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## ORIGINAL ARTICLE

# Patient preferences for pilonidal sinus treatments: A discrete choice experiment survey

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## Abstract

**Aim:** A range of treatments are available for pilonidal sinus disease (PSD), each of which has a different risk/benefit profile. The aim of this study was to collect patient views on which interventions they would rather avoid and which outcomes they most value for PSD. **Method:** We conducted an online survey using the discrete choice experiment (DCE) method. The DCE task involved participants choosing the best treatment option when presented with a set of competing hypothetical treatment profiles. Participants with symptomatic PSD referred for elective surgery were recruited from 33 National Health Service trusts between 2020 and 2022. Collected DCE data were analysed using regression analyses.

**Results:** In all, 111 participants completed the survey. In the overall group, low risk of infection/persistence was the most important characteristic when making a treatment decision (attribute importance score 70%), followed by treatments with shorter recovery time with an attribute importance score of 30%. The results demonstrated that patients are willing to accept trade-offs between treatment recovery time and risk of infection/persistence. Patients above 30 years old are willing to accept a higher chance of treatment failure in exchange for rapid treatment recovery (risk tolerance between 22.35 and 34.67 percentage points). Conversely, patients in the younger age groups were risk averse and were only willing to accept a small risk of 1.51–2.15 in exchange for a treatment with faster recovery time. All patient groups appear to reject the excision and leave open technique due to the need for protracted nursing care.

**Conclusion:** This study highlights the need for shared decision making when it comes to surgery for PSD.

## KEYWORDS

discrete choice experiment, patient preference, pilonidal sinus, shared decision making

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## INTRODUCTION

Pilonidal sinus disease (PSD) is a common condition that affects 26 in 100000 of the population [1]. Patients—predominantly of working age—acquire an abscess or sinus due to the obstruction and subsequent rupture of hair follicles in the natal cleft [2, 3]. As a chronic condition, patients present to primary or emergency care services experiencing a cycle of pain and infection significantly impacting psychosocial wellbeing [4, 5].

The optimal treatment for pilonidal disease should result in rapid healing with minimal postoperative complications. However, it is not clear which if any surgical option meets these requisites, perhaps explaining why clinical practice varies across the UK [6, 7]. Whilst there is a large body of literature to guide practice, this research mainly consists of single-centre cohort studies using different classification systems and outcome measures [6]. Surgical treatment typically involves different excision procedures of the affected area. The wound may be left open to heal by secondary intention or closed using techniques such as fibrin glue [8], midline or asymmetric closure with sutures, or rotational skin flaps. Some interventions (e.g., rotational flaps) may result in the need for longer hospital stay and recovery or prolonged nursing care with protracted periods of physical adaptations (e.g., leave open) [9]. Conversely others (e.g., Endoscopic Pilonidal Sinus Treatment, laser, Bascom I, pit picking and glue) may be minimally invasive, with rapid recovery but a higher chance of persistent disease and the need for further intervention. Whilst patients may be involved in making shared decisions about their treatment, many are often uninformed of and unprepared for the burden of potential postprocedural care on daily living or conversely the risk of persistent disease [9].

In 2018, the National Institute for Health Research commissioned the Pilonidal Sinus Treatment: Studying the Options (PITSTOP) study. PITSTOP is a multicentre ( $n = 33$ ) observational study exploring the effectiveness of excision and closure techniques in the UK [10]. To enhance our understanding of patient treatment preferences, we conducted a discrete choice experiment (DCE). This quantitative survey method is used to elicit preferences for treatment characteristics (also called attributes) [11]. The DCE task involves participants choosing the best treatment option when presented with a set of competing hypothetical treatment profiles. The DCE data can then be analysed to reveal the relative importance of treatment attributes and to understand what trade-offs respondents are willing to make between two competing attributes. DCEs have increasingly been used to identify patient preferences in health and healthcare [11–14]. However, the application of this method to pilonidal disease has not yet been undertaken. The aim of this study was to collect patient views on which interventions they would rather avoid and which outcomes they most value.

## METHODS

### Development of the survey

The survey contained four sections: (1) patient characteristics and disease history, (2) treatment ranking exercise, (3) DCE tasks (Figure 1) and (4) survey feedback questions.

### What does this paper add to the literature?

This is the first discrete choice experiment to be conducted to assess treatment preferences for pilonidal sinus disease. It shows that, if given a choice, patients would elect for procedures with low risk of infection/wound issues and high chance of cure. However, they would trade these attributes for a more rapid recovery and there are age-related differences. Excision and leave open techniques with the need for protracted nursing care should not be offered as first-line therapy. The importance of shared decision making in pilonidal sinus surgery is highlighted, along with the need for surgeons to be able to offer an armamentarium of different techniques to match patient preference.

The DCE and ranking task were developed by conducting qualitative interviews with 20 patients to identify key attributes and important levels that they considered when choosing a treatment. Further details of the qualitative interview process are reported elsewhere [9]. Thematic analysis of the qualitative interviews identified a list of factors that patients considered to be important when choosing a treatment for PSD (see Data S1). Patient representatives and clinicians in the team reviewed the initial list of themes and helped to select the most important attributes by first grouping similar themes into attributes for the ranking task and then selecting the two attributes that are most important for the DCE through iterative rounds of discussions. Nine attributes were included in the ranking task: (1) type of excision and closure, (2) type of anaesthetic, (3) length of hospital stay, (4) wound care, (5) pain medication requirement, (6) infection risk, (7) healing time, (8) risk of recurrence and (9) scarring. Clinicians in the team generated a treatment classification containing five groups of treatments. This classification development was important because there were approximately 12 different types of procedures used in the UK for PSD [6, 15] and asking patients to rank a large number of treatments was too cognitively taxing. The final treatment descriptions for the ranking task based on the classification and the nine attributes were developed with clinical input and information from the literature and were piloted with patients prior to survey rollout (see Figure 2).

Only two attributes—risk of infection/persistence and recovery time—were included in the DCE because (1) these two were deemed the most important attributes according to patients and clinicians and (2) a DCE can only include attributes that are independent to avoid presenting implausible combinations of attribute and level profiles. Levels for the DCE were selected based on plausible values published in the literature and based on clinical input. The choice tasks were constructed based on an orthogonal design using a

FIGURE 1 Example DCE task.

**Example DCE task**

Please imagine this scenario:

- You have pilonidal disease.
- You are experiencing pain, itchiness, discharge and some discomfort when you move.
- You've had emergency surgery to drain an abscess but your symptoms persist.
- You are told that you need further surgery to cure the pilonidal disease.
- You are now considering which treatment option you should choose next to cure this disease.

Now we would like to understand which outcomes would affect your decision to choose a treatment for the scenario described above. To help us understand how important the different outcomes of surgery are to you, we are going to ask you to make a series of 16 choices. In each choice you will be asked to choose between two treatments that you can take.

The two treatments differ in:

- **Recovery time** - which is the usual time a patient takes to get back to doing normal activities without pain, such as bending and putting on socks, being able to go to work or attend school. In the two treatments recovery time can vary from 1 week, 2 weeks, 6 weeks to 12 weeks.
- **Risk of infection and persistence of symptoms** - for a proportion of people who have surgery, the pilonidal sinus does not get better. This means that you will need further treatment. In the two treatments the risk of infection and persistence of symptoms can vary from 5%, 10%, 20% to 30%. For example, a 5% risk means that if 100 people had the same surgery for pilonidal disease, 95 people would be cured of the pilonidal disease but for 5 people the symptoms will continue and the disease will not get better.

We will now move onto the questions where you have to make a treatment choice. In total there are 16 choices to consider.

	Treatment A	Treatment B
Recovery time	12 weeks	1 week
Risk of infection/persistence	In 5 out of 100 (5%) patients pilonidal sinus will persist	In 30 out of 100 (30%) patients pilonidal sinus will persist

Which treatment would you choose?

design catalogue [16]. The questionnaire contained 16 hypothetical DCE tasks. In the DCE tasks patients were asked to choose between two combinations of outcomes with varying levels (see Figure 1). We presented forced unlabelled choices 'treatment A' or 'treatment B' to respondents avoiding the use of an 'opt out' alternative for the purposes of realism. The DCE also included dominant tasks where one treatment option was logically better to test if participants understood the DCE task.

The survey was piloted with three patients to gain feedback on comprehension, interpretation and complexity of the tasks. Upon receiving the pilot feedback, we included the ranking task information in a table (see Figure 2), changed a free text question to a

multiple-choice question, and made some formatting changes to the text of the survey.

## Sampling

Sample sizes for DCE studies vary substantially in the literature, with sizes ranging from 100 to 1000+ respondents [17]. We adopted the rule of thumb formula used by Orme [18] to estimate the sample size necessary to achieve the minimum sample size required which we estimated to be 63 patients ( $N = 500 \times (4[\text{maximum number of levels}]) / (2[\text{number of alternatives}] \times 16[\text{number of tasks}]))$ ).

### Treatment ranking exercise

Please imagine this scenario:

- You have pilonidal disease.
- You are experiencing pain, itchiness, discharge and some discomfort when you move.
- You've had emergency surgery to drain an abscess but your symptoms persist.
- You are told that you need further surgery to cure the pilonidal disease.
- You are now considering which treatment option you should choose next to cure this disease.
- Your consultant has presented to you 5 different treatment options.

The following table is a summary of the 5 treatments.

	Excision of skin and leave the wound open	Excision of the skin and closure of the wound with stitches	Excision of the skin and closure of the wound with a skin flap and stitches	Excision of the sinuses and closure of the wound with glue	Excision of the sinuses only and leave open the wound to heal
Type of excision and closure	Cutting out all the diseased skin and leave open	Cutting out all the diseased skin and close with stitches	Cutting out all the disease skin and close with stitches and a skin flap	Scraping away debris and close using glue	Cutting, destroying or scraping the sinus only and leave open to heal
Type of anaesthetic	General anaesthetic	General anaesthetic	General anaesthetic	Local anaesthetic	Local anaesthetic
Length of hospital stay	Day operation	Day operation	Stay one/two nights in hospital	Day operation	Day operation
Wound care	Nurse support 2 or more times a week	No need for nurse support, but you will need to change dressings at home	No need for nurse support, but you will need to change dressings at home	Should not need dressing changes	No need for nurse support, but you will need to change dressings at home
Pain medication required	More than 2 weeks	2 weeks	2 weeks	Not usually required after the initial 1-2 days after surgery	Few days
Infection risk	1 in 20 people	2 to 4 in 20 people	1 in 20 people	1 in 20 people	1 in 20 people
Healing time	Few months	2 to 3 weeks	2 to 3 weeks	A few days	A few days
Risk of recurrence	2 to 4 in 20 people	2 to 4 in 20 people	1 in 20 people	5 in 20 people	1 to 2 in 20 people
Scarring	Large scar	Small scar	Large scar	Small dimple/no scar	Small scar

Now that you know more about the treatment options available to you, we would like you to consider which treatments you would prefer. Please rank these treatments in order of preference: 1= best preferred treatment and 5= least preferred treatment.

- \_\_\_\_\_ Excision of skin and leave the wound open
- \_\_\_\_\_ Excision of the skin and closure of the wound with stitches
- \_\_\_\_\_ Excision of the skin and closure of the wound with a skin flap and stitches
- \_\_\_\_\_ Excision of the sinuses and closure of the wound with glue

FIGURE 2 Treatment ranking exercise.

### Participants and recruitment

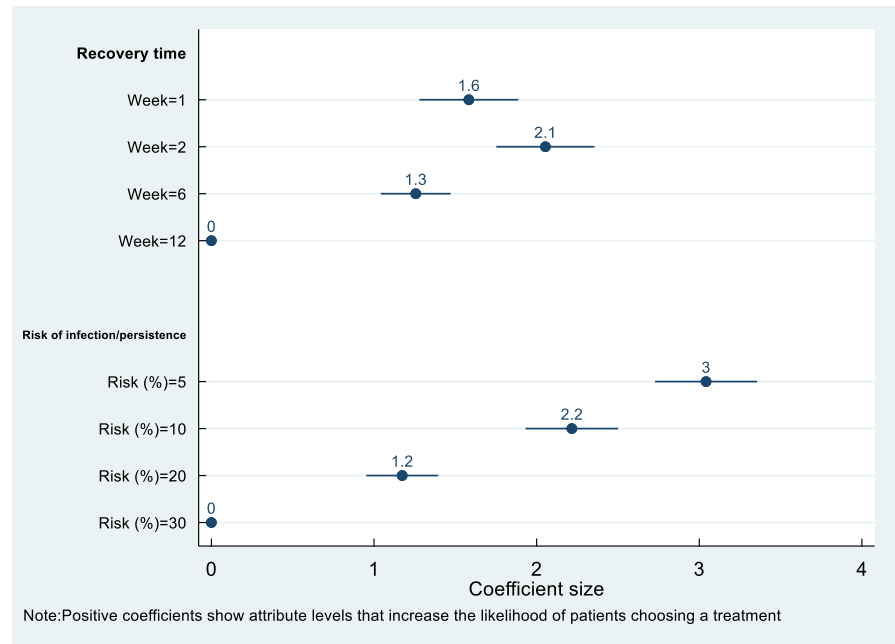
All participants aged 16 and above with symptomatic PSD, referred for elective surgical treatment and participating in the PITSTOP cohort, were invited to take part in the DCE survey. Participants were emailed a link via Qualtrics which included a participation information sheet including data protection information, consent form and the questionnaire. Patients with symptomatic PSD not participating in the PITSTOP cohort study could also take part in the questionnaire by accessing a QR code advertised on a study leaflet. The study leaflet was displayed in 33 National Health Service Foundation Trust

colorectal outpatient clinics. The study leaflet was also shared on the PITSTOP study Twitter page.

### Data analysis

Descriptive statistics were calculated for patient characteristics, disease history and survey feedback variables. DCE responses were modelled using conditional logistic regression where the dependent variable was the preferred treatment choice and independent variables were risk of infection/persistence and recovery time. Linearity

**FIGURE 3** Regression model 1 results reproduced in a diagram.



of the attributes was assessed (Figure 3) before deciding to treat risk as a linear variable. Regression coefficients were used to estimate the relative importance of attributes. Maximum acceptable risk is the rate at which patients are willing to give up a benefit in one attribute in exchange for an improvement in another attribute. Maximum acceptable risks were calculated by taking the ratio of recovery time coefficients divided by the infection/persistence coefficient and 95% confidence intervals calculated using the delta method [19]. Furthermore, latent class models were used to analyse individual heterogeneity and to identify subsets of patients with varying preferences. The optimal number of classes was selected using the Bayesian information criterion (BIC) and the consistent Akaike information criterion (CAIC) and model parsimony. Data were analysed using STATA 17.

## RESULTS

### Participants

Between April 2020 and February 2022 there were 423 unique visitors to the online survey platform and of these 150 participants consented to take part in the survey and three people declined, giving a response rate of 35%. Of the 150 participants who consented, 111 participants completed the survey giving a completion rate of 74%.

The characteristics of the 111 participants who completed the survey are reported in Table 1. The majority of respondents were men (68%), age between 17 and 29 years (66%), employed (80%), white (87%) and educated to A-level or above (81%). The majority of participants had at least one PSD surgery with only six patients reporting not having surgery and one person having 10 surgeries. The types of surgeries included excision of the skin and closure of the wound with stitches (midline closure, Bascom cleft closure or Karydakis) (26%), excision of skin and leave the wound open (23%)

and excision of the sinuses only/pit picking (23%), excision of sinuses and glue to close (19%) and rotational flap procedures (rhomboid, Limberg, Dufourmental) (9%).

### Patient preferences

Regression modelling results are presented in Table 2; positive coefficients show attribute levels that are preferable to patients and negative coefficients indicate attribute levels that decrease the likelihood of choosing a treatment. Patients considered both recovery time and risk of infection/persistence attributes to be important when deciding a treatment for PSD. However, risk of infection/persistence was the strongest predictor of choice of treatment in the experiment with an attribute importance score of 70%. Treatments with shorter recovery time had an attribute importance score of 30%. The modelled results show that the direction of effects is as expected where, on average, patients prefer treatments with lower risk of infection/persistence (see Figure 3). Also, compared to a treatment with a 12-week recovery period, participants prefer treatments with shorter (1, 2 or 6 weeks) recovery periods. However, preferences for recovery time attribute levels were not linear as participants preferred a 2-week recovery period over a 1-week recovery period relative to 12 weeks (Figure 3).

### Maximum acceptable risk

According to the DCE results the optimum treatment that patients would prefer would have the lowest risk of infection/persistence with the fastest recovery times, but currently available treatments do not necessarily align with this scenario, so patients made trade-offs and chose a treatment with some limitations but that on balance was acceptable to them. To measure this trade-off, the maximum





TABLE 2 DCE modelled preferences

Attributes	Model 1: All attributes categorical	Model 2: Risk attribute linear
	Coefficient (SE)	Coefficient (SE)
Constant	0.356*** (0.068)	0.368*** (0.067)
Recovery time		
Week 12 (reference level)	0.000	0.000
Week 1	1.583*** (0.155)	1.556*** (0.151)
Week 2	2.054*** (0.154)	2.035*** (0.152)
Week 6	1.256*** (0.109)	1.250*** (0.109)
Risk of infection/persistence		
Risk (%) = 30 (reference level)	0.000	–
Risk (%) = 20	1.173*** (0.113)	–
Risk (%) = 10	2.217*** (0.145)	–
Risk (%) = 5	3.042*** (0.160)	–
Risk of infection/persistence as a linear variable		
Risk (%)	–	–0.119*** (0.006)
Observations	3552	3552
Log-likelihood	–768.95	–771.78
BIC	1605.24	1588.45
Attribute importance score: a relative measure of the impact that an attribute has on a respondent's choices within the DCE exercise		
Risk of infection/persistence	70.10%	
Recovery time	29.90%	

Note: Positive (negative) coefficients increase (decrease) the likelihood of choosing a treatment.

Abbreviations: BIC, Bayesian information criterion; DCE, discrete choice experiment.

\*\*\* $p < 0.001$ .

TABLE 3 Estimated maximum acceptable risk (MAR)

Treatment benefit (for selected level changes)	MAR of infection/persistence	95% confidence interval calculated using the delta method
Recovery time reduction from 12 weeks to 2 weeks	17.08 <sup>a</sup>	14.83–19.33
Recovery time reduction from 12 weeks to 6 weeks	10.49	8.76–12.22
Recovery time reduction from 6 weeks to 2 weeks	6.59	4.88–8.30

<sup>a</sup>MAR of 17.08: patients were willing to accept a 17.08 percentage points increase in risk of infection/persistence to have a treatment with a faster recovery period—2 week compared to 12 week recovery period.

TABLE 4 Estimated maximum acceptable risk (MAR) based on subgroups

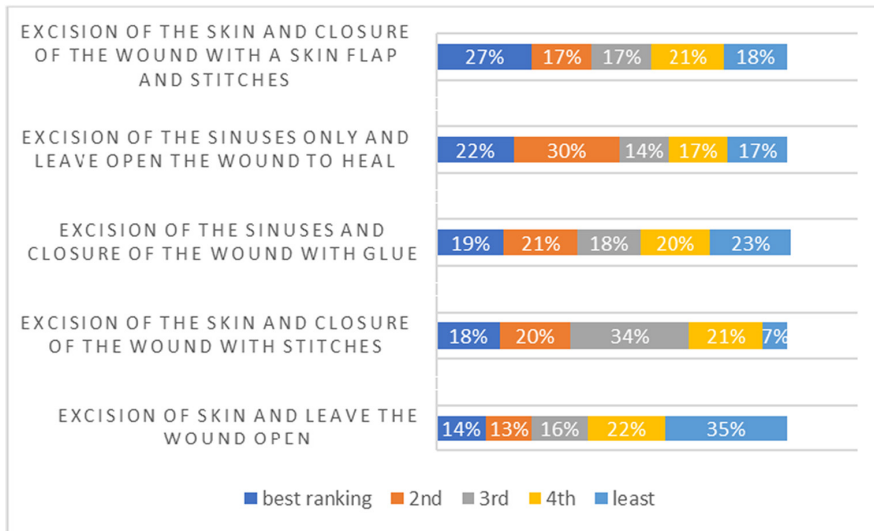
Treatment benefit (for selected level changes)	Subgroup 1 (class 1) MAR of infection/persistence (95% CI)	Subgroup 2 (class 2) MAR of infection/persistence (95% CI)
Recovery time reduction from 12 weeks to 2 weeks	2.15 (–0.03, 4.34)	34.67 (28.24, 41.10)
Recovery time reduction from 12 weeks to 6 weeks	1.51 (–0.11, 3.13)	22.35 (17.35, 27.35)

## Participants understanding and engagement of the survey

The overall survey comprehension was high (see Table 5) with most participants reporting that they understood the DCE tasks (91%)

and ranking task (86%). The median time to complete the survey was 12 min with a large range between 4 and 5388 min (as participants were able to stop and return to the survey). Most participants (84%) correctly answered the dominance DCE tests, where one treatment was logically superior to the other treatment. None of the





**FIGURE 4** Ranking of treatments chart option.

respondents answered the DCE questions by choosing the treatment profile in the same position for all the 16 tasks (e.g., left side only or right side only). However, the constant term was significant indicating that respondents had a general tendency to choose the treatment profile on the right side of the questionnaire, exhibiting right side bias (see Table 2).

## DISCUSSION

This study assessed patient treatment preferences for PSD by conducting a DCE survey. The main finding is that the average patient prioritised risk of infection/persistence relative to recovery time when choosing a treatment. Despite this preference, patients were willing to make compromises and accept treatments with varying degrees of higher risk of infection/persistence in exchange for treatments that provided faster recovery. These results provide insight into which treatments are more likely to be valued and accepted by patients. In the overall group, patients were willing to tolerate an up to 17 percentage point increase in risk of infection/persistence and accept treatments with faster recovery. This suggests that some patients are willing to accept treatments such as glue or pit picking over excision and leave open treatment because these minimal interventions have faster recovery periods despite a possibly higher risk of infection/persistence. Similar results were found in the ranking task, where open surgery was ranked the least favourite treatment. This result is perhaps unsurprising given the likely protracted wound care in this group and its impact on wellbeing [5].

In addition, our results also showed preference heterogeneity, indicating the need for providing tailored treatments to suit subgroups of people with distinct preferences. People in the age group 30+ prioritized treatments with fast recovery and they were willing to accept a much higher risk of infection/persistence of around 35 percentage points. This suggests that people in the 30+ group would be willing to forgo leave open treatment and would much rather take the other treatments with shorter recovery. In our sample, people

above 30+ were much more likely to report that they were either homemaking, retired or caring for someone else; these responsibilities may have influenced their preference for treatments with shorter recovery time. In contrast, people in the younger age group (17–29) were risk averse and were only willing to accept about 2 percentage points increase in risk of infection/persistence in exchange for treatments with shorter recovery period. These differences in preference heterogeneity highlight the importance of involving patients in the early stages of decision making to overcome decisional regret.

The literature on surgery for PSD is immense, perhaps reflecting the variety of surgical interventions that are advocated [20]. As there is no commonly used classification system [15], there is no stratification of disease and no universally accepted treatment algorithm. Judging by the plethora of papers detailing large single-centre cohorts of particular techniques [6], individual surgeons have their own preferred technique, and many patients have little choice in the decision. Outcomes are poorly reported, and some patients have not been asked what is important to them before surgery [9]. There is no core outcome set for pilonidal disease [21]. Assessing the literature in general, some broad assumptions can be made. For example, minimally invasive procedures usually result in rapid recovery but may not be as successful (in terms of reduced recurrence) than more invasive interventions (such as rotational flaps), particularly for more severe or recurrent disease [8, 22]. Allowing a large wound to heal by secondary intention usually results in prolonged recovery [23]. Such implications should be discussed with the patient through a shared decision making process. There is a growing body of literature that supports this approach [9, 24, 25]. The surgeon should be able to offer several treatment options tailored to these expectations as well as the severity of the disease.

This study is the first to conduct a DCE to assess treatment preferences for PSD. We used robust DCE methodology throughout. For example, the DCE was developed by conducting extensive qualitative interviews, piloting the survey with patient representatives and involving a large experienced clinical team in the development of the DCE

**TABLE 5** Survey comprehension and internal validity

	N	%
Internal validity (dominance questions) passed or failed?		
Failed	18	16%
Passed	93	84%
Always choose the same side (e.g., left profile) in all the DCE questions?		
Yes	0	0%
No	111	100%
I found the ranking question made sense—please tell us how strongly you agree		
Strongly disagree	3	3%
Disagree	2	2%
Uncertain	10	9%
Agree	60	54%
Strongly agree	36	32%
I understood the questions about making choices between different treatment options		
Strongly disagree	1	1%
Disagree	1	1%
Uncertain	8	7%
Agree	59	53%
Strongly agree	42	38%
When choosing options, I needed more information than was provided		
Strongly disagree	16	14%
Disagree	43	39%
Uncertain	24	22%
Agree	21	19%
Strongly agree	7	6%
I found making a choice between different treatments confusing		
Strongly disagree	21	19%
Disagree	56	50%
Uncertain	15	14%
Agree	15	14%
Strongly agree	4	4%
Median time in minutes to complete survey (range)	12 (4–5388)	

Abbreviation: DCE, discrete choice experiment.

and the survey. Moreover, internal validity checks were conducted and showed good task comprehension, allowing confidence in the findings.

Nevertheless, our study has some limitations. The number of participants was sufficient to estimate the overall modelled preferences, but larger sample sizes would have allowed us to test the robustness of our results by conducting subgroup analyses and would have identified further subgroups with heterogeneous preferences. Every effort was made to increase the final response rate using several recruitment methods. However, it was hard to engage with this population due to their young age demographic [26]. There is also no consensus on the classification of treatments

for PSD in the literature [15]. The clinicians in the team developed the five treatments for the ranking task based on the literature and their clinical experience. A different team of clinicians may have made different classification decisions, particularly differentiating midline from asymmetric closure. Moreover, the DCE included only the two key attributes to avoid presenting implausible combinations of attribute and level profiles. However, in the real-world patients may consider other factors that were not included in the DCE task when making a treatment decision. Also, 16% of the sample failed the internal validity test, indicating that this group of people may not have understood the risk information

presented in the DCE tasks. Hence, future studies could include a numeracy test as part of the internal validity check or further support patients by presenting risk information using pictorial icon arrays. Finally, whilst the cohort studied is reflective of the real-world experience of patients in the UK, other countries may have a different treatment algorithm with different intervention preferences. For instance, the use of endoscopic and laser techniques as minimally invasive procedures may be more prevalent and may have resulted in different patient preferences.

## CONCLUSION

Patients with PSD, particularly those above the age of 30, are willing to accept a higher chance of treatment failure in exchange for a more rapid recovery. This supports the use of minimally invasive procedures even if recurrent disease is more likely. Conversely, procedures that may result in a more protracted hospital stay and initial recovery such as rotational flaps may be preferred by some (especially the younger age group) if they offer a higher chance of cure. The heterogeneity in preferences suggests that surgeons should offer a range of interventions and tailor treatments to individual patient preferences.

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## CONFLICTS OF INTEREST

The authors declare no conflict of interest. The study received approval from East of England Cambridge South Research Ethics Committee (REC reference 18/EE/0370).

## DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

## INFORMED CONSENT

Informed consent was obtained from all individual participants included in the study.

## CLINICAL TRIAL REGISTRATION

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## SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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