Global COF

Ostomy *Life Study* 2016/17 Review

The Ostomy Life Study Review is a recurring publication developed by Coloplast in cooperation with expert ostomy care nurses in the Global Coloplast Ostomy Forum. The aim is to raise awareness about important aspects of ostomy care by sharing evidence based data and clinical insights in order to improve the standard of care.

Table of contents

How can we support patients with a chronic condition in *getting the most out of life?*

Living with a chronic condition is a continuous process of balancing the demands of the condition and the demands of everyday life. Self-care (or "chronic homework", see p. 17) has physical, psychological and social aspects, and all require time and effort: When being discharged from hospital, people need to take time out to perhaps learn new routines, products and perhaps prescriptions, dealing with endless trial and error cycles, visits to the hospital, etc. All this can lead to a stressful situation between managing the condition, and the life the individual hopes to have. To manage the stress, many people with a chronic condition might simply focus their energy on maintaining a somewhat 'basic' daily life, while sacrificing some of what they truly consider meaningful in life.

Focus on the hidden issues of chronic conditions

This edition of the Ostomy Life Study Review introduces how we constantly have to bring forward and illuminate the hidden burdens of people with chronic conditions and encourage behavioural changes through improved training and support. Often, the struggle to manage a chronic condition leads to people hiding and accepting problems that could have been solved by an expert. Managing a challenging ostomy can become a habit, a burden that is just considered "part of life" with an ostomy, affecting people's quality of life.

The new Ostomy Life Study puts focus on different peristomal body profiles

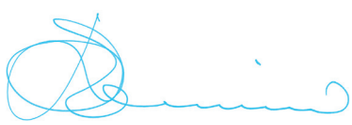
The basis of this review is the Ostomy Life Study 2016[1], conducted to understand the challenges of people's peristomal body profiles and the challenges that they are dealing with in their everyday life. In 2014 Coloplast conducted the first Ostomy Life Study, published in the Gastrointestinal Nursing[2].

The Body Profile Terminology helps improve understanding and knowledge sharing

The Body Profile Terminology (see p. 7) can provide a common platform for knowledge sharing on treatment and leakage prevention[2], because it helps standardise the description of peristomal areas under the umbrella of the three overall categories: 'Regular' – 'Inward' – 'Outward'.

This can support the expert intervention: In providing the right training, the right products and the right education. But any intervention means a change in habits, sometimes a radical change. And daily habits are powerful. In fact, daily habits may be the most powerful of all behaviours.

Understanding the psychology of long-term behaviour change is key – and we hope this edition of the Ostomy Life Study Review will inspire you to once again consider the varied needs of the individual - and how you can help them adapt to their change in conditions.



Lena Ehmsen Lachenmeier
Director of Medical Marketing
at Coloplast A/S

[1]Coloplast Ostomy Life Study, 2016, Data on file; [2]Claessens et al., 2015, GIN

A note from the co-editors

The Ostomy Life Study Review represents an ambition to gather and share new insights about how people live with their ostomy. In the Global Coloplast Ostomy Forum we find this project to be incredibly important. And we must take these insights very seriously, as we lack information on how people manage their ostomy after they leave our care.

Data and insights like the ones presented in the Ostomy Life Study Review increases the knowledge of how to recognise individual needs and find appropriate solutions and guidance based on that knowledge.

What we find unique and important about the Ostomy Life Study is that we learn more from the perspective of the patients, which helps us get a much better understanding of the high impact that leakage and other complications can have on people's quality of life. And finally, it directly shows how our work influences the everyday life of people with chronic conditions – and how we can help them even better.

– Global Coloplast Ostomy Forum

The Global Coloplast Ostomy Forum group consists of 13 ostomy care nurses from 9 different countries with many years of experience and a high level of expertise within ostomy care.

A closer look at *peristomal body profiles*

Why talk about peristomal body profiles? And, what are peristomal body profiles? These may be questions you would like to ask. In 2010 Coloplast conducted a market research study[1] showing that 6 years after discharge, 74% of people with an ostomy reported leakage monthly. Hence, leakage problems in people dependent on ostomy products were still unsolved. Why? Maybe because it was difficult to find the right ostomy products that fit optimally to different bodies with different needs[1]. Therefore, Coloplast made a promise to focus on "Fit to body" solutions going forward.

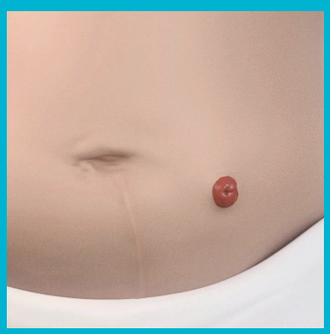
A common language was required – and in cooperation with ostomy care nurses in the Coloplast Ostomy Forum around the world, the Body Profile Terminology was "born".

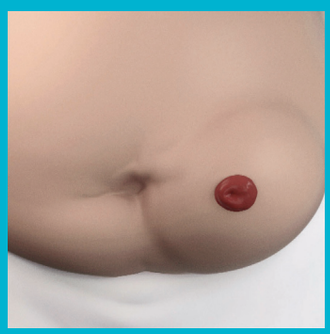
The three overall peristomal body profiles

Regular, where the area around the ostomy is more or less even with the abdomen.

Inward, where the area around the ostomy sinks into the abdomen creating a hollow.

Outward, where the area around the ostomy rises from the abdomen creating a peak.





Following the definitions set by the Body Profile Terminology[2], the peristomal body profile can either be described as 'Regular', 'Inward' or 'Outward' (see above box for definition). To follow up on the market research from 2010, Coloplast has conducted two Ostomy Life Studies, one in 2014[3] and the recent Ostomy Life Study 2016. The Ostomy Life Study 2016[4] delves deeper into what characterises individuals with different peristomal body profiles in terms of complications and choice of ostomy products. The Ostomy Life Study 2016[4] includes more than 4000 people with an ostomy from all over the world.

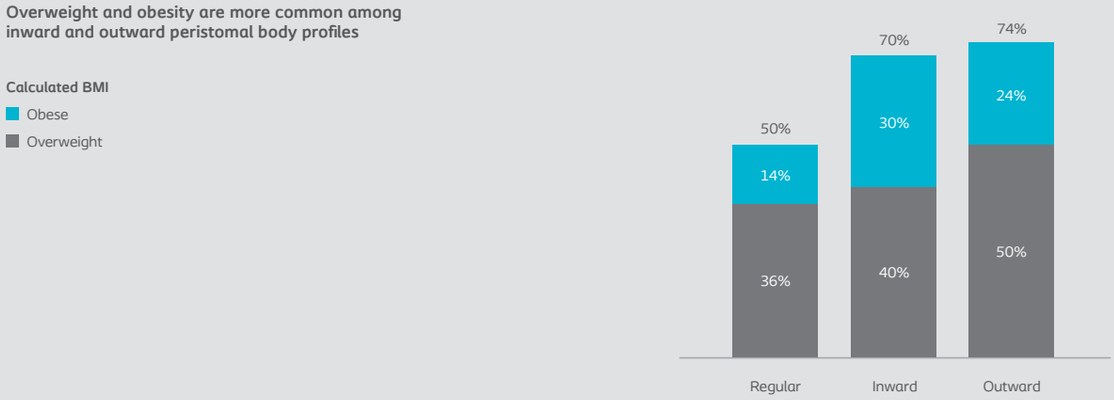
From the findings, it seems clear that people with a 'challenging' peristomal body profile (i.e. both those characterised as inward and outward) have a lot in common and have to deal with very specific challenges. It is also clear that a 'one size fits all' approach is certainly not sufficient.

Findings among people with challenging peristomal body profiles:

- For people with inward and outward peristomal body profiles, a higher percentage experience leakage "daily or weekly" and they worry about leakage to a high or very high degree
- People with regular and outward peristomal body profiles primarily use flat ostomy products whereas people with inward peristomal body profiles primarily use a convex product
- Leakage and worrying about leakage leads to less physical activities which may be associated with weight issues
- Both outward and inward peristomal body profiles are highly represented among obese or overweight people, which may add to the challenge of finding the right appliance fit

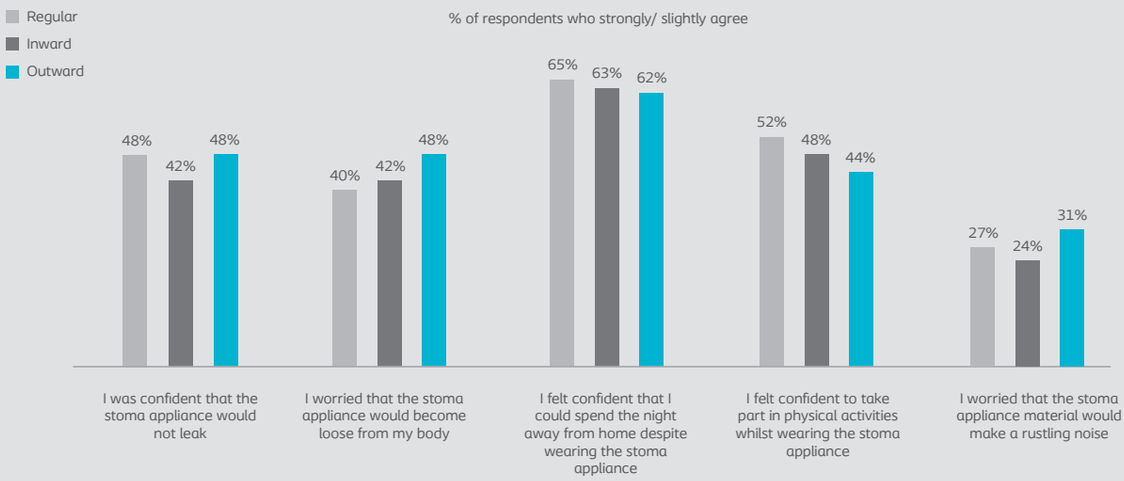
These facts clearly underline the need for developing ostomy products which meet the specific needs of individuals with challenging peristomal body profiles.

Overweight and obesity are more common among inward and outward peristomal body profiles



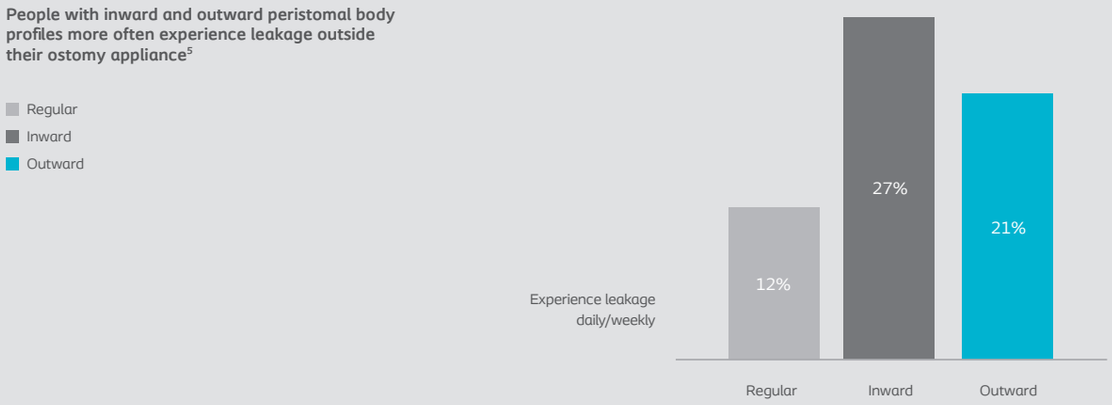
Q: What is your current height and weight?

Looking across all peristomal body profiles, we see that many people are lacking confidence in their ostomy appliance which may lead to a lower quality of life



Q: When thinking about the past 7 days, please indicate whether you agree or disagree with the statements related to how confident you feel using your stoma appliance

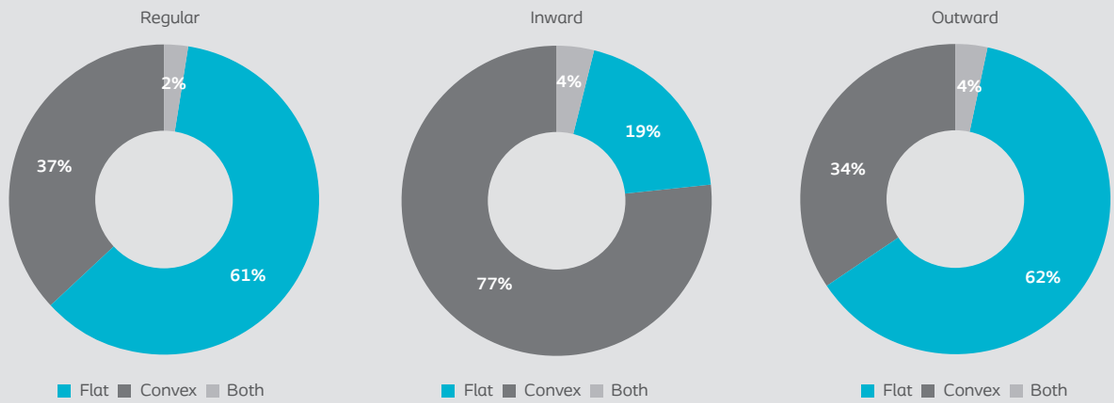
People with inward and outward peristomal body profiles more often experience leakage outside their ostomy appliance[5]



Q: How often do you experience output outside bag/baseplate?

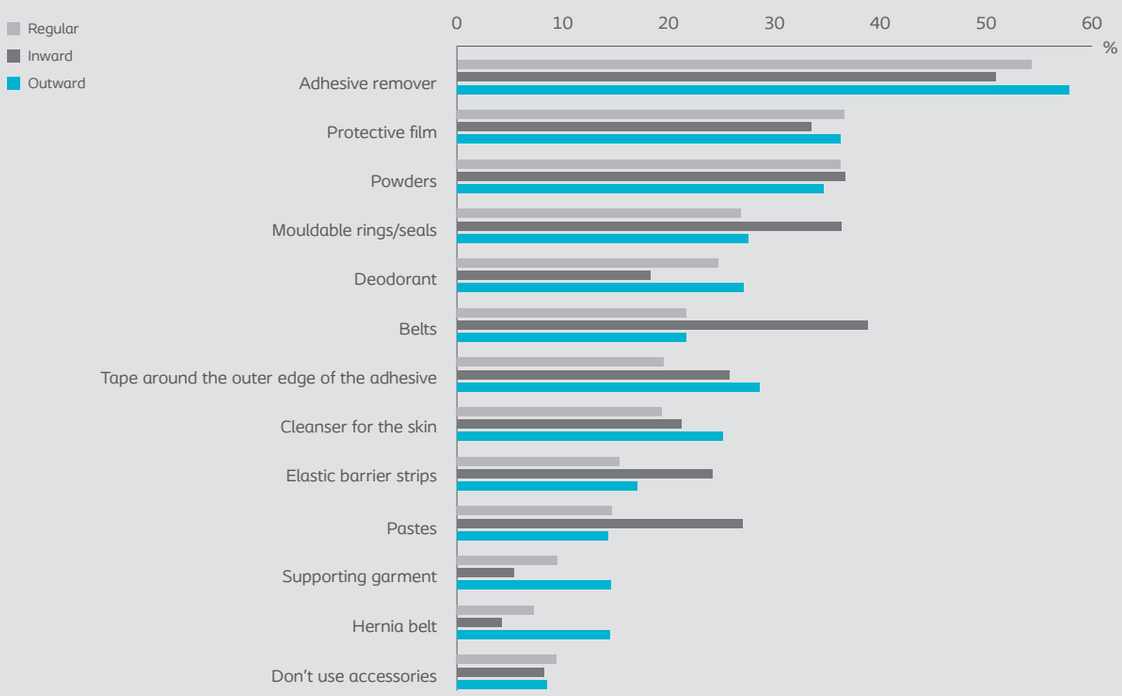
These findings from the Ostomy Life Study 2016[4] highlight how individual body profiles have different needs in terms of ostomy products, but it also sheds a light on the high impact of associated complications and challenges such as leakage experience – on both quality of life[6], and the need for ostomy accessories[4].

People with an inward peristomal body profile are much more likely to be using a convex baseplate



Q: Is the part of your stoma appliance that sticks to the skin (the baseplate) flat or convex?

More than 90% of all people with an ostomy use accessories, however type of accessories used varies depending on the individual peristomal body profile



Q: Which of the following stoma accessories do you use? Multiple answers allowed.

[1]Coloplast Market Research, 2010, Data on file; [2]Ostomy Life Study 2015/16 Review [3]Claessens et al., 2015, GIN; [4]Coloplast Ostomy Life Study, 2016, Data on file; [5]Coloplast Usage Pattern Study, 2015, Data on file; [6]Ostomy Life Study 2016/17, Review (p 10-11)

How the peristomal body profile impacts quality of life

The Ostomy Life Study 2016[1] shows that the peristomal body profile has a direct effect on the quality of life of the individual with an ostomy.

Quality of life - a deeper understanding

There is more to quality of life than just a score[2]. Recently the introduction of a new assessment tool has made it possible to gain a better understanding of how ostomy appliances affect everyday life activities such as shopping and exercising, and what impact it has on the more health related aspects of quality of life[3].

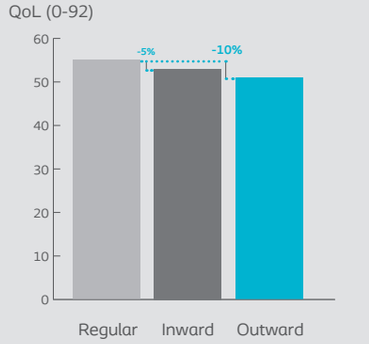
Facts about the new assessment tool

The tool has been designed to capture the effect ostomy appliances have on the experienced quality of life of people dependent on ostomy appliances.

It consists of 23 questions, that consider four overall parameters of ostomy related quality of life: discretion, comfort, confidence and social life and relationships.

What affects quality of life?

With the notion in mind that several underlying factors contribute to assessing quality of life, it is only natural to investigate the link between answers in the quality of life assessment tool and physical characteristics. Indeed, that is one focus of this new Ostomy Life Study 2016[1] conducted among more than 4000 people with an ostomy from all over the world. The survey uses the quality of life tool to consider aspects of quality of life affected by using an ostomy appliance.

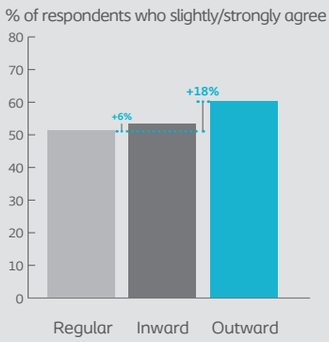


Quality of life overall score for the three peristomal body profiles 'regular', 'inward' and 'outward'. The score goes from 0-92 with 92 being the best possible score.

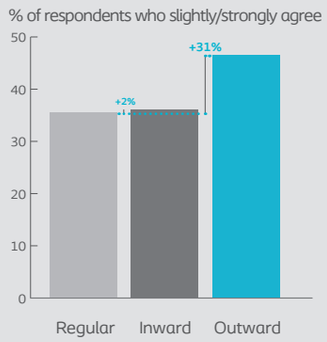
Challenging peristomal body profiles affect quality of life

As indicated in the figure on the previous page, the experienced quality of life is higher for those with a regular peristomal body profile, compared to those with an inward or an outward peristomal body profile[4]. The picture is the same, when looking into how confident people with an ostomy are about using an ostomy appliance - and how they feel about everyday life situations.

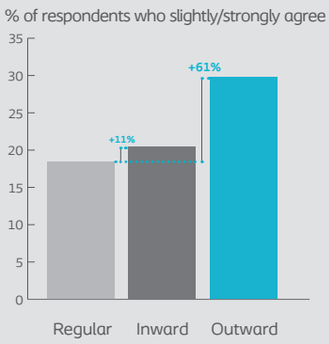
Presented in the figures on this page are examples of questions and the amount of participants that answered 'slightly agree' or 'strongly agree' for each peristomal body profile. The five questions are among a series of questions under the four overall ostomy related quality of life parameters in the quality of life assessment tool[3].



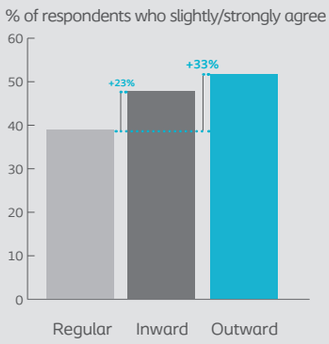
The stoma appliance limited the choice of clothes that I could wear.



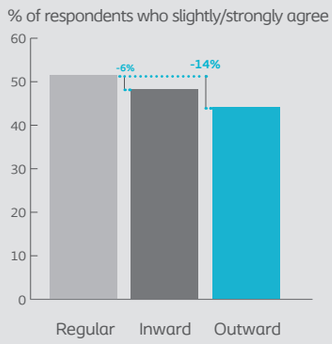
I was self-conscious about the appearance of the stoma appliance.



I avoided close physical contact with family and friends because of the stoma appliance.



I worried about whether the stoma appliance would affect my sex life.



I felt confident to take part in physical activities (for example, sports) whilst wearing the stoma appliance.

A need for special attention

The answers provided by the survey indicate that individuals with inward or outward peristomal body profiles are more likely to have concerns and emotional issues from using ostomy appliances. They feel more restricted in every-day life situations and less self-confident about using an ostomy appliance, which may have an impact on how they engage with their family and friends.

For ostomy care nurses this underlines the need to provide extra support to people with inward and outward peristomal body profiles to help them overcome their challenges. Both in terms of helping them find the right ostomy product and by supporting them on an emotional level.

[1]Coloplast Ostomy Life Study, 2016, Data on file; [2]Ostomy Life Study 2015/16, Review [3]Nafees et al., 2016, Submitted for publication; [4]Ostomy Life Study 2016/17, Review (p 10)

Have the needs of people with *outward peristomal body profiles been overlooked?*

Data from the Coloplast Ostomy Life Study 2016 indicates that individuals with an outward peristomal body profile show a high degree of worrying about their ostomy appliance being visible - and they struggle with making their baseplate fit.

As seen previously in this review there are specific challenges relating to each peristomal body profile. This applies both in terms of complications (see p. 8-9) and effect on ostomy-related quality of life (see p. 10-11). However, a deeper look into data from the Ostomy Life Study 2016[1] indicates that individuals with an outward peristomal body profile – about one third of all people with an ostomy – have very distinct challenges in dealing with their situation.

Summary of findings

People with outward peristomal body profiles are more likely to be obese or overweight than those with regular peristomal body profiles[1]. They use more accessories[2], are more worried about leakage[1], are more concerned about lack of discretion[1], and have more uncontrollable bellies and stretched skin[1]. These findings indicate a need for special care when looking for the right ostomy appliance.

What the data shows about people with outward peristomal body profiles[3]

39% worry about leakage to a 'high or very high degree'

44% experience that their ostomy appliance is visible through clothing

84% have an ostomy above skin level (protruding)

64% are 60+ years old

57% are male

74% are overweight or obese

63% find it difficult to hide the ostomy appliance because of ballooning

56% use a 1-piece appliance

Outward peristomal body profile challenges are worthy of special care

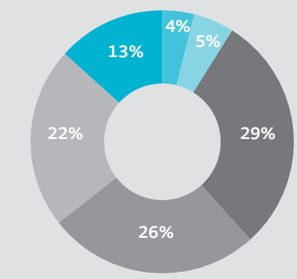
Many circumstances contribute in making it difficult for individuals with an outward peristomal body profile to obtain a proper ostomy product fit. For one, the curved shape of the area makes it difficult to obtain a tight seal and proper adherence of the baseplate – even when the ostomy location is perfect. Outward areas come in many different sizes, making it difficult to point to one solution suitable for all.

When you combine how people with an outward peristomal body profile experience a large negative impact on their quality of life, it is clear that there is good reason to focus more on these individuals, both in terms of research and product innovation.

Outward peristomal areas come in many sizes

The outward peristomal area of individuals with an outward peristomal body profile can vary from below 5 cm to over 20 cm in size.

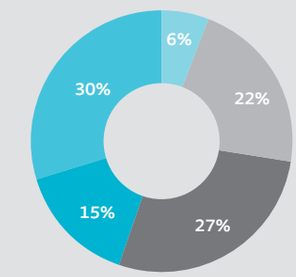
Size of outward peristomal areas



Outward peristomal areas can develop late

It is most common (50%) for outward areas to develop within the first 6 months after surgery. However, for almost a third of people (30%) with outward peristomal body profiles, the area didn't develop until more than a year after surgery.

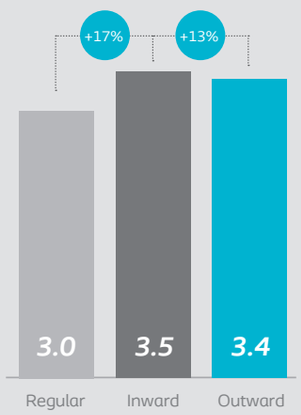
When outward peristomal areas develop

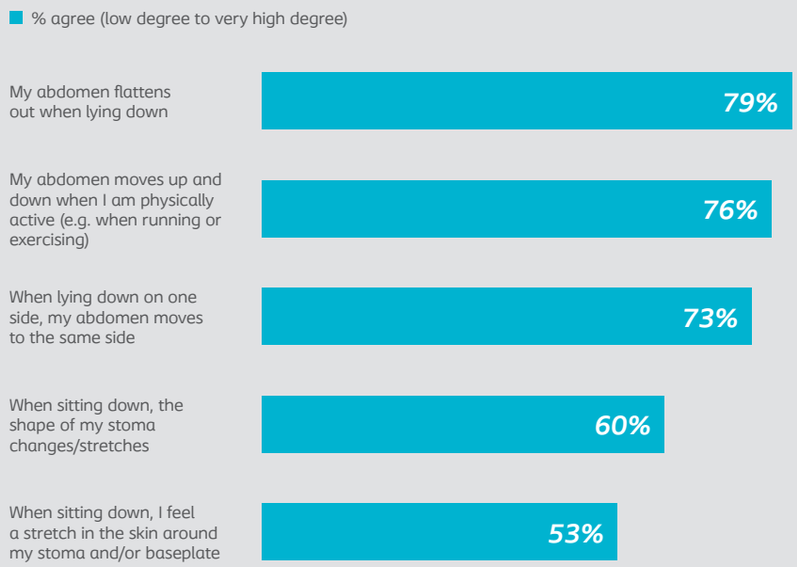


People with outward peristomal body profiles use more accessories

Similar to inward peristomal body profiles, outward peristomal areas require more accessories to obtain proper fit and care.

Average number of accessories used





Outward peristomal body profiles are challenged by body movement

- Many people with outward peristomal areas experience stretching of the ostomy shape when they change body position.
- The findings show that many people with outward peristomal body profiles have uncontrollable bellies as they move up and down when active and moves to the side when lying down.
- A little more than half of the people with an outward peristomal body profile experience stretching of the skin when sitting down.

[1]Coloplast Ostomy Life Study, 2016, Data on file; [2]Ostomy Life Study 2016/17, Review (p 13) [3]For more data on this and other peristomal body profiles, please refer to the datasheet on p. 22-23

How much do we know about *peristomal bulges?*

With Coloplast's focus on "Fit to Body" within Ostomy Care, people with regular and inward peristomal body profiles (as defined in the Body Profile Terminology[1]), have been the primary focus. And for the majority of these individuals, the flat and convex ostomy products available on the market, fit their need.

People with an outward peristomal body profile have had less focus. However, the data from the Ostomy Life Study 2016 shows that this group seems to have challenges similar to people with an inward peristomal body profile.

A literature review was conducted to separate 'myths' from facts regarding peristomal bulges. Its objective was to uncover whether or not there is robust scientific evidence behind some of the wide held beliefs about the cause and management of an outward peristomal body profile or peristomal bulge. The overview of identified 'myths & facts' was shared with Coloplast Ostomy Forum boards all over the world for validation.

A common complication following ostomy surgery is the development of a peristomal bulge[2] and many of these bulges have shown to be parastomal hernias. From the literature[2-8;16] we see that the incidence of parastomal hernias varies from 11% to 60% depending on the study method and type of ostomy.

Parastomal hernias are mainly seen as a non-symptomatic challenge and thus not repaired[9], but in 10-30% of the cases, chronic peristomal pain or intestinal incarceration and strangulation require a reoperation[5]. However, patients who have bulges due to weak abdominal muscles will probably not benefit from surgical repairment.

Even though the issue is common, how robust is the available knowledge about peristomal bulges? A main challenge when searching for evidence-based knowledge on peristomal bulges including parastomal hernias is the inconsistency in definitions. When reading the literature, you may not know if the incidence of a parastomal hernia is a true hernia or just a bulge.

Question #1
Is a bulge in the peristomal area always a hernia?

A bulge can be difficult to distinguish from a parastomal hernia by clinical examination only[11]. And a lack of a uniform definition of a true parastomal hernia makes it difficult to determine the genuine incidence[12]. A bulge in the abdominal area could also be related to e.g. a subcutaneous prolapse where the fascia is intact but the prolapsed bowel lies subcutaneously (a sliding hernia) or excessive subcutaneous fat creating a bulge[13].

Question #2
Does the risk for developing a peristomal bulge increase with age?

With age, our abdominal muscles become thinner and weaker and may not provide adequate support for the ostomy[14]. This may explain the results of some retrospective studies, which found that a bulge e.g. parastomal hernia is more likely to occur in elderly people over 55 years of age[2, 4, 7, 26].

Question #3
Can exercise or heavy lifting increase the risk for developing peristomal bulges or parastomal hernias?

Standard of care recommends nurses to advise patients against lifting and stretching as this may cause damage and discomfort[15]. However, no studies have found the association between exercise or heavy lifting and development of a parastomal hernia, and there is a lack of evidence supporting that specific restrictions prevent hernia formation[16].

Question #4
Does exercise and/or support garments prevent the development of a peristomal bulge?

Three studies have shown that the combination of exercise, support garments and recommendations regarding heavy lifting might reduce the incidence of parastomal hernias[17-20]. However, no studies showed that exercise or support garments alone reduce the incidence of parastomal hernias.

Question #5
Does the site of the ostomy influence the risk for parastomal hernias?

There is good reason for bringing the bowel through the rectus muscle; it is the most stable site for providing support for the ostomy[12] and for fitting the appliance to the skin[21]. This is probably why there is near universal acceptance of the idea that an ostomy created through the rectus muscle also lowers the risk of herniation. However, there is no clear evidence to support that practice[3-4, 7-8, 18, 22-25].

Question #6
Does bulging/a parastomal hernia lead to the ostomy becoming retracted or can it influence its shape or size?

A review paper states, that when a parastomal hernia develops the ostomy can become retracted. However, no evidence was provided[26]. When it comes to the ostomy shape or size, studies showed that bulging/parastomal hernia may be associated with an increase in the ostomy diameter (aperture size)[27].

Question #7
Does new and improved surgical techniques prevent peristomal hernias?

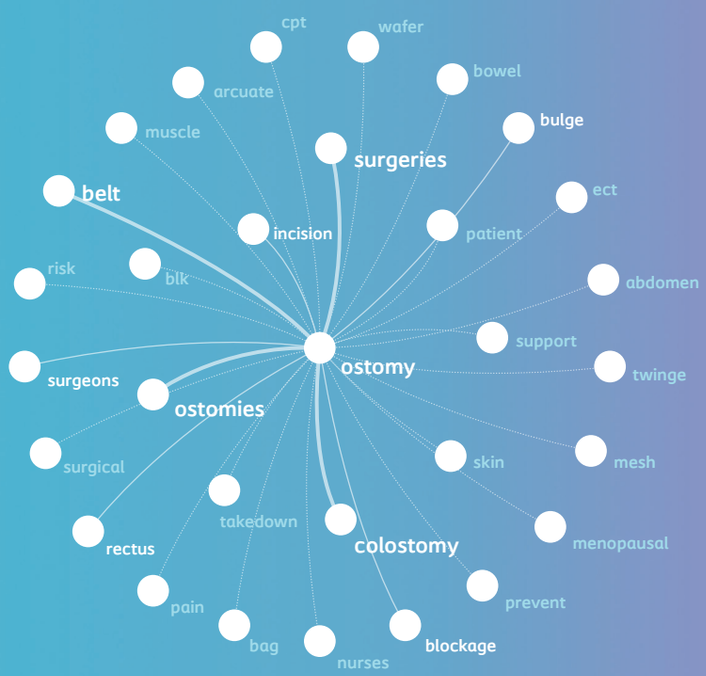
Even though newer surgical techniques and synesthetic prosthetic mesh materials might have reduced recurrence rate, the recurrence rate is still up to 22%[28]. It is still to be documented if laparascopic surgical techniques will change the incidence of outward peristomal body profiles including bulges and parastomal hernias.

[1]Ostomy Life Study 2015/16 Review; [2]Ripoche et al., 2011, J Visc Surg; [3]Leong et al., 1994, BJS; [4]Londono-Schimmer et al., 1994, Dis Colon Rectum, [5]Moreno-Mathias et al., 2009, Colorectal Dis; [6]van Djik et al., 2015, World J Surg; [7]Pilgrim et al., 2010, Dis Colon Rectum; [8]Williams et al., 1990, Br J Surg; [9]Glasgow and Dharmaian, 2016 Clin Colon Rectum, [10]Roussel, 2012, J Visc Surg; [11]Gurmu et al., 2011, Int J Colorectal Dis; [12]Israelsson, 2005, World J Surg; [13]Rubin, 2004, Intestinal Stomas: Principals, Techniques and Management, [14]Williams, 2003, ia Journal; [15]Kane et al., 2004, Nurs Stand; [16]Pommergaard et al., 2014, Hernia; [17]North, 2014, Br J Nurs, [18]Thompson and Trainor, 2005, GIN; [19]Thompson and Trainor, 2007, GIN; [20]Varma, 2009, Br J Nurs; [21]Shellito, 1998, Dis Colon Rectum; [22]Sjödahl et al., 1988, Br J Surg; [23]Eldrup et al., 1982, Ugeskr Laeger; [24]Hardt et al., 2013, Cochrane Database Syst Rev; [25]Hardt et al., 2015, Colorectal Dis, [26]Burch, 2010, Br J Nurs; [27]Hong et al., 2012, JKSS; [28]Nagy et al., 2004, Zentalbl Chir.

Hernias and peristomal bulges:
A social taboo?

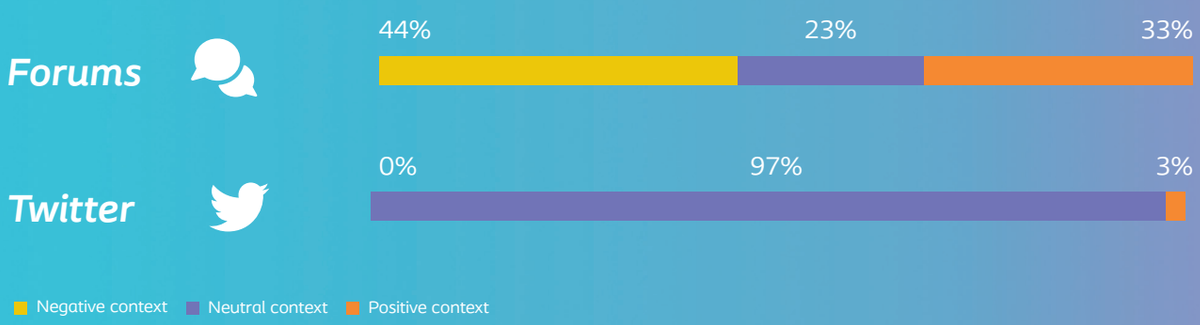
A social media listening study has been conducted to monitor the mentioning of hernia or bulges in ostomy-related contexts on social media, blog posts, community forums or traditional news outlets.

This study is conducted by searching for mentions of selected keywords and then mapping out what other words appear close to them.



All quiet on the hernia front
The main finding is that while there is plenty of social media chatter about ostomy, there is very little mention of hernia or bulges compared to the overall volume of social media mentions. When hernia is mentioned on social media channels in connection with ostomy, it is mainly associated with words like “surgery”, “surgeon”, “bowel” and “complications”, suggesting that “official” medical language and news sources are dominating the conversations. It is very difficult to find people with an ostomy discussing their hernia experiences.

The ‘real voices’ are in closed forums
Interestingly, a sentiment analysis (measuring if a social media post is positive, negative or neutral in language) shows that on the social media channel Twitter, mentions of hernia and ostomy in connection are almost always neutral (as expected from ‘external’ news sources and medical device manufacturers), while mentions in discussion forums are much more polarized and emotionally charged. This seems to support the hypothesis that living with an ostomy and a hernia is considered somewhat embarrassing or even taboo, and only discussed in the safe space of a community of peers.



Chronic condition means *chronic homework*

Research shows that nurses play a key role in helping patients cope with the 'chronic homework' of taking care of their ostomy on a daily basis.

There is more to having a chronic condition than following your treatment. Learning how to live with your condition everyday is just as important – and naturally doctors and nurses play a major role in teaching patients how to cope with this 'chronic homework.'

This is one of the conclusions in a recent article by Ayo Wahlberg, Professor at the Department of Anthropology at the University of Copenhagen[1]. And while this may not be surprising news to an ostomy care nurse, it certainly highlights the importance of helping patients with the transition from being hospitalised and in treatment to living a normal life with an ostomy.

Chronic homework

More and more patients, who would have been terminally ill 10 or 20 years ago, are now living with their ostomy[2]. Obviously this is a good thing - but it also represents a challenge. In his article Ayo Wahlberg cites anthropologist Cheryl Mattingly and her colleagues, who have used the term 'chronic homework' to describe the amount of work that patients with a chronic condition put into keeping their daily lives on track[3,4].
For people with an ostomy this would entail daily tasks such as changing their ostomy pouches and keeping the skin around the ostomy healthy. On a general level patients are, however, also conscious about how they can fit their chronic homework into their daily activities. *How will I live my life with a chronic condition?* [5]

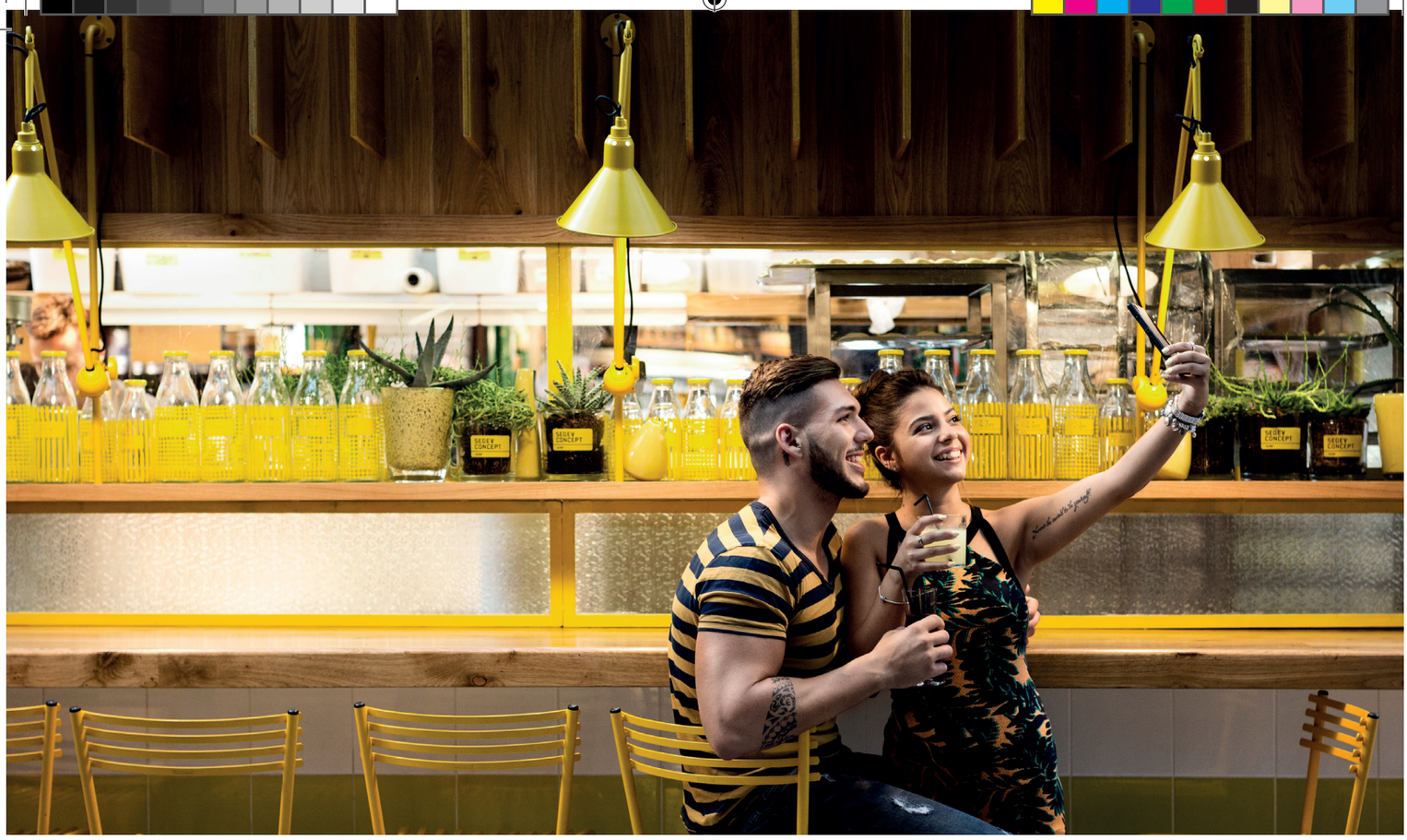
A life changing experience

According to Professor Wahlberg, it is important to acknowledge how much the amount of chronic homework can weigh down on people with an ostomy and affect their quality of life. It's life changing to receive a chronic diagnosis[6,7,8]. Ostomy care nurses play a key part in helping patients learn how to deal with the added stress of dealing with chronic homework in addition to recovering from major surgery. This includes encouraging patients to check their peristomal body profile regularly in order to make sure their ostomy appliance still fits over time.

Ostomy care nurses as chronic homework coaches

Indeed the role of ostomy care nurses is shifting from being strictly medical towards more of a coaching role. And while it's obviously still important for patients to follow their treatment, it's equally important for them to learn how to live with the 'chronic homework' of their chronic condition. And the person they will turn to for guidance will almost certainly be their nurse.

[1]Manderson and Smith-Morris, 2010, Fluid States: Chronicity and The Anthropology of Illness; [2]Mattingly et al., 2014, Cult Med Psychiatry; [3]Pols, 2013, Sci Technol Stud; [4]Becker, 1998. Disrupted lives: How people create meaning in a chaotic world; [5]Bury, 1982, Sociol Health Ill; [6]Charmaz, 1983, Sociol Health Ill; [7]Wahlberg, 2009, Contested Categories: Life Sciences in Society.



How to understand patient behaviour – ***and how to affect change***

Rune Nørager, MSc., PhD behavioural psychology,
*CEO **d**esign**p**sychology.*

Both for patients and health care professionals, changing behaviour to adapt to new circumstances is critical. Why do some patients succeed, while others struggle? What can health care professionals do to understand and help their patients change behaviour when dealing with a new situation?

All humans have a capacity for changing their behaviour. As we grow up, we constantly learn new behaviours (e.g. walking), and let go of old ones (crawling). But even for adults, the ability to change behaviour remains important.

Some changes in behaviour are simple and happen almost automatically – like adjusting to a new phone, or taking a new route on the way to work.

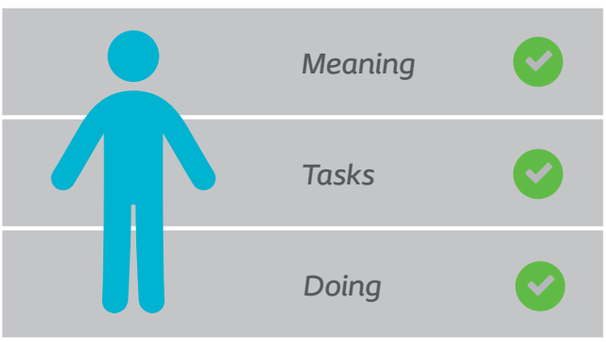
But in some situations behaviour change requires great effort and can keep us struggling to adopt for a long time. For patients, it could be suddenly having to deal with a chronic condition. For health care professionals, it could be adopting new medical practices that challenge familiar and trusted habits. In both cases, not adapting to the new behaviour will lead to frustration.

The building blocks of behaviour

To understand behavioural change and how we can support it, we need to know about the psychological building blocks of behaviour. Everything we do as individuals has three layers; the top most layer is the meaning level: "Why do we do it". The next level the action planning "What to do". Finally, there is the "How to do it". Together, the last two levels are the "doing" aspect of behaviour.

Three building blocks of behaviour

New behaviour is typically formed as a transition from conscious meaning to learning what and how that eventually may become subconscious automated behaviour.



Two typical barriers to behaviour change

Patient knows what to do and how, but not why (can't see the meaning).

Patient understands the why (get the meaning) - but doesn't have the skills or knowledge.

To learn a new behaviour, we need to be aware of...

... **the "why"** ("The old train doesn't fit my timetable, it is important I get to work on time"), and then plan ...

... the "what" (eg. "I need to take the bus instead"), then maybe the need to learn a new ...

... "how" ("I should take the bus from the central, and buy a bus ticket")

To truly adopt a change in behaviour, all this information needs to be automated. If we have to think about which bus to take every morning, we have not truly adapted to a new behaviour yet. This requires resources – research, effort and practice, until eventually it becomes habitual and unnoticed.

Behavioural change succeeds when we understand all three levels of a current and a new behaviour and address each of them with the resources needed.

But behavioural change fail when we only consider one level by itself. For instance, patients might know "why" they should take care of themselves in a certain way, but not understand "what" exactly they should do or "how" to do it because they lack the resources to do the necessary research. Perhaps their health care professional simply explained the importance of good hygiene, but for some patients it may be a huge effort to figure out what exactly 'good hygiene' means.

On the other hand, even though a patient knows the "how" and "what" of self-care, she may not put those skills into action because she lacks an understanding of "why".

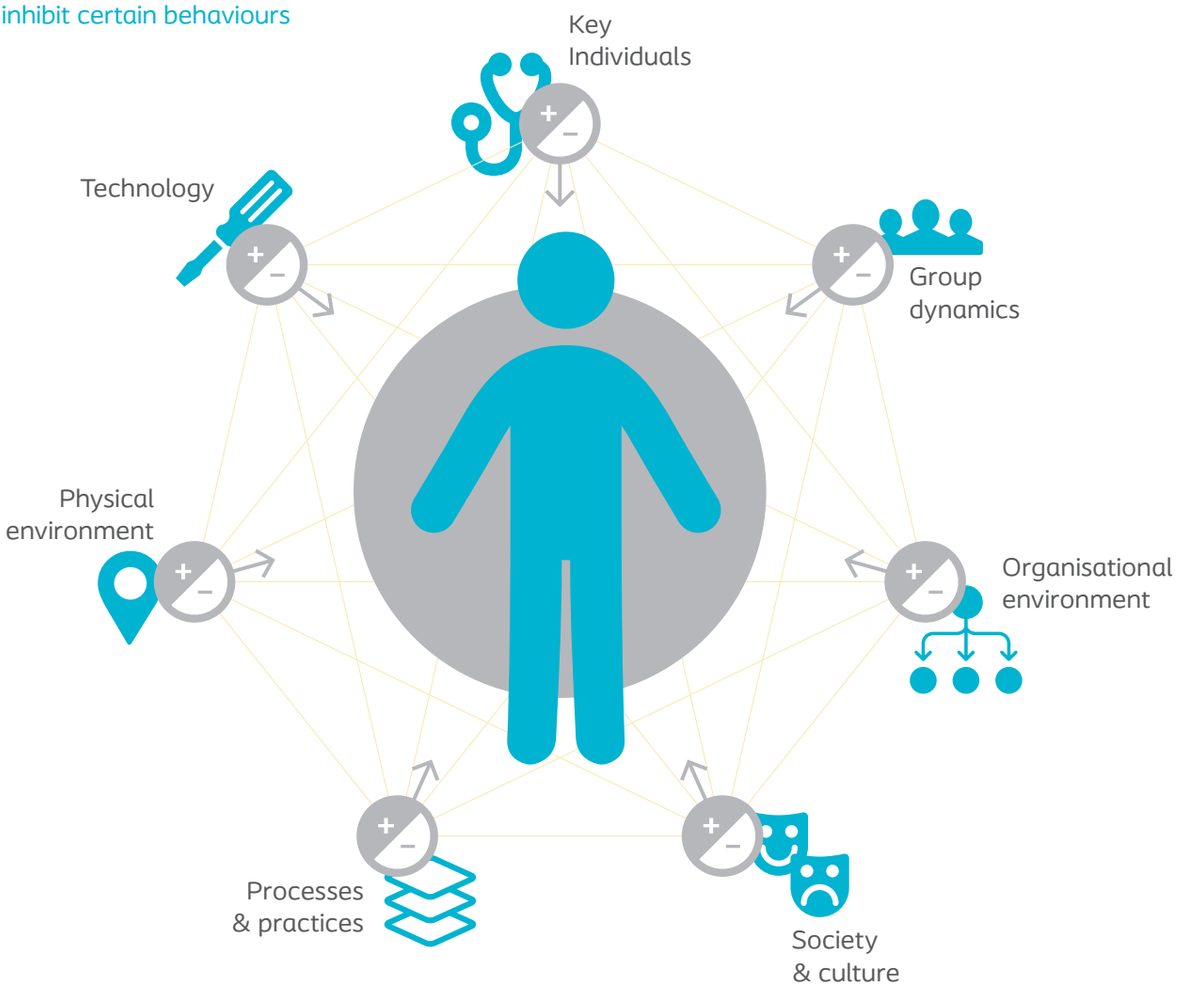
Behaviour is put together of many different “blocks”

In addition to behavioural building blocks at the individual level, there are important building blocks in the world around us – culture, social and group dynamics, technology, etc. For instance, if patients have to pay for ostomy products themselves, it tends to affect their behaviour and increase the wear time of the product.

To really support patients in adopting a new behaviour that is good for them, we therefore need to consider all the ‘behaviour blocks’ their current behaviour is built on, even those inside the patient. If we only consider the behaviour we can observe, it can be very difficult to make sense of – sometimes even to the point where we might call it irrational (e.g. patients that seem to be completely ignoring the routine their health care professional has prescribed).

If we understand the full picture, we have a much better starting point for helping patients change behaviour.

Individual behaviour is shaped by many different factors around the patient that can either promote or inhibit certain behaviours



Sometimes a nudge is not enough

Sometimes, it can be a very small aspect of one of the building blocks that keeps us from doing what is right – say, wash our hands or throw out the garbage. We can help patients overcome such barriers with small pushes in the desired direction, often called "nudges". It could be an image of a pair of eyes over the bathroom sink, that reminds us of the social norm ("if somebody was looking, you would wash your hands") and increases the likelihood that we wash our hands. This could be called a "pro-social reference nudge".

In many cases, however, especially in the health care system, the change in behaviour is much more radical, and it often means that the patient has to let go of old habits that were efficient, perhaps even loved. It is easier to adopt a new behaviour if it is clearly better than the old – like walking instead of crawling. For some patients, learning a new behaviour is more like having to crawl, when you are used to walking.

Summary box

Change behaviour is critical when faced with new situations

- Changing trusted habits requires effort and time to adapt
- To support successful behavioural changes it is important to understand the psychological building blocks: "what do we need", "how do we do it", and "why do we do it"
- Surrounding building blocks such as culture and social group dynamics are important to obtain the full picture
- Understanding the full picture ensures a better starting point for achieving behavioural changes

Supporting radical change requires effort

This requires a lot of effort and creates challenges at all behavioural building blocks. Here a nudge will not do. Instead, a much more carefully planned and resourceful approach is needed. We have to address all relevant "building blocks": What understanding do they need? What practical knowledge? Do they need to change something in their physical environment, such as their home? etc.[1]

To succeed with behavioural change, we need to get rid of simplistic and judgemental labels like patients needing more "motivation", having "irrational behaviour", and being "resistant to change".

Instead we should empathize with the dynamics and levels of current and new behaviour: We must understand that change is sometimes very difficult. And understand why it is difficult. Only then can we help patients successfully adopt a change in behaviour.

[1]A validated and effective behavioral model that incorporates these levels of behaviour and considered barriers and resources in the environment is the Health Action Process Approach (HAPA).

A snapshot of *the ostomy population*

Demographic data from the Coloplast Ostomy Life Study 2016

Gender

People with a **regular** peristomal body profile

47% 53%

People with an **inward** peristomal body profile

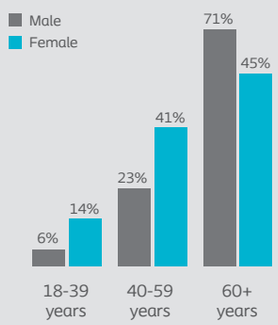
32% 68%

People with an **outward** peristomal body profile

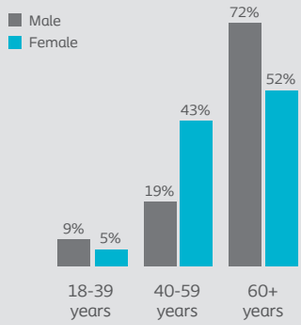
57% 43%

Age (male/female)

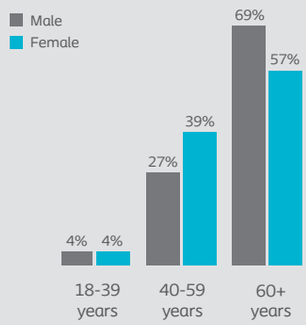
People with a **regular** peristomal body profile



People with an **inward** peristomal body profile

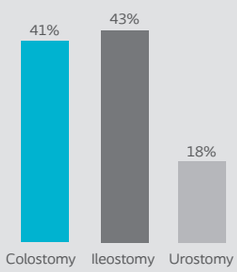


People with an **outward** peristomal body profile

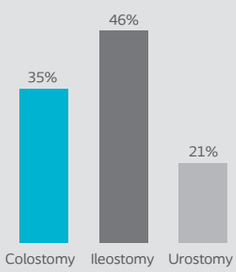


Stoma type

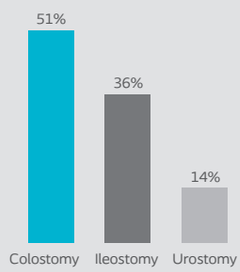
People with a **regular** peristomal body profile



People with an **inward** peristomal body profile



People with an **outward** peristomal body profile



% of people with an ostomy that worry about leakage from a low to a high degree

People with a **regular** peristomal body profile

92%

People with an **inward** peristomal body profile

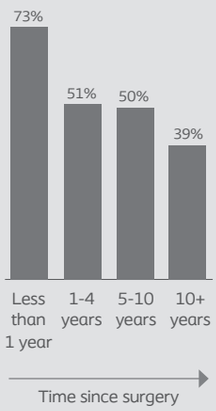
94%

People with an **outward** peristomal body profile

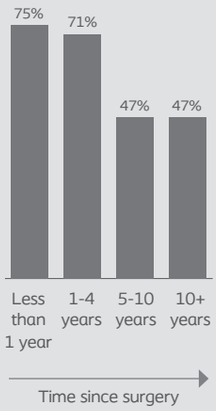
96%

% of people with an ostomy who normally visit their ostomy care nurse at least once per year

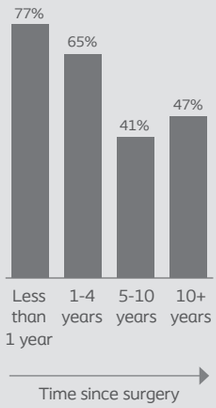
People with a **regular** peristomal body profile



People with an **inward** peristomal body profile



People with an **outward** peristomal body profile



% of people with an ostomy that exercise less since surgery

People with a **regular** peristomal body profile

44%

People with an **inward** peristomal body profile

54%

People with an **outward** peristomal body profile

62%

Coloplast develops products and services that make life easier for people with very personal and private medical conditions. Working closely with the people who use our products, we create solutions that are sensitive to their special needs. We call this intimate healthcare.

Our business includes ostomy care, continence care, wound and skin care and urology care. We operate globally and employ more than 10,000 employees.

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