

# This New Part of Me: Psychological Outcomes and

# **Experiences Following Stoma Surgery**

being a thesis submitted in partial fulfilment of the

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#### **Overview**

The portfolio thesis is composed of three parts: a systematic literature review, an empirical paper, and appendices. This thesis aims to explore psychological outcomes following stoma surgery.

#### Part One: Systematic Literature Review

The systematic literature review explored self-esteem following stoma surgery. Six quantitative studies met the inclusion criteria following a systematic search of the literature. The Synthesis Without Meta-Analysis (SWiM) method was used to synthesise data and structure results. A modified checklist from the Johanna Briggs Institute (JBI) was used to assess the quality of the included studies. Results suggested that whilst self-esteem was lower in ostomised patients when compared with non-ostomised samples, their self-esteem levels were still in a satisfactory range. However, only tentative conclusions can be made due to several limitations within the data and synthesis methods. Recommendations for further research are discussed.

#### Part Two: Empirical Paper

The empirical paper explored young men with stomas who had modified their bodies. A qualitative Interpretative Phenomenological Analysis (IPA) methodology was utilised. Six participants completed semi-structured interviews. Four themes were developed: "the destabilisation of identity", "the separation of self and stoma", "the need for connection" and "contributors to self-acceptance". Body modification aided participants in reclaiming control over their bodily autonomy and increasing their self-confidence. This study emphasised the importance of addressing body image concerns amongst young men in clinical settings. Recommendations for further research are presented, along with the implications for clinical practice.

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## Part Three comprises the Appendices:

The appendices offer supplementary information for the systematic literature review and empirical paper, and they further examine the researcher's role in the epistemological and reflective statements.

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## Part One – Systematic Literature Review

This paper is written in the format ready for submission to the

#### Journal of Mental Health

Please see Appendix A for submission guidelines.

# Outcomes for Self-Esteem following Stoma Surgery- A Systematic Review using the Synthesis Without Meta-analysis (SWiM) Method.

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#### Abstract

Self-esteem refers to how favourably one views themselves, with lower self-esteem being linked to emotional difficulties and less positive life outcomes. Research has suggested that self-esteem can be negatively affected following stoma surgery. However, there has been no comprehensive review of this evidence. This review aims to systematically review the literature on self-esteem following stoma surgery. A search of electronic databases Medline, PsycInfo, CINAHL, Academic Search Premier, and PsycARTICLES identified six quantitative studies included in this review. These quantitative studies used the Rosenberg's Self-Esteem Scale (RSES) to assess selfesteem. The Synthesis Without Meta-Analysis (SWiM) method was used to synthesise data and structure results. Results suggested that whilst self-esteem was lower in ostomised patients when compared with non-ostomised samples, their self-esteem levels were still in a satisfactory range. However, only tentative conclusions can be made due to several limitations within the data and synthesis methods. Clinical implications and areas for future research are discussed. This review highlights a considerable gap in the current literature of self-esteem following stoma surgery and emphasises the need for further research within this field using more robust research methodologies.

#### Keywords: self-esteem, stoma, ostomy, bowel, bladder, review

#### Introduction

#### Stomas

A stoma refers to a surgical procedure where an artificial opening is created on the abdomen of the body, allowing for an alternative way for waste to be excreted (Hyland, 2002). It is often the result of necessary medical intervention to alleviate adverse symptoms resulting from illness. The three main types of stomas are: colostomies (from the colon), urostomies (from the bladder) and ileostomies (from the ileum) (Burch, 2008). There are over 200,000 people in the UK living with stomas, with 21,000 people receiving

stoma surgery every year (Coulter, 2022). Crohn's disease<sup>1</sup>, ulcerative colitis<sup>2</sup>, colorectal cancer, bladder cancer, and accidental injury are the leading causes for the creation of stomas (Kettle, 2019).

Although stoma surgery is performed to improve the overall wellbeing of an individual and alleviate symptoms of illness, they result in a notable change to the function and appearance of the body. This can often have a negative impact in both physical and psychological domains, irrespective of being temporary or permanent (Dabirian et al., 2011; Siassi et al., 2008). Many individuals with stomas report concerns with odour, noise concerns, skin irritation, leakage, alongside depression, anxiety, and overall reduction in enjoyment of activities (Richbourg et al., 2007; Dabirian et al., 2011).

As well as learning how to physically care for a stoma, affected individuals often require psychological adjustment to this significant event. Physical healing after a stoma creation can take up to three months (NHS, 2023), and typical psychological adjustment may take up to six months (Carta et al., 2009). This adjustment can be affected by several factors, such as one's own acceptance of the stoma, social support, and interpersonal relationships (Simmons et al., 2007). Whilst proper management of the stoma can support adjustment, this only has a small part in this overall process. There have been numerous studies researching the impact of living with a stoma, with many reports of reduced quality of life, altered relationships and sexual functioning, alongside negative changes to physical health and activity (Richbourg et al., 2007; Brown & Randle, 2005). Additionally, stomas often impact one's body image and self-perception. Many have found that stomas can result in a disturbed body image, feelings of reduced attractiveness, and reduced self-esteem (Jayarajah & Samarasekera, 2017; Ang et al., 2013).

<sup>&</sup>lt;sup>1</sup> Crohn's disease is a chronic inflammatory disorder of the gastrointestinal tract, characterised by abdominal pain and diarrhoea.

<sup>&</sup>lt;sup>2</sup> Ulcerative colitis is a chronic inflammatory bowel disease characterised by inflammation and ulcers in the lining of the colon and rectum.

#### Self-Esteem

The term "self-esteem" is used to describe a complicated and variable psychological construct of how an individual views themselves (Bailey, 2003). Whilst there are many definitions of self-esteem, Rosenburg's (1965a) is one of the more commonly known, having described self-esteem as having an overall favourable or unfavourable attitude towards the self. Rosenburg's (1965a) definition takes a structural stance towards self-esteem, assuming it to be a relatively stable state. This is based on the theory that self-esteem develops slowly over one's own life experiences (Holloway, 2016). However, self-esteem is vulnerable to fluctuations dependent on varying current contextual factors (Savin-Williams & Demo, 1983).

The lack of consensus on the definition of self-esteem can influence the validity of the tools used to measure it (Demo, 1985). However, there is a general consensus that having high self-esteem rating, i.e., an overall favourable view of the self, can be a positive predictor of wellbeing (Paradise & Kernis, 2002; Orth & Robins, 2014). Additionally, there have been numerous rigorous longitudinal studies which have investigated the prospective effects of self-esteem on life outcomes (Orth et al., 2010; Orth et al., 2012). These found that higher levels of self-esteem were a predictor of many positive life outcomes. This included, but is not limited to, ratings of increased satisfaction in marriage, close relationships, physical health, mental health, and job satisfaction (Orth & Robins, 2014). Comparatively, low levels of self-esteem have been associated with difficulties such as adjustment problems and suicidal ideation (Sharma & Agarwala, 2015). Furthermore, low self-esteem can have negative influences on psychological difficulties such as anxiety, depression, isolation, and loneliness (Sharma & Agarwala, 2015). Self-esteem is thought to be a crucial factor acting as an "anxiety buffer", therefore promoting the development of coping behaviours and emotions in response to stressors (Pyszczynski et al., 2004).

#### Rationale for This Review

Whilst self-esteem is considered a stable state, it is not immutable. Research has suggested that a significant life event such as a stoma can have a negative impact on self-esteem as well as other areas. Having discussed the significance of self-esteem and its influence on later life outcomes, psychological outcomes and responses to stressors, it is key to understand more about self-esteem following stoma surgery, as it may help to inform service provisions to improve the care that this population receives. This information could be used in future research to determine to what extent outcomes such as depression and anxiety are linked directly with the stoma, or if self-esteem may have a role in these other psychological outcomes. Presently, comparing studies on self-esteem is limited, given the variety of definitions and measures available. To date, there has been no synthesis of literature that has explored the impact of stoma surgery on self-esteem. The aims of this paper are as follows:

- To conduct a systematic review of the literature on outcomes for self-esteem following stoma surgery.
- To evaluate the quality of the current evidence base.
- To draw conclusions about the outcomes found by current studies.
- To identify areas for future research.

The research question for this review is:

• Does stoma surgery influence self-esteem?

#### Method

#### Search Strategy

An initial search using the Cochrane database was conducted to investigate whether any systematic literature reviews had been completed to assess self-esteem as an outcome following stoma surgery. None were found. A systematic literature search was undertaken in January 2024, and repeated in May 2024. The latter search did not reveal any new literature suitable for inclusion in this study. The search engine EBSCOhost was used to retrieve literature from the following databases: Academic Search Ultimate, APA PsycArticles, APA PsycInfo, CINAHL Ultimate, and MEDLINE. These databases were selected as they provide a wide variety of literature from psychology, nursing, and other health disciplines, as the majority of literature on stomas and self-esteem are published in these domains.

#### Search Terms

The following search terms were used:

stoma\* OR ostom\* OR colostom\* OR ileostom\* OR urostom\* OR jejunostom\*

#### AND

#### self esteem OR self-esteem OR self-worth OR self worth

The search terms were selected after several preliminary searches of the literature and identifying keywords from relevant articles. Different combinations of search terms were piloted to determine which terms were most sensitive and appropriate for literature retrieval.

#### Search Limits

Search limiters were used to return articles that were written in the English language and were peer reviewed articles. Due to the low volume of papers returned, no time limiters were set.

The following inclusion criteria was established to determine eligibility:

- The study must assess adults with a stoma, aged 18 and above.
- Articles with a quantitative research methodology must have used Rosenburg's Self-Esteem Scale (1965b) as a measure of self-esteem. This was selected as it is the most used scale in self-esteem research (García et al., 2019). This is likely

due to its reliability, with excellent stability and excellent internal consistency, alongside its concurrent, predictive and construct validity (Rosenburg, 1979).

• Articles with a qualitative research methodology must seek to explore self-esteem as a research aim, rather than reporting self-esteem from emerging data.

The following exclusion criteria were applied to inform eligibility:

- Studies not in English. The author was unable to read other languages, and the research budget was not sufficient for translation services.
- Reviews of existing literature, as the present paper sought primary sources.
- Biographical or auto-biographical accounts of self-esteem following stoma surgery, to ensure quality control.
- Lack an empirical basis i.e., lack a discernible research methodology.
- Not peer-reviewed, to ensure quality control.

## Results from the Systematic Search Strategy

The initial database search yielded 348 articles, of which 94 were duplicates. This left 254 for screening. Titles and abstracts were read and compared against the inclusion criteria. From this, 15 articles were selected for complete review. Forward and backward searching was completed from these 15 articles for any other potentially relevant studies, which yielded a further three papers for complete review, see Figure 1.

## Figure 1

PRISMA (The Preferred Reporting Items for Systematic Reviews and Meta-Analyses) Flow Diagram (Page et al., 2021) depicting article selection process.



Four of these papers explored qualitative data, but they did not explicitly explore self-esteem as a research aim. The remaining papers were of quantitative design. One paper could not be fully retrieved, one study reused the same participant data from another study included in full review, and three papers used an alternative scale for selfesteem. A further three papers had poor research methodology or lacked sufficient detail for analysis. This left six articles from this that appropriately met the inclusion criteria. Articles selected for full review but rejected are listed in Appendix B.

#### Methodological Quality

It was apparent from the results of article selection that research investigating selfesteem in ostomised people was limited, with no appropriate studies using qualitative methodological design. The included studies fell into two types of research quantitative design: descriptive cross-sectional and case-control. Many guality assessment tools of guantitative research are not suitable for these studies, as they are often designed for more rigorous experimental and thorough observational study designs. In fact, there are few quality assessment tools designed for descriptive cross-sectional research (Ma et al., 2020). Therefore, to assess methodological quality a checklist was developed by integrating two quality assessment tools from the Johanna Briggs Institute (JBI), see Appendix C. One of these was developed to critically appraise descriptive cross-sectional studies (Munn et al., 2015), and the other for case-control studies (Moola et al., 2017). These comprehensive tools undergo rigorous peer review and can be adapted by the user when needed. This checklist included 10 questions which can be applied to both crosssectional and case-control studies, and a further five questions for exclusive use with case-control studies. For comparison and interpretation, assessed studies are rated as a percentage out of their respective totals.

To measure the reliability of this tool, two independent raters were each given three of the included studies. Inter-rater reliability was assessed using Cohen's Kappa and found to be 0.60. This indicated a 'moderate' agreement. If a discrepancy was identified, the ratings were reviewed, and a new agreed score was determined.

### Data Extraction

A data extraction form (Appendix D) was used to collect the significant information from the included six studies. The data collected from each study included: reference, main aims, details of the sample, methodology, main findings, limitations, conclusions, and quality rating. All the selected studies investigated another variable alongside self-esteem.

This included the use of different measures of quality of life, emotional intelligence, body image, sexual functioning, and marital adjustment. As this review is solely seeking to synthesise the research on self-esteem following stoma surgery, these other variables will not be discussed in data synthesis. Additionally, synthesis focusing solely on these variables would be inappropriate, as there is likely other literature available on these variables to conduct a review in their own right.

#### Data Synthesis

Due to the methodological approach that was used in the selected studies, the quantitative data collected was limited, and not amenable for meta-analysis. Whilst a narrative synthesis approach can be used for quantitative data, there are limited guidelines on how to complete this in a transparent and clear way. This often results in criticism and scrutiny of this method (Campbell et al., 2019). To address this issue, the SWiM (synthesis without meta-analysis) guidelines were recently developed (Campbell et al., 2020). Therefore, the SWiM method used for this review. See Appendix E for this protocol.

#### Results

#### **Grouping Studies for Synthesis**

Four of the descriptive studies were of descriptive, cross-sectional design (Kelman & Minkler, 1989; Salomé et al., 2014; Ferreira et al., 2017; Saati et al., 2021). Of these studies, three investigated quality of life (QoL) alongside self-esteem (Kelman & Minkler, 1989; Salomé et al., 2014; Ferreira et al., 2017), whilst the other investigated emotional intelligence alongside self-esteem (Saati et al., 2021). The remaining two studies were of observational case-control design which studied body image, sexual functioning, and marital adjustment (Kiliç et al., 2007) and QoL (Dias et al., 2019) alongside self-esteem.

In total, 501 participants were recruited across the six studies included in this review. Of these, 416 were ostomised adults. All participants were approached via convenience sampling, with researchers recruiting participants registered to hospital

ostomy outpatient clinics or official ostomy registries. The remaining 85 participants were used in control samples. From the control group, 20 were "healthy" adults, matched for age and gender of their relevant study (Kiliç et al., 2007). The remaining 65 control participants had received surgical intervention for colon cancer but did not receive a stoma as a result (Dias et al., 2019).

The mean age for ostomised participants was 56.75 years, whilst the mean age for the control groups was 50.68 years. Regarding gender, 188 (45%) of the ostomised participants were men, 225 (54%) were female and the gender of three (1%) participants was not disclosed. In the control group, 50 (59%) were men, and the remaining 35 (41%) were women. In terms of stoma type, 193 (46%) were colostomies, 65 ileostomies (16%), and four urostomies (1%). One study investigated 155 (37%) people with colostomies and ileostomies but did not collect data on the proportions of this group (Saati et al., 2021). Another had more stoma frequencies than participants (Kelman & Minkler, 1989), which implies some participants may have had multiple stomas.

In terms of geographical setting, one study was American (Kelman & Minkler, 1989), one Iranian (Saati et al., 2021), one Turkish (Kiliç et al., 2007), and three were Brazilian (Salomé et al., 2014; Ferreira et al., 2017; Dias et al., 2019). Table 1 describes the characteristics of the six identified studies.

# Table 1

# Study titles, methodology, aims, setting, sample size, and conclusions.

Study	Methodology	Study Aims	Setting	Sample size <i>(n)</i>	Conclusions
Kelman & Minkler, (1989)	Descriptive cross-sectional study.	To examine the impact of an ostomy on quality of life and self-esteem.	USA	50	There is a significant correlation between quality of life and self-esteem in ostomised patients. Ostomised patients demonstrated high levels of self-esteem.
Salomé et al., (2014)	Descriptive cross-sectional study.	To investigate the quality of life and self-esteem in patients with intestinal stomas.	Brazil	70	Participants demonstrated moderate levels of self- esteem and low quality of life.
Ferreira et al., (2017)	Descriptive cross-sectional study.	To assess self-esteem and health- related quality of life in ostomised patients with colorectal cancer.	Brazil	36	Participants self-esteem was considered satisfactory. Location of the stoma can have significantly different impacts on self-esteem.
Saati et al., (2021)	Descriptive correlational, cross-sectional study.	This study aimed to determine the correlation between emotional intelligence and self-esteem in patients with an ostomy.	Iran	155	Participants had satisfactory levels of emotional intelligence and self-esteem. This study showed a positive correlation between emotional intelligence and self-esteem.
Kiliç et al., (2007)	Observational, case-control study.	The aim of this study was to investigate the effects of permanent ostomy on body image, sexual functioning, self-esteem, and marital adjustment.	Turkey	Case: 40 Control: 20	Ostomy patients, when compared to the control group, had significant disturbances in self-esteem, body image, marital adjustment, and sexual functioning.
Dias et al., (2019)	Observational, case-control study.	To assess if individuals with stomas have reduced quality of life and lowered self-esteem.	Brazil	Case: 65 Control: 65	Those with stomas had poorer quality of life and lower self-esteem than the control group. Those with stomas continued to struggle with their changed situation at six months or longer after surgery. This suggested that patients more pre- and post-operative assistance.

#### Rosenburg's Self-Esteem Scale (RSES)

With the RSES (Rosenberg, 1965b) being the most commonly used measure of selfesteem (García et al., 2019), it was selected as the measure for this review. Whilst there are multiple measures of self-esteem with varying methods of scoring, interpretation, and validity, only the RSES was assessed to ensure consistency of scoring interpretation. Whilst it was originally designed as a Guttman scale, it is more commonly scored as a Likert scale (Tinakon & Nahathai, 2012). It has a reproducibility of 0.92, demonstrating excellent internal consistency, as well as excellent stability and test-retest reliability (Rosenberg, 1979). It has been internationally validated (Çuhadaroğlu, 1986; Meurer et al., 2012) and has been used in studies across 53 nations (Schmitt & Allik, 2005). Furthermore, Saati et al., (2019) conducted their own validity analysis of the RSES, with a Cronbach's alpha correlation of 0.86, demonstrating good internal consistency.

The RSES is made up of 10 items with five positively coded statements and five negatively coded statements. Participants can respond from "Strongly Disagree", "Disagree", "Agree", and "Strongly Agree". Typically, the RSES scoring ranges from a minimum score of 10 and a maximum score of 40. However, depending on how responses are coded and summed, some studies may also report ranges from 0-30 (Sinclair et al., 2010). For these studies, this can be resolved by adding 10 to the RSES scores. Usually, RSES is interpreted by comparing the mean overall group score from one group with another (Rosenberg, 1965b). However, some have suggested that RSES scores can be categorised into three rankings of self-esteem: low (10-24), moderate (25-29) and high (30-40) (García et al., 2019), with a population average score of 32.62 (Sinclair et al., 2010).

Some studies in this review reverse-scored the RSES, meaning that high RSES scores were interpreted as having low self-esteem, instead of high self-esteem (Kelman &

Minkler, 1989; Salomé et al., 2014; Ferreira et al., 2017). To resolve this issue, scores for these studies were inverted by the researcher to aid comparison of results.

#### Synthesis

As previously discussed, meta-analysis of results was not appropriate for this review. This was due to the lack of effect size stated in the available studies, which are normally found in experimental study designs, which measure the effect of an intervention. Given the nature of stoma surgery, and it often being the result of necessary medical intervention, there are many ethical issues which reasonably prevent it from being measured as an "intervention" in the same way other intervention-based research is conducted. Synthesis of the included studies involved a variety of alternative synthesis methods (McKenzie & Brennan, 2019). This included synthesis of summary statistics, and combining of p-values:

Synthesising summary statistics:

This allows for the use of other summary statistics to synthesise data. All the included studies included the mean score of the RSES, and all but one (Ferreira et al., 2017) included the standard deviation of this mean. Authors were contacted for missing data; no responses were received. Some studies included medians and ranges in their descriptive data, which will be used when appropriate. A weighted mean will be calculated using the following formula, see Figure 2.

#### Figure 2

Formula for calculating weighted average (Cochran, 1977), where W = weighted average, n = number of terms to be averaged,  $W_i$  = weights applied to X values,  $X_i$  = data values to be averaged.

$$\overline{x} = \frac{\sum_{i=1}^{n} w_i \cdot x_i}{\sum_{i=1}^{n} w_i}$$

Combining of P-values:

This is an appropriate form of synthesis for studies which include p-values in their results. The combination of p-values was calculated using Fisher's method (Becker, 1994), which was compared against the Chi-squared statistic for degrees of freedom (McKenzie & Brennan, 2019), see Figure 3.

#### Figure 3

Fisher's method for combining P values, where  $P_i$  is the one-sided P value from study<sup>i</sup> and K is the total number of P values.

$$X^{2} = -2\sum_{i=1}^{k} \ln(P_{i}).$$

#### Criteria Used to Prioritise Results for Summary and Synthesis

All six studies were included in synthesis using summary statistics, and the two case-control studies (Kiliç et al., 2007; Dias et al., 2019) were synthesised by combining P-values. These studies contained the RSES means and standard deviations from both the case and study groups and used statistical analysis using the Students t-tests and Mann-Whitney U test, respectively, to compare the differences between these groups. These results will be initially prioritised in terms of design, with the case-control studies taking priority before the cross-sectional studies. This is due to them having more detailed quantitative data to synthesise. Following this, studies will be organised by sample size, with larger sample sizes taking priority. This is because larger sample sizes are more representative of the target population, which often is more accurate (Andrade, 2020).

#### Investigation of Heterogeneity

Formal measures of heterogeneity were not used due to insufficient data. Therefore, informal descriptive methods of heterogeneity were used, see Table 2. This displays heterogeneity between studies. As stated above, studies will be characterised in the results by study design and sample size.

## Table 2

Further study characteristics to display heterogeneity between studies. Duplicate information is included from Table 1 to consolidate

reader's understanding of sample differences.

Study	Study Design	Scoring Method	Time since stoma surgery	Gender Mean age (Years)		Ostomy Type %	
Dias et al., (2019)	Observational, case- control study.	Typical scoring	> 6 months	Case: 48% Male 52% Female	Case: 59.1	100% Colostomy	
				Control: 62% Male 38% female	Control: 57.2		
Kiliç et al., (2007)	Observational, case- control study.	Typical scoring	> 1 month	Case: 50% Male 50% Female	Case: 46.3	60% lleostomy	
				Control: 50% Male 50% Female	Control:44.15	40% Colostomy	
Saati et al., (2021)	Descriptive, correlational, cross- sectional study.	Typical scoring	> 1 month	49% Male 51% Female	54.23	Unspecified Ratio of Colostomy & Ileostomy	
Salomé et al., (2014)	Descriptive cross- sectional study.	Reverse scoring	Not specified.	26% Male 74% Female	64.5	77% Colostomy 23% Ileostomy	
Kelman & Minkler, (1989)	Descriptive cross- sectional study.	Reverse scoring	62% > 60 months, 28% = 12-60 months 8% = 6-12 months 2% < 6 months.	46% Male 48% Female 6% Unknown	52.4	50% Colostomy 43% Ileostomy 8% Urostomy	
Ferreira et al., (2017)	Descriptive cross- sectional study.	Reverse scoring	27.8% > 60 months 33.3% 13-60 months 38.9% < 12 months.	56% Male 44% Female	63.97	92% Colostomy 8% Ileostomy	

#### Certainty Of Evidence

Cochrane Guidelines recommend using the GRADE (Grading of Recommendations Assessment, Development and Evaluation) approach to evaluate the certainty of evidence for systematic reviews (Schünemann et al., 2019). This is divided into four rankings of evidence certainty: high, moderate, low, and very low. Observational trials, including studies of case-control design, begin at a rating of "low", and cross-sectional studies cannot surpass the "very low" rating. Acknowledging that this tool would not provide a great amount of information of how research quality varies amongst the studies selected in this study, the Johanna Briggs Institute (JBI) integrated tool for cross-sectional and casecontrol studies was used to aid understanding of quality between assessments (as detailed in Methodological Quality).

#### Quality Assessment

The integrated Johanna Briggs Institute (JBI) tool guided quality assessment and interpretation. The quality of studies ranged from 40% to 73%, with the average rating being 60.50% (SD = 11.55), see Appendix F. The study with the lowest ranking of quality assessment was Kiliç et al.'s (2007) with 40%, and the highest ranking of quality assessment was from Dias et al., (2019), with 73%. Interestingly, these studies were also the only two case-control studies. Some weaknesses in the study by Kiliç et al., (2007) were the lack of detail and clarity in the description of both the procedure and the statistical analysis, which made it difficult to interpret some elements of the research. Additionally, there was weakness in the reporting of some statistics, with missing data such as p-values for correlation statistics, although fortunately there was enough data from the RSES to include in synthesis.

All papers were limited in terms of sample collection method. Participants were collected by a convenience sample method, which lacks generalisability and therefore comparability of the results. Dias et al.'s (2019) participants were required to attend an

"Ostomised Patients Support Group" as a part of the inclusion criteria, which may have had an unknown influence on self-esteem. Also, Kiliç et al.'s (2007) participants were recruited from a private healthcare setting, in a country which provides universal healthcare. It could be possible that those who have access to private healthcare may have different self-esteem outcomes than those who do not.

Additionally, only one study calculated a minimum sample size needed for their study (Saati et al., 2019), which also had the largest sample size out of all included studies. When using Daniel's (1978) formula for calculating minimum sample sizes, when assuming a proportion rate of 0.02 (Coulter, 2022), a minimum sample size was calculated to be between 275-304 people, see Figure 4. This sample size is not met by any of the included studies, although this may be due to differing prevalence rates of stomas across varying regions.

#### Figure 4

Formula to calculate sample population size, where Z = confidence interval, P = proportion and d = precision.

$$n = \frac{Z^2 P(1-P)}{d^2}$$

As mentioned previously, there was a varied approach in the scoring of the RSES, with papers varying between scoring between ranges 0-30 and 10-40, and some papers reverse-scoring their results for undisclosed reasons, see Table 2. None of the cross-sectional papers compared their mean RSES score with an average population norm or pre-determined scoring range, which raises questions on how they interpreted their results. This limited the researchers' reported interpretations and conclusions from their findings.

Many papers lacked clear, repeatable procedures which limited reliability of results. Two of these papers did not report or acknowledge any limitations with their studies (Kiliç et al., 2007; Salomé et al., 2014). Some studies had participants who were illiterate (Dias et al., 2019; Salomé et al., 2014), and it is not clear how this may have influenced results. Whilst Dias et al., (2019) acknowledged this limitation, and reported a researcher followed a qualitative research procedure to collect data from illiterate participants, this procedure is unclear. Salomé et al., (2014) included no detail on how illiterate participants completed the RSES. Additionally, the study by Salomé et al., (2014) included several errors which altered its reliability, where the reviewer had to make assumptions as a result, leading to limitations in the validity and interpretation of the data. This included inconsistent reports of gender prevalence data in text when compared to data reported in their tabulations of data. Whilst there were no obvious errors regarding RSES data, errors in peer-reviewed studies raises concerns over quality and reliability of results.

Overall, quality varied between studies. The primary issues were concerns over generalisability of results, and repeatability of studies due to insufficient procedure detail. No study asked a research question or suggested a null hypothesis to reject. This is expected in the cross-sectional studies which have exploratory aims, but a null hypothesis would have been appropriate for the case-control studies. This will be considered in the discussion.

#### Results from synthesis

## Table 3

Table of included studies, ordered by study design and sample size (M = mean, SD = standard deviation, MD = mean difference, n =

sample size, R = range).

		Synthesis 1: Summary Statistics							Synthesis 2: Combing P-Values		
	Quality	Case Outcome				Control outcome				2-sided	1-sided P
Study ID	Rating (%)	(n)	(M)	(SD)	(R)	(n)	(M)	(SD)	(MD)	P value	value
Case-Control											
Dias et al., (2019)	73.00	65	27.80	4.90		65	30.30	2.80	2.50	0.001	0.0005
Kiliç et al., (2007)	40.00	40	28.22	3.61		20	32.45	4.26	4.23	0.001	0.0005
Cross-Sectional											
Saati et al., (2019)	70.00	155	29.10	4.26	17-40 (23)						
Salome et al., (2014)	60.00	70	29.19	5.40							
Kelman & Minkler, (1989)	60.00	50	39.48	0.93	36-40(4)						
Ferreira et al., (2017)	60.00	36	31.12		10-31 (21)						

*Combing P-values:* Two of the six included studies provided p-values for differences between a case group and control group (Dias et al., 2019; Kiliç et al., 2007). The weighted mean average of the control groups from these case-control studies was 30.80, with the weighted average of the two case-control studies being 27.96, resulting in a weighted mean difference of 2.84. The combining of p-values found this difference to be statistically significant (P < 0.001, 2 studies) between both groups.

*Summary statistics:* The total mean RSES score across all six studies was calculated to be 30.24. Scores were weighted by sample size. A weighted standard deviation could not be calculated due to missing data from Ferreira et al., (2017). When compared to the average population RSES score of 32.62 (Sinclair et al., 2010), five out of the six studies were below this range, with the exception being Kelman and Minkler (1989). When assessed using the RSES scoring ranges, four (Dias et al., 2019; Kiliç et al., 2007; Saati et al., 2021; Salomé et al., 2014) out of the studies means ranked in the "moderate" range and two (Kelman & Minkler, 1989; Ferreira et al., 2017) ranked in the "high" self-esteem range (García et al., 2019), see Table 3 and Figure 5.

#### Figure 5

Bar chart depicting mean Rosenberg Self-Esteem Scale (RSES) scores across case groups and respective controls. Standard deviations labelled where available.



#### Discussion

Analysis revealed that the overall weighted RSES mean across studies was lower than average (Sinclair et al., 2010), however due to limitations in analysis methods, it is not known if this difference is statistically significant. However, for the two case-control groups, the case sample was significantly lower than the control group, suggesting that ostomised participants have poorer self-esteem than when compared with a control group. However, both these scores were still in the "moderate" ranges for self-esteem (García et al., 2019), suggesting that while self-esteem is lower, it may not be possible to conclude that ostomised participants have low self-esteem overall.

Additionally, two of the studies reported that ostomised participants had "high" ratings of self-esteem (Kelman & Minkler, 1989; Ferreira et al., 2017), with Kelman and Minkler's (1989) mean population score being only 0.52 points away from the maximum self-esteem score. This discrepancy is acknowledged by the authors, who stated that most participants only provided positive responses, which may be due to a formatting error and unclear instructions. This may impact the validity of the results from this study. Furthermore, Ferreira et al.'s (2017) study had the smallest population size, which further limits the reliability of their results. Researcher's made various conclusions from their findings, ranging from participants having "satisfactory" (Ferreira et al., 2017), "low" (Salomé et al., 2014), "disturbances in" (Kiliç et al., 2007) self-esteem. This again highlights the disparities in study results and interpretations of scores.

All studies except for one (Kiliç et al., 2007) included participants that had both temporary and permanent stomas whereas Kiliç et al. (2007) involved permanent stomas only. It may have been helpful to have data regarding self-esteem for both stoma types (permanent or temporary), to compare this variable between groups. In terms of consistency and generalisability, it may have been appropriate if all available participants

had the same stoma type to aid comparison. However, with already limited sample sizes, this may have been difficult to achieve.

Additionally, three of the studies did not specify a minimum time since having stoma surgery (Kelman & Minkler, 1989; Salomé et al., 2014; Ferreira et al., 2017), and two only required a minimum time of one month since surgery (Saati et al., 2021; Kiliç et al., 2007). This is concerning, given that physical healing and psychological adjustment after stoma surgery can last from between three to six months (NHS, 2023; Carta et al., 2009). The only study which required participants to have a stoma for more than six months was from Dias et al., (2019). For most studies to have not included this minimum post-surgery period in participant recruitment raises some concerns regarding the reliability of the results, considering many participants would still be physically and psychologically recovering from this life-changing surgery. This ongoing recovery and adjustment process may have impacted the participants self-esteem at the time of the study.

Interestingly, the study with the lowest RSES mean (Dias et al., 2019) was also the study with the highest quality rating. This case-control study had both the case and control group include adults who had surgery for colon cancer, but only the case group received a permanent ostomy. This may be a more comparable control group than Kiliç et al.'s (2007) who compared their case group with healthy controls. However, neither study described the rationale for the inclusion criteria of their control groups, which limits full evaluation of their approach.

Finally, regarding the setting of the research, half of the studies were based in Brazil, and the remaining studies were based in America, Turkey, and Iran. Interestingly, the American study (Kelman & Minkler, 1989) was the oldest resource, preceding the next paper by 18 years. This demonstrates that whilst research involving self-esteem following stoma surgery is not a recent concept, there has still been significantly limited research since this initial paper. It is interesting that no papers were published in the UK, where this

review is based. Knowing the variability of study location, it is worth considering the generalisability of results, considering that each of these countries will have their own cultures and beliefs around self-esteem, as well as beliefs about illness and stomas. However, whilst there may be differences between cultures that may influence various aspects of the studies, they all use the internationally validated RSES which aids interpretation.

#### Strengths and limitations

Limitations of this review include the synthesis methods used. Robust methods such as meta-analysis can provide more detailed estimates of effect estimates, variance and quantify occurrences of heterogeneity. However, due to limited information included within the selected studies, alternative methods of synthesis were used. Using summary statistics as a synthesis method does not account for differences in the relative sizes of the studies. Whilst a weighted average was calculated to compensate for this, it still is limited in terms of synthesis strength. Additionally, whilst combining p-values is an alternative way of synthesising data without meta-analysis, it provides no information on the magnitude of effects, and does not take sample size into account. Additionally, the studies did not include a null hypothesis, which limited the p-value synthesis.

However, this review was strengthened by its adherence to the SWiM reporting guidelines, allowing for a more transparent method of data synthesis and reporting over other methods such as narrative synthesis for quantitative data.

#### **Clinical Implications**

Given the limited data used in synthesis, and the variety of RSES outcomes, it is difficult to suggest definitive clinical implications. Primarily, this review highlighted the need for further comprehensive research regarding self-esteem following stoma surgery, with more rigorous and valid research methods. This research has found that there have been extremely limited studies researching the influence of stoma surgery on self-esteem. One

recommendation is for future research further exploring self-esteem following stoma surgery, to allow for more definitive recommendations to be made. If future research finds self-esteem to result in poor self-esteem following stoma surgery, it may highlight the need for pre- and post-operative psychological assessment and intervention. Perhaps research that highlights predictors or risk factors of low self-esteem could aid clinicians at identifying those more at risk of having psychological difficulties or poorer life outcomes. Currently, studies suggest that whilst self-esteem can be negatively impacted following stoma surgery, particularly when compared with a control group, it is often still in high or moderate levels.

Research has suggested that having a high self-esteem rating can be a positive predictor of wellbeing and positive life outcomes (Paradise & Kernis, 2002; Orth & Robins, 2014), whilst also playing a key role in distress and emotional management (Pyszczynski et al., 2004). Additionally, poorer self-esteem is associated with mental health difficulties such as suicidal ideation, anxiety, low mood, and loneliness (Sharma & Agarwala, 2015). Knowing this, results from this review may tentatively suggest that self-esteem in this population group is not negatively affecting these psychological outcomes such as depression and anxiety. However, given the disparity of results and variability in method and procedure, this suggestion should be considered with apprehension.

Given the variety of methods used to score the RSES, it may be useful to use or develop an alternative measure for self-esteem which does not allow for this variability in procedure. However, this may still occur due to the current lack of consensus regarding the definition of self-esteem, which may continue to impact its validity (Demo, 1985). Studies recommended the continued or improved provision of support after stoma surgery. This could involve better provision of stoma support nurses, or facilitation of stoma support groups. However, it would be beneficial for further research in this area to provide more

information on what this support might look like, and evidence how it benefits people with stomas.

#### Future research

The literature reviewed has highlighted that there is limited research available regarding self-esteem following stoma surgery. Primarily, there was no appropriate qualitative research available regarding self-esteem following stoma surgery. Qualitative research on self-esteem may offer an alternative insight into the perspectives of people living with stomas, which would allow for contradictions in data. This may be useful considering that this review found contradictory findings which impeded the forming of definitive conclusions. Alternatively, research which involves mixed method designs may also be appropriate for future research in this area, which would have the benefits of using a standardised and validated measure to aid comparison between participants, but also allow for individual contexts and understandings to be considered. This could provide a more developed understanding of cultural differences of self-esteem and stomas.

Quantitative research in this area would benefit from more rigorous procedures and planning. Studies in this review were limited in terms of procedure detail, sampling methods and data analysis methods. Whilst it is unlikely that stoma surgery can be used as a measured intervention in a randomised controlled trial due to a variety of ethical reasons, there may be scope for more thorough experimental research designs. This could include longitudinal measures for self-esteem for ostomised people, or potentially pre- and post-surgery design measures. This would address the need for more appropriate data, such as effect sizes and variances, to complete a meta-analysis.

Finally, future research may benefit from further research across diverse cultures and countries. It would be helpful to have a study based in a UK population, where this review is based, or an updated study in an American population which addresses the

formatting issue which occurred in the only American study available (Kelman & Minkler, 1989).

#### Conclusion

This review revealed that there has been extremely limited research regarding selfesteem following stoma surgery. Available research was restricted to methodological designs which were poor in quality and rigour. These studies were also limited in terms of generalisability and validity. Therefore, definitive conclusions following this review cannot be made. The synthesis of data revealed that there was an overall reduced self-esteem rating in ostomised individuals, particularly when compared with a control group. However, studies had inconsistent results and interpretations, with some studies reporting high and low ratings of self-esteem in individuals following stoma surgery. Most studies lacked a control group or rigorous methodological design, and none completed measures before surgical intervention. This systematic review highlights a considerable gap in the literature which seeks to evaluate any changes to self-esteem following stoma surgery. Specifically, future research needs to be more reliable, repeatable, and generalisable, particularly in terms of methodology and procedure.
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# Part Two – Empirical Paper

This paper is written in the format ready for submission to the

# Body Image Journal

Please see Appendix G for submission guidelines.

# This New Part of Me: Young Men's Experiences of Body Image and Body Modification Following Stoma Surgery.

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### Abstract

Stomas are artificial openings on the body, typically required due to essential medical interventions. However, they can be associated with adverse physical, psychological, and social outcomes, including negatively impacted body image. Most research exploring body image post-stoma surgery focuses on women. There is no research exploring men's experiences of body modification following stoma surgery. This study sought to address these gaps by interviewing six young men, generating gualitative data that was analysed using Interpretative Phenomenological Analysis (IPA). Four themes were developed: "the destabilisation of identity", "the separation of self and stoma", "the need for connection" and "contributors to self-acceptance". Themes encompassed the varying shifts in identity participants experienced post-surgery, including the changed relationship participants had with their bodies. Body modification was perceived as one of the 'contributors to self-acceptance', allowing participants to reclaim control over their bodily autonomy and increase their self-confidence. Participants benefited from inclusion, peer-support and acceptance following their surgery. Furthermore, findings highlighted the need for increased diverse representations of ostomised people in healthcare and wider contexts. This study emphasised the importance of addressing body image concerns amongst young men in clinical settings. Further research could explore if body modification has a positive impact in the long-term.

### Keywords: stomas, image, modification, men, experiences, IPA

### Introduction

### Stomas

There are over 200,000 people in the UK living with stomas, with 21,000 people receiving stoma surgery every year (Coulter, 2022). Stomas, otherwise known as ostomies, are small, artificial openings on the body often required due to necessary medical intervention (Perrin, 2019). There are three types of stomas: colostomies (from

the colon), urostomies (from the bladder) and ileostomies (from the ileum) (Burch, 2008). The leading causes for stoma surgery are colorectal or bladder cancer, Crohn's disease, ulcerative colitis and accidental injury (Kettle, 2019).

Although stomas are created to remove certain threats to life or alleviate adverse symptoms, they often have undesirable consequences. Stomas can result in significant changes to the body's function and appearance (Jayarajah & Samarasekera, 2017). Regardless of whether these stomas are temporary or permanent, they can have a negative impact on quality of life (Dabirian et al., 2011; Siassi et al., 2008).

Psychological adjustment after a stoma can be impacted by one's own acceptance of the stoma, social support received and interpersonal relationships (Simmons et al., 2007). Specifically, the process of adjustment can be influenced by an individual's existing knowledge and comprehension of stoma surgery. Studies have demonstrated that receiving psychological preparation before the surgery can have a beneficial effect, particularly in alleviating anxiety after the procedure (Clark et al., 2023).

Research has suggested stomas can negatively impact physical activity, relationships, and sexual functioning, resulting in anxiety, depression and reduced enjoyment of activities (Richbourg et al., 2007; Brown & Randle, 2005; Dabirian et al., 2011). Additionally, body image is often negatively impacted following stoma surgery (Jayarajah & Samarasekera, 2017).

#### Men's Body Image

Body image is a multidimensional concept, mainly focusing on the perceptions, attitudes, and beliefs one has towards one's own body (Cash & Pruzinsky, 1990). Individuals may evaluate the satisfaction (or dissatisfaction) they have with their body's appearance/image as positive, neutral, or negative (Tylka & Wood-Barcalow, 2015).

A negative body image, or body dissatisfaction, occurs when an individual is dissatisfied with an aspect of their appearance. This is associated with adverse

psychological consequences. A recent UK survey has found that 35% of adults experience feelings of shame or depression due to their body image, indicating direct repercussions on public health (Health and Social Care Committee [HSCC], 2022). The survey revealed that 80% of participants either agreed or strongly agreed that their body image adversely affected their mental health, whilst 61% expressed agreement or strong agreement regarding the negative influence of body image on their physical health.

Body image research often focuses on women (McCabe & Ricciardelli, 2004). This has suggested that women place more importance on their body image and are more dissatisfied with their appearance than men (Quittkat et al., 2019; Cash et al., 2004a; Cash et al., 2004b). However, other research has found that men and women did not vary in terms of body image disturbances (Silberstein et al., 1988) and that the research emphasis on female body dissatisfaction has contributed to male body dissatisfaction being underreported (Strother et al., 2012).

How men and women are portrayed in society may contribute to discrepancies in body image and ideals (Silberstein et al., 1988). A positive association between regular social media use and negative body image was found (Fardouly & Vartanian, 2016), with longitudinal studies showing that this association may strengthen over time (Saiphoo & Vahedi, 2019). Appearance comparisons are important in linking this association (Fardouly & Vartanian, 2016), as individuals are encouraged to compare themselves to the images that are promoted to them. Given that younger adults (18-29 years old) have the highest rates of social media use (Auxier & Anderson, 2021), they may be at increased risk of body dissatisfaction.

Recent consumer media's focus on creating an ideal self-image has further encouraged body dissatisfaction (Featherstone, 2010). Young men with body dissatisfaction are at risk of negative self-evaluations when this exposure occurs (Blond, 2008). Recently, men in popular culture are more increasingly portrayed as trim,

muscular, sexual objects, with men reporting to feel as much societal pressure to improve their physical appearance as women (Miller & Halberstadt, 2005). Additionally, younger men have greater levels of body dissatisfaction than older men (Hockey et al., 2021).

### Body Image and Stomas

Stoma surgery can negatively impact body image (Ang et al., 2013), particularly amongst younger women and men (Jayarajah & Samarasekera, 2017). Individuals who received stomas post-colorectal surgery had a poorer body image than those who did not (Sharpe et al., 2011). Notably, individuals with reversed stomas often reported no improvement in body image, potentially due to identity transition or residual scarring (Camilleri-Brennan & Steele, 2002). Body dissatisfaction in ostomised individuals continues to deteriorate over time, which is a predictor of anxiety, distress, and depression (Ang et al., 2013). Some individuals described feeling "shocked" and "disgusted" when initially seeing their altered body, reporting "feelings of alienation within their bodies" (Ang et al., 2013, p.589).

Regarding ostomised men, research has found they can feel "incapable", "unimportant" and "less masculine" after their stoma surgery (Hong et al., 2014). This may be due to a significant negative relationship between body image disturbance and the perception of self-efficacy post-ostomy (Jayarajah & Samarasekera, 2017). More research on body image in ostomised men is needed, as most studies focus on mixed-gender or female-only samples. These studies often overlook the influence of culture and society on stoma acquisition and body image, particularly given the Western media's portrayal of men as muscular and fit.

# **Body Modification**

Individuals dissatisfied with their bodies may seek to modify it. Body modification, a voluntary and aesthetic process, aims to change physical appearance (Lane, 2017). This includes: tattoos, piercings, cosmetic surgery and bodybuilding. Notably, body

dissatisfaction in young men is associated with steroid use and exercise dependence (McCabe, & Ricciardelli, 2004), potentially with the aim of modifying their bodies to an ideal. Many studies report an increased steroid use in young men, to potentially enhance muscularity due to body dissatisfaction (Goldman et al., 2019; Pope et al., 2017). Body modification, including tattooing, has been practiced for thousands of years (Deter-Wolf, 2013). Research shows that women perceive tattooed men as "healthier" compared to non-tattooed men (Wohlrab et al., 2009). Additionally, individuals seeking cosmetic surgery typically exhibit lower self-esteem compared to a normative sample. Here, cosmetic surgery may be viewed as a means to enhance self-esteem (Klassen et al., 1996; Sarwer & Crerand, 2004).

### Motivations for Body Modification

From a psychoanalytic perspective, there is a distinction between the superficial and decorative body modifications, and an underlying, more compelling pursuit of body modification. This pursuit reflects unconscious phantasies about self and identity (Lemma, 2010), which underpin individuals' desires to modify their body. In the "perfect match" phantasy, one uses body modification to create and maintain an "ideal body" to gain another's love and desire. In the "reclaiming phantasy", body modification attempts to "rescue" the self from a foreign or alien presence within the body. These phantasies are often thought to stem from early experiences.

Research indicates that complex abdominal surgery often leads to feelings of vulnerability (Sutton et al., 2024), potentially activating unconscious phantasies. However, research on young men's experiences post-stoma surgery and subsequent body modification remains limited. The function of such modification, whether positive or negative, and its role in managing internal conflicts or emotional distress, remains unclear. Therefore, it is worth considering if, and how, these phantasies align with the experiences of young, ostomised men. Lemma's (2010) theory, initially based on early attachment

relationships, suggests that the concept of the "alien" presence could also be an experience that men have of their stomas. Given the invasive nature of the procedure, it is worth investigating if these young men resonate with the concept of the body feeling "alien" and the idea of "reclaiming phantasy". This is particularly pertinent given that participants in Ang et al.'s (2013) study reported "feelings of alienation" within their bodies, despite the absence of any body modifications in this research. Additionally, the "perfect match" phantasy may be relevant to young ostomised men who hope to feel connected and accepted by others following stoma surgery.

Body modification may also have a role in the grieving process. Research has found that tattoos can be a therapeutic tool following bereavement (Swann-Thomas et al., 2024). Also, experiencing loss can be a precipitating factor in bodybuilding, providing a coping mechanism or constructive distraction for managing emotions (Foster, 2019). The long-term impact of body modification on processing grief remains unknown. However, grieving may occur after stoma surgery due to significant physical and psychological adjustments (Kelly, 1985).

### **Rationale and Research Questions**

Few studies have explored how and if stoma surgery affects body image in young men. There is no research investigating if individuals with stomas engage in body modification and their experience of undergoing this. The current study focuses on men aged 18-29, corresponding with Arnett's (2007, 2014) life stage of "emerging adulthood". This life stage involves individuals exploring their identity and focusing on their personal development. Requiring stoma surgery during this "unstable" life change may impact this self-exploration, adding further instability into these individuals' lives. Knowing this, and the positive association between regular social media use and negative body image (Fardouly & Vartanian, 2016; Saiphoo & Vahedi 2019), this age range may be more vulnerable to body image dissatisfaction than other adult cohorts.

This study will investigate the detailed and individual perspectives of young men living in the UK with a stoma, with a specific focus upon how young men experience and make sense of their bodies. Information gathered will not only expand the literature in this field but could provide an insight into the societal and emotional pressures these young men have regarding their appearance. Given the limited research in this field, it is not known if body modification serves a positive or negative function and what might be the psychological impact of modifying the body. Information received from this study could inform clinical practices by aiding in the psychological preparation and recovery of stoma patients undergoing surgery, facilitating their adjustment to living with a stoma. Furthermore, this study could contribute to the psychological understanding of body modification, including its functions, motivations, reported benefits or challenges.

### **Research Questions**

- 1. How do young men experience and view their bodies after having a stoma?
- 2. How do young men with stomas who have modified their bodies make sense of their experiences?

### Method

### Design

Semi-structured interviews were utilised to collect qualitative data on subjective lived experiences of being a young man with a stoma who had engaged in body modification (See Appendix H). Interpretive Phenomenological Analysis (IPA) (Smith et al., 2021) was used to hermeneutically analyse data case-by-case. Additional demographic information was obtained before interviews to contextualise the data, using a demographic questionnaire as part of the consent form (See Appendix I).

### Participants

The recommended sample size for IPA studies on professional doctoral programmes is between 6-10 participants (Smith et al., 2021). Participants were young men who had

undergone stoma surgery and body modification, see Table 1. There were no incentives

offered in exchange for participation.

# Table 1

Inclusion and exclusion criteria and rationale.

Inclusion Criteria	Exclusion Criteria	Rationale
Participants must be cis-gendered and male.		Individuals identifying as transgender or gender- nonconforming were not included in this study as reported body image dissatisfaction could be linked to an incongruity between gender identity and biological sex (Owen-Smith et al., 2018).
Must be aged between 18-30 years old.	Participants aged outside this age bracket.	This was to align with Arnett's (2007) concept of "early adulthood". An additional year was added for recruitment purposes.
Stoma surgery must have occurred between the ages of 17- 29 years old.	Participants who had their stoma surgery as a child.	Stoma surgery before this time will have been during a different life stage and therefore could impact the homogeneity of the sample.
Must have engaged body modification following stoma surgery. This includes (but is not limited to): piercings, tattoos, cosmetic surgeries, scarification and/or Bodybuilding.	Those who have not engaged in permanent, or only have temporary, modifications.	As the research is interested in the impact of body modification in young men with stomas.
Participants must have had their stoma for a minimum period of 6 months.		This is to allow for physical healing of the stoma. This time frame is consistent in similar studies (Simmons et at., 2007; Gautam & Poudel, 2016).
Participants must have a permanent abdominal stoma.		To maintain the homogeneity of the sample. Those with temporary stomas may have alternative opinions regarding body image and modification if they are aware their stoma can be reversed within a shorter time period.
	Participants who do not speak proficient English	The researcher's language proficiency is limited to English for speaking, understanding, and transcribing, and the research

funds do not allow for hiring a translator.

Six participants were recruited through voluntary sampling, see Table 2. The mean age of participants during the interview was 24.5 years, whilst the mean age at the time of stoma surgery was 21 years.

### Table 2

Participant characteristics.

Pseudonym	Aidan	Blake	Charlie	Daniel	Emmett	Finn
Body Modification	Bodybuilding/ Fitness	Bodybuilding/ Fitness	Bodybuilding/ Fitness	Bodybuilding/ Fitness, and Tattoos	Bodybuilding/ Fitness	Bodybuilding/ Fitness
Stoma Type	Colostomy	lleostomy	lleostomy	lleostomy	lleostomy	lleostomy
Reason for surgery	Abdominal Complication	Ulcerative Colitis	Crohn's Disease	Ulcerative Colitis	Crohn's Disease	Ulcerative Colitis

### Ethics

The Faculty of Health Science Research Committee (FHSRC) at the University of Hull (REF: FHS22-23.71), approved ethical approval for this study (Appendix H). A further amendment was made in October 2023, in relation to extending the participant age range. Verbal and written consent was obtained to record video and audio elements of the interview.

### Procedure

The researcher contacted Crohn's and Colitis UK, Colostomy UK in September 2022, and Bowel Cancer UK in September 2023 via email to gain support with participant recruitment (Appendix J). All these organisations agreed to promote the study via their own online promotional methods following ethical approval. The trainee contacted 38 UK stoma support groups via email who agreed to promote the study where feasible (Appendix J). The research study was promoted via digital and physical posters, (Appendix K). This included online advertisements via the professional social media accounts (Instagram, Facebook, X and LinkedIn) affiliated with bowel and/or stoma related

charities and/or the researcher. Physical posters advertising the study were displayed in various gyms, tattoo studios and piercing studios within the Yorkshire and East Riding area. Staff at these locations were asked to promote this study via word-of-mouth. Potential participants were asked to complete the online interest form (Appendix L) to register interest or enquire about study, or to contact the researcher directly via email. Participants were sent the information sheet (Appendix M) and consent form (Appendix I) via email, which were signed and returned. Upon this, the researcher and participant agreed a time and date for an online interview.

Online interviews were selected over in-person interviews due to their practicality and manageability, minimising travel distance and lone working. Six participants were interviewed by the principal investigator for 25-50 minutes (M = 33 minutes) using MS Teams between July-November 2023.

To follow the principles of IPA, the interview was semi-structured and included open-ended questions to encourage participant discussion (Appendix N). The interview structure encouraged participants to talk about their experiences of body image before and after their stoma, alongside their experiences with body modification following stoma surgery. Prompting questions encouraged further responses. Upon interview completion, participants were emailed a document containing contact information for relevant national charities and support services should they need further support (Appendix O). Participants were able to contact the researcher directly for any further questions regarding the study. Transcription of interviews were stored on an NHS encrypted laptop. Anonymity, confidentiality, and the right to withdraw were detailed before the interview. Personally identifiable data was removed during transcription and random pseudonyms were generated for reporting results.

### Methodological Analysis

Interpretative Phenomenological Analysis (IPA) (Smith et al., 2021) was used to analyse data from the transcripts. IPA was selected as this allows for a thorough exploration of the meanings and lived experiences of young men with stomas regarding how they perceive, view, and modify their body. IPA is suited to research topics which have limited existing research as it provides a detailed and rich account from the sample's perspective, including experiences that the researcher may not have considered (Reid et al., 2005).

Using IPA involves exploring scripts with an idiographic approach, analysing them caseby-case. This process involves a double hermeneutic, as whilst the participant is trying to make sense of their own experiences being a young man with a stoma, the researcher is attempting to make sense of the participants subjective lived experiences. Consequently, it was necessary to acknowledge the impact of the researchers' own pre-conceptions and potential biases prior to data analysis. Smith et al.'s (2021) guidelines for IPA were used for analysis (see Appendix P for example):

- The researcher reads the transcript several times to become familiar with the contents.
- 2. Line-by-line examination of each transcript, using annotations to code anything noteworthy or significant in the right-hand margin.
- 3. Themes and patterns are considered for each participant.
- 4. Identifying commonalities and differences across participant accounts. Initial codes are created and linked with supporting quotes.
- 5. The scripts are reanalysed to refine the codes. This allows further exploration and evaluation of how the codes interact.
- 6. Initial personal experiential themes are formed and organised.

7. Creating an interpretative account, combining the meaning of the data, with the understanding and knowledge of the researcher.

### Quality Assurance and Reflexivity

During this double hermeneutic the researcher is influenced by their own experiences, beliefs, and ideas, whilst attempting to make sense and understand the participants own sense-making. The researcher is a white, British/Irish, middle-class, young adult female, with no personal experience of ostomies or bowel related health conditions. The researcher attempted to conduct outsider research, intending to demonstrate a not-knowing, non-judgemental stance. This outsider position may have limited data collection, as the participants willingness to share their difficult personal experiences may have been impacted due to concerns of being judged or misunderstood (Dwyer & Buckle, 2009). The researcher acknowledged they were also a young person with a long-term health condition, with their own experiences of disturbed body image and body modification. This may have influenced their interpretation of the participants' experiences. An epistemological statement (Appendix Q) is available for information regarding the researcher's epistemological position.

A reflective journal was used by the researcher to demonstrate transparency and coherence (Yardley, 2000) where reflections, past experiences and pre-conceptions were recorded (Ortlipp, 2008), see Appendix R for reflective statement. Furthermore, the cyclical nature of the data analysis procedure encouraged a detailed and thorough engagement with the data, demonstrating thoroughness and commitment (Yardley, 2000). To ensure further methodological quality, the researcher followed the four qualities set by Nizza et al. (2021), see Table 3.

### Table 3

The criteria for identifying high-quality IPA research as set by Nizza et al. (2021).

Quality Indicators	Method of achieving quality
Developing a compelling narrative.	By forming themes to develop a coherent story.
Developing a vigorous experiential account.	By encouraging the participants to reflect on their personal experiences with their body image.
Close analytic reading of participants' words.	By going through an annotated section of a transcript (see Appendix P) with another researcher to allow for other interpretations.
Attending to convergence and divergence.	Analysing data with an idiographic approach, with aims to appreciate that individual experiences will have similarities and differences.

# Results

Participants were asked to talk about their experiences of viewing their body before and after their stoma surgery, and their experiences of body modification. Participants' experiences were grouped into four main personal experiential themes and 13 subthemes, see Table 4.

# Table 4

Personal experiential themes and subthemes.

Personal experiential themes	Subthemes		
1. The destabilisation of identity	1.1 The satisfied self		
	1.2 The self in crisis		
	1.3 The integrated self		
	1.4 The instability of self-perception		
2. The separation of self and stoma	2.1 Sudden loss of bodily autonomy to illness		
	2.2 The stoma as a threat		
	2.3 The stoma as an ally		
3. The need for connection	3.1 The experience of isolation		
	3.2 The fear of stigma		
	3.3 Creating a supportive community		
4. Contributors to self- acceptance	4.1 Taking back control		
	4.2 Shaping self-confidence		
	4.3 Demystifying the stoma		

Each theme was supported by direct quotations (italicised) from participant interviews. Ellipses within brackets indicate brief pauses or omitted content to condense each quote.

### 1. The destabilisation of identity

Participants described their experience as a journey, from before their stoma surgery, their period of illness, the immediate period after surgery, and their current self. From this, four subthemes were comprised.

### 1.1 The satisfied self

Participants had variable experiences of illness prior to their surgery. They often spoke about their pre-stoma body as a separate identity, and often in a more approving way. Aidan idealised his pre-stoma body, stating:

### "I felt kind of invincible and [...] perfect."

Participants had more positive opinions of their body when their activities of daily living or health were not limited. Both Blake and Charlie respectively explained:

"I kind of liked my body image when I was feeling well, enough, to actually go

# out and have relationships."

"When my health was under control it [body image] was less of an issue for me, because I just felt more happy within myself."

Emmett and Finn reported satisfaction with their bodies prior to surgery, having held little value on body image as they both felt *"happy"* with their bodies appearances (respectively):

"It's not something I'd ever really thought about before, uh, my stoma operation."

"I personally never struggled with any body image issues. I was always pretty happy [...] It wasn't something that was at the forefront of my mind."

Whilst Daniel reported feeling unhappy with how he looked prior to stoma surgery, he reported wanting to return to *"the normal' that I was"* suggesting a preference or comfort towards his pre-stoma body.

### 1.2 The self in crisis

In the immediate period following stoma surgery, all participants described having negative or uncomfortable emotions and thoughts, describing their experiences akin to that of the early stages of grief. Aidan explained his feelings of loss and bargaining:

*"I felt like it's probably the end for me. It felt like nothing really matters anymore."* 

"Everything in the flood of my mind was just 'let things just go back, let things just go back and let me wake up.""

Participants described feeling overwhelmed and in denial following their stoma surgery. Whilst Blake's surgery was elective, seeing his stoma resulted in him questioning his own judgements. Blake recalled thinking *"Oh God, this is just- what have I got myself into?"* and having *"not regret but like, doubt"* following surgery.

Charlie and Finn described similar experiences of "*uncertainty*" regarding their future following surgery. Alongside these worries, both Aidan and Daniel reflected on how they isolated themselves by "*pushing*" people away, potentially to avoid coming to terms with their stoma. Daniel commented:

"I'd shut that many people out, I [...] went, 'Well, it doesn't matter if I look like crap, because at end of the day, nobody's gonna be seeing me."

Emmett and Finn shared how they avoided looking at themselves for days after their surgery. Emmett explained that seeing his body for the first time resulted in an adverse reaction, by having *"really bad thoughts"* of *"I hate the way that I looked"*. This denial of the stoma was explained by Finn: "Maybe I didn't want to come to terms with it? Or I didn't want to accept that it was real? Or I thought the longer that I didn't look at it [...] I could make up that it wasn't as big, as big of a thing in my head if I didn't look at it and it wasn't real [...] I remember just looking at the ceiling [...] because I didn't even wanna catch a glimpse

### of it."

This theme was categorised by experiences of shock, distress, avoidance, worry, and grief. However, this state is also characterised by its instability, with participants consciously developing strategies to try to cope with their stomas.

#### 1.3 The Integrated Self

Following this, participants described a process of self-development, often using the terms "maturation" and "acceptance". This acceptance was characterised by a balanced view of oneself, integrating both the positives and negatives perspectives they had of their body. Charlie reflected how he appreciated his stoma, that he felt "positively" about it once he "learned [...] this has saved my life". He later described this balanced viewpoint as "the pros outweigh the cons". Similarly, whilst Blake acknowledged the stoma's significance in his life, it had become a routine aspect of his daily reality:

"Stoma stuff for me now it's been, you know, life changing. But it's also incredibly boring [...] as you know, laundering your underwear and putting on a clean pair of socks on every day."

Finn also described gratitude towards his stoma, explaining that he *"never purposefully think[s] about the downsides of it*", acknowledging that ruminating on the negative aspects of the stoma is not beneficial. However, Finn acknowledged that whilst he accepted his stoma, he still felt *"conscious"* of it, particularly regarding how he was viewed by others, demonstrating this balanced perspective. Daniel explained that whilst he found the stoma distressing, he *"could make something good out of it"*,

displaying optimism and resilience. However, Daniel also reflected that he was not fully accepting of himself, as he was not *"all the way there",* particularly when it came to social situations where his stoma may be visible.

Both Aidan and Emmett compared their current body satisfaction with their prestoma body. Both mentioned how their sense of body image had improved since the immediate period following stoma surgery, but not to the same standard they held for their pre-stoma body. When asked how he felt about himself currently, Aidan explained,

> *"I would say better than when I was […], immediately after the surgery […] Though I'm still far, far away from being who I was before surgery."*

Additionally, both Emmett and Aidan respectively described that they were still in the process of accepting themselves by *"making an effort"* to improve their bodyimage.

### 1.4 The instability of self-perception

All participants reflected that how they viewed and perceived themselves fluctuated over time and context. Blake and Charlie explained, respectively:

"There were ups, downs [...] It's not one specific feeling." "It sorta' has chopped and changed over the years [...] I would say it got better as I got older".

Some participants reported that even when they felt more accepting of their body, they could still mourn for their pre-stoma body. Aidan explained:

"My mind, still flashes back to, [...] the good old days where, [...] I felt invincible."

Both Daniel and Finn shared that other people's reactions to their bodies could challenge their own opinions of themselves. Finn explained this feedback could prompt him to doubt his own judgement, thinking *"maybe I don't like how I look"*, but he

described this as being "*never more than a wobble*", highlighting that how he perceived himself was not immutable.

### 2. The separation of self and stoma

This theme was comprised of three subthemes, with participants indicating that they were experiencing a mind and body split.

### 2.1 Sudden loss of bodily autonomy

This subtheme was encompassed by accounts of losing control of one's body. Participants often described how they felt their illness or stoma had taken control over their self/mind. Many reported losing control over the function and/or appearance of their body because of their illness and stoma. Charlie explained:

*"I felt that I looked bad on the outside and I felt bad physically on the inside."* Half of the participants spoke about how their stoma was sudden and

unexpected, resulting from emergency surgery. Daniel shared:

"The surgeon was knocking on my door telling me, "You're having the surgery, because if not, you're gonna die within a week". So it was... I didn't have much time to come to terms with it, in my head? I had, literally had twenty-four hours."

These accounts reflect the sudden loss of control one can have over their health and body. Whilst Aidan and Blake did not require emergency surgery, they also described a loss of control and power over their mind/body in the immediate period following their surgery, respectively:

"My mind didn't actually belong to me anymore at that point because I felt like I was just off. I was completely off. Nothing."

"When you first have stoma surgery, you're an absolute amateur, [...] you're actually forced to look at it quite a lot and spend a lot of time in its company."

With Blake referring to himself as an "*amateur*", this implies that his stoma was the "master", or a potentially more powerful presence.

For both Emmett and Finn, their sudden decline in physical health challenged their previously held beliefs over their bodies. Finn explained how his illness prevented him from pursuing his desired activities:

"It was one of those things that now it was taken away from me".

These experiences again highlight the lack of bodily autonomy and choice participants had over their bodies.

### 2.2 The stoma as a threat

Most participants described their stoma as a separate, threatening entity, particularly in the immediate period leading up to and after surgery. Aidan shared his thoughts after seeing his stoma:

### "Oh no, this is not me".

### "This is something else. Something new... and negative."

Here, Aidan described a disconnect from his body and identity. Furthermore, by describing his stoma as "*something else*", he is alluding to the stoma feeling inhuman or alien. Additionally, the terms "*new*" and *"negative*", this implies the stoma to be an ominous, unknown entity.

Similarly, other participants indicated having disturbed reactions to their stomas, which impacted their relationship with it. Blake initially described his stoma as "*pretty gnarly*" and "*really grim*". Daniel described his stoma in a separate, detached, way, referring to it as "*this thing*", and his ileostomy bag was a "*disgusting pink* [...] bag of *crap hanging off you*", suggesting feelings of resentment and shame.

Finn explained that the appearance of his stoma was so significantly disturbing that it minimised his previous bodily insecurities:

*"I was worried about all these stretch marks, and this looks like somebody's just butchered my insides".* 

Emmett and Finn also described their experiences of feeling a strong aversion to needing a stoma. Emmett explained:

"When I got diagnosed with Crohn's, the first thing I wanted was "I don't want

the bag."

Finn had a similarly adverse response when he learned that he potentially needed stoma surgery:

"I remember coming home and saying to my parents, [...] 'If I get to that point like I'll probably kill myself.' And it, you know, it's not a funny joke to make. But [...] I did say it as a joke because I never thought it would get to that point."

These expressive accounts highlighted how participants not only had adverse reactions to seeing their stomas, but also had significantly perturbed reactions to the prospect of even needing stoma surgery.

# 2.3 The stoma as an ally

Contrastingly, most participants voiced that they later began to appreciate the benefits of their stoma. Daniel described that with time, he began to view his stoma more optimistically:

"It wasn't until [...] I'd had the time to mentally come to terms with it [...] that I started to really go, 'Actually, you know, at least I'm here. It could have been a hell of a

lot worse.""

For some, the stoma allowed participants to regain control of their physicality and health. Charlie reflected that he felt *"empowered"* by the new lease of life that was granted by the stoma:

"This [stoma] has saved my life, so that then fed into how I felt about my body because my body felt stronger and therefore I was happier with it."

Blake recalled feeling held back and controlled by his illness, and explained the advantages of his stoma:

"I have a sense of dualism, that I think about myself as different, not entirely the same thing as my body. Blake wants to do these things. Before, the body was holding me back. Now it's not, and I can just do whatever the hell I want now... and that's

### really freeing."

Here, Blake illustrated experiencing an initial split or incongruence between mind and body before surgery. Following surgery, he is no longer "*held back*" or trapped by his body, demonstrating integration of his mind and body. Finn also echoes this distinction between self and body, although this is more implicit. When Finn reflects how he appreciates and positively values his stoma, he states:

"I love it and I tell everyone that I love him."

During this statement, Finn uses two separate pronouns for his stoma, "*it*" and "*him*". This illustrated Finn's conflicted views of his stoma as both a part of himself, but also as a separate entity with its own individual identity and gender. However, he is connecting with this, viewing his stoma with "*love*".

### 3. The need for belonging

This theme was characterised by 3 subthemes, encompassing isolation, stigma and the desire for community.

#### 3.1 The experience of isolation

Participants had varying accounts of loneliness. Some participants struggled to give a detailed, verbal account of how they felt after stoma surgery. Aidan suggested that one can only experience what it is like to have a stoma, as it cannot be described linguistically:

"You know, you can't actually have the experience if it hasn't happened to you."

Many described isolating themselves whilst they adjusted to their stomas.

Participants often reflected on how they felt different from others in society due to their

stoma, and often felt the need to hide this part of themselves indicating a possible sense of shame. Charlie explained:

"I still have anxiety about like being visible in public [...] I guess there's still a level of anxiety around it being obvious to people that I have a stoma... If I've not chosen to tell them."

Participants' feelings of isolation continued even when they compared their stomas with others. Finn explained:

"I remember looking down and thinking this isn't, this isn't what any of them look like on anybody else."

It was apparent that these young men with stomas felt isolated within their own community, as there was lack of diversity in stoma representation, both in terms of age and gender. Daniel explained:

"I got presented a leaflet and I can tell you now there, there was not one person under the age of fifty in that leaflet [chuckles]."

"There's a lot of stuff out there for women to help them feel a bit more body confident. You know, they've got some lovely bikinis and underwear, but if you then go to, erm, the men's stuff, it looks a bit old [...] it's never attractive. [...] the general lack of stuff out there kind of doesn't help the body image stuff for a, for a younger person."

Participants had concerns of being viewed as different to who they were before their surgery. Blake voiced concerns that his romantic relationships would be limited or *"cut short"* by his stoma. Blake also used the phrase *"I wasn't like suddenly some weird, alien"* when talking about his family's reaction to his stoma. This statement could imply worries of rejection or isolation for being viewed as different, or *"alien"*.

# 3.2 The fear of stigma

Participants were concerned about being stigmatised due to their stoma. Blake described fear of stigma and rejection by new romantic partners:

"You meet someone, you go home, take your clothes off, and then they're like, 'Oh my God, what the fuck is that?' and leave."

Daniel also spoke of the rejection and stigma he experienced from potential romantic partners:

"I found people quite rude. You know, I'd often get, [...] "What's that?" And then you tell them and they just block you. [...] That was quite... quite damaging for body image. You know that-that kind of... Fuelled the thought of, if 'I showed somebody this, are they just gonna run for the hills?"

Participants described concerns of ostracisation, ridicule and shame from others. Emmett explained:

"I just didn't want like people like looking at it, questioning it and it's the reason why I've never gone swimming while I've had a stoma [...] I've just seen on the news a while ago that one person got kicked out of like a water park for having a stoma. So, I didn't want that same situation for me."

Participants reflected how their stoma was a physical marker of their health status, which could result in judgement, fear and scrutiny. Finn explained:

"Now that I have this thing, [...] physically stuck to me, that's like almost a sign of being unhealthy, I have to physically overcompensate for and prove that I am

healthy."

These accounts highlight the lack of knowledge of stomas in the wider community, leading to misinformation and perpetuating stigma.

# 3.3 Creating a supportive community

Participants described creating and nurturing their own communities. Having a self-made community aided participants' acceptance of themselves and stoma. Emmett shared:

"The main reason for accepting my body was definitely finding like the right support groups and talking to good people about it."

Both Emmett and Daniel valued peer-support, which promoted feelings of validation and inclusion. Daniel explained:

"Working with the younger males in-in the group and [...] sharing the feeling of, you know, they've got the same thoughts that I've got. I'm not alone in this."

For some, their community consisted of accepting, supportive friends and family members. This was essential in some participants' acceptance of their stoma. Aidan explained:

"I was completely in the dark. [...] I was in this... box, cage, where I was completely covered. I was locked up, not seeing anything. And you know, with support and help from my family, the box has been taken off and I can see the light, but I'm still

in the cage. [...] So the box is taken off, still in the cage, but I feel light."

This highlighted the significant impact of external acceptance on participants' individual acceptance of their stoma.

### 4. Contributors to self-acceptance

This theme consisted of 3 subthemes detailing how participants aided their journey of self-acceptance following their stoma surgery.

#### 4.1 Taking back control

Whilst participants had experienced varying degrees of loss of control and bodily autonomy due to their illness/stoma, they all attempted to reclaim this control, usually by modifying their bodies. Participants described how body modification (via exercise) was a way of reclaiming their control, bodily autonomy, and body image. Blake explained:

*"I can do whatever I want with it [my body] and push it further and further and further."* 

*"Becoming a bit more physically fit"* offered Charlie a way to lose weight gain resulting from steroid treatment prior to surgery. Blake, Daniel, and Finn shared that by modifying their bodies, they had more control over people's reactions to them poststoma surgery. Finn and Daniel explained:

"Everybody knew me as fat. So I thought, [...] if I can turn around and I haven't seen anyone in ages cause I've been ill and [...] I've lost loads of weight and I look really healthy... that-that all stemmed from hoping to take the, the attention away from the stoma."

*"If I was to gain more body muscle at the time […] it was a positive because people were looking elsewhere?"* 

Aidan and Emmett reflected that they modified their body to manage their feelings of distress following surgery. Both were keen to use exercise as an activity which would resolve their uncontrollable and overwhelming feelings. Additionally, both men had used fitness prior to surgery to improve or maintain their body image. They reflected that as fitness had been a positive part of their lives prior to surgery, this could partially relieve the psychological distress they were experiencing. Emmett shared:

*"I just wanted to like, like my body again. I thought doing routine exercises would be a fast track to me liking that."* 

Finally, Daniel described getting his first tattoo after his surgery, which had been "*inspired*" by the adversities he had overcome. Daniel explained:

"For my first tattoo, I think, there was the, the journey I'd been on as an inspiration for it [...] at that point I'd kind of gone, [...] 'This is me, take it or leave it."

This tattoo seems to mark his acceptance of his new self, demonstrating Daniel's purposeful reclamation of his body.

### 4.2 Increasing self-confidence

All participants shared that modifying their body increased their confidence in their appearance, capabilities, and skills. Body modification seemed to offer a sense of observable personal achievement, offering a positive distraction from distressing thoughts about one's stoma. Daniel explained:

"Seeing the development... that my body was going through during that time, it kind of erm, gave me the confidence that kind of detracted away from the bag." Aidan explained his motivations for fitness:

"Let me just keep myself busy instead of just thinking and wishing for crazy things that possibly won't happen. Why not just do something that can actually

happen? [...] It became something I looked forward to every day."

This reflected how fitness offered a physical and positive distraction from the discomfort that the participants experienced. Emmett added:

"I just felt good about myself for, like trying to improve my body and putting a lot of hard work into something. Erm... which then had [...] a payoff. It made me look good."

Additionally, body modification increased participants' confidence in their physical abilities. Charlie stated:

"It's improved how I feel about myself. Erm, and it's not, not necessarilynecessarily so much because I've lost weight. [...] It's made me feel stronger and fitter within my own body."

Some described body modification as a temporary aid, or "*catalyst*" in their journey of self-acceptance. As mentioned previously, community, peer-support, and acceptance from others had a significantly positive impact on participants' selfacceptance. However, participants added that they needed self-confidence to seek out these connections with others. Here, body modification had a significant role in increasing participants' confidence prior to initiating these connections, and reduced feelings of shame. Once this confidence had been achieved, and the community found, body modification was no longer as essential. Emmett explained:

"That [body modification] was the catalyst for... reaching out for help from people and I think if I hadn't, if I hadn't got my body to a state that I was confidence with- confident with it enough to ask people for help, [...] it'd be the exact same situation. I would just have a negative outlook and just praying that my reversal operation just happened."

Aidan added:

"When I started doing some exercises at home, I felt [...] the burden was being lifted off, you know, it, it was like a cloud for me over my mind and everything. I just locked everything up, but, um, when I started that, I felt a little bit of relief and I was seeing the lights come back ... and I started connecting with people again. [...] it gave me the relief."

For Finn, he reflected that whilst body modification had a generally positive impact on his confidence, he felt he had an intense awareness of his body and its appearance.

"[Body modification was] a double-edged sword [...] There are days where I feel a lot more confident in myself... and there are days that I feel a lot less confident in myself because it brought that sort of hypersensitivity towards what I looked like that I

### didn't have before."

However, this perceived "*hypersensitivity*" Finn had about his body may partially be a result of insecurities around his stoma, and the limited positive physical change body modification can have. Finn described feeling that no matter how much he altered his body, his stoma would be the first thing people would look at, resulting in some feelings of hopelessness.

### 4.3 Demystifying the stoma

Participant accounts revealed that having a greater understanding of their stoma, the surgery, and healing process facilitated a swifter and smoother adjustment. Blake and Charlie had a thorough understanding of their stomas prior to the surgery. Consequently, whilst they experienced worries and uncertainties, they were able to view the stoma objectively and factually. Blake explained how this aided his adjustment:

"It demystifies it slightly [...] I'm no doctor, but being able to take like, a kind of studious interest in your own stoma [helped]. It's not scary. It's just a piece of muscle."

For the other participants whose operations were sudden, this lack of preparation and knowledge of the stoma seemed to have more of a negative impact. This could lead to seeking reassurance from those who were more experienced. Finn explained:

"I was like 'Oh God, this is even, this is even worse than I thought it was gonna be' [...] I did go into a bit of a panic. Uh, and they [nurses] had to reassure me [...] that things would get better."

Most participants acknowledged the need for a wider, societal understanding of stomas. Many were keen for increased representation to demystify stomas and reduce their stigma. Charlie said:

"I think that representation [...] would be beneficial because ultimately [...] any sort of TV show, ninety-nine percent of people are able bodied and don't have a stoma or don't have any form of disability [...] if it changed, would make a huge difference to

### myself and other people with stomas."

When discussing stomas in the media, Daniel added:

"People are gonna know what it's like, and they're probably gonna be a bit more understanding about it. So that that helps, seeing it around more." These accounts highlighted the need for the increased promotion and representation of stomas in society, finding that this could promote further acceptance from others.

### Discussion

### **Overview of Findings**

This study aimed to explore young men's experiences of body image and body modification following stoma surgery. Four themes were developed: "the destabilisation of identity", "the separation of self and stoma", "the need for connection" and "contributors to self-acceptance". The themes included the various shifts in identity participants experienced post-surgery, as well as the altered relationship they had with their bodies. These results may fit with the concept of transitioning identity following stoma surgery as an ongoing *"journey"* or *"maturation"*. All participants experienced some degree of distress following their stoma surgery. However, the duration of this distress varied, potentially reflecting differences in the adjustment process.

Participants' prior knowledge and experiences of stomas seemed to impact their adjustment and self-acceptance. Blake and Charlie had either conducted extensive research or possessed prior experience with stomas. Although this knowledge did not entirely ready them for the stoma surgery experience, it likely contributed to a heightened sense of control. Specifically, these participants likely possessed greater understanding of the stoma and its recovery process compared to those without such background knowledge, which may have made psychological adjustment feel more manageable. Consequently, these individuals often exhibited greater acceptance and gratitude towards their stomas compared to those lacking similar knowledge or prior experience.

Other participants such as Daniel, Emmett and Finn had their stoma surgery in emergency circumstances and had little time to prepare or research stomas. Participants
with limited familiarity with stomas likely experienced diminished feelings of control, resulting in heightened distress following the surgery. Additionally, participants such as Emmett and Finn also felt negatively about the prospect of needing surgery. To manage this, many participants seemed to use defence mechanisms such as avoidance, denial, and dissociation. These transient defence mechanisms are believed to mitigate the intensity of the experience and consequently alleviate distress (Brennan 2001; Brennan 2018). Ultimately, all participants achieved some degree of acceptance of their stomas. However, individuals with limited knowledge or understanding of stoma surgery experienced notably higher levels of distress and required more time to adjust. This aligns with previous research indicating the beneficial effects of preoperative psychological preparation for stoma surgery (Clark et al., 2023).

Additionally, body modification could be viewed as an alternative-coping strategy, offering a distraction from the young men's new reality. The distraction provided them with time to adjust to their new body with a stoma, which may have helped in the short-term. Moreover, employing fitness for body modification purposes appeared to have a positive effect on participants' mental well-being. Many described how this fitness regime notably alleviated their distressing thoughts. The decrease in distress could be linked to their regained sense of bodily autonomy, particularly as they were able to physically witness their bodies changing under their control.

The experience of grief was also encapsulated in the results, through accounts of denial, bargaining, depression, and acceptance (Kubler-Ross & Kessler, 2005). Participants underwent a grieving period, grieving for both the loss of their previously "satisfactory" body, and loss of control over their bodily autonomy. Knowing this, body modification could be viewed as a therapeutic tool, echoing previous research findings on the positive impact of bereavement tattoos (Swann-Thomas et al., 2024). Additionally, our findings are in line with Foster's (2019) research, which proposed bodybuilding as a coping

mechanism or a positive distraction for individuals experiencing loss. However, it should be noted that the "losses" experienced in this study do not refer to literal deaths.

The participants' experiences of body modification shared some commonalities with unconscious phantasies posited by Lemma (2010). The theme of "separation of self and stoma" described the participants' disintegration of themselves from their body and stoma. When participants viewed their stoma as a "threat", they described it in detached, repulsed language indicating shame, including "this thing", "disgusting", and "something new and negative". Additionally, participants often feared stigma, or being "othered" by society. This could be akin to participants feeling "alien" or "foreign" due to their body and stoma. Participants may subsequently endeavour to "reclaim" their bodies from this "alien" presence (Lemma, 2010). This reclamation is encompassed through the theme "taking back control", where participants utilised body modification to regain control over their bodies' appearance and function. Additionally, the "perfect match" phantasy may also encompass ostomised young men's motivations for modification. The aims of this were to not only to create an "ideal body" for achieving secure acceptance from significant others, but also from their community and wider society. Here, participants described the experience of modifying their appearance to "*detract*" or distract society's attention away from their stoma. Whilst Lemma's perspective appears to align with some participants' accounts, the primary understanding of body modification was rooted in early attachment relationships. The current study did not focus on the impact of early experiences. However, given that major surgery heightens feelings of vulnerability (Sutton et al., 2024), it is plausible that infantile experiences of helplessness or dependence may have been evoked. Further research exploring body image and body modification across the life cycle is recommended. Furthermore, Lemma's (2010) research focused on skin-related body modifications, whereas most of the modifications in this study pertained to bodybuilding and fitness.

Notably, this study highlighted the intersectionality of marginalisation and isolation. This isolation was exacerbated by the prevailing representation of stomas in both healthcare settings and broader societal contexts. Participants expressed that the supportive materials they received exclusively featured older adults, which resulted in perceived misrepresentation. Moreover, participants experienced underrepresentation and insufficient support regarding gender, perceiving that women with stomas were prioritised in terms of access to stoma accessories and support aids. Additionally, there was a clear lack of representation and visibility in the wider societal context. Participants reported a general lack of representation of stomas in the media, emphasising the absence of younger adults with disabilities, including those with stomas.

Nevertheless, social media also had positive influences on the experiences of these young men. Participants commended individuals within the ostomy community who engaged with social media platforms. These individuals showcased their accomplishments and daily routines online whilst living with a stoma. Participants believed that their portrayal, which predominantly featured younger individuals with stomas, not only normalised the presence of stomas amongst young people, but also fostered a sense of community and belonging, whilst reducing shame.

### Strengths and limitations

Some participants were unfamiliar with the concept of body image, particularly when asked how they "viewed" or "felt" about their body's appearance. For some, this concept was too abstract, and required further prompting. Many participants struggled to separate their accounts of their physical feelings from their emotions, often reporting their experiences of pain before and after their stoma surgery. This may stem from the phrasing of the interview questions, which might have been tailored for an audience assumed to have some understanding of body image. However, the researcher was able to prompt

the participants to recall their thoughts and emotions, encouraging the participants to make sense of their experiences of their body following stoma surgery.

Another limitation was the narrow inclusion criteria. The objective of this study was to bridge the literature gap concerning younger men with stomas who had engaged in body modification. However, in the wider context of this research it may have been helpful to target a broader sample prior to this study. For example, either a broader age range of men with stomas who had engaged in body modification, or young adults (mixed gender) with stomas who had engaged in body modification. If these broader studies had been available, they could have enhanced the interpretation of this study's results by offering a more developed understanding of stomas. Nevertheless, the homogeneity in this study was still considered a strength and the sample size was deemed appropriate (Smith et al., 2021).

It became evident that despite the sample's rigorous homogeneity, participants had differing pathways which led to their stoma surgery. Specifically, a divergence emerged in the accounts of participants who underwent elective surgery versus those whose procedures were performed in emergency circumstances. Potentially, those who had elective surgery may have had a greater sense of control over their life and body, particularly when compared to those who had emergency surgery. Additionally, this study did not take into account participants' illness history or previous body modifications. However, these disparities facilitated the interpretative process of these young men's experiences, by providing diverse perspectives of adjustment, enabling a comprehensive development of interpretative themes.

Finally, the researcher's gender could have influenced the participants' willingness to disclose their accounts and experiences (Broom et al., 2009). These young men may have felt vulnerable discussing body experiences and their connections to masculinity with a female researcher. However, the researcher attempted to build rapport with the

participants prior to the interview, and attempted to have a non-judgemental, open, and curious regard. This was received positively by the participant sample, who ultimately seemed to feel comfortable to share their personal experiences with the researcher.

### Implications for Research and Clinical Practice

This study has several implications for further research. This study explored a gap in the existing literature by providing initial research in trying to understand body modification following stoma surgery. These results indicate that body modification served a positive function for the young men participating in the study. Here, body modification often facilitated participants adjustment to their stoma, promoting a sense of reclaimed control over their body. Furthermore, participants reported an increase in their confidence, with body modification acting as a "catalyst" in this regard. This resulting increase in confidence facilitated further positive coping strategies and support mechanisms, such as seeking peer support. However, body modification may not provide long-term benefits for individuals living with body image issues after stoma surgery. Notably, one participant reflected that although body modification was overall a positive experience, it heightened his awareness and perception of his body and appearance, which he found difficult. This participant could be describing an increased preoccupation or pursuit of body image and modification, as described by Lemma (2010). This could potentially be unhelpful in the long-term, as some research suggests that outcomes following body modification may not always be positive (Sarwer & Crerand, 2004). This information could advise pre- and postoperative care strategies for these young men, with healthcare providers utilising this to emphasise the importance of creating a sense of control and community for this client group. This could include conversations normalising the psychological process following stoma surgery, which could potentially reduce feelings of isolation and shame.

It is noteworthy that all participants utilised exercise/bodybuilding as a means of body modification. Whilst this study focused on bodybuilding as a method of body

modification, its use raises questions about the role of exercise in adjustment after stoma surgery. Existing research has already highlighted the positive impact of exercise on mental health (Schuch & Vancampfort, 2021). Further research on bodybuilding as both a form of body modification and exercise could provide further understanding of the psychological benefits of these physical activities.

This study may serve as a foundation for numerous other avenues of research. For example, exploring the role of body modification after stoma surgery with alternative forms of modifications, such as piercings and cosmetic surgery. Additionally, further research may explore those who experience a "pursuit" of body modification (Lemma, 2010). There is also a need for more longitudinal studies exploring stomas, body image and modification.

This study highlighted the need for representation and inclusion for this client group. Young men not only felt socially excluded due to their stoma, but due to their age and gender. This lack of representation was perceived both in the wider social context and stoma community. Knowing this, supportive materials offered to individuals with stomas (i.e. information leaflets, promotional posters) should aim for greater inclusivity, featuring ostomised individuals from diverse backgrounds. This includes diversity based on age, gender, ability, race, and culture. Moreover, advocating for the visibility of ostomised individuals within broader media platforms would address this underrepresented gap. This increased representation would not only promote a sense of recognition and visibility for individuals with stomas, but also could contribute to the destigmatisation and normalisation of their experiences.

Notably, the research highlighted men's experiences of body image following stoma surgery. These men often felt excluded in terms of body image support due to their gender. This may be due to the current research emphasis on female body dissatisfaction, leading to men's body dissatisfaction being underreported (Strother et al., 2012). Further

research is not only needed to expand on the literature of men's body image, but also the potential bias of clinicians supporting men with stomas. Findings from these studies could contribute to the development of more precise and beneficial support services for these young men.

### Conclusion

This study was the first of its kind, aiming to not only to explore how young men experience their bodies after stoma surgery, but also their experiences of body modification within this context. Results from this study highlighted the challenging experiences of these young men, including distress, stigmatisation, isolation, loss of bodily autonomy and changes in identity. Body modification was described as having a positive impact by restoring a sense of control and subsequently increasing confidence, potentially acting as a coping strategy. This increased confidence aided these young men in actively seeking connections with others, promoting a sense of acceptance within themselves and their community. However, body modification may only act as a temporary aid whilst these young men adjust and become accepting of their stoma. It is not known if there are any long-term benefits, or if some individuals could potentially become more preoccupied with their body and continue to pursue body modification. Participants had concerns of being misunderstood and stigmatised by others due to their stomas. This highlighted the necessity for increased promotion of stoma awareness within the broader societal context. Moreover, the existing portrayal of ostomised individuals lacks diversity, exacerbating the isolation experienced by those who do not conform to the conventional demographics of this group. Further research should investigate the role of body modification within a more expansive ostomised cohort, and understanding the factors that predispose individuals to body image distress or the pursuit of body modification. Furthermore, studies could further explore bodybuilding as both a mode of body modification and exercise post-stoma

surgery. This could provide valuable insights for optimising preoperative and postoperative care.

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# Part Three – Appendices

# Appendix A – Journal of Mental Health Submission Guidelines

## About the Journal

Journal of Mental Health is an international, peer-reviewed journal publishing high-quality, original research. Please see the journal's Aims & Scope for information about its focus and peer-review policy. Please note that this journal only publishes manuscripts in English.

Journal of Mental Health accepts the following types of articles:

- Original Articles; Research and Evaluation Articles
- Review articles
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Taylor & Francis is committed to peer-review integrity and upholding the highest standards of review. Once your paper has been assessed for suitability by the editor, it will then be single anonymous peer reviewed by two independent, anonymous experts. If you have shared an earlier version of your Author's Original Manuscript on a preprint server, please be aware that anonymity cannot be guaranteed. Further information on our preprints policy and citation requirements can be found on our Preprints Author Services page. Find out more about what to expect during peer review and read our guidance on publishing ethics.

# Preparing Your Paper

# Review articles

Should be written with the following elements in the following order: Title; Abstract (Background, Aims, Methods, Results, Conclusions); Keywords; Main text introduction; Materials and methods; Results; Discussion; Acknowledgments; Declaration of interest statement; References (in the correct format); Appendices (where appropriate - to be uploaded separately); Table(s) and caption(s) (on individual pages) - to be uploaded separately; Figures and figure captions (as a list) - to be uploaded separately. Should be no more than 6000 (excluding abstracts, tables, and references) words. Should contain an unstructured abstract of 200 words.

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### Appendix B – List of Excluded Studies

- Cardoso, D. B. R., Almeida, C. E., Santana, M. E., Carvalho, D. S. d., Sonobe, H. M., & Sawada, N. O. (2015). Sexuality of people with intestinal ostomy. *Northeast Network Nursing Journal*, *16*(4), 576-585.
- Cetolin, S. F., Beltrame, V., Cetolin, S. K., & Presta, A. A. (2013). Social and family dynamic with patients with definitive intestinal ostomy. *ABCD.Arquivos Brasileiros De Cirurgia Digestiva (São Paulo),* 26, 170-172.
- Gozuyesil, E., Taylan, S., Manav, A. I., & Akil, Y. (2017). The evaluation of self-esteem and sexual satisfaction of patients with bowel stoma in Turkey: Self-esteem sexual satisfaction in patients with bowel stoma. *Sexuality and Disability, 35*, 157-169.
- Hong, K. S., Oh, B., Kim, E., Chung, S. S., Kim, K. H., & Lee, R. (2014). Psychological attitude to self-appraisal of stoma patients: prospective observation of stoma duration effect to self-appraisal. *Annals of Surgical Treatment and Research*, *86*(3), 152.
- Manderson, L. (2005). Boundary breaches: the body, sex and sexuality after stoma surgery. *Social Science & Medicine*, *61*(2), 405-415.
- Medeiros Melo, M. D., Pereira da Silva, I., Silva de Oliveira, D. M., de Araújo Medeiros, A.
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  Persons. *Revista Mineira De Enfermagem, 22.*
- Melo, M. D. M., Queiroz, C. G., Freitas, L. S., Silva, I. P. d., Xavier, S. S. d. M., & Costa, I.
  K. F. (2019). Situational low self-esteem nursing diagnosis in people with an ostomy: a diagnostic accuracy study. *Revista Da Escola De Enfermagem Da USP, 53*, e03514.
- Mihalopoulos, N. G., Trunnell, E. P., Ball, K., & Moncur, C. (1994). The psychologic impact of ostomy surgery on persons 50 years of age and older. *Journal of Wound Ostomy & Continence Nursing*, 21(4), 149-155.

- Nasiriziba, F., Saati, M., & Haghani, H. (2020). Correlation between self-efficacy and selfesteem in patients with an intestinal stoma. *British Journal of Nursing, 29*(16), S22-S29.
- Purba, C. I. H., Ibrahim, K., & Rahayu, U. (2020). The Experiences of Rectal Cancer Survivors With Stomas In West Java Indonesia. *GSTF Journal of Nursing and Health Care (JNHC), 5*(1).
- Yuan, J. M., Zhang, J. E., Zheng, M. C., & Bu, X. Q. (2018). Stigma and its influencing factors among Chinese patients with stoma. *Psycho-oncology*, *27*(6), 1565-1571.

# Appendix C – Quality Assessment Checklist

Reference:

Major Components For Both Case-control and cross- sectional	Response options						
1. Was the sample frame appropriate to address the target population?	Yes (1)	No (0)	Unclear (0)	Not applicable (0)			
2. Were study participants sampled in an appropriate way?	Yes (1)	No (0)	Unclear (0)	Not applicable (0)			
3. Was the sample size adequate?	Yes (1)	No (0)	Unclear (0)	Not applicable (0)			
4. Were the study subjects and the setting described in detail?	Yes (1)	No (0)	Unclear (0)	Not applicable (0)			
5. Was the data analysis conducted with sufficient coverage of the identified sample?	Yes (1)	No (0)	Unclear (0)	Not applicable (0)			
6. Were valid methods used for the identification of the condition?	Yes (1)	No (0)	Unclear (0)	Not applicable (0)			
7. Was the outcome measured in a standard, reliable way for all participants (and controls, if case- control)	Yes (1)	No (0)	Unclear (0)	Not applicable (0)			
8. Was there appropriate statistical analysis?	Yes (1)	No (0)	Unclear (0)	Not applicable (0)			
9. Was the response rate adequate, and if not, was the low response rate managed appropriately?	Yes (1)	No (0)	Unclear (0)	Not applicable (0)			
<ol> <li>Was the outcome measured in a standard, reliable way for all participants (and controls, if case- control)</li> </ol>	Yes (1)	No (0)	Unclear (0)	Not applicable (0)			
For case-control only							
1. Were the groups comparable other than the presence of disease in cases or the absence of disease in controls?	Yes (1)	No (0)	Unclear (0)	Not applicable (0)			
2. Were cases and controls matched appropriately?	Yes (1)	No (0)	Unclear (0)	Not applicable (0)			
3. Were the same criteria used for identification of cases and controls?	Yes (1)	No (0)	Unclear (0)	Not applicable (0)			
4. Was the condition measured in the same way for cases and controls?	Yes (1)	No (0)	Unclear (0)	Not applicable (0)			
<ol><li>Were confounding factors identified?</li></ol>	Yes (1)	No (0)	Unclear (0)	Not applicable (0)			
6. Were strategies to deal with confounding factors stated?	Yes (1)	No (0)	Unclear (0)	Not applicable (0)			
Total Notes:							

# Appendix D – Data Extraction Form

Reference	
Main Aims	
Details of the	Tuno of sample:
Sample	Type of sample.
	Number of Participants:
	Stoma Details (Time since stoma, permanent or temporary):
Methodology	Design:
	Measures:
	Data collection method and time period:
	Analysis:
Main Findings	
Limitations	
Conclusions and	
Recommendations	
Quality Rating	

### Appendix E – SWiM Protocol

### Synthesis Without Meta-analysis (SWiM) reporting items

The citation for the Synthesis Without Meta-analysis explanation and elaboration article is: Campbell M, McKenzie JE, Sowden A, Katikireddi SV, Brennan SE, Ellis S, Hartmann-Boyce J, Ryan R, Shepperd S, Thomas J, Welch V, Thomson H. Synthesis without meta-analysis (SWiM) in systematic reviews: reporting guideline BMJ 2020;368:16890 <a href="http://dx.doi.org/10.1136/bmj.16890">http://dx.doi.org/10.1136/bmj.16890</a>

SWiM is intended to complement and be used as an extension to PRISMA									
SWiM reporting	Item description	Page in manuscript	Other*						
item		where item is reported							
Methods									
1 Grouping	1a) Provide a description of, and rationale for, the groups used in the synthesis (e.g., groupings of								
studies for	populations, interventions, outcomes, study design)								
synthesis									
	1b) Detail and provide rationale for any changes made subsequent to the protocol in the groups used								
	in the synthesis								
2 Describe the	Describe the standardised metric for each outcome. Explain why the metric(s) was chosen, and								
standardised	describe any methods used to transform the intervention effects, as reported in the study, to the								
metric and	standardised metric, citing any methodological guidance consulted								
transformation									
methods used									
3 Describe the	Describe and justify the methods used to synthesise the effects for each outcome when it was not								
synthesis	possible to undertake a meta-analysis of effect estimates								
methods									
4 Criteria used	Where applicable, provide the criteria used, with supporting justification, to select the particular								
to prioritise	studies, or a particular study, for the main synthesis or to draw conclusions from the synthesis (e.g.,								
results for	based on study design, risk of bias assessments, directness in relation to the review question)								
summary and									
synthesis									

# Synthesis Without Meta-analysis (SWiM) reporting items

SWiM reporting	Item description	Page in manuscript	Other*
item		where item is reported	
5 Investigation	State the method(s) used to examine heterogeneity in reported effects when it was not possible to		
of	undertake a meta-analysis of effect estimates and its extensions to investigate heterogeneity		
heterogeneity in			
reported effects			
6 Certainty of	Describe the methods used to assess certainty of the synthesis findings		
evidence			
7 Data	Describe the graphical and tabular methods used to present the effects (e.g., tables, forest plots,		
presentation	harvest plots).		
methods			
	Specify key study characteristics (e.g., study design, risk of bias) used to order the studies, in the text		
	and any tables or graphs, clearly referencing the studies included		
Results			
8 Reporting	For each comparison and outcome, provide a description of the synthesised findings, and the		
results	certainty of the findings. Describe the result in language that is consistent with the question the		
	synthesis addresses, and indicate which studies contribute to the synthesis		
Discussion			
9 Limitations of	Report the limitations of the synthesis methods used and/or the groupings used in the synthesis, and		
the synthesis	how these affect the conclusions that can be drawn in relation to the original review question		

PRISMA=Preferred Reporting Items for Systematic Reviews and Meta-Analyses.

\*If the information is not provided in the systematic review, give details of where this information is available (e.g., protocol, other published papers (provide citation details), or website (provide the URL)).

# Appendix F – Methodological Quality Scores

Article	1	2	3	4	5	6	7	8	9	10	11*	12*	13*	14*	15*	Total
Dias et al. (2019)	1	0	0	1	1	1	0	1	1	1	1	0	1	1	1	11
Kilic et al. (2007)	1	0	0	1	1	1	0	0	1	0	1	0	0	0	0	6
Saati et al. (2019)	1	0	1	1	1	1	0	1	1	0						7
Salome et al. (2014)	1	0	0	1	1	1	0	1	1	0						6
Kelman & Minkler. (1989)	1	0	0	1	1	1	0	1	0	1						6
Ferreira et al. (2017)	1	0	0	1	1	1	0	1	1	0						6
Total	6	0	1	6	6	6	0	5	5	2	2	0	1	1	1	

## Appendix G – Body Image Journal Submission Guidelines

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Methodological / protocol articles (articles that explicate an innovative research study design in which data are currently being collected)

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Scale development / adaptation articles (multi-study/sample articles that investigate the

psychometric properties of a newly developed or existing scale relevant to body image;

scale translations and applications to different samples are welcome)

Replication studies (consistent with Open Science initiatives, we encourage articles that replicate--or fail to replicate--existing body image research)

Theoretical review articles (typically invited; however, if you have an idea, propose it to the Editor-in-Chief)

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It is important that the file be saved in the native format of the word processor used. The text should be in single-column format. Keep the layout of the text as simple as possible. Most formatting codes will be removed and replaced on processing the article. In particular, do not use the word processor's options to justify text or to hyphenate words. However, do use bold face, italics, subscripts, superscripts etc. When preparing tables, if you are using a table grid, use only one grid for each individual table and not a grid for each row. If no grid is used, use tabs, not spaces, to align columns. The electronic text should be prepared in a way very similar to that of conventional manuscripts (see also the Guide to Publishing with Elsevier). Note that source files of figures, tables and text graphics will be required whether or not you embed your figures in the text. See also the section on Electronic artwork.

To avoid unnecessary errors you are strongly advised to use the 'spell-check' and 'grammar-check' functions of your word processor.

#### Article structure

#### Introduction

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State the objectives of the work and provide an adequate background, avoiding a detailed literature survey or a summary of the results.

#### Material and methods

Provide sufficient details to allow the work to be reproduced by an independent researcher. Methods that are already published should be summarized, and indicated by a reference. If quoting directly from a previously published method, use quotation marks and also cite the source. Any modifications to existing methods should also be described.

#### <u>Results</u>

Results should be clear and concise, describing the findings and their associated statistical basis. Consider the use of tables and figures for statistical details.

#### **Discussion**

This section should present the theoretical, empirical, and applied implications of the results, not simply repeat the findings. The study's limitations should be explicitly recognized. A combined Results and Discussion section may be appropriate.

#### **Conclusions**

The main conclusions of the study may be presented in a short Conclusions section, which may stand alone or form a subsection of a Discussion or Results and Discussion section.

#### <u>Appendices</u>

If there is more than one appendix, they should be identified as A, B, etc. Formulae and equations in appendices should be given separate numbering: Eq. (A.1), Eq. (A.2), etc.; in a subsequent appendix, Eq. (B.1) and so on. Similarly for tables and figures: Table A.1; Fig. A.1, etc.

#### Essential title page information

• Title. Concise and informative. Titles are often used in information-retrieval systems. Avoid abbreviations and formulae where possible.

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Author names and affiliations. Please clearly indicate the given name(s) and family name(s) of each author and check that all names are accurately spelled. You can add your name between parentheses in your own script behind the English transliteration. Present the authors' affiliation addresses (where the actual work was done) below the names. Indicate all affiliations with a lower-case superscript letter immediately after the author's name and in front of the appropriate address. Provide the full postal address of each affiliation, including the country name and, if available, the e-mail address of each author.
Corresponding author. Clearly indicate who will handle correspondence at all stages of refereeing and publication, also post-publication. This responsibility includes answering any future queries about Methodology and Materials. Ensure that the e-mail address is given and that contact details are kept up to date by the corresponding author.

• Present/permanent address. If an author has moved since the work described in the article was done, or was visiting at the time, a 'Present address' (or 'Permanent address') may be indicated as a footnote to that author's name. The address at which the author actually did the work must be retained as the main, affiliation address. Superscript Arabic numerals are used for such footnotes.

#### **Highlights**

Highlights are mandatory for this journal as they help increase the discoverability of your article via search engines. They consist of a short collection of bullet points that capture the novel results of your research as well as new methods that were used during the study (if any). Please have a look at the example Highlights.

Highlights should be submitted in a separate editable file in the online submission system. Please use 'Highlights' in the file name and include 3 to 5 bullet points (maximum 85 characters, including spaces, per bullet point).

#### <u>Abstract</u>

A concise and factual abstract is required. The abstract should state briefly the purpose of the research, the principal results and major conclusions. An abstract is often presented separately from the article, so it must be able to stand alone. For this reason, References should be avoided, but if essential, then cite the author(s) and year(s). Also, non-standard or uncommon abbreviations should be avoided, but if essential they must be defined at their first mention in the abstract itself.

The abstract should be between 150 and 200 words.

#### Graphical abstract

Although a graphical abstract is optional, its use is encouraged as it draws more attention to the online article. The graphical abstract should summarize the contents of the article in a concise, pictorial form designed to capture the attention of a wide readership. Graphical abstracts should be submitted as a separate file in the online submission system. Image size: Please provide an image with a minimum of 531 × 1328 pixels (h × w) or proportionally more. The image should be readable at a size of 5 × 13 cm using a regular screen resolution of 96 dpi. Preferred file types: TIFF, EPS, PDF or MS Office files. You can view Example Graphical Abstracts on our information site.

#### Keywords

Immediately after the abstract, provide a maximum of 6 keywords, using American spelling and avoiding general and plural terms and multiple concepts (avoid, for example, 'and', 'of'). Be sparing with abbreviations: only abbreviations firmly established in the field may be eligible. These keywords will be used for indexing purposes.

#### <u>Abbreviations</u>

For economy, consider using abbreviations or acronyms for key terms that appear often in the paper. Introduce the abbreviation parenthetically after the term's first mention in the paper. Ensure consistency of abbreviations throughout the paper. Such abbreviations that

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are unavoidable in the abstract must be defined at their first mention there, as well as in the footnote. Ensure consistency of abbreviations throughout the article.

#### <u>Acknowledgements</u>

Collate acknowledgements in a separate section at the end of the article before the references and do not, therefore, include them on the title page, as a footnote to the title or otherwise. List here those individuals who provided help during the research (e.g., providing language help, writing assistance or proof reading the article, etc.).

#### Formatting of funding sources

List funding sources in this standard way to facilitate compliance to funder's requirements: Funding: This work was supported by the National Institutes of Health [grant numbers xxxx, yyyy]; the Bill & Melinda Gates Foundation, Seattle, WA [grant number zzzz]; and the United States Institutes of Peace [grant number aaaa].

It is not necessary to include detailed descriptions on the program or type of grants and awards. When funding is from a block grant or other resources available to a university, college, or other research institution, submit the name of the institute or organization that provided the funding.

If no funding has been provided for the research, it is recommended to include the following sentence:

This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.

#### Math formulae

Please submit math equations as editable text and not as images. Present simple formulae in line with normal text where possible and use the solidus (/) instead of a horizontal line for small fractional terms, e.g., X/Y. In principle, variables are to be presented in italics. Powers of e are often more conveniently denoted by exp. Number

consecutively any equations that have to be displayed separately from the text (if referred to explicitly in the text).

#### **Footnotes**

Footnotes should be used sparingly. Number them consecutively throughout the article. Many word processors can build footnotes into the text, and this feature may be used. Otherwise, please indicate the position of footnotes in the text and list the footnotes themselves separately at the end of the article. Do not include footnotes in the Reference list.

#### <u>Artwork</u>

Electronic artwork

#### General points

- Make sure you use uniform lettering and sizing of your original artwork.
- Embed the used fonts if the application provides that option.
- Aim to use the following fonts in your illustrations: Arial, Courier, Times New Roman,

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- Number the illustrations according to their sequence in the text.
- Use a logical naming convention for your artwork files.
- Provide captions to illustrations separately.
- Size the illustrations close to the desired dimensions of the published version.
- Submit each illustration as a separate file.
- Ensure that color images are accessible to all, including those with impaired color vision.

A detailed guide on electronic artwork is available.

You are urged to visit this site; some excerpts from the detailed information are given here.

#### Formats

If your electronic artwork is created in a Microsoft Office application (Word, PowerPoint, Excel) then please supply 'as is' in the native document format.

Regardless of the application used other than Microsoft Office, when your electronic artwork is finalized, please 'Save as' or convert the images to one of the following formats (note the resolution requirements for line drawings, halftones, and line/halftone combinations given below):

EPS (or PDF): Vector drawings, embed all used fonts.

TIFF (or JPEG): Color or grayscale photographs (halftones), keep to a minimum of 300 dpi.

TIFF (or JPEG): Bitmapped (pure black & white pixels) line drawings, keep to a minimum of 1000 dpi.

TIFF (or JPEG): Combinations bitmapped line/half-tone (color or grayscale), keep to a minimum of 500 dpi.

Please do not:

• Supply files that are optimized for screen use (e.g., GIF, BMP, PICT, WPG); these typically have a low number of pixels and limited set of colors;

Supply files that are too low in resolution;

• Submit graphics that are disproportionately large for the content.

#### **Formats**

Regardless of the application used, when your electronic artwork is finalised, please "save as" or convert the images to one of the following formats (Note the resolution requirements for line drawings, halftones, and line/halftone combinations given below.):

EPS: Vector drawings. Embed the font or save the text as "graphics".

TIFF: Colour or greyscale photographs (halftones): always use a minimum of 300 dpi. For colour images always use RGB.

TIFF: Bitmapped line drawings: use a minimum of 1000 dpi.

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TIFF: Combinations bitmapped line/half-tone (colour or greyscale): a minimum of 500 dpi is required.

DOC, XLS or PPT: If your electronic artwork is created in any of these Microsoft Office applications please supply "as is".

Please do not:

• Supply embedded graphics in your wordprocessor (spreadsheet, presentation) document;

• Supply files that are optimised for screen use (like GIF, BMP, PICT, WPG); the resolution is too low;

· Supply files that are too low in resolution;

• Submit graphics that are disproportionately large for the content.

#### Color artwork

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Ensure that each illustration has a caption. Supply captions separately, not attached to the figure. A caption should comprise a brief title (not on the figure itself) and a description of the illustration. Keep text in the illustrations themselves to a minimum but explain all symbols and abbreviations used.

#### <u>Tables</u>

Please submit tables as editable text and not as images. Tables can be placed either next to the relevant text in the article, or on separate page(s) at the end. Number tables consecutively in accordance with their appearance in the text and place any table notes below the table body. Be sparing in the use of tables and ensure that the data presented in them do not duplicate results described elsewhere in the article. Please avoid using vertical rules and shading in table cells.

#### <u>References</u>

#### Citation in text

Please ensure that every reference cited in the text is also present in the reference list (and vice versa). Personal communications may be cited (with exact date) in the text but are not included in the reference list. Unpublished studies or papers may be cited but must include a date (year) and follow APA style. Citing reference as "in press" indicates that the work has been accepted for publication."

#### Data references

This journal encourages you to cite underlying or relevant datasets in your manuscript by citing them in your text and including a data reference in your Reference List. Data references should include the following elements: author name(s), dataset title, data repository, version (where available), year, and global persistent identifier. Add [dataset] immediately before the reference so we can properly identify it as a data reference. The [dataset] identifier will not appear in your published article.

#### Preprint references

Where a preprint has subsequently become available as a peer-reviewed publication, the formal publication should be used as the reference. If there are preprints that are central to your work or that cover crucial developments in the topic, but are not yet formally published, these may be referenced. Preprints should be clearly marked as such, for

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example by including the word preprint, or the name of the preprint server, as part of the reference. The preprint DOI should also be provided.

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Please ensure that the words 'this issue' are added to any references in the list (and any citations in the text) to other articles in the same Special Issue.

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#### Reference style

Text: Citations in the text should follow the referencing style used by the American Psychological Association. You are referred to the Publication Manual of the American Psychological Association, Seventh Edition, ISBN 978-1-4338-3215-4, copies of which may be ordered online.

List: references should be arranged first alphabetically and then further sorted chronologically if necessary. More than one reference from the same author(s) in the same year must be identified by the letters 'a', 'b', 'c', etc., placed after the year of publication. <u>Video</u>

Elsevier accepts video material and animation sequences to support and enhance your scientific research. Authors who have video or animation files that they wish to submit with their article are strongly encouraged to include links to these within the body of the article. This can be done in the same way as a figure or table by referring to the video or animation content and noting in the body text where it should be placed. All submitted files should be properly labeled so that they directly relate to the video file's content. In order to ensure that your video or animation material is directly usable, please provide the file in one of our recommended file formats with a preferred maximum size of 150 MB per file, 1 GB in total. Video and animation files supplied will be published online in the electronic version of your article in Elsevier Web products, including ScienceDirect. Please supply 'stills' with your files: you can choose any frame from the video or animation or make a separate image. These will be used instead of standard icons and will personalize the link to your video data. For more detailed instructions please visit our video instruction pages. Note: since video and animation cannot be embedded in the print version of the journal, please provide text for both the electronic and the print version for the portions of the article that refer to this content.

#### Supplementary material

Supplementary material such as applications, images and sound clips, can be published with your article to enhance it. Submitted supplementary items are published exactly as they are received (Excel or PowerPoint files will appear as such online). Please submit your material together with the article and supply a concise, descriptive caption for each supplementary file. If you wish to make changes to supplementary material during any stage of the process, please make sure to provide an updated file. Do not annotate any corrections on a previous version. Please switch off the 'Track Changes' option in Microsoft Office files as these will appear in the published version.

#### Research data

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This journal requires and enables you to share data that supports your research publication where appropriate, and enables you to interlink the data with your published articles. Research data refers to the results of observations or experimentation that validate research findings, which may also include software, code, models, algorithms, protocols, methods and other useful materials related to the project.

Below are a number of ways in which you can associate data with your article or make a statement about the availability of your data when submitting your manuscript. When sharing data in one of these ways, you are expected to cite the data in your manuscript and reference list. Please refer to the "References" section for more information about data citation. For more information on depositing, sharing and using research data and other relevant research materials, visit the research data page.

#### Data linking

If you have made your research data available in a data repository, you can link your article directly to the dataset. Elsevier collaborates with a number of repositories to link articles on ScienceDirect with relevant repositories, giving readers access to underlying data that gives them a better understanding of the research described.

There are different ways to link your datasets to your article. When available, you can directly link your dataset to your article by providing the relevant information in the submission system. For more information, visit the database linking page.

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In addition, you can link to relevant data or entities through identifiers within the text of your manuscript, using the following format: Database: xxxx (e.g., TAIR: AT1G01020; CCDC: 734053; PDB: 1XFN).

#### Research Elements

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This journal enables you to publish research objects related to your original research – such as data, methods, protocols, software and hardware – as an additional paper in a Research Elements journal.

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During submission, you will be alerted to the opportunity to prepare and submit a manuscript to one of the Research Elements journals.

More information can be found on the Research Elements page.

#### Data statement

To foster transparency, we encourage you to state the availability of your data in your submission. This may be a requirement of your funding body or institution. If your data is unavailable to access or unsuitable to post, you will have the opportunity to indicate why during the submission process, for example by stating that the research data is confidential. The statement will appear with your published article on ScienceDirect. For more information, visit the Data Statement page.

# Appendix H – Confirmation of Ethical Approval with Amendment



University of Hull Hull, HU6 7RX United Kingdom T: +44 (0)1482 463336 | E: Maureen.Twiddy@hyms.ac.uk w: www.hull.ac.uk

PRIVATE AND CONFIDENTIAL Megan Heaver Faculty of Health Sciences University of Hull Via email

Tuesday 30<sup>th</sup> May 2023

Dear Megan,

#### FHS 22-23.71 – Young men with stomas: understanding body image and body modification.

Thank you for your responses to the points raised by the Faculty of Health Sciences Research Ethics Committee.

Given the information you have provided I confirm approval by Chair's action.

Please refer to the <u>Research Ethics Committee</u> web page for reporting requirements in the event of any amendments to your study.

Should an Adverse Event need to be reported, please complete the <u>Adverse Event Form</u> and send it to the Research Ethics Committee <u>FHS-ethicssubmissions@hull.ac.uk</u> within 15 days of the Chief Investigator becoming aware of the event.

I wish you every success with your study.

Yours sincerely

MaureanInddy

Dr Maureen Twiddy Chair, FHS Research Ethics Committee



Maureen Twiddy | Senior Lecturer in Applied Health Research Methods | Faculty of Health Sciences University of Hull Hull, HUG 7RX, UK www.hull.ac.uk Maureen.Twiddy@hyms.ac.uk| 01482 463336

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University of Hull Hull, HUG 7RX United Kingdom T: +44 (0)1482 463336 | E: Maureen.Twiddy@hyms.ac.uk w: www.hull.ac.uk

#### PRIVATE AND CONFIDENTIAL Megan Heaver Faculty of Health Sciences University of Hull Via email

Thursday 19th October 2023

Dear Megan,

#### REF FHS 22-23.71 - Young men with stomas: understanding body image and body modification

Thank you for your notice of amendment. Given the information you have provided I confirm approval by Chair's action.

The approval is valid until 19<sup>th</sup> September 2024. If you require an extension to this end date or you need to report any further amendments to your study please complete Form C which can be found at Research Ethics (sharepoint.com) for staff and Student Research Ethics (sharepoint.com) for students.

Should an Adverse Event need to be reported, please complete the Adverse Event Form and send it to the Research Ethics Committee FHS-ethicssubmissions@hull.ac.uk within 15 days of the Chief Investigator becoming aware of the event.

I wish you every success with your study.

Yours sincerely

Curtifierd

Dr Clare Whitfield Deputy Chair, FHS Research Ethics Committee



Clare Whitfield RN PGCE FHEA Lecturer | Faculty of Health Sciences Module Lead: MSc Dissertations Programme Director: MSc Leadership Pathways (Legacy) University of Hull, Hull, HUG 7RX, UK <u>www.hull.ac.uk</u> c.whitfield@hull.ac.uk | 01482 463222 | Dearne 104 @UniOfHull /UniversityOfHull universityofhull



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# Appendix I – Consent Form with Demographic Questionnaire

Version number and date: Version 4 17/10/2023

# CONSENT FORM

Title of study: Young men with stomas: understanding body image and body modification.

Name of Researcher: Megan Heaver

- 1. I confirm that I have read the information sheet dated 17/10/2023 version 4 for the above study, and I meet the stated requirements to take part in this study. I have had the opportunity to consider the information, ask questions and have had any questions answered satisfactorily.
- 2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected. I understand that once I have completed my interview, I cannot withdraw my anonymised data after 2 weeks of it taking place. I understand that the data I have provided up to the point of withdrawal will be retained. I understand that my anonymised verbatim quotes may be used in research reports and conference presentations.
- 3. I understand that the research data, which will be anonymised (not linked to me), will be retained by the researchers and may be shared with others and publicly disseminated to support other research in the future.
- 4. I understand that my personal data will be kept securely in accordance with data protection guidelines, and will only be available to the immediate research team. I am aware the entirety of my interview will be electronically audio and video recorded on an encrypted laptop, and the call will be recorded via MS Teams to allow for automatic transcription.
- 5. I give permission for the collection and use of my data to answer the research question in this study.

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6. I agree to take part in the above study.

Please answer the following questions for demographic purposes and to confirm participant suitability:

- a) What is your current age?
- b) What type of stoma do you have? For example, colostomy, ileostomy, urostomy
- c) Why did you need stoma surgery? For example, due to health condition?
- d) What age were you when you had your stoma surgery?

Name of Participant	Date	Signature
Name of Person	Date	Signature
taking consent		

# Appendix J – Recruitment Email

# Participant Recruitment email

# Hello,

My name is Megan, and I am a Trainee Clinical Psychologist based at the University of Hull. I am getting in touch as you may be able to take part in my research project which forms part of my doctorate thesis research.

I have attached an information form which contains more details about this research. Should you wish to take part in this study, I have also attached a consent form for you to sign and return (a typed signature or photograph of the completed form is fine). If you have any more questions, please let me know and I will do my best to get back to you as soon as I can.

Best wishes, Megan Heaver Trainee Clinical Psychologist

Organisational Recruitment Email

Hello,

My name is Megan, and I am a Trainee Clinical Psychologist based at the University of Hull. I am getting in touch as you may be able to take help me with recruitment for my research project. This forms part of my doctorate thesis research.

We are undertaking Clinical Psychology research which aims to understand young men's body image after having a stoma and their experience of making changes to their body or appearance. This could be through tattoos, piercings, cosmetic surgery or Bodybuilding/building muscle mass.

It is hoped that the results will be helpful in improving pre and post-operative care and provide the best possible service to young men in the future.

I am aware of your role in *organisation/support group,* and I would really appreciate if you could distribute my research poster to aid recruitment. I have attached an information form

which contains more details about this research. If you have any more questions, please let me know and I will do my best to get back to you as soon as I can.

Many thanks, Megan Heaver Trainee Clinical Psychologist

#### Appendix K – Recruitment Poster

# ARE YOU A YOUNG MAN WITH A STOMA?

HAVE YOU TRIED TO CHANGE YOUR APPEARANCE AFTER HAVING A STOMA?

We are undertaking Clinical Psychology research which aims to understand young men's body image after having a stoma and their experience of making changes to their body or appearance. This could be through tattoos, piercings, cosmetic surgery or body building/building muscle mass.

It is hoped that the results will be helpful in improving pre and post-operative care and provide the best possible service to young men in the future.

We are inviting **cis-gendered men\* aged between 18 and 29 years** to take part in an interview to gain some initial information. Your involvement is greatly appreciated and your answers will be kept confidential.

If you have any questions or would like further information, please contact: Megan Heaver (Trainee Clinical Psychologist) - M.H.Palmer-2021@hull.ac.uk Dr Lesley Gibson (Clinical Psychologist) - Lesley-Ann.Gibson@hull.ac.uk Or visit https://forms.office.com/e/Us4z4Re9Pm to be contacted by the research team

\*cis-gendered men are men who were assigned male at birth and identify as male

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SCAN ME

to help out

Appendix L – Online Interest Form

# Research study: Young men with stomas: understanding body image and body modification

We are undertaking Clinical Psychology research which aims to understand young men's body image after having a stoma and their experience of making changes to their body or appearance. It is hoped that the results will be helpful in improving pre and post-operative care and provide the best possible service to young men in the future.

We are inviting cis-gendered men\* aged between 18 and 29 years to take part in a brief survey to gain some initial information. Your involvement is greatly appreciated and your answers will be kept confidential.

The last question asks if you might be interested in taking part in the research study. Although we very much hope that you will be willing to help us, we would like to stress that you are under no obligation to take part.

Your involvement is greatly appreciated.

If you have any questions or would like further information, please contact

Megan Heaver (Trainee Clinical Psychologist) M.H.Palmer-2021@hull.ac.uk

Dr Lesley Gibson (Clinical Psychologist) Lesley-Ann.Gibson@hull.ac.uk

\*cis-aendered men are men who were assianed male at birth and identify as male

- 1. After having a stoma have you noticed any change in how you feel about your body or your appearance?
  - YesNo
  - Not sure

2.	Have you	tried	to c	hange	your	body of	or	appearance	since	after	having
	a stoma?										

◯ Yes	
O No	
O Not sure	

3. If you have answered yes to question 2, please tell us what kinds of changes you have made to your body or appearance:

Tattoo(s)	
Piercing(s)	
Scarification(s)	
Cosmetic surgery or other cosmetic procedure	
Body building/building muscle mass	
Other	

4. If you have any further information regarding any changes you have made to your body or appearance, please type here:

5. Would you be interested in taking part in the research study? (This involves attending an online interview to further discuss your experiences in relation to body image and body modification.)

$\bigcirc$	Yes
$\bigcirc$	No
$\bigcirc$	Maybe

6. If you answered yes or maybe to question 5, please provide your contact details below.

Name and email address:

This content is neither created nor endorsed by Microsoft. The data you submit will be sent to the form owner.

📑 Microsoft Forms

# Appendix M – Information Sheet

Version Number 4 17/10/2023

# Image: Construction Number Wersion Number UNIVERSITY OF HULL INFORMATION SHEET FOR PARTICIPANTS

# YOU WILL BE GIVEN A COPY OF THIS INFORMATION SHEET

# Title of study

# Young men with stomas: understanding body image and body modification.

I would like to invite you to participate in a research project which forms part of my doctorate thesis research. The sponsor for this research is the University of Hull. Before you decide whether you want to take part, it is important for you to understand why the research is being done and what your participation will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please ask me if there is anything that is not clear or if you would like more information.

# What is the purpose of the study?

The purpose of the study is to understand how young men view and feel about their body after having a stoma and undergoing body modification. The body can be modified or changed through having tattoos, piercings, scarification, cosmetic surgery, Bodybuilding or building muscle mass. No research to date has explored men's experience of this, for example, whether there are helpful or unhelpful aspects to body modification and if it changes how men feel about themselves and their bodies. It is hoped that the results will be helpful in improving the future care of young men living with a stoma.

# Why have I been invited to take part?

You have been invited to participate in this study because you are a young (18-30 years old) cis-gendered male (identify as male and was assigned male at birth) who had permanent stoma surgery at least six months ago. You must have had your surgery between the ages of 17-29 years old. You have also engaged in some form of body modification since having stoma surgery. This includes (but is not limited to): piercings, tattoos, cosmetic surgeries, scarification Bodybuilding (or purposefully engaging in fitness with the goal to alter the body's appearance.)

# What will happen if I take part?

If would like to take part, please send your contact details to the researcher's email address below. You will then be asked to complete and return a consent form, and arrange a suitable time to attend an online interview. In the online interview, you will be asked to provide some brief demographic information (your current age, the type of stoma you have, the age you were when you had your stoma surgery and why you needed a stoma). There will then be some further questions to explore how you feel about your body's appearance and your body modification. The interview will last approximately 60 minutes. Participation will take place via Microsoft Teams on a mutually agreed date and time between May-December 2023. During the interview, you will be asked about your experiences with your stoma, and how you feel about yourself and appearance. As part of participation your interview will be audio recorded and later transcribed and anonymised. After this transcription has taken place, all recordings will be permanently deleted.

# Do I have to take part?

Participation is completely voluntary. You should only take part if you want to and choosing not to take part will not disadvantage you in any way. Once you have read the information sheet, please contact us if you have any questions that will help you make a decision about taking part. If you decide to take part, we will ask you to sign a consent form and you will be given a copy of this consent form to keep.

# What are the possible risks or disadvantages of taking part?

Participating in this study will require some of your time. However, we will ensure that the interview can take place at a time/date which is suitable for you.

The study involves talking about how you view and feel about your body in relation to your stoma and body modification. There is a possibility that you might find these topics distressing.

You will be offered support if this happens, for example we can pause the interview at any point and you will be given some written information about services you can access after the interview.

You will also be able to withdraw from the study up to 2 weeks after completing the interview.

# What are the possible benefits of taking part?

Although there is no direct benefit from participating, taking part in the study will allow you to discuss your thoughts, feelings and experiences and to be listened to. You are also provided with some information about services and organisations that are available to support you after the interview. It is hoped that the findings from this study may help to improve pre- and post-operative care for future young men living with stomas.

# How will we use information about you?

We will keep all information about you safe and secure. Information will be kept confidential and will be stored on a secure device (NHS encrypted laptop). Files will be kept in a password protected folder. Contact information will be stored on a separate password protected document to the interview recordings. You will be able to withdraw from the study up until 2 weeks after your interview. After this point the data will be anonymised and retained for analysis. Anonymisation will include alteration of names, and removal of identifiable information.

Once we have finished the study, we will keep some of the data so we can check the results. You will not be identifiable in any reports or papers.

Your data will be processed in accordance with the UK-GDPR and the Data Protection Act 2018.

# What are your choices about how your information is used?

You are free withdraw up until 2 weeks after your interview without having to give a reason.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

# Where can you find out more about how your information is used?

You can find out more about how we use your information:

- By asking one of the research team
- By contacting the University of Hull Data Protection Officer by emailing <u>dataprotection@hull.ac.uk</u> or by calling 01482 466594 or by writing to the Data Protection Officer at University of Hull, Cottingham Road, Hull, HU6 7RX
- By reviewing the University of Hull Research Participant privacy notice: <u>https://www.hull.ac.uk/choose-hull/university-and-region/key-</u> <u>documents/docs/quality/research-participant-privacy-notice.pdf</u>

# **Data Protection Statement**

The data controller for this project will be the University of Hull. The University will process your personal data for the purpose of the research outlined above. The legal basis for processing your personal data for research purposes under GDPR is a 'task in the public interest'

If you are not happy with the sponsor's response or believe the sponsor processing your data in a way that is not right or lawful, you can complain to the Information Commissioner's Office (ICO) (<u>www.ico.org.uk</u> or 0303 123 1113).

# What will happen to the results of the study?

The results of the study will be summarised as part of a written thesis as part of a Doctorate in Clinical Psychology. This will also be submitted for publication in a scientific journal. A report regarding the findings from this study will also be made available to the participants should you wish for this to be made available. The thesis will be available on the University of Hull's on-line repository https://hydra.hull.ac.uk.

# Who has reviewed this study?

Research studies are reviewed by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and been given a favourable opinion by The Faculty of Health Sciences Ethics Committee, University of Hull.

# What if I have further questions, or if something goes wrong?

If you wish to make a complaint about the conduct of the study, you can contact the University of Hull using the details below for further advice and information:

Researcher: Megan Heaver (Trainee Clinical Psychologist): m.h.palmer-2021@hull.ac.uk Supervisor: Dr Lesley Gibson (Clinical Psychologist) <u>Lesley-Ann.Gibson@hull.ac.uk</u>

# **Further information**

If you have any questions or require more information about this study, please contact me using the following contact details:

# Megan Heaver

Clinical Psychology Aire Building The University of Hull Cottingham Road Hull HU6 7RX Tel: 07511597864 E-mail: M.H.Palmer-2021@hull.ac.uk

If you wish to make a complaint about the study, you can contact the University of Hull using the research supervisor's details below for further advice and information:

# **Dr Lesley Gibson**

Clinical Psychology Aire Building The University of Hull Cottingham Road Hull HU6 7RX Email address: <u>Lesley-Ann.Gibson@hull.ac.uk</u>

Thank you for reading this information sheet and for considering taking part in this research

## Appendix N – IPA Interview Schedule

#### Interview Schedule

#### IPA questions

I am now going to ask you some questions about how you view and feel about your body. I am curious about how you feel or felt about the appearance of your body, rather than the medical/physical aspect. Does that make sense?

1. Can you tell me about how you viewed and felt about your body before having stoma surgery?

Prompt: I am wondering about how you felt about your body overall?

What were your thoughts and feelings at the time?

Can you remember a specific occasion when you felt or thought that?

I am interested in how important your body image is to you?

Did you spend any amount of time or have thoughts on maintaining or improving

your appearance?

Has that changed at all over time?

2. Can you tell me about how you viewed and felt about your body's appearance in the first few weeks after having your stoma surgery?

Prompt: Could you explain a little more?

How did that feel?

I'm interested in your initial reaction/thoughts/feelings over the first few weeks. What

thoughts and feelings did you have?

What was going on in your mind at the time?

3. Can you tell me about how you have tried to modify or change your body's appearance

after having a stoma and your reasons for doing this?

Prompt: For example, having a tattoo, Bodybuilding?

What were your hopes?

Have these body modifications changed how you think and feel about yourself?

Can you think of an example?

How do you feel about how you look now?

4. Can you tell me about anything else that has helped or supported you with how you

view and feel about your body's appearance?

Prompt: This might be support from others, information, body modification?

Can you think of anything that might have helped?

What might help you now?

# Appendix O – Sources of Support Handout

#### Sources of Support

If you would like to access some support after this interview, you may choose to make an

appointment with your GP who can help you access local services and support.

If you need urgent support the NHS has a tool to find your local crisis line:

https://www.nhs.uk/service-search/mental-health/find-an-urgent-mental-health helpline

You may also find the information below helpful:

Stoma-related charities:

## Crohn's & Colitis UK

Information or support: Call 0300 222 5700 (Monday-Friday: 9am-5pm)

Email: helpline@crohnsandcolitis.org.uk

Website (Includes LiveChat): https://crohnsandcolitis.org.uk/info-support/support-for-

you/helpline-service

#### **Colostomy UK**

24-hour free helpline for practical and emotional support: 0800 328 4257

Email: hello@colostomyuk.org

Website (Includes LiveChat): https://www.colostomyuk.org/support/

#### **Ileostomy & Internal Pouch Association**

Phone 0800 0184 724.

Website: https://iasupport.org/information-support/i-want-to-speak-to-someone/

#### **Urostomy Association**

Helpline: 01386 430140

Website: https://urostomyassociation.org.uk/about/local-branches/

#### **General Support Charities**

#### Samaritans

Provides confidential, non-judgmental emotional support for people experiencing feelings

of distress or despair, including those that could lead to suicide. You can phone, email,

write a letter or in most cases talk to someone face to face.

24-hour helpline: 116 123

Email: jo@samaritans.org

Website: https://www.samaritans.org/

#### Hub of Hope

The Hub of Hope is the UK's leading mental health support database. It is provided by

national mental health charity, Chasing the Stigma, and brings local, national, peer,

community, charity, private and NHS mental health support and services together in one

place for the first time.

Website: https://hubofhope.co.uk/

#### Mind

Mind provides confidential mental health information services.

With support and understanding, Mind enables people to make informed choices. The Infoline gives information on types of mental health problems, where to get help, drug treatments, alternative therapies, and advocacy. Mind works in partnership with around

140 local Minds providing local mental health services.

www.mind.org.uk/information-support/helplines

Tele: 0300 123 3393 (9am-6pm Monday to Friday)

Text: 86463

Email: info@mind.org.uk

Thank you for taking part in this research.

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# Appendix P – Example of Data Analysis

Transcript (R= Researcher, P=	Descriptive codes	Interpretative codes
Participant)		
R: What was it like to kind of see		
yourself for the first time or the first		
few times?		
P: I… I know I really struggled the	Denial? Avoided	Avoidance of
first couple of days. Erm, it actually	looking at new self.	accepting reality.
took me three or four days to look at		
it. [The] nurses were very conscious		
that I should look at it, cause they	Lack of power of	
wouldn't send me home until I	self/choices? Others	Loss of bodily
learned to maintain it and change it	with more knowledge	autonomy due to
myself, obviously. In the first couple	choose when he can	stoma.
of days, I'd have to ask them to	go home?	
come in and, and sort of, do the	Reliance on others,	
stuff for me because I… I didn't want	loss of independence.	
to look at it. I didn't, I didn't know		
what it was gonna look like. Erm,		Stoma is as a
and I don't think I'm- I don't think I	Didn't want stoma	fearful, threatening
wanted to see it. I was- it is probably	even in theory.	concept.
worth saying I was really against the		
idea of stoma. When I was		
diagnosed and they had mentioned	Death is preferable to	Stoma as a last
it as a, they're like, "Oh, some	the possibility of	option- reluctant
people in really rare cases have to	stoma? Humour to	ally?
have a stoma."	avoid seriousness of	
R: Mmm.	information?	
P: I remember coming home and		
saying to my parents, like, "I'll just,		
if-if I get to that point like I'll probably		
kill myself." And it, you know, it's not	"Old person thing"-	
funny joke to make. But I, you know,	previous experience	Lack of
I did say it as a joke because I never	and assumptions of	representation for

thought it would get to that point.	stomas? Concept that	younger people with
And I was I-I didn't like the idea of	"people like me don't	stomas.
it because I'd always thought, "Oh,	have stomas". Stomas	Stigma- I will be
it's like an old person thing" or it's…	are "weird".	considered "weird"
I don't know. It's-it's, I would have, I		and "fragile" for
would have called it weird, honestly.	Illness can make you	having a stoma.
So, I was really against it and then,	change your	Change in identify
erm, leading up to it, I was really,	assumptions and	and beliefs.
really ill. I actually rang them and	strongly held beliefs.	
begged them to, to give me one		Instability of one's
[laughs].	Life can change	life and health.
R: Wow!	suddenly and without	
P: So they gave me an emergency	warning or preparation.	Loss of
aft- within… It was probably two	Reliance on others.	independence.
days between that phone call and		
when I woke up and had the, had	Even as an alternative	Denial of needing
had the surgery. Umm… and I kind	to death/	stoma. Stoma is
of jumped into it like eyes closed	unsustainable poor	stigmatised.
feet first. I was like, I knew it would	health, a stoma is still	Reluctant ally?
be the right thing to do, but then I	undesirable.	Change of identity
remember waking up and thinking	Lesser of two evils?	and confidence in
"Oh, I still don't like it. I still don't like	Doubt of own	self
the idea of it" and I didn't wanna	judgement and	
look at it. And it took, it did take me	choices.	
a couple of days to even look at it.		Desire to accepted
And it took me a little bit longer to…		for stoma.
to come round and accept that it	Keen to get things	
was there and that, you know, weigh	right?	
up whether I'd made the right		
decision or not.		
R: Mmm-hmm.		
P: I don't know if that's-		
R: Umm, tell me about- oh sorry, go		
on.		

P: No, no, no. I'm just gonna say I		
don't know if that's answering any		
questions.		Dissociation of
R: It is- all questions, when you talk,		reality and
questions are being answered.		experience during
Please do not worry about that.	Unsure of previous	adjustment period.
P: Yeah.	experiences.	
R: So first few days, you said that	Avoidance, denial.	
you didn't even want to look at it.	Deny new reality.	Denial as coping
Kind of, what thoughts were popping		mechanism.
in your head? What were you	Avoid pain of reality if I	
thinking at the time?	don't confirm it's real.	The separation of
P: Umm, I don't know. I guess it was		mind, body and
kind of like a… maybe I didn't want	Avoidance of new self.	stoma.
to come to terms with it? Or I didn't	"it"- detached. Sounds	
want to accept that it was real? Or I	like "it" as aversive	
thought the longer that I didn't look	"thing" or "other".	Distress accepting
at it, the Yeah, the-the I could, I		new reality and
could make up that it wasn't as big,	Use of "I couldn't" vs	existence.
as big of a thing in my head if I didn't	"wouldn't" lack of	
look at it and it wasn't real. And I, I	choice? Literally	
remember just looking at the	unable to look at	
ceiling Not for days, because I	stoma due to potential	Separation of stoma
would do other things, but when	distress?	and person.
they'd come in and do the checks,		
and they do them every couple of	"it was" vs "I was"	The stoma is
hours, I just spent them staring up at	going to be ugly. The	something to be
the ceiling because I didn't even	stoma not part of him?	avoided.
wanna catch a glimpse of it. I	Visual graphic	Isolated and
couldn't… I couldn't look at it. I	description- blunt.	misunderstood due
thought maybe Imaybe I looked,	Expectation that others	to stoma.
maybe it was hideous. Or that it	will not know or	
was erm you know, I-I knew it was	understand what	All or nothing
gonna be ugly because it's my	stomas are or look like.	perspective.

insides, you know- In the nicest way, I don't know how- I imagine you're pretty aware of them- but it's my insights pinned to the outside of my stomach. And I was like, "Oh, this is, there's no way this is gonna look... cute or nice or attractive." And I was, I was twenty years old. I was, I was a man was like... I-I didn't have a girlfriend. I was like, "Oh, this is, you know, gonna literally destroy any chances I've got of being..." And I should say at this time, it was in my head. So when I was ill, those last couple of months when I was really ill, I was pretty much stuck in my room. And I remember thinking I'd never exercised, I never really cared for exercise, but it was one of those things that now it was taken away from me. It was all I could think about. I was like "I wish I could just go and run" or learn to run. Or lose loads of weight. I've, you know, I think it was like... I didn't know what I had until it was taken away kind of thing? And I was thinking a lot about it and my own image. And then I was thinking, well, this is, this has put a stop to anything. I think at the time when I've had it done, I was like, "Nothing I do now, is gonna take away from the fact that I have a

Fixed perspectivestoma cannot be The stoma is a viewed as something threat to one's positive or pleasant. autonomy and "Destroy"- ending the happiness. existence. Ceasing Illness also removes new relationships, new connections. bodily autonomy Illness also removes and independence. independence and choice. Regretting not Mourning for taking advantage of previous self. independence when he had the chance? Stoma is a significant life event, "this has put a stop to stopping one from anything"- Ending of achieving goals. this part of my lifedeath? Loss of identity to stoma. Stoma his most defining trait? "release waste"-One will be othered factual? Distanced? and stigmatised due Blunt reality. to stoma. No matter how hard you can work, your other qualities and Loss of identity. achievements will be secondary to the stoma.

hole in my stomach that that I you		Doubt of self-worth
know, release waste out of." I could	People will see stoma	and capabilities.
have the biggest shoulders, the	before they see me?	
biggest arms, you know, nice chest,		
could have a great jawline, full head	Remorse, regret over	Different stages of
of hair. It could, I could have the	previous decisions.	self and identity.
best face in the world, but I'm still		
going to have this hole in my		Stigma for having
stomach, and this is how I thought	Blaming of past-self.	stoma.
at the time. I mean, I-I feel		
completely the other end about it		Separation of self
now, but I do remember at the time	Viewed as undesirable	and stoma.
thinking like "This is, I've-I've not	due to stoma.	
cared about how I looked before		
and now that I do care about it, I've,	"This thing"- makes	
have I jeopardised sort of any	stoma sound like	
chance I've got at being attractive	creature, parasite.	
to-to anybody with this, with this,		
with this thing on my stomach?" I		
think that's probably the-the root		
cause of it all.		
### Appendix Q – Epistemological Statement

This statement refers to the ontological and epistemological stance of the researcher. These positions guided and underpinned the research design and methodology for this portfolio thesis. It is necessary for the researcher to be aware of their pre-conceptions, assumptions, beliefs, biases, and values, as this can influence how they experience and perceive the world around them.

Ontology refers to the study of the nature of being, existence, or reality (Heidegger, 2010). There are two predominant and opposing ontological positions: realism and relativism. A realist stance assumes that there is an observable, measurable "truth" or reality independent of the researcher. This can make findings from research generalisable (Willig, 2012). Conversely, a relativist stance assumes that there is no measurable truth and that there are multiple, valid interpretations of reality (Nicholls et al., 2013).

Epistemology refers to the study of knowledge, how one understands what knowledge is, and how knowledge can be acquired (Audi, 2010). The two predominant opposing epistemological stances are objectivist and subjectivist (sometimes referred to as interpretivist). However, there are other alternative perspectives positioned on the spectrum between these two contrasting stances. An objectivist stance assumes that objective knowledge about the world that can be discovered through observation, reason, and evidence. This epistemological position is often associated with quantitative research. A subjectivist stance assumes that knowledge is theory-determined, or theory-dependent. Essentially, knowledge is constructed by individuals, which has variability due to one's own unique experiences, beliefs, and interpretations (Hiller, 2016). This position is often associated with qualitative research.

Different combinations of these ontological and epistemological stances can be used to describe a researcher's philosophical position. This includes (but is not limited to) positions such as positivist (realist and objectivist), critical realist (realist and subjectivist),

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and constructivist (relativist and subjectivist) (Fryer, 2022). For this research, the researcher adopted a critical realist stance. This stance assumes an external, observable truth which is independent of the researcher, whilst also acknowledging that these observations are flawed as they are shaped by the researcher's existing knowledge or conceptual frameworks (Kemp, 2005). Essentially, critical realists believe that reality itself is not socially constructed, but the frameworks we use to understand it and the methodologies we employ to explore it are (Pilgrim, 2019). Consequently, it is these human interpretations that need to be studied and understood (Danermark et al., 2019).

This stance is appropriate for this research given its separate quantitative and qualitative methodologies. The systematic literature review initially aimed to explore both qualitative and quantitative data, however only quantitative data was available. Having a critical realist stance appreciates the strengths of quantitative methodologies, such as providing measurable evidence of cause and effect. Notably, none of the papers included in the review stated their philosophical stance, although given the quantitative, measurable nature of these studies, they likely had a positivist stance. However, these studies are limited in terms of their often positivist approach, which has limited opportunity for reflection. Ultimately, no definitive conclusions could be drawn regarding how stoma surgery impacts one's self-esteem, as research available was limited in several ways. However, even if more definitive conclusions were formed on this matter, only the question "does stoma surgery impact self-esteem" could have been addressed. This quantitative stance can form evidence-based conclusions on how stoma surgery impacts self-esteem when using a validated scale, which is useful for making generalisable statements about a population sample. However, limited knowledge is created on what causal factors take place in these observations. This quantitative research would be unable to offer further suggestions on "how" or "why" self-esteem is impacted. This can only be achieved through gualitative research, which allows richer, subjective accounts of how one experiences their

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self-esteem following stoma surgery. Consequently, the researcher proposed that future research could benefit from a qualitative methodology, which could address this need for subjective accounts and experiences. This is because the experiences of self-esteem post-stoma surgery are idiographic, thus perceived by the researcher as a subjective encounter.

The researcher's critical realist stance also influenced their methodology for the empirical paper. There is a lack of research regarding young men with stomas, particularly in terms of body image and body modification. Due to this, the researcher determined that a qualitative methodology would be most appropriate for this research. Ultimately, Interpretative Phenomenological Analysis (IPA) (Smith et al., 2021) was selected as the most appropriate methodology. IPA has roots in critical realism (Bhaskar, 1978), given they both acknowledge the importance of the subjective nature of human experiences beyond surface observations. Both approaches highlight the significance of context and the social, cultural, and historical factors that influence individuals' perceptions and experiences. IPA was selected over other qualitative methodologies due to its in-depth focus on individuals' experiences. This study aimed to develop an understanding of how young men (individual) experience and make sense of their bodies and its image (phenomenon) following stoma surgery (context). There was an additional interest in understanding the role of body modification (phenomenon) in this experience. Additionally, IPA acknowledges the researcher's role in the co-construction of meaning. Here, a double hermeneutic is created, as the researcher is making sense of the participants sensemaking of their experiences (Smith et al., 2021). This acknowledgement was important for the research, given the researcher's outsider position.

In conclusion, this research is founded on a critical realist stance, recognising the complex relationship between objective reality and subjective interpretation. By embracing both quantitative and qualitative methodologies within this framework, more

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comprehensive understanding of complex phenomena can be understood and explored, such as the lived experiences of individuals post-stoma surgery.

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#### Appendix R – Reflective Statement

A narrative approach has been used for this reflective statement (Winter, 2012) to reflect on the process and content of this portfolio thesis. This encompasses a 3-year period from the conceptualisation of the study to its final draft. Gibb's reflective cycle (Gibbs, 1988) has been considered throughout this statement.

#### **Empirical Study**

#### Conceptualisation of the Research Question

This research journey began during my ClinPsyD interview. Here, I was asked something along the lines of "If you were on the course, do you know what your thesis project would be?". At the time, I was unsure. I had some interest and experience in gualitative research and had completed my undergraduate dissertation a few weeks prior. When I began the doctorate, I was still unsure of my research topic, and was conflicted between two very different research areas. My previous research had explored the experiences of carers of individuals with traumatic brain injuries over the COVID-19 pandemic, which I found very rewarding. Having this prior knowledge and experience, I had initially considered expanding this research to carers of a different cohort. However, it was during a research fair that two research topics caught my attention. These two topics were investigating the "experiences of long-term health conditions in young adults" and "the psychological aspects of body modifications". Both these topics resonated with me, as I considered myself to be a young adult, with a long-term health condition, who had engaged in a variety of body modifications. Reflecting on the concept of body modification, I also began to consider including body image as a part of my research. During my research, I found myself drawn to the ostomy community. Whilst I have no personal experiences of bowel-related illness or ostomies, I began to reflect on what it would be like to need stoma surgery. I had engaged with some online content from young adults with stomas and therefore had some prior knowledge of the ostomy community. Interestingly,

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as I began to research the psychological impact of stoma surgery, I noticed that most of the literature was with female-only or mixed gender studies. Additionally, the average age of participants in the research was frequently over 50 years. Knowing this, I reflected on who this research didn't represent; younger people in general, and men. This began the formation of my research topic.

Thankfully, my research supervisor, Dr Lesley Gibson, also found this topic interesting, and agreed to supervise my study. Due to the lack of available literature, I thought that a qualitative approach would be the most suitable for this study, recognising its ability to yield fresh insights and understanding. I was keen to use Interpretative Phenomenological Analysis (IPA), given my prior familiarity with this methodology. Mainly, I was eager to explore the experiences of this cohort regarding their bodies post-stoma surgery. I also valued the double hermeneutic that guides IPA (Smith et al., 2021), given that I was researching a topic which I felt quite connected to.

#### Ethics Process and Recruitment

At the time, the process of applying and receiving ethical approval felt lengthy and time consuming. However, in reflection, this part of the research process was relatively simple. I applied via the Faculty of Health Sciences' Research Ethics Committee and did not apply for NHS Ethical Approval. Whilst I had considered that obtaining NHS Ethical Approval would help further promote my study, I was concerned it could result in significant delays in commencing the data collection process.

Prior to ethical approval, I had emailed some relevant charities to seek support in the recruitment process. Many charities were remarkably supportive throughout the recruitment process and demonstrated a keen interest in the study. Many had shared the frustration that there was a lack of research concerning young men's body image following stoma surgery. Additionally, some contacts at these charities expressed that I would not struggle with recruitment. This fostered a sense of optimism within me concerning the

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recruitment process. Following ethical approval, I began to advertise my study both online and in-person. In the following days, I had several potential participants show interest in my study, which again left me feeling optimistic about the recruitment process. Although numerous individuals registered interest in the study, a significant portion did not respond to my contact attempts. Furthermore, certain respondents would request financial compensation for their participation, which was not possible in this study. This experience left me somewhat disheartened and led to doubts about the value of my research. I also had concerns that I would not recruit enough participants, and what implications this could have had on my study. This later led to me applying for amendments via ethics, to facilitate participant recruitment. This primarily pertained to a participant whose stoma surgery fell just a few days short of meeting the inclusion criteria.

I also received some negative online feedback from the public, which I found surprising and upsetting. Whilst some of this feedback stemmed from transphobia, other individuals perceived the study itself as transphobic. Some individuals expressed frustration regarding the term "cisgendered men", seemingly displaying transphobic views regarding the concept of both cisgendered and transgendered men. I chose not to directly interact with individuals who posted transphobic comments on my advertisements. Instead, I reported them to the forum administrators, who would then remove both the individual and their transphobic comments from my advertisement. However, I felt particularly distressed when I was accused of harboring transphobic views myself. This feedback suggested that by not including transgendered men in this study, the study was harmful and exclusionary. The decision to not include transgender men had not been taken lightly. Prior literature suggested that body image dissatisfaction could be linked to an incongruity between gender identity and biological sex (Owen-Smith et al., 2018). I had also consulted with a member of the transgender community, who had clinical experience working within gender services. Following this consultation and research, I was reassured

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that the study was not biased or transphobic, especially when considering the rationale behind its inclusion criteria. In these cases, I acknowledged that the impact of stomas in the transgender community warranted its own research project. Additionally, including both cisgender and transgender men, with likely vastly different body image experiences, would likely impact the homogeneity in a study investigating body image. I'm uncertain if these challenges could have been prevented, but it might have been wiser not to respond to any comments on my posts, and instead leave the forum administrators to have this responsibility.

### Data Collection and Transcription

I had conflicting feelings during the interviews with participants. I experienced some anxiety, mainly due to the internal pressure to "get it right". I was extremely appreciative of all the participants' time, and openness. I did reflect if my gender would have an impact on how freely they felt they could speak. However, my gender likely had a minimal impact, as they spoke freely and openly. Participants had known that they would be asked about their body image, and likely knew that their interviewer would be female, given my name is commonly associated with women.

During my interviews, I became aware that my interviews were shorter than I had anticipated. I began to worry that I was not collecting sufficient data, a concern compounded by my ongoing struggle with recruitment. Due to this, I contacted Dr Emma Wolverson for advice, as she had provided teaching on interviewing techniques, data collection and IPA. I was very grateful that she met with me exceptionally quickly and reassured me that qualitative research was about "quality over quantity". She queried whether I felt my existing data was "rich", to which I agreed. She then offered me some personalised interviewing techniques, encouraging the use of flexible prompt questions, which aided the data collection of further interviews. I have wondered how this change in interview technique may have impacted my final themes, and if any new insights or

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experiences may have been shared. However, I reflected on this positively, knowing that the data I had was still incredibly useful and valuable.

I enjoyed transcribing my data and found it rewarding. It provided me with a sense of productivity, without necessarily having a heavy cognitive burden. In hindsight, I would probably have invested in a transcription foot pedal to aid with the transcription process. However, I was already halfway through my transcriptions by the time I learned about their existence, and I thought that they would have little benefit at that stage. Yet, with my later interviews being longer, I came to regret this choice as transcription was a time-consuming task. Fortunately, conducting interviews through MS Teams proved to be not only convenient but also provided partial transcription of my interviews, which I found immensely beneficial.

#### Data Analysis

I had been very eager to commence data analysis. At this point, I took a break from my empirical research to concentrate on my systematic literature review, finding it challenging to work on both simultaneously. In supervision I had reflected on how excited I was to start this process, driven by my strong passion for the research. However, this excitement diminished slightly when I realised that analysis would also be a lengthy process.

During analysis, I wondered if I was "doing it right", reflecting on the "interpretative" part of IPA. During teaching on qualitative research methods, I had been taught of the similarities between IPA and other methodologies. I was worried that I may inadvertently be completing a Thematic Analysis (Braun & Clarke, 2006), and only establishing broader patterns across participants accounts. Here, I found the IPA guide written by Smith et al. (2021) incredibly helpful and reassured me that I was conducting IPA appropriately.

Whilst I had used IPA during my undergraduate degree, I realised that this was to a different quality to my current study. This research led me to revisit my undergraduate

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analysis, where I realised that I had also undertaken a substantial amount of work for that project, something I hadn't fully appreciated at the time. This, in turn, made me reflect on the amount of work I had accomplished so far, which I struggled to take pride in and still find difficult to fully appreciate.

During my analysis, I felt some sadness when I was unable to include all participants' experiences in the final themes. One participant had an extremely rich and detailed account of how he perceived his body image prior to stoma surgery, which was impacted by another part of his appearance. Unfortunately, this did not relate to the research questions, and therefore it wasn't included in the results. However, his interpretation of his experience's pre-stoma surgery assisted my own analysis of the data that related to the research questions.

Additionally, analysis prompted reflections regarding my own health. I found it somewhat ironic that all my participants engaged in fitness/bodybuilding following their stoma surgery, whilst I was physically limited due to my own long-term health condition. I found it interesting how participants often spoke about the positive elements of exercise on both their mental and physical health, whilst I have only had negative experiences with exercise, which I have associated with pain and exclusion. Instead, I have modified my body in other ways, mainly through tattoos and piercings. Hearing these new positive accounts of fitness and exercise broadened my previous assumptions and beliefs.

During supervision, I frequently contemplated how my personal experiences might influence my interpretation of the data. Ultimately, I adopted the mindset of "being good enough", attempting to be compassionate towards myself and my work. Additionally, I endeavored to maintain my own wellbeing, and found peer-support very beneficial for this.

# Systematic Literature Review (SLR)

During the teaching for the SLR, I was presented with constant reminders that it would be a time-consuming and lengthy process. I am glad that I heeded this advice, as I

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had underestimated how challenging this process would be. My initial SLR topic had sought to explore both body image and self-esteem from quantitative studies. Whilst I had completed the literature search for this, I was unsure how to analyse the data. I sought support from Dr Sue Becker on how I could best approach this. During this meeting, I learned that by investigating two separate psychological outcomes. I would need to perform two separate forms of analysis. Knowing the limitations of time and word count, we agreed that it would be more appropriate to look at only one of these variables. Recognising the number of extensive reviews and literature on body image and stomas, I elected to investigate the less commonly researched area of self-esteem following stoma surgery. This resulted in conflicting feelings. I had initially felt overwhelmed by the prospect of analysing both body image and self-esteem following stoma surgery, as I knew this would be a complicated and difficult process. I was therefore extremely relieved to have altered my SLR to only investigate one psychological outcome, self-esteem. However, I felt somewhat frustrated that I had invested a considerable amount of time screening the literature and researching analysis methods for a project I was no longer pursuing. I had some feelings of guilt for not researching body image for my SLR, although I reasoned that there had already been several systematic reviews for this topic. I also reflected that as my empirical focused on body image, I was still able to contribute to this research field.

Whilst I had initially been open to completing a mixed methods review; I realised that only quantitative papers met my inclusion criteria after screening. As I began to research various methods of data synthesis, my anxiety and self-doubt increased. Whilst I had received teaching in research methods during my undergraduate degree, I was worried about this piece of work. After further meetings with Sue, we determined that Synthesis Without Meta-Analysis (SWiM) would be appropriate for my data. However, with this being a relatively new method, there was limited guidance and resources available on this, which resulted in some worry. To alleviate feeling overwhelmed, I took all my

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research leave in one block, allowing me to dedicate all my attention to the Systematic Literature Review. I found this incredibly helpful and would recommend this strategy to other researchers on a similar doctoral programme. I also found it beneficial to complete the SLR before starting the data analysis of the empirical research. Given the complexities of each research component, this approach enabled me to dedicate my complete focus to both.

### Journal Choices

For my empirical study, the Body Image Journal was selected due to the focus on body image and body modification. This journal welcomes research from a range of disciplines, including psychology. The Body Image Journal shares that whilst physical appearance constitutes a significant aspect of body image, it is not the sole element. They share that how a person interacts with the world through their body, and the value of body functionality are also integral aspects of body image. I found that this perspective aligned well with my empirical study, which influenced my decision when choosing a journal.

As my SLR focused on self-esteem following stoma surgery, the Journal of Mental Health was deemed an appropriate choice. This international journal aims to facilitate communication and research between the diverse fields involved in mental health research and practice. This was considered particularly appropriate, given how this SLR may benefit both medical and psychological research fields.

#### Final Reflections

Throughout this research, I have felt a mixture of emotions. Although there have been times of frustration and worry, there have also been many moments of excitement, relief and pride. Thankfully, the stress of this project has not discouraged me from further research and academic pursuits. If anything, I am eager to continue my research on both individuals with stomas and those involved in body modification. I am continuously inspired by my participants, especially those who have expressed how much they value the

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research I have conducted. Whilst plenty of work still needs to be done, I hope that this research offers the validation and recognition that this community needs and deserves. Hopefully, this work marks just the start of increased representation for the ostomy community.

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