Experiences of Feminine Identity and Suicidality in Women with Polycystic Ovary Syndrome (PCOS)

Lenita J. Wambeek

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Coventry University, Faculty of Health and Life Sciences

University of Warwick, Psychology Department

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List of Abbreviations

ACT	Acceptance Commitment Therapy
APA	American Psychological Association
ASSIA	Applied Social Sciences Index and Abstracts
BMI	Body Mass Index
CASP	Critical Appraisal Skills Programme
CBT	Cognitive Behavioural Therapy
CFT	Compassion Focused Therapy
CINAHL	Cumulative Index of Nursing and Allied Health Literature
DEP	Depressive Symptoms
eMERGe	Meta-ethnography Reporting Guidance
EThOS	E-Theses Online Service
GDPR	General Data Protection Regulation
HRQOL	Health Related Quality of Life
INQ-15	Interpersonal Needs Questionnaire – 15 Item Version
IPA	Interpretative Phenomenological Analysis
IPTS	Interpersonal Theory of Suicidal Behaviour
mPCOSQ	Modified Polycystic Ovary Syndrome Questionnaire
NHS	National Health Service
NICE	The National Institute for Health and Care Excellence
PB	Perceived Burdensomeness
PCOS	Polycystic Ovary Syndrome
PHQ-9	Patient Health Questionnaire – 9 Item Version
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-analyses
QOL	Quality of Life
SBQ-R	The Suicide Behaviours Questionnaire- Revised
SPIDER	Sample, Phenomenon of Interest, Design, Evaluation, Research type
SPSS	Statistical Package and Service Solutions
TB	Thwarted Belongingness
TTC	Trying To Conceive
UK	United Kingdom
US	United States
WHOQOL	The World Health Organisation Quality of Life Scale

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Declaration Summary

This thesis is submitted to the University of Warwick in support of my application for the degree of Doctorate in Clinical Psychology. It has been composed by myself and has not been submitted in any previous application for any degree. The thesis was carried out under the academic supervision of Dr Anthony Colombo (Director of Research, Coventry University), who assisted at all stages of the research process from development of initial ideas, statistical analysis, refinement of qualitative synthesis and providing feedback on draft chapters. James Andrew Bodel, a fellow trainee clinical psychologist, provided second quality assessment ratings in the systematic literature review chapter. Apart from the previously mentioned collaborations, all the material presented in this thesis is my own work. Chapters one and two will be adapted for publication in Women's Reproductive Health and Health Psychology Open, respectively. Dr Anthony Colombo will be listed as a co-author in any resulting publications.

Summary

This thesis is comprised of three chapters. Chapter one is a meta-ethnographic review of 15 studies exploring how women with polycystic ovary syndrome (PCOS) experience conventional forms of feminine identity. Three main themes were developed: Identifying Differences, Meaning and Responses. It is proposed that women with PCOS recognise that their PCOS symptoms differ from conventional forms of femininity and this is interpreted as a threat to their identity as women and as mothers. They then respond to this threat by attempts to control their symptoms or avoiding certain situations. Raising awareness, psychoeducation and community interventions are suggested.

Chapter two is a mediation analysis of 618 women with PCOS aged 18-40 who completed an online survey about their psychological wellbeing. Support was established for a model where the relationship between PCOS and suicidality was mediated by quality of life, depressive symptoms, thwarted belongingness and perceived burdensomeness. Variations of the model were also supported, but each time the principle mediating variables were depressive symptoms and perceived burdensomeness. Employment, level of education, age and relationship status were only shown to be important covariates in the relationship between PCOS symptom severity and quality of life. Recommendations are made for symptom control, community interventions, mental health screening and appropriate psychological interventions.

Chapter three is a reflective account that focusses on the interplay between personal and professional identity in the context of a personally meaningful research project. Johns' reflective model has been used to engage in reflective practice exercises and develop reflections further. This piece discusses the implications of researchers working on projects where they are part of the target population and the potential sources of bias.

Overall word count: 19,904

Chapter I: Systematic Literature Review

How do Women with Polycystic Ovary Syndrome (PCOS) Experience Conventional Forms of Feminine Identity: a Meta-ethnographic Review

This chapter will be adapted for submission to Women's Reproductive Health.
See Appendix A for author instructions.
See Appendix B for certificate of ethical approval.

Overall chapter word count at submission (excluding abstract, tables, figures and references): 8,326

Abstract

AIM: To explore how women with polycystic ovary syndrome (PCOS) experience conventional forms of feminine identity. RESEARCH METHODS: A systematic literature review of published literature and grey literature produced between 2000-2020 was performed, following recommendations from PRISMA and eMERGE guidelines. The studies were retrieved from 10 electronic databases (APA PsycArticles, APA PsycInfo, International Political Science Abstract, Embase, CINAHL, ASSIA, ProQuest Central, Dissertations & Thesis, Open Grey and EThOS). Search terms related to the concepts of PCOS, feminine identity, self-identity and experiences were incorporated into search algorithms. Inclusion criteria consisted of: participants aged over 13 years; qualitative research designs; focus on the experiences of women with PCOS and identification of themes related to feminine or self-identity. A total of 874 records were identified and 15 articles satisfied the inclusion criteria. Quality assessments were conducted by two reviewers using the Critical Appraisal Skills Programme (CASP) qualitative checklist tool. Meta-ethnography was used to synthesise the included studies. RESULTS: Three main themes and six subthemes were identified: identifying differences (Outside in and inside out), meaning (Threats to womanhood and threats to motherhood) and responses (Controlling and avoiding). CONCLUSION: This review provides support for raising awareness of PCOS in both healthcare settings and in public, a need for suitable psychoeducational materials, policies to encourage exercise participation and the potential for third wave CBT interventions.

Introduction

Review Subject and Significance

This systematic review will draw together qualitative evidence to understand how women[1] with Polycystic Ovary Syndrome (PCOS) experience conventional forms of feminine identity. PCOS is a common endocrine condition that affects women of a reproductive age (Hoeger et al., 2021). Diagnosis of PCOS is made on the basis of two of the following three criteria: hyperandrogenism; ovulatory dysfunction and polycystic ovary morphology (Hoeger et al., 2021).

Hyperandrogenism is often described as an excess of 'male' hormones (Kitzinger & Willmott, 2002), and this can lead to acne, alopecia and hirsutism. Alopecia, in the context of hyperandrogenism, refers to hair on the head thinning and becoming finer (Quinn et al., 2014). Hirsutism is a term only applied to women, which indicates excess hair growth in a 'male distribution', for example, on the lip, chin, sideburns, chest and abdomen (Keegan et al., 2003). Differences between expected hair growth for men and women is difficult to quantify due to hair removal or covering practices and the variation seen between women from different age groups and ethnicities (Keegan et al., 2003). Nevertheless, this diagnostic label has been significantly associated with higher levels of psychological distress in women with PCOS (Kumarapeli et al., 2011).

Ovulatory dysfunction refers to problems with ovulation, which leads to absent or irregular menstrual periods and ovary morphology pertains to the appearance of polycystic ovaries which can be diagnosed by an ultrasound. These clinical conditions lead to problems with conception. In an Australian community-based cohort study, 72% of women with PCOS reported infertility (Joham et al., 2015). PCOS is also linked to an increased risk of pregnancy complications (Kriedt et al., 2019). Overall, many women with PCOS may struggle to conceive and

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[1] It is worth acknowledging here that although PCOS is a condition that affects people who are biologically female; not all people with this diagnosis will identify as women. At the time of writing, there is insufficient literature available to appropriately describe how the experiences of this group of people may differ from cis-gendered women with PCOS. Therefore, despite the limitations, the term 'women' will be used throughout this paper.

consequently bring a child to full-term, and infertility is linked with poorer quality of life in women with PCOS (Naumova et al., 2020).

In addition to this, women with PCOS have a 4-fold higher risk of developing obesity; this is usually a long-term difficulty and weight gain trajectories may begin in childhood (Hoeger et al., 2021). A 5-10% reduction in body weight is reported to bring about clinically significant reductions in symptoms (Teede et al., 2018). Body mass index (BMI) is reported to be a significant predictor of anxiety and depression in women with PCOS (Ali et al., 2018).

Infertility, hirsutism, menstrual irregularity and high BMI have been shown to be associated with poorer self-esteem and body dissatisfaction in women with PCOS (Bazarganipour et al., 2013). There is also an interpersonal nature to this distress as women with PCOS have reported bullying and unsolicited advice regarding their symptoms (Otusanya, 2020; Wright et al., 2020). There is significant evidence to suggest that PCOS symptoms clearly have an impact on psychological distress, especially depression, anxiety, eating disorders and poor quality of life (Dokras et al., 2018). One of the underlying reasons for this distress is thought to relate to experiences of conventional feminine identity (Zangeneh et al., 2012).

Judith Butler describes gender identity as a performance compelled by the regulatory practices of gender coherence within a culture (Butler, 2011). That is, a woman will enact 'feminine identity' by engaging in practices that are recognised as feminine by her culture at that point in history. Pickens and Braun (2018) highlight that women often feel tension between so-called 'new femininity' ideals and the lived experience of expectations reflecting traditional femininity. In western cultures, new femininity refers to sexual assertiveness, equal employment opportunities, choosing to have children later in life, having fewer or no children and the freedom to remain single or seek divorce (Pickens & Braun, 2018). However, many women report a continued pressure to conform to conventional notions of sexual purity, beauty standards, coupling and childbearing (Pickens & Braun, 2018).

Evaluation of Previous Reviews

Pastoor et al. (2018) conducted a review and meta-analysis on the topic of sexual function in women with PCOS. In this study, sexual function was defined broadly and included specific states during sexual activity (for example, sexual desire, arousal, lubrication); frequency of sexual activity; sexual satisfaction, sexual self-image and sexual distress. This review examined 18 studies published prior to 30th June 2017. Included studies contained a formal PCOS diagnosis made using widely recognised criteria; an adequate definition of sexual function; validated sexuality questionnaires or visual analogue scales; use of a control group and participants over the age of 14 years. This study found small but significant differences in sexual function between women with PCOS and controls. Women with PCOS reported significantly lower total scores, arousal, lubrication, orgasms, sexual thoughts and sexual satisfaction. In addition to this, women with PCOS were more likely to report that they found themselves less sexually attractive, excessive body hair impacted their sex life and their appearance made it difficult to engage in social contact. Effect sizes were small to large.

A literature review has been carried out by Paganini et al. (2018) on the overlap between PCOS and eating disorders. They included empirical studies published between 1991 and 2016 that focussed on PCOS in eating disorder populations or eating disorders in PCOS populations. Twenty-one articles were included in the review. Depression, anxiety, body image dissatisfaction, eating disorders, low life satisfaction and sexual disorders were found to be associated with PCOS. 30-50% of participants with PCOS reported overeating, emotional eating, eating without hunger or reported the presence of an eating disorder. In addition to this, features of PCOS were common in populations of women with eating disorders.

Garside (2008) conducted a meta-study focussing on the experiences of women undergoing hysterectomy for benign conditions. Studies were included if they were qualitative studies focusing on the experience of hysterectomy for benign conditions among pre-menopausal women. Twenty studies were included in the analysis. The conceptual framework of the resulting synthesis included three main themes: relationships, individual body and sociocultural meanings. The relationship theme included the support that women receive from partners, friends, and healthcare professionals, and how this helps or hinders help-seeking and recovery. In terms of the individual body theme, women reported that their symptoms had an impact on them physically and mentally prior to surgery and that recovery can bring a sense of freedom from symptoms, menstruation and worries about contraception and pregnancy. The socio-cultural theme referred to the symbolic meaning of the ovaries and womb. Women were found to report a sense of loss over the loss of their womb, their fertility, and the symbolic loss of womanhood. Women also reported concerns about losing physical attractiveness following hysterectomy and were wary of stigma associated with this surgery and used strategies to avoid disclosing their surgery to others.

Rationale and Aim of the Current Review

There are currently no systematic literature reviews that have addressed the issue of feminine identity in women with PCOS. There is widespread acknowledgement that PCOS impacts on feminine identity, for example it is included in the latest NICE guidelines for PCOS (National Institute for Health and Care Excellence, 2018). A review of the research in this area will provide clarity and strength to these assertions and provide a theoretical explanation for this phenomenon.

In addition to this, there have been no qualitative syntheses in any area of PCOS research, therefore it is hoped that a qualitative review will highlight the experiences and voices of women with PCOS and contribute to a theoretical understanding of feminine identity navigation in this context.

Table 1

SPIDER Diagram to Demonstrate Key Criteria Relevant to the Research Question

Key Criteria	Description
S- Sample	Young women with a formal diagnosis of PCOS
PI- Phenomenon of Interest	Sense of conventional feminine identity
D-Design	Interviews, content analysis and focus groups that contain first person accounts of people with PCOS
E- Evaluation	Perceptions and experiences of PCOS symptoms
R- Research Type	Qualitative studies, Mixed

Table 1 illustrates the key criteria relevant to this review, presented using the SPIDER tool (Cooke et al., 2012). This review is focussed on the experiences of young women with a diagnosis of PCOS and their sense of conventional femininity. There will be a focus on the perceptions and experiences of PCOS symptoms, therefore qualitative studies are likely to yield the most appropriate information. In terms of design, primary studies using first person accounts of women with PCOS will be the focus of this review, whether this be by interviews, focus groups or by analysing written content.

This review will address the following research question:

How do women with PCOS experience conventional forms of feminine identity?

Methods

Systematic Literature Search

The synthesis was in relation to the subject of PCOS and experiences of conventional feminine identity, therefore the disciplines of psychology, sociology and medicine were relevant. On this basis, the following databases were searched: PsycArticles, International Political Science Abstract, APA PsycInfo, ASSIA, CINAHL, Embase and ProQuest Central (Social Sciences and Sports Medicine Collections). Grey literature in the form of Doctoral theses were included, as these pieces are typically subject to the same quality checks and peer reviews but precludes publication bias (Adams et al., 2017). Grey literature was explored by searching Proquest Dissertation & Theses, Open Grey and EThOS. The searches were carried out in April 2021. Hand searches were also conducted by reviewing the reference lists of articles that matched the search criteria.

Table 2
Key Search Terms

Concept	Synonyms	Location
Polycystic Ovary Syndrome	PCOS Polycystic Ovarian Syndrome	Title, Abstract, Full Text
Feminine identity	Femininity Gender identity Gender role Woman's role Sex role	Title, Abstract, Full Text
Self-identity	Self-concept Self-esteem Self-perception Self-representation Self-image	Title, Abstract, Full Text
Experiences	Perceptions Perspectives Concerns Impact Effect Affect Influence View Opinion Attitude Belief	Title, Abstract

As can be seen in Table 2, the search strategy firstly involved searching in the title, abstract and full text for PCOS terminology. Initially, for completeness, principal symptoms of PCOS were also entered into the algorithm, including: hyperandrogenism, androgen, hirsutism, excess hair, obesity, overweight, infertility, acne, anovulation, amenorrhoea, oligomenorrhoea, menstruation and menstrual cycle. However, adding PCOS AND symptom terms seemed to limit the number of articles returned while PCOS OR symptom terms seemed to capture too broad a range of articles. Secondly, terms associated with feminine identity and self-identity were searched in the title, abstract and full text. Finally, terms associated with experiences were searched within the title and abstract only, as these are common words which can be used in the full text for a variety of unrelated issues.

To capture differences in psychological and sociological databases, two different searches were completed across the databases related to each discipline. The first search used terms related to ‘feminine identity’ which may be more relevant in sociological journals and the second search used terms related to ‘self-identity’ which may be more common in psychology journals.

Irrespective of the database searched, the following broad algorithms were used:

1) “Polycystic Ovary Syndrome” or PCOS or “Polycystic Ovarian Syndrome” AND Femininity or “Gender identity” or “Gender roles” or “Woman’s role” or “Sex role” AND Experiences or Perceptions or Perspectives or Concerns or Impact or Effect or Affect or Influence or View or Opinion or Attitude or Belief

2) “Polycystic Ovary Syndrome” or PCOS or “Polycystic Ovarian Syndrome” AND Self-identity or Self-concept or Self-esteem or Self-perception or Self-representation AND Experiences or Perceptions or Perspectives or Concerns or Impact or Effect or Affect or Influence or View or Opinion or Attitude or Belief

Table 3
Databases and Associated Search Term Algorithms

	Boolean Search Algorithm	
Databases	Feminine Identity Terms	Self- Identity Terms
APA PsycArticles, International Political Science Abstract, APA PsycInfo, Embase	("Polycystic Ovary Syndrome" OR PCOS OR "Polycystic Ovarian Syndrome") AND (Feminin* or Gender adj4 Ident* OR Gender adj4 role* OR sex adj4 role* OR wom#n* adj4 role).af. AND (Experienc* OR Perception* OR Perspective* OR Concern* OR Impact* OR Effect* OR Affect* OR Influenc* OR View* OR Opinion* OR Attitude* OR Belie*).ab	("Polycystic Ovary Syndrome" OR PCOS OR "Polycystic Ovarian Syndrome") AND (Self-identity OR Self-concept* OR Self-esteem OR Self-perception OR self adj4 perception OR Self-representation OR self adj4 representation OR self adj4 image).af. AND (Experienc* OR Perception* OR Perspective* OR Concern* OR Impact* OR Effect* OR Affect* OR Influenc* OR View* OR Opinion* OR Attitude* OR Belie*).ab.

CINAHL	("Polycystic Ovary Syndrome" OR PCOS OR "Polycystic Ovarian Syndrome") AND (Feminin* OR Gender N4 Ident* OR Gender N4 role* OR sex N4 role* OR wom#n* N4 role) AND AB (Experienc* OR Perception* OR Perspective* OR Concern* OR Impact* OR Effect* OR Affect* OR Influenc* OR View* OR Opinion* OR Attitude* OR Belie*)	"Polycystic Ovary Syndrome" OR PCOS OR "Polycystic Ovarian Syndrome") AND (Self-identity OR Self-concept* OR Self-esteem OR Self-perception OR self N4 perception OR Self-representation OR self N4 representation OR self N4 image) AND AB (Experienc* OR Perception* OR Perspective* OR Concern* OR Impact* OR Effect* OR Affect* OR Influenc* OR View* OR Opinion* OR Attitude* OR Belie*)
ASSIA ProQuest Dissertations & Thesis A&I ProQuest Central	("Polycystic Ovary Syndrome" OR PCOS OR "Polycystic Ovarian Syndrome") AND (Feminin* OR Gender NEAR/4 Ident* OR Gender NEAR/4 role* OR sex NEAR/4 role* OR wom#n* NEAR/4 role) AND ab(Experienc* OR Perception* OR Perspective* OR Concern* OR Impact* OR Effect* OR Affect* OR Influenc* OR View* OR Opinion* OR Attitude* OR Belie*)	("Polycystic Ovary Syndrome" OR PCOS OR "Polycystic Ovarian Syndrome") AND (Self-identity OR Self-concept* OR Self-esteem OR Self-perception OR self NEAR/4 perception OR Self-representation OR self NEAR/4 representation OR self NEAR/4 image) AND ab(Experienc* OR Perception* OR Perspective* OR Concern* OR Impact* OR Effect* OR Affect* OR Influenc* OR View* OR Opinion* OR Attitude* OR Belie*)
Open Grey EThOS	Polycystic Ovary Syndrome OR PCOS OR Polycystic Ovarian Syndrome	

As can be seen in Table 3, different databases allowed different search operators and so the algorithm was adapted accordingly. Open Grey and EThOS had the least sophisticated search functions, and so only PCOS search terms were utilised. In most databases, one of the three PCOS terms: ‘Polycystic Ovary Syndrome’; ‘Polycystic Ovarian Syndrome’ and ‘PCOS’ was required to be present in the title, abstract or full text. In addition to this, the algorithm required at least one of the feminine identity terms or one of the self-identity terms to also be present in the title, abstract or full text. Speech marks were utilised to search for phrases in a group. The asterisk was used as a truncation operator to find different suffixes for the key terms, for example identity, identities. Hash symbols were used as wild cards, for example to use ‘wom#n’ to find both ‘women’ and ‘woman’. Some databases allowed proximity operators, so here ‘ADJ’, ‘NEAR’ or ‘N’ was used to find instances where the word ‘gender’ was within 4 words of the term ‘role*’. Similar proximity searching was completed for the terms: Role and sex or ‘wom#n*’; Self and perception, representation or image.

Inclusion and Exclusion Criteria

Table 4
Inclusion and Exclusion Criteria

	Criteria	Inclusion	Exclusion
S-Sample	Country	Any	None
	Time Period	2000-2020	Prior to 2000, after 2020
	Age	≥13 years	<13 years
	Sex	Women	Men
PI-Phenomenon of Interest	Research concepts	Studies where authors identified ‘Feminine identity’ or ‘Self-identity’ as a theme or relevant issue in studies of women with PCOS	Studies that exclusively focus on attitudes towards the social roles of women in society
D- Design	Research Design	Thematic Analysis, Grounded Theory, Interpretative Phenomenological Analysis, Content Analysis, Ethnography, Discourse Analysis	Cross sectional survey designs, Experimental, Randomised controlled trials
E- Evaluation	Content	Studies that focus on experiences of the phenomenon of feminine identity	Studies that exclusively focus on attitudes towards the concept of feminine identity
R- Research	Epistemology	Qualitative, Mixed	Quantitative

In terms of literature type, this study included peer reviewed empirical articles published in the English language only, where the full text was available.

As can be seen in Table 4, the search was limited to articles published between 2000 and 2020. References to the widely cited study by Kitzinger and Willmott (2002) first appeared in Willmott (2000), therefore this was the beginning of the conversation about feminine identity in women with PCOS. Feminist writers assert that the concept of feminine identity is not static (Allender & Spencer, 2021); however, for the purpose of this research it was assumed that conventional ideas about femininity will not have changed significantly during this 20-year period. Women's bodily experiences and practices are influenced by intersectional aspects of identities such as ethnicity, social class, sexuality, ability and spirituality, leading to significant differences within social groups and cultures (Sabik, 2016). In addition to this, there is evidence of some cross-cultural norms in terms of social constructions of conventional femininity, for example, the traditional role of women in child rearing (Wood & Eagly, 2002). Therefore, no search limits were set on the location of the study. Age of participants were restricted to those over the age of 13, as it would be unlikely for a young woman to be diagnosed with PCOS prior to this (Hoeger et al., 2021). At this age adolescents are aware of their developing gender identity (Gülgöz et al., 2019) and adolescents with PCOS have been found to report concerns about the social implications of their condition (Mani et al., 2014).

This review was limited to studies where authors identified that 'feminine identity' or 'self-identity' was a theme or relevant issue in their studies of women with PCOS, and there were illustrative quotes from participants about their experiences of this phenomenon. Studies that exclusively explored attitudes and commentaries on the social role of women were not included.

In terms of research design, qualitative and mixed methodologies were included, however, only the qualitative aspects of the studies were subject to analysis. Qualitative research designs consisted of thematic analysis, grounded theory, interpretative phenomenological analysis, content analysis, ethnography, and discourse analysis.

Classification of Studies

Figure 1

PRISMA Flow Diagram

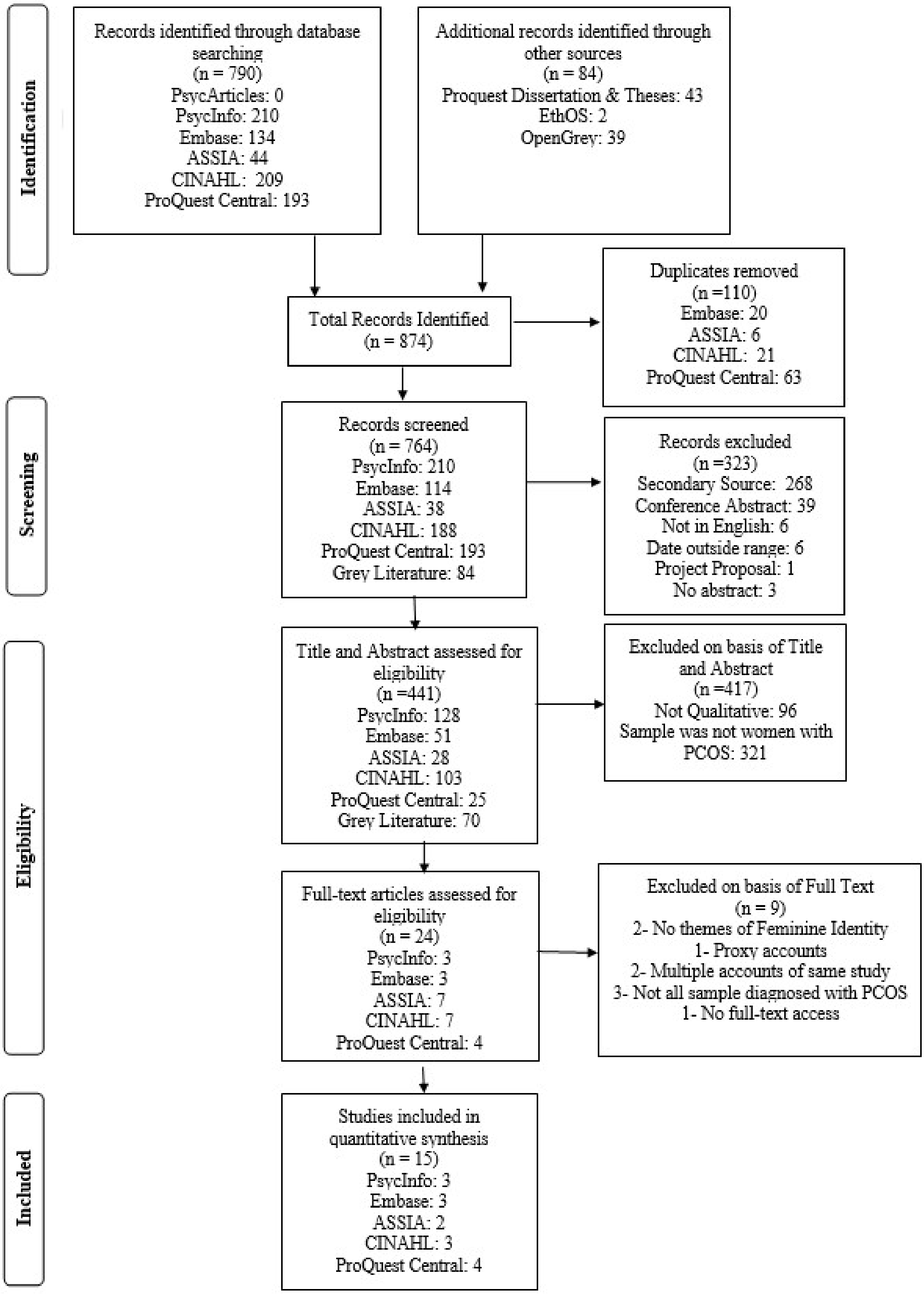

Figure 1 shows the study classifications in a ‘Preferred Reporting Items for Systematic Reviews and Meta-Analyses’ or ‘PRISMA’ flow diagram (Moher et al., 2009). A total of 874 records were identified through database and grey literature searching. No additional records were found through hand searching. After duplicates were removed, 764 records were subject to screening and 323 records were excluded at this stage. Title and abstract screening of the remaining 441 records determined that a further 417 studies were ineligible. The full text of 24 articles were reviewed, and a further nine were excluded. This resulted in 15 papers being included in the final qualitative synthesis.

Quality Assessment Checks

The appropriateness and utility of quality assessment in qualitative synthesis is debated. Some studies advocate for using such assessments to exclude studies of a low quality and others use the information to assess the impact of lower quality studies on the synthesis findings (Long et al., 2020). Authors can be influenced by journals in what they choose to report, and quality assessment tools can only measure what is published (Carroll & Booth, 2015). It can be argued that lack of reporting does not necessarily equate to poorly executed studies, and it is common practice in meta-ethnography to not exclude studies based on poor quality assessment scores (Sattar et al., 2021). Instead, meta-ethnography studies may use quality assessment scores to ensure higher quality papers are translated first (Sattar et al., 2021) or may choose to use richness of data to guide decisions to exclude poor quality studies (France et al., 2019b).

Quality assessment was conducted using the 10-item Critical Appraisal Skills Programme (CASP) qualitative checklist tool (Critical Appraisal Skills Programme, 2018). This checklist is commonly used in health-related qualitative evidence syntheses and is recommended for novice qualitative researchers (Long et al., 2020). Scores were given for each of the ten criteria, two points were given where the criterion was fully met; one point where the criterion was partially met, and no score was given where the criterion was not reported. This gives a score range from zero to 20 (See Appendix C).

To test reliability, each paper in this review was scored independently by two raters. A consensus meeting was then arranged to discuss discrepancies in scoring.

Overall interrater reliability was calculated by entering the scores into SPSS and producing a Kappa coefficient statistic.

CASP scores ranged from 5-18 (See Table 5) and as full rater consensus was reached, each paper had a Kappa reliability coefficient of $\kappa = 1.0$, which indicates high levels of inter-rater reliability (Frey, 2018). Two papers scored less than 10 points on the CASP (50%) and were deemed low quality. These papers did not clearly describe their research question, recruitment strategy and approach to analysis, which made it difficult to rate the rigour, appropriateness of the methods and the value and clarity of the findings. However, these studies were assessed for conceptual richness and were retained in the synthesis (France et al., 2019b). In this context, conceptual richness was assessed by the theoretical explanations developed by the authors to explain the metaphors in their study (Booth et al., 2013). Further details of quality assessment scores and inter-reliability are available in Appendix D.

Table 5
Study Characteristics

Authors, year, country, study design and sampling method	Research aims	Sample size, recruitment and participants	Method of data collection Method of data analysis	Key findings	CASP Score (Kappa Coefficient; κ)
Kitzinger & Willmott 2002 United Kingdom Qualitative Purposive	To explore women's own experiences of PCOS and how they negotiate their identities as women, using feminist perspective.	N=30 women with PCOS aged 21-42 years. Recruited through flyers distributed to members of UK charity Verity.	Semi structured interviews. Thematic Analysis, based on Kissling (1996).	Dominant theme was 'Freakishness' with three main subthemes:1. Bearded ladies and hairy monsters 2. Irregular women 3. Infertility: my whole purpose of being a woman was gone.	17 (κ =1.00)
Keegan et al. 2003 United Kingdom Qualitative Purposive	To explore meanings of body hair and their relationship to social contexts to develop a theoretical framework from which to view hirsutism in women.	N=34 women with PCOS and hirsutism, aged 27-42. Recruited from an outpatient reproductive endocrinology clinic.	2x Individual semi structured interviews 1x Semi structured interview as research dyad. Discourse analysis.	Four main themes: 1. The abnormal norm and its regulation 2. Hair as sexing men and women 3. Unwanted hair as dirt 4. Deviance, stigma and 'passing'.	12 (κ =1.00)

Authors, year, country, study design and sampling method	Research aims	Sample size, recruitment and participants	Method of data collection Method of data analysis	Key findings	CASP Score (Kappa Coefficient; κ)
Pfister & Rømer 2014 Denmark Qualitative Purposive	To explore the lived experiences of women with PCOS who have hirsutism.	N=21 women with PCOS aged 21-36 years. Recruited from larger physiological study.	Semi structured interviews. Thematic Analysis informed by Kvale & Brinkmann (2009).	Four main themes: 1. Experiences of difference 2. Trivialisation of hirsutism 3. Coping strategies 4. Femininity and sexual relations.	14 (κ =1.00)
Naz et al. 2019 Iran Qualitative Purposive	To explore the experiences of adolescents with PCOS.	N=15 adolescent girls with PCOS aged 13-19 years. Recruited from university health centre.	Semi structured interviews. Qualitative content analysis as described by Graneheim and Lundman (2004).	Main theme: Threats to feminine identity, including: 1. Concerns about attractiveness including fashion and loss of physical beauty. 2. Concerns about femininity including worrying about future marriage prospects, anxiety about future infertility and stress about menstrual abnormalities.	17 (κ =1.00)
Amiri et al.2014 Iran Qualitative Purposive	To explore the perceptions and experiences of Iranian women with PCOS that influence their personal gender role.	N=23 women with PCOS aged 18-40 recruited from reproductive endocrinology research centre.	Semi structured interviews. Content Analysis.	Four main themes:1. Lack of perceived physical attractiveness 2. Loss of womanhood 3. Disrupted sexual function 4. Disrupted fertility function.	17 (κ =1.00)

Authors, year, country, study design and sampling method	Research aims	Sample size, recruitment and participants	Method of data collection Method of data analysis	Key findings	CASP Score (Kappa Coefficient; κ)
Sharma & Mishra 2018 India Qualitative Purposive	To investigate awareness of and after effects of PCOS in Economically Weaker Section (EWS) women in India.	N=35 women with PCOS recruited from a gynaecological outpatient department of a hospital.	Semi structured interviews Interpretative. Phenomenological Analysis (IPA).	Four main themes: 1. PCOS as a tabooed disease 2. Infertility: a major consequence of PCOS 3. Lack of awareness about the disease 4. Social construction of PCOS.	7 (κ =1.00)
Hadjiconstinou et al. 2017 United Kingdom Qualitative Purposive	To identify support needs and explore the acceptability of group education sessions for women with PCOS.	N=12 women with PCOS aged 17-51 years. Approached at outpatient clinic or via hospital advertising.	Semi structured interviews. Audio recorded and transcribed verbatim. Constant comparative approach.	Four main themes: 1. Symptoms and delays in receiving a diagnosis 2. Psychological distress 3. Practical implications of living with the condition 4. Coping with PCOS and perceived support needs.	18 (κ =1.00)
Williams et al. 2015 United Kingdom Qualitative Purposive	To explore the impact of PCOS on quality of life.	N=9 women with PCOS recruited from PCOS support groups on Facebook. Participants were aged 20-41 years.	Interviews via Skype. Thematic Analysis.	Four themes: 1. Change 2. Support 3. Co-morbidities 4. Identity	18 (κ =1.00)

Authors, year, country, study design and sampling method	Research aims	Sample size, recruitment and participants	Method of data collection Method of data analysis	Key findings	CASP Score (Kappa Coefficient; κ)
Snyder 2006 United States Qualitative Purposive	To explore the lived experience of women diagnosed with PCOS.	N=12 women with PCOS aged 21-48 years recruited from a women's healthcare practice.	Semi structured interviews. Phenomenological Analysis based on Giorgi (1985).	Seven themes: 1. Identifying differences 2. Acknowledging impact on femininity 3. Searching for answers 4. Wanting to be normal 5. Gaining control 6. Letting go of guilt 7. Dealing with it.	18 (κ =1.00)
Williams et al. 2014 United Kingdom Qualitative Purposive	To explore the impact that PCOS can have on an individual's quality of life.	N=9 women with PCOS aged 20-45 years. Recruited from PCOS charity, Verity's website.	Photovoice methodology. Thematic Analysis.	Three major themes: 1. Control (Symptom Management, PCOS as controlling) 2. Perception (Feminine Identity, Identity) 3. Support (The Healthcare system, Education, Relationships)	17 (κ =1.00)
Sanchez & Jones 2016 United States Qualitative Purposive	To explore how digital magazines portray women with PCOS.	170 articles containing "PCOS" or "Polycystic Ovary Syndrome". Women's magazines with a circulation of over 1,000,0001 in USA Data collected between Jan-Feb 2015.	Textual Analysis. Grounded Theory.	Three main themes: 1. Women's social roles and responsibilities 2. Personal responsibility to improve health 3. Personal experience with PCOS to advocate for women's health.	15 (κ =1.00)

Authors, year, country, study design and sampling method	Research aims	Sample size, recruitment and participants	Method of data collection Method of data analysis	Key findings	CASP Score (Kappa Coefficient; κ)
Smith-Tran 2018 United States Qualitative Autoethnography	How can women who are coping with a polycystic ovarian syndrome (PCOS) diagnosis and subsequent illness management overcome the emotional tensions that arise?	N=1. Black woman with PCOS. Middle class, late 20's, recently diagnosed, BMI 25, former college athlete.	Field notes No clear description of analysis.	Four discussion points: 1. Diagnosing the trifecta 2. Disclosing my condition 3. Treatment 4. Taking action.	12 (κ =1.00)
Pathak 2019 India Qualitative Purposive	To investigate concern with fertility within urban middle class Indian women with PCOS.	N=30 middle class Indian women with PCOS aged 21-50 years. Recruited from social circles.	Participant observation, interviews, ethnographic fieldwork. Method of analysis unclear.	Four main themes: 1. 'It doesn't really bother you' 2. Rise of companionate marriage in post-liberalisation India 3. Subfertility, pragmatism and companionate marriage 4. Fertility and middle-class distinction projects.	5 (κ =1.00)

Authors, year, country, study design and sampling method	Research aims	Sample size, recruitment and participants	Method of data collection Method of data analysis	Key findings	CASP Score (Kappa Coefficient; κ)
Washington 2008 United States Qualitative Snowball	To explore the impact of PCOS on daily activities, self-esteem and experiences in employment of pre-menopausal women with PCOS.	N=11 women with PCOS aged 25-39 years old who have been in full time employment for past 20 months. Recruited from Women's clinics, PCOS support groups, word of mouth.	Interviews. Has not explicitly referenced a type of analysis- details of procedure in the article.	Seven main themes: 1. Descriptions of experiences associated with pain related to PCOS 2. Impact of PCOS on self-concept 3. Ways in which excessive hair and hair loss associated with PCOS are addressed 4. Issues related to uncontrolled emotions as a result of PCOS 5. Impact of PCOS symptoms in the workplace 6. The impact of PCOS on employment 7. Impact of PCOS on conception.	14 (κ =1.00)
Ee et al. 2020 Australia Qualitative Purposive	To explore the experiences of obese/overweight Australian women living with PCOS to inform and guide care.	N=10 women with PCOS and a BMI >25 kg/m². Participants were aged 27-46 years. Recruited through social media.	Focus groups and individual interviews. Constant Comparison Approach. Thematic Analysis.	Five themes: 1. Complex nature of PCOS 2. Difficulties with diagnosis 3. Negative online experiences 4. Need for support 5. Frustration over lack of cure 6. Impact of symptoms and sequalae.	17 (κ =1.00)

As can be seen in Table 5, most of the papers were completed by separate research teams, except for the two Williams et al. studies, and one contributor to the Amiri et al. paper was also involved in the Naz et al. paper. The studies were geographically diverse, with studies conducted in the UK (5), US (4), Iran (2), India (2), Denmark (1) and Australia (1). All included studies were qualitative and most utilised purposive sampling, with the exception of Washington (2008) who used snowball sampling, and Smith-Tran (2018) whose autoethnography focussed on her own experiences.

The studies explored feminine identity within the areas of: experiences of PCOS symptoms; impact on quality of life and coping and managing with the symptoms.

Studies recruited between one and 35 participants, ranging in age from 13 to 51 years. Some studies required participants to meet certain additional criteria including: adolescents aged 13-19; middle class; experiences of hirsutism; currently employed and BMI greater than 25 kg/m^2.

Most of the studies utilised interviews as a research method, two studies additionally included focus groups and participant observation. Three studies did not use interviews, these studies instead used written first-person accounts of women with PCOS in magazine articles, photovoice diary entries and personal field notes made during the diagnosis process. The most common forms of analysis used were thematic analysis (3), content analysis (2) and the constant comparative method, which is an analysis method associated with grounded theory (2). Other analyses used discourse analysis, interpretative phenomenological analysis (IPA) and grounded theory. Three studies did not reference an established method of analysis. Washington (2008) provided a detailed description of the analysis process used, which involved coding transcripts and generating themes, which appeared to be a form of thematic analysis. Smith-Tran (2018) and Pathak (2019) have utilised ethnographic methodologies, however, little detail is given about the analysis process.

Analytic Review Strategy

This review utilises meta-ethnography as a means of qualitative synthesis. This approach was described by Noblit and Hare (1988) and has recently been developed further by France et al. (2019b) and Sattar et al. (2021).

Table 6

The Analysis Process in Meta-ethnography as described by France et al. (2019b) and Sattar et al. (2021)

Phase of Analysis	Description
Phase 1: Getting started	Deciding on the focus of the synthesis.
Phase 2: Deciding what is relevant to the initial interest	Defining focus of the synthesis, developing inclusion and exclusion criteria and completing quality assessments.
Phase 3: Reading studies	‘Metaphors’ or themes are identified and recorded. The raw data includes first and second order constructs, these are the quotes from participants and also the primary author’s interpretation of these quotes.
Phase 4: Determining how the studies are related	Studies are compared and recurring concepts are identified.
Phase 5: Synthesising the translations into one another	Starting with an identified index study, subsequent studies are examined for reciprocal and refutational concepts, and metaphors are developed that encompass the concepts described in the original studies.
Phase 6: Synthesising translations	This phase involves producing a ‘line of argument’ or new conceptualisation of the findings.
Phase 7: Expressing the synthesis	Communicating the synthesis to the chosen audience.

Table 6 outlines the analysis process used in this review (See Appendix F and Appendix G for further details). ‘Metaphor’ is a term used by Noblit and Hare (1988) and refers to the concepts, themes and perspectives revealed by qualitative studies, and is used in an attempt to highlight the interpretative nature of meta-ethnography. ‘Line of argument’ refers to the new inferences or interpretations that are produced by the meta-ethnography following the translation and synthesis of the included studies (France et al., 2019b).

CASP scores were used to determine the order in which the papers were read. The software programme NVivo was used during phases 3-5 to record metaphors, enable comparison between papers and to organise and synthesise themes as the analysis developed (Toye et al., 2014). Focus remained on themes that were related to the research question, as described by Erasmus (2014). To maintain the context, the original articles were frequently referred to throughout the analysis process.

During phase 5, studies were arranged according to conceptual richness, beginning with the richest paper. The studies are listed in this order in Table 5.

The synthesised translations were discussed and refined with another member of the research team during Phase 6. To ensure the line of argument was grounded in the primary study data, original articles were reviewed in light of the final line of argument. In terms expressing the synthesis, this review has followed the 'eMERGE' framework to report the findings (France et al., 2019a).

Results

The aim of this review was to examine how women with PCOS experience conventional forms of feminine identity. Following a meta-ethnographic synthesis of the evidence from 15 studies, it was possible to organise the data into three key themes. Firstly, 'identifying difference' makes sense of the various ways in which women with PCOS become aware of and start to recognise that there are aspects of their bodily appearance or their experiences that identify them as 'different' to conventional constructions of femininity in their culture. Secondly, 'meaning' highlights how the women in these studies have attributed meaning to these differences and interpret these differences as threatening their sense of feminine identity. Thirdly, the 'responses' theme identifies the range of approaches that women with PCOS employ to hide differences in their bodily appearance that are viewed as most threatening to their sense of conventional feminine identity. Table 7 below illustrates the relationships between studies and the main lines of argument.

Table 7

Synthesis of Metaphors in Analysis

Themes	Identifying Difference		Meaning		Responses	
Subthemes	Outside In	Inside Out	Threats to Womanhood	Threats to Motherhood	Controlling	Avoidance
Kitzinger and Willmott (2002)	•	•	•	•	•	•
Keegan et al. (2003)	•	•	•		•	•
Pfister and Rømer (2017)	•	•	•		•	•
Naz et al. (2019)		•	•	•	•	
Amiri et al. (2014)	•	•	•	•	•	•
Sharma and Mishra (2018)	•	•	•	•	•	
Hadjiconstantinou et al. (2017)		•	•	•	•	•
Williams et al. (2015)	•	•	•	•	•	
Snyder (2006)		•	•	•	•	
Williams et al. (2014)		•	•	•	•	
Sanchez and Jones (2016)	•			•	•	
Smith-Tran (2018)		•	•	•	•	•
Pathak (2019)				•		
Washington (2008)		•	•	•	•	•
Ee et al. (2020)	•	•	•		•	

Theme 1: Identifying Difference

Fourteen out of 15 papers contributed to this line of argument (See Table 7). This theme is about the way that women become aware of differences by two principal sources. ‘Outside in’ refers to how external influences project messages that women with PCOS are abnormal and ‘inside out’ relates to how outside influences and women’s own observations shape how they see themselves as different.

Identifying Difference: Outside In

Outside influences on feeling different were specifically mentioned in eight out of 15 papers. These influences came in the form of comments from others, cultural notions of freakishness and portrayal of women in the media.

There were several examples of women in these studies referring to incidents where other people, including husbands, acquaintances, medical professionals, female relatives, and strangers in the street, had commented on their symptoms, identifying them as different. “…he [husband] always blamed me for my masculine manners” (Participant, Amiri et al., 2014, p. 4) “…someone passing said ‘oh you need a shave’” (Participant, Keegan et al., 2003, p. 338) “He [dermatologist] told me your hair loss is abnormal” (Participant, Amiri et al., 2014, p. 4). “My in-laws keep taunting me for not having a baby.” (Participant, Sharma & Mishra, 2018, p. 134)

Some studies referred to the concept of the ‘bearded lady’ that participants understood as a joke in society and reported fearing that others will use this cultural reference to ridicule and shame them.

> Facial hair is particularly upsetting for many women with PCOS. The ‘‘bearded woman’’ (Gita’s phrase) is not only ‘‘socially unacceptable’’ (Penny) she is a circus act, a joke, an anomaly: “A woman with a beard is, you know, terrible. [...]I think the hair is the worst thing because it’s visible and it’s so abnormal and quite often there are jokes on the telly about women with moustaches or beards and everything, and I go cold when that happens.” (Helen). (Kitzinger & Willmott, 2002, p. 353)

In some studies, there was reference to the impact of the media on projected ideas about femininity and how a woman "should" be. "If you look at how the media portrays what is feminine, lack of body hair, thinness, and a beautiful complexion, you don't have these with PCOS and wish you did." (Participant, Snyder, 2006, p. 389) "Advertisements for women's depilatory products show only smooth skin—even when representing pre-depilation—and any depilatory activity featured is private, with perhaps the exception of a woman drawing a razor over an already hairless leg" (Snyder, 2006, p. 342). Kitzinger and Willmott (2002) assert that the media has a powerful influence over how the image of femininity is portrayed, and all women are exposed to unrealistic images of female bodies which can affect their expectations of themselves, but women with PCOS perceive themselves to be much further away from achieving these ideals.

Identifying Difference: Inside Out

This subtheme was supported in 13 out of 15 papers. Studies reported that women with PCOS begin to feel that there is something wrong with them, they compare themselves to other women in their lives and use male terminology to refer to themselves.

Women with PCOS internalise the outside influences on their ideas about femininity and identify themselves as abnormal. "…when someone pointed it out to me I immediately thought "oh, there's something not right here" (Participant, Keegan et al., 2003, p. 337) . "My body has a coarse hair male like pattern, which my husband frankly comments on. It really affected me and this makes me very uncomfortable…" (Participant, Amiri et al., 2014, p. 4)

It was apparent that the evidence from several studies showed that women with PCOS compared themselves to other women in their lives and found themselves to be different in terms of their body weight, lack of a regular menstrual cycle, growth of unwanted body hair, acne, heavy and continuous menstrual cycles and severe mood swings. "When I do not get my periods on time I think that something is wrong with me. All my friends get their periods on time" (Sharma & Mishra, 2018, p. 153). "Most of my friends can wash their smooth faces without thinking about the pimple days of the past" (Smith-Tran, 2018, p. 477). "It's hard to look, be different than other women. I feel different because none of my friends have problems like this. I guess with the females in my family, I sort of feel different and like an outcast." (Participant, Snyder, 2006, p. 388)

Authors noticed how the women in their studies adopted "male" terminology to refer to themselves. For example, using the following terms to refer to facial and body hair: "moustache", "5 o'clock shadow", "stubble", "beard", "sideburns", "goatee", "chest mat", "male-type hair" (Kitzinger & Willmott, 2002, p. 353; Pfister & Rømer, 2017, p. 182; Williams et al., 2014, p. 5). Women also used these kinds of phrases to refer to weight distribution, hair loss and their emotions: "man's beer belly" (Williams et al., 2014, p. 5), "male pattern baldness" and "masculine feelings" (Amiri et al., 2014, p. 4). Others joked about turning into men "I've got a very good sense of humour about it because sometimes I swear I'm just like one penis away from turning into a guy" (Participant, Williams et al., 2015, p. 7)

Theme 2: Meaning

The second line of argument is that once women are aware of the differences caused by their PCOS discussed in theme one, this will have meaning to them, primarily influencing their perceptions of themselves as woman and as a mother. All studies in the analysis supported this theme.

Meaning: Threats to Womanhood

Studies referred to participants having a threatened sense of their female identity in 13 out of 15 studies. This involved a perceived loss of physical attractiveness, wanting to feel normal and feeling dehumanised.

Beauty and physical attractiveness were seen as key aspects of conventional feminine identity. "Beauty is very important for a woman" (Participant, Amiri et al., 2014, p. 4). "I just want to feel female. I just want to feel pretty. I just want to feel normal and I don't" (Participant, Keegan et al., 2003, p. 340). "The study findings showed that due to physical effects of the syndrome, especially obesity, hirsutism, hair loss, and acne, most of the women affected had poor unsatisfactory self-body images, besides considering themselves unattractive and feeling ashamed and embarrassed." (Amiri et al., 2014, p. 4). "One implication of this, which is not directly spoken, is that sexually attractive heterosexual women cannot display facial and body hair" (Keegan et al., 2003, p. 339).

Studies identified that women with PCOS are affected by cultural interpretations of normal feminine identity.

> The interviewees appeared to have internalized the cultural norms regarding the "proper" distribution of facial and body hair for women and judged themselves as deviant. Their continuing attempts to regulate themselves, via depilatory practices and/or medical treatments to meet the prescribed criteria for proper womanhood is communicated as conceptually if not practically unproblematic. (Keegan et al., 2003, p. 342)

Women with PCOS reported a desire to be normal, but also questioned the notion of "normal". ''It would be nice to have a normal cycle ... you know, just be normal, whatever normal is''(Participant, Kitzinger & Willmott, 2002, p. 359). In addition to this, some participants who had experiences of living in other cultures outlined how certain symptoms such as body hair, fatigue or risk of diabetes, were more normalised in other cultures.

> But with the facial hair, in Africa it's okay because a lot of women have it. It's just here in England … you have to shave your legs and you have to shave this and that, when back home it's not like that. (Participant, Hadjiconstantinou et al., 2017, p. 326)

It was also apparent that as women internalise ideas about conventional feminine identity, they begin to feel dehumanised. "Their own hairy, unfeminine, monstrous bodies are contrasted with the supposed bodies of normal women" (Kitzinger & Willmott, 2002, p. 354). Women also used creature-like terms to describe themselves such as "completely hairy monster", "gorilla"; "rat's tail"; "monkey" and "beast" (Kitzinger & Willmott, 2002, p. 354; Naz et al., 2019, p. 44; Pfister & Rømer, 2017, p. 181). Women with PCOS were shown to refer to their body hair as "dirty" and hair re-growth and depilatory routines served as a constant reminder to women of their abnormality. ''I come out of the shower every day and look at them [my leg hairs] ….and I have this feeling of dirt'' (Participant, Kitzinger & Willmott, 2002, p. 353). "When I'm hairy, I feel dirty, but when I'm waxed and I'm de-furred, I feel clean and smooth" (Participant, Keegan et al., 2003, p. 340).

Meaning: Threats to Motherhood

This theme was seen in 12 out of 15 papers and related to the importance of regular menstruation, fertility and pregnancy to feminine identity and the cultural challenges to openly discussing these issues.

It was apparent that regular menstrual cycles are understood to be a sign of normal femininity. Kitzinger and Willmott (2002) outline how feminist writings have attempted to undermine the cultural notion that motherhood completes a woman; however, menstruation is still heralded as a unifying experience across women. Some studies identified that women with unpredictable menstrual cycles did not feel like “real” women or reported feeling “like a little girl” with some participants expressing a desire for a normal cycle, and others celebrating when their cycles fell within the usual range. Periods achieved through use of the contraceptive pill are described by participants as “artificial”, “fake” or “false” and contrasted to the “natural”, “normal” or “authentic” bleeding of “regular women” (Kitzinger & Willmott, 2002, p. 356).

A central theme in the articles reviewed, was the importance of motherhood in feminine identity and the fear of infertility. Women described dreaming about having a family from a young age and being devastated by the threat that PCOS brought to these plans. Participants spoke of having “niggles at the back of the mind that it might be harder to get pregnant” (Hadjiconstantinou et al., 2017, p. 325) and being advised by healthcare professionals to start planning for a family sooner. Those who experienced infertility, used phrases such as “failure as a woman”; “waste of space”; “whole purpose of being a woman was gone” and “am I a good enough woman if I can’t have children” (Kitzinger & Willmott, 2002, p. 357).

> It makes me feel quite unfeminine. Because if you were say like to have a Martian land (laugh) and they wanted you to explain in the most basic terms the differences between men and women, it’s that women have kids and men don’t. And so I said to my friend, Helena, I said, ‘‘You know, I might as well be a bloke’’. (Participant, Kitzinger & Willmott, 2002, p. 357)

In some cultures, infertility carries more weight. Marriage and motherhood have traditionally been very important for women in India, and infertile women can be subject to harassment, particularly from their in-laws (Pathak, 2019; Sharma & Mishra, 2018). Amiri et al. (2014) describe that the primary purpose of marriage is to produce children in Iranian culture, and it is felt to be a basic human behaviour. One participant speaks of how in African cultures, infertility is taboo and may lead to rejection from one's community:

> … it's not normal for a woman not to, to have (children), especially in African cultures it's like taboo. I can say like you might be cast out if you can't have any children and people call you names and say things like that. (Hadjiconstantinou et al., 2017, p. 326)

There was also acknowledgement that women from more privileged backgrounds were empowered by the reproductive assistive technology, which is not available to all women with PCOS. "As educated, urban, middle-class individuals, my interlocutors had the economic and sociocultural capital to access reproductive technologies, and they could afford to be proactive about seeking biomedical care" (Pathak, 2019, p. 786). "… "if you encounter difficulties conceiving I won't be able to help much further. It isn't covered by your insurance"… Both she [doctor] and I were constrained by the capitalist, machine-like medical institution" (Smith-Tran, 2018, p. 483)

Cultural taboos surrounding menstruation and fertility also prevent women from openly speaking about these difficulties. "Mother told me that this should not be discussed with anyone, not even with father" (Sharma & Mishra, 2018, p. 132). "I debated incessantly about whether or not to tell her [Mother], but whenever I thought about talking to her about it my palms would sweat" (Smith-Tran, 2018, p. 479)

> … Infertility was a closely guarded secret this was especially so for women who were currently undergoing fertility treatment. ''I don't let people know, because [...] I don't want to feel like a failure or a freak'' (Julia). Amina feels ''ashamed'' of her infertility; Olivia and Brooke describe their embarrassment at requiring fertility treatment: ''I'm embarrassed to sort of say what my symptom is [infertility]. I avoid it'' (Olivia). (Kitzinger & Willmott, 2002, p. 358)

Theme 3: Responses

This theme was supported by 14 out of 15 studies. This final line of argument refers to ways that women with PCOS responded by trying to hide differences in their bodily appearance that were viewed as threats to their feminine identity. This was achieved by trying to manage and control their symptoms and employing avoidance strategies.

Responses: Controlling

Fourteen out of 15 studies provided evidence that young women with PCOS have strategies to maintain their personal feminine identity such as cosmetic and pharmacological treatments to reduce symptoms, efforts to lose weight and efforts to hide their symptoms and management routines from others.

Symptom management routines included: shaving; plucking; laser treatment; contraceptive pills; spironolactone, metformin, wearing makeup and covering their body with clothing. Participants reported spending time, money and thinking on management of symptoms, and some referred to how exhausting these efforts were. "I've spent a lot of money on skin, special skin preparations to cover the areas and whatever, and so I feel my camouflage has been developed pretty well by now" (Participant, Keegan et al., 2003, p. 341)

> Now I have to shave my neck every single morning in the shower. I shave more often than my husband does. If I don't it will be apparent, you can see it and it makes me feel uncomfortable, it's embarrassing to me. (Participant, Washington, 2008, p. 16)

Weight loss efforts were also common, as many women understood that improving weight was likely to improve their periods, mental health and hyperandrogenism. "I have learnt by attending PCOS conferences that eating is very important, especially eating the right things" (Participant, Williams et al., 2014, p. 7).

> A consistent theme across all participants was the long struggle they had had with losing weight and the number of interventions they had tried. (Ee et al., 2020, p. 6)

In addition to steps to manage symptoms, there was a sense that for some participants this needed to be kept a secret. “The image (of a ‘naturally’ feminine woman) must maintain its mystery if it is to remain prevalent, therefore the tools of transformation must be hidden, and practices conducted in private” (Kitzinger & Willmott, 2002, p. 355).

> On the one hand, the participants felt stigmatized while on the other, they successfully adopted the strategy of ‘passing’. However, these women must also negotiate between their public and their private realities. This is reflected in being unable to talk openly about their hair growth. (Keegan et al., 2003, p. 341)

Responses: Avoidance

Seven out of 15 studies supported this subtheme. ‘Avoidance’ refers to how women with PCOS avoid certain activities such as exercise and communal changing facilities, social interaction and sexual intimacy.

Women with PCOS report avoiding exercise, swimming and other activities that make concealing symptoms difficult. “…even when I wanted to go to the gym for swimming (as I like swimming very much), I did not go” (Participant, Amiri et al., 2014, p. 4) “When sweating, it is also difficult for her to hide her facial hair with makeup, so most of the time she leaves out sports and exercise in summer” (Pfister & Rømer, 2017, p. 176).

> If I’m going to the gym or going for a swim and so I have to go and take all my war paint off and then I sort of creep out thinking “Oh God” my face is all red, everybody is going to be looking at me thinking I look a bit strange. (Participant, Keegan et al., 2003, p. 341)

Avoidance strategies also have a significant impact on the social lives of women with PCOS. Women speak of covering their face with their hands, moving quickly to prevent observation, avoiding physical contact, or limiting the social interactions that they engage in. “When someone is talking to me, I feel like they’re looking at my upper lip. I start covering my face or talking to somebody else and then go back to them. I just feel so self-conscious” (Participant, Keegan et al., 2003, p. 341)

Finally, PCOS symptoms have an impact on women’s experiences of relationships and sexual intimacy. Some women report feeling uncomfortable appearing in front of their partner, they also notice decreased sexual desire and enjoyment. “ …that can affect the relationship with my boyfriend because then I’m not comfortable with my body and then it [sex] isn’t fun.” (Participant, Pfister & Rømer, 2017, p. 179). Kitzinger and Willmott (2002) described that it was the feeling as well as the sight of body hair that caused problems in intimate relationships. Participants reported that they would not want their partner to touch them when they perceive their hair to be ‘prickly’, ‘spiky’ or ‘stubble’.

> … (I’ve) had lots of discussions (with partner) about that and the impact it has on my overall confidence which then has an impact on our sexual relationship because I don’t feel confident, I don’t feel sexy so why would anybody else think I look sexy…(Hadjiconstantinou et al., 2017, p. 326)

> … [I’m] bashful towards men no matter what, I mean to show my body. And in this case PCOS … has set a limit to my whole life … I mean in relation to love life and sex life and things like that” (Participant, Pfister & Rømer, 2017, p. 179)

Discussion

This systematic literature review aimed to explore how women with PCOS experience conventional forms of feminine identity. According to the evidence drawn from this synthesis, women with PCOS may firstly identify their symptoms as indicators of being different from other women in two ways: outside-in influences such as comments from other people and media portrayals of femininity; and inside-out where a woman compares herself to other women and likens herself to men. These differences may then be given meaning in terms of threats to womanhood such as loss of physical attractiveness, not meeting cultural norms of femininity and feeling dehumanised; and threats to motherhood in terms of irregular menstrual cycles and infertility. Women with PCOS may respond to these observed differences and associated threats to female identity by controlling their symptoms via cosmetic and pharmacological interventions and weight loss; and by avoiding others detecting their symptoms by not exercising, minimising social interactions, and evading sexual intimacy. As there have been no previous systematic literature reviews in this area, a useful way of interpreting these findings is to discuss them within the context of what psychology currently understands about notions of self and social identity, and physical and mental health distress.

Relation to Previous Literature

Identity can be defined as an individual and socio-cultural self-perception that fluctuates over time and is related to a sense of belonging (Urrieta & Noblit, 2018). Two forms of positioning are thought to be important in the development of identity. Firstly, individuals will, in themselves, recognise characteristics that they believe constitutes membership of a particular identity and will use self-management to present themselves in a way that makes sense with this interpretation (Urrieta & Noblit, 2018). This is apparent in the way some women with PCOS respond to the threats to their femininity. They can spend time, money and effort controlling and concealing their symptoms to ensure they can present themselves in a culturally acceptable version of femininity. The second form of positioning, is other positioning, where others in an individual's social world will impose a label on them (Urrieta & Noblit, 2018). It is clear, that women with PCOS can be mindful of the comments and judgements of others in their environment and could fear being positioned in a way that would threaten their feminine identity.

Butler (2011) describes gender as a series of attributes rather than a noun that one can 'be', therefore there is no female beyond the person enacting attributes their culture understands to be female. Individuals who cannot be recognised according to these norms, are deemed 'unintelligible' and the very personhood of the individual is questioned. This was reflected in this review, where women with PCOS used dehumanising and animal-related terminology to refer to themselves. Likewise, in a meta-study of women who have undergone hysterectomy, participants similarly referred to themselves using animal imagery (Garside, 2008).

Gender identity is understood to be regulated by cultural norms, and traditionally cultures have been dominated by masculine, heteronormative power with reproductive narratives (Butler, 2011). Therefore, when a woman's physical attractiveness and ability to bear children is threatened, this is likely to affect her feminine identity. However, the traditional patriarchal, heterosexual, binary interpretation of gender is beginning to change with non-binary gender identities being acknowledged (Thorne et al., 2019). Consequently, as more diversity in sexuality and gender expression becomes more socially acceptable, and potentially ‘culturally intelligible’ it is possible that cultural regulation of feminine identity may adapt in ways that is positive for women with PCOS.

Outside of the academic understandings of identity, the experience of conventional feminine identity for women with PCOS clearly causes significant psychological distress and has wide ranging implications for both their physical and mental health. The finding that women with PCOS may avoid exercise as a way of managing their feminine identity, is an important finding as weight loss is at the crux of PCOS management (Hoeger et al., 2021). Exercise has been shown to bring about improvements in insulin resistance, risk of cardiovascular disease, reproductive function and psychological wellbeing in women with PCOS (Woodward et al., 2020). Therefore, this finding is significant.

Additionally, this study has identified that some women with PCOS enact weight loss efforts to control their symptoms and maintain their sense of feminine identity. An etiological integrative model of binge eating and PCOS has hypothesised that in addition to the physiological aspects that leave women with PCOS vulnerable to binge eating, deviation from cultural norms is likely to induce problems with self-esteem, body dissatisfaction and body shame that may precipitate and perpetuate binge eating disorders (Paganini et al., 2018). This hypothesis is supported by evidence that both overweight and normal weight women with PCOS are more likely to report body shape concerns compared to controls, and exhibit restricted eating habits, which puts them more at risk of eating disorders (Başar Gökcen et al., 2020).

Finally, this review has identified that some women with PCOS may resort to avoiding social interactions to manage their feminine identity. There is evidence that women with PCOS have higher rates of social phobia, panic disorder and score higher than normal controls on scales of social avoidance and distress (Barry, 2019). These interpersonal problems can leave women with PCOS vulnerable to low mood and social isolation. Women with PCOS are more likely to be given diagnoses of personality disorders, autism spectrum disorders, psychotic illnesses and suicidal behaviour (Barry, 2019; Cesta et al., 2016).

Clinical Implications

The main implication of these findings is the need for a greater awareness of the psychological impact of PCOS symptoms in healthcare settings and for the public. Women with PCOS often report that healthcare providers do not take their symptoms seriously or show a lack of empathy in their care (Blackshaw et al., 2019; Williams et al., 2015). Kitzinger and Willmott (2002) suggest that the way that medical professionals present PCOS in terms of ‘excess male hormones’ may contribute to the feelings of abnormality of women with PCOS. It is recognised that the name ‘Polycystic Ovary Syndrome’ is misleading and an alternative name may help to educate health professionals and the public about the metabolic risk factors and lifestyle interventions that are relevant to this condition (Teede et al., 2014). However, no consensus has been reached on a suitable alternative, as there are no universal clinical features common to all women with PCOS (Azziz, 2014).

This review provides support for clinical psychologists to be involved in the design of psychoeducational materials about symptom management that validate concerns, provide practical advice but also gently challenge conventional ideas about feminine identity. Post diagnostic support with online or in-person support groups may provide a platform for women with PCOS to share strategies and advice with one another and normalise their experiences with PCOS symptoms. Collaboration between the NHS and third sector organisations and charities may help to support these efforts.

Previous literature has established links between PCOS and anxiety, depression and eating disorders (Dokras et al., 2018). Therefore, it is likely that mental health professionals will encounter many women with this common endocrine disorder and may wish to enquire about the impact of their symptoms on their feminine identity. The main findings of this review- difference, meaning and response- relate to existing models of psychological distress. For example, the power, threat, meaning framework (Johnstone et al., 2018) and compassion focussed therapy formulations (Lee & James, 2012) both acknowledge interpersonal sources of power that may lead to certain threats or fears; individuals then find ways to manage and keep themselves safe from these fears; which may then have unintended consequences on their quality of life. Third wave CBT approaches such as acceptance commitment therapy or compassion focussed therapy may be useful for improving acceptance, self-compassion and body image (Moradi et al., 2020; Seekis et al., 2019). Such interventions have been associated with improvements in weight, emotional eating, binge eating, anxiety, depression, stress and quality of life in individuals who are overweight (Lawlor et al., 2020).

There is also a need to improve the relationship between women with PCOS and exercise. Studies have found that adolescent girls in general can find that body image concerns and low confidence can cause avoidance behaviour in school physical education classes (Carmona et al., 2015). Part of the issue can be related to communal changing facilities and the lack of opportunities to reapply makeup and style hair following classes (Robbins et al., 2003). Menstruation has also been shown to affect how women engage with exercise (Kolić et al., 2021). Schools play an important role in introducing girls to exercise, and policies should be developed to encourage sensitive enquiry when students show a reluctance to engage in exercise and develop plans to encourage their participation. There may be a role for group sessions for girls to discuss their worries about exercise together. Sporting facilities in schools and public sports centres should consider private washing and dressing facilities where possible.

Conclusion

Strengths

This review is the first qualitative synthesis in the area of PCOS research and was informed by recent guidelines concerning the procedure and reporting of meta-ethnography (France et al., 2019a, 2019b; Sattar et al., 2021). Evidence from 15 studies, with a total of 231 participants informed the final line of argument. This study suggests that women with PCOS may identify difference in relation to their conventional feminine identity from internal and external influences, this may then be ascribed meaning in terms of threats to womanhood and motherhood; which may lead to responses such as controlling symptoms or avoiding particular activities.

Limitations

There were three main limitations to this review. Firstly, the included papers were heterogenous in terms of their geography and research aims, while this did provide a broad overview of the area, a narrower focus may have led to more detailed and specific findings. Secondly, the articles contained limited information on reflexivity which limited the extent to which the findings could be contextualised with the author’s position. Finally, although measures were taken to the limit the impact, the majority of this synthesis was completed by one researcher, and so did not benefit from the perspectives of others at all stages of the analysis.

Reflexivity

Please see Chapter 3 for reflections on issues of reflexivity.

Recommendations for Future Research

There is evidence to suggest that body positive advertising campaigns can improve self-esteem and mood in women (Selensky & Carels, 2021). Recent trends have seen advertising campaigns that depict menstrual blood and body hair (Gurrieri, 2020). Future studies could evaluate the impact of such adverts on the self-esteem and body image of women with PCOS. This would lead to potential interventions in the form of social media campaigns.

In addition to this, the studies reviewed focussed heavily on the experiences of cis-gendered, heterosexual women with PCOS. There is a need for more qualitative research into the perspectives of those with PCOS who identify with other sexual orientations and gender identities and how their symptoms may impact on their experiences of gender identity.

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Chapter II: Empirical Paper

Factors Affecting Suicidality in Young Women with Polycystic Ovary Syndrome (PCOS): A Mediation Analysis

This chapter will be adapted for submission to Health Psychology Open.

See Appendix H for author instructions.

Overall chapter word count at submission (excluding abstract, tables, figures and references): 8,344

Abstract

BACKGROUND: Polycystic Ovary Syndrome (PCOS) is a common endocrine disorder that affects women. Symptoms include menstrual irregularity, hirsutism (excess hair growth), acne, androgenic alopecia (loss of hair on the head), reduced fertility and obesity. Those with PCOS have consistently been shown to report greater symptoms of depression, anxiety and poorer quality of life compared to the general population, and an association between PCOS and an increased risk of suicidal behaviour has been established. The interpersonal theory of suicidal behaviour describes the importance of two interpersonal constructs: thwarted belongingness and perceived burdensomeness in the development of suicidality. AIM: To determine whether the distal psychosocial constructs (poor quality of life and depressive symptoms) and the proximal interpersonal constructs (thwarted belongingness and perceived burdensomeness) mediate the relationship between PCOS symptom severity and suicidal behaviour in young women with PCOS. METHODS: 618 participants with PCOS aged between 18-40 years completed an online survey which assessed PCOS symptoms (mPCOSQ); depressive symptoms (PHQ-9); quality of life (WHOQOL); thwarted belongingness and perceived burdensomeness (INQ-15) and suicidal behaviour (SBQ-R). RESULTS: Sequential mediational analysis provided evidence that the relationship between PCOS symptom severity and suicidal behaviour is mediated by quality of life, depressive symptoms, thwarted belongingness and perceived burdensomeness. CONCLUSION: These results suggest the importance of screening young women who present with symptoms of depression for signs of thwarted belongingness and perceived burdensomeness. Collaboration with third sector and voluntary organisations is recommended to provide social support, practical advice and psychoeducational materials for young women with PCOS.

Introduction

Research Aims and Significance

Polycystic Ovary Syndrome (PCOS) is a common endocrine disorder that affects up to 21% of women of a childbearing age (Lizneva et al., 2016). A formal diagnosis of PCOS requires that at least two of the three following conditions are present: oligo- or anovulation (Irregular or absent ovulation); clinical or biochemical signs of hyperandrogenism (Elevated levels of androgens) and polycystic ovaries (Fauser, 2004). In turn, these biological maladies tend to give rise to a combination of symptoms including: menstrual irregularity, hirsutism (excess hair growth), acne, androgenic alopecia (loss of hair on the head), reduced fertility and obesity (Rodriguez Paris & Bertoldo, 2019).

Women with PCOS describe struggling to negotiate their identity as 'embarrassing' symptoms often take the individual further away from cultural ideas about the female body (Wright et al., 2020). Qualitative studies have described how women with PCOS can feel 'freakish' and 'abnormal' (Kitzinger & Willmott, 2002). In addition to this, some people with PCOS report experiences of discrimination, bullying and microinvalidations (Otusanya, 2020) and describe feeling lonely and misunderstood (Jiskoot et al. 2019). As a result, those with PCOS have consistently been shown to report greater symptoms of depression, anxiety and to experience a poorer quality of life compared to the general population (Dokras et al., 2018).

Despite NICE guidelines indicating the importance of screening women with PCOS for signs of anxiety and depression (National Institute for Health and Care Excellence, 2018); many health professionals continue to have limited awareness of the condition and its potential psychological impact (Crete & Adamshick, 2011; Tomlinson et al., 2017).

One possible psychological consequence is suicidal behaviour, also referred to as suicidality, which can be understood in terms of a continuum from experiencing occasional thoughts or ideas about killing oneself, to having intentional plans about ending one's own life, and, for some, making actual attempts to die (Sveticic & De Leo, 2012).

In the UK, around a fifth of adults report they have had thoughts of taking their own life (McManus et al., 2014). Around 8% of women report a suicide attempt at some point in their life, with the rate of suicide attempts reported by young women aged 16-24 being notably higher (McManus et al., 2014). There is also compelling evidence demonstrating a causal link between mood disorders, especially depression, and suicide (San Too et al., 2019). As a result, the association between PCOS and suicidality may constitute a substantive risk. However, the nature of this causal pathway association has not yet been empirically tested.

Evaluation of the Previous Literature

Previous literature has established a direct association between PCOS and suicidality. Two studies have used the MINI International Neuropsychiatric Interview (Sheehan et al., 1998) to demonstrate that women with PCOS are more likely to report suicidality compared to control groups (Hussain et al., 2015; Månsson et al., 2008). Data from genetic linkage studies have also shown an increased risk of attempted suicide in women with PCOS and their sisters (Cesta et al., 2016). Adolescents with PCOS have also been shown to be twice as likely to report suicidal thoughts (Almis et al., 2020).

The Androgen Excess- Polycystic Ovary Syndrome Society developed a position statement which included a systematic review of literature concerning health related quality of life (HRQOL) in women with PCOS (Dokras et al., 2018). This statement outlined consistent evidence that women with PCOS experience reduced HRQOL compared to control groups. Adolescent girls with PCOS have also been found to have reduced quality of life (Kaczmarek et al., 2016; Wilson & Pena, 2020), however some studies have not identified any differences in this age group, compared to adolescent controls (Coban et al., 2019). Several studies have assessed the impact of specific symptoms in PCOS and found that women with PCOS show a poorer quality of life compared to women without PCOS who experience the same symptoms such as obesity (Coffey, 2006) and/or infertility (Naumova et al., 2020; Santoro et al., 2016).

Associations between PCOS symptoms and depression are well established (Ali et al., 2018; Nayar et al., 2019; Shi et al., 2011). The position statement by Dokras et al. (2018) asserts that women with PCOS have a higher prevalence of clinically significant depressive symptoms, that cannot be fully accounted for by infertility, obesity and androgen excess.

The directional relationship between quality of life and depression has not been empirically validated and is likely to be bi-directional. For example, depression and psychological distress have been observed to be the biggest contributors to poor quality of life in women with PCOS (Karjula et al., 2020; Sidra et al., 2019) and in other populations, quality of life has been shown to predict depressive symptoms (McIntyre et al., 2019; Riaz et al., 2016). In addition to this, there is evidence that depression may affect the way that women with PCOS perceive their quality of life (Greenwood et al., 2018). In the current study, it is hypothesised that women with greater PCOS symptom severity will experience a greater impact on their quality of life, which in turn increases the risk of depressive symptoms.

Rationale

The existing literature base has four key limitations, which will be addressed in the current study:

1) The association between PCOS and suicidality has been broadly established, however the link is assumed to be direct. No studies have considered the possibility of causal paths between PCOS and suicidality, for example, the mediating role of quality of life and depression, which have both been shown to be important distal causal factors in other suicide studies (Joshi et al., 2017).

2) Previous studies have not attempted to account for the principal theories of suicidality and the influence of their key proximal variables on suicidal behaviour. To address this, the current study will be informed by the interpersonal theory of suicidal behaviour (IPTS), which asserts the importance of two factors, ‘Thwarted Belongingness’ (TB) and ‘Perceived Burdensomeness’ (PB) (Van Orden et al., 2010). TB refers to the unmet need for social connectedness. Social isolation has long been recognised as a risk factor for suicidality and those who feel rejected are more likely to engage in self-defeating behaviour, including suicidal behaviour (Van Orden et al., 2010). PB refers to low self-esteem and the perception that one is a burden to their loved ones, and has been shown to be triggered by family conflict, unemployment and physical illness (Van Orden et al., 2010). Numerous studies have

demonstrated the importance of PB as a proximal causal factor in suicidal behaviour (Brailovskaia et al., 2019; Chu et al., 2017; Damirchi et al., 2019; Kinory et al., 2020; Zhao et al., 2020). In fact, a recent systematic review suggested that the relationship between suicidal ideation and PB has been established across 82.6% of the studies examined (Ma et al., 2016).

3) The existing literature has not considered the wider context, for instance the contributing role of factors such as age, relationship status, employment status, ethnicity and education (Alves et al., 2016; Eikelenboom et al., 2019). The current study will include these variables as co-variates.

4) Previous research usually only includes a one-dimensional measure of suicidality, usually suicidal ideations (Ma et al., 2016). This study will use the Suicide Behaviours Questionnaire-Revised (SBQ-R) which takes a multi-level approach and looks at past suicidal conduct (thoughts, plans, attempts), current suicidal ideations, suicidal threats and perceived future suicidal risk (Osman et al., 2001).

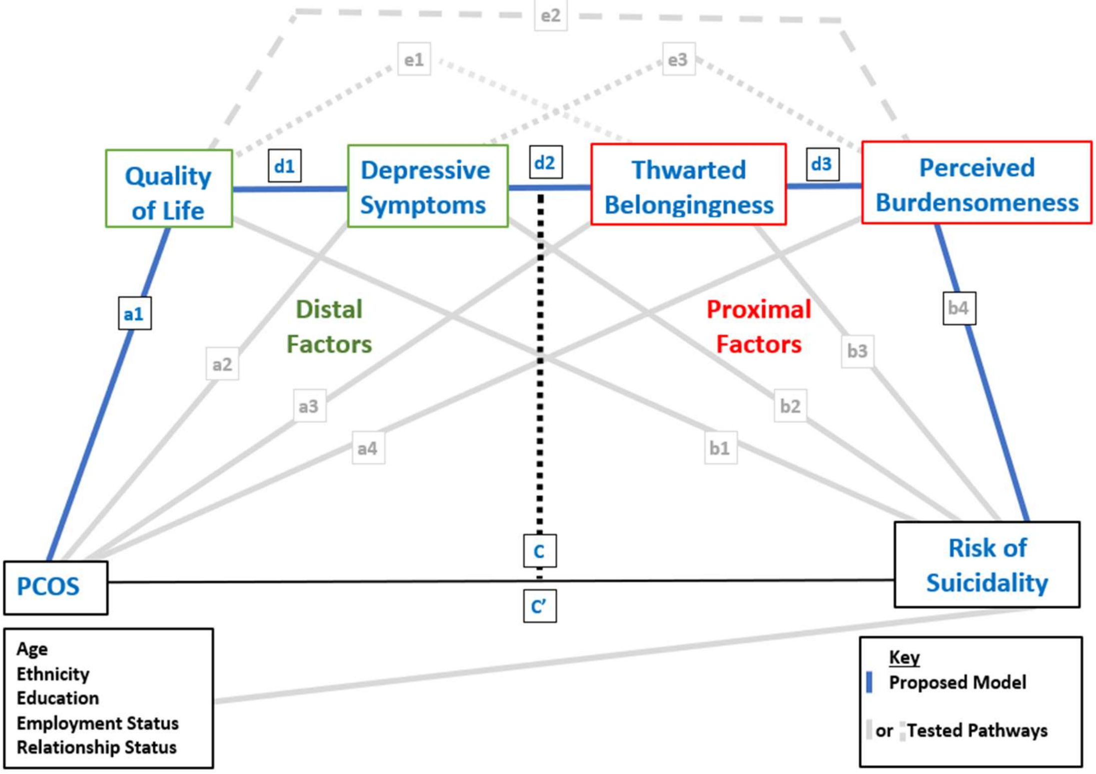
Research Question and Hypotheses

The research question that this study aims to investigate is:

Do the distal psychosocial constructs (poor quality of life and depressive symptoms) and the more proximal interpersonal constructs (TB and PB) mediate the relationship between PCOS symptom severity and suicidal behaviour in young women? (See Figure 2 below)

Figure 2

The Sequential Mediational Relationship between PCOS and Risk of Suicidality: Distal and Proximal Variables



In an effort to test this theoretical risk prediction model, the following hypotheses will be tested:

1. Young women with severe PCOS symptoms will experience a poorer quality of life (QOL). (Figure 2, path- a1)
2. Young women who experience a poorer QOL will be more vulnerable to depressive symptoms (Dep). (Figure 2, path- d1)
3. Young women who are more vulnerable to depressive symptoms will experience thwarted belongingness (TB) (Figure 2, path- d2)
4. Young women who experience TB will also experience perceived burdensomeness (PB) (Figure 2, path- d3)
5. Young women who experience PB will be most at risk of suicidal behaviour (SB). (Figure 2, path- b4)

Methods

Research Design

This study is organised around the principles of positivism. This epistemological position relies on operationalising phenomenon of interest into variables that can be measured and establishing relationships via statistical analysis, in order to make generalisations and predictions about the nature of these phenomenon (Chirkov, 2016). Therefore, the conclusions generated by this study are assumed to provide a more generalised understanding of the associated causal factors of suicidal behaviour.

The study uses a cross-sectional design which examined a group of participants at one time point (Blischke & Murthy, 2014). The advantage of this design is that it enabled the study of a large sample population in a cost-effective way. Furthermore, even though the sample was not extracted using probability methods, and therefore cannot be said to be fully representative of the universal population, survey designs help reach a large number of participants within pre-defined inclusion criteria (Mendoza, 2014).

Sampling Design

This study employs non-probability sampling, which means that the process of choosing participants did not include randomisation (Cunningham et al., 2013). Within this design a purposive sample was used, this strategy involves setting criteria to specifically target a group of people who have relevant knowledge or experiences related to the phenomenon of interest (Etikan et al., 2016). The advantage of using this particular sampling design and method for the current study is that it enabled us to recruit a large, homogenous group of people with experiences relevant to the research question.

This study was supported by the UK charity, Verity, who support women with PCOS. An advert was posted on their research blog and social media feeds, inviting participants to take part and providing the link to the online survey.

Table 8
Inclusion and Exclusion Criteria

Criteria	Inclusion	Exclusion
Sex	Female	Male
Age	18-40 years	Under 18 years, Over 40 years
Condition	Self-reported diagnosis of PCOS, meeting Rotterdam criteria	No diagnosis of PCOS
Language	English speaking	Non-English speaking

It can be seen from Table 8, that the sample was determined by four inclusion criteria. Only female participants were included as PCOS is a condition that only affects women. Due to the sensitive nature of the study, women under 18 were not included due to ethical concerns about adolescent women's ability to provide informed consent and capacity to seek appropriate support if required. Women over the age of 40 were excluded because menopausal and perimenopausal symptoms can affect menstrual cycles, fertility, mood and quality of life, and less than 1% of women would be expected to begin the menopause process prior to the age of 40 (National Institute for Health and Care Excellence, 2015). This study required participants to have a diagnosis of PCOS, therefore women who wished to participate were asked to self-report that they had been given this diagnosis. English speaking participants were recruited as there were no resources to adequately translate the materials.

Participant Characteristics

Recent meta-analyses suggest that the pooled effect sizes of both depression and quality of life are large in women with PCOS (Yin et al. 2021). A power analysis using the programme G*Power, indicated that a total sample of 131 participants would be required to detect a large effect size (*d*=0.55) with 99.9% power, using a linear multiple regression with 11 predictor variables and alpha set at .001. A total of 618 participants completed the study.

Table **9** shows the characteristics of this sample.

Table 9

Participant Characteristics

Demographic Variable	*N* (%)
Age	
18-24	117 (18.93)
25-29	187 (30.26)
30-34	173 (27.99)
35-40	141 (22.82)
Ethnicity	
White British/ English/ Northern Irish/ Scottish/Welsh	522 (84.50)
White- Other	30 (4.90)
Mixed/Multiple ethnic background	25 (4.00)
Asian/Asian British	26 (4.20)
Black/African/Caribbean/Black British	9 (1.50)
Any other Ethnic Group	5 (0.80)
Employment	
Full-Time	392 (63.40)
Part-Time	96 (15.50)
Full-Time Mother	26 (4.20)
Student	59 (9.50)
Unemployed	41 (6.60)
Relationship Status	
Married/ Civil Partnership with children	102 (16.50)
Married/Civil Partnership with no children	121 (19.60)
Cohabiting with children	40 (6.50)
Cohabiting without children	155 (25.10)
In a relationship, not living together	73 (11.80)
Separated/Divorced/Not currently in a relationship	39 (6.30)
Never lived with a partner or been married/civil partnership	18 (13.90)
Education	
Degree Qualification or higher	318 (51.50)
Higher National Certificate or Diploma	108 (17.5)
A-Levels or equivalent	122 (19.70)
GCSEs or equivalent	60 (9.70)
Other qualifications	4 (0.60)
No formal qualifications	2 (0.30)
BMI	
<20	3 (0.50)
20-24.9	97 (15.70)
25-29.9	98 (15.90)
30-39.9	240 (38.80)
≥40	133 (21.50)

As can be seen in Table 9, participant ages ranged between 18-40 with a mean age of 29.7 and standard deviation of 5.4. The 25-29 years age range was the most well represented age group in this study with 30.26% of participants falling in this category. The least represented age group was 18-24 years, with 18.93% of participants in this age range.

In terms of ethnicity, the participants were reasonably representative of the general population, with 89.4% of the sample identifying as White, 4.2% as Asian, 1.5% as Black, 4% as Mixed and 0.8% as Any Other ethnicity. Census data from 2011 shows that 86% of the population in England and Wales identifies as White, 7.5% as Asian, 3.3% as Black, 2.2% as Mixed and 1% as Other (Office for National Statistics, 2020b).

The majority of the sample were employed (63.4% full-time, 15.5% part-time), which is comparable to the estimated employment rate for women (72.0%) in England and Wales in 2020 (Office for National Statistics, 2021).

In terms of relationship status, 36.1% of the sample were married and 31.6% were cohabiting and 32% were not currently living with a partner. The sample presented here is more likely to be married or cohabiting compared to the national estimates for women aged 16-40 in England and Wales, where 30.6% are married, 21.6% cohabiting and 47.8% not currently living with a partner (Office for National Statistics, 2020a).

Our sample was slightly over-representative of more educated groups, with 51.5% of the participants holding a degree level qualification, compared to 42% of adults in England and Wales with this level of education (Office for National Statistics, 2017).

In terms of body mass index (BMI), 76.20% of this sample had a BMI in the overweight, obese or severely obese range. This aligns with the literature, which suggests that between 38-88% of women with PCOS are overweight or obese (Barber et al., 2006).

Measuring Instruments

The online survey was comprised of the following five measures:

- **Modified Polycystic Ovary Syndrome Questionnaire (mPCOSQ; Barnard et al., 2007).**

  The mPCOSQ developed by Barnard et al. (2007) is a 30-item questionnaire based on the PCOSQ (Cronin et al., 1998). The original PCOSQ focused on the symptom areas of emotions, body hair, weight, infertility, and menstrual problems; and the mPCOSQ has included a measure of distress related to acne. Participants are asked to indicate the degree to which they have been bothered by specific symptoms in the previous two weeks. The original PCOSQ showed good test re-test reliability ranging from .89 to .95. The mPCOSQ has good internal consistency with Cronbach's α= .73 (Barnard et al., 2007). In the current study, the Cronbach's alpha coefficient value was .89, which demonstrates high internal consistency (Hinton et al., 2014).

  For the purposes of this study, the questionnaire has been adapted to ask about symptom severity over the past 6 months. The response scale is a 7-point Likert scale with options ranging from 1 'All of the time'/'Severe Problem' to 7 'None of the time'/'No problem'. This measure represented the study's independent variable. A composite score was created for each participant by adding together the symptom severity scores for each of the six symptom areas: emotional disturbance; weight; hirsutism; acne; fertility; menstrual symptoms and menstrual predictability. This reflects the fact that women with a diagnosis of PCOS tend to suffer multiple symptoms at the same time each with different degrees of seriousness (Elsenbruch et al., 2006). See Appendix I, page 141.

- **Patient Health Questionnaire (PHQ-9; Kroenke et al., 2001).**

  The PHQ-9 is the most evaluated screening tool for depression (El-Den et al., 2018) and is commonly used in research as a self-report measure of depressive symptoms (Thorp et al., 2020). The questionnaire consists of nine items which ask participants about their depressive experiences over the past two weeks. The response scale is a four-point ordinal scale ranging from 0 'not at all' to 3 'nearly every day'. This self-report questionnaire asks participants about the symptoms experienced over the past two weeks. Test re-test reliability has been found to range from .84-.94 and internal consistency ranges from .67-.94 (El-Den et al., 2018). In the current study, the Cronbach's alpha coefficient value was .85, which demonstrates high internal consistency (Hinton et al., 2014). See Appendix I, page 149.

- **The World Health Organization Quality of Life Scale (WHOQOL Group, 1998).**

  This 26-item measure is abbreviated from the 100 item WHOQOL-100 (World Health Organization, 1995). There are four domains: physical, psychological, social and environment. Respondents are asked to indicate their level of satisfaction with aspects of their life using a 5-point Likert scale, with options ranging from 1 'Very poor'/'Not at all'/'Very dissatisfied' to 6 'Very Good'/'An extreme amount/ 'Very satisfied'. Cronbach's α has been found to be marginal for the social domain (.68) but good (>.80) for the other three domains (Skevington et al., 2004). In the current study, the Cronbach's alpha coefficient value was .85, which demonstrates high internal consistency (Hinton et al., 2014). Ten relevant items were chosen for inclusion in the survey, covering the domains of bodily appearance, personal relationships, sex life, sleep, health, and overall attitudes towards one's quality of life. See Appendix I, page 154.

- **Interpersonal Needs Questionnaire (INQ-15; Van Orden et al., 2012) .**

  The INQ-15 is a 15 item self-report questionnaire that measures two key constructs within the interpersonal psychological theory of suicidality (IPTS): thwarted belongingness (TB) and perceived burdensomeness (PB). This measure utilises a 7-point Likert scale, with options ranging from 1 'Very untrue for me' and 7 'Very true for me'. The INQ-15 is one of the recommended versions of the INQ for research purposes (Hill et al., 2015). Internal consistency has been shown to be good with Cronbach's α ranging between .75 and .90 (Hill et al., 2015). In the current study, the Cronbach's alpha coefficient value was .89 for the TB domain and .96 for the PB domain, which demonstrates high and excellent internal consistency (Hinton et al., 2014). See Appendix I, page 150.

- **Suicide Behaviours Questionnaire-Revised (SBQ-R; Osman et al., 2001)**

  The SBQ-R is a four item self-report questionnaire that asks about previous history of suicidal thoughts or attempts, recent history of suicidal ideations, history of threats to commit suicide and future likelihood of attempting suicide. This measure has been validated using high school students, adolescent psychiatric inpatients, adult psychiatric inpatients and undergraduate students. Internal consistency is strong and ranges from .76-.88 (Osman et al., 2001). In the current study, the Cronbach's alpha coefficient value was .86, which demonstrates high internal consistency (Hinton et al., 2014). This measure represented the dependent variable in this study. See Appendix I, page 153.

Participants were also asked for basic demographic information such as age, height, weight, employment status, relationship status, ethnicity and highest level of education. Appendix I, page 142.

Methods of Data Collection

The secure platform Online Survey (Formerly Bristol Online Survey) was used to host the questionnaire measures. Participants used a link to access the survey and answered via a fixed response format. On average, it took participants 13 minutes and 36 seconds to complete the survey. The survey opened on 24th April and closed on 30th November 2020. Data was collated and exported into SPSS for analysis.

The advantage of using an internet-based questionnaire was that participants could choose when to complete the questionnaire and there is less risk of interviewer bias (Das et al., 2018). In terms of disadvantages, there is a greater self-selection bias with internet surveys, and lack of internet or lack of reliable internet access may affect participation from certain age groups or ethnicities (Das et al., 2018).

However, there is evidence that 99% of adults aged under 44 in the UK had access to the internet in 2019 (Office for National Statistics, 2019). No negative feedback was received regarding difficulties completing the survey.

Ethical Considerations

Participants were shown an information sheet at the beginning of the survey, which outlined the purpose of the study and the potential risks involved (See Appendix I, page 138). A series of forced response questions were then presented which records explicit confirmation of informed consent (See Appendix I, page 141). These questions included:

- I have read and understood the above information. I agree to take part in this questionnaire survey. I confirm that I am aged 18 or over.
- I recognise that I will be asked sensitive questions which may cause some distress.
- I understand that I can stop participating in the study at any time by simply exiting the survey.

There was a possibility that the discussion of distress and suicidality might have brought about heightened emotion for participants. The potential for distress was clearly stated in the participant information sheet and consent form to warn participants of the potential for distress and reminding them of their right to withdraw at any time. A comment reminding participants they can save their progress and return at another time was added at the bottom of each page of the survey. In addition to this, the debriefing information presented at the end of the study included sources of help such as helpline numbers, as well as information on how to express concerns about the nature of the study (See Appendix I, page 156).

This study was guided by the British Psychological Society code of conduct for research (The British Psychological Society, 2014) and was approved by Coventry University Ethics Committee (See Appendix J).

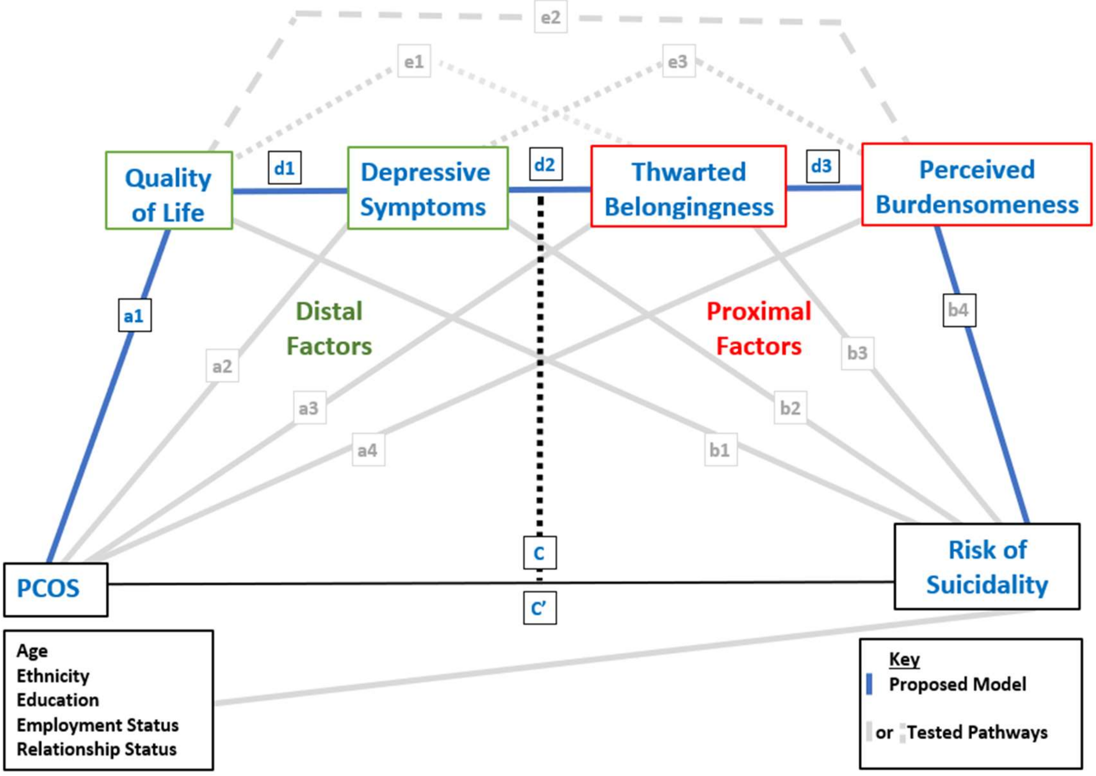
In terms of data protection, the platform Online Survey is GDPR compliant, and data was stored on the Coventry University OneDrive storage facility. Only the research team have had access to the data. Participants were assigned a participant number only and no identifying information was collected. Data will be retained and destroyed according to the policy of the Coventry University clinical psychology department.

Methods of Data Analysis

The aim of this study is to test a theoretical risk prediction model of suicide in young women with PCOS. The variables included in this model are presented in Figure 3.

Figure 3

The Sequential Mediational Relationship between PCOS and Risk of Suicidality: Key Variables and Covariates



As can be seen in Figure 3, the main theoretical model to be tested is the independent variable PCOS (X), the four mediating variables: quality of life (M1), depressive symptoms (M2), thwarted belongingness (M3), perceived burdensomeness (M4), and the dependent variable risk of suicidality (Y).

Data from the Online Survey was collated into an SPSS Version 25 data file and the PROCESS macro was used to carry out a sequential mediational analysis (Model 6). Confidence intervals were generated using bootstrapping set at 5,000 samples (See Appendix K).

The data was cleaned, missing data was checked and was below 0.5% for each measure. A total score was calculated for each measure and this composite variable was then used to carry out the mediation analysis. The data met the statistical assumptions required for regression except for normality, where the distributions tended to be skewed. This is not unusual for many psychological variables (Cain et al., 2017). However, the use of confidence intervals via bootstrapping helps to adjust for this.

All analyses were performed using the following covariates: relationship status, employment status, age, ethnicity, and education. Due to the large sample size and number of variables, a significance level of $p<.001$ was used. This runs the risk of Type 1 errors but also ensures that the study results are interpretable by removing statistical 'white noise' generated by lower significant probability values.

While PROCESS does not require evidence of a correlational association between the study's principal variables, mediational analysis is still vulnerable to the effects of multicollinearity. The matrix below shows that there is a strong relationship between all the key variables.

Table 10

Correlations between Mediator Variables and Suicidality

Variable	PCOS Symptoms	Quality of Life	Depressive Symptoms	Thwarted Belonging	Perceived Burden	Suicidal Behaviour
PCOS Symptoms	1	.49***	-.46***	-.35***	-.34***	-.24***
Quality of Life	.49***	1	-.57***	-.74***	-.57***	-.45***
Depressive Symptoms	-.46***	-.57***	1	.54***	.53***	.44***
Thwarted Belonging	-.35***	-.74***	.54***	1	.63***	.47***
Perceived Burden	-.34***	-.57***	.53***	.63***	1	.69***
Suicidal Behaviour	-.24***	-.45***	.44***	.47***	.69***	1

Note. *** p<.001, 2-tailed.

As can be seen in Table 10, the variables were all significantly correlated with one another. PCOS symptom severity showed a small correlation (r=-.24) with suicidal behaviour (Cohen, 1992). Correlations between the other mediating variables ranged from small correlations (PCOS symptoms and PB, *r*=-.34) to large (Quality of life and TB, *r*=-.74) It is worth noting, that while strong correlational relationships were found between these variables, with the exception of quality of life and TB, none have exceeded 0.7, therefore, there is less risk of violating the assumption of multicollinearity (Hanushek et al., 1977). In addition to this, collinearity statistics were reviewed, see Appendix K, page 162. No tolerance values were below 0.1 (.36-.91) and no VIF values exceeded 10 (1.09-2.82), indicating no need for further investigation into multicollinearity (Ho, 2014).

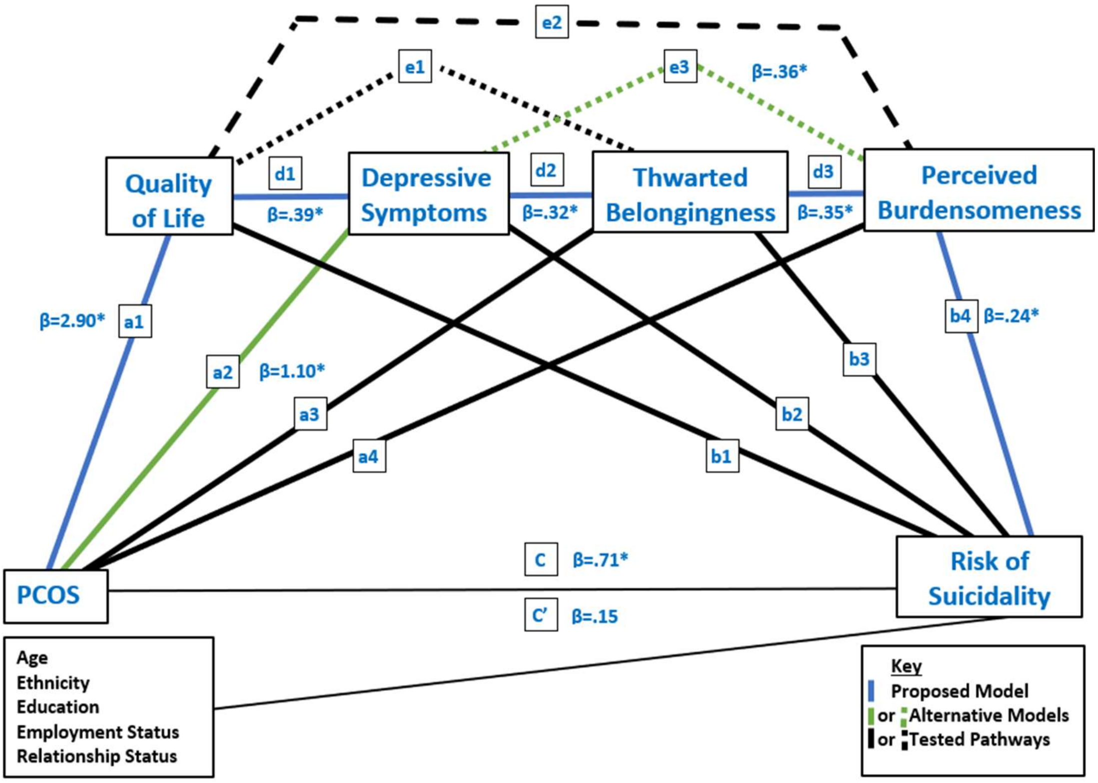
Results

Based on previous empirical evidence the association between PCOS and suicidality has been broadly established (Hussain et al., 2015). However, the link is assumed to be direct and so no attempt has been made to consider the influence of other mediating factors empirically shown to be causally related to PCOS or suicidal behaviour, namely: quality of life (Dokras et al., 2018), depression (Dokras et al., 2018), thwarted belongingness (Kinory et al., 2020) and perceived burdensomeness (Zhao et al., 2020).

In terms of the chain of causation amongst mediators, the interpersonal psychological theory of suicidal behaviour (IPTS; Van Orden et al., 2010) asserts that both the thwarted belongingness (TB) and perceived burdensomeness (PB) constructs should be considered as having a proximal (close) relationship to suicidal behaviour, while variables such as quality of life and depression tend to be more distal (detached). On the basis of this evidence, the results presented below will test the integrity of a new risk prediction model which posits that the distal psychosocial constructs (quality of life and depression) and the more proximal interpersonal constructs (TB and PB) will mediate the relationship between PCOS symptom severity and suicidal behaviour in young women (See Figure 4).

Figure 4

The Sequential Mediational Relationship between PCOS and Risk of Suicidality



**p*<.001

In an effort to assess this theoretical risk prediction model, the following directional hypotheses were tested:

H1. Young women with severe PCOS symptoms will experience a poorer quality of life (QOL). (Figure 4, path-a1)

H2. Young women who experience a poorer QOL will be more vulnerable to depressive symptoms. (Figure 4, path-d1)

H3. Young women who are more vulnerable to depressive symptoms will experience an increased sense of thwarted belongingness (TB). (Figure 4, path-d2)

H4. Young women who experience TB will experience an increased sense of perceived burdensomeness (PB). (Figure 4, path-d3)

H5. Young women who experience PB will be most at risk of suicidal behaviour (SB). (Figure 4, path-b4)

The first result to note from the sequential mediational output presented in Figure 4 is the regression equation between PCOS and risk of suicidality (c-path). This assesses the relationship between the independent and dependent variables, while ignoring all mediators. The unstandardised beta value is significant [β= -.71, $t(577)=-4.76$, $p <.001$, 95% CI [1.00, -0.42] which confirms that having a diagnosis of PCOS does seem to increase the risk of suicidal behaviour. However, it can also be noted that the c'-path is not significant [β= .15, $t(573)=1.16$, $p =.246$, [-0.10, 0.41] which suggests that some form of mediation is taking place.

Table 11

Indirect Effects Model for X on Y

Model	Effect	BootSE	BootLLCI	BootUCLI	Key
Ind 15*	-0.03	0.01	-0.05	-0.02	PCOS→ QOL→ DEP→ TB→ PB→ SB

*= Confidence Interval does not include 0.

H1. Young women with severe PCOS symptoms will experience a poorer quality of life (QOL). (Figure 4, a1-path)

In terms of the study's theoretical risk prediction model, the first causal path to consider is the regression of PCOS on the mediator quality of life (Figure 4, a1-path) which is significant β= 2.90, $t(577)=12.36$, $p < .001$, 95% CI [2.44, 3.36]. Thus, the null-hypothesis is rejected. Therefore, as the symptoms of PCOS become more severe for the young women in the study, they are likely to experience a worsening in their quality of life.

However, it is also important to note that the regression of QOL on suicidal risk (b1-path) is not significant β= -0.04, $t(573)=-1.46$, $p =.145$, 95% CI [-0.10, 0.01]. This suggests that on its own, QOL does not have a sufficient indirect effect to mediate the relationship between PCOS and suicidal risk.

In terms of the five covariates included in the analysis, the results suggest that PCOS symptom severity is not the only factor that may influence participants' QOL, and that extreme circumstances arising from other socio-demographic variables may make life more difficult especially: having no partner/living alone - relationship status $\beta = 0.93$ $t(577) = 4.49$, $p < .001$, 95% CI [0.52, 1.33]; being unemployed- employment status $\beta = -0.85$ $t(577) = -4.16$, $p < .001$, [-1.25, -0.45];

being over 35 years old- age *β* = -1.30 *t*(577) = -5.32, *p* < .001, [-1.78, -0.82] and having limited/no formal qualifications- education *β* = -0.91 *t*(577) = -3.80, *p* < .001, [-1.39, -0.44]. There was no significant correlation between ethnicity and QOL *β* = -0.66 *t*(577) = -2.35, *p*=.019, [-1.20, -.11].

H2. Young women who experience a poorer QOL will be more vulnerable to depressive symptoms. (Figure 4, d1-path)

The next causal relationship to consider in the study's theoretical risk prediction model is the regression of QOL on depressive symptoms (Figure 4, d1-path), which is significant β = -0.38 *t*(576) = -11.85, *p* < .001, 95% CI [-0.45, -0.32]. This suggests that the null hypothesis can be rejected. Therefore, as the quality of life of our study participants worsens, they are at greater risk of showing signs of depression. However, there also appears to be a significant relationship between PCOS and depressive symptoms (a2-path) β = -1.10 *t*(576) = -5.36, *p* < .001, [-1.51, -0.70]. This suggests that, in addition to QOL, PCOS symptoms may also contribute to increasing the risk of depression.

It is also worth noting that the regression of depressive symptoms on suicidal risk (b2-path) is not significant β=0.06, *t*(573)= 2.13, *p* =.033, 95% CI [0.00, 0.11]. This suggests that on its own, depression symptoms do not have a sufficient indirect effect to mediate the relationship between PCOS and suicidal risk.

There were no significant associations between depressive symptoms and any of the covariates. This suggests that both PCOS symptom severity and QOL have a significantly stronger influence on depressive symptoms relative to all five socio-demographic variables: relationship status β = -0.18 *t*(576) = -1.07, *p* =.29, 95% CI [-0.50, 0.15]; employment status β = 0.42 *t*(576) = 2.57, *p*=.011, [0.10, 0.73]; age β = -0.25 *t*(576) =-1.26, *p*=.209, [-0.63, 0.14]; ethnicity β = 0.21 *t*(576) = 0.95, *p* = .342, [-0.22, 0.64]; and education β = -0.13 *t*(576) = -0.68, *p*=.499, [-0.50, 0.25].

H3. Young women who are more vulnerable to depressive symptoms will experience thwarted belongingness (TB) (Figure 4, d2-path)

The risk model's third causal pathway is represented by the regression of depressive symptoms on TB (Figure 4, d2-path), which appears to be significant β = 0.32 *t*(575) = 4.74, *p* < .001, 95% CI [0.19, 0.45]. This suggests that the null hypothesis can be rejected. As the symptoms of depression worsen amongst our study participants, they are at greater risk of showing signs of TB. No significant relationship was found between PCOS and TB (a3-path) β = 0.63 *t*(575) = 1.87, *p*=.063, [-0.03, 1.30] and QOL and TB (e1-path) β=-1.05 *t*(575)= 18.15, *p*=.059, [-1.17, 0.94]. This suggests that depressive symptoms act as a unique causal contributor to increasing the risk of TB.

It is also worth noting that the regression of TB on risk of suicidality (b3-path) is not significant β=-0.00 *t*(573)=0.03, *p*=.977, 95% CI [-0.03, 0.03]. This suggests that on its own, TB does not have a sufficient indirect effect to mediate the relationship between PCOS and risk of suicidal behaviour.

There were no significant associations between TB and any of the covariates. This suggests that depressive symptoms have a significantly stronger influence on the risk of TB relative to all five socio-demographic variables: relationship status β= 0.13 *t*(575) = 0.48, *p*=.634, 95% CI [-0.39, 0.64]; employment status β = 0.05 *t*(575) = 0.18, *p*=.859, [-0.47, 0.56]; age β = -0.67 *t*(575) =-2.13, *p*=.034, [-1.28, -0.05], ethnicity β = 0.75 *t*(575) = 2.14, *p*=.033, [0.06, 1.44]; education β = 0.38 *t*(575) = 1.23, *p*=.219, [-0.22, 0.98].

H4. Young women who experience TB will also experience perceived burdensomeness (PB) (Figure 4, d3-path)

The final causal path in the risk prediction model involves the two main IPTS constructs and is the regression of TB on PB (Figure 4, d3-path), which is also significant β = 0.35 *t*(574) =8.69, *p* < .001, 95% CI [0.27, 0.43]. Thus, the null-hypothesis is rejected. Therefore, as feeling of TB becomes more severe for the young women in the study, they are likely to experience a stronger sense of PB. It is also worth noting that no significant relationship was found between PCOS and PB (a4-path) β =-0.11 *t*(574) = -0.34, *p* =.735, [-0.76, 0.54], or between QOL and PB (e2-path) β= -0.19, *t*(574)=-2.62, *p*=.069, [-0.33, -0.05]. Both findings suggest that neither PCOS symptom severity nor experiencing a poor QOL are directly sufficient to increase the risk of experiencing PB. However, it would appear that depression does, along with TB, have a direct influence of PB (e3-path) β= 0.36, *t*(574)=5.46, *p*<.001 [0.23, 0.49].

As with all other mediating variables, on its own, PB does not have a sufficient indirect effect to mediate the relationship between PCOS and risk of suicidal behaviour.

There were no significant associations between PB and any of the covariates. This suggests that TB and depressive symptoms have a significantly stronger influence on the risk of PB relative to all five socio-demographic variables: relationship status β= 0.37 *t*(574) = 1.45, *p*=.149, 95% CI [-0.13, 0.87]; employment status β = 0.59 *t*(574) = 2.33, *p*=.020, [0.09, 1.09]; age β = -.87 *t*(574) =-2.83, *p*=.005, [-1.47, -0.27], ethnicity β = -0.04 *t*(574) = -0.12 *p*=.903, [-0.72, 0.63]; education β = 0.13 *t*(574) = 0.43, *p*=.665, [-0.46, 0.71].

H5. Young women who experience PB will be most at risk of suicidal behaviour. (Figure 4, b4-path)

It is also important to note that the regression of PB on risk of suicidal behaviour (b4-path) is significant - β=0.24 *t*(573)=14.58 *p*<.001, 95% CI [0.21, 0.27]. Thus, the null-hypothesis is rejected, suggesting that while as a unique mediator the PB variable may not be a *sufficient* casual influence, as part of an overall mediational model it is indeed *necessary.* It is necessary because it is the only variable included in the study's theoretical risk prediction model to have a direct relationship to suicidality; as feelings of PB become more severe for the young women in the study, they are likely to experience a higher risk of suicidal behaviour.

Testing the integrity of a new mediation model for predicting the risk of suicidal behaviour amongst young women with a diagnosis of PCOS

Results for the indirect effect of X on Y for model 15 (see Table 11) show that the full mediation model presented in this study has empirical integrity: (Ind 15) β = -0.03 (SE=0.01), 95% CI [-0.05, -0.02]. Thus, following a diagnosis of PCOS, symptom severity can lead to a poorer quality of life (Figure 4, a1-path), which in turn can increase the risk of depressive symptoms (d1-path), depressive symptoms can then lead to an increase in participants' sense of thwarted belongingness (d2-path), and TB can in turn cause heightened feelings of perceived burdensomeness (d3-path), and it is this heightened perception of feeling a burden to others that seems to be uniquely responsible for triggering suicidal behaviours (b4-path).

Discussion

Discussion of Findings

This study has provided empirical evidence to support the proposed model that the relationship between PCOS symptom severity and suicidal behaviour is mediated by quality of life, depressive symptoms, thwarted belongingness (TB) and perceived burdensomeness (PB). Furthermore, this study has demonstrated that the demographic variables employed as covariates (employment, education, age and relationship status) seemed to have an important influence on quality of life but did not seem to have a strong influence on the other three mediators: depressive symptoms, TB and PB.

Relation to Previous Literature

This study provides further evidence for the link between PCOS and poorer quality of life. Previous studies have identified that women with PCOS show poorer quality of life compared to controls (Kumarapeli et al., 2011; Panico et al., 2017; Shishehgar et al., 2016).

Existing literature has also established an association between PCOS and depression (Dokras et al., 2018). The current study data provides additional supportive evidence by showing both a direct and indirect link between PCOS and depressive symptoms. In terms of an indirect link, it appears that quality of life may mediate the relationship between PCOS symptom severity and depression. The relationship between quality of life and depression has been previously explored by Sidra et al. (2019) who found that depression is a significant predictor of quality of life in women with PCOS. Thus, it would appear that young women with PCOS may be at risk of becoming depressed as a result of either a decline in their quality of life or due to a worsening of their symptomatology.

Previous studies have identified that women with PCOS are more likely to attempt suicide and exhibit suicidality compared to controls (Cesta et al., 2016; Månsson et al., 2008). Adolescents with PCOS are also more likely to report suicidal thoughts compared to adolescents without PCOS (Almis et al., 2020). However, these studies assumed a direct relationship between PCOS and suicidality. The current findings add to this existing knowledge by showing not only that these psychosocial variables are important mediators, but also that quality of life and depressive symptoms function as distal mediators in the relationship between PCOS symptoms and suicidality. In other words, this study has also shown that, while important, poor quality of life and depression do not have a sufficient effect to fully mediate this relationship. This finding makes sense, as it is recognised that although there is a strong relationship between depression and suicidality, depression lacks directional specificity as a predictor, as most people who are suicidal present with depressive symptoms, but the majority of people who are depressed do not develop suicidal behaviour (Handley et al., 2018).

As previously discussed, the interpersonal theory of suicidal behaviour (IPTS) describes the importance of two interpersonal constructs: thwarted belongingness (TB) and perceived burdensomeness (PB) in the development of suicidality (Van Orden et al., 2010). This study has shown that both TB and PB are important mediators of suicide in the population of women with PCOS.

In terms of TB, no direct link was established with PCOS, however, there is evidence that PCOS is associated with psychosocial variables (quality of life and depression) that may generate the conditions that may lead to TB. Qualitative studies have demonstrated that women with PCOS can describe a feeling of ‘freakishness’ or ‘abnormality’ (Kitzinger & Willmott, 2002). Other studies have outlined how PCOS symptoms can cause women to avoid social interaction and intimate relationships (Hadjiconstantinou et al., 2017). This is likely to lead to feelings of loneliness and social isolation, which may amount to TB. TB was not a sufficient nor a necessary mediator of suicidal behaviour in this sample, but it did appear to mediate the relationship between depressive symptoms and PB within the model. Reviews of IPTS constructs have shown that TB is more important in studies of lower risk suicidal behaviours such as occasional suicidal ideation, rather than plans or attempts (Ma et al., 2016). Therefore, as this study used an overall suicidality score, it may not have identified any predictive value that TB may have had specifically on suicidal ideation.

Perceived burdensomeness (PB) is conceptualised as an individual feeling that they are a burden to one or more significant people in their life (Van Orden et al., 2010). This is generally accompanied by thoughts such as ‘the people in my life would be better off if I were gone'. This construct also includes self-hate in the form of low self-esteem, self-blame and shame (Van Orden et al., 2010). Previous reviews have identified that women with PCOS have been shown to report poorer self-esteem, self-blame and impaired social relationships (Azizi & Elyasi, 2017). PB is identified as a strong predictor of suicidal thoughts, plans and attempts (Forrest & Smith, 2017). This study identified that PB was a necessary proximal mediator between PCOS and suicidality in this sample.

The study findings showed that four demographic variables had a significant impact on quality of life. This is in line with previous studies that have shown an association between quality of life and age (Sabbah et al., 2013); level of education (Augustus et al., 2009); employment status (Rueda et al., 2011) and relationship status (Gattino et al., 2013; Moulavi et al., 2008) in other populations. The demographic variables collected in this study did not predict suicidality, whereas previous studies have noted a relationship between suicidality and ethnicity (Bhui et al., 2012); educational attainment (Gunnell et al., 2011); employment status (Kposowa et al., 2019); marital status and age (Casey et al., 2012). It may be the case that these demographic factors are important but that the principal variables included in this study, depression, TB and PB have a more meaningful or direct impact when predicting risk of suicidal behaviour. For example, factors such as ethnicity, formal educational attainment and age are static (conditions over which people have very little, if any, control) and as such they may operate largely as background risk predictors relative to more proximal and dynamic constructs such as depression, TB and PB which are more variable.

Clinical Implications

This study has demonstrated some important findings that have implications for clinical policy and practice.

Previous literature has outlined how women with PCOS have reported disappointment in how healthcare professionals respond to their concerns regarding their symptoms, and often feel that they do not receive sufficient support or information about symptom management (Kitzinger & Willmott, 2002; Pfister & Rømer, 2017; Williams et al., 2015). This study has demonstrated that greater symptom severity predicts psychosocial and interpersonal difficulties that can lead to an increased risk of suicidal behaviour. Thus, in terms of primary prevention and early intervention, these risks can be ameliorated by supporting those with PCOS to achieve better control of their symptoms. This can be achieved by ensuring that health professionals are aware of the latest research and guidelines concerning PCOS and ensuring young women have access to comprehensive information and advice regarding their symptoms.

In terms of policy implications, this study provides further support for the importance of screening young women with PCOS for depression and ensuring that appropriate support is provided (National Institute for Health and Care Excellence, 2018). A recent mini-review has advocated for all women with PCOS to be systematically screened for psychological distress (Hoeger et al., 2021). This study provides evidence for taking this one step further and ensuring that young women with PCOS who are found to report signs of depression are screened using measures of TB and PB, such as the INQ-15 or brief measures of loneliness or self-esteem such as the Three-Item Loneliness Scale (Hughes et al., 2004) or the Brief Rosenberg Self-Esteem Scale (Monteiro et al., 2021). Formal assessment of suicidal ideation, planning and attempts, should be implemented when signs of TB and PB are present. Most of these measures are brief, and require fixed format responses, and so could be completed very quickly by patients with PCOS and could be made available on apps and mobile devices.

This study has also highlighted the need to find psychological interventions that may benefit young women with PCOS. Cognitive Behavioural Therapy (CBT) principles have been incorporated into lifestyle interventions and have resulted in reasonable weight loss (Jiskoot et al., 2020b) and significant improvements in measures of depression and self-esteem (Jiskoot et al., 2020a). Mindfulness-based interventions have also showed promise in reducing depression, anxiety and stress in women with PCOS (Stefanaki et al., 2015).

In addition to this, it may be the case that women with PCOS may not be able to manage their symptoms in the way that they would like to, in which case, interventions that alter a person’s relationship with their symptoms may be beneficial in this population. Third wave CBT interventions such as acceptance commitment therapy (ACT) or compassion focussed therapy (CFT) have been shown to be effective for people with a wide range of physical health and mental health difficulties (Lawlor et al., 2020; Thompson et al., 2021; Wilson et al., 2019). Interventions offered in a group format could reduce feelings of abnormality and improve self-esteem.

Finally, this study provides support for the role of third sector and voluntary organisations in offering support groups for young women with PCOS to reduce social isolation and exchange advice about symptom management and local resources. Healthcare professionals could also collaborate with third sector and voluntary organisations to produce accessible psychoeducational materials about symptom management and psychological wellbeing advice. Healthcare professionals should ensure that young women with PCOS are being signposted to reputable sources of information and support. There may also be a role for educating the wider public to increase awareness of the prevalence of PCOS and the common symptoms, to encourage the public to recognise symptoms and seek help more quickly, as well as increasing community understanding and acceptance of symptoms. It is hoped that these measures would increase knowledge about PCOS symptom management and empower young women to take steps to support their psychological wellbeing.

Conclusion

Strengths

This study provides empirical support for a model that suggests that the relationship between PCOS and suicidality is mediated by quality of life, depressive symptoms, thwarted belongingness and perceived burdensomeness. This research challenges previous literature that assumed a direct relationship between PCOS and suicidality and incorporates the influence of psychosocial variables and concepts related to key theories of suicidal behaviour.

Limitations

This study has identified some new knowledge in the field of PCOS wellbeing research, however it is important to acknowledge the limitations of the findings.

Firstly, a composite score was used to measure PCOS symptom severity. It is possible that there is something about the underlying biological mechanisms in PCOS that may account for the relationship between PCOS and distress. For example, evidence suggests that women with PCOS frequently show signs of insulin resistance, inflammation and endocrine abnormalities which may be interrelated with depression (Farrell & Antoni, 2010). However, it is also possible that it is not PCOS per se that is related to suicidality, but perhaps the presence of some key symptoms, which would not be identified by this study. For example, higher BMI has been shown to be linked with suicidal ideation and perceived burdensomeness (Dutton et al., 2013). However, it is worth noting that in the current study when the PCOS independent variable was replaced with a continuous measure of BMI, the theoretical model was not fully realised, though depression and PB were still important risk indicators.

Secondly, while this study did examine age, education, ethnicity, relationship status and employment status, there are additional variables that we did not measure that have been shown to be significant predictors of suicidality. For example, residing in a rural area (Casey et al., 2012); lower socio economic status (Huang et al., 2017); insomnia, mental health problems and drug dependence (Lin et al., 2018) have been linked to a higher risk of suicidality.

Thirdly, it could be argued that some of the correlation between PCOS symptom severity and depressive symptoms may be explained by the mPCOSQ including three items that pertain to depression and self-esteem. However, the depression related items on the mPCOSQ refer to the impact that the condition has on an individual’s mood, whereas the items on the PHQ-9 refer to symptoms that are indicative of a clinically depressed state. Similarly, it may be argued that the association between thwarted belongingness and suicidality may be partly explained by four items in the TB section of the INQ-15 referring to the one’s death and ‘being gone’. However, the INQ-15 focusses on how one perceives their absence would be received by their network, whereas the SBQ-R relates to thoughts, plans, attempts, and threats about actively killing oneself. Moreover, there were no concerns regarding multicollinearity in the data, therefore while individual items on these measures may appear to be similar, there is no indication that the overall composite scores share predictive power.

Additionally, this study was conducted during the coronavirus pandemic, and 74% of the participants completed the survey in the month of May 2020, while the first UK lockdown was still in effect. It is worth acknowledging that this was an exceptionally difficult period for many individuals, and this may have influenced participants to report higher levels of depressive symptoms and TB. Consequentially, it may be important to repeat these findings in the future, outside the context of a global pandemic.

Finally, the SBQ-R questionnaire that was used in this study collected data on historical and current suicidal thoughts, plans and attempts; communicating suicidality and perception of future risk. This information was collated using a composite score for the analysis. This measure is often used in research as a way to provide a more contextualised measure of suicidality, as opposed to only measuring one aspect such as suicidal ideations. However, using a composite score has limited inferences that can be made about the influences of the variables on thoughts, plans and attempts. For example, there is evidence that TB has a greater influence on suicidal ideation, rather than plans or attempts (Ma et al., 2016). This was partly confirmed by a re-analysis of the data using only item 2 of the SBQ-R, which relates to recent suicidal ideation, as the dependent variable. Here the results showed a link between TB and suicidal ideation. However, the theoretical model did not hold, the link between TB and PB was not significant, and overall it was difficult to draw out any meaningful conclusions from the data.

Recommendations for Future Research

The interpersonal theory of suicidal behaviour (IPTS), emphasised the importance of an individual experiencing a sense of hopelessness about the states of TB and PB (Van Orden et al., 2010). However, a review of the evidence for the IPTS suggested that there was insufficient empirical evidence for the construct of hopelessness due to a lack of appropriate measures (Chu et al., 2017). The interpersonal hopelessness scale has been developed, and it has been established that interpersonal hopelessness specifically, rather than general hopelessness has a relationship with suicidality (Tucker et al., 2018). Incorporating measures of hopelessness alongside measures of TB and PB appears to account for more of the variance in suicidal thinking (Mandracchia et al., 2019). Therefore, future studies could investigate the role of interpersonal hopelessness as a mediating factor in the relationship between PCOS and suicidality.

In addition to this, women with PCOS have spontaneously discussed their experiences of self-harm and suicidal thoughts in qualitative studies (Williams et al., 2015). However, to date, there have been no qualitative studies explicitly focussing on the experiences of women with PCOS who experience suicidality. Such qualitative studies would provide rich information with regards to how women with PCOS experience suicidal thoughts and behaviour and would further develop theoretical knowledge about this important area.

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Chapter III: Reflective Chapter

The Interplay of Personal and Professional Identities in Research

Overall chapter word count at submission: 3,234

Introduction

Reflective practice can be defined as a journey of self-inquiry in the context of a particular situation, with the goal of becoming the practitioner you desire to be (Johns, 2013). Not only is reflection important for examining clinical interactions, it also has an important role in developing one's professional identity (Wald, 2015). The journey to becoming a reflective scientist is a core part of clinical psychology training (The British Psychological Society, 2019).

In academic research, Mortari (2015) asserts that researchers do not only observe phenomenon, they actively portray it, therefore reflective practices become ethically imperative. Mortari (2015) outlines four main types of reflective styles used in research: pragmatist; critical perspectives; hermeneutic practice and phenomenological understanding. Pragmatist reflective styles are action orientated and are focussed on increasing effectiveness. Critical perspectives relate to how oppression related to class, gender and race may operate within research contexts. Hermeneutic practices value the importance of maintaining a distance from the actions and providing an environment from which to make conscientious choices. Phenomenological understanding is the process of gaining insight into the internal world of the researchers.

In the following account I have summarised my reflections about my research journey, the impact it had on me and I on it, and how this changed throughout the process. I began by completing a mindfulness exercise and a continual writing exercise about my experiences, as recommended by Johns (2013). I have recognised that each of the styles of reflective practice discussed by Mortari (2015) have been present in my initial writing. This included: attempts to identify learning points; critical identification of potential oppressive biases in my work; at times creating a mindful distant mindset from which to reflect and at other times observing my mind and seeking to understand it. I have used John's Structured Model of Reflection and influences grid (Version 16; Johns, 2013) to develop my initial reflections further.

The Interplay of Personal and Professional Identities in Research

The overarching theme that I have noticed, is the interplay between one's professional identity and one's personal identity in research. In addition to this, I chose a topic – Polycystic Ovary Syndrome (PCOS)- which is a condition I have been diagnosed with. Throughout my thesis, and prior to beginning my doctoral training, I have realised the impact that my PCOS has had, and how it causes friction between my personal and professional identity.

Devising a Research Idea

I did not start out intending to design a research study focussing on women with PCOS, it was the third or fourth idea I considered after other ideas proved unfruitful. However, the idea was an organic one borne of my own experiences, and knowledge I had gained in my personal, rather than professional life. My official PCOS diagnosis arrived around the same time that I started my doctoral training. Around this time, I had several life changes occur in a short space of time and I noticed that the quality of my anxiety had changed and was more physiological rather than cognitive in nature. Being a curious scientist, my first action was to search literature about this phenomenon, as I wondered if there was a biological reason that I might be feeling such physiological arousal. I discovered that there is an established link with anxiety and PCOS (Dokras et al., 2018) and women with PCOS may experience greater physiological stress responses (such as significantly higher cortisol and heart rate) compared to controls (Barry, 2019). I then searched for more information on PCOS, and strategies to manage the symptoms. I used social media to connect with other women with PCOS and found that it was very common for women on these groups to talk about their experiences of anxiety and depression. Therefore, in the beginning, my personal experiences had clearly contributed to my decision to study PCOS and therefore there was a joining of the personal and the professional in this project.

The Impact the Thesis had on the Personal

This thesis has been the biggest project I have worked on in my life, and it has clearly, at times, impacted on my personal life during this process. Most of my thesis work took place in the context of the coronavirus pandemic. It is difficult to know, whether in different circumstances, without restrictions in social life, movement, and human interaction, whether the thesis would have been as big a feature in my life, as it has been for the past year.

The first way that the thesis has had an impact on me personally, is in how I have connected with other women with PCOS. When working on my empirical paper, I was overwhelmed by the numbers of women who decided to take part in my project. I reached my initial recruitment target within two hours of the link being advertised on social media. Although, these were numbers on a page, it was not difficult to remember that these were real women with real stories, who had taken the time to complete this study and share their experiences. I hope I have managed to retain a focus on real women in the way I have presented this thesis, as this is an important part of my values. In addition to this, the number of participants communicated to me that I had identified a research gap that there was a real appetite for in the community of women with PCOS. As part of the agreement with the charity Verity, who advertised my study, I am intending to share a lay-person summary of my research which will be published on Verity's research blog. This thesis project has helped me to establish a personal connection with the Verity charity. I have participated in other PCOS studies advertised by Verity and I hope to engage with the community events and fundraising efforts in the future.

The second way, this thesis has impacted on me personally, is through the focus it brought to my PCOS and lifestyle decisions. Throughout the process of developing my research ideas, I was immersed in information and statistics about PCOS and the accounts of women who were diagnosed with it. In recognising the impact that PCOS had on these women, I was repeatedly drawn into a space of reflecting on my own experiences of PCOS. For me, the biggest feature has been irregular menstrual cycles, and with that symptom comes an uncertainty about one's ability to conceive and become pregnant. Psychoeducational materials about PCOS assure women that it is generally possible to become pregnant by use of ovulation inducing medications (NHS, 2019). However, through reading the many articles about infertility in PCOS I was also aware that there was a good likelihood that the path to parenthood may be more difficult for me. The question mark about my fertility has been in my own mind since I was around 15 years old, and played a significant role in major life decisions, particularly the decision to apply for clinical psychology training. Working on this thesis meant that concerns that had previously been "slight niggles at the back of the mind that it might be harder to get pregnant" (Participant, Hadjiconstantinou et al., 2017, p. 325) developed into more looming fears of the unknown status of my fertility. These concerns, together with other personal factors led to the decision to try for a baby sooner than originally planned, and I am now five months pregnant.

The Impact of the Personal on my Thesis

There is a risk apparent in conducting personally relevant research, as it raises questions about the researcher's ability to remain objective, and some researchers feel the need to downplay or conceal their personal connection to the subject matter (Jones & Bartunek, 2019). However, it can be argued that all research pertaining to the behaviour of human beings is subjective in nature, regardless of epistemological orientation (Bowden & Green, 2010).

"Not Quite an Insider"

A diagnosis of PCOS requires an individual to meet two out of three clinical features of the condition, which results in four phenotypes of PCOS (Hoeger et al., 2021). Therefore, there is a wide variation in the symptoms each woman with PCOS will exhibit. My PCOS would be categorised as phenotype 'D', which means I have ovulatory dysfunction and polycystic ovarian morphology apparent on ultrasound, but I do not have androgen excess. Phenotype D is not one of the classic presentations of PCOS, and women with this phenotype do not experience the hirsutism, alopecia or acne that can accompany hyperandrogenism. In addition to this, I would consider myself to have 'lean-type' PCOS, as I am not overweight. When I first approached a doctor with concerns about my irregular menstrual cycle I was told "I can tell just by looking at you, that you don't have PCOS". For these reasons, I feel like a non-prototypical woman with PCOS (Okimoto & Wrzesniewski, 2012). Therefore, throughout the research process, I considered myself "not quite an insider" (Jones & Bartunek, 2019, p. 18).

Impact on the Empirical Project

Throughout the design of my empirical project, I felt like my personal knowledge of PCOS helped me to negotiate the literature and have an awareness and understanding of issues that may become relevant to the project. For example, I am aware that the phenotypes I have mentioned above, are not routinely made explicit to women with PCOS, and it would be very difficult to determine these phenotypes from the participants in an accurate way. Therefore, no attempts were made to distinguish between different phenotypes in my empirical study. It was also advantageous to have a personal understanding of the kinds of resources that are available to women with PCOS when I was considering the practical implications of my project. I was aware of my own experiences of diagnosis and the supportive resources I have encountered online, and also the experiences of women who have shared their stories on social media about the aspects of their healthcare they found helpful and unhelpful.

Impact on the Systematic Literature Review

My status as “not quite an insider” became more relevant in the systematic literature review. In qualitative research, there is a greater awareness and space for reflexivity. I kept a research diary throughout the research process, but I was particularly mindful during the systematic literature review to record feelings of affinity with participants and assumptions I noticed myself making. It is worth bearing in mind, that when I completed the analysis section of this review, I was in the second trimester of my pregnancy. Therefore, as my own fears around fertility had been significantly quelled by this stage, I felt even more separated in terms of my status as a woman with PCOS. However, reading the accounts of some of these women still struck a powerful chord.

As I do not have the classic symptoms of PCOS, I felt I was approaching some of the themes with a more critical, distanced view. The main thing I noticed, was in the accounts of women with of hirsutism, I felt like they did not appreciate the concerns and pressures that all women face in the management of body hair, and some quotes appeared to idealise the experiences of non-hirsute women. This is something that Kitzinger and Willmott (2002) and Keegan et al. (2003) raised in their studies, that the beauty standards for women reflect unnatural states, therefore all women are faced with the decision about the extent they will conform to an abnormal norm. However, I do appreciate as a middle-class, married, white woman educated in the field of psychology, I am commenting from a place of privilege. My psychology training and awareness of feminist perspectives has enabled me to maintain a critical view of social norms, which allows me some distance from their power. In addition to this, my identity as an academic and a professional, gives me power and social confidence which means I am less reliant on conforming to conventional beauty norms to feel socially acceptable. To manage the effect that my personal opinions had, I first needed to acknowledge them. When I was writing about this issue in the chapter, I ensured that I was distinguishing between the first order and second order constructs, making the distinction between the participant views and the author views, and was mindful about my word choices, attempting to portray the issue neutrally.

In contrast to this, there were some issues where I really connected to some of the accounts of the women, namely I recognised the affinity I felt with Smith-Tran (2018). This autoethnography described detailed experiences of Smith-Tran’s internal world as she was diagnosed and began to manage her PCOS. Unlike the short excerpts from participants with pseudonyms, this study allowed for the reader to understand Smith-Tran’s inner monologue, contextualised in information about her life, and how she challenged her own thinking and how her attitudes developed over time. Smith-Tran describes herself as a highly educated, middle class woman with a background in medical sociology, and she outlines how although she knew the complex and structural reasons why a person’s body may be overweight or subject to a health condition, she still feared how the people in her life would judge her. I found I could relate to this, how having academic knowledge and a critical attitude towards social norms does not necessarily release you from their power. Smith-Tran also approached her PCOS diagnosis by educating herself with online resources and began weightlifting, which mirrors my response. As Smith-Tran writes, I also felt that exercise and weight loss had shifted in my mind from ‘I want to look good’ to ‘I need to control my PCOS and hopefully have a baby someday’. Weightlifting as a means to manage PCOS is a strange paradox where one is engaging with a traditionally masculine activity in an attempt to retain the feminine. There were several aspects of Smith-Tran’s paper that I found personally very validating and intriguing. I was wary of how I used insights from Smith-Tran’s paper as I was conscious of how personally relevant it was to me.

As a woman with PCOS, it was impossible not to have a vested interest in how the findings would portray women with PCOS. I was aware that as the themes were shaping up, womanhood seemed to be reduced to looking pretty and having babies, which I found frustrating. I did not want these things to be the crux of what constitutes a woman, as it feels superficial. However, there are three relevant issues here. Firstly, this is what the data was saying, there were no other themes coming through the studies I was reviewing. Therefore, it may be that either, these are the only two aspects of feminine identity that are affected by PCOS, or that these are the only aspects that are recognised by enough participants and authors to constitute a pattern or theme. Secondly, as discussed in chapter I, these manifestations of feminine identity make sense in societies that have been dominated by masculine power and heteronormative ideals for centuries (Butler, 2011). Thirdly, I believe I have personally been exposed to feminist critiques of the conventional socialisation of women (Dobson, 2015) and also the cultural ridiculing of feminine behaviours (Rogan, 2018). For example, in Erin May Kelly's poem, she writes "Little girls don't stay little forever, why would they want to? When we live in a world that has been taught to hate everything to do with teenage girls. We hate the books they read and the bands they like. Is there anything the world makes fun of more than One Direction and Twilight?" (Rhyse, 2021). I wonder if such criticisms of feminine pastimes, have led me to internalise this de-valuing of conventional feminine identities and deny the importance of such matters. Ultimately, looking pretty and having babies is very important to me, and I would consider these relevant to my feminine identity, however, there is something that feels uncomfortable about admitting this as a highly educated, professional, feminist woman.

Finally, my own experiences have influenced what I expected to find in this review. For example, I was surprised that social media was not a significant feature in the accounts of women with PCOS. Rogan (2018) argues that for millennial and post-millennial women in the UK, there is no longer a distinction between online and in-real life identities. The widespread use of social media by celebrities and social influencers for 'self-branding', has led to a blurring between the celebrity and the everyday, it seems the special beauty efforts once limited to special occasions, is now expected in routine life. In addition to this, the abundance of photo editing apps and makeup tutorials encourage young women to engage in extensive 'aesthetic labour' and fitness tracking apps perpetuate notions of self-discipline and self-control. Rogan also identifies the role of the 'feminised gaze' where social media content is produced with a female consumer in mind. My personal experience has certainly been that the aesthetic labour I have engaged in, is more frequently with a female observer in mind, rather than a male. I was surprised that this was not explicitly voiced in the studies I reviewed. Perhaps this is due to my experiences of cultural gender norms being mainly enforced by female family members, or perhaps my experience of meeting my husband at a young age has reduced my personal investment in what men think about my appearance throughout my adult life. Alternatively, social media use may be more prevalent and integral to the identities of younger generations or cohorts of women and this may result in future studies identifying this theme.

Conclusion

This thesis has required my personal and professional identity to influence one another in various ways over the past three years. I believe that a thesis on any topic would have demanded an interplay of the personal and professional (Dwyer & Buckle, 2009), however, choosing to study PCOS has made this more emotionally salient for me. Working in a field that is personally relevant, always presents the risk of over-identification, for example failure to recognise themes and assume a critical stance (Ochieng, 2010). The nature of my empirical study and my systematic literature review meant that I did not interact with any women with PCOS directly, which has allowed for a degree of separation from the issues at hand. I was also fortunate that I became pregnant during this thesis process, but there was a risk that working on a project that was so personally relevant, could have become very upsetting if circumstances had been different, and I struggled to conceive or experienced a miscarriage during the process of the thesis. The British Psychological Society code of conduct and ethics states that psychologists must be aware of their own competence and seek appropriate support if personal problems are impairing their ability to practice (The British Psychological Society, 2009). In the domain of therapy, clinicians who have managed to successfully work with client groups that they identify with have reported maintaining effective work boundaries, with clear roles, building an active personal life, connecting with other professionals and having good personal support systems outside of work (Cadwell, 1994). For me, I have recognised the value of maintaining a good work-home life balance, reflecting on my work, and working closely with a supervisor. This thesis project has truly been an important piece of work for me personally and professionally, and I have learnt a lot from it.

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Appendix A
Author Instructions for ‘Women’s Reproductive Health’

About the Journal

Women's Reproductive 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.

Women's Reproductive Health accepts the following types of article: original articles and book and media reviews.

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Preparing Your Paper

Structure

Your paper should be compiled in the following order: title page; abstract; keywords; main text introduction, materials and methods, results, discussion; acknowledgments; declaration of interest statement; references; appendices (as appropriate); table(s) with caption(s) (on individual pages); figures; figure captions (as a list).

Word Limits

Please include a word count for your paper. There are no word limits for papers in this journal.

Style Guidelines

Please refer to these quick style guidelines when preparing your paper, rather than any published articles or a sample copy.

Please use American spelling style consistently throughout your manuscript.

Please use double quotation marks, except where “a quotation is ‘within’ a quotation”. Please note that long quotations should be indented without quotation marks.

Submissions should follow the style guidelines described in the APA Publication Manual (6th ed.). Merriam-Webster’s Collegiate Dictionary (11th ed.) should be consulted for spelling.

Formatting and Templates

Papers may be submitted in Word format. Figures should be saved separately from the text. To assist you in preparing your paper, we provide formatting template(s).

Word templates are available for this journal. Please save the template to your hard drive, ready for use.

If you are not able to use the template via the links (or if you have any other template queries) please contact us here.

Figures should be saved separately from the text. The main document should be double-spaced, with one-inch margins on all sides, and all pages should be numbered consecutively. Text should appear in 12-point Times New Roman or other common 12-point font.

References

Please use this reference guide when preparing your paper.

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Checklist: What to Include

Author details. All authors of a manuscript should include their full name and affiliation on the cover page of the manuscript. Where available, please also include ORCiDs and social media handles (Facebook, Twitter or LinkedIn). One author will need to be identified as the corresponding author, with their email address normally displayed in the article PDF (depending on the journal) and the online article. Authors' affiliations are the affiliations where the research was conducted. If any of the named co-authors moves affiliation during the peer-review process, the new affiliation can be given as a footnote. Please note that no changes to affiliation can be made after your paper is accepted. Read more on authorship.

Should contain an unstructured abstract of 100 words.

You can opt to include a video abstract with your article. Find out how these can help your work reach a wider audience, and what to think about when filming.

Between 3 and 5 keywords. Read making your article more discoverable, including information on choosing a title and search engine optimization.

Funding details. Please supply all details required by your funding and grant-awarding bodies as follows:
For single agency grants
This work was supported by the [Funding Agency] under Grant [number xxxx].
For multiple agency grants
This work was supported by the [Funding Agency <] under Grant [number xxxx];

[Funding Agency >] under Grant [number xxxx]; and [Funding Agency &] under Grant [number xxxx].

Disclosure statement. This is to acknowledge any financial interest or benefit that has arisen from the direct applications of your research. Further guidance on what is a conflict of interest and how to disclose it.

Biographical note. Please supply a short biographical note for each author. This could be adapted from your departmental website or academic networking profile and should be relatively brief (e.g. no more than 200 words).

Supplemental online material. Supplemental material can be a video, dataset, fileset, sound file or anything which supports (and is pertinent to) your paper. We publish supplemental material online via Figshare. Find out more about supplemental material and how to submit it with your article.

Figures. Figures should be high quality (1200 dpi for line art, 600 dpi for grayscale and 300 dpi for colour, at the correct size). Figures should be supplied in one of our preferred file formats: EPS, PS, JPEG, TIFF, or Microsoft Word (DOC or DOCX) files are acceptable for figures that have been drawn in Word. For information relating to other file types, please consult our Submission of electronic artwork document.

Tables. Tables should present new information rather than duplicating what is in the text. Readers should be able to interpret the table without reference to the text. Please supply editable files.

Equations. If you are submitting your manuscript as a Word document, please ensure that equations are editable. More information about mathematical symbols and equations.

Units. Please use SI units (non-italicized).

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Appendix B
Certificate of Ethical Approval for Systematic Literature Review

A Meta-Ethnographic Review of how young women with Polycystic Ovary Syndrome (PCOS) experience conventional forms of Feminine Identity. P121666

Coventry University

Certificate of Ethical Approval

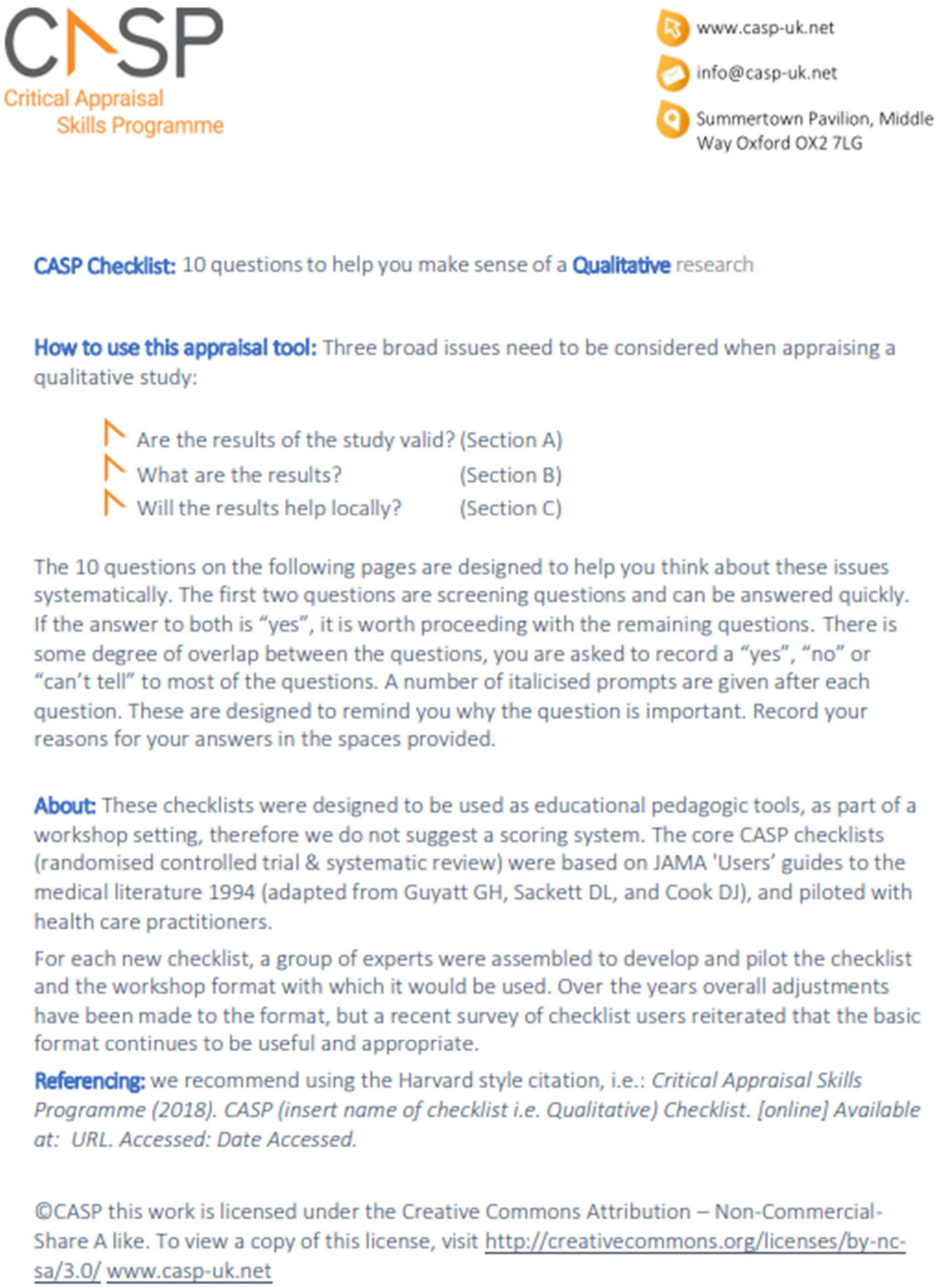
Applicant:	Lenita Wambeek
Project Title:	A Meta-Ethnographic Review of how young women with Polycystic Ovary Syndrome (PCOS) experience conventional forms of Feminine Identity.

This is to certify that the above named applicant has completed the Coventry University Ethical Approval process and their project has been confirmed and approved as Low Risk

Date of approval:	20 Apr 2021
Project Reference Number:	P121666

Lenita Wambeek (D62PY) Page 1 20 Apr 2021

Appendix C
Critical Appraisal Skills Programme Qualitative Checklist



CASP
Critical Appraisal
Skills Programme

www.casp-uk.net
info@casp-uk.net
Summertown Pavilion, Middle
Way Oxford OX2 7LG

CASP Checklist: 10 questions to help you make sense of a **Qualitative** research

How to use this appraisal tool: Three broad issues need to be considered when appraising a qualitative study:

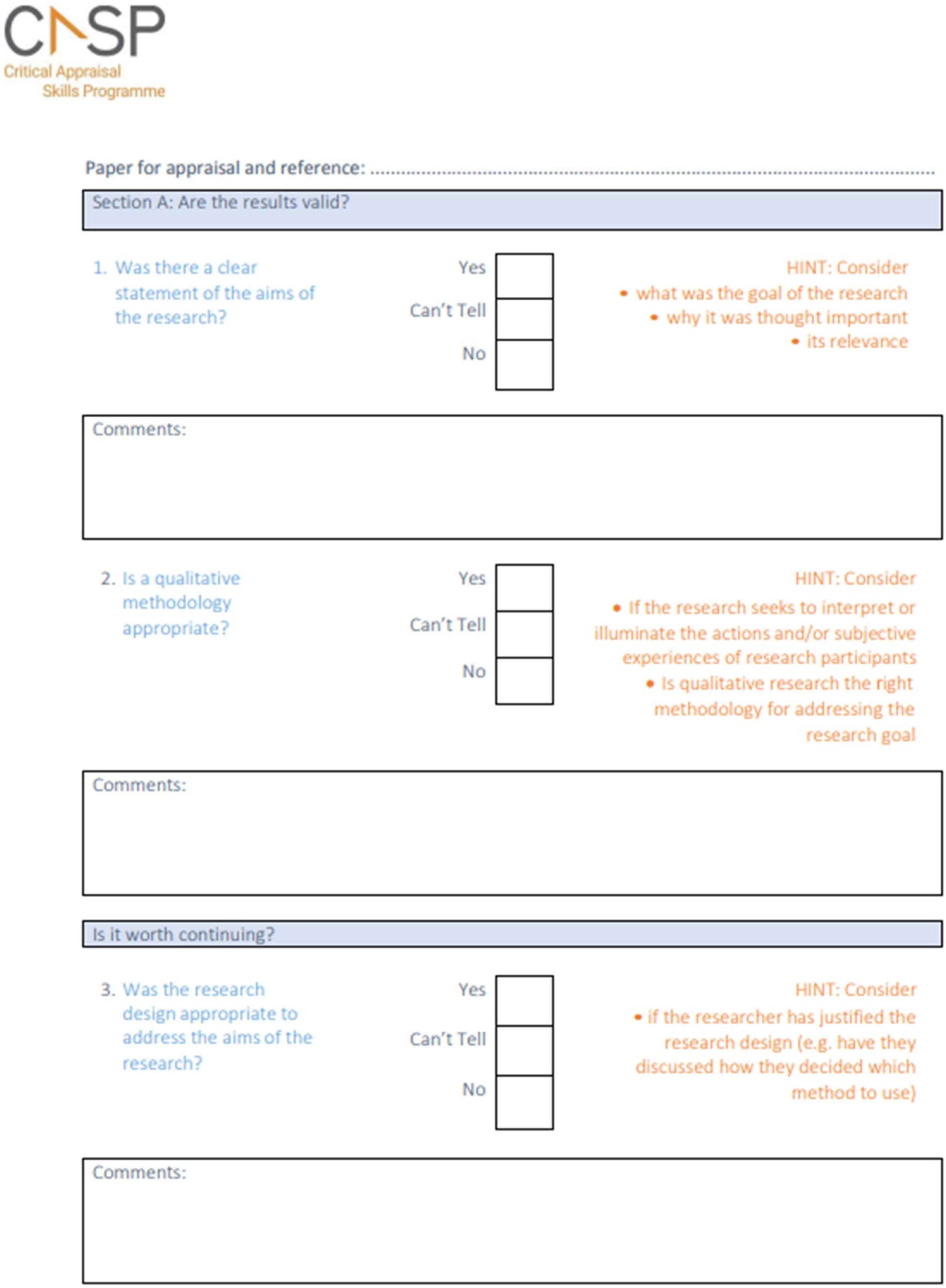
- Are the results of the study valid? (Section A)
- What are the results? (Section B)
- Will the results help locally? (Section C)

The 10 questions on the following pages are designed to help you think about these issues systematically. The first two questions are screening questions and can be answered quickly. If the answer to both is "yes", it is worth proceeding with the remaining questions. There is some degree of overlap between the questions, you are asked to record a "yes", "no" or "can't tell" to most of the questions. A number of italicised prompts are given after each question. These are designed to remind you why the question is important. Record your reasons for your answers in the spaces provided.

About: These checklists were designed to be used as educational pedagogic tools, as part of a workshop setting, therefore we do not suggest a scoring system. The core CASP checklists (randomised controlled trial & systematic review) were based on JAMA 'Users' guides to the medical literature 1994 (adapted from Guyatt GH, Sackett DL, and Cook DJ), and piloted with health care practitioners.

For each new checklist, a group of experts were assembled to develop and pilot the checklist and the workshop format with which it would be used. Over the years overall adjustments have been made to the format, but a recent survey of checklist users reiterated that the basic format continues to be useful and appropriate.

Referencing: we recommend using the Harvard style citation, i.e.: *Critical Appraisal Skills Programme (2018). CASP (insert name of checklist i.e. Qualitative) Checklist. [online] Available at: URL. Accessed: Date Accessed.*



CASP
Critical Appraisal
Skills Programme

Paper for appraisal and reference: ....

Section A: Are the results valid?

1. Was there a clear statement of the aims of the research?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- what was the goal of the research
- why it was thought important
- its relevance

Comments:

2. Is a qualitative methodology appropriate?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants
- Is qualitative research the right methodology for addressing the research goal

Comments:

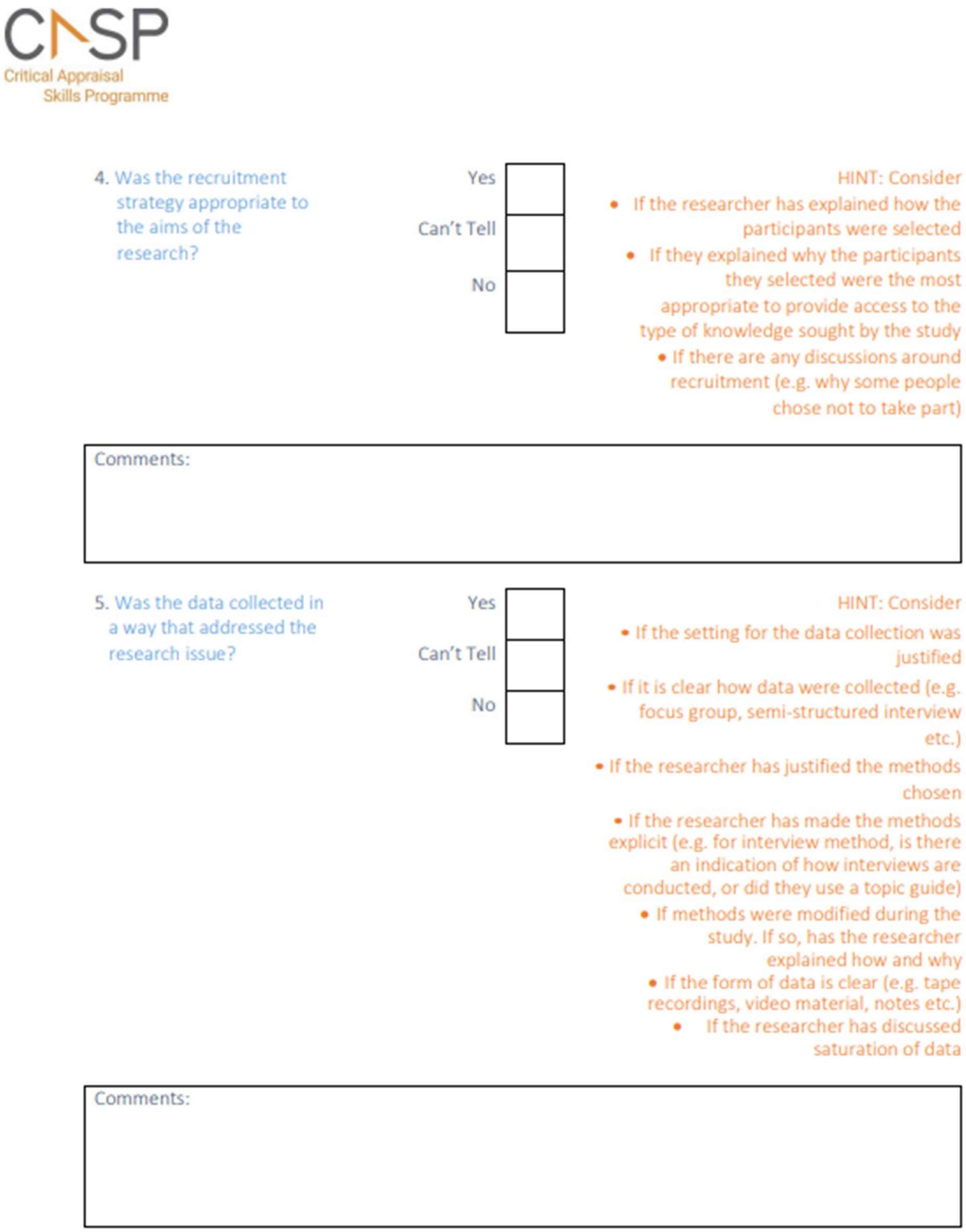
Is it worth continuing?

3. Was the research design appropriate to address the aims of the research?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- if the researcher has justified the research design (e.g. have they discussed how they decided which method to use)

Comments:



CASP
Critical Appraisal
Skills Programme

4. Was the recruitment strategy appropriate to the aims of the research?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- If the researcher has explained how the participants were selected
- If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study
- If there are any discussions around recruitment (e.g. why some people chose not to take part)

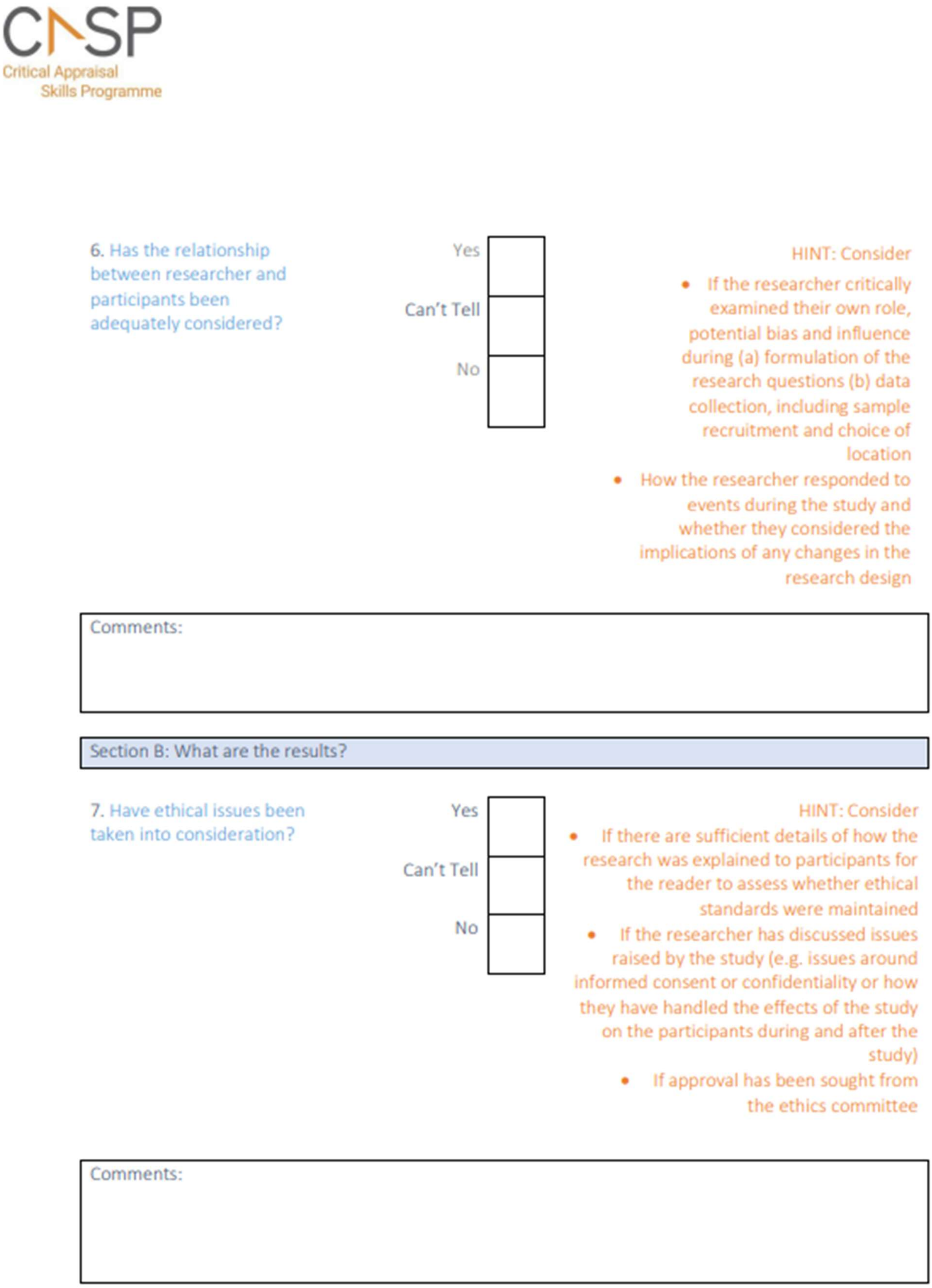
Comments:

5. Was the data collected in a way that addressed the research issue?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- If the setting for the data collection was justified
- If it is clear how data were collected (e.g. focus group, semi-structured interview etc.)
- If the researcher has justified the methods chosen
- If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews are conducted, or did they use a topic guide)
- If methods were modified during the study. If so, has the researcher explained how and why
- If the form of data is clear (e.g. tape recordings, video material, notes etc.)
- If the researcher has discussed saturation of data

Comments:



CASP
Critical Appraisal
Skills Programme

6. Has the relationship between researcher and participants been adequately considered?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- If the researcher critically examined their own role, potential bias and influence during (a) formulation of the research questions (b) data collection, including sample recruitment and choice of location
- How the researcher responded to events during the study and whether they considered the implications of any changes in the research design

Comments:

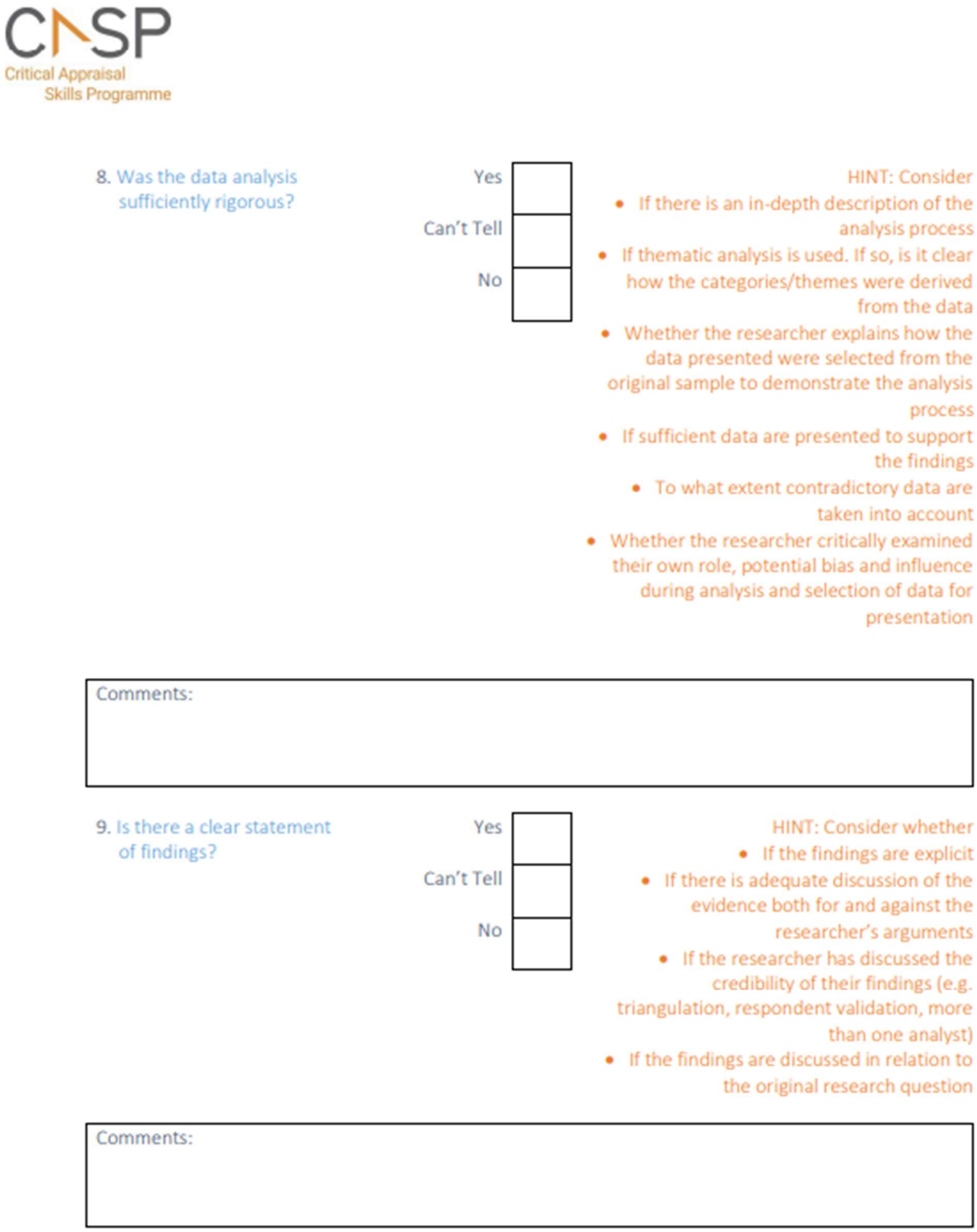
Section B: What are the results?

7. Have ethical issues been taken into consideration?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained
- If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)
- If approval has been sought from the ethics committee

Comments:



CASP
Critical Appraisal
Skills Programme

8. Was the data analysis sufficiently rigorous?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- If there is an in-depth description of the analysis process
- If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data
- Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process
- If sufficient data are presented to support the findings
- To what extent contradictory data are taken into account
- Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation

Comments:

9. Is there a clear statement of findings?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider whether
- If the findings are explicit
- If there is adequate discussion of the evidence both for and against the researcher's arguments
- If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst)
- If the findings are discussed in relation to the original research question

Comments:

CASP
Critical Appraisal
Skills Programme

Section C: Will the results help locally?

10. How valuable is the research?

HINT: Consider
- If the researcher discusses the contribution the study makes to existing knowledge or understanding (e.g. do they consider the findings in relation to current practice or policy, or relevant research-based literature
- If they identify new areas where research is necessary
- If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used

Comments:

Appendix D
Quality Assessment and Interrater Reliability

Table D1

Quality Assessment- CASP Scores

Study	Pfister and Rømer (2017)		Pathak (2019)		Williams et al. (2015)		Amiri et al. (2014)		Smith-Tran (2018)		Sharma (2018)		Kitzinger and Willmott (2002)	
Rater	1	2	1	2	1	2	1	2	1	2	1	2	1	2
CASP Questions														
Q.1	2	2	0	0	2	2	2	2	2	2	1	1	2	2
Q.2	2	2	1	1	2	2	2	2	2	2	2	2	2	2
Q.3	0	0	0	0	2	2	2	2	2	2	1	1	2	2
Q.4	2	2	1	1	2	2	2	2	2	2	0	0	2	2
Q.5	2	2	1	1	2	2	2	2	2	2	1	1	2	2
Q.6	0	0	0	0	0	0	0	0	2	2	0	0	1	1
Q.7	2	2	2	2	2	2	2	2	0	0	1	1	2	2
Q.8	1	1	0	0	2	2	2	2	0	0	0	0	2	2
Q.9	2	2	0	0	2	2	2	2	0	0	1	1	1	1
Q.10	1	1	0	0	2	2	1	1	2	2	0	0	2	2
Total (Out of 20)	14	14	5	5	18	18	17	17	12	12	7	7	17	17

	Snyder (2006)		Ee (2020)		Naz (2019)		Hadjiconstantinou et al. (2017)		Williams (2014)		Keegan et al. (2003)		Sanchez and Jones (2016)		Washington (2008)	
Rater	1	2	1	2	1	2	1	2	1	2	1	2	1	2	1	2
CASP Questions																
Q.1	2	2	2	2	2	2	2	2	2	2	0	0	2	2	2	2
Q.2	2	2	2	2	2	2	2	2	2	2	1	1	2	2	2	2
Q.3	2	2	2	2	1	1	2	2	2	2	1	1	0	0	0	0
Q.4	2	2	2	2	2	2	2	2	2	2	1	1	2	2	2	2
Q.5	2	2	2	2	2	2	2	2	2	2	2	2	1	1	2	2
Q.6	0	0	2	2	0	0	0	0	1	1	0	0	1	1	0	0
Q.7	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2
Q.8	2	2	2	2	2	2	2	2	1	1	2	2	2	2	1	1
Q.9	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2
Q.10	2	2	1	1	2	2	2	2	2	2	1	1	2	2	1	1
Total (Out of 20)	18	18	17	17	17	17	18	18	17	17	12	12	15	15	14	14

Table D2

Inter-rater reliability coefficient (Kappa) outputs for all papers

Study	*k* value	Significance (*p* value)
Pfister and Rømer (2017)	1.00	.000
Pathak (2019)	1.00	.000
Williams et al. (2015)	1.00	.000
Amiri et al. (2014)	1.00	.000
Smith-Tran (2018)	1.00	.000
Sharma and Mishra (2018)	1.00	.000
Kitzinger and Willmott (2002)	1.00	.000
Snyder (2006)	1.00	.000
Ee et al. (2020)	1.00	.000
Naz et al. (2019)	1.00	.000
Hadjiconstantinou et al. (2017)	1.00	.000
Williams et al. (2014)	1.00	.000
Keegan et al. (2003)	1.00	.000
Sanchez and Jones (2016)	1.00	.000
Washington (2008)	1.00	.000

Appendix E
Detailed Participant Characteristics

Table E1

Detailed Participant Characteristics

Study Total Number of Participants Location	Age Range (Mean)	Occupation	Relationship Status	Child Status	Ethnicity	Socioeconomic Status
Pfister and Rømer (2017) N=21 Copenhagen, Denmark	21-36	Professional 8 Service & Sales 6 Technicians 2 Students 4 Unemployed 1	Married 4 In a relationship 11 Single 6	None 20 ≥ 1 Child 7	Danish 18 Kurdish 1 Iranian 1 Indian/Pakistani 1	Not Stated
Pathak (2019) N=30 Mumbai, India	21-50	Not Stated	Married/ Previously Married 20 Single 10	None 20 ≥ 1 Child 10	Not Stated	Middle Class
Williams et al. (2015) N=10 UK	20-41	Not Stated	Not Stated	Not Stated	Not Stated	Not Stated
Amiri et al. (2014) N=23 Tehran, Iran	18-40	Housewives 10 Employees 4 Self-employed 4 Student 4 Farmer 1	Married 15 Single 8	Not Stated	Not Stated	Not Stated
Smith-Tran (2018) N=1 Ohio, US	Late 20s	Assistant Professor of Sociology	Married	None	Black	Middle Class

Study Total Number of Participants Location	Age Range (Mean)	Occupation	Relationship Status	Child Status	Ethnicity	Socioeconomic Status
Sharma and Mishra (2018) N=35 Jammu, India	Not stated	Not Stated	Married 11 Not Married 24	None 33 ≥ 1 Child 2	Not Stated	Economically Weaker Section
Kitzinger and Willmott (2002) N=30 UK	21-42 (29)	Managers 4 Professionals 8 Clerical Support 7 Service & Sales 2 Voluntary 2 Student 4 Homemaker 3	Married 18 Single 6 Cohabiting 5 Widowed 1	None 10 None (F) 10 ≥ 1 Child 3 ≥ 1 Child (F) 7	White 24 Asian 3 Arab 1 Med 1	Not stated
Snyder (2006) N=12 Northeast US	21-48	Not Stated	Married 9 Single 3	None 4 ≥ 1 Child 2 ≥ 1 Child (F) 6	White 10 Black 2	Not Stated
Ee et al. (2020) N=10 Sydney, Australia	27-46 (43.5)	Full time Employment 9 Unknown 1	Married 5 Not married 4 Unknown 1	None 9 ≥ 1 Child 1 Not TTC - 3 TTC >12m- 5 TTC <12m- 2	European 5 Asian 3 Oceanic 1 Unknown 1	Not Stated
Naz et al. (2019) N=15 Tehran, Iran	13-19	Not Stated	Married 2 Single 13	Not Stated	Not Stated	High 4 Middle 8 Low 3
Hadjiconstantinou et al. (2017) N=12 Leicestershire, UK	17-51	Not Stated	Not Stated	Not Stated	White British 7 South Asian 4 Black African 1	Not Stated
Williams et al. (2014)	20-45	Not Stated	Not Stated	Not Stated	Not Stated	Not Stated

Study Total Number of Participants Location	Age Range (Mean)	Occupation	Relationship Status	Child Status	Ethnicity	Socioeconomic Status
N=9 UK						
Keegan et al. (2003) N=4 UK	27-42	Clerical Support 3 Student 1	Married 2 Cohabiting 1 Single 1	None 3 ≥ 1 Child 1	Not Stated	Not Stated
Sanchez and Jones (2016)	NA	NA	NA	NA	NA	NA
Washington (2008) N=11 Oklahoma, Texas, Louisiana (US)	25-39 (30.36)		Married 7	None 10 ≥ 1 Child 1	Caucasian 5 Indian 2 African American 4	Not Stated

Note. TTC- Trying to Conceive, (F)- Denotes fertility treatment.

Appendix F
Examples of Meta-ethnographic Analytic Process

Table F1
Example of an early draft of the synthesis

Themes	Papers
1. Experiences of being different	5
Bearded ladies and hairy monsters	7
Hair growth described as dirty and distressing	2
Relating to other women with PCOS or symptoms	8
Fashion-related stress	3
Feeling like a Man	6
Terminology associated with men	5
Loss of physical beauty	5
'Proper' and 'Irregular' women	10
Body experienced as betraying their identity as a woman	3
Comparison to other women	8
Unfeminine, abnormal	8
2. Managing or controlling symptoms	8
Approval and criticism of others	4
Coping with being different- Not upholding	1
Boundary Figure	1
Doing gender differently	2
Humour	1
Normal for my race	3
Talking about difficulties	2
Criticism of feminine beauty ideals and concept of hirsutism	5
Discrepancy between self-rating of hair	1
Deviance, stigma and ‘passing’	10
Evaluations of others	1
Exhaustion and Effort trying to meet standards	7
Privilege and health lifestyles	3
3. Infertility ‘‘My whole purpose of being a woman was gone’’	3
Acknowledging women without PCOS can be infertile	1
'Crushing'	4
Feminist writings pulled in two directions on motherhood	1
Feminists undermining idea that Motherhood is ultimate fulfilment	2
Feminists writing about pregnancy and childbirth as defining women	2
Infertility easier to talk about	1
Terminology is degrading and centres on lack	1
Thoughts about future fertility	10

Figure F1

An Example of an NVivo Comparison Diagram from early in the synthesis process

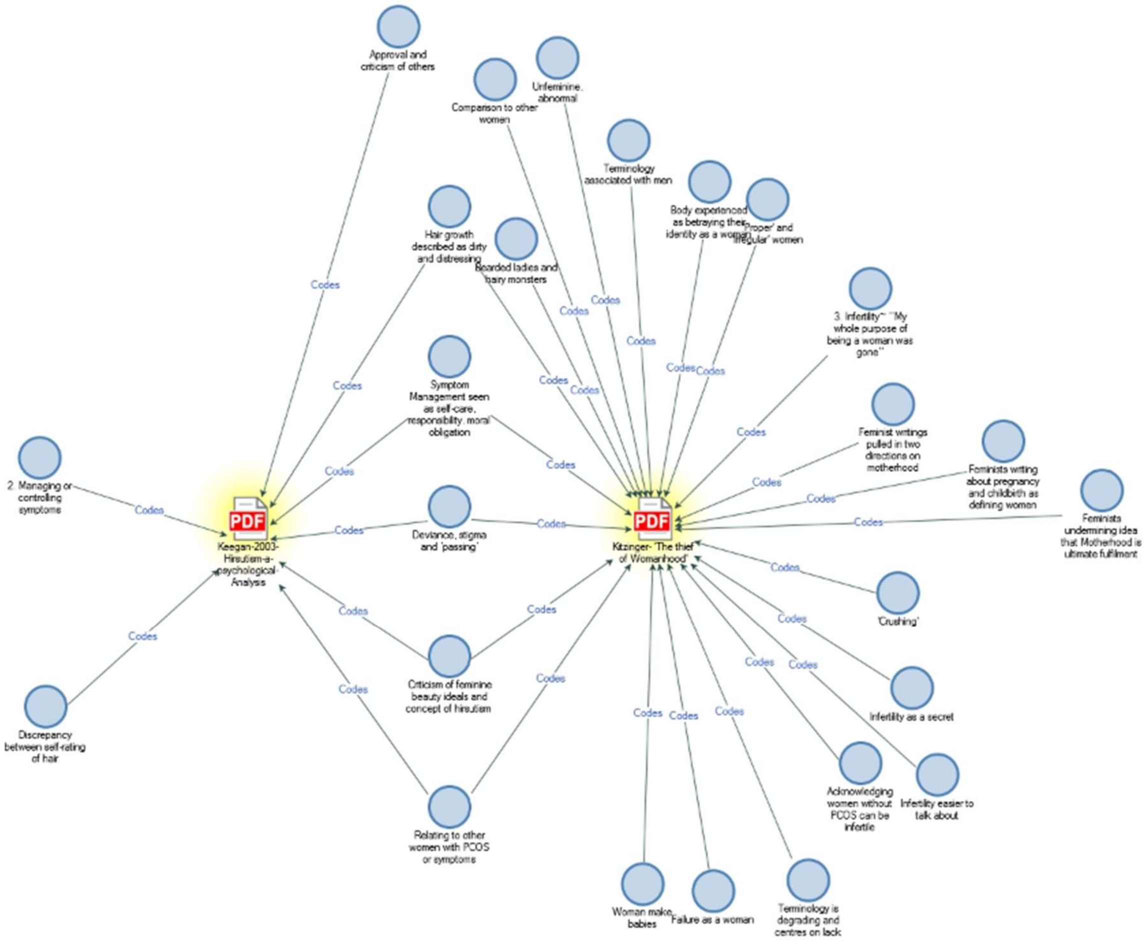
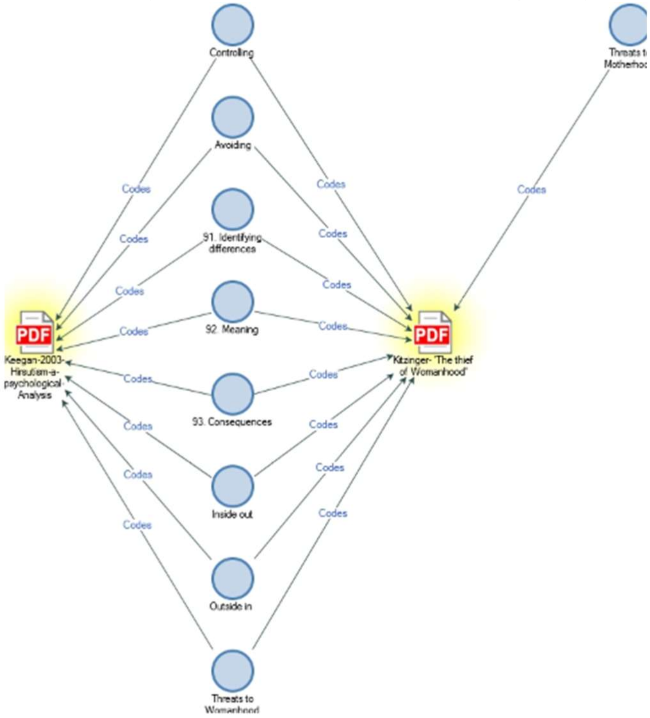


Figure F2

An Example of an NVivo Comparison Diagram from later in the synthesis process



Appendix G

Examples of how First-, Second- and Third Order Constructs are Synthesised

Table G1

Example of First-, Second- and Third- Order Constructs contributing to the subtheme "Control"

Study	First Order Constructs	Second Order Constructs	Third Order Constructs
Kitzinger and Willmott (2002)	Reports of hair removal Talk of secrecy surrounding hair removal and fertility	Women experienced their body and facial hair as betraying their identity as women and took steps to remove it. Women with PCOS go to great lengths to keep hirsutism hidden to others. Women with PCOS feel that revealing their irregular or absent periods might lead to their identity as women being under scrutiny.	Women respond to the threat to femininity by attempting to control or minimise symptoms.
Keegan et al. (2003)	Feeling abnormal Strategies for managing symptoms Shame when imagining not being able to manage symptoms Secrecy	Women with PCOS internalise cultural ideals of femininity, feel deviant and stigmatized and respond by attempts at 'passing'. Myth of female hair growth continues unchallenged.	
Pfister and Rømer (2017)	Reports of hair removal Feeling more feminine when hair is removed Hair removal is more difficult for women with PCOS	Women with PCOS have coping strategies that involve removing unwanted hair	
Naz et al. (2019)	Fortnightly laser treatments Weight loss attempts	Women with PCOS are exhausted due to constant hair removal and feel anxiety about obesity and weight control	
Amiri et al. (2014)	Reports of using clothing to conceal acne	The symptoms of PCOS lead women to perceive themselves to be less attractive, and this has an impact on them.	

Sharma and Mishra (2018)	Seeking treatment for fertility issues prior to marriage	Women with PCOS have goals to improve their fertility and bear children
Hadjiconstantinou et al. (2017)	Using contraceptive pills and metformin to manage androgen excess	Women with PCOS use pharmacology to cope with symptoms.
Williams et al. (2015)	Feeling like PCOS is out of control	Women with PCOS try to control their PCOS by trying medications, hair removal and skin care strategies.
Snyder (2006)	Describing feeling in control and out of control	Women feel out of control when their ability to have a child is uncertain. They feel more in control when they have a good health care provider.
Williams et al. (2014)	Describing hair removal practices and diets.	Women with PCOS use symptom management to gain a sense of control.
Sanchez and Jones (2016)	Describing weight loss success with exercise and diet	Women with PCOS feel personally responsible for managing their health and use diets, exercise and hard work to 'fight' against PCOS.
Smith-Tran (2018)	Hair removal, exercise and diet	Camouflaging symptoms Attempts to stay in control Re-framing exercise as medicine Women with PCOS must work to combat masculine symptoms.
Washington (2008)	Description of excess hair, hair loss. Reports of hair removal and altering hairstyles.	Women deal with masculine traits by finding ways to address the symptoms.
Ee et al. (2020)	Acknowledgement of links between hormone imbalances and other symptoms	Women feel a lack of control over the manifestations of their PCOS and desire to improve all aspects.

Appendix H
Author Instructions for Health Psychology Open

6. Preparing your manuscript

6.1 Word processing formats

The preferred format for your manuscript is Word. LaTeX files are also accepted. Word and (La)Tex templates are available on the Manuscript Submission Guidelines page of our Author Gateway.

6.2 Artwork, figures and other graphics

For guidance on the preparation of illustrations, pictures and graphs in electronic format, please visit SAGE's Manuscript Submission Guidelines

Figures supplied in color will appear in color online.

6.3 Title, keywords and abstracts: helping readers find your article online

The title, keywords and abstract are key to ensuring readers find your article online through online search engines such as Google. Please refer to the information and guidance on how best to title your article, write your abstract and select your keywords by visiting SAGE's Journal Author Gateway Guidelines on How to Help Readers Find Your Article Online.

Keywords: 5-10 to accompany the abstract. They should, if possible, be drawn from the MeSH list of Index Medicus and be chosen with a view to useful cross-indexing of the article**.**

Abstract: The abstract should accurately and concisely reflect the content of the article, and should be limited to 100 words. Please avoid reference citations and undefined abbreviations in the abstract.

6.4 Word length of manuscripts

Articles of any word length will be considered. Tables and Figures count nominally as 500 words each in lieu of text. Supplemental files will be published online together with the paper, subject to peer review.

6.5 Units of measurement

Units of measurement should be expressed in SI and metric units; older conventional units may be added in parentheses.

6.6 Nomenclature

Use the generic or chemical name of any drug, in lower case; the specific trade name (capitalized) may be given in parentheses after the first text reference.

6.7 Standard abbreviations and symbols

Standard Abbreviations and symbols should be used, then defined in full in the first instance unless they are standard units of measurement. Avoid any use of abbreviations in the article title and abstract.

6.8 Supplemental material

This journal is able to host additional materials online (e.g. datasets, podcasts, videos, images etc) alongside the full-text of the article. For more information please refer to our guidelines on submitting supplementary files

6.9 Reference style

Health Psychology Open adheres to the SAGE Harvard reference style. Please review the guidelines on SAGE Harvard to ensure your manuscript conforms to this reference style.

If you use EndNote to manage references, you can download the SAGE Harvard output file here.

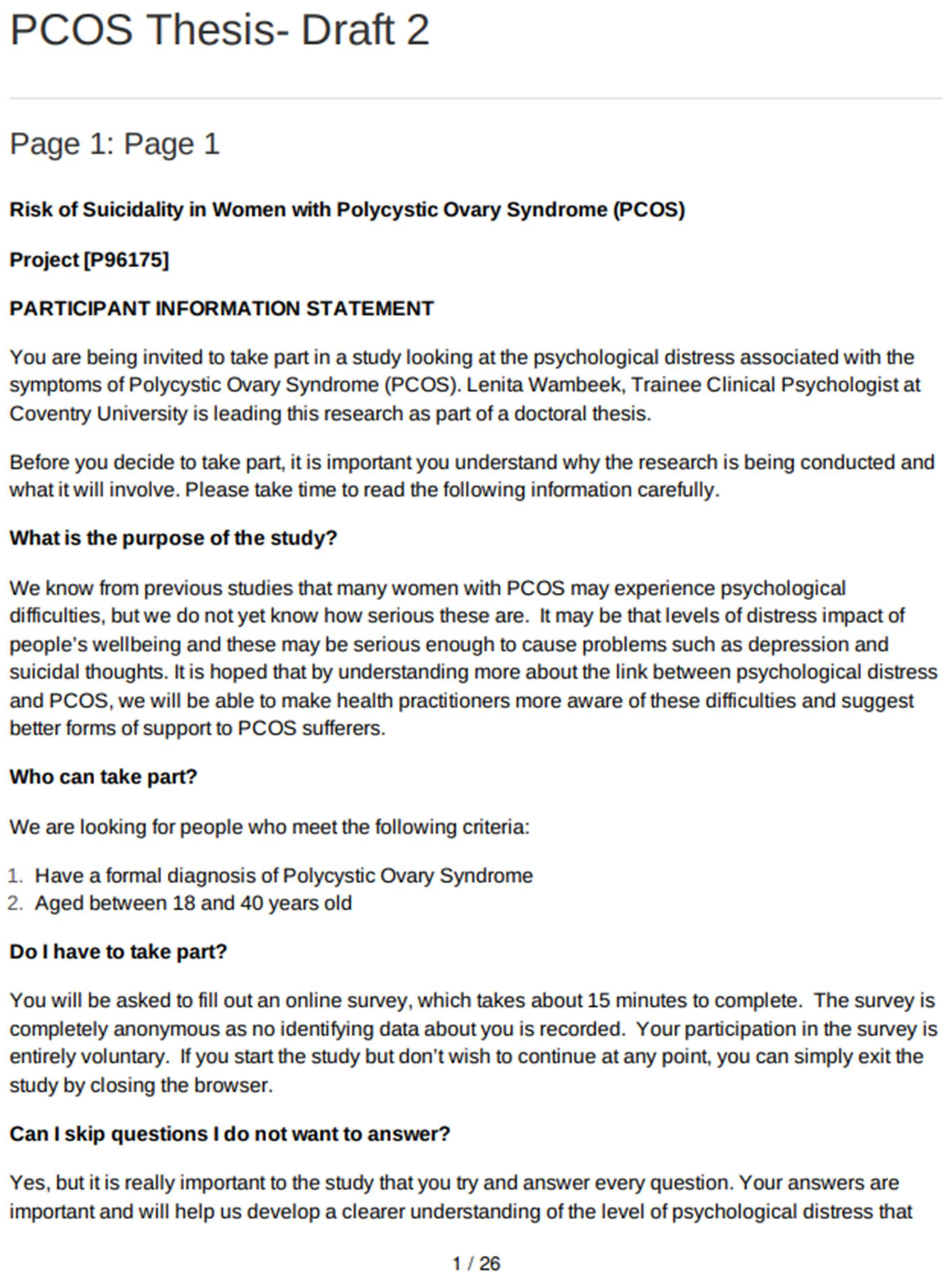
6.10 Statistical analyses

Where statistical analyses have been carried out please ensure that the methodology has been accurately described. In comparative studies power calculations are required. In research papers requiring complex statistics the advice of an expert statistician should be sought at the design/implementation stage of the study.

6.11 English language editing services

Authors seeking assistance with English language editing, translation, or figure and manuscript formatting to fit the journal’s specifications should consider using SAGE Language Services. Visit SAGE Language Services on our Journal Author Gateway for further information.

Appendix I
Participant Information, Consent, Questionnaire Content and Debrief



PCOS Thesis- Draft 2

Page 1: Page 1

Risk of Suicidality in Women with Polycystic Ovary Syndrome (PCOS)

Project [P96175]

PARTICIPANT INFORMATION STATEMENT

You are being invited to take part in a study looking at the psychological distress associated with the symptoms of Polycystic Ovary Syndrome (PCOS). Lenita Wambeek, Trainee Clinical Psychologist at Coventry University is leading this research as part of a doctoral thesis.

Before you decide to take part, it is important you understand why the research is being conducted and what it will involve. Please take time to read the following information carefully.

What is the purpose of the study?

We know from previous studies that many women with PCOS may experience psychological difficulties, but we do not yet know how serious these are. It may be that levels of distress impact of people's wellbeing and these may be serious enough to cause problems such as depression and suicidal thoughts. It is hoped that by understanding more about the link between psychological distress and PCOS, we will be able to make health practitioners more aware of these difficulties and suggest better forms of support to PCOS sufferers.

Who can take part?

We are looking for people who meet the following criteria:

1. Have a formal diagnosis of Polycystic Ovary Syndrome
2. Aged between 18 and 40 years old

Do I have to take part?

You will be asked to fill out an online survey, which takes about 15 minutes to complete. The survey is completely anonymous as no identifying data about you is recorded. Your participation in the survey is entirely voluntary. If you start the study but don't wish to continue at any point, you can simply exit the study by closing the browser.

Can I skip questions I do not want to answer?

Yes, but it is really important to the study that you try and answer every question. Your answers are important and will help us develop a clearer understanding of the level of psychological distress that people with PCOS may be experiencing. If you do not wish to answer a question, just answer 'I do not wish to answer this question'.

Are there any risks associated with taking part?

The project has been reviewed and approved through the formal Research Ethics procedure at Coventry University. The risks involved in taking part relate to the fact that answering the questions may cause you to become upset or cause you to worry about your current or future physical health.

The questionnaire starts by asking some very general questions about you including: your age, ethnicity, relationship status and your education. You will be asked for your height and weight, as research suggests that body mass index (BMI) is a relevant factor in psychological distress. It then asks about your PCOS symptoms and how they affect you. There are then four sections looking at your psychological wellbeing with regards to depression, your quality of life, your views of yourself and others and your experiences of self-harm and suicidal thoughts (if any).

The risks involved in taking part relate to the fact that answering the questions may cause you to become upset.

For further information, or if you have any queries, please contact the lead researcher, Lenita Wambeek (wambeekl@coventry.ac.uk).

If you have any concerns that cannot be resolved through the lead researcher, please contact Tony Colombo, Research Tutor (a.colombo@coventry.ac.uk).

If you feel any distress after completing the survey or would like further support or information regarding your PCOS, you can use the following resources:

- Your GP
- The Verity Website (https://www.verity-pcos.org.uk/)
- The PCOS Awareness Association Crisis Line (Text PCOS to 741741).
- The NHS website (https://www.nhs.uk/conditions/polycystic-ovary-syndrome-pcos/)
- You may access NHS talking therapies via your GP or by self-referral to the Improving Access to Psychological Therapies (IAPT) service (https://www.nhs.uk/service-search/other-services/Psychological%20therapies%20(IAPT)/LocationSearch/10008)

If you are feeling acutely distressed or actively suicidal, we would strongly encourage you to contact:

- The Samaritans
  Telephone: 116 123 (Service available 24/7)
  Email: Jo@samaritans.org (24-hour response)
- NHS 111
- **If there is an immediate danger to life, you should contact 999 emergency services**

What are the benefits of taking part?

By sharing your experiences with us, you will be helping us understand more about the link between psychological distress and PCOS, so that we can make health practitioners more aware of these difficulties and suggest better forms of support to PCOS sufferers.

What will happen with the results of this study?

The results of this study may be summarised in published articles, reports and presentations. All key findings will always be made anonymous.

Data Protection and Confidentiality

Your answers will be treated confidentially and the information you provide will be kept anonymous in any research outputs/publications. Your data will be processed in accordance with the General Data Protection Regulation 2016 (GDPR) and the Data Protection Act 2018. Your data will be held securely on the Coventry University OneDrive storage facility and will only be viewed by the researcher/research team. All data will be deleted by October 2026.

Can I withdraw my data after I have completed the study?

You are free to withdraw your questionnaire responses from the project data set until the end of November 2020. The data will be fully anonymised in our records on 1st December 2020. At the end of the survey, you will be prompted to save the webpage, this will contain your unique participant number. If you wish to withdraw, you may contact the lead researcher (contact details below) and give them the participant number. Please also contact the Faculty Research Support Office (email researchproservices.fbl@coventry.ac.uk; telephone +44(0)2477658461) so that your request can be dealt with promptly in the event of the lead researcher's absence. You do not need to give a reason. A decision to withdraw, or not to take part, will not affect you in any way.

You should note that your data may be used in the production of formal research outputs (e.g. journal articles, conference papers, theses and reports) prior to this date and so you are advised to contact the university at the earliest opportunity should you wish to withdraw from the study.

Data Protection Rights

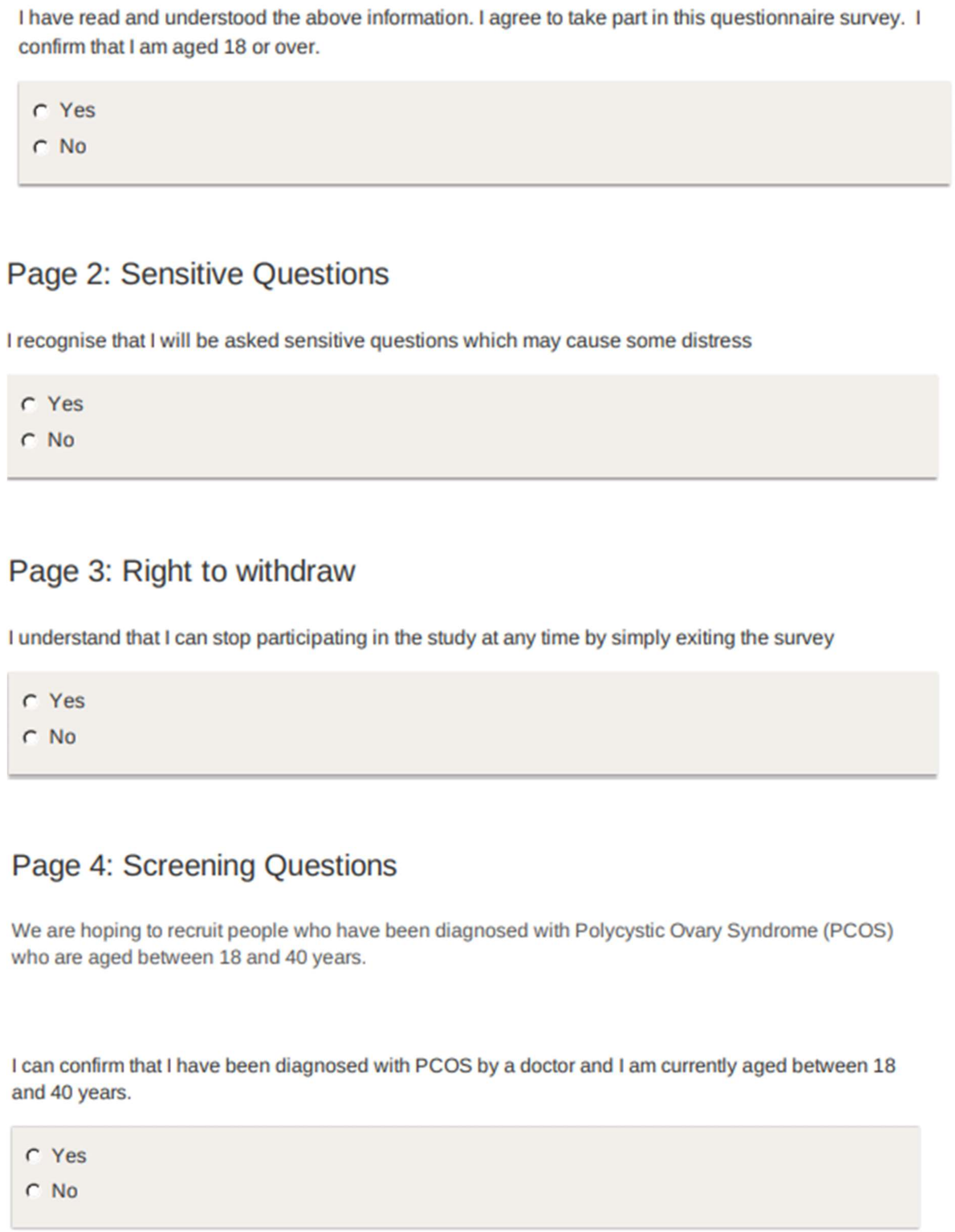
Coventry University is a Data Controller for the information you provide. You have the right to access information held about you. Your right of access can be exercised in accordance with the General Data Protection Regulation and the Data Protection Act 2018. You also have other rights including rights of correction, erasure, objection, and data portability. For more details, including the right to lodge a complaint with the Information Commissioner's Office, please visit www.ico.org.uk Questions, comments and requests about your personal data can also be sent to the University Data Protection Officer - enquiry.ipu@coventry.ac.uk

Making a Complaint

If you are unhappy with any aspect of this research, please first contact the lead researcher, Lenita Wambeek (wambeekl@coventry.ac.uk). If you still have concerns and wish to make a formal complaint, please write to Tony Colombo, Research Tutor, Coventry University, Coventry, CV1 5FB. Email: (a.colombo@coventry.ac.uk).

In your letter/ e-mail please provide information about the research project, specify the name of the researcher and detail the nature of your complaint.

Thank you for taking the time to participate in this survey. Your help is very much appreciated.



I have read and understood the above information. I agree to take part in this questionnaire survey. I confirm that I am aged 18 or over.

○ Yes
○ No

Page 2: Sensitive Questions

I recognise that I will be asked sensitive questions which may cause some distress

○ Yes
○ No

Page 3: Right to withdraw

I understand that I can stop participating in the study at any time by simply exiting the survey

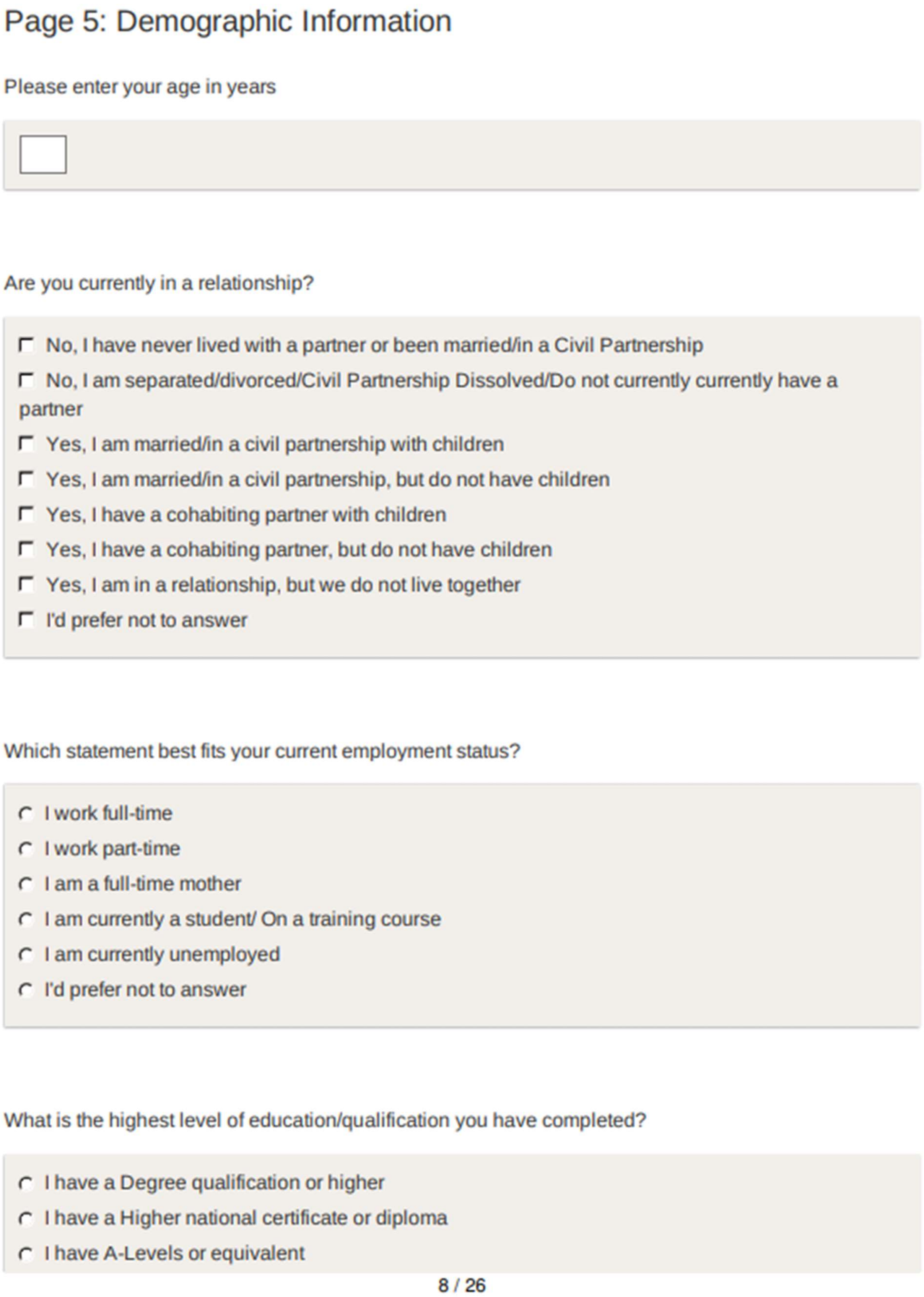
○ Yes
○ No

Page 4: Screening Questions

We are hoping to recruit people who have been diagnosed with Polycystic Ovary Syndrome (PCOS) who are aged between 18 and 40 years.

I can confirm that I have been diagnosed with PCOS by a doctor and I am currently aged between 18 and 40 years.

○ Yes
○ No



Page 5: Demographic Information

Please enter your age in years

☐

Are you currently in a relationship?

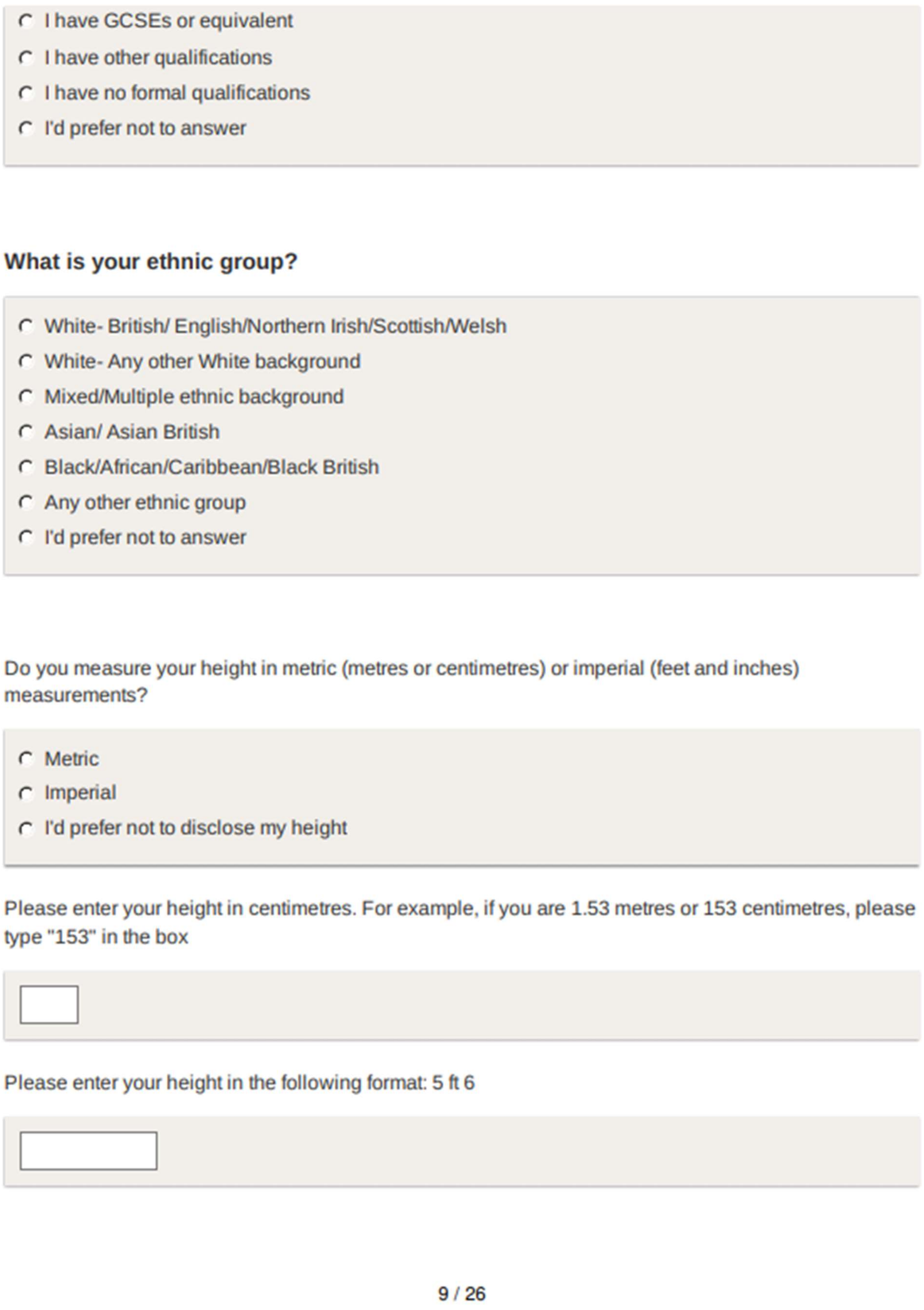
- ☐ No, I have never lived with a partner or been married/in a Civil Partnership
- ☐ No, I am separated/divorced/Civil Partnership Dissolved/Do not currently currently have a partner
- ☐ Yes, I am married/in a civil partnership with children
- ☐ Yes, I am married/in a civil partnership, but do not have children
- ☐ Yes, I have a cohabiting partner with children
- ☐ Yes, I have a cohabiting partner, but do not have children
- ☐ Yes, I am in a relationship, but we do not live together
- ☐ I'd prefer not to answer

Which statement best fits your current employment status?

- ○ I work full-time
- ○ I work part-time
- ○ I am a full-time mother
- ○ I am currently a student/ On a training course
- ○ I am currently unemployed
- ○ I'd prefer not to answer

What is the highest level of education/qualification you have completed?

- ○ I have a Degree qualification or higher
- ○ I have a Higher national certificate or diploma
- ○ I have A-Levels or equivalent



○ I have GCSEs or equivalent
○ I have other qualifications
○ I have no formal qualifications
○ I'd prefer not to answer

What is your ethnic group?

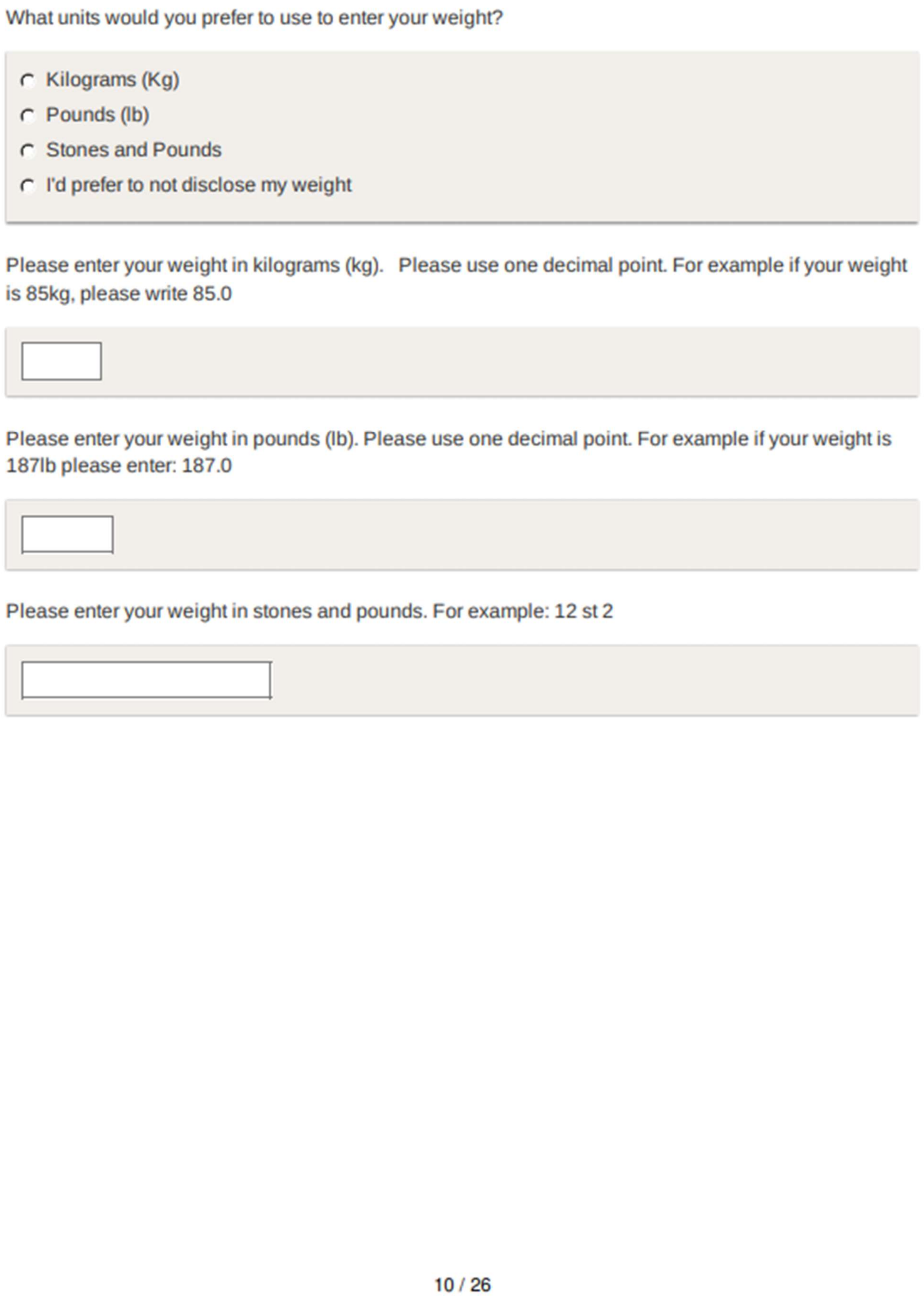
○ White- British/ English/Northern Irish/Scottish/Welsh
○ White- Any other White background
○ Mixed/Multiple ethnic background
○ Asian/ Asian British
○ Black/African/Caribbean/Black British
○ Any other ethnic group
○ I'd prefer not to answer

Do you measure your height in metric (metres or centimetres) or imperial (feet and inches) measurements?

○ Metric
○ Imperial
○ I'd prefer not to disclose my height

Please enter your height in centimetres. For example, if you are 1.53 metres or 153 centimetres, please type "153" in the box

Please enter your height in the following format: 5 ft 6



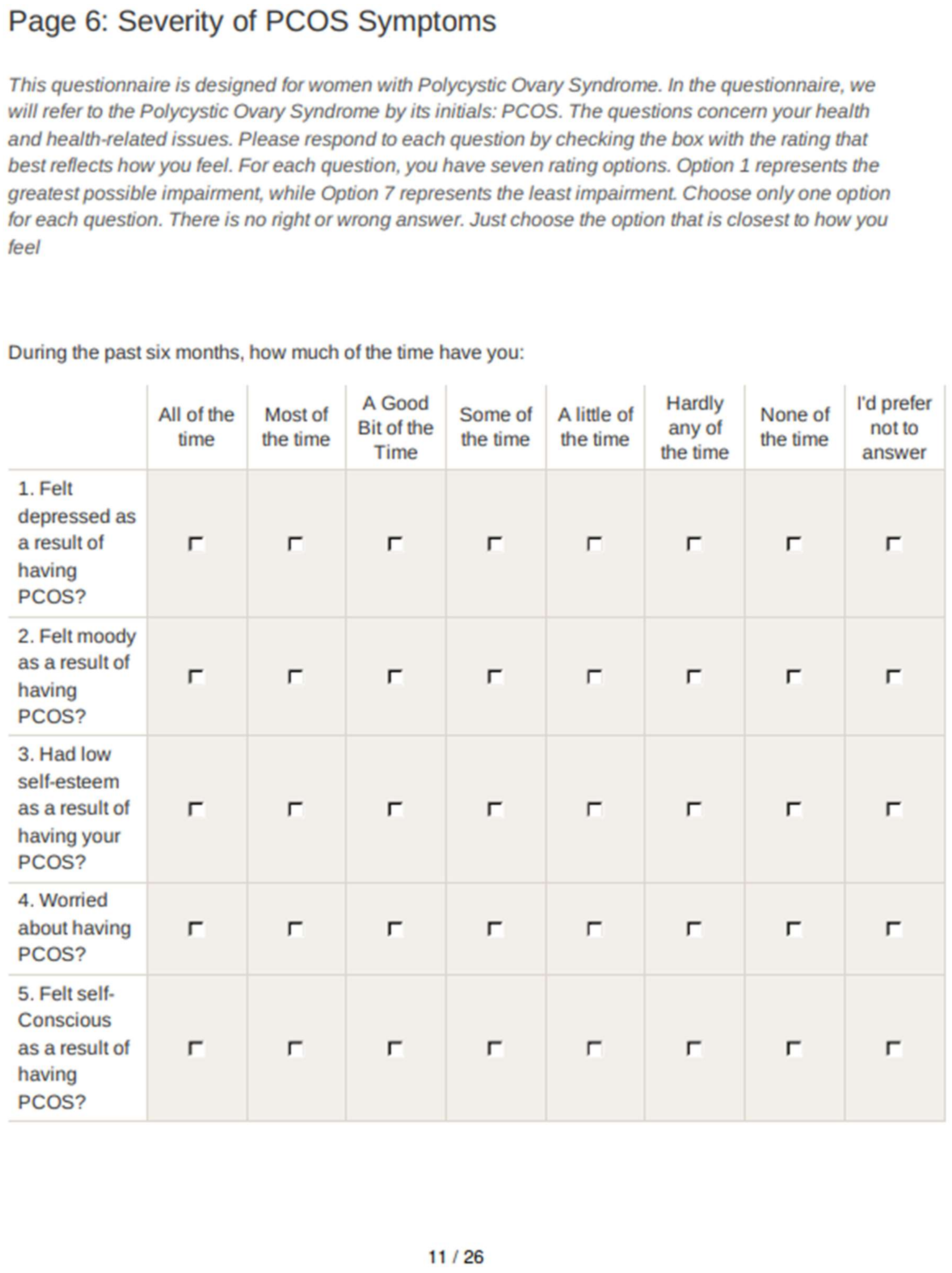
What units would you prefer to use to enter your weight?

○ Kilograms (Kg)
○ Pounds (lb)
○ Stones and Pounds
○ I'd prefer to not disclose my weight

Please enter your weight in kilograms (kg). Please use one decimal point. For example if your weight is 85kg, please write 85.0

Please enter your weight in pounds (lb). Please use one decimal point. For example if your weight is 187lb please enter: 187.0

Please enter your weight in stones and pounds. For example: 12 st 2



Page 6: Severity of PCOS Symptoms

This questionnaire is designed for women with Polycystic Ovary Syndrome. In the questionnaire, we will refer to the Polycystic Ovary Syndrome by its initials: PCOS. The questions concern your health and health-related issues. Please respond to each question by checking the box with the rating that best reflects how you feel. For each question, you have seven rating options. Option 1 represents the greatest possible impairment, while Option 7 represents the least impairment. Choose only one option for each question. There is no right or wrong answer. Just choose the option that is closest to how you feel

During the past six months, how much of the time have you:

	All of the time	Most of the time	A Good Bit of the Time	Some of the time	A little of the time	Hardly any of the time	None of the time	I'd prefer not to answer
1. Felt depressed as a result of having PCOS?	☐	☐	☐	☐	☐	☐	☐	☐
2. Felt moody as a result of having PCOS?	☐	☐	☐	☐	☐	☐	☐	☐
3. Had low self-esteem as a result of having your PCOS?	☐	☐	☐	☐	☐	☐	☐	☐
4. Worried about having PCOS?	☐	☐	☐	☐	☐	☐	☐	☐
5. Felt self-Conscious as a result of having PCOS?	☐	☐	☐	☐	☐	☐	☐	☐

6. Felt a lack of control over the situation with PCOS?	☐	☐	☐	☐	☐	☐	☐	☐
7. Felt frightened of getting cancer?	☐	☐	☐	☐	☐	☐	☐	☐

During the past six months, how much of the time have you:

	All of the time	Most of the time	A Good Bit of the Time	Some of the time	A little of the time	Hardly any of the time	None of the time	I'd prefer not to answer
8. Had difficulties staying at your ideal weight?	☐	☐	☐	☐	☐	☐	☐	☐
9. Had trouble dealing with your weight?	☐	☐	☐	☐	☐	☐	☐	☐
10. Felt frustrated in trying to lose weight?	☐	☐	☐	☐	☐	☐	☐	☐
11. Felt concerned about being overweight?	☐	☐	☐	☐	☐	☐	☐	☐
12. Felt like you are not sexy because of being overweight?	☐	☐	☐	☐	☐	☐	☐	☐
13. Felt easily tired?	☐	☐	☐	☐	☐	☐	☐	☐

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Over the last six months, to what extent have the following issues been a problem for you?

	A Severe Problem	A Major Problem	A Moderate Problem	Some Problem	A Little Problem	Hardly any Problem	No Problem	I'd prefer not to answer
14. Growth of visible hair on upper lip?	☐	☐	☐	☐	☐	☐	☐	☐
15. Growth of visible hair on your face?	☐	☐	☐	☐	☐	☐	☐	☐
16. Growth of visible hair on chin?	☐	☐	☐	☐	☐	☐	☐	☐
17. Embarrassment about excessive body hair?	☐	☐	☐	☐	☐	☐	☐	☐
18. Growth of visible body hair?	☐	☐	☐	☐	☐	☐	☐	☐

During the past six months, how much of the time have you:

	All of the time	Most of the time	A Good Bit of the Time	Some of the time	A little of the time	Hardly any of the time	None of the time	I'd prefer not to answer
19. felt unattractive because of acne?	☐	☐	☐	☐	☐	☐	☐	☐
20. felt depressed as a result of acne?	☐	☐	☐	☐	☐	☐	☐	☐

To what extent was acne a problem for you:

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	A Severe Problem	A Major Problem	A Moderate Problem	Some Problem	A Little Problem	Hardly any Problem	No Problem	I'd prefer not to answer
21. During the last six months?	☐	☐	☐	☐	☐	☐	☐	☐
22. During your last menstruation?	☐	☐	☐	☐	☐	☐	☐	☐

How much time during the last six months did you:

	All of the time	Most of the time	A Good Bit of the Time	Some of the time	A little of the time	Hardly any of the time	None of the time	I'd prefer not to answer
23. Feel concerned with infertility problems?	☐	☐	☐	☐	☐	☐	☐	☐
24. Feel afraid of not being able to have children?	☐	☐	☐	☐	☐	☐	☐	☐
25. Feel sad because of infertility problems?	☐	☐	☐	☐	☐	☐	☐	☐

In relation to your **last menstruation**, how much were the following issues a problem for you:

	A Severe Problem	A Major Problem	A Moderate Problem	Some Problem	A Little Problem	Hardly any Problem	No Problem	I'd prefer not to answer
26. Menstrual cramps?	☐	☐	☐	☐	☐	☐	☐	☐
27. Abdominal bloating?	☐	☐	☐	☐	☐	☐	☐	☐
28. Headaches?	☐	☐	☐	☐	☐	☐	☐	☐
29. Irregular menstrual periods?	☐	☐	☐	☐	☐	☐	☐	☐
30. Late menstrual period?	☐	☐	☐	☐	☐	☐	☐	☐

If you need a break you can click "Finish later" below.

Page 7: PHQ-9

Over the last 2 weeks, how often have you been bothered by any of the following problems?

	Not at all	Several days	More than half the days	Nearly everyday	I'd prefer not to answer
1. Little interest or pleasure in doing things	☐	☐	☐	☐	☐
2. Feeling down, depressed, or hopeless	☐	☐	☐	☐	☐
3. Trouble falling/staying asleep, sleeping too much	☐	☐	☐	☐	☐
4. Feeling tired or having little energy	☐	☐	☐	☐	☐
5. Poor appetite or overeating	☐	☐	☐	☐	☐
6. Feeling bad about yourself – or that you are a failure or have let yourself or your family down.	☐	☐	☐	☐	☐
7. Trouble concentrating on things, such as reading the newspaper or watching television.	☐	☐	☐	☐	☐
8. Moving or speaking so slowly that other people could have noticed. Or the opposite – being so fidgety or restless that you have been moving around a lot more than usual.	☐	☐	☐	☐	☐
9. Thoughts that you would be better off dead or of hurting yourself in some way.	☐	☐	☐	☐	☐

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Page 8: INQ-15

The following questions ask you to think about yourself and other people. Please base your responses on how you've been feeling recently based on your own current thoughts and experiences. There are no right or wrong answers: we are interested in what you think and feel.

	Very untrue for me	Untrue for me	Slightly untrue for me	Neither untrue or true for me	Slightly True for me	True for me	Very True for me	I'd prefer not to answer
1. These days the people in my life would be better off if I were gone	☐	☐	☐	☐	☐	☐	☐	☐
2. These days the people in my life would be happier without me	☐	☐	☐	☐	☐	☐	☐	☐
3. These days I think I am a burden on society	☐	☐	☐	☐	☐	☐	☐	☐
4. These days I think my death would be a relief to the people in my life	☐	☐	☐	☐	☐	☐	☐	☐
5. These days I think the people in my life wish they could be rid of me	☐	☐	☐	☐	☐	☐	☐	☐

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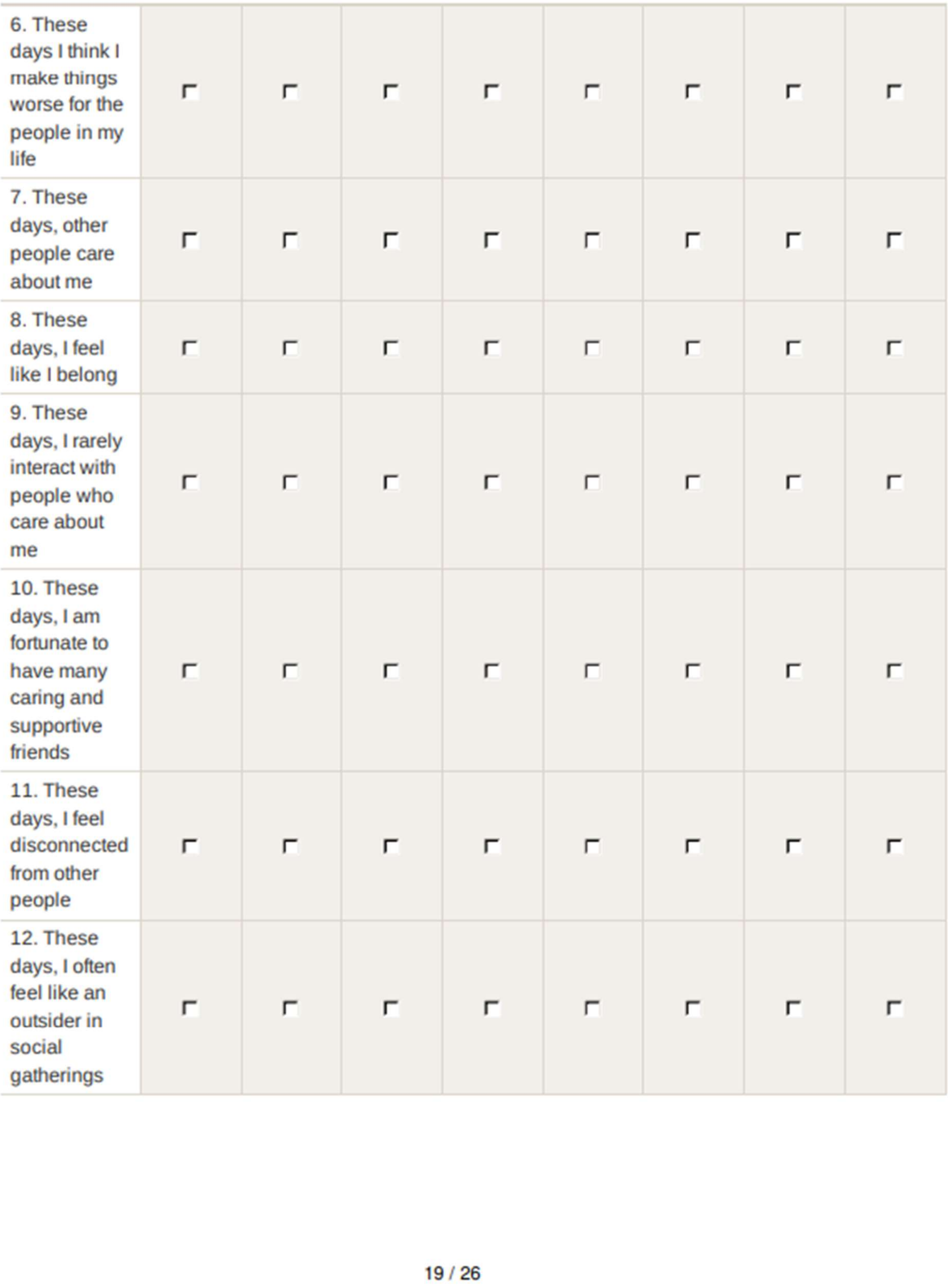

6. These days I think I make things worse for the people in my life	☐	☐	☐	☐	☐	☐	☐	☐
7. These days, other people care about me	☐	☐	☐	☐	☐	☐	☐	☐
8. These days, I feel like I belong	☐	☐	☐	☐	☐	☐	☐	☐
9. These days, I rarely interact with people who care about me	☐	☐	☐	☐	☐	☐	☐	☐
10. These days, I am fortunate to have many caring and supportive friends	☐	☐	☐	☐	☐	☐	☐	☐
11. These days, I feel disconnected from other people	☐	☐	☐	☐	☐	☐	☐	☐
12. These days, I often feel like an outsider in social gatherings	☐	☐	☐	☐	☐	☐	☐	☐

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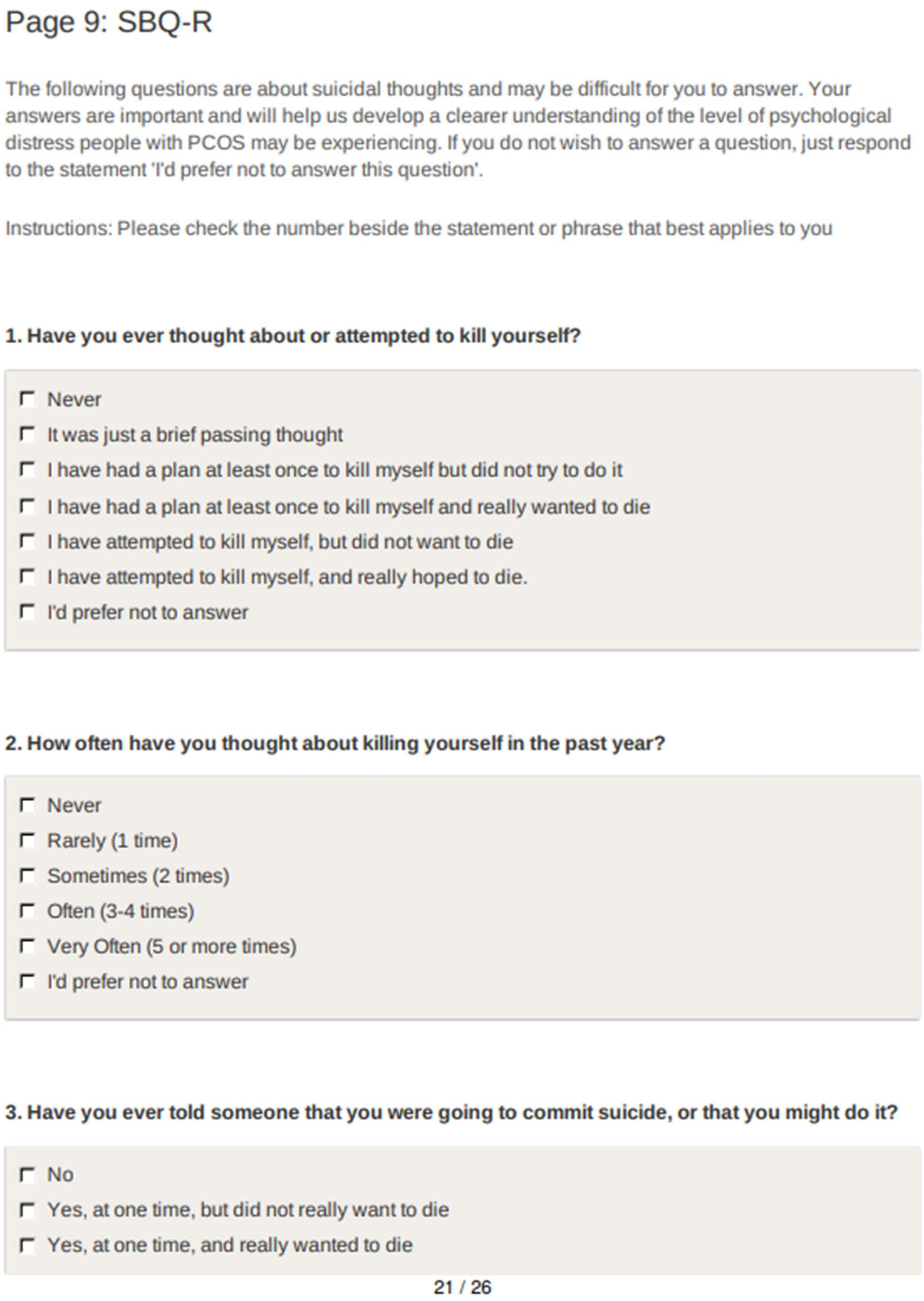
13. These days, I feel that there are people I can turn to in times of need	☐	☐	☐	☐	☐	☐	☐	☐
14. These days, I am close to other people	☐	☐	☐	☐	☐	☐	☐	☐
15. These days, I have at least one satisfying interaction every day	☐	☐	☐	☐	☐	☐	☐	☐

If you need a break you can click "Finish later" below.



Page 9: SBQ-R

The following questions are about suicidal thoughts and may be difficult for you to answer. Your answers are important and will help us develop a clearer understanding of the level of psychological distress people with PCOS may be experiencing. If you do not wish to answer a question, just respond to the statement 'I'd prefer not to answer this question'.

Instructions: Please check the number beside the statement or phrase that best applies to you

1. Have you ever thought about or attempted to kill yourself?

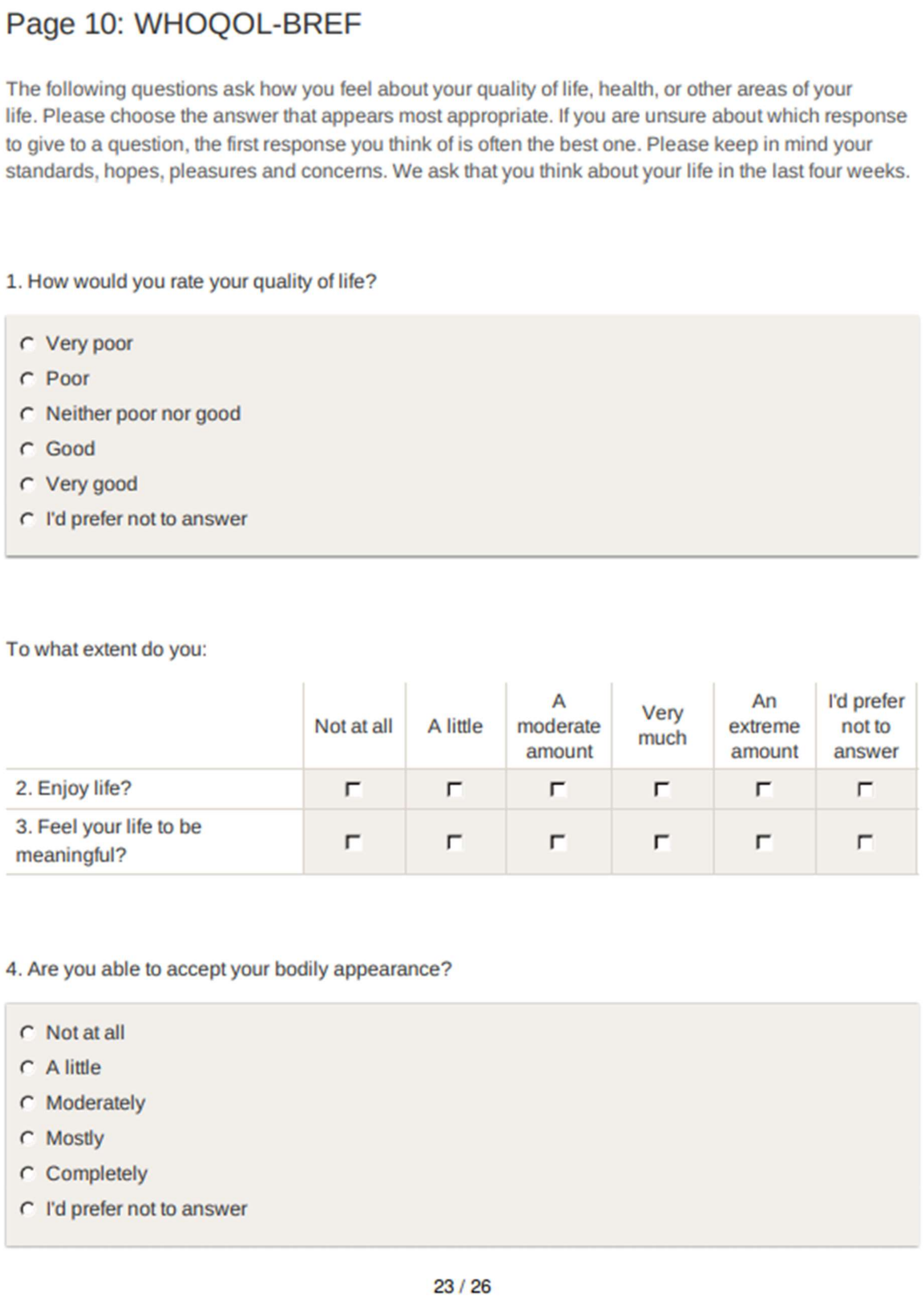
☐ Never
☐ It was just a brief passing thought
☐ I have had a plan at least once to kill myself but did not try to do it
☐ I have had a plan at least once to kill myself and really wanted to die
☐ I have attempted to kill myself, but did not want to die
☐ I have attempted to kill myself, and really hoped to die.
☐ I'd prefer not to answer

2. How often have you thought about killing yourself in the past year?

☐ Never
☐ Rarely (1 time)
☐ Sometimes (2 times)
☐ Often (3-4 times)
☐ Very Often (5 or more times)
☐ I'd prefer not to answer

3. Have you ever told someone that you were going to commit suicide, or that you might do it?

☐ No
☐ Yes, at one time, but did not really want to die
☐ Yes, at one time, and really wanted to die



Page 10: WHOQOL-BREF

The following questions ask how you feel about your quality of life, health, or other areas of your life. Please choose the answer that appears most appropriate. If you are unsure about which response to give to a question, the first response you think of is often the best one. Please keep in mind your standards, hopes, pleasures and concerns. We ask that you think about your life in the last four weeks.

1. How would you rate your quality of life?

- ○ Very poor
- ○ Poor
- ○ Neither poor nor good
- ○ Good
- ○ Very good
- ○ I'd prefer not to answer

To what extent do you:

	Not at all	A little	A moderate amount	Very much	An extreme amount	I'd prefer not to answer
2. Enjoy life?	☐	☐	☐	☐	☐	☐
3. Feel your life to be meaningful?	☐	☐	☐	☐	☐	☐

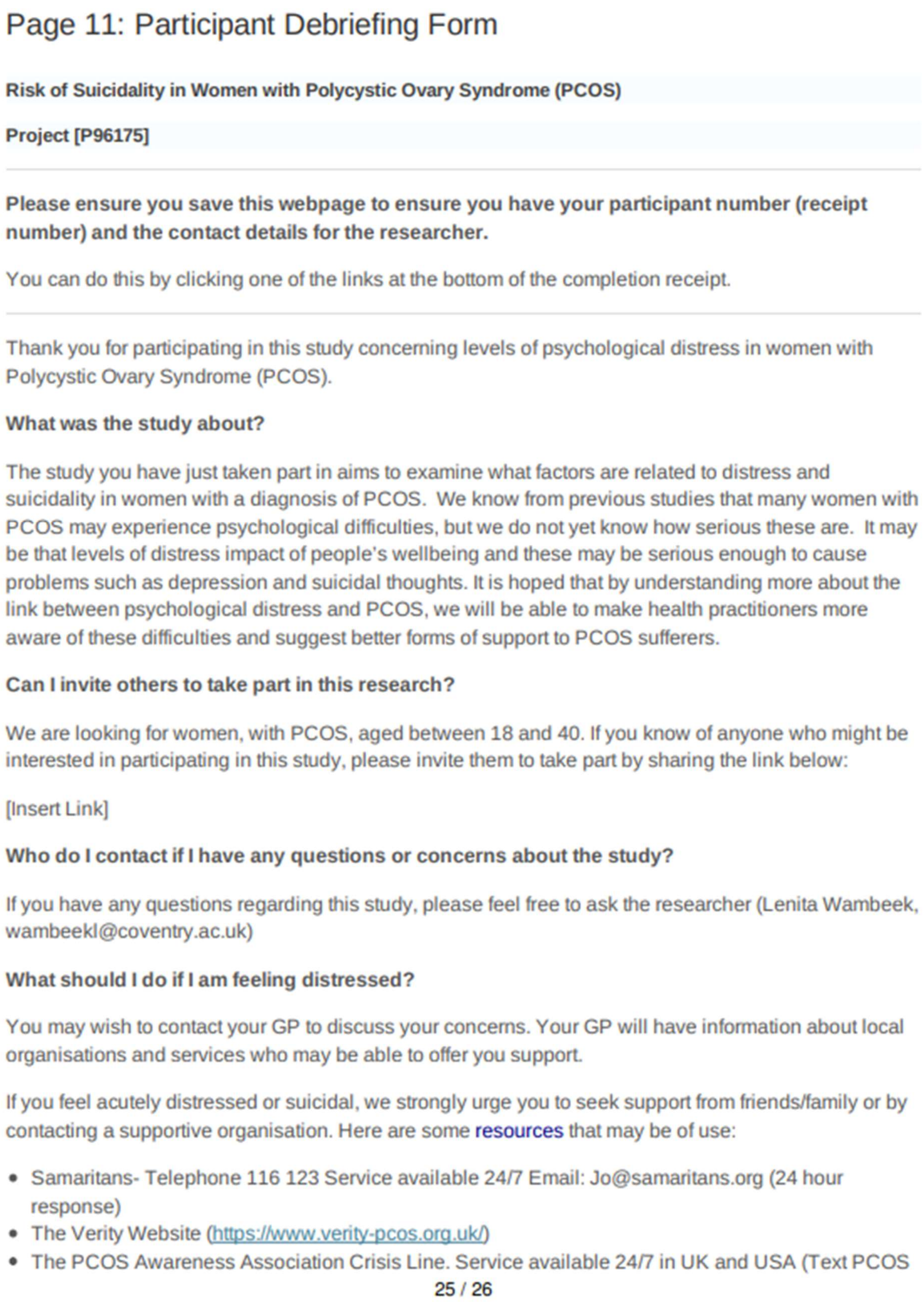
4. Are you able to accept your bodily appearance?

- ○ Not at all
- ○ A little
- ○ Moderately
- ○ Mostly
- ○ Completely
- ○ I'd prefer not to answer

How satisfied are you with:

	Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied	I'd prefer not to answer
5. Your health?	☐	☐	☐	☐	☐	☐
6. Your sleep?	☐	☐	☐	☐	☐	☐
7. Yourself?	☐	☐	☐	☐	☐	☐
8. Your personal relationships?	☐	☐	☐	☐	☐	☐
9. Your sex life?	☐	☐	☐	☐	☐	☐
10. The support you get from your friends?	☐	☐	☐	☐	☐	☐

If you need a break you can click "Finish later" below.



Page 11: Participant Debriefing Form

Risk of Suicidality in Women with Polycystic Ovary Syndrome (PCOS)

Project [P96175]

Please ensure you save this webpage to ensure you have your participant number (receipt number) and the contact details for the researcher.

You can do this by clicking one of the links at the bottom of the completion receipt.

Thank you for participating in this study concerning levels of psychological distress in women with Polycystic Ovary Syndrome (PCOS).

What was the study about?

The study you have just taken part in aims to examine what factors are related to distress and suicidality in women with a diagnosis of PCOS. We know from previous studies that many women with PCOS may experience psychological difficulties, but we do not yet know how serious these are. It may be that levels of distress impact of people's wellbeing and these may be serious enough to cause problems such as depression and suicidal thoughts. It is hoped that by understanding more about the link between psychological distress and PCOS, we will be able to make health practitioners more aware of these difficulties and suggest better forms of support to PCOS sufferers.

Can I invite others to take part in this research?

We are looking for women, with PCOS, aged between 18 and 40. If you know of anyone who might be interested in participating in this study, please invite them to take part by sharing the link below:

[Insert Link]

Who do I contact if I have any questions or concerns about the study?

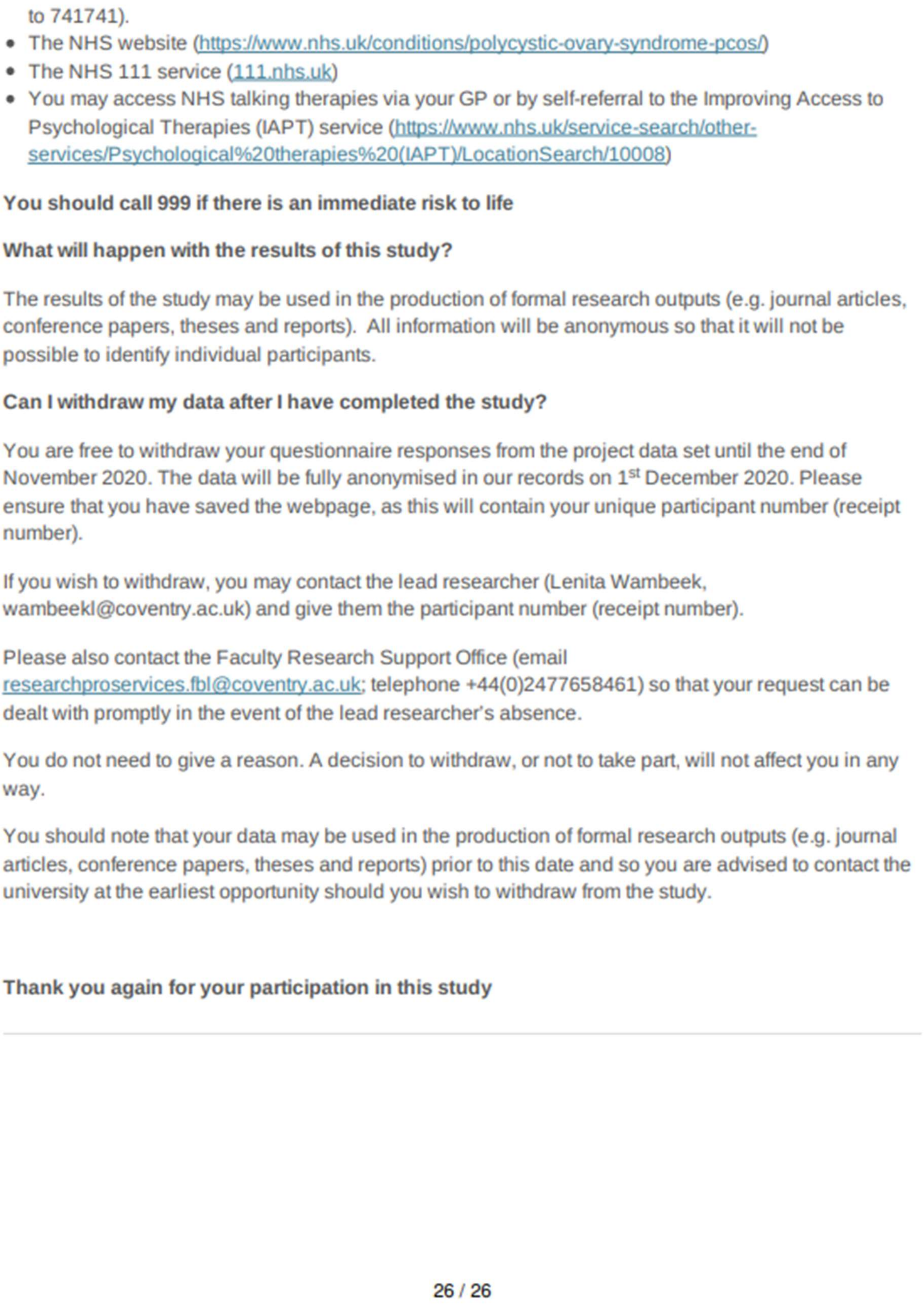
If you have any questions regarding this study, please feel free to ask the researcher (Lenita Wambeek, wambeekl@coventry.ac.uk)

What should I do if I am feeling distressed?

You may wish to contact your GP to discuss your concerns. Your GP will have information about local organisations and services who may be able to offer you support.

If you feel acutely distressed or suicidal, we strongly urge you to seek support from friends/family or by contacting a supportive organisation. Here are some resources that may be of use:

- Samaritans- Telephone 116 123 Service available 24/7 Email: Jo@samaritans.org (24 hour response)
- The Verity Website (https://www.verity-pcos.org.uk/)
- The PCOS Awareness Association Crisis Line. Service available 24/7 in UK and USA (Text PCOS



to 741741).

- The NHS website (https://www.nhs.uk/conditions/polycystic-ovary-syndrome-pcos/)
- The NHS 111 service (111.nhs.uk)
- You may access NHS talking therapies via your GP or by self-referral to the Improving Access to Psychological Therapies (IAPT) service (https://www.nhs.uk/service-search/other-services/Psychological%20therapies%20(IAPT)/LocationSearch/10008)

You should call 999 if there is an immediate risk to life

What will happen with the results of this study?

The results of the study may be used in the production of formal research outputs (e.g. journal articles, conference papers, theses and reports). All information will be anonymous so that it will not be possible to identify individual participants.

Can I withdraw my data after I have completed the study?

You are free to withdraw your questionnaire responses from the project data set until the end of November 2020. The data will be fully anonymised in our records on 1st December 2020. Please ensure that you have saved the webpage, as this will contain your unique participant number (receipt number).

If you wish to withdraw, you may contact the lead researcher (Lenita Wambeek, wambeekl@coventry.ac.uk) and give them the participant number (receipt number).

Please also contact the Faculty Research Support Office (email researchproservices.fbl@coventry.ac.uk; telephone +44(0)2477658461) so that your request can be dealt with promptly in the event of the lead researcher's absence.

You do not need to give a reason. A decision to withdraw, or not to take part, will not affect you in any way.

You should note that your data may be used in the production of formal research outputs (e.g. journal articles, conference papers, theses and reports) prior to this date and so you are advised to contact the university at the earliest opportunity should you wish to withdraw from the study.

Thank you again for your participation in this study

Appendix J
Certificate of Ethical Approval for Empirical Project

Certificate of Ethical Approval

Applicant:

Lenita Wambeek

Project Title:

Risk of Suicidality in Women with Polycystic Ovary Syndrome (PCOS)

This is to certify that the above named applicant has completed the Coventry University Ethical Approval process and their project has been confirmed and approved as Medium Risk

Date of approval:

02 April 2020

Project Reference Number:

P96175

Appendix K
SPSS Output

PROCESS v3.5

```
Model  : 6

   Y  : Total_Su
   X  : PCOS_Tot
  M1  : WHOQoL_L
  M2  : PHQ_Tota
  M3  : INQ_TB_T
  M4  : INQ_PB_T

Covariates:
Q6_Relat
Q7_Emplo
Age_4Grp
Q9_Ethni
Q8_Educa


Sample
Size:  584


**************************************************************************
OUTCOME VARIABLE:

WHOQoL_L


Model Summary
       R         R-sq      MSE        F              df1       df2          p
    .5418    .2935   37.1789    39.9595    6.0000   577.0000    .0000


Model
                 coeff       se           t             p         LLCI      ULCI
constant   25.5399    1.2695   20.1182    .0000    23.0465    28.0333
PCOS_Tot  2.9029     .2349   12.3589    .0000    2.4416    3.3643
Q6_Relat     .9253     .2061     4.4891    .0000     .5204    1.3301
Q7_Emplo    -.8504     .2044   -4.1605    .0000   -1.2519    -.4489
Age_4Grp   -1.2989     .2443   -5.3161    .0000   -1.7788    -.8190
Q9_Ethni    -.6555     .2789   -2.3503    .0191   -1.2032    -.1077
Q8_Educa    -.9149     .2411   -3.7948    .0002   -1.3884    -.4414


**************************************************************************
OUTCOME VARIABLE:
```

```
 PHQ_Tota

Model Summary
       R      R-sq       MSE         F       df1       df2         p
    .6142     .3772   22.6186   49.8362    7.0000   576.0000     .0000

Model
                   coeff        se              t                 p      LLCI      ULCI
constant    36.2906    1.2916    28.0975     .0000    33.7538    38.8274
PCOS_Tot    -1.1036     .2060    -5.3565     .0000    -1.5083     -.6990
WHOQoL_L  -.3847     .0325   -11.8461     .0000     -.4484     -.3209
Q6_Relat     -.1750     .1635   -1.0697     .2852     -.4962      .1463
Q7_Emplo      .4152      .1618     2.5660      .0105      .0974      .7330
Age_4Grp     -.2458      .1952    -1.2591      .2085     -.6291      .1376
Q9_Ethni      .2079      .2186      .9510      .3420     -.2214      .6371
Q8_Educa     -.1288      .1904     -.6765      .4990     -.5027      .2451
***************************************************************************
OUTCOME VARIABLE:
INQ_TB_T
Model Summary
          R      R-sq       MSE               F                 df1       df2               p
    .7548     .5698   58.1540   95.1953    8.0000   575.0000     .0000

Model
                   coeff        se              t                   p          LLCI      ULCI
constant    52.1605    3.1887    16.3579     .0000    45.8975    58.4234
PCOS_Tot     .6314      .3385    1.8652      .0627     -.0335     1.2962
WHOQoL_L -1.0541      .0581    -18.1542     .0591    -1.1681      .9400
PHQ_Tota    .3165       .0668     4.7369      .0000      .1853      .4477
Q6_Relat      .1251      .2625      .4767       .6338     -.3904      .6407
Q7_Emplo      .0465      .2609      .1780       .8588     -.4660      .5589
Age_4Grp     -.6670      .3134    -2.1283      .0337    -1.2826     -.0515
Q9_Ethni      .7488      .3507     2.1351      .0332      .0600     1.4377
Q8_Educa      .3762      .3054     1.2320      .2185     -.2236      .9760


***************************************************************************
OUTCOME VARIABLE:
 INQ_PB_T

Model Summary
       R           R-sq       MSE         F                 df1       df2               p
    .6869     .4718   55.2082   56.9769    9.0000   574.0000     .0000

Model
           coeff        se              t          p      LLCI      ULCI
```

```
constant    1.0758    3.7609    .2861    .7749   -6.3111    8.4627
PCOS_Tot  -.1119    .3308    -.3383    .7353    -.7617    .5378
WHOQoL_L  -.1856    .0710    -2.6161    .0691    -.3250    .0463
PHQ_Tota    .3623    .0664    5.4599    .0000    .2320    .4926
INQ_TB_T   .3530    .0406    8.6886    .0000    .2732    .4329
Q6_Relat    .3701    .2558    1.4468    .1485    -.1323    .8726
Q7_Emplo    .5914    .2542    2.3263    .0203    .0921    1.0908
Age_4Grp   -.8680    .3066   -2.8313    .0048   -1.4701    -.2658
Q9_Ethni   -.0419    .3431    -.1222    .9028    -.7158    .6319
Q8_Educa    .1291    .2979    .4332    .6650    -.4561    .7142
**************************************************************************
OUTCOME VARIABLE:
 Total_Su

Model Summary
       R      R-sq       MSE        F       df1       df2        p
    .6985     .4879     8.5756    54.5958    10.0000   573.0000     .0000

Model
           coeff       se        t                       p      LLCI      ULCI
constant    4.0042    1.4824    2.7012    .0071    1.0927    6.9158
PCOS_Tot    .1516    .1304    1.1626    .2455   -.1045    .4077
WHOQoL_L .0410    .0281    -1.4592    .1451    -.0963    .0142
PHQ_Tota    .0572    .0268    2.1340    .0333    .0046    .1099
INQ_TB_T   -.0005    .0170    -.0286    .9772    -.0339    .0330
INQ_PB_T   .2398    .0165   14.5756    .0000    .2075    .2721
Q6_Relat    .0833    .1010    .8248    .4098    -.1151    .2817
Q7_Emplo    .2270    .1007    2.2544    .0245    .0292    .4247
Age_4Grp   -.1940    .1217   -1.5949    .1113    -.4330    .0449
Q9_Ethni   -.1396    .1352   -1.0327    .3022    -.4052    .1260
Q8_Educa   -.0569    .1174    -.4843    .6284    -.2875    .1738

************************** TOTAL EFFECT MODEL ********************
OUTCOME VARIABLE:
 Total_Su

Model Summary
       R      R-sq       MSE        F                 df1       df2                p
    .3241     .1051    14.8831    11.2904    6.0000   577.0000     .0000

Model
                          coeff       se             t        p        LLCI      ULCI
constant                8.7202    .8032   10.8566    .0000    7.1426   10.2977
PCOS_Tot   -.7071    .1486   -4.7580    .0000    -.9990    -.4152
Q6_Relat   -.0693    .1304    -.5315    .5953    -.3254    .1868
Q7_Emplo    .6476    .1293    5.0077    .0700    -.3936    .9016
```

```
Age_4Grp   -.1886    .1546   -1.2199    .2230    -.4922    .1150
Q9_Ethni    .1061    .1765    .6013    .5479   -.2405    .4527
Q8_Educa    .2033    .1525   1.3327    .1832    -.0963    .5029

************** TOTAL, DIRECT, AND INDIRECT EFFECTS OF X ON Y ***

Total effect of X on Y
   Effect       se        t          p         LLCI      ULCI
   -.7071    .1486   -4.7580    .0000    -.9990    -.4152

Direct effect of X on Y
   Effect       se        t          p                 LLCI      ULCI
    .1516    .1304   1.1626    .2455          -.1045    .4077

                  coeff      se            t        p        LLCI      ULCI
PCOS_Tot  2.9029     .2349   12.3589    .0000    2.4416    3.3643
WHOQoL_L  -.0410    .0281   -1.4592    .1451    -.0963    .0142


Indirect effect(s) of X on Y:
       Effect    BootSE   BootLLCI   BootULCI
TOTAL    -.8587     .1109   -1.0741    -.6425
Ind1     -.1192     .0821    -.2881     .0368
Ind2     -.0632     .0354    -.1372     .0044
Ind3     -.0003     .0121    -.0287     .0231
Ind4     -.0268     .0769    -.1765     .1247
Ind5     -.0639     .0333    -.1286     .0047
Ind6      .0015     .0510    -.0979     .1031
Ind7     -.1292     .0511    -.2365     .0362
Ind8      .0002     .0060    -.0119     .0119
Ind9     -.0959     .0294    -.1607    -.0458
Ind10     .0534     .0300    -.0032     .1140
Ind11     .0002     .0061    -.0121     .0121
Ind12    -.0970     .0282    -.1598    -.0479
Ind13    -.2590     .0424    -.3469     .1807
Ind14    -.0296     .0092    -.0498    -.0143
Ind15    -.0299     .0084    -.0484    -.0154


********************** ANALYSIS NOTES AND ERRORS ***************

Level of confidence for all confidence intervals in output:
  95.0000
```

```
Number of bootstrap samples for percentile bootstrap confidence intervals:
  5000


------ END MATRIX -----
```

Coefficients[a]

Model		Unstandardized Coefficients		Standardized Coefficients			95.0% Confidence Interval for B		Correlations			Collinearity Statistics	
		B	Std. Error	Beta	t	Sig.	Lower Bound	Upper Bound	Zero-order	Partial	Part	Tolerance	VIF
1	(Constant)	3.116	1.425		2.187	.029	.317	5.914					
	Total Emotional Difficulties Score	.040	.024	.074	1.711	.088	-.006	.086	-.270	.071	.051	.467	2.141
	Total Weight Difficulties Score	.016	.017	.033	.954	.340	-.017	.049	-.102	.040	.028	.723	1.384
	Total Hirsutism Difficulties Score	-.026	.015	-.057	-1.729	.084	-.055	.004	-.159	-.072	-.051	.808	1.238
	Total Acne Difficulties Score	.013	.016	.024	.781	.435	-.019	.045	-.067	.032	.023	.921	1.086
	Total Fertility Difficulties Score	.007	.020	.012	.364	.716	-.032	.046	-.082	.015	.011	.857	1.167
	Total Menstrual Difficulties Score	-.006	.020	-.010	-.307	.759	-.045	.033	-.124	-.013	-.009	.792	1.263
	Total Depression Score	.068	.027	.101	2.523	.012	.015	.121	.436	.104	.075	.553	1.810
	Total Perceived Burdensomeness Score	.247	.016	.618	15.195	.000	.215	.279	.687	.533	.452	.533	1.876
	Total Thwarted Belongingness Score	.001	.017	.002	.032	.975	-.033	.034	.472	.001	.001	.377	2.654
	Total Life Difficulties Score	-.043	.028	-.076	-1.515	.130	-.098	.013	-.441	-.063	-.045	.355	2.817

a. Dependent Variable: Total_Suicide