

NHS Liverpool Clinical Commissioning Group

**Report of Engagement with Stoma
Patients and Other Stakeholders**

V.6

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Summary

- 108 responses were received for a survey regarding proposed changes to stoma prescribing designed to inform final service design
- The vast majority of respondents indicated strong support for the proposed service changes and thought that the changes would lead to a better service
- The largest patient responder group was patients who had been using stoma products for more than 12 months
- The majority of respondents recognised that there were issues with the current service
- The most frequent complaint from users concerned ordering issues for their stoma products once they are released from hospital using the current service
- The majority of respondents would prefer to be contacted by the new service on weekdays during the day time
- There were no significant issues raised relating to protected characteristics groups

Acknowledgements

- Our thanks go out to the Liverpool CCG team for curating this survey, contacting and surveying the stoma respondents, and collating the information to be analysed. In addition to this, we express our thanks to the CCG for allowing us to analyse their data, and support our training needs
- Our thanks are also given to the survey respondents for completing the survey and providing us with detailed feedback, without which we could not have written this report

Introduction

A Brief Background

This report presents the findings of the engagement undertaken to inform proposed changes to arrangements for stoma prescriptions for Liverpool patients.

A stoma is an opening on your abdomen that can be connected to either your digestive or urinary system. There are three main types: colostomy, ileostomy and urostomy. Stoma surgery is undertaken to treat a range of illnesses including cancer, diverticulitis and Crohn's disease or following a trauma to the abdomen.

Issues related to the prescribing or use of continence products can, and has, led to both the physical and social condition of patients degrading, and are part of the reason why the changes to service have been proposed.

In Liverpool stoma patients are currently experiencing a number of issues related to the management of their condition once they are discharged from hospital. At the moment, patients are discharged from hospital and repeat prescriptions for stoma products are issued by their GP.

The Proposed Change

The NHS in Liverpool wants to improve care for adults and children using stoma products. The proposed change is to introduce a specialist stoma prescribing service overseen by stoma nurses, instead of products being issued by GPs. The proposed service changes would also include a monthly remote check-in with patients and a yearly face-to-face review with a specialist stoma nurse.

The full list of the proposed service changes are listed below:

- Provide a safe and effective centralising prescribing service responsible for all stoma-related prescribing needs
- Deliver a prescription ordering service that is easy to access, responsive, timely and incorporates clinical support
- Issue prescriptions for stoma appliance products, authorised by a specialist Nurse Prescriber who has in depth understanding of stoma care, thus removing this responsibility from General Practice
- Ensure prescribed product quantities, product type and any changes of product are in response to clinical need
- Allow patient choice of dispenser i.e. Community Pharmacies and Dispensing Appliance Contractors (DACs)
- Provide clinical support from a specialist Nurse Practitioner and ensure every patient in the service receives an annual review
- Respond effectively to secondary and community care services in terms of new patients requiring access to the service and existing patients where a review or change in treatment has taken place
- Have robust mechanisms to refer patients to appropriate NHS and social support services where further intervention outside of the scope of the service is required

The benefits of the new service are anticipated as:

- One central service for patients and carers to contact with any appliance and product queries
- A proactive telephone ordering service
- Increased quality of life for patients by ensuring the best appliances and products to meet patient need are prescribed, and prescribed correctly
- Access to specialist advice and the introduction of a specialist annual review
- Reduction in prescribing waste meaning money can be invested where needed

The Objectives of the Engagement

NHS Liverpool CCG carried out a public engagement from 30th July – 23rd September 2019, using a survey to record the views of stoma patients on the new proposal, (Appendix 1). The engagement aimed to:

- Engage with patient groups that will be directly affected by the proposed changes (stoma patients) to find out about current difficulties they experience and ensure this feedback is considered in the development of the service
- Share the potential solutions that have been considered and present the preferred option
- Understand how the preferred option may impact on service users and their views on the proposed changes

Promotion

- Printed surveys were distributed to patients by the stoma clinics at the Royal Liverpool, Aintree and Alder Hey hospitals.
- An online survey was circulated to local and national patient groups, professionals and those involved in previous planning for this change.
- The engagement was promoted on NHS Liverpool CCG's website and social media accounts (see appendix 2), and featured on the Envisage TV screens in Liverpool GP practices.
- The CCG used its communications channels with general practice in Liverpool – intranet site, fortnightly email bulletin and desktop wallpaper – to make GPs and other practice staff aware of the engagement.

Risk Management

The survey responses were collected by NHS Liverpool CCG staff. This was done in accordance with all legal data gathering requirements and internal SOPs, without bias or discrimination.

The survey responses were processed in NHS Liverpool CCG in collaboration between the CCG and two Trainee Health Informatics Healthcare Science trainees from the Royal Liverpool and Broadgreen University Hospitals NHS Trust: Louis Bloomfield and Yu Qiao. This was done in accordance with NHS Liverpool CCG's wishes and to support the training requirements of both Louis and Yu.

Both Louis and Yu signed confidentiality agreements and declared that there was no conflict of interest between them, the Royal Liverpool and Broadgreen University Hospitals NHS Trust, or NHS Liverpool CCG, with regards to the stoma survey responses.

Methods

Quantitative Data Analysis

The data was collected using a paper and online survey with paper survey results entered by NHS Liverpool CCG staff. Headline results are presented from the online survey tool.

The programmes used for automated analysis were Python v3.7, including relevant data processing modules (csv, matplotlib, numpy, os, and pandas) and R v3.61.

Qualitative Data Analysis

Free text collation and analysis was done manually as the variation between comments made automated analysis unviable for the scope of the project.

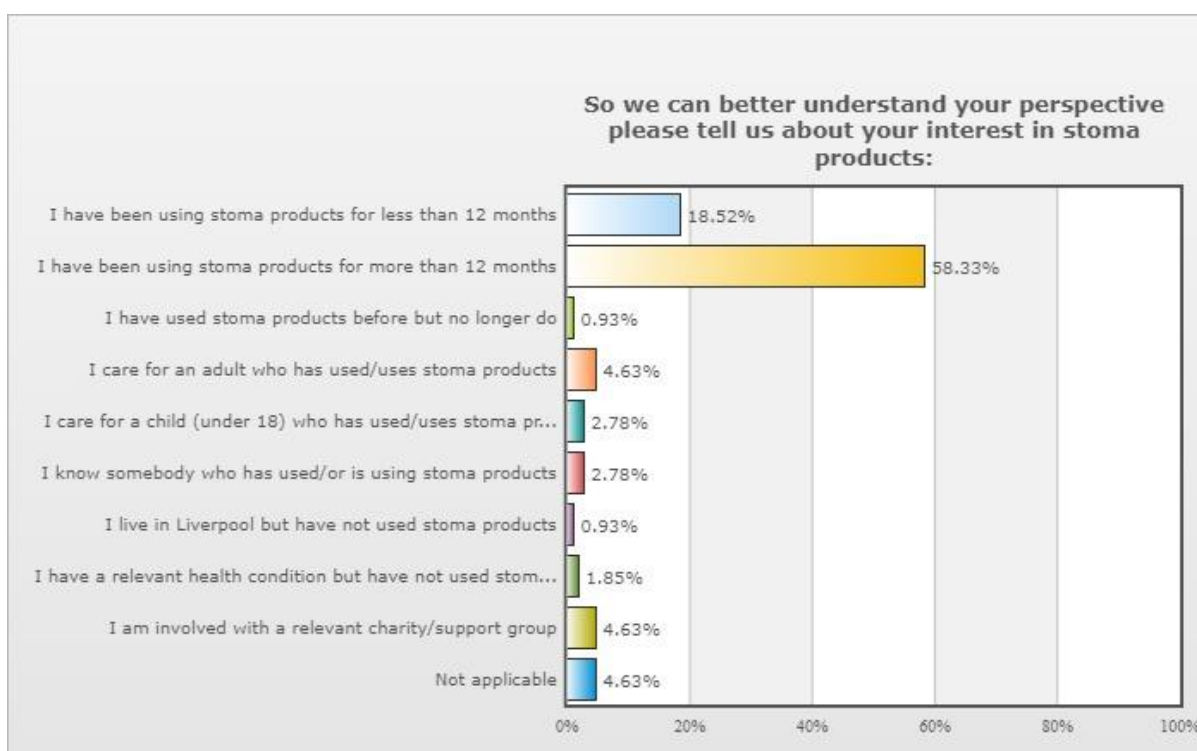
Visual Graphs

The graphs and charts were generated by SmartSurvey's inbuilt function and using Python (module matplotlib).

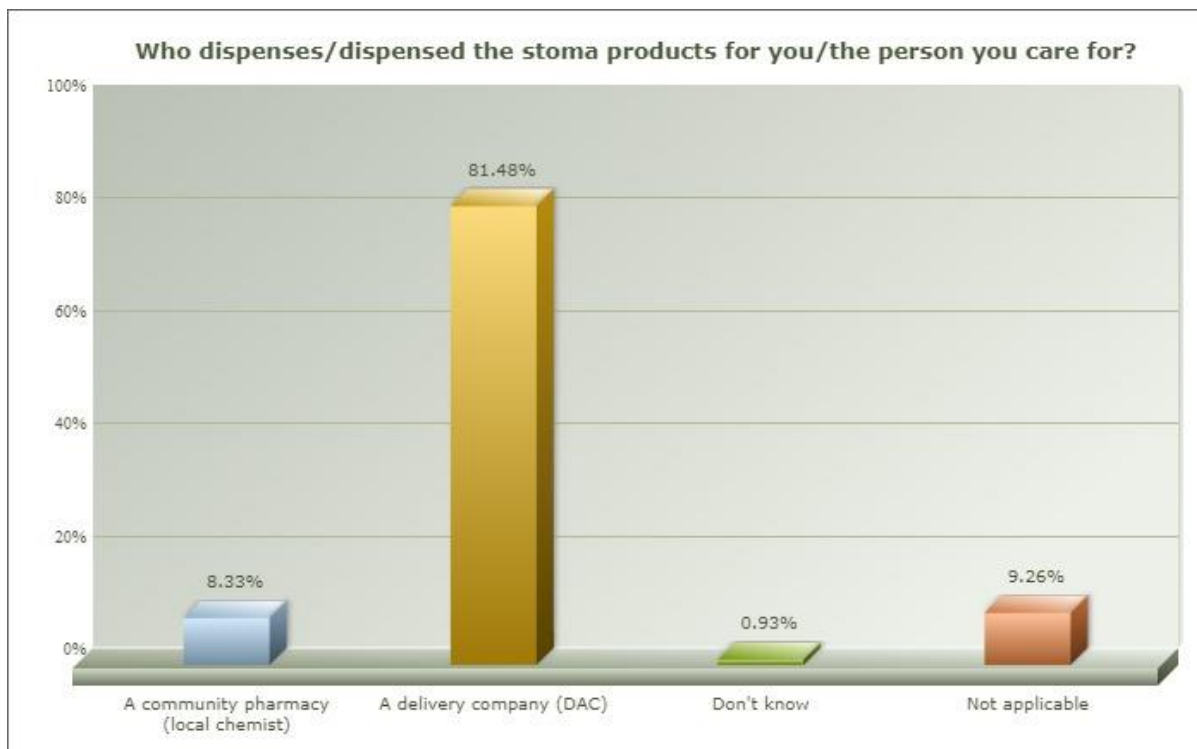
Results

A total of 108 responses were received, of which 54 were in digital format and another 54 in physical format. 6 individuals who had postcodes outside of Liverpool were excluded from the analysis, as the Stoma service outside of Liverpool cannot be determined and may be different from the ones provided in Liverpool. The remaining 102 (94.444 %) were included in the analysis, which consists of individuals, carers or GPs with a Liverpool postcode, organisations providing Stoma services, and support/charity groups involved in the stoma care provision with a headquarters postcode in and outside of Liverpool.

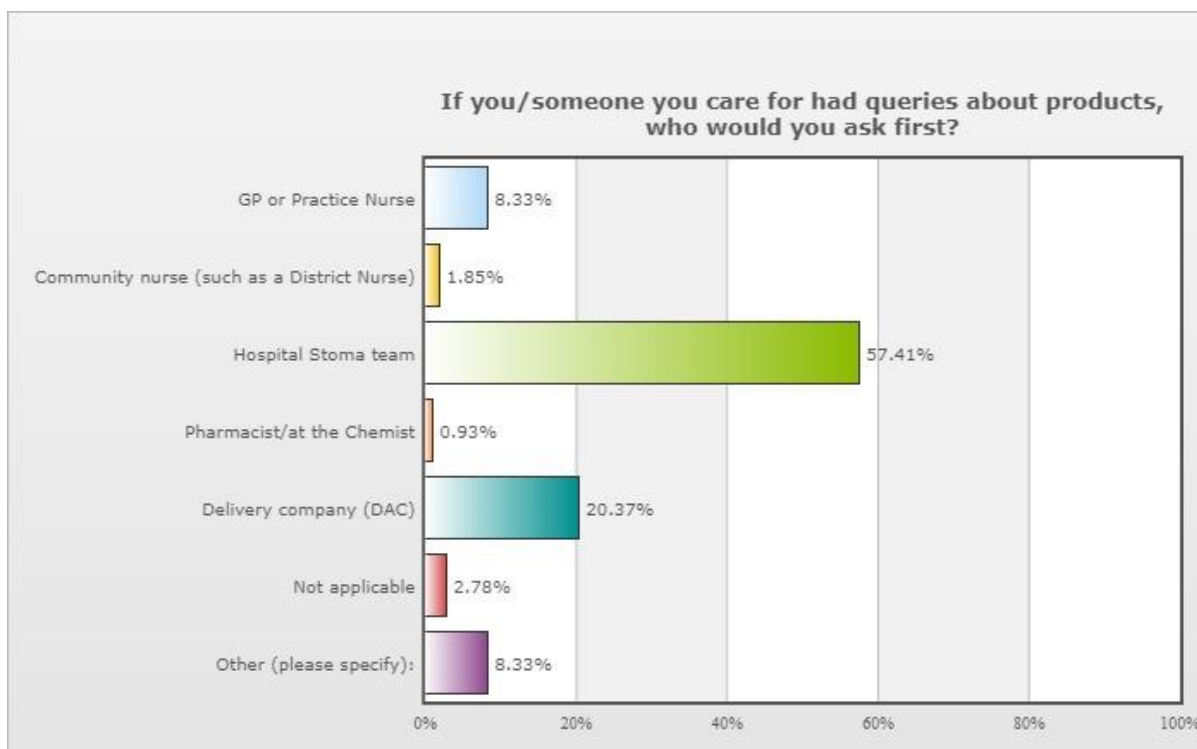
There were a range of respondents (shown below) from multiple areas, with the majority being those that had used stoma products for over 12 months prior to the survey.



The vast majority of respondents had their stoma products dispensed by their delivery company (shown below).



With regards to who respondents would seek information from about stoma products, the majority responded that they would ask the hospital stoma team first, (shown below).

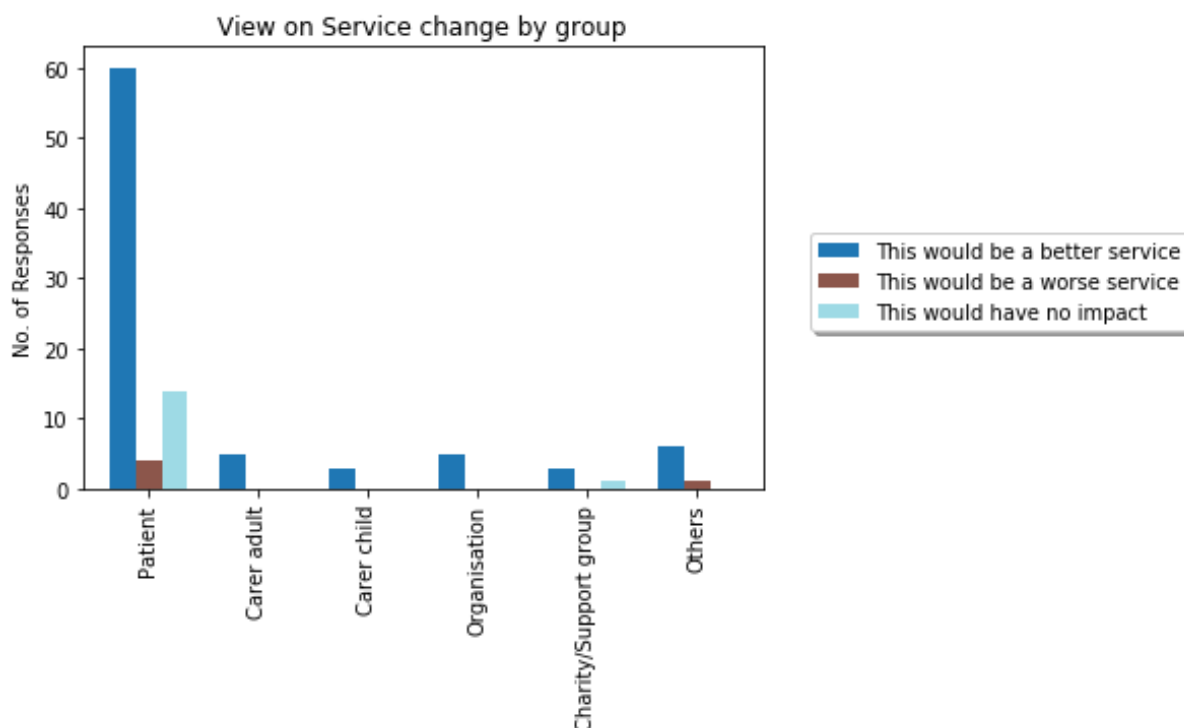


Why did some respondents consider themselves as N/A to this question in this survey?

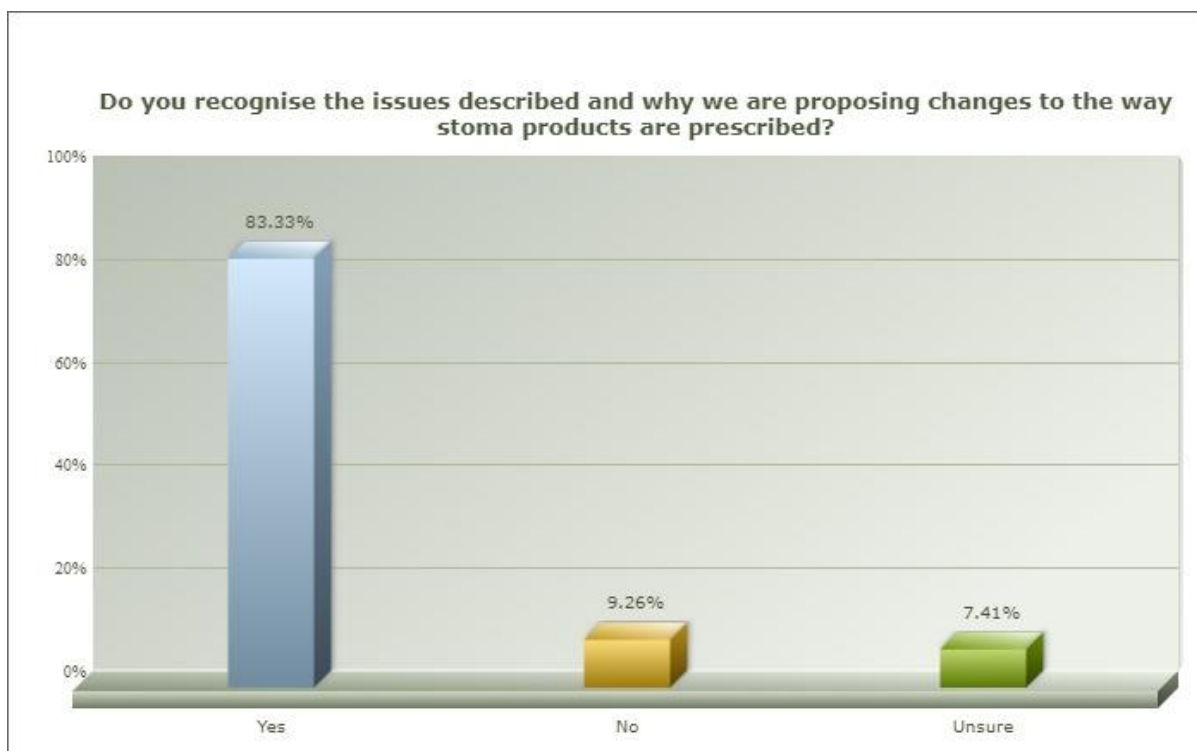
Four of the five N/A responses were from GP surgeries, with the remaining response from an individual. The individual received an email from NHS Liverpool CCG, but there was no response indicating that they used stoma products, or had any contact with anyone who did use the products.

What were the main themes of the responses?

Regarding Q4, users were separated into group (groups of patients, carers, organisation, charity/support groups and other relevant individuals). The majority of users, from all demographics, strongly agreed that the proposed service changes are an improvement on the current service. In the figure below, both caring groups for adult and child as well as organisation and charity support groups also agreed that this would be a better service. Other individuals also agreed that this would be a better service.



Regarding Q7, over 83% of respondents recognised why the CCG proposed changes to the way stoma products are currently prescribed due to the current issues faced, (shown below).



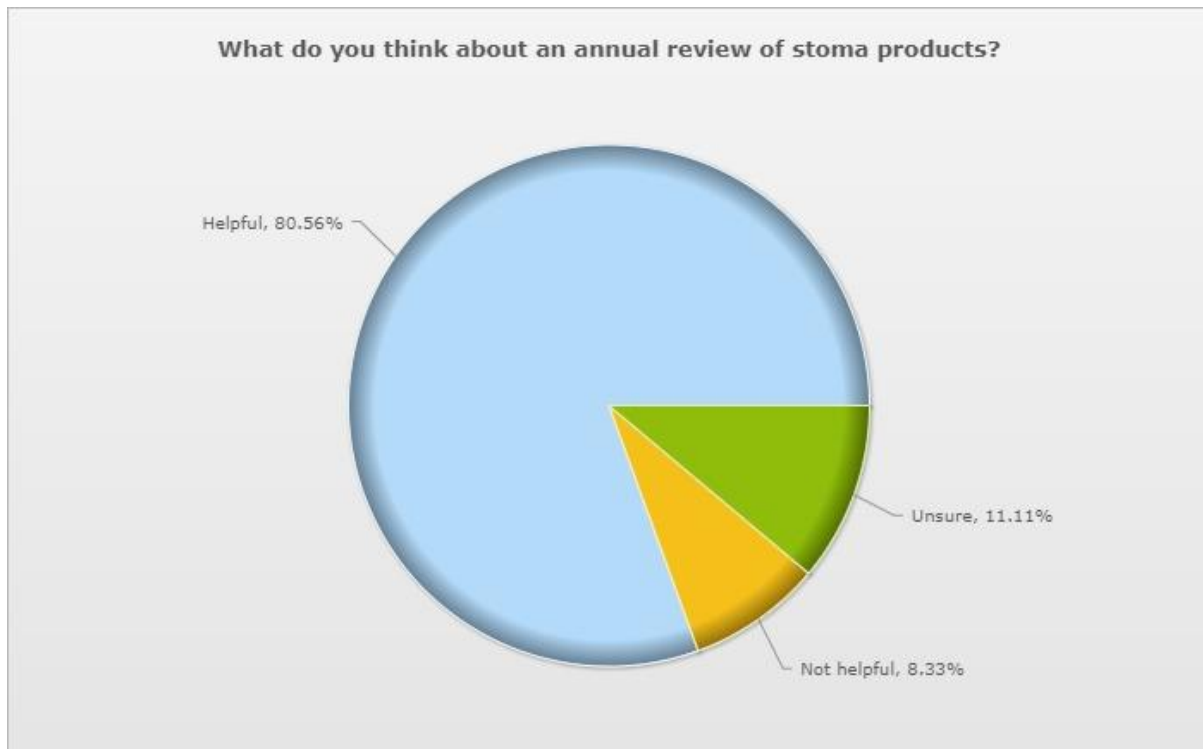
Some people disagreed with the proposal. What kind of comments did they leave?

9.26% of respondents didn't agree with the issues described and 7.41% didn't know. Those who responded that they did not think the changes would have an impact, or would result in a worse service, gave comments indicating that they already had a good experience with their stoma services, and saw no need for change.

The most common comments across all user demographics were complaints around GP prescriptions. GP complaints seem to originate from the deliveries patients receive at home, with GPs or the suppliers providing insufficient/wrong products, as well as ordered items not being delivered at the same time. The nature of the complaints varied from GPs not authorising companies to provide the products in time, to confusion/frustration over how long the ordering process takes once orders have been placed.

In addition to this, users complained that GPs do not have enough knowledge about stoma patients, and as a result they cannot give enough support and information to stoma patients about what products are best.

The majority of respondents indicated that the annual review of stoma products would be helpful for them, (shown below).



What were the general concerns/themes of the responses?

Users indicated that a stoma specialist who is knowledgeable in stoma products would ensure their service is personalised to their needs. Their comments also indicated that monthly contact would give service users more control over their products, and increase their patient care experience.

Users indicated that their stoma situations change over time, and a regular review could ensure that stoma changes are monitored so that patients can be informed if their changes are normal or not. Users also implied that an informed specialist stoma service could help inform them of stoma products that they are not aware of.

Users have expressed concerns around having repeat prescriptions that are a set amount of stoma product every month, as the amount of stoma product can vary each month depending on the user's needs. Also, there were concerns that users need to be able to get extra stoma products should they need it.

Users were worried that there would not be enough resources to make the changes effective, as some already struggle getting contact/appointments with the stoma team. In addition to this, concerns were noted around the amount of time and resources required to train the specialist service before it becomes effective. As part of the proposed service changes, users were worried about the suppliers of products being

reduced or dictated to them. Users also expressed concerns that the service should remain impartial as different products are suitable for different stoma sizes/types.

Users indicated that contacting the stoma nurses that currently care for them, for advice or support, can be difficult as they are frequently busy or unavailable.

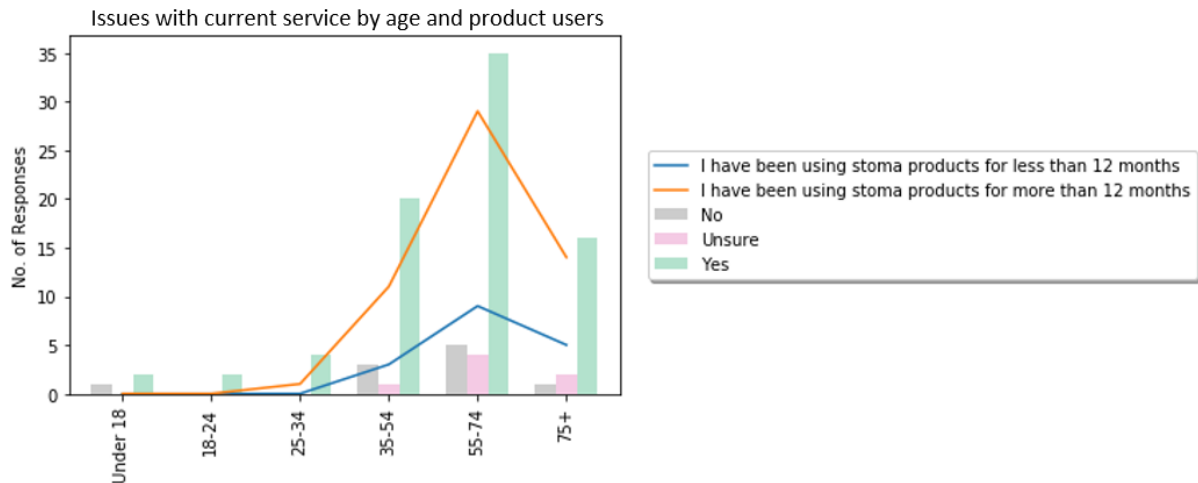
Many respondents felt that having the Stoma Prescribing Service responsible for prescribing and managing stoma products would alleviate the GP prescription issues that they experienced.

Did short-term and long-term views differ?

The short-term (<12 months) and long-term (>12 months) users of stoma products both expressed concerns with the DAC and GP communication around getting their products on time, with long-term users giving the greatest number of responses around this issue. These ordering issues for all users also included incorrect/delayed orders and GPs not knowing enough about stomas to suggest the best products for an individual's needs due to the variability between stoma patients. Both short-term and long-term user comments suggested that they want a single service to organise prescriptions, instead of having to constantly go between GPs and DACs, in order to avoid the aforementioned ordering issues. The vast majority of respondents who had complaints about the current system implied that the proposed stoma specialist team ordering their products would be a better service, ensuring they received the correct products, as well as avoiding them over or under-stocking stoma products.

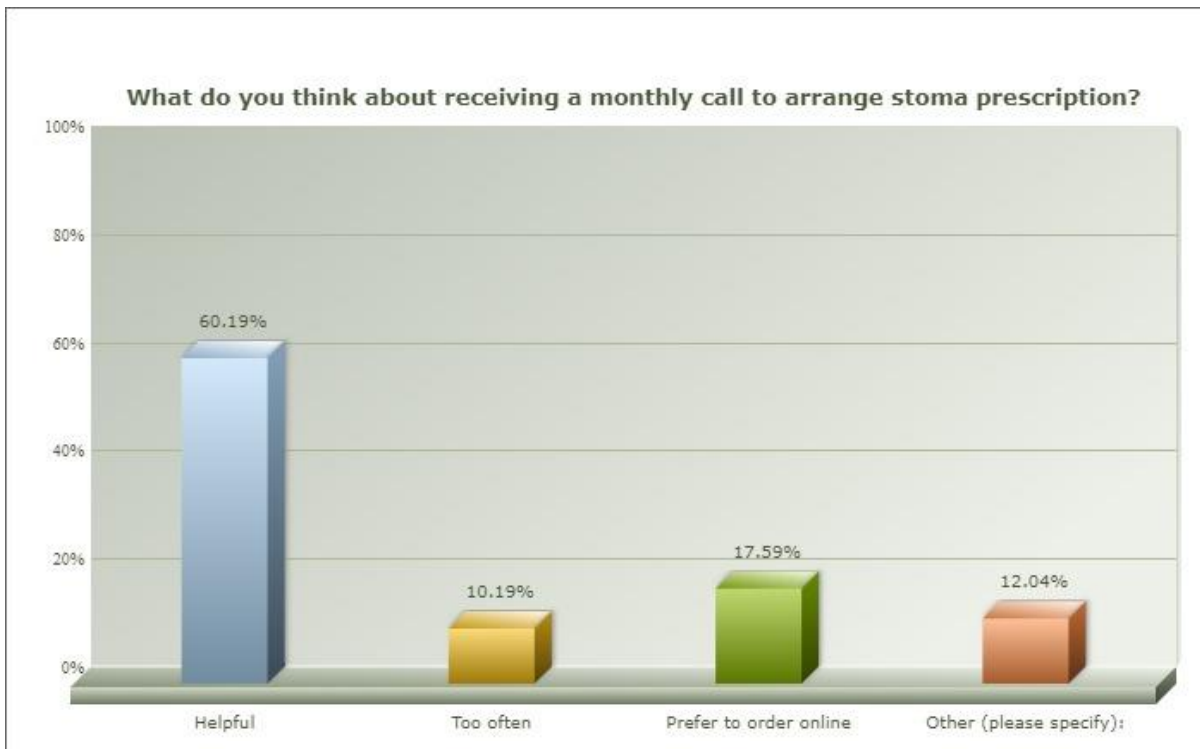
Short-term users seek reassurance and support from health services that their stomas are being dealt with properly, as stomas undergo change over time which can worry patients unduly if they lack support.

Short-term users reported fewer issues with the current service and were more likely to answer that they were unsure. After adjusting for the number of respondents in each group, it was found that the responses of short-term and long-term users both reported recognising issues with the current stoma service at an almost identical ratio across age groups (shown below).



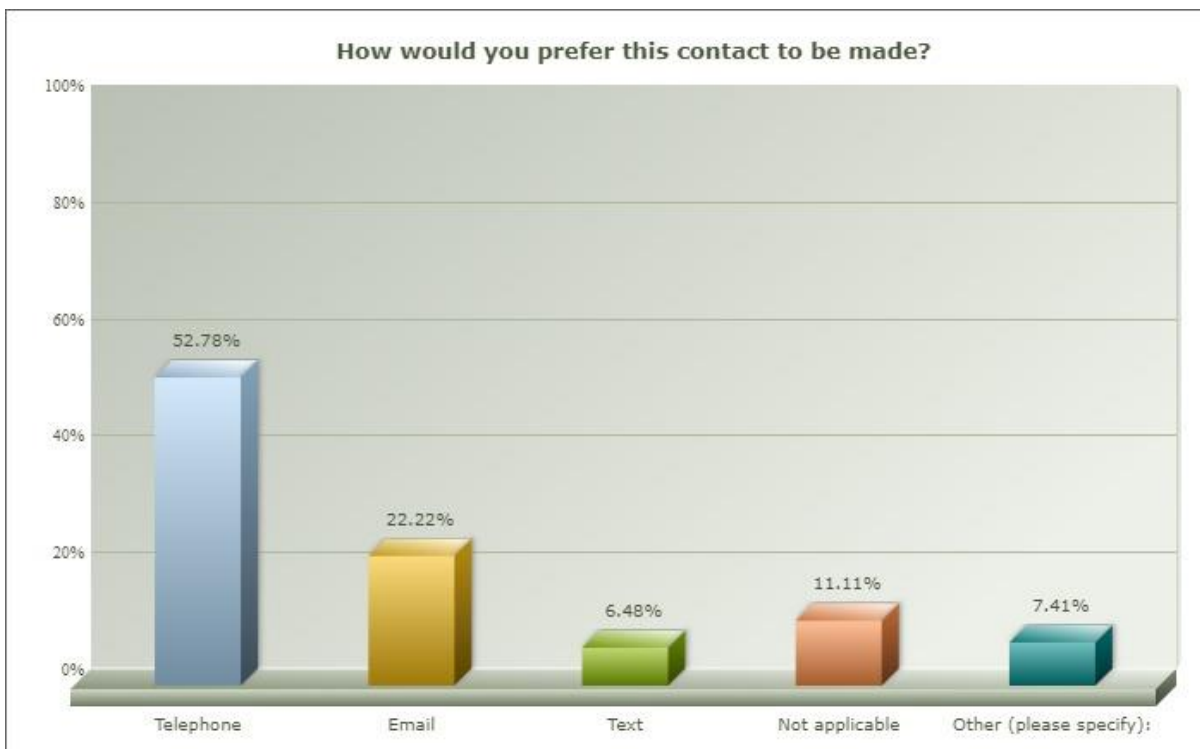
More long-term users expressed their support for having a stoma specialist in the comments for Q7, Q8 & Q9. This support was mirrored by more long-term users who expressed their concerns around the difficulties of stoma delivery delays from the GP/DAC. Older users expressed their views more strongly than younger users, but also provided more suggestions on the changes that are found throughout this report. Long-term users differed from short-term users where they were concerned over the new service leading to disruptions in their current service, as well as money being saved at the expense of patient care. This was countered by comments showing that users expected the changes in service to cause disruption as they are implemented, however all user groups were positive as a whole with the majority wanting the proposed changes in service to be made.

Overall, the majority of respondents indicated that a monthly call to arrange stoma products would be helpful, (shown below).



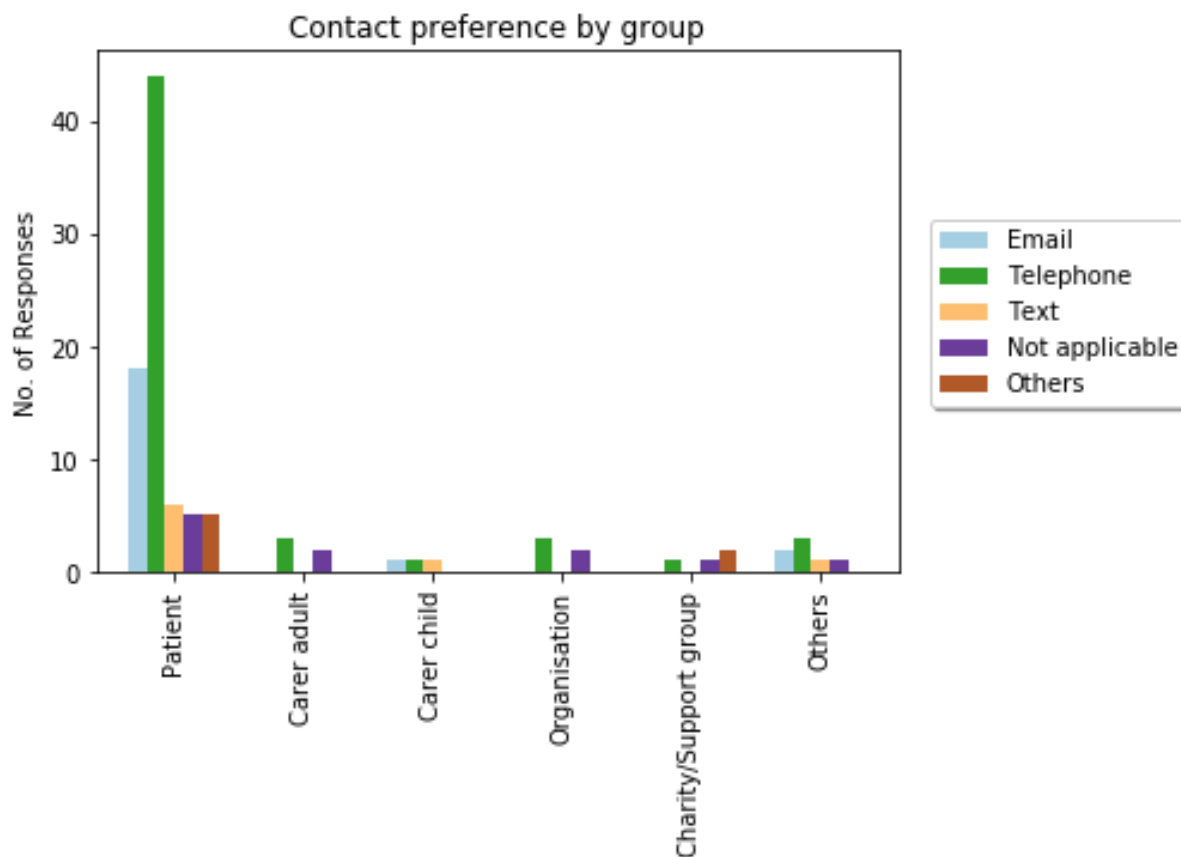
How Would Users like to be contacted?

Overall, the majority of respondents preferred telephone contact followed by email then text, (shown below).

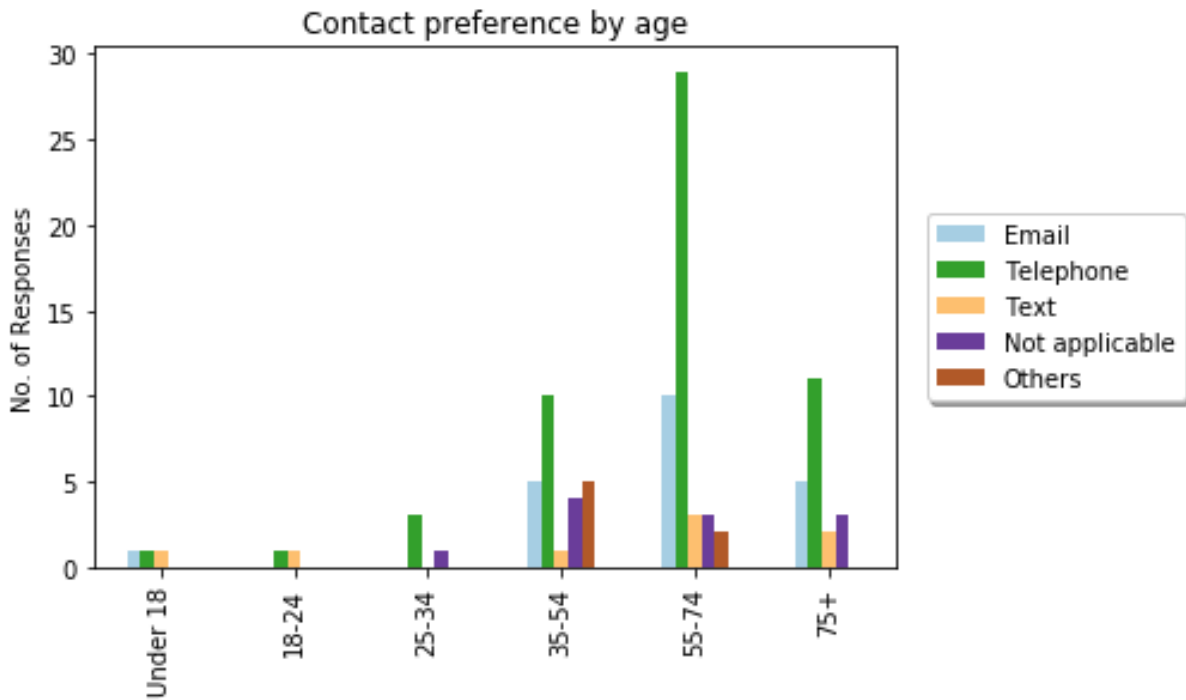


The majority of individual patients preferred to be contacted by telephone, followed by email then text. The responses from all other

groups were varied but few so no trends were conclusively found, (Shown below).

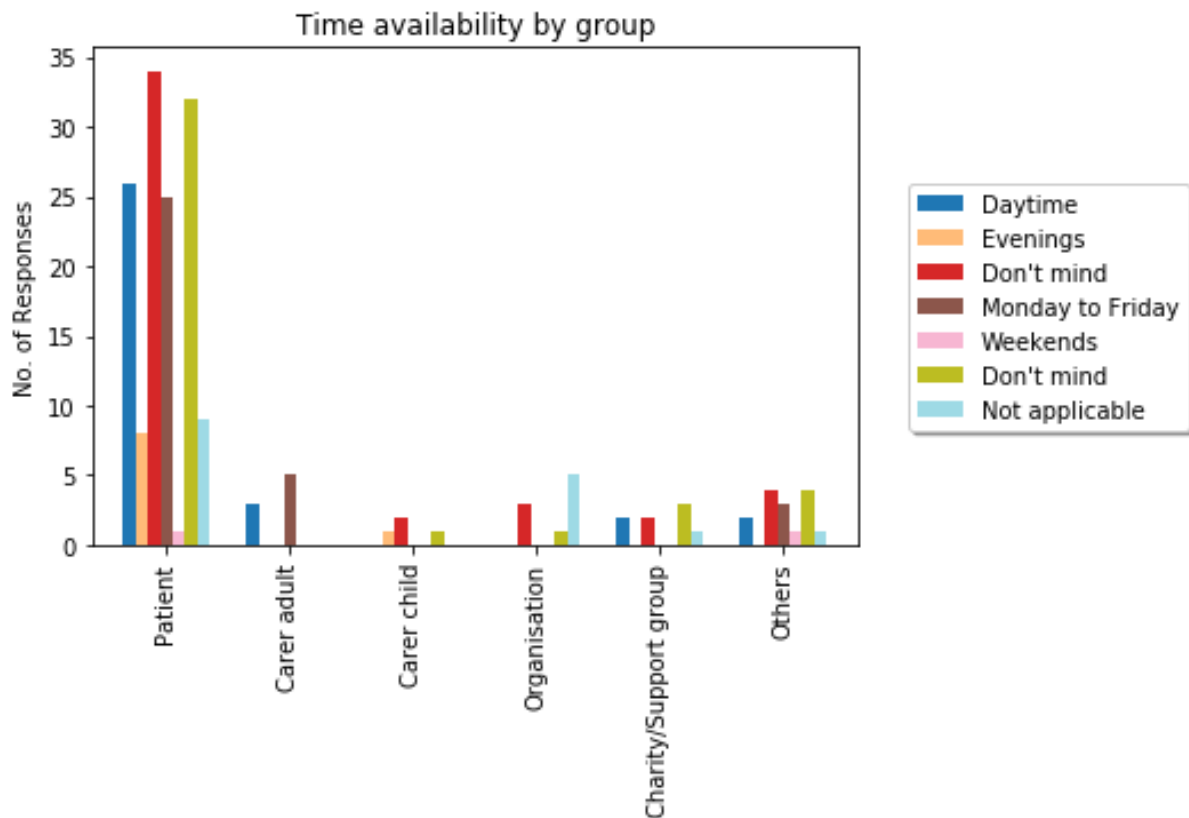
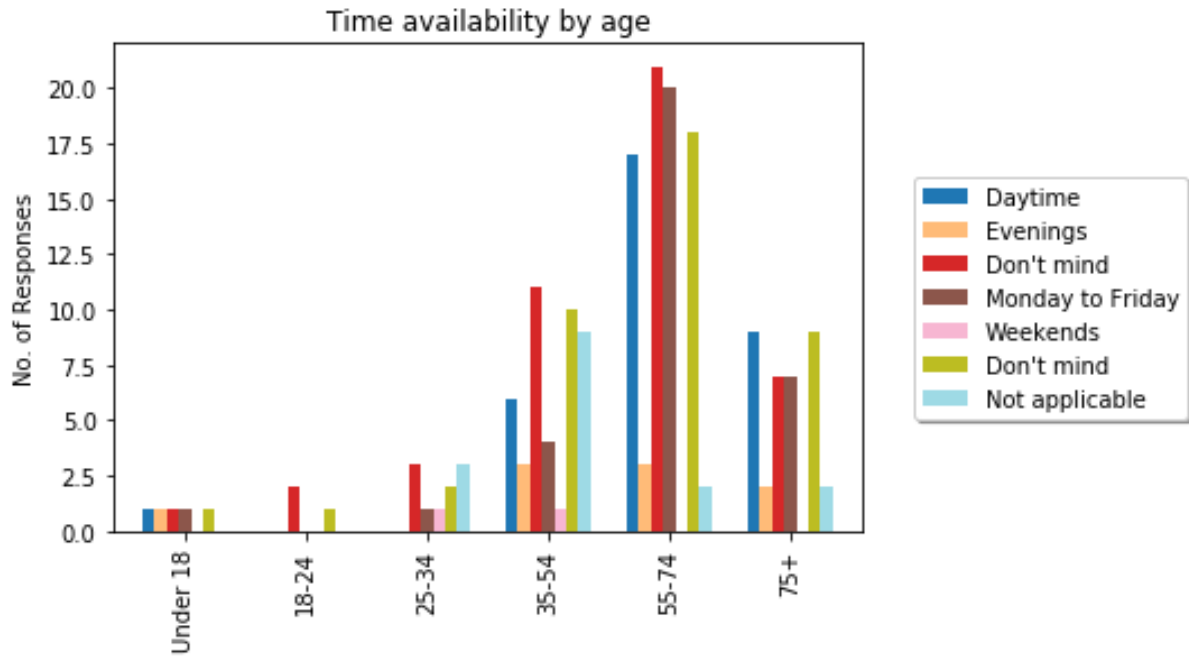


The majority of the users prefer to be contacted by telephone and email, whereas N/A responses were generally from organisations or charity/support groups. There is no significant difference between groups on the preferred contact media aside from those in the 55-74 age group where respondents preferred telephone over other forms of contact (Shown below).



What time Would Users like to be contacted?

The time preferences for most age groups were extremely mixed based on the individual. There were no preferences shown from the Under 18 and 18-24 age groups. Ages 25-34 do not mind on day or evening times, with mixed preferences on whether to contact them on weekdays or weekends. Ages 35+ preferred contact during the day on weekdays, with mixed desire for contact during the evenings or weekends depending on individual needs. Overall, respondents preferred day-time contact on weekdays, but there was also a significant proportion of respondents who did not mind when they were contacted as long as it did not interfere with their personal lives, (shown below for both age ranges and groups).



Some users responded that they/their phones do not accept calls from private numbers, so the phone calls from staff may not be received by them. Calling times would have to be arranged on a person-by-person

basis, as the user's needs and availability vary too much to be grouped together cohesively.

Those who responded that something might make the proposed service difficult to use were concerned about

- maintaining choice of product
- staff having the right skills and also capacity
- that communication between all the teams may break down
- privacy in receiving calls
- personalisation of service and continuity of care

One respondent was concerned about the service being removed from the NHS. There was a single response that questioned whether language needs could be met, however that same comment also highlighted that a translator service could be used with their current service.

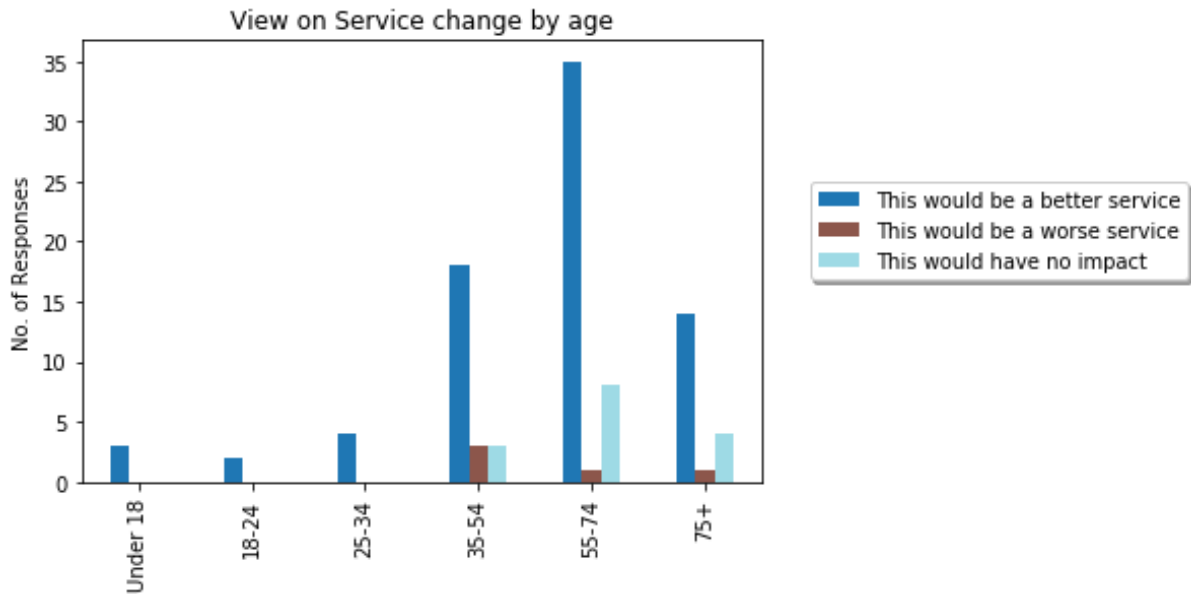
Patient responses indicated it would be beneficial if they could have a point of contact at weekends/unsocial hours to allow emergency supplies in case of emergency or insufficient supplies.

Users indicated that stoma patients are unique in their cases, and that monthly reviews should preferably be done with an individual who was familiar with their case. This would ensure that the individual doing the review can recommend the right stoma products.

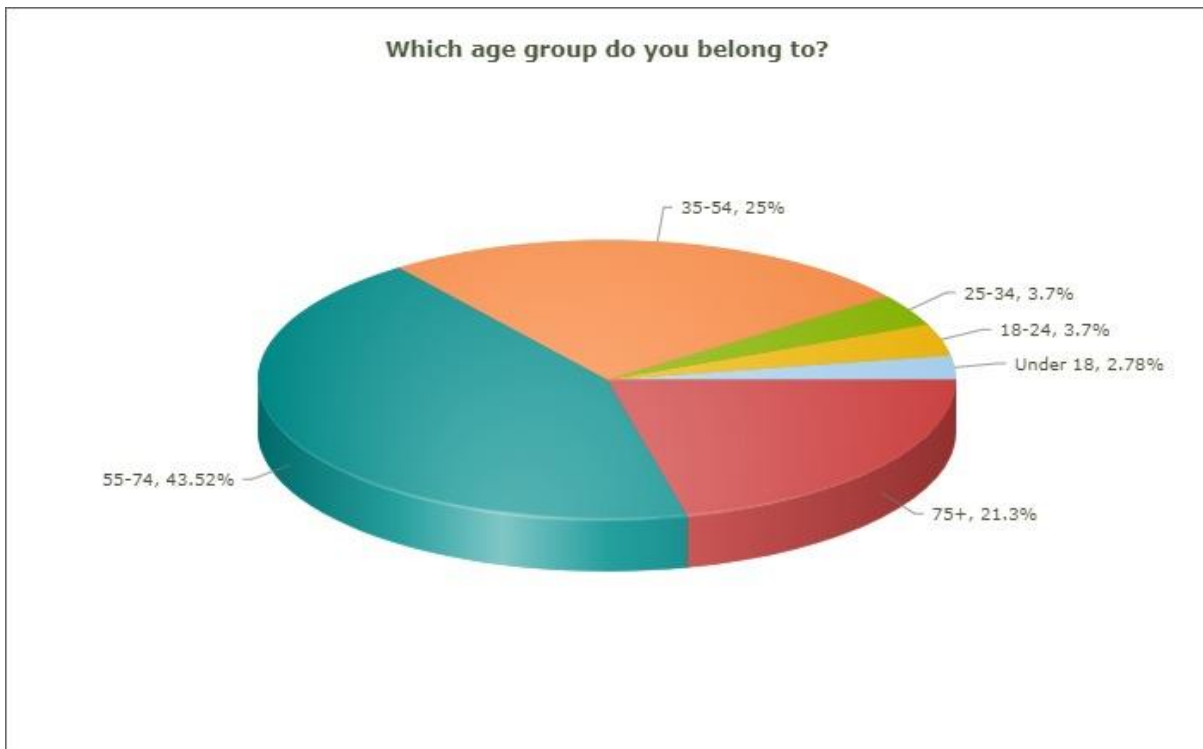
Protected Characteristics

Age

The most common age group was 55-74, and across all age ranges, responders were overwhelmingly positive with regards to Q8, (Shown below). Except where it was otherwise noted above, there was no significant difference between the views of this protected characteristic after adjusting for the number of responses.



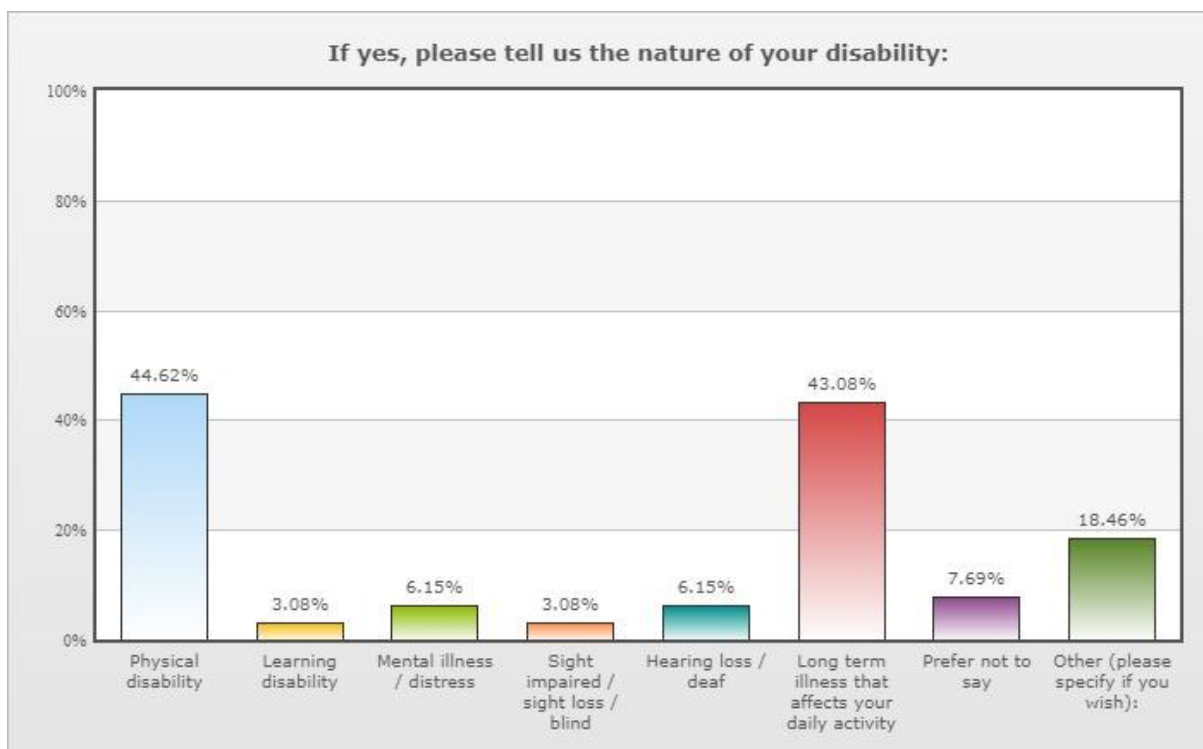
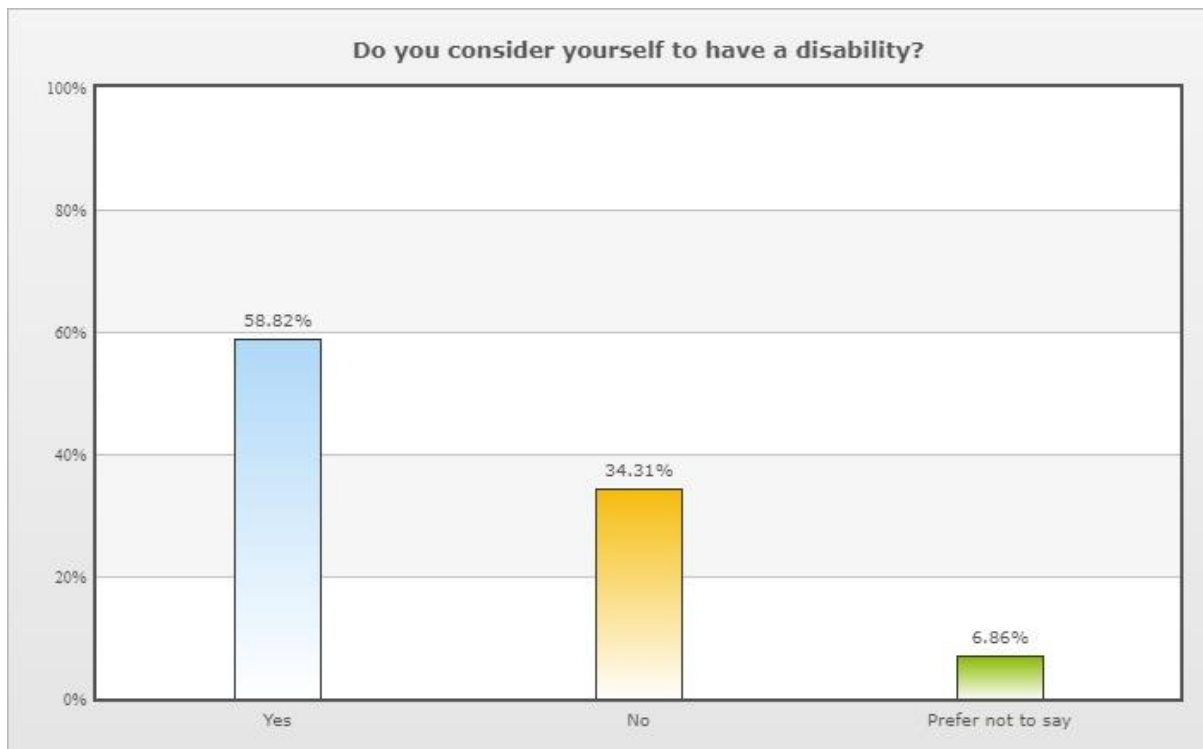
Age group demographics from all respondents are shown below:



Disability

There were no individuals that did not identify as disabled who then marked they had a disability, hidden or otherwise. The number of responses between Q18 and Q19 was markedly greater than those identifying as having a disability. This was due to individuals who identified as disabled who stated more than one disability. Not every responder who identified as disabled gave the nature of their disabilities.

There was no significant difference between the views of this protected characteristic group, or those that did not identify as disabled. [Disability group demographics from all respondents are shown below:](#)



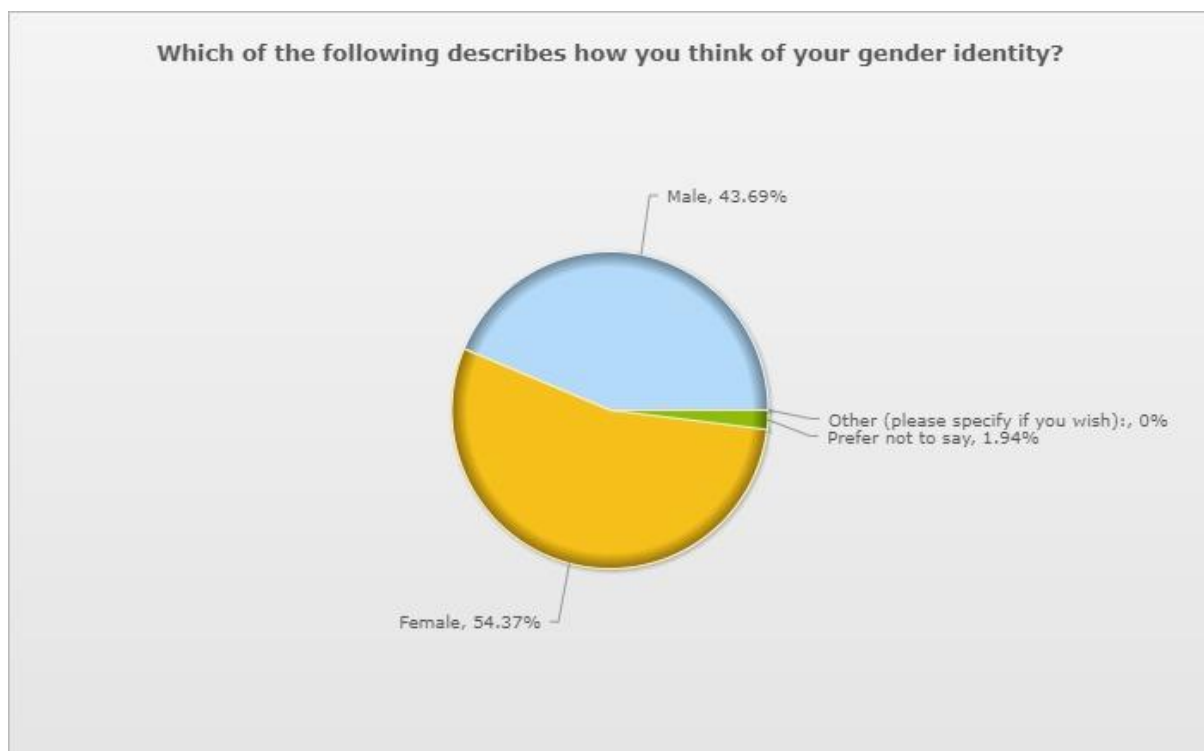
Gender and Gender Reassignment

Female responders provided more responses overall and also appeared more concerned about the impartiality of the service with regards to not

allowing one supplier to have a monopoly on supplying products. Female responders also gave more positive comments on the service they already have. Female responders were also more positive in their comments about the service changes whereas male responders gave more critical responses and were concerned that the service changes were more focused on cost-cutting rather than improving patient care.

Male responders expressed concerns over losing their personal relationship with their service providers, should it be replaced by a remote contact service. In addition to this they expressed more concerns over issues with GP ordering services and disliking resources being wasted. There was a higher proportion of males reporting that they were unsure about having an annual review of stoma products, although the total amount of unsure responses was still quite low.

Finally, a few female users responded that having a stoma was an invisible disability. There were no male responders who stated that having a stoma is an invisible disability. Gender group demographics from all respondents are shown below:

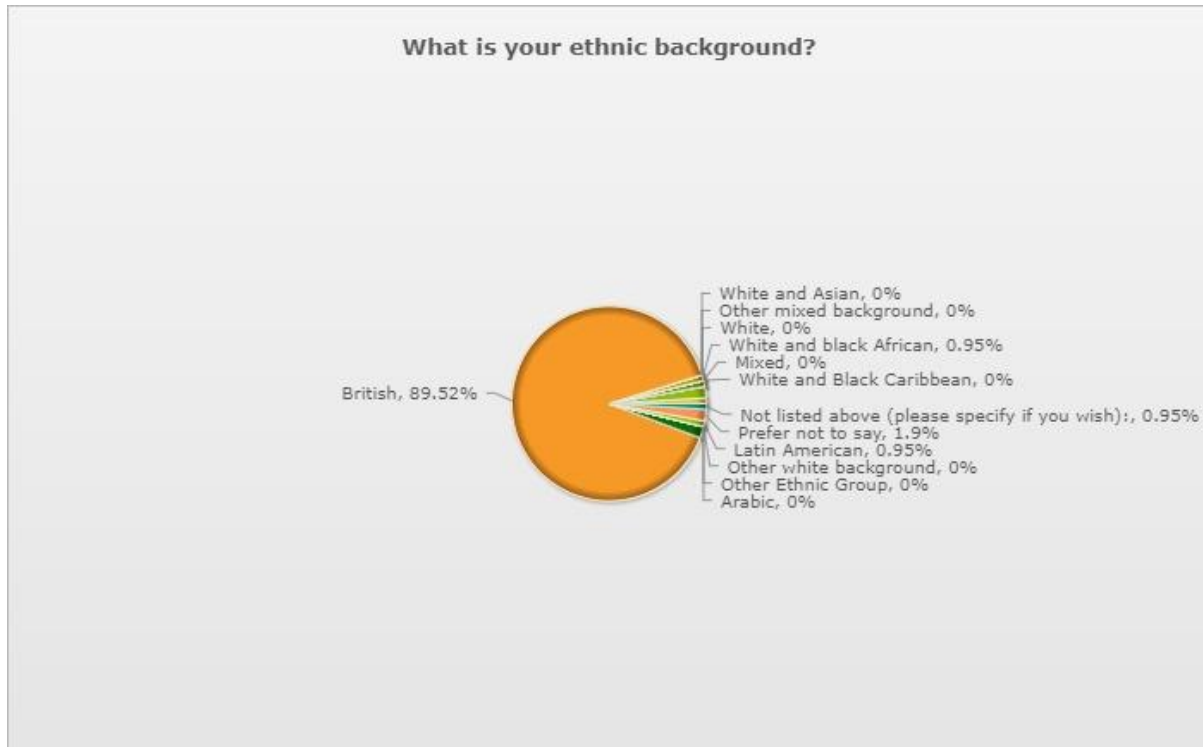


Marriage and Civil Partnership

This protected characteristic was not surveyed, so there was no indication that this protected characteristic group had any difference in views.

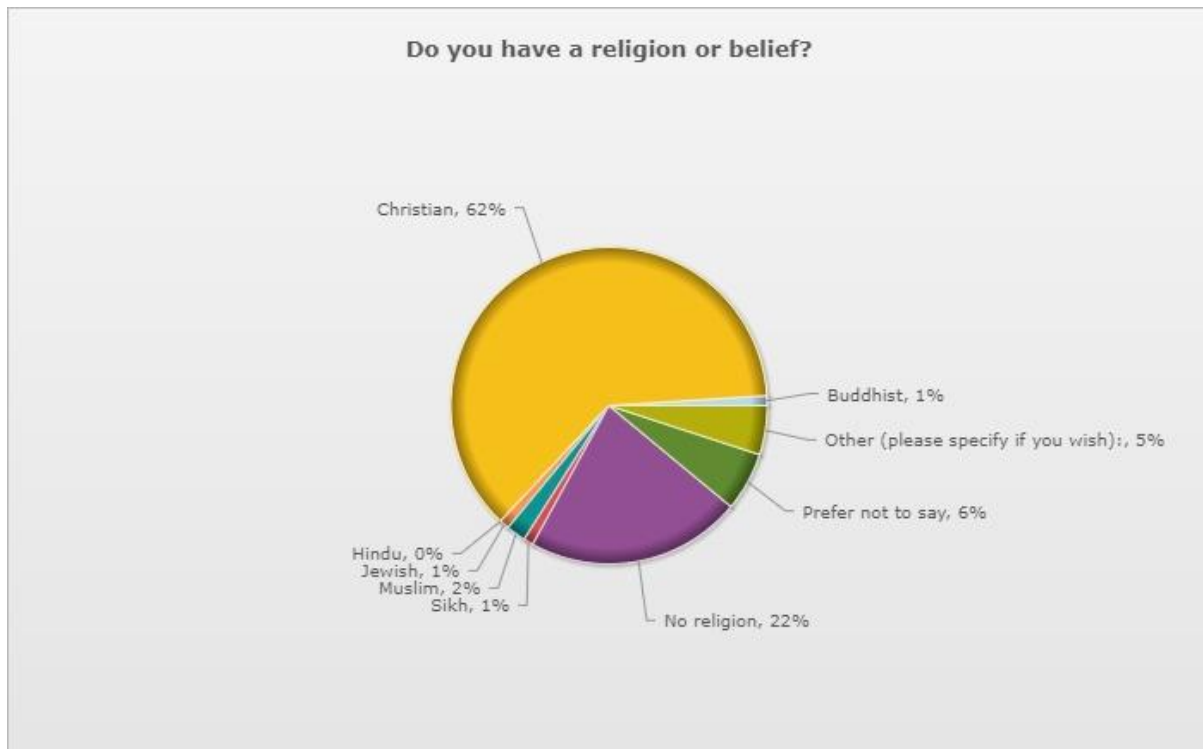
Race

There was no significant difference between the views of this protected characteristic groups and the overall responses. Race group demographics from all respondents are shown below:



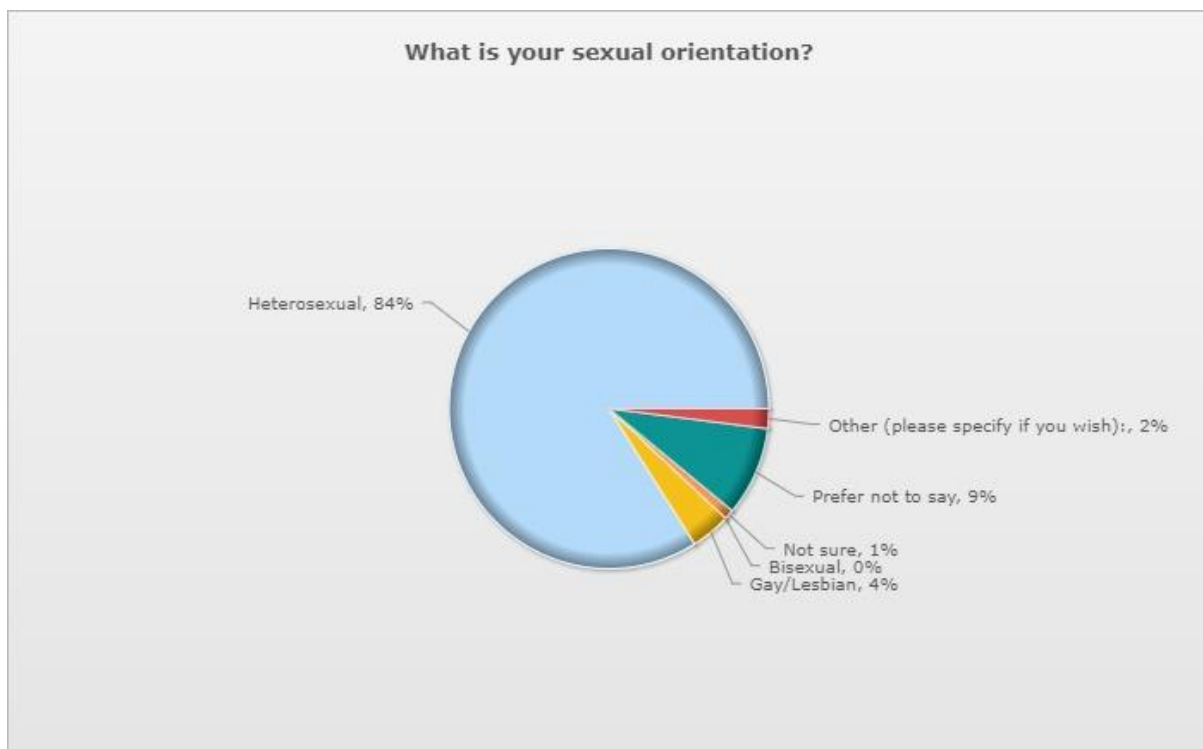
Religion or Belief

There was no significant difference between the views of this protected characteristic groups and the overall responses. Religion group demographics from all respondents are shown below:



Sexual Orientation

There was no significant difference between the views of this protected characteristic groups and the overall responses. Sexual orientation group demographics from all respondents are shown below:



Recommendations

Suggestions for change, or no changes if appropriate, are placed here. This could include reference to relevant frameworks.

The overwhelming majority involved with the service are supportive of the proposed Stoma Prescribing Service, indicated by the previous results and discussions. Based on the highlighted analysis results and patients' agreement, it appears to be in the best interests of service users to implement the proposed service changes. Responses indicate this change would improve the allocation of health resources and staffing, and that it would also improve the care and support provided to stoma patients.

Patients indicated that staff will need to manage individual patient's usage of stoma products to prevent under/over-stocking. In addition to this, patient responses indicated it would be beneficial if they could have a point of contact at weekends/unsocial hours to allow emergency supplies in case of emergency or insufficient supplies.

Patients expressed the desire to have their contact in the Appliance Management Service be familiar with their case and have a personal rapport with them.

Conclusion

Concluding statements

The majority of respondents are both willing and ready for the proposed changes to the stoma service to be implemented as long as the issues outlined in this report are appropriately addressed.

Appendix 1 – Stoma Survey Questions

1) Are you responding to this survey as an individual or on behalf of an organisation?

- Individual
- Organisation (please state the name):

2) Which age group do you belong to?

- Under 18
- 18-24
- 25-34
- 35-54
- 55-74
- 75+

3) Please enter your postcode:

4) So we can better understand your perspective please tell us about your interest in stoma products:

- I have been using stoma products for less than 12 months
- I have been using stoma products for more than 12 months
- I have used stoma products before but no longer do
- I care for an adult who has used/uses stoma products

5) Who dispenses/dispensed the stoma products for you/the person you care for?

- A community pharmacy (local chemist)
- A delivery company (DAC)
- Don't know
- Not applicable

6) If you/someone you care for had queries about products, who would you ask first?

- GP or Practice Nurse
- Community nurse (such as a District Nurse)
- Hospital stoma team
- Pharmacist/at the chemist
- Delivery company (DAC)
- Not applicable
- Other (please specify):

7) Do you recognise the issues described and why we are proposing changes to the way stoma products are prescribed?

- Yes
- No
- Unsure

8) What do you think of the plan to have a specialist service managing stoma prescriptions in the way we have described?

- This would be a better service
- This would have a worse service
- This would have no impact

9) What do you think about an annual review of stoma products?

- Helpful
- Not helpful
- Unsure

10) What do you think about receiving a monthly call to arrange stoma prescription?

- Helpful
- Too often
- Prefer to order online
- Other (please specify):

11) How would you prefer this contact to be made?

- Telephone
- Email
- Text
- Not applicable
- Other (please specify)

12) When would you prefer this contact to be made?

- Daytime
- Evenings
- Don't mind
- Monday to Friday
- Weekends
- Don't mind
- Not applicable

13) Is there anything in the proposed service that you think may make it difficult to use? E.g. communications requirements/cultural issues?

- Helpful
- Not helpful
- Unsure

14) Do you have any further comments about the proposal?

15) Where did you hear about this survey?

- The nurse/doctor/receptionist at my hospital/clinic appointment
- My GP practice
- NHS Liverpool CCG Website
- Email from NHS Liverpool CCG
- Facebook
- Twitter
- Other (please specify):

16) What is your ethnic background?

- Indian
- Pakistani
- Bangladesh
- Other Asian background
- Caribbean

- African
- Other black background
- Chinese
- Other Chinese background
- White and black Caribbean
- White and black African
- White and Asian
- Other mixed background
- British
- Gypsy/Traveller
- Irish
- Polish
- Other white background
- Arabic
- Latin American
- Prefer not to say
- Not listed above (please specify if you wish):

17) Do you have a religion or belief?

- Buddhist
- Christian
- Hindu
- Jewish
- Muslim
- Sikh
- No religion
- Prefer not to say
- Other (please specify if you wish):

18) Do you consider yourself to have a disability?

- Yes
- No
- Prefer not to say

19) If yes, please tell us the nature of your disability:

- Physical disability
- Learning disability
- Mental illness/distress
- Sight impaired/sight loss/blind
- Hearing loss/deaf
- Long term illness that affects your daily activity
- Prefer not to say
- Other (please specify if you wish):

20) Which of the following describes how you think of your gender identity?

- Male
- Female
- Prefer not to say
- Other (please specify if you wish):

21) Have you gone through any part of a process (including thoughts or actions) to change from the sex you were described as at birth to the gender you identify with, or do you intent to? (This could include changing your name, wearing different clothes taking hormones or having any gender reassignment surgery).

- Yes
- No
- Prefer not to say

22) What is your sexual orientation?

- Heterosexual
- Gay/Lesbian
- Bisexual
- Not sure
- Prefer not to say
- Other (please specify if you wish):

Appendix 2 – Social media statistics

Twitter

- Posts: 9
- Impressions: 4,483
- Likes: 3
- Retweets: 5
- Link clicks: 11
- Replies: 0

Facebook

- Posts: 9
- Impressions: 1,069
- Likes: 7
- Shares: 8
- Link clicks: 5
- Comments: 1