

Survey of experiences among ostomists living with a parastomal hernia

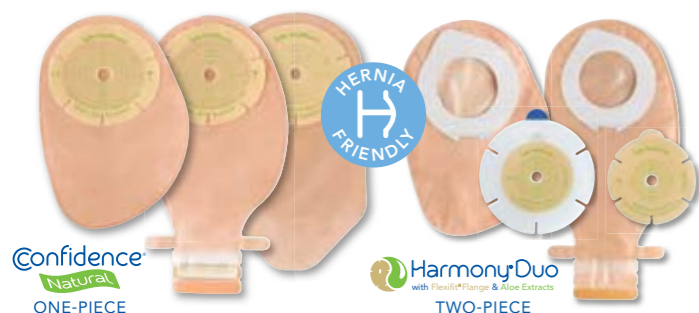
Fieldwork, December 2010



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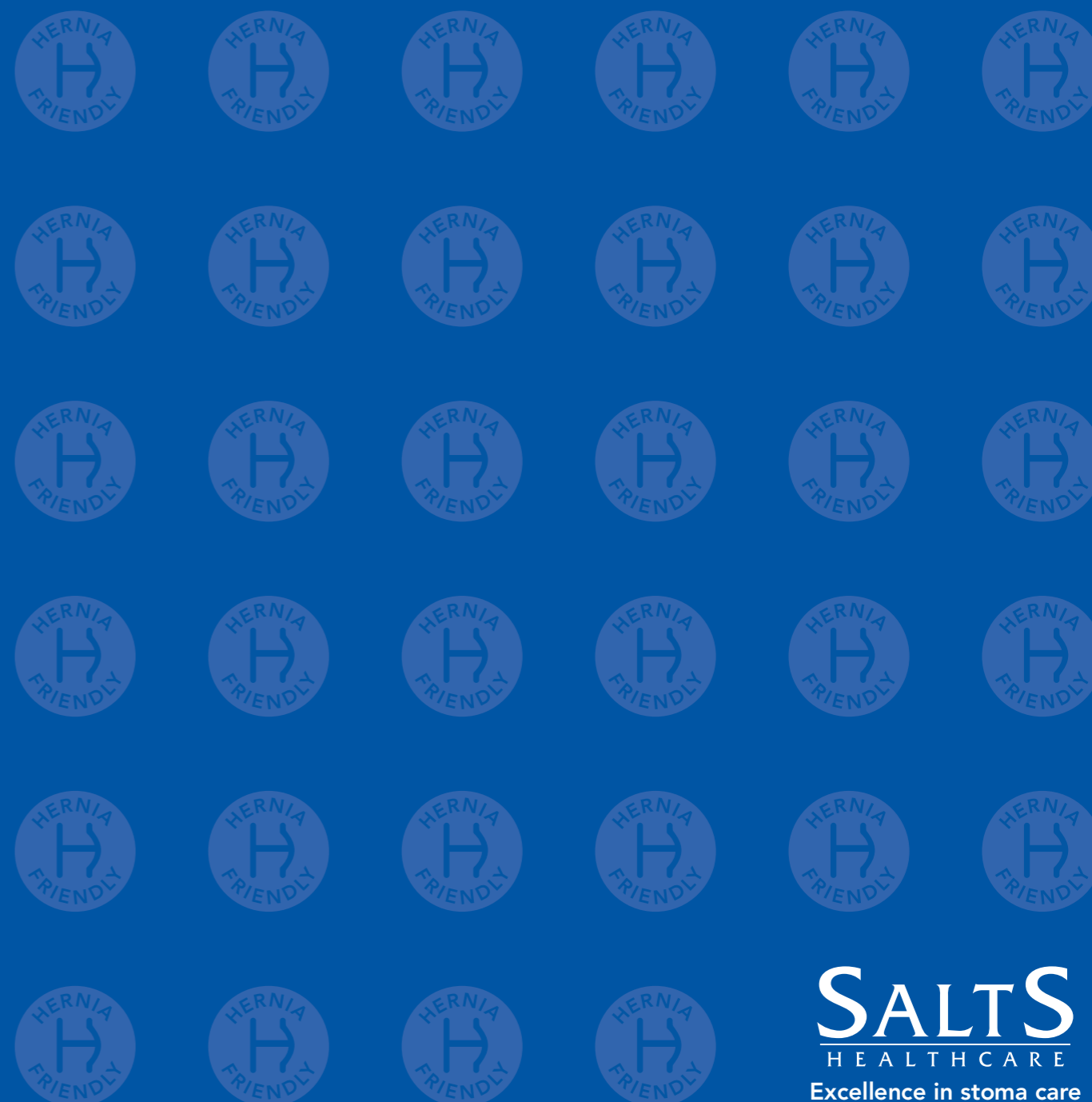
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INTRODUCTION

Salts Healthcare undertook a major research study in the UK among patients with a parastomal hernia. This report presents the findings and conclusions of that study.

A parastomal hernia is defined as a bulging of peristomal skin, indicating the passage of one or more loops of bowel through a fascial defect around the stoma and into the subcutaneous tissues (Rolstad and Boarini 1996).

The incidence of parastomal hernias among ostomists varies according to stoma type: It has been reported that rates can vary between 4 to 48.1% for end colostomies; Loop colostomies 0 to 30.8%; end ileostomies 1.8 to 28.3%; loop ileostomies 0 to 6.2% (Carne et al 2003).

Another study reported incidence levels across all stoma types is 10 to 50% of patients (Raymond and Abulafi 2002; Williams 2003).

OBJECTIVES

The objectives for the study were to improve understanding of the experiences of patients living with a parastomal hernia – such as leaks, skin condition, changing stoma sizes, and changing product type. Also the length of time between stoma formation and the development of a hernia was examined across stoma types, as well as the incidence of further surgery. Just as important to the study was to examine the ways in which the parastomal hernia affects the patients.

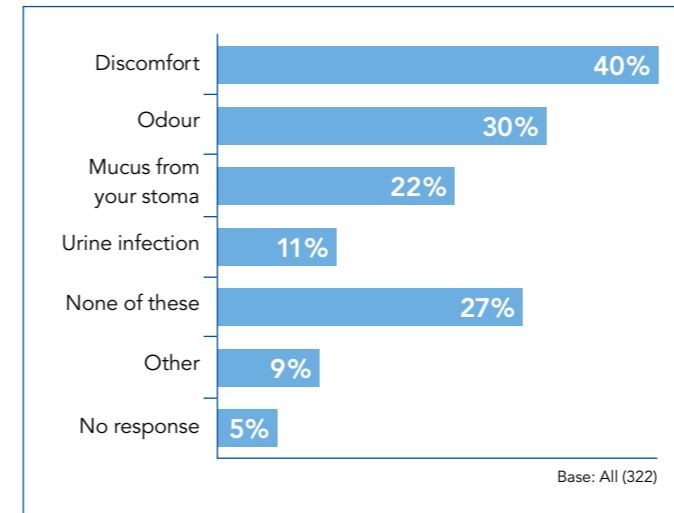
Improve understanding of the experiences of patients living with a parastomal hernia

METHODOLOGY

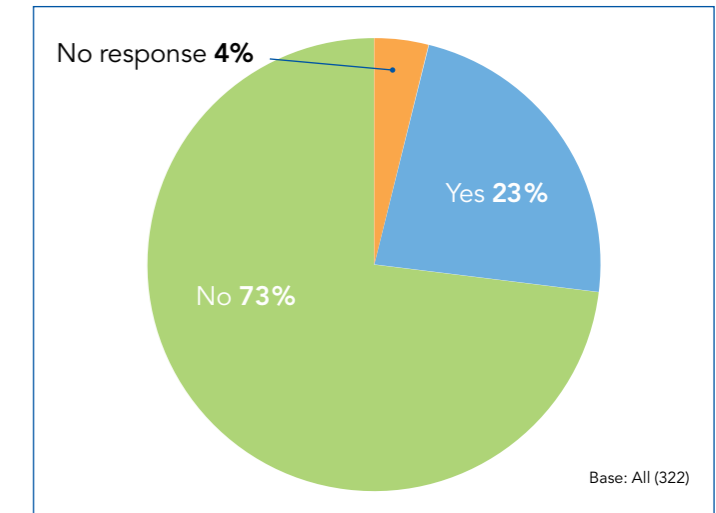
A sample of 1876 patients, all using a support belt or support garment, were sent a letter of invitation to take part, a self-completion questionnaire and a reply-paid envelope. 322 questionnaires were returned by patients who had a diagnosed hernia (response rate 17%).

MAIN FINDINGS: Patient pathway continued

Which problems do you experience regularly?



Has your parastomal hernia led to further surgery?



MAIN FINDINGS: Background

Sample Profile – Sex and age

	N	%
All	322	100
Males	144	45
Females	177	55
No response	1	–
Aged 24 or under	7	2
25–44	6	2
45–65	81	25
65 plus	228	71

Sample Profile – Perception of weight

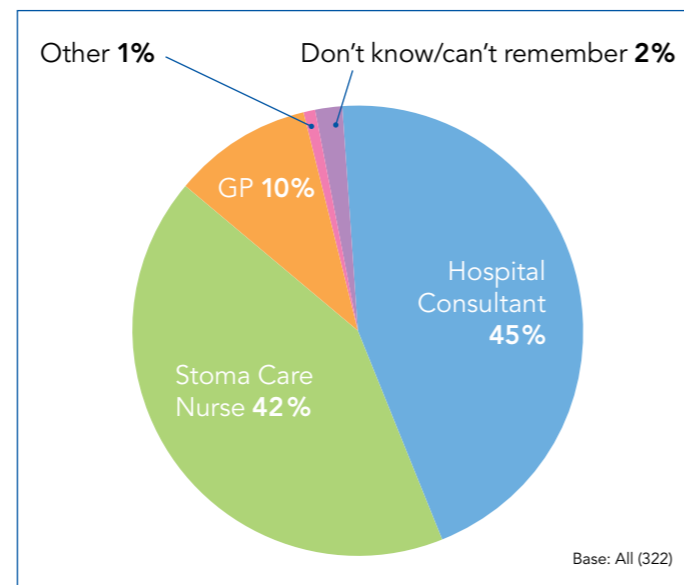
	N	%
All	322	100
Overweight	138	42
Underweight	15	5
About right	168	52
No response	1	–

Sample Profile – Type and age of stoma

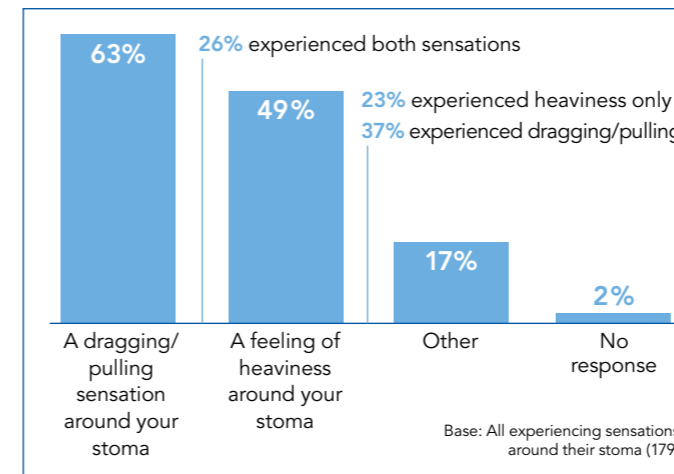
	N	%
All	322	100
Colostomy	177	55
Ileostomy	105	33
Urostomy	33	10
No response	7	2
In the last year (2010)	18	5
1–5 years ago (2005–9)	147	46
6–10 years ago (2000–4)	60	19
11 years ago (1999 or before)	97	30
Average age of stoma	9 years	

MAIN FINDINGS: Patient pathway

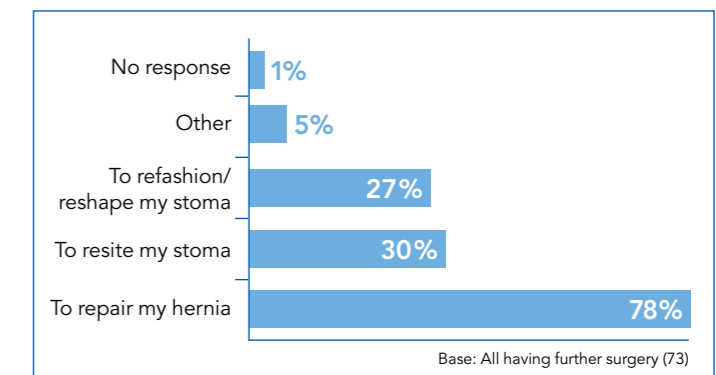
Who diagnosed your parastomal hernia?



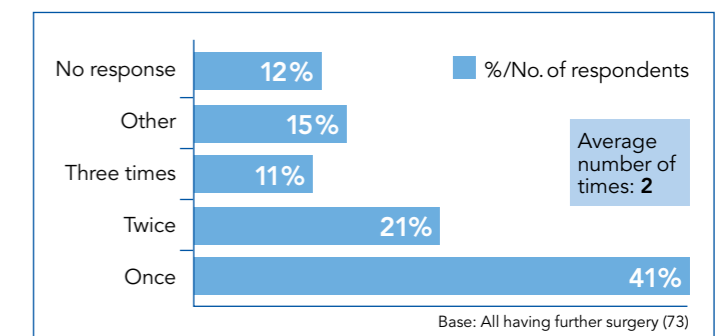
Which types of sensation have you experienced?



What were the reasons for your further surgery?



How often have you had surgery to repair your hernia?



Just over one in five parastomal hernias had led to further surgery and 20% had undergone surgery more than twice

How long after your stoma was formed were you diagnosed by stoma type?

Base:	Colostomy (177)	Ileostomy (105)	Urostomy (33)^	All
	%	%	%	%
Up to 1 year	59	42	55	53
1–5yrs	27	31	24	27
5–10yrs	3	4	6	4
Over 10yrs	3	18*	9	9
Approx. average	1yr 8months	3yrs 4months*	2yrs 5months	2yrs 4months

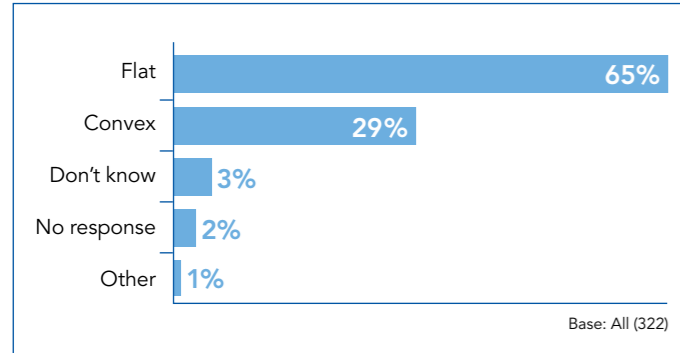
^Note small sample size *Statistically significant compared to Colostomists

Summary and conclusions: Patient pathway

- Virtually all parastomal hernias diagnosed by a medical professional
- About half diagnosed within a year of stoma formation
- Discomfort was a frequent experience, followed by odour
- Experience of sensations around the stoma (especially dragging/pulling) and a feeling of heaviness were widespread
- Just over one in five parastomal hernias had led to further surgery and 20% had undergone surgery more than twice
- Hernia repair was the main reason for most further surgery, with resiting of stoma and refashioning/shaping being less likely reasons

MAIN FINDINGS: Leakage

Is the adhesive flat or convex (i.e. curved)?



How often do you change your pouch?

	Colostomy (177)	Ileostomy (105)	Urostomy (33)^	All
	%	%	%	%
Less than once a day	7	41*	33*	21
Once a day	22	27	36	25
1-2 times a day	32*	9	6	22
2-3 times a day	25*	3	3	15
More than 3 times a day	9	7	6	8

^Note small sample size *Statistically significant compared to other ostomists in that row

Those experiencing leakage were likely to have the problem both day and night

Summary of type of leakage experienced

Base: All experiencing leakage	Colostomy (105)	Ileostomy (79)	UROSTOMY (26)^
	%	%	%
Daytime only	17	13	11
Night-time only	18*	6	4
Both day and night-time	64	76	85

^Note small sample size *Statistically significant compared to Ileostomists

Summary of severity of daytime leakage by stoma type

Base: All experiencing day leakage	Colostomy (88)^	Ileostomy (70)^	Urostomy (25)^
	%	%	%
Very/fairly bad	41	58*	52
Not very/not at all bad	58	43	48
Average severity	2.49	2.68	2.52

^Note small sample size *Statistically significant compared to Colostomy in that row



Summary of severity of night-time leakage by stoma type

Base: All experiencing night leakage	Colostomy (88)^	Ileostomy (66)^	Urostomy (23)^
	%	%	%
Very/fairly bad	56	73*	65
Not very/not at all bad	44*	27	35
Average severity	2.62	2.91	2.91

^Note small sample size *Statistically significant compared to Colostomy or Ileostomy in that row

Summary and conclusions: Leakage

- Experience of leakage under the adhesive onto the skin was a common occurrence
- Among those experiencing leakage, the likelihood of it being daytime or night-time was virtually the same
- Colostomists statistically more likely to experience night time leakage than Ileostomists (18% compared to 6%)
- Severity of night-time leakage was likely to be greater
- Those experiencing leakage were likely to have the problem both day and night

MAIN FINDINGS: Skin problems

Frequency of skin problems around the stoma

Base: All (322)	Before	Since	Difference +/- %
	%	%	
Very often/regularly had problems	11	24*	+13
Sometimes had problems	23	30*	+7
Seldom had problems	61*	41	-21
Never had problems	39	21*	-18
Average frequency of problems	1.97	2.52*	+0.55

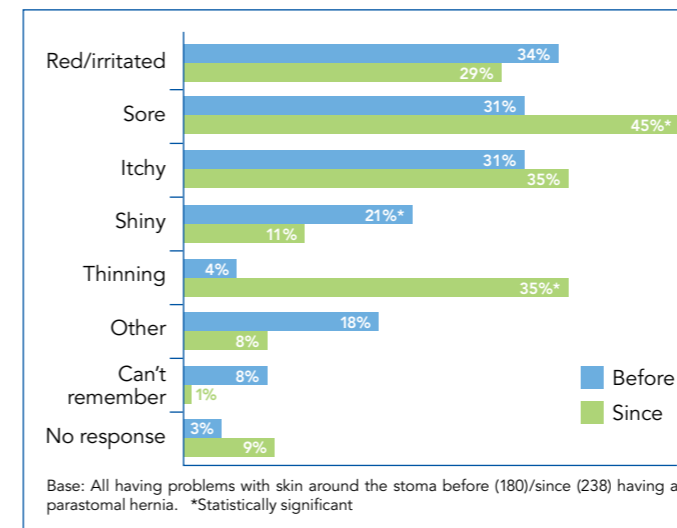
*Statistically significant compared to other data in that row

Severity of skin problems around the stoma

Base: All with problems	Before (180)	Since (238)	Difference +/- %
	%	%	
Very/fairly bad	20	32*	+12
Not very/not at all bad	69	65	-4
Average severity	1.93	2.11*	+0.18

*Statistically significant compared to other data in that row

Description of the skin around the stoma before, and after, the parastomal hernia



Average change in size of stoma since having a parastomal hernia

Base: All ostomists whose stoma has changed (134)	
	%
Average size at first	31.9mm
Average size changed to	39.4mm
Average change in size	7.51mm



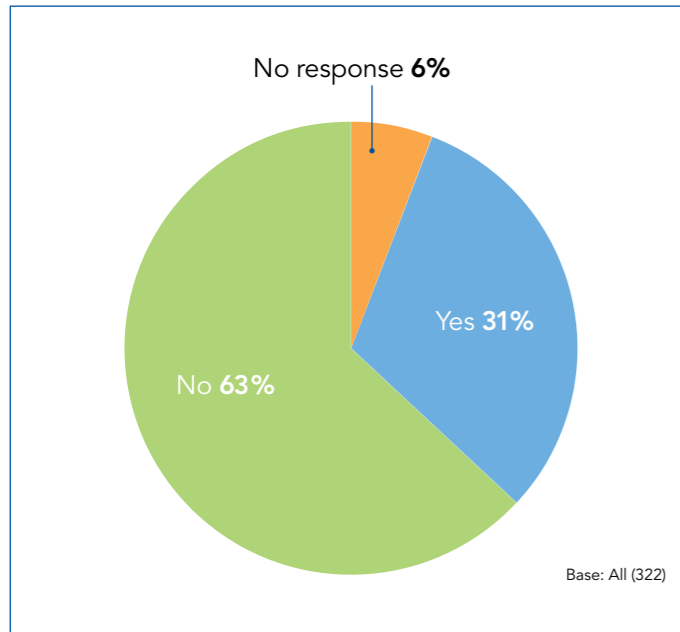
An increase in frequency of skin problems around the stoma had been experienced since having a parastomal hernia

Summary and conclusions: Skin problems

- An increase in frequency of skin problems around the stoma had been experienced since having a parastomal hernia. (The average frequency of problems increased from 1.97 to 2.52)
- Severity of skin problems was also likely to have increased since having a parastomal hernia, although the proportion with not very bad/not at all bad remained relatively similar
- There were noticeable increased levels of sore and thinning skin 'before' and 'since' having a parastomal hernia
- The average number of problems with skin around the stoma also increased
- Two in every five stomas had changed shape since having a parastomal hernia; the average increase in size was 7.51mm

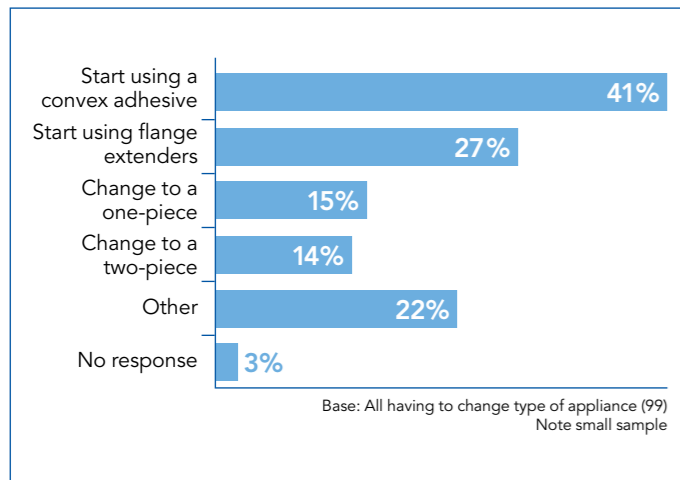
MAIN FINDINGS: Changing appliances

Have you had to change the type of appliance you use since you have had a parastomal hernia?



Just under a third of parastomal hernias had led to a change in type of appliance used

In which ways have you had to change the type of appliance you use?



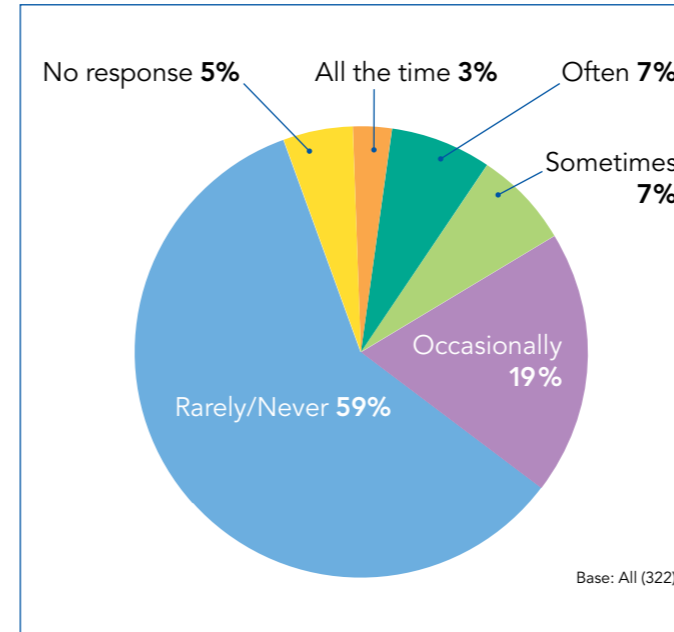
Summary and conclusions: Changing appliances

- Just under a third of parastomal hernias had led to a change, in type of appliance used
- Changing to a convex adhesive was the most likely change followed by starting to use flange extenders



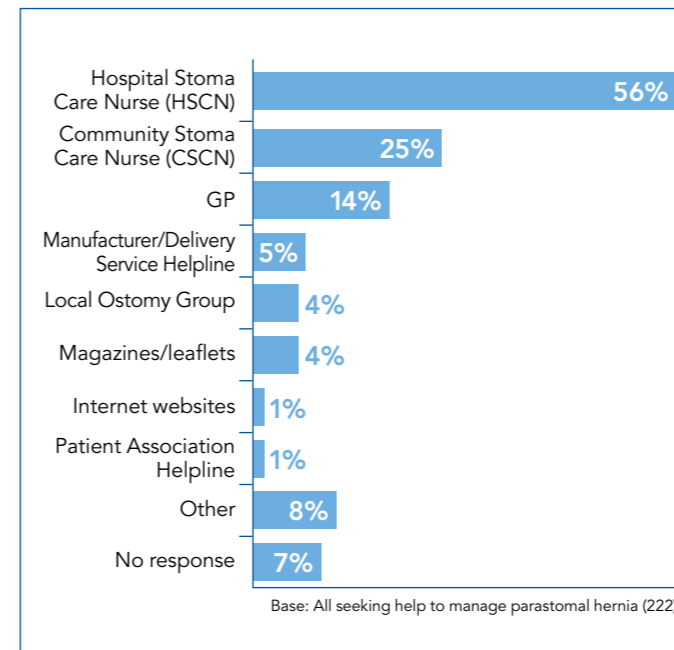
MAIN FINDINGS: Seeking help

How often do you seek help to manage your parastomal hernia?



Stoma Care Nurses were the main source of help, and far more likely to be used than any other source

Who do you seek help from?



How far do you agree or disagree with the following statements about parastomal hernias?

Statement	'Agree' %
My parastomal hernia has made me more self-conscious	63
My parastomal hernia has made it more difficult to put on a pouch	47
My parastomal hernia has made no difference to the way I manage my stoma	46
My stoma has changed shape since I was diagnosed with a parastomal hernia	38
Having a parastomal hernia is not something I worry about	36
Since I have had a parastomal hernia, the output from my stoma has become more erratic	30

Base: All (322)

Summary and conclusions: Seeking help

- 59% of ostomists had rarely/never sought help
- Stoma Care Nurses were the main source of help, and far more likely to be used than any other source
- A majority of ostomists 'agreed' that their parastomal hernia had made them more self-conscious
- Just under half 'agreed' that it had made their pouch more difficult to put on

References

Carne et al (2003), Parastomal hernia. *British Journal of Surgery*, 90:784-793

Rolstad and Boarini (1996), Principles and techniques in the use of convexity. *Ostomy Wound Manager*

Raymond and Abulafi (2002), Parastomal hernia repair: A novel approach. *Colorectal Disease*, 4

Williams (2003), Parastomal hernia, *IA Journal*. 181 Autumn