

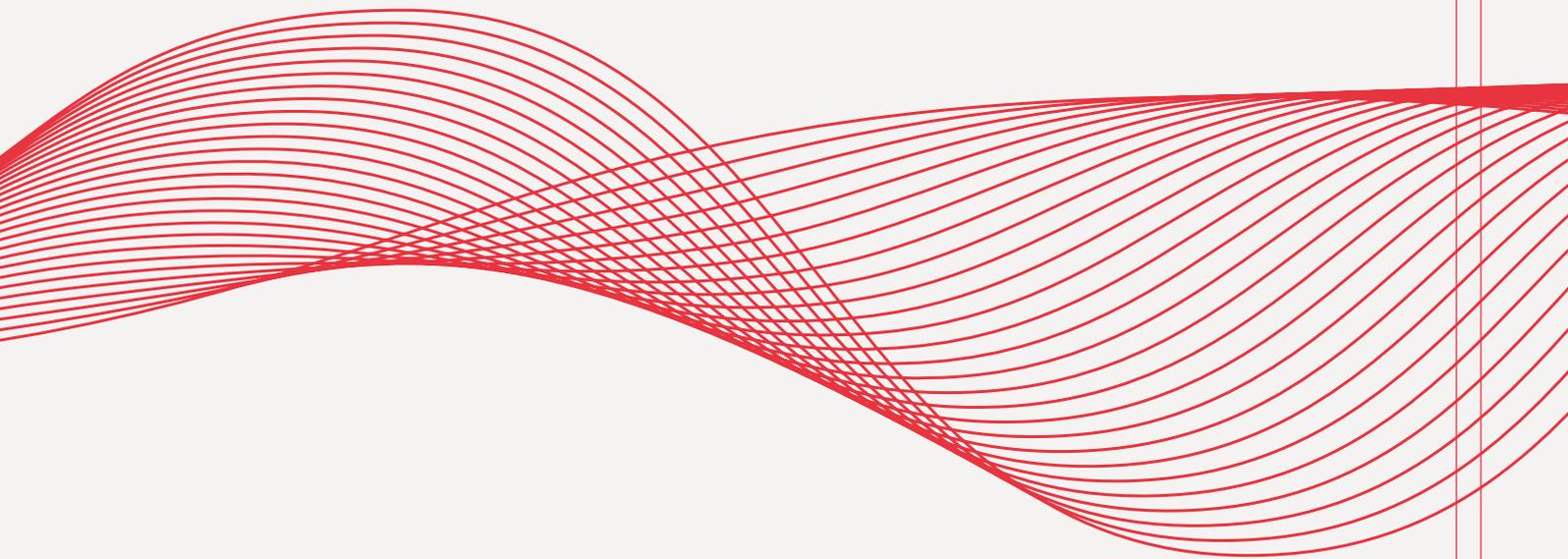
Atos

Breathing-Speaking-Living
atosmedical.com

What is it like to live with a laryngectomy?

A quantitative study

ReD Associates for Atos Medical in collaboration
with the Netherlands Cancer Institute (NKI)



A large global ethnographic and quantitative study

In 2018 Atos Medical commissioned the largest patient study of its kind to better understand where to improve laryngectomy care and quality of life for patients.

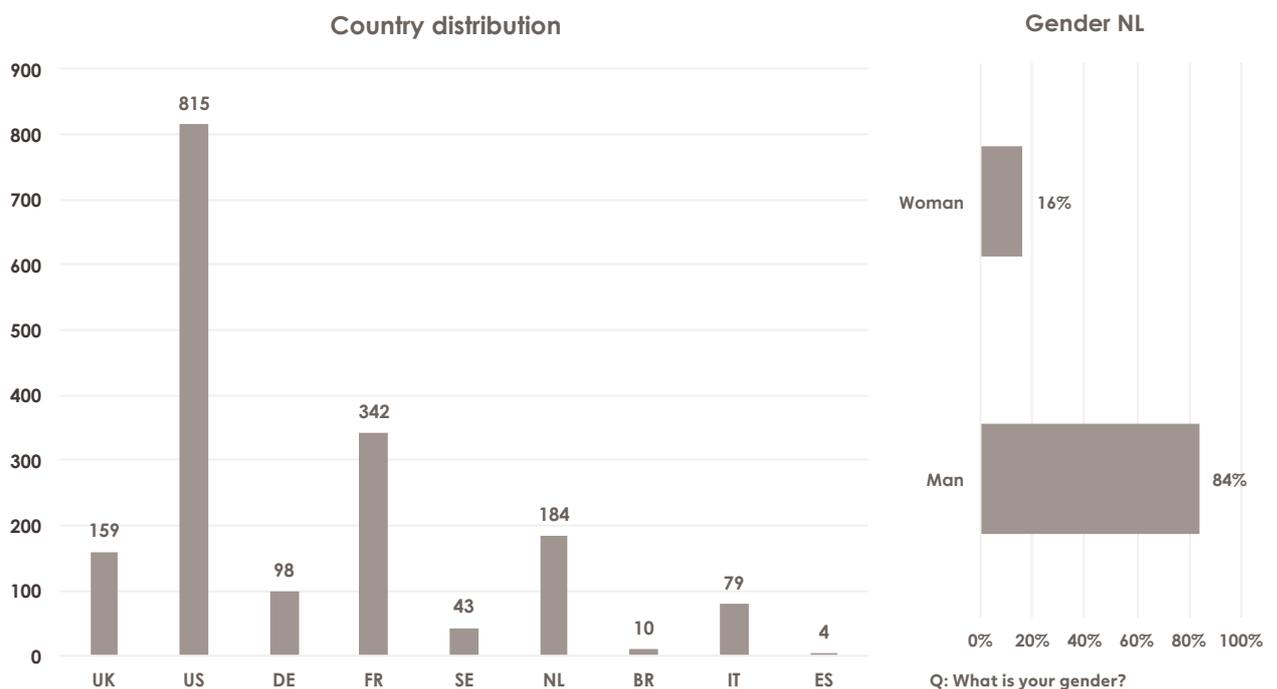
The study was a combined battery of ethnographic and quantitative methods. A survey was sent to 8184 patients, and in total 1734 patients (21%) took part in this global quantitative study.

The study was conducted in collaboration between ReD Associates, a global anthropology and sociology consulting company focusing on studying human behavior, and the Netherlands Cancer Institute, an internationally recognised center of scientific and clinical laryngectomy expertise.

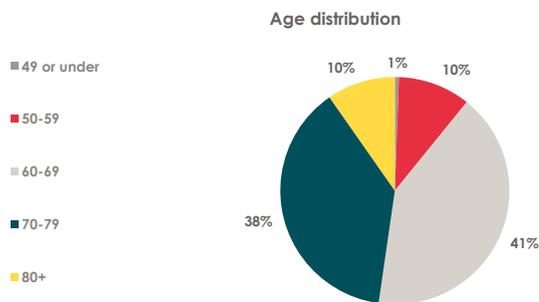
The patients participating in the study were screened to represent a spread in demography, time since surgery, and product use. The study includes results from nine different countries.



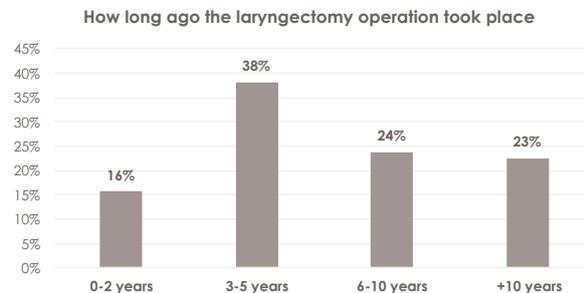
In total, 1 734 patients in 9 different countries took part in the study. The majority were men.



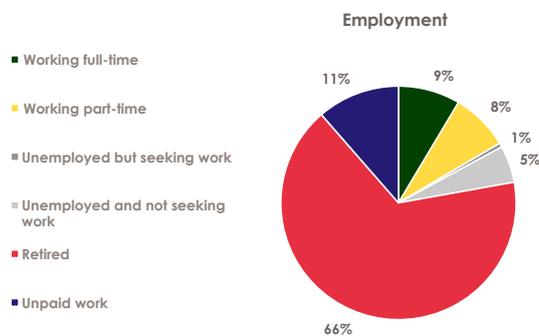
The patients who took part in the study can be considered an accurate representation of the laryngectomy population.



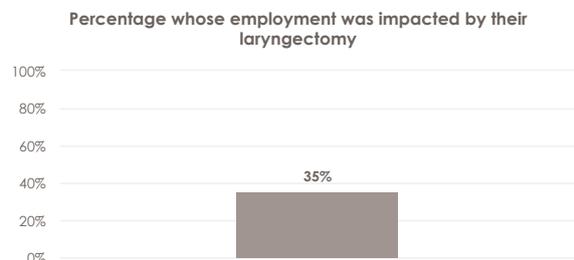
Q: What is your age?



Q: When did you have your laryngectomy operation?



Q: Which statement best describes your employment status?



Q: Did your employment status change because of your laryngectomy?

Design and data collection

Pre-study: Ethnographic research in 4 countries

- Face to face interviews with patients and health care professionals.

Quantitative study: Quantitative online survey in 9 countries

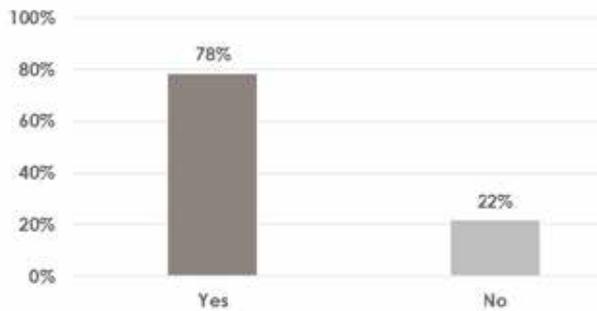
- 12 different categories with multiple choice questions covering demographics, overall and in-depth health issues and issues specific to people gone through a laryngectomy.
- Participating patients were screened to represent a spread in demography, time since surgery, and product use.

Subjects

- Pre-study: 18 patients and 18 health care professionals in 4 countries (US, UK, FR, NL).
- Quantitative study: 8184 patients across 9 countries (UK, US, DE, FR, SE, NL, BR, IT, ES) received the survey.
- Response rate 21% (1734 patients).

Most patients had used an HME and an adhesive in the last three months. The use of a tube or a button was less frequent.

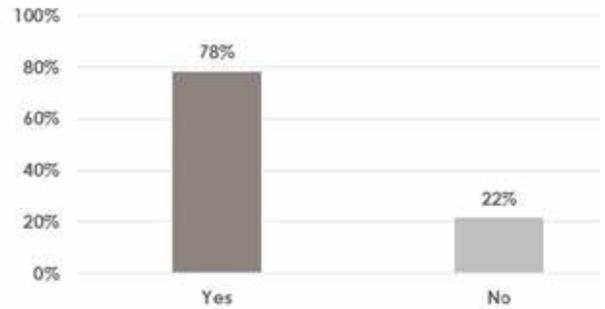
The proportion of respondents who have used an HME the last 3 months.



Question:

Have you used HMEs in the last 3 months? An HME, sometimes called a “filter” or a “cassette” is a Heat and Moisture Exchanger that goes in front of your stoma.

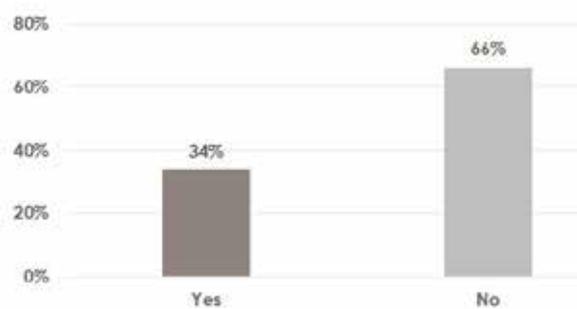
The proportion of respondents who have used an adhesive the last 3 months.



Question:

Have you used an adhesive, tube or button in the last 3 months? These are used to keep the HME in front of the stoma.

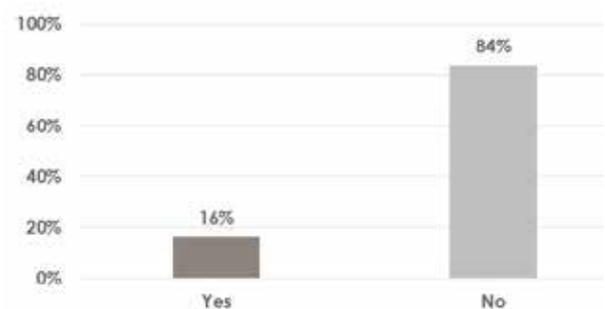
The proportion of respondents who have used a tube the last 3 months.



Question:

Have you used an adhesive, tube or button in the last 3 months? These are used to keep the HME in front of the stoma.

The proportion of respondents who have used a button the last 3 months.



Question:

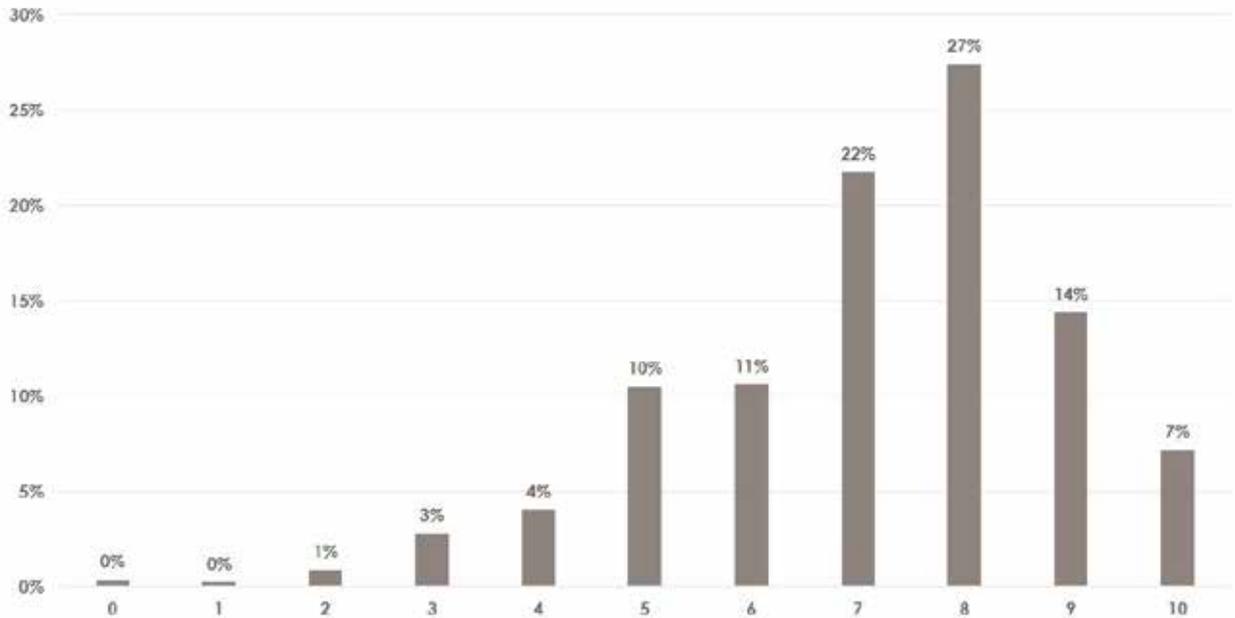
Have you used an adhesive, tube or button in the last 3 months? These are used to keep the HME in front of the stoma.



Hidden problems

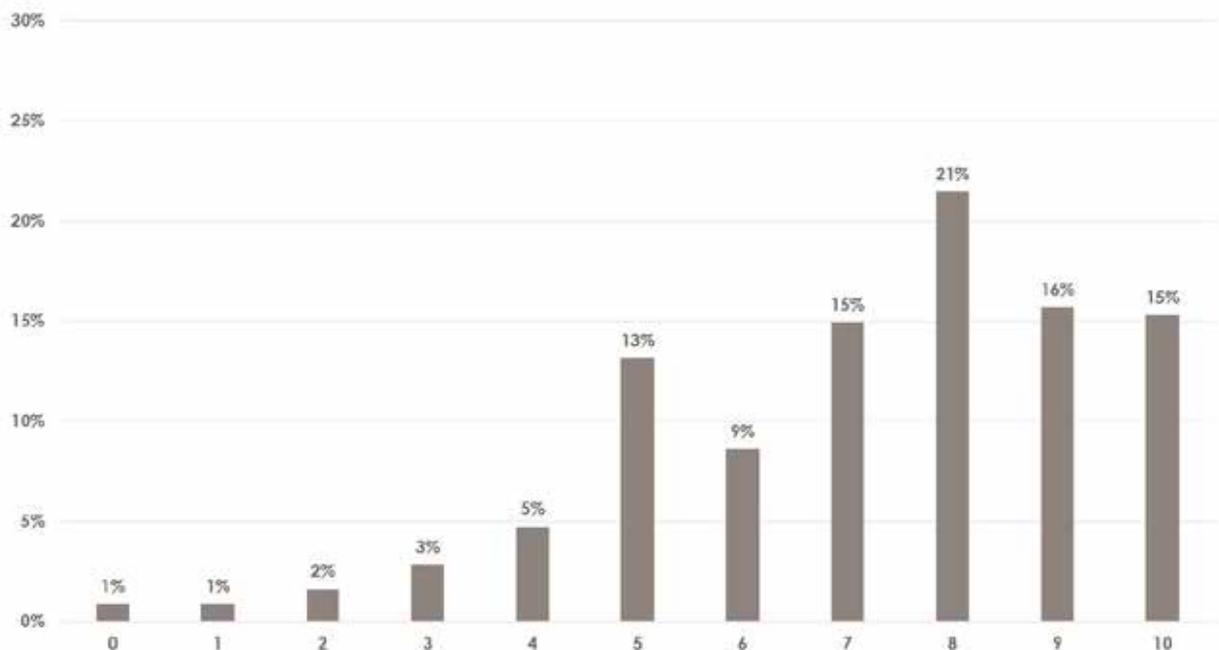
The reported problems can be split into everyday issues and situational issues

Across the study, we found that patients, self-reportedly, felt healthy and fairly independent.



Question:

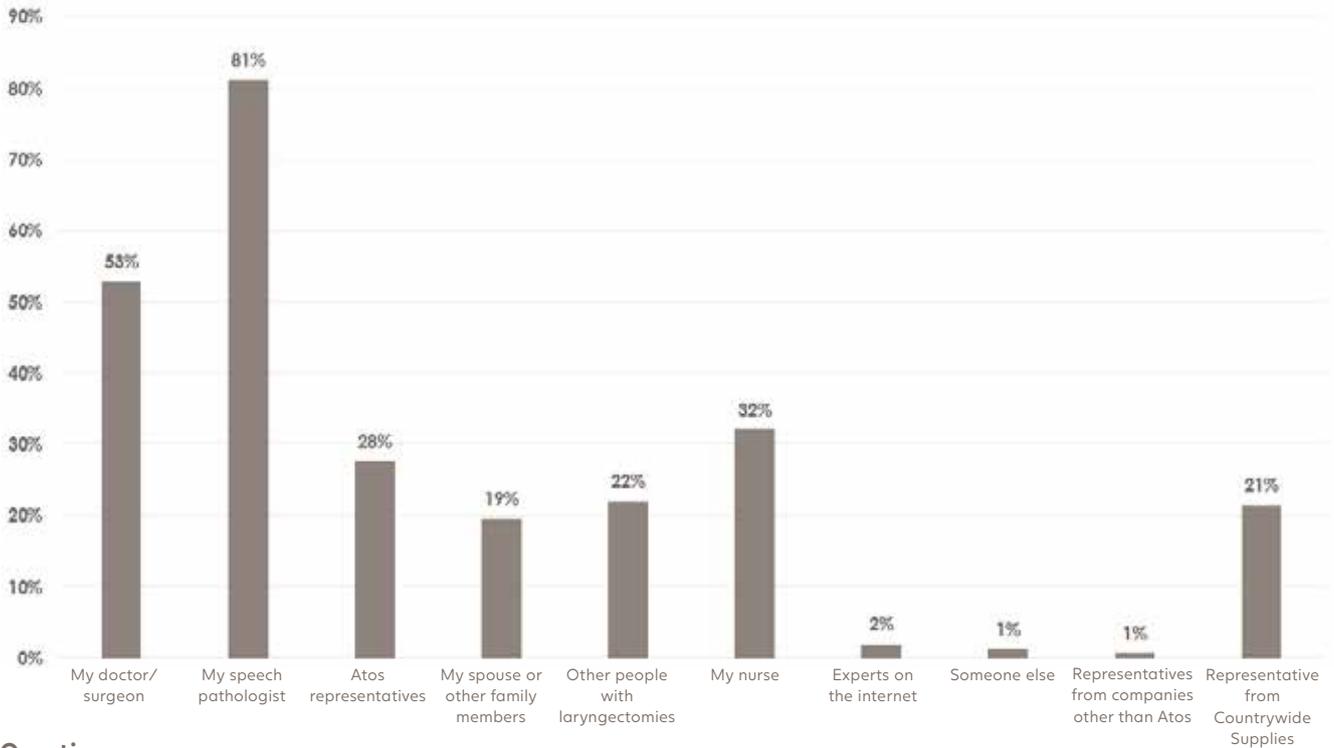
How would you rate your overall health from 0 to 10? 0 means worst imaginable health state 10 means best imaginable health state



Question:

On a scale from 0 to 10, how independent do you feel in completing the activities you want? 0 means the least imaginable independence in completing the activities you want 10 means the most imaginable independence in completing the activities you want

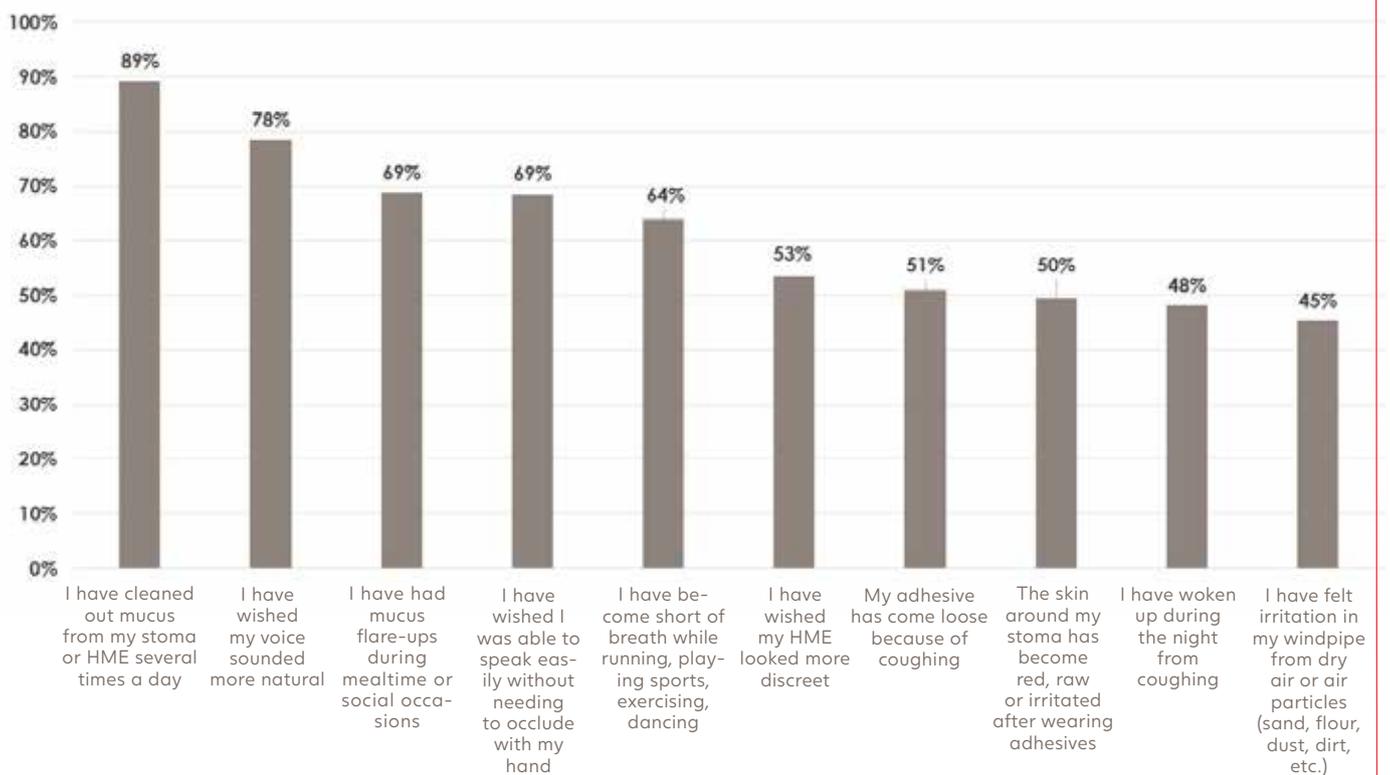
The patients had a high degree of trust in their clinician for advice.



Question:

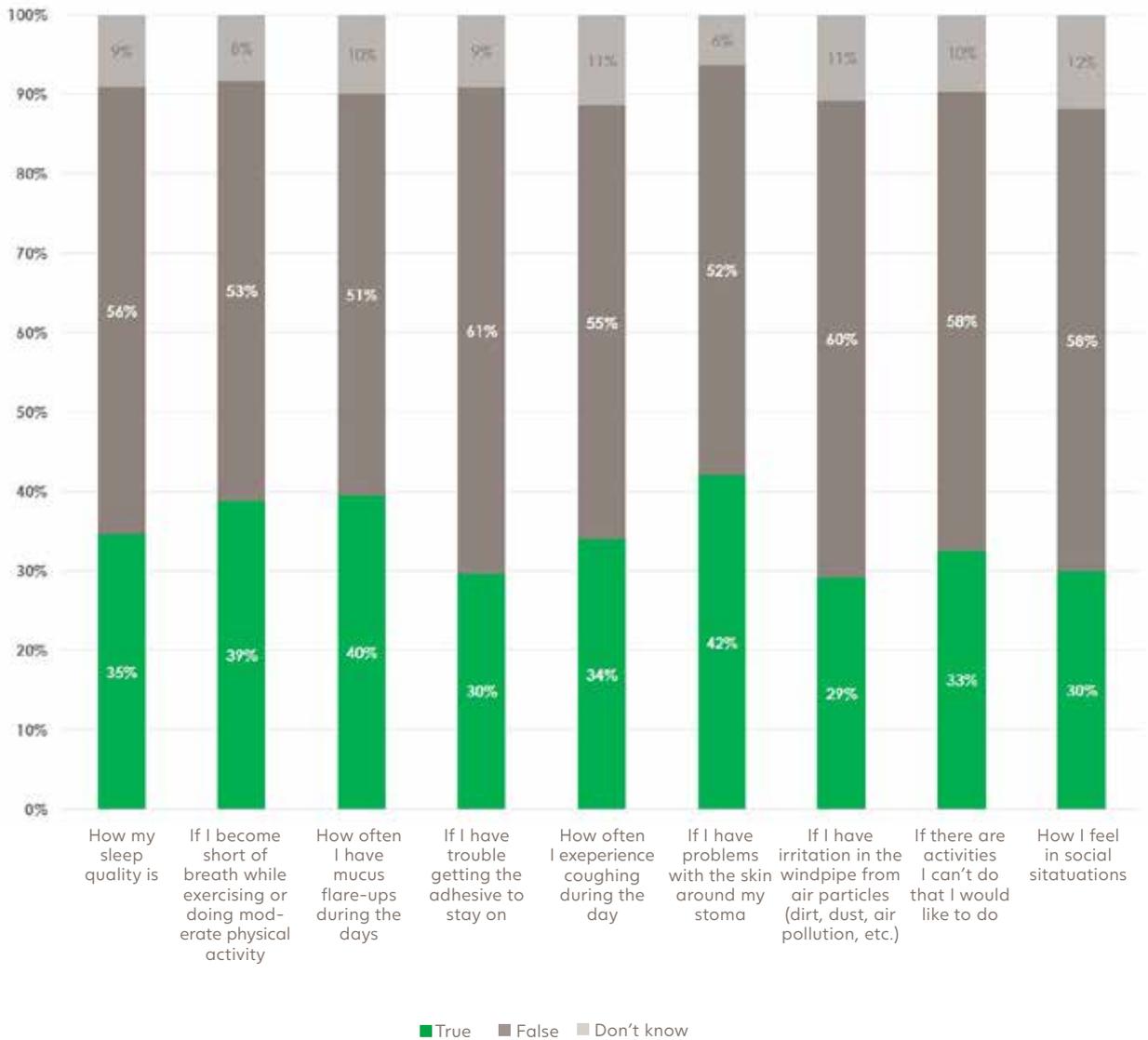
Who do you trust to provide you with advice on stoma care? Please choose the three options from the list who you trust most.

The patients reported suffering from a wide variety of issues.



The majority however did not speak about their issues.

What respondents discussed with their clinician the past year.



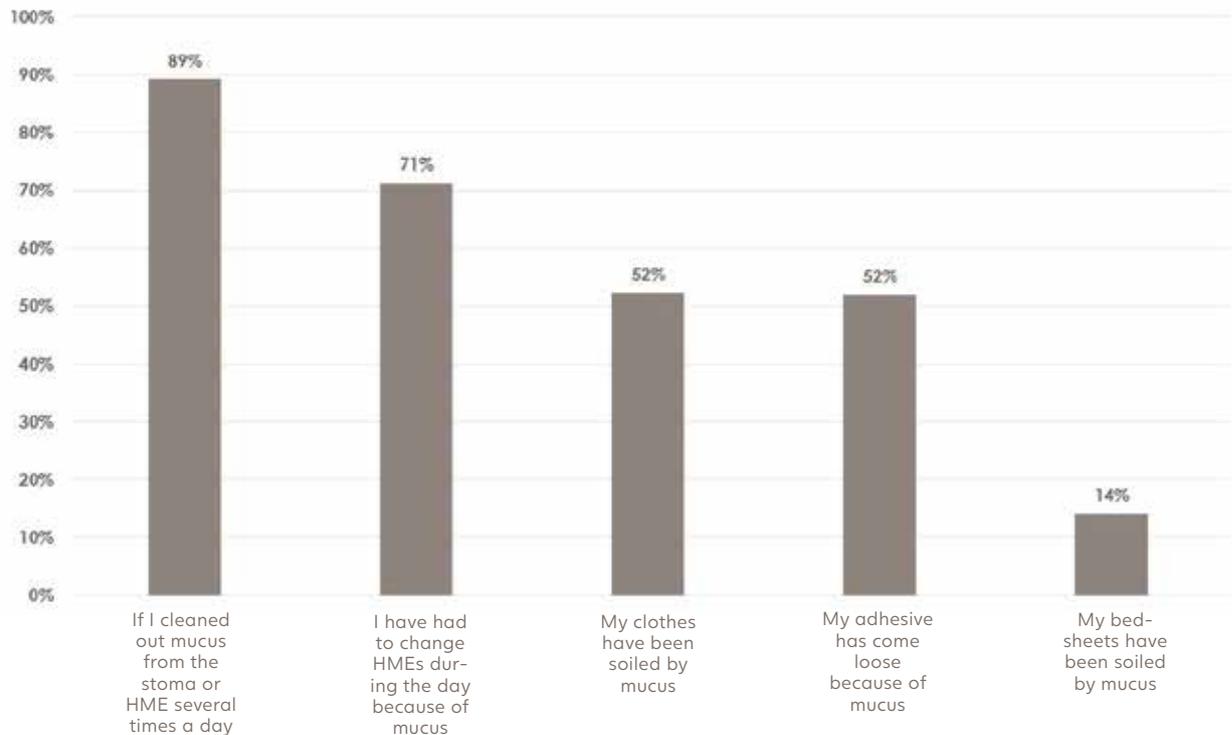


Everyday issues

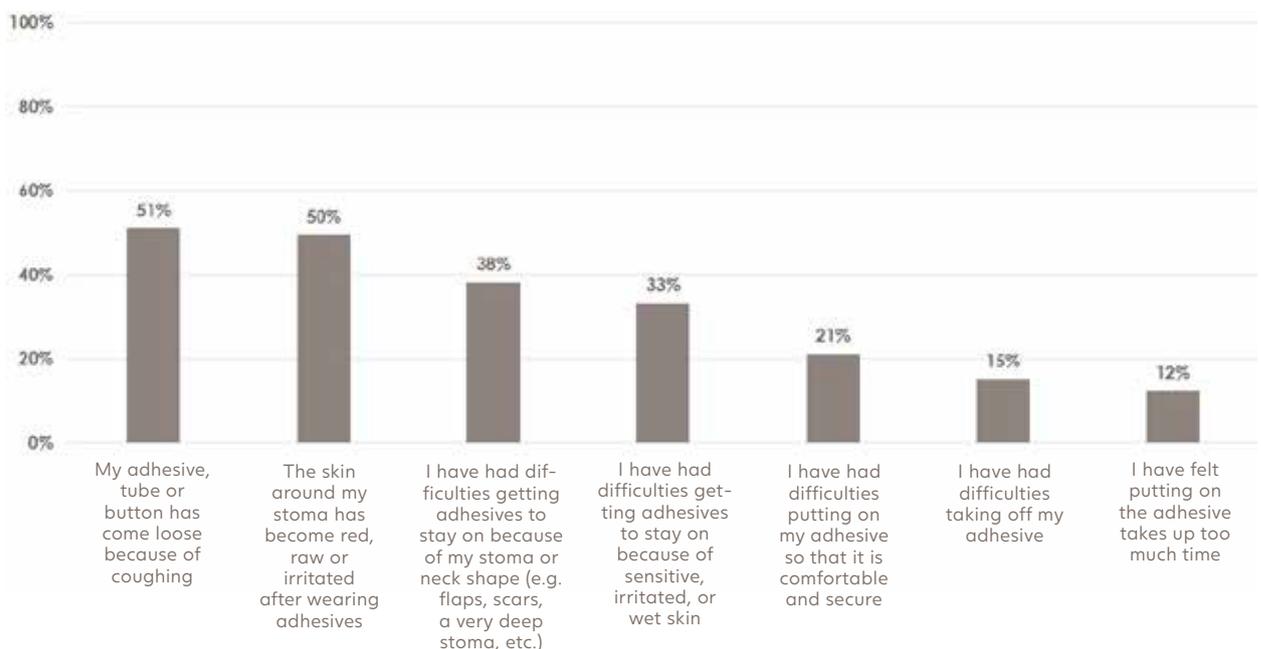
The reported problems ranged from pulmonary to communicative to aesthetic

Pulmonary issues

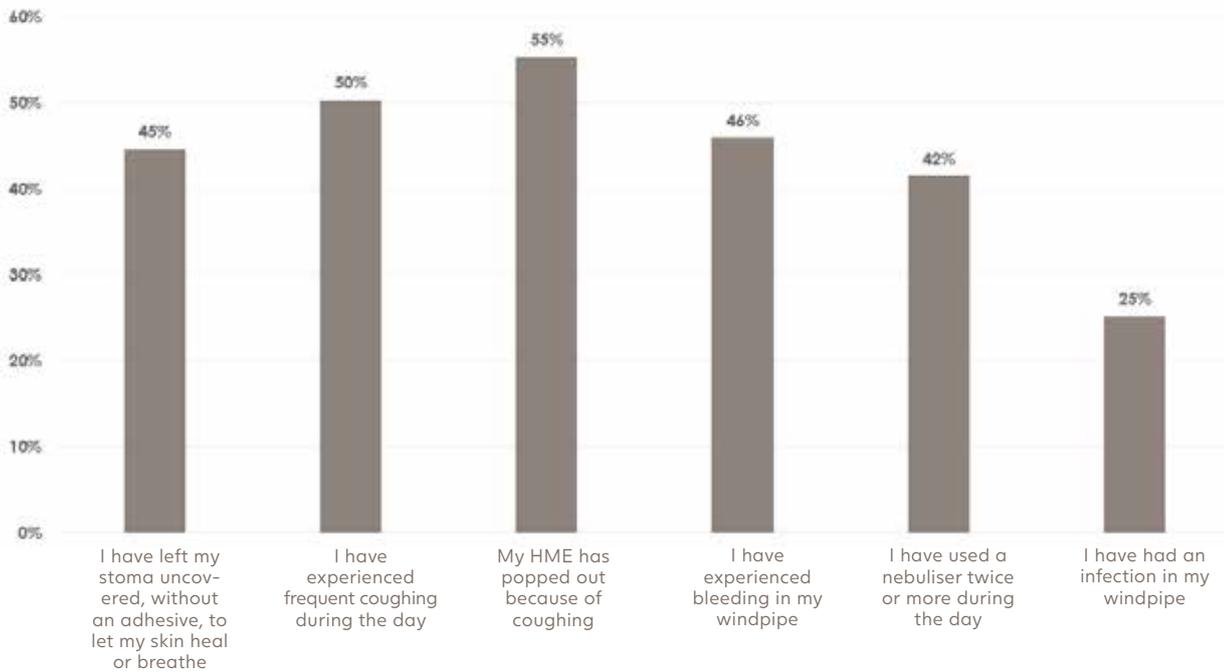
The most prevalent pulmonary problems related to mucus impacting several aspects of daily life.



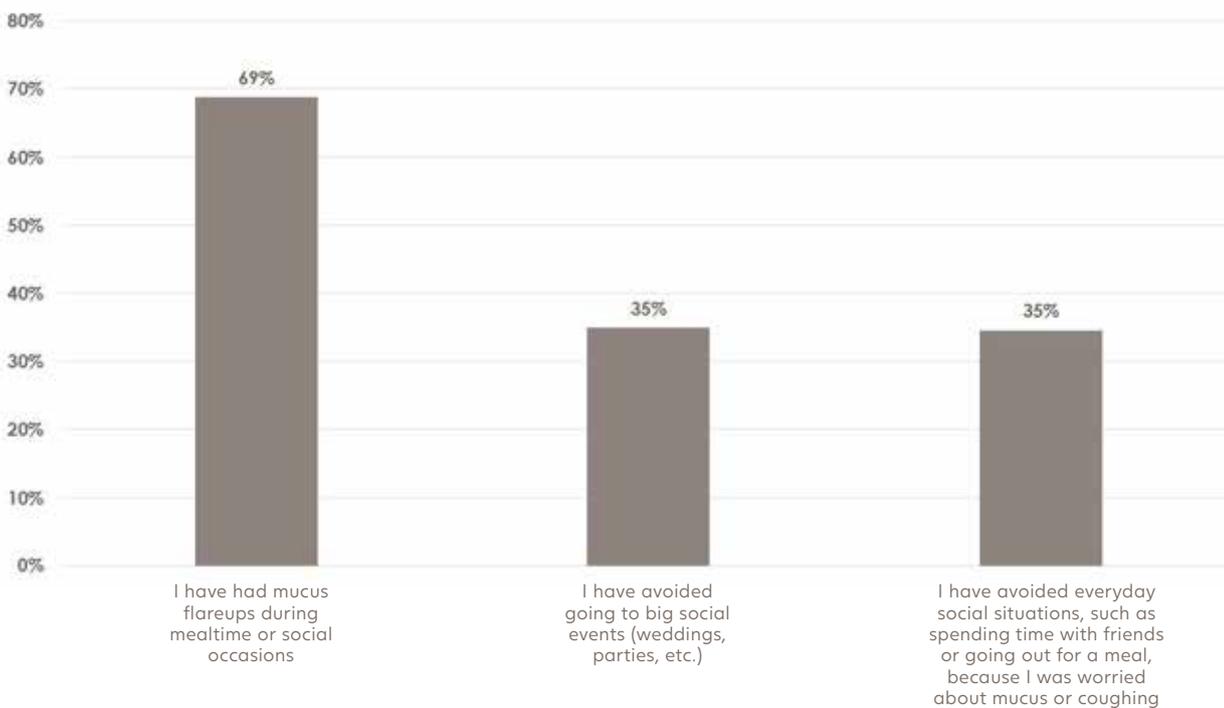
Another significant problem was around adhesives. ~50% had experienced the adhesive coming loose due to coughing, or the skin around the stoma becoming red, raw or irritated.



A number of pulmonary problems were related to general health. 50% experienced frequent coughing during the day, 45% had left the stoma uncovered.

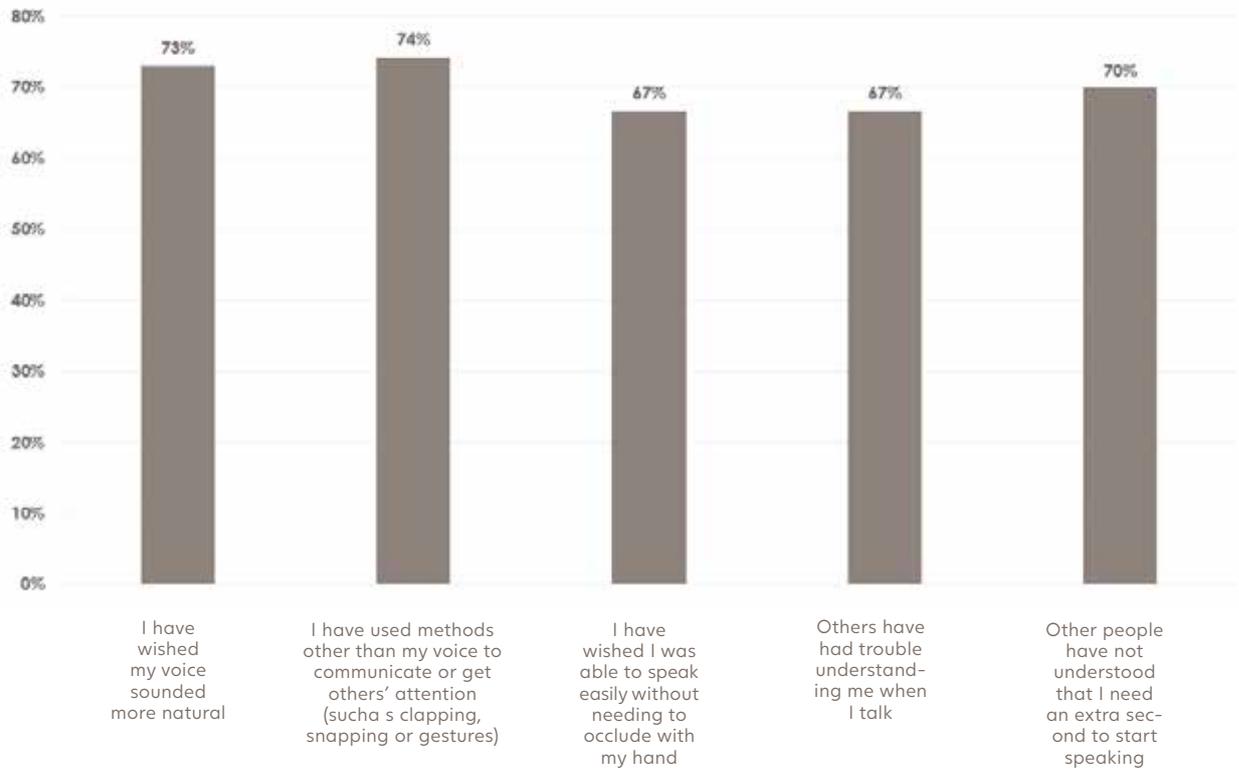


Some pulmonary problems had an impact on patients' everyday lives. Many had mucus flare-ups even preventing them from taking part in social activities.

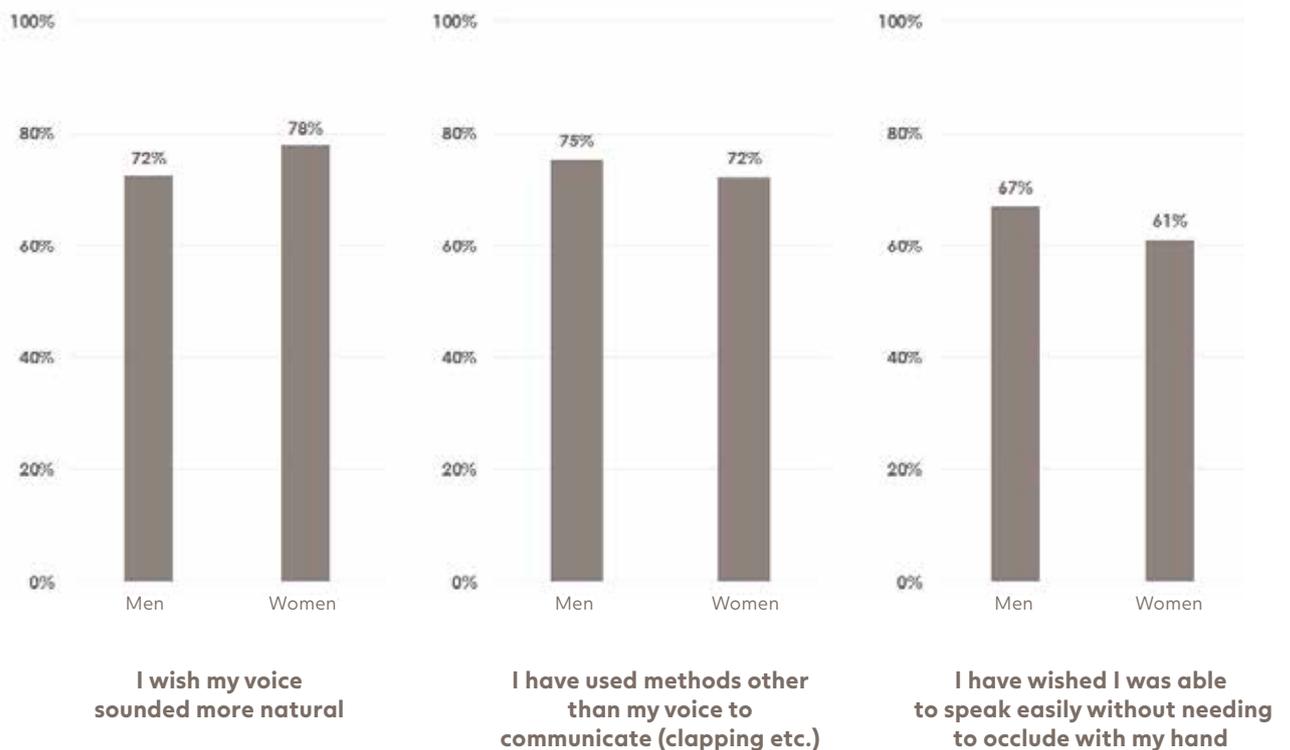


Communicative issues

A second set of everyday problems experienced by patients revolved around speaking.

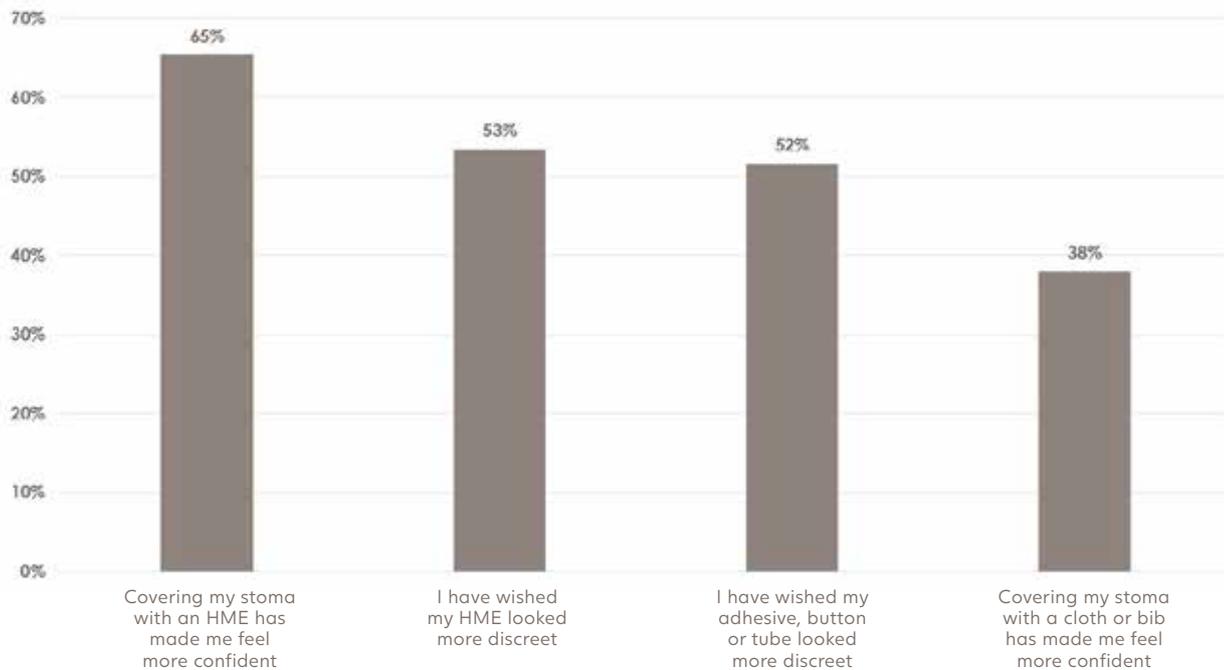


Women and men reported same level of issues with speaking.



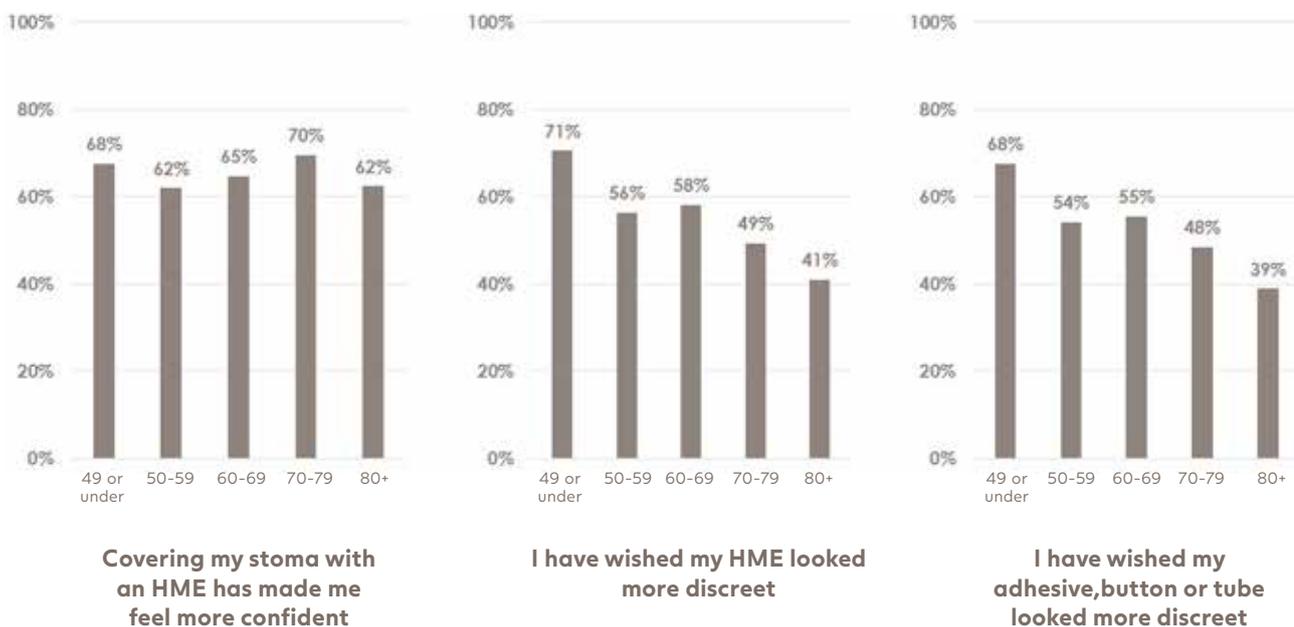
Aesthetic issues

The last set of everyday issues reported by patients were focused on aesthetics. 53% wished for the HME to look more discreet.



Everyday issues

Younger patients tended to be more concerned about discreteness than older patients.



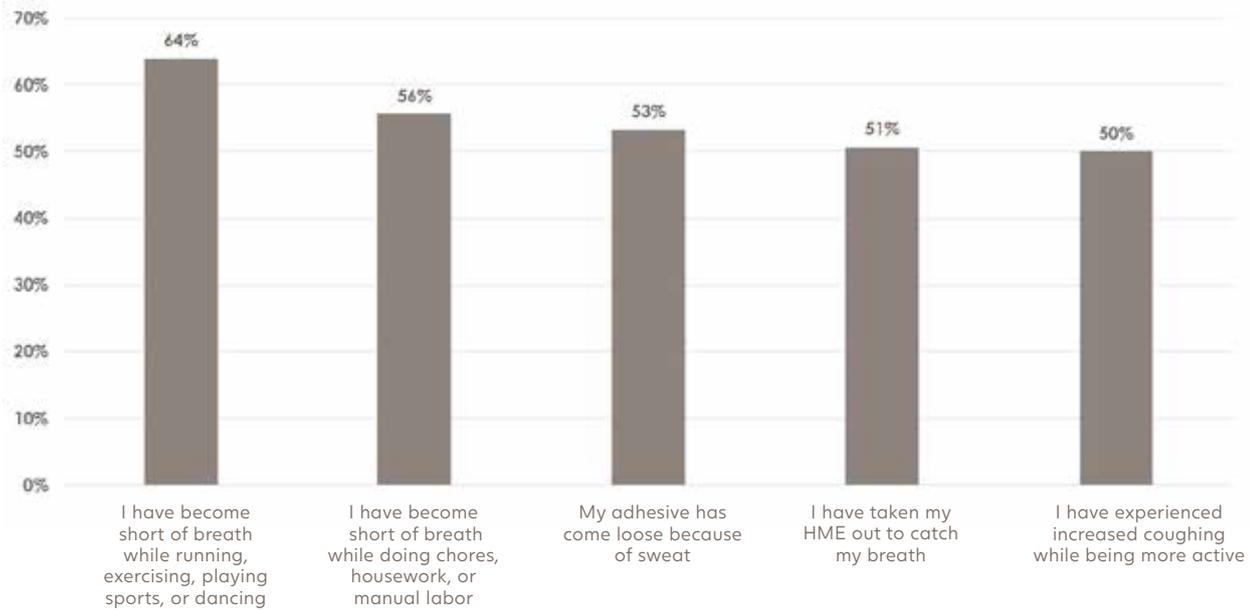


Situational issues

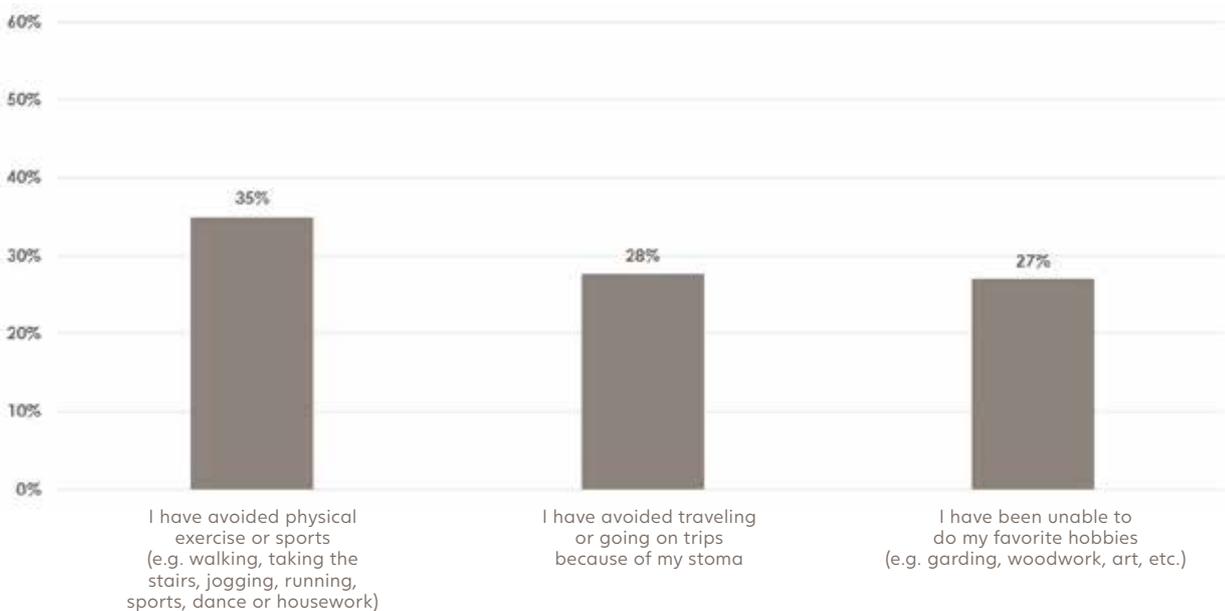
Situational problems can be split into three subsections: activity, environmental and sleep

Activity

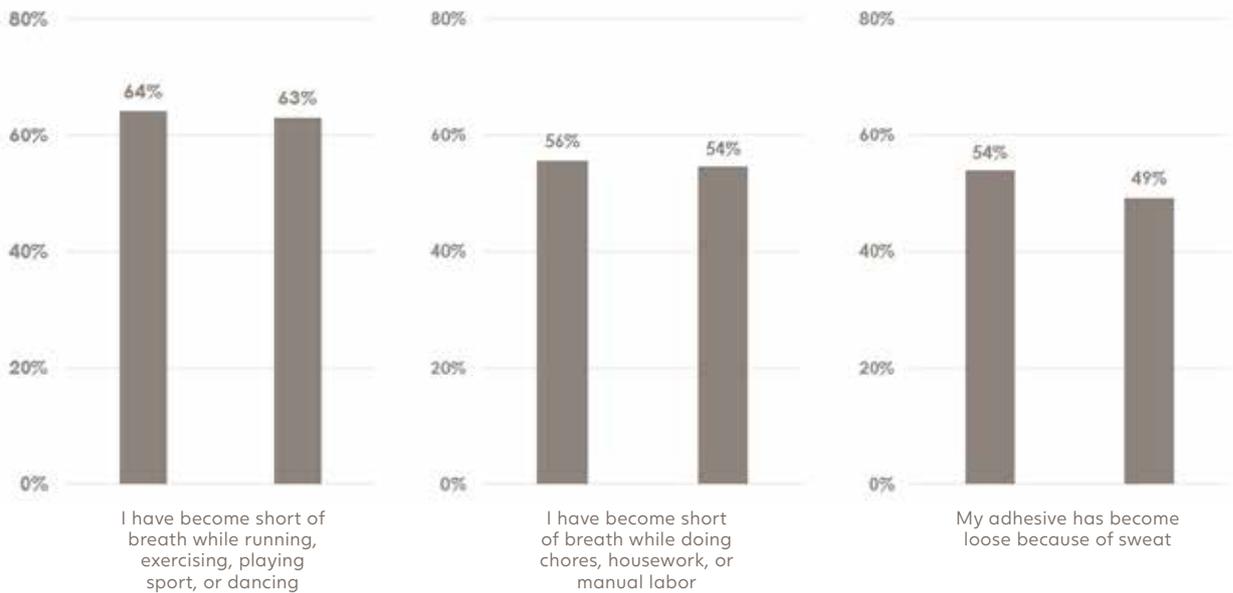
64% of the patients had been short of breath during physical activities, 51% taking the HME out to catch their breath.



35% of the patients avoided physical activities, and 27% have been unable to do their favourite hobbies.

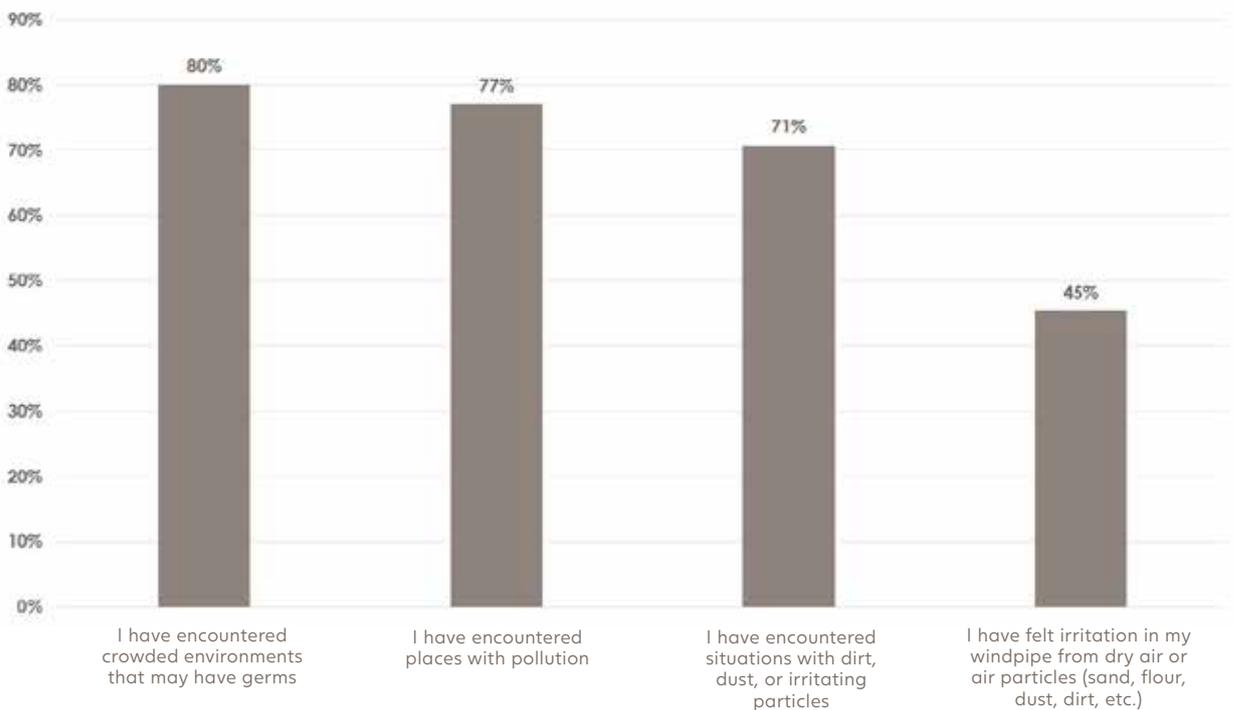


There were no major difference between men and women in terms of activity-related problems



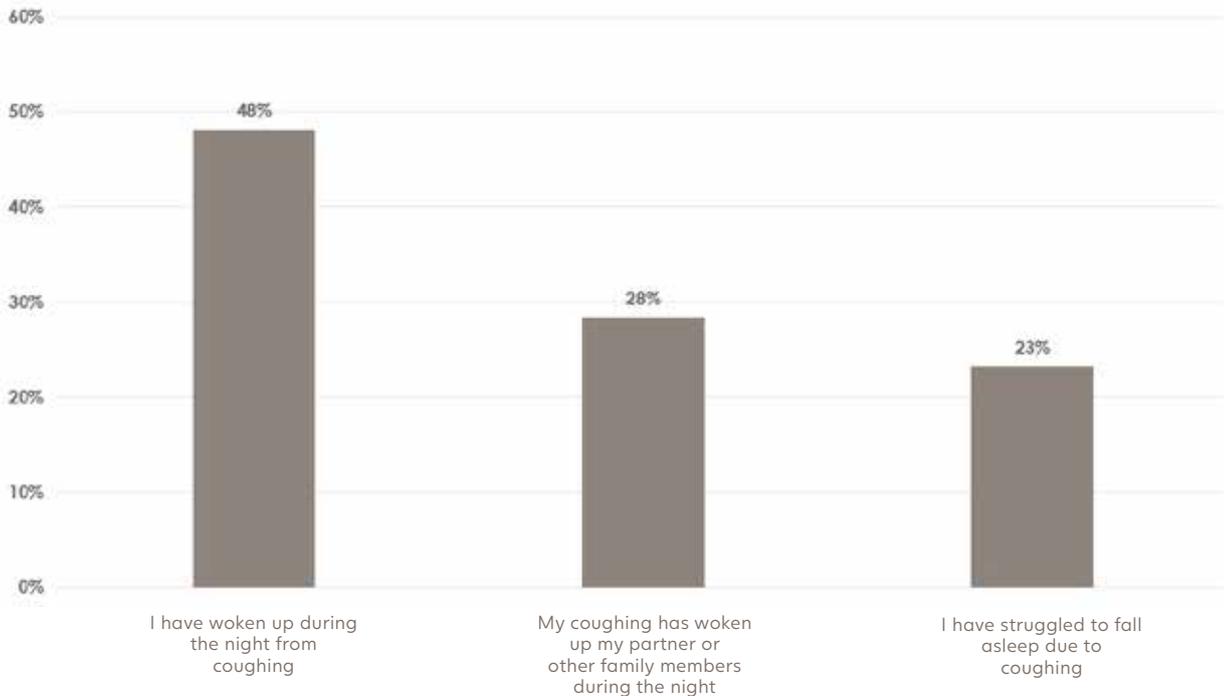
Environmental

Many patients reported encountering crowded, dusty and polluted situations, 45% had felt irritation in windpipe due to air particles.

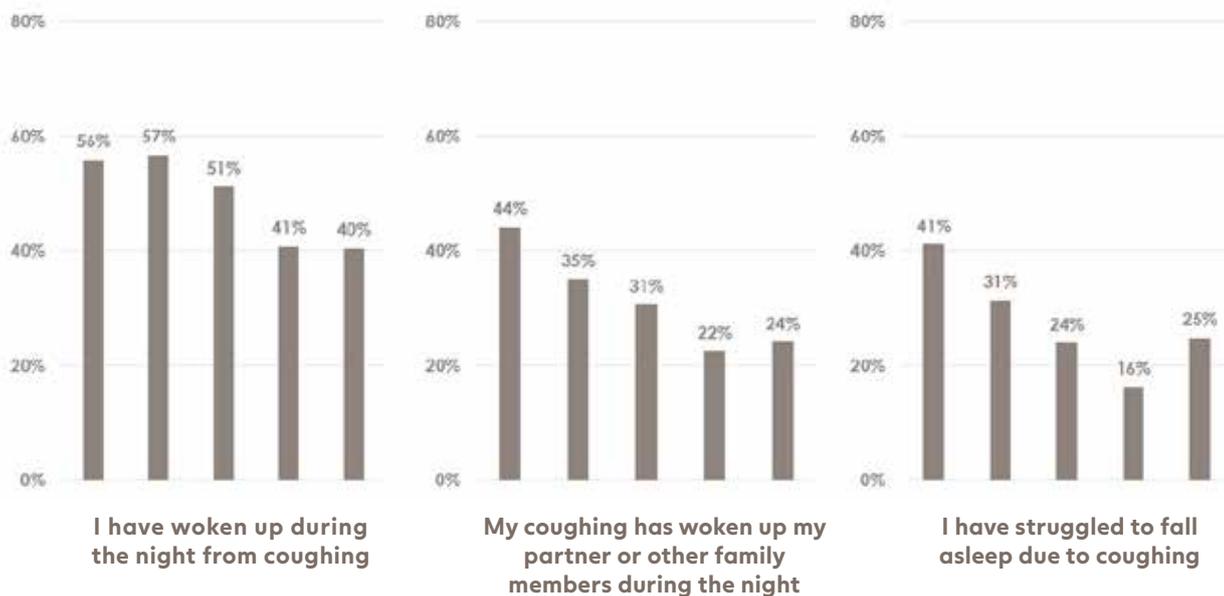


Sleep

A third situational issue revolved around problems with sleep. 48% had woken up from coughing, and also reported impact on their partners' sleep.



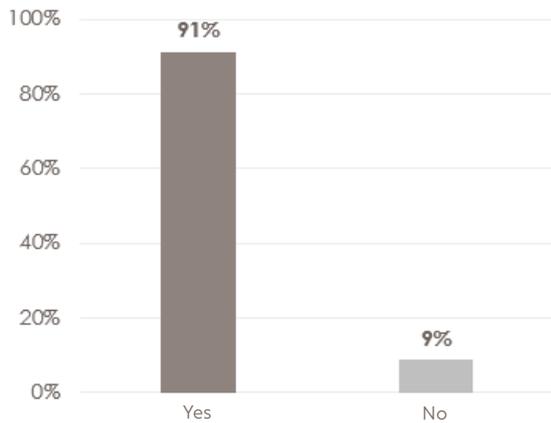
Age had an impact on sleep-related problems. Younger patients had more issues than older patients.



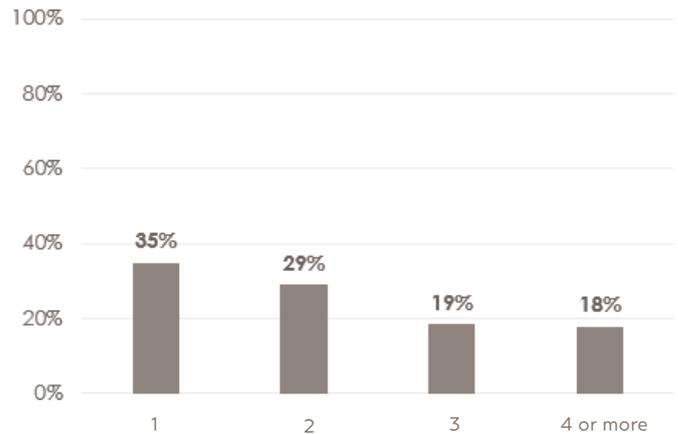


HME use to increase quality of life

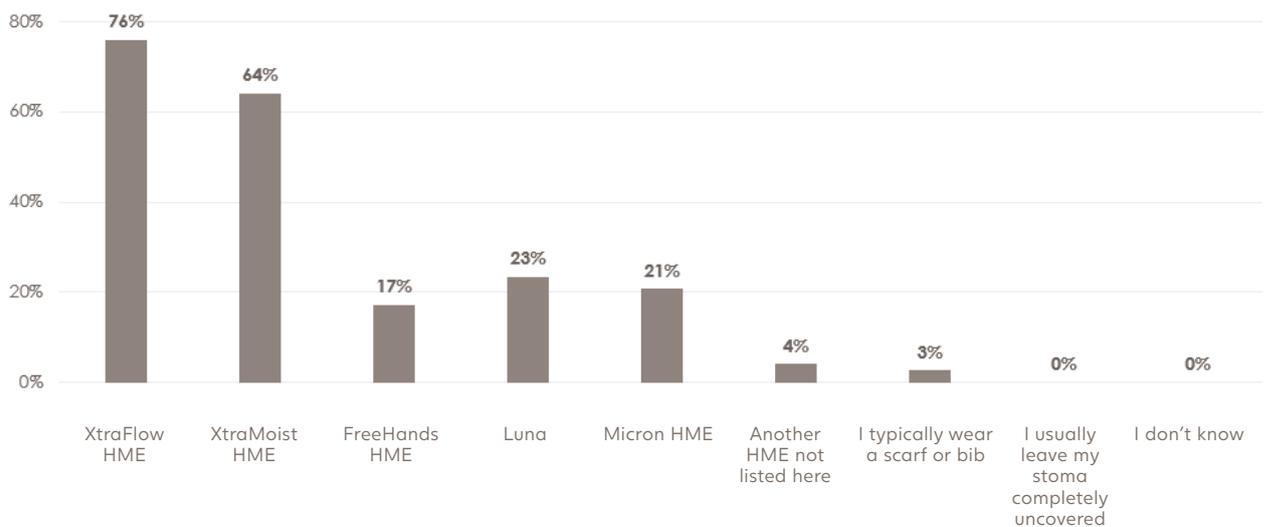
The vast majority of the patients used HMEs. 66% used two or more HMEs per 24 hours. Many used different types of HMEs.



Question:
Have you used HMEs in the last 3 months?

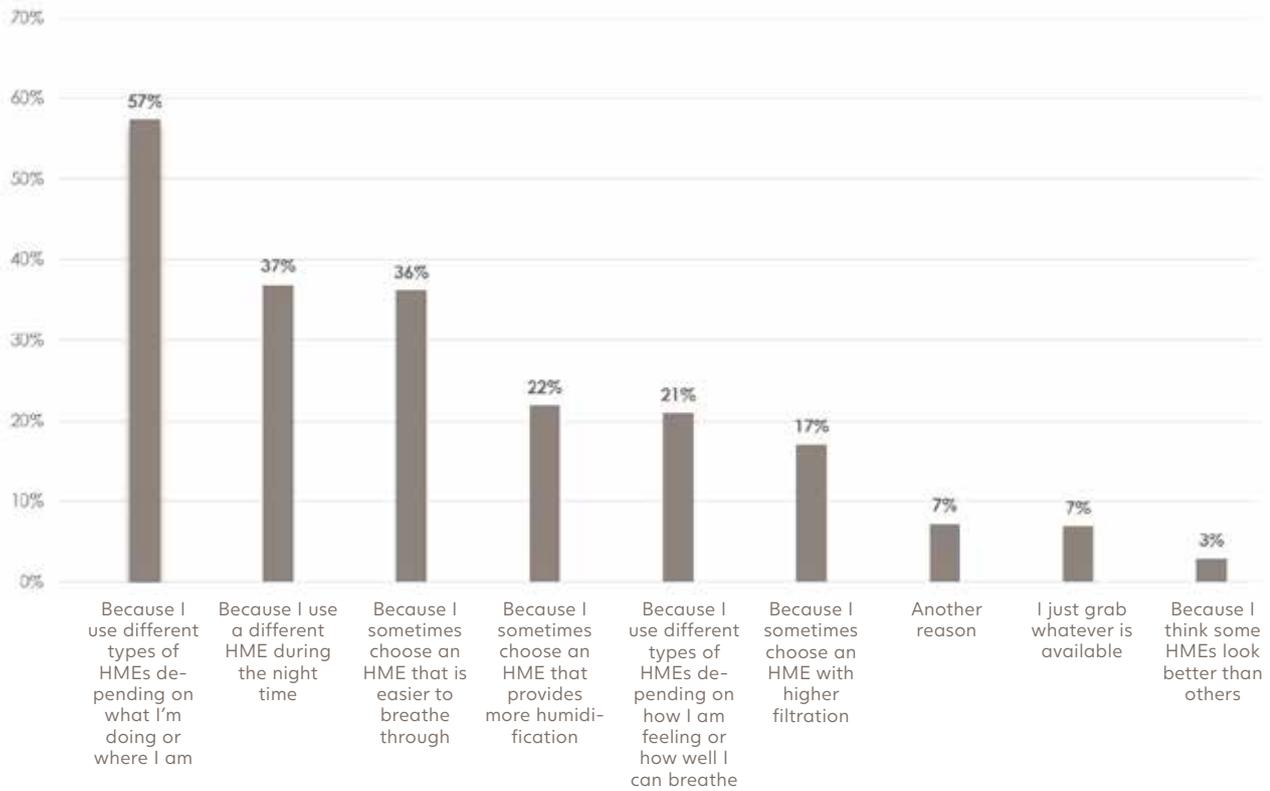


Question:
How many HMEs do you use in a 24 hour period?



Question:
What product do you use in a typical week?

Among those who used more than one type of HME, the most common reason was to adapt to a specific situation.



Question:

Which of the following statements explains why you typically use more than one type of HME each week?

Patients expressed an interest to change their HME during the day to improve their quality of life.



Question:

Would you consider changing your HME several times during the day if it could improve your quality of life?

Conclusion

The patients reported a good overall health status, but when asked about specific problems they reported a wide range of issues, indicating hidden problems. The most prevalent issues related to pulmonary health, voicing, skin irritation, and issues associated with physical activity, sleep, and social interactions. Additional support and product development should be considered to help resolve these issues and improve quality of life.



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At Atos Medical, we are committed to giving a voice to people who breathe through a stoma, with design solutions and technologies built on decades of experience and deep understanding of our users.

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