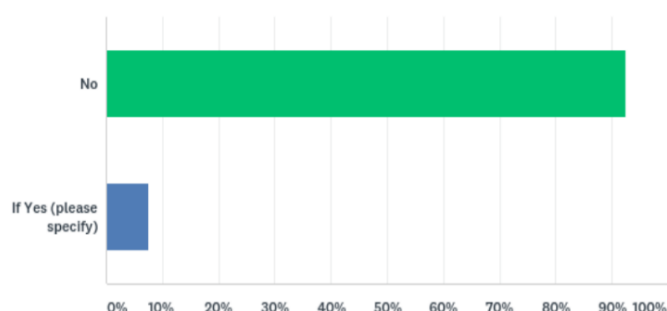
Q22 Are your stoma products delivered to you in discreet packaging?



There were 98% of responses that confirmed that their products are delivered in discreet packaging while 2% replied that they do not. One ostomate reported that they receive their products supplied in a clear carrier bagk, which is unacceptable.

Some community pharmacies have introduced a £5 delivery charge.

Q23 Are you purchasing products which are available on prescription, but your stoma nurse or GP will not allow?



The majority of the responses (92%) indicated that ostomates are not buying their own products which are available on prescription.

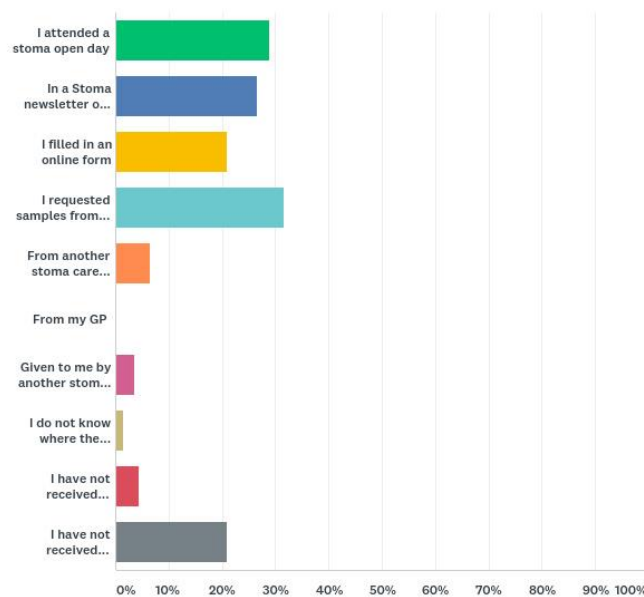
Most areas in the region have formularies in place which do not include deodorisers. Some nurses will only prescribe deodorisers if it has become a psychological issue for the ostomate. Nurses prescribe on an individual basis.

g. Sampling

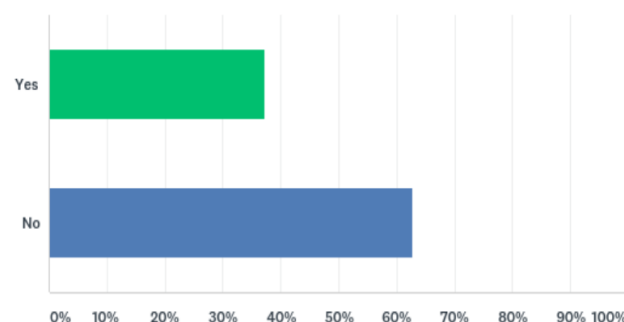
Ostomates obtain samples from a variety of sources:

- Stoma open days
- Stoma newsletters
- By completing an online request
- Other ostomates
- DACs

Q25 If you have received samples where did they come from? Please tick all that apply



Q26 Did you request that any of these stoma related products were then added to your prescription?



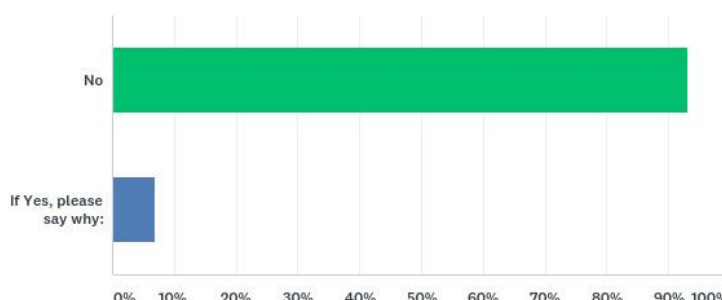
Approximately a third of the respondents replied that they did request additions to their prescriptions. These may not have been clinically appropriate. There were 57% of responses that were given products from sources other than their SCN.

The majority of ostomates (98%) felt that they do not receive products that they do not require.

Ostomates (92%) confirmed that they do receive free disposal bags and wipes. Disappointingly, 2% do not. Most DACs give free wipes and disposal bags while some pharmacies do not. All dispensers of stoma products are required to provide free disposal bags and wipes.

h. Standards of Stoma Care Service

Q29 Have you ever had an occasion to complain about the standard of stoma care service from your stoma nurse?



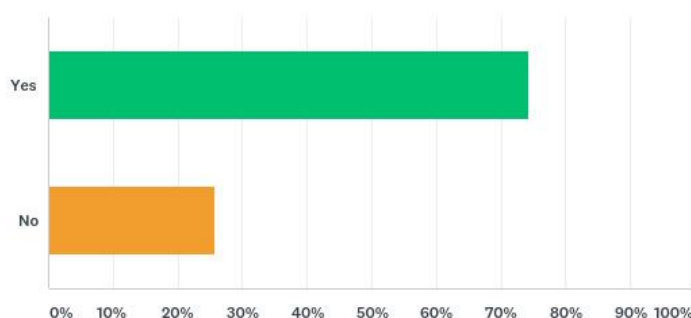
The majority of ostomates (93%) have not had an occasion to complain about the standard of service from their SCN.

Of the 7% of respondents who did have an occasion to complain the trends were relating to:

- Obtaining their prescription via their GP or DAC
- Difficulty in contacting their SCN for advice

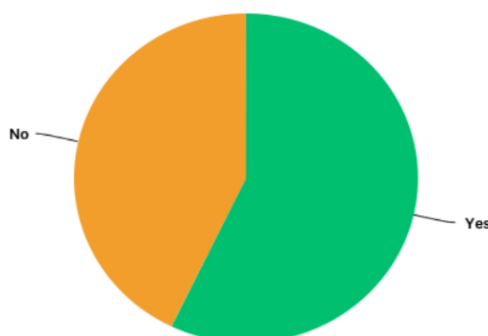
Ostomates should have access to a telephone voicemail messaging service which is responded to within 24 hours.

Q30 If Yes, were you satisfied with the outcome of your complaint?



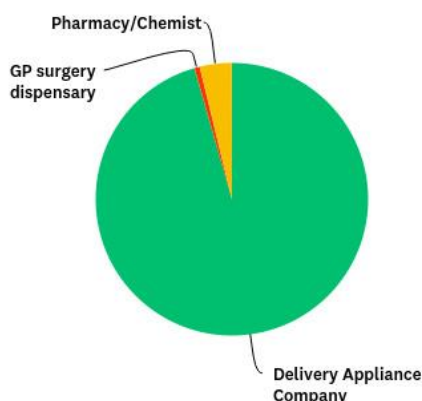
There were 74% of complaints that were resolved while 26% were not resolved.

Q31 Do you receive a good standard of stoma care service from your GP?



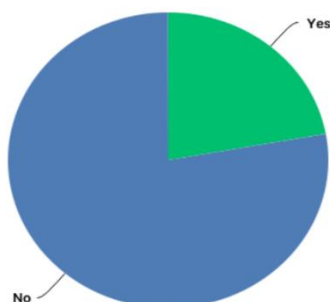
47% of respondents felt that they received a good standard of service from their GP while the remainder who feel they do not, state that they felt their SCN is their first port of call if there are any problems and their GPs generally have limited knowledge about stoma care.

Q32 Where do you get your stoma supplies from?



Most people obtain their products from a DAC (95%) whilst the remaining rely on their GP surgery dispensary (1%) or community pharmacy (4%).

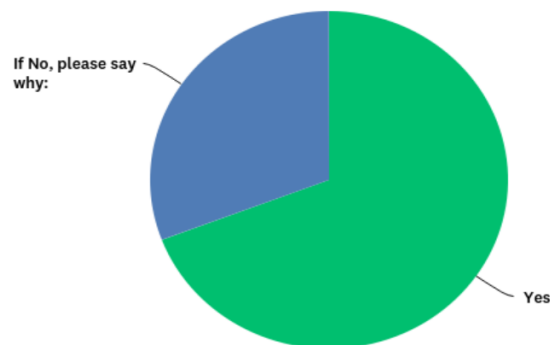
Q33 Have you ever had an occasion to complain about obtaining stoma supplies?



- 22% yes
- 78% no, indicating a general level of satisfaction

SCNs commented that there may be a delay in the prescription being dispensed and sometimes deliveries are delivered to the wrong place.

Q34 If Yes, were you satisfied with the outcome of your complaint?



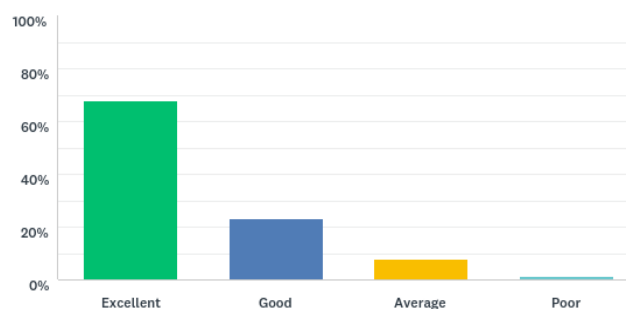
- 70% were satisfied with the outcome
- 30% were not satisfied

Manufacturers should ensure there are satisfactory quality assurance checks of their products. Dispensers should ensure that they hold enough stock to avoid distress to ostomates.

i. Patient Experience

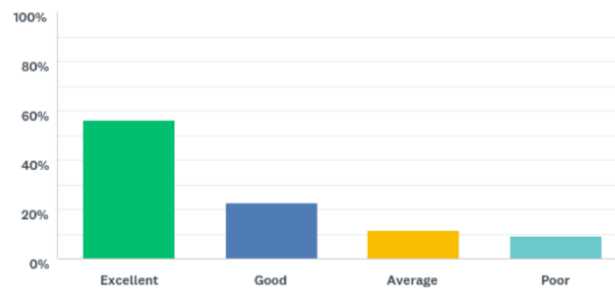
There were 9% of the respondents that felt that their stoma nurse support was poor or average, while the majority of 90% felt that their experience was excellent or good.

Q35 Overall how would you rate your experience of stoma nurse support in the hospital when you had your operation?



- Excellent 67%
- Good 23%
- Average 7%
- Poor 2%

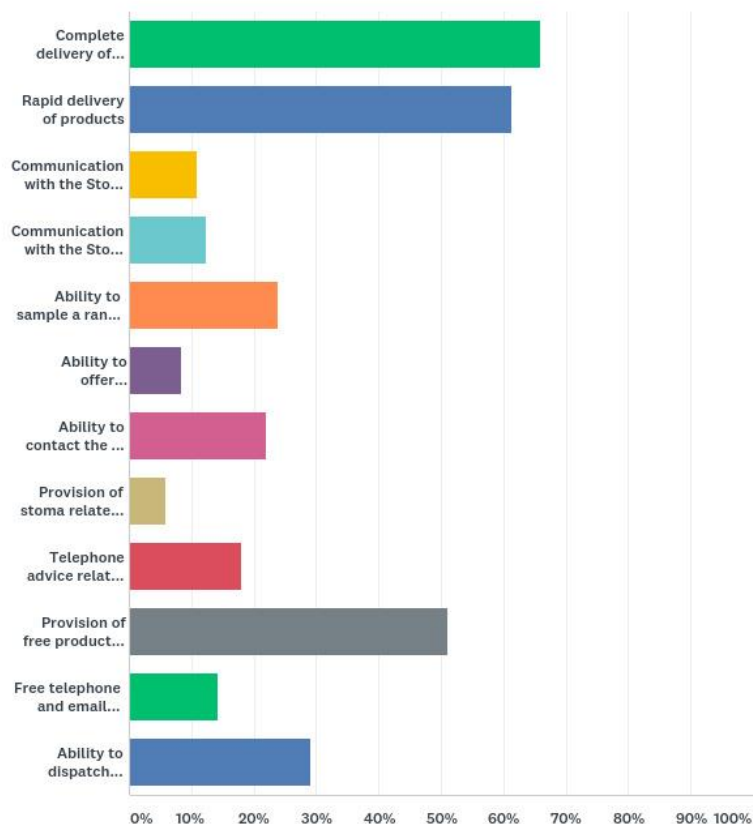
Q36 Overall how would you rate your experience of stoma nurse support after your operation, when you went home?



- Excellent 56%
- Good 23%
- Average 12%
- Poor 9%

There are a variety of pathways in place in the region. Some acute hospital SCNs will follow up with home visits in the community while some ostomates will be passed over to the community SCN on discharge from hospital.

Q37 Please rank the THREE most important factors that you would associate with an excellent Dispensing Appliance Contractor/Home Delivery Supplier:



The trends appeared to be that delivery of products in a timely and efficient way is the most important factor, as well as the provision of free wipes and disposal bags in discreet packaging.

Some ostomates like the ability to trial and sample different products.

Ostomates responded that they value being able to have contact or access their Stoma Care Nurse Team although some ostomates suggested that communication could be improved with the Stoma Care Nurse Team.

Ostomates felt supporting patient literature and information leaflets on lifestyle, skin problems would be useful.

There could be improvements to the prescription process.

Annual Reviews are recommended by some of the patients who have responded.

One ostomate reported that they only receive one wipe per day which is unacceptable particularly if they have a high output stoma.

There were many individual comments praising the relationship and service the ostomates receive from their SCNs.

The prescribing process can be challenging in ordering and receiving supplies.

Overall, ostomates are very satisfied with the service from their DACs.

5. Recommendations:

When establishing stoma care services or introducing new pathways, consideration should be given to ensure that a telephone messaging service is available for ostomates to access.

STPs/ICSs will need to consider whether their patient population who have had their stomas for over 5 years may require less intervention than patients with newly formed stomas.

STPs/ICSs may need to consider service redesign and standardisation of their stoma services and patient pathways as there appear to be a variety of pathways in place across the region.

When commissioners are planning services for ostomates, consideration will need to be given that other services will be required such as mental health/counselling, dietitians etc.

Patient registers for ostomates would help to ensure that patients are not lost in the system to follow up.

When establishing stoma care services or introducing new pathways, consideration should be given to ensure that a telephone messaging service is available for ostomates to access.

SCNs recommend that some accessories (such as deodorants, underwear and pouch covers) should be removed from Part IX of the Drug Tariff.

The SCNs suggested that only pouches should be demonstrated at Stoma Patient Open Days.

Prescriptions given on discharge should not exceed 2 weeks as the stoma itself goes through a period of change settling down after the operation. This prevents wastage of products no longer required.

SCNs should advise on what is clinically appropriate for patients.

As a result of this survey and subsequent focus group, one acute hospital will change its patient letters to request ostomates to attend an annual review.

An alert should be set up when patients continually decline their review to ensure they are still prescribed clinically effective products.

It is recommended that STPs look at their nurse capacity to deliver annual clinical reviews with an increasing population and age demographic.

Patient information leaflets should be available to inform the patients of the many DACs available. Patient leaflets require an annual review to ensure they contain the correct information and advice. Verbal guidance and advice where possible should be backed up with written patient literature information leaflets.

Ostomates should be advised on where to obtain their products by their own choice.

The choice of products should be based on type rather than brand.

All stoma packaging and wrapping should be in discreet packaging.

Samples should not be given without discussing with SCN to ensure the products are clinically appropriate.

There should be a nurse review following a request to change products.

There should be an annual review to prevent or minimise products being prescribed that are no longer required.

Ostomates should be advised not to request products on their prescriptions if they no longer need them to minimise waste.

All dispensers of stoma products are required to provide free disposal bags and wipes.

Ostomates should have access to a telephone voicemail messaging service which is responded to within 24 hours.

Manufacturers should ensure there are satisfactory quality assurance checks of their products.

Dispensers should ensure that they hold enough stock to avoid distress to the ostomates.

A robust pathway should be in place and be agreed at STP level to ensure equitable access to ostomates.

6. Acknowledgements

We would like to thank all the ostomates who participated in this survey and whom were able to give us inciteful comments and feedback on their stoma service experiences.

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