CREATING GUIDELINES FOR PRACTITIONERS ON COMMUNICATION REGARDING THE MANAGEMENT OF THE PSYCHOLOGICAL AND INTERPERSONAL IMPACT OF VULVODYNIA: A DELPHI STUDY

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Thesis Abstract

Women's experiences of communicating with practitioners regarding the psychological, interpersonal and emotional impact of vulvodynia highlight significant barriers to this process. Women report having to face stigma, and practitioner discomfort and inexperience discussing issues pertinent to managing the impact of vulvodynia holistically. Impacts are on sexuality, relationships and psychological wellbeing. Further, practitioners may experience personal and structural barriers to conversations regarding the impact of vulvodynia, including embarrassment, lack of expertise and knowledge, and limited resources and time to explore these issues. As a result, women's experiences of interacting with healthcare systems regarding vulvodynia largely highlights negative iatrogenic experiences of interfacing with professionals. This can contribute to the worsening of the negative psychological impact of living with chronic pain, and sometimes difficulties with sexuality, relationships and identity. Practitioners are required to use key skills of good communication and shared decision making to enhance patient care and outcomes. Some examples of good practice in this area exist, although there is no guidance on how practitioners should approach and adapt communication with women with vulvodynia in order to ensure conversations are occurring to highlight women's idiosyncratic and holistic needs. The aim of this study was to utilise a method of generating consensus to develop guidelines for practitioners on communication regarding managing the impact of vulvodynia, based on the views of experts by experience on best practice in this area.

The Delphi Method was used to develop a set of good practice guidelines for practitioners to use when communicating with women regarding the psychological, interpersonal and emotional impact of managing vulvodynia. The Delphi consisted of three rounds, and participants were seven women with vulvodynia and seven professionals with experience of managing vulvodynia. Round One comprised individual interviews with each participant (termed ‘panellists’ in this process), in order to elicit examples of best practice and difficulties in communication, resulting in the panellist generating two to three guidelines at the end of the interview. A Round Two survey constructed by the main author consisted of all 40 guidelines generated by the entire panel. This was sent out to all panellists for comment and ratings of importance. Feedback from the Round Two survey was then used to amend and combine certain guidelines based on panellist feedback, before final ratings and comments were given by the panel. Consensus was considered to have been achieved if ratings of the guideline as important or essential met an a priori consensus agreement level of ≥70%. The final endorsed guidelines were supplemented with clinical vignettes based on the experiences of participants of difficulties, or best practice, in communication.

There were 19 guidelines that achieved consensus. These guidelines fell under themes of overarching good clinical practice points, initial consultation, including understanding symptoms and impact, follow-up, and future planning and longer-term care.

The study was limited by a homogenous sample of practitioner participants, compromising the generalisability of applying the guidelines. This research utilised experts by experience to co-produce a resource for practitioners to aide communication regarding important aspects of holistic vulvodynia management, based on participants lived experience of managing vulvodynia or practicing clinically with this population.

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I would like to thank Dr Anna Tickle and Dr Danielle De Boos, without whom this research would not have been possible. Their compassion, support and approach to the research, and their commitment to helping me to develop professionally, is not something I will readily forget. Thank you also to Dr Sanchia Biswas for helping to bring the research to life.

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Statement of Contribution

The project was designed and developed by the author in collaboration with Dr Anna Tickle and Dr Danielle De Boos. Both co-authors provided research supervision and feedback throughout the research execution process, consulted on the wording of guidelines and clinical vignettes, and the process of understanding consensus as generated by the panel through the surveys.

Dr Sanchia Biswas supported in the development of the research aims and Delphi design.

The author was responsible for submitting and obtaining ethical approval, participant recruitment, conducting interviews, constructing and disseminating surveys, data analysis and synthesis, and the project write-up.

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Systematic Literature Review

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The Efficacy of Cognitive Behavioural Therapy for Vulvodynia: A Systematic Review.

Abstract

Introduction: Vulvodynia is a chronic pain condition characterised by unexplained vulvar pain, which can be provoked or unprovoked. Treatments for vulvodynia are varied and most commonly include medical management and psychological therapies. Cognitive Behavioural Therapy (CBT) is recommended for the psychological treatment of chronic pain, which has been adapted to target pain, sexual functioning and psychological distress in women with vulvodynia. However, there is a lack of consensus and limited rigorous research studies into the efficacy of psychological therapies in this population, particularly CBT, despite its common use.

Aim: This review aims to investigate the efficacy of CBT for vulvodynia, as well as update existing reviews on the subject area.

Methods: A systematic search of EMBASE, PsycINFO, MEDLINE and CINAHL was conducted and quality assessment of included papers undertaken. A meta-analysis was intended for nine identified quantitative papers, though this was not possible due to disparities in comparators, populations and outcomes. Effect sizes were calculated for pre- and post-treatment data within CBT conditions across the studies, and comparisons made.

Results: There is an overall modest effect across studies indicating CBT treatment impacts positively on outcomes for vulvodynia from pre- to post-treatment. Methodological quality of studies was variable.

Conclusions: There is a dearth of literature examining the efficacy of psychological therapies, in particular CBT, for vulvodynia. Findings indicate CBT can facilitate significant reductions in pain, and improvements in sexual functioning and psychological distress. However, existing studies are disparate in their conceptualisation of the problem and approach to evaluating the efficacy of CBT on outcomes. As a result, findings are tentative and more robust research is required to build on this evidence base, and identify the components of CBT which may be effective, as well as predictors of outcomes.

Key Words: Vulvodynia; Generalised Vulvodynia; Provoked Vestibulodynia; Cognitive Behavioural Therapy.

Introduction

Vulvodynia is a condition characterised by idiopathic vulvar pain without an identifiable cause [1], affecting approximately 25% of women across their life span [2]. The International Society for the Study of Vulvovaginal Disease (ISSVD) groups vulvodynia into two subtypes: provoked vestibulodynia (PVD; formerly known as vulvar vestibulitis syndrome), and unprovoked or generalised vulvodynia (GVD). PVD is characterised by pain at the vaginal vestibule which is aggravated by touch or pressure at the specific location of the vestibule [3]. In contrast, GVD is more widely spread pain occurring in the absence of identifiable triggers [4].

There is a lack of clarity as to whether the subtypes are distinct disorders, and debate that provoked and unprovoked vulvodynia may be on a continuum of the same condition [5]. This is demonstrated in a study by Edwards [6] who found overlap in provoked and unprovoked pain and location in a sample of 60 patients, suggesting this imposed distinction is far from straightforward. The lack of clarity in symptomology of vulvodynia subtypes is demonstrated in the populations selected for research, with many studies focusing on the provoked subtype. Disaggregation may allow for measurable variables yielding higher statistical power, yet limit research findings and subsequent clinical implications for women who experience similar symptoms, outcomes and effects. Further, disaggregation can constrain data synthesis towards a consistent evidence base in the field.

There is also a lack of consensus regarding the causes of vulvodynia, with studies suggestive of medical contributors such as inflammation [7], neurological factors, or psychopathological causes [8]. Studies have found higher levels of psychological distress in women with vulvodynia [9], and more deleterious outcomes for women with major depressive disorder and vulvodynia than the general population [10]. However, conclusions regarding the temporality of psychological distress and vulvodynia have not been established. This may complicate treatment efforts, particularly where psychological treatments are concerned, if the distinction between exposures and outcomes is inconsistent in the literature.

Due to uncertainty regarding the aetiology of this condition, there is extremely limited universal agreement on appropriate treatments [11]. There are also few randomised control trials (RCTs) examining the efficacy of treatments for vulvodynia, and a recent systematic review by De Andres et al. [12] concluded that the optimal therapy for vulvodynia remains unclear. As a result, treatment is based on expert and clinical experience and opinion in most cases [13]. Recommended management is holistic and tailored with a combination of the use of topical agents, tricyclic antidepressants, physiotherapy, acupuncture, and in the case of provoked vulvodynia, sometimes surgery [14]. Where psychological therapies are concerned, there are currently no guidelines on appropriate evidence-based first-line psychological treatment, and a lack of research into the efficacy of existing interventions, despite treatment packages for vulvar pain conditions commonly involving some form of psychological intervention [15].

The majority of psychological treatments for vulvodynia are supportive psychotherapy or CBT [16]. A systematic review and meta-analysis by Morley [17] evidences the efficacy of CBT in the treatment of chronic pain, and further research has suggested that CBT contributes to reductions in pain and distress in this population, and improvements in daily functioning [18]. Similar psychological processes involving higher pain catastrophizing and lower pain self-efficacy [19] have been found to be more frequently reported in women with vulvodynia, therefore it follows that the rationale for CBT for vulvodynia is sound. Furthermore, recent research points towards the effectiveness of the integration of third-wave therapies such as Acceptance and Commitment Therapy into CBT therapies for chronic pain [20]. These advancements may be promising for psychological therapies for vulvodynia, and anecdotally are already used in practice.

Despite the use of CBT in the treatment of vulvodynia in practice, there is little research examining its efficacy, or factors that may predict treatment success or non-response. A review by LoFrisco [21] found CBT to be effective for female sexual pain disorders, however this publication lacked quality appraisal of included studies and synthesised data from several different populations including “dyspareunia” (painful sex), and “vaginismus” (pain upon penetration). A recent systematic review and meta-analysis by Flanagan et al. [22] attempted to examine differences in what they termed ‘medically defined’ and ‘psychiatrically defined’ vulvar pain. Medically-defined disorders were those presumed to be medical in aetiology, such as vulvodynia. In comparison, psychiatrically defined disorders such as dyspareunia and vaginismus were considered psychiatric in origin. The review found psychological and medical treatments to be equivalent in outcomes across the board for both medically and psychiatrically defined disorders, suggestive of further similarities between presumably distinct subtypes. However, statistical analyses compared few papers examining highly disparate medical treatments such as surgery and CBT, thus introducing Type I error bias and limiting advancements in knowledge in the field. This previous review [22] also examined several vulvar pain conditions including sexual pain disorders such as vaginismus and dyspareunia, related solely to painful sex or penetration. Although attempts were made to compare medically-defined and psychiatrically-defined conditions, it could be argued that there is homogeneity in symptomology even in these sub categories [23].There was also a focus on psychological treatment, which included several types of therapy including CBT, biofeedback and bibliotherapy, limiting conclusions to be drawn regarding the efficacy of any one psychological treatment.

Thus, there remains limited clarity on the efficacy of CBT for vulvodynia. Existing studies cover a broad spectrum of female sexual dysfunction and pain disorders or disaggregate subtypes. Working on the assumption that vulvodynia subtypes are likely to exist on a spectrum with crossover in symptomology, pain, sexual functioning issues and psychological distress, this review has chosen to aggregate vulvodynia, in the form of PVD and GVD, considering that similar psychological factors may influence processes involved in these variables.

There is clinical relevance to examining the efficacy of CBT, considering evidence that CBT and surgery may have equivalent effects [22]. Furthermore, in line with evidence that there can be deleterious outcomes in the areas of pain, sexual functioning and psychological distress for women with vulvodynia, there is a need to expand existing knowledge regarding treatments for this condition. Further examination may guide recommendations for the treatment and management of vulvodynia from a psychological perspective, and inform decision-making around treatments options which are minimally invasive and less permanent than current medical or surgical treatments.

Aims

This review seeks to expand on the findings of Flanagan et al. [22] and address methodological issues regarding overly-inclusive and expansive definitions and terminology pertaining to vulvodynia, to streamline the exploration of the efficacy of CBT further.

The aim of this review is to systematically identify, critically appraise and synthesise available evidence for the efficacy of CBT in the treatment of vulvodynia on pain, sexual functioning and psychological distress. Efficacy research is considered to be an assessment of intervention gain under controlled conditions with carefully selected samples. This is different to effectiveness research, which is conducted in real-world settings as a pragmatic measure of the appropriateness of an intervention [24]. This review utilises data from predominantly controlled trials, and therefore looks to examine the efficacy of CBT as an intervention for vulvodynia. This will be achieved through synthesis of current evidence on the efficacy of CBT on vulvodynia pre- and post-treatment outcomes. Where comparators are used in studies, these will be commented on in narrative synthesis. Meta-analysis of quantitative data was intended where appropriate.

Methods

Searching

Four databases were searched (EMBASE, PsycINFO, CINAHL, and MEDLINE) in July 2018, for studies published from the earliest date to present. Reference lists of included studies were also searched by hand. Search terms were derived from keywords in the field, and reading current systematic reviews on the topic. Relevant search terms were broad to encompass third-wave CBT-based therapies, and included the following combined with ‘OR’: *CBT, CBT-based, CBT-based treatment, cognitive behavio**, *cognitive therapy, behaviour therapy, behavior therapy, behavioural therapy, behavioral therapy, psychosocial therapy, psychological intervention, psychological therap**, *psychological treatment$, psychotherapy, third-wave CBT, third-wave cognitive behavio**, *third-wave psychotherap**, *ACT, acceptance and commitment, acceptance based, acceptance-based, acceptance* *and commitment therapy, dialectical behaviour*, dialectical behavior*, schema therapy, mindfulness, mindfulness-based, MBCT, gCBT, cCBT*. Terms for CBT therapies and vulvodynia were combined using the ‘AND’ function. Terms for vulvodynia combined with ‘OR’ were: *vulvodynia, vulv*, vulvar pain, vestibulodynia, vulvar vestibulitis, vestibulitis, provoked vestibulodynia, PVD.*

Vaginismus and dyspareunia were excluded as search terms due to being considered in the Diagnostic and Statistical Manual of Mental Disorders (DSM-5; [25]) as related specifically to pain on penetration or painful sex, under the label ‘Genito-Pelvic Pain or Penetration Disorder; GPPPD). In contrast, vulvodynia does not feature as a psychiatric diagnosis or disorder of sexual functioning in the DSM-5 [25], but is considered a chronic pain disorder [26]. Where chronic pain disorders such as vulvodynia can manifest as secondary sexual disorders, there can be professional and conceptual confusion regarding whether the primary problem is considered psychiatric, and much debate in the field still exists regarding this. In line with recent commentary by Vieira-Baptista & Lima Silva [27] this review considers that vulvodynia and GPPPD are distinct but overlapping and sometimes comorbid conditions requiring different therapeutic approaches, and therefore specifically vulvodynia was used as the focus of this review, and the search strategy.

Inclusion and Exclusion Criteria

Studies were included if the sample was women with vulvodynia, over the age of 16, who received a form of CBT therapy. RCTs and non-controlled before-after studies were included, therefore comparators varied between other interventions, wait-list controls and no comparator. Studies were also required to be in English and peer-reviewed to ensure quality control as well as contain data to quantify a measure of effect for the purpose of an intended meta-analysis.

Exclusion criteria were studies of vulvovaginal conditions or diseases without a primary idiopathic pain component, for example skin disorders such as lichen sclerosis, qualitative studies with no data to quantify effect size, follow-up studies, and studies where sexual functioning was the predominant problem e.g. studies investigating women with vaginismus or dyspareunia, unless vestibulodynia was stated as the cause of dyspareunia. Studies were not excluded if women met criteria for Axis I psychiatric disorders as per the DSM-5 [25] due to the link between vulvodynia and disorders such as Major Depressive Disorder [10].

Data Extraction

Data was extracted by the first author into data abstraction templates generated in Microsoft Excel, where information regarding the population, intervention, comparator and outcome (PICO) was combined with information on key findings and study design. Data extraction was informed by previous systematic reviews [22, 28] and was performed prior to assessment of study quality in order to limit bias for lower quality studies.

Data in the form of Means (M) and Standard Deviations (SD) were extracted for pre- and post-treatment CBT conditions on outcomes for pain, sexual functioning and psychological distress. Outcome measures were decided on via a hierarchical method, in which standardized measures were examined in order of priority based on frequency of the measure used, and then reliability and validity of measures where more than one measure was utilised. Due to the examination of pre- and post-treatment values in the same condition, effect sizes were computed using M and SD values and standardized for test re-test reliability. A study by Corsini-Munt [29], observed a pre-post correlation of $r = 0.58$, and this value was adopted for all measures in keeping with recommendations from Balk et al. [30]. The authors suggested that due to poor estimates of r as common in the literature, a value of $r = 0.59$ is recommended for continuous outcomes for within-groups, for the purpose of statistical efficiency. Due to the similarity between the value reported in these two papers [29, 30] an r of 0.58 is used across measures in this study, where effect sizes are not reported.

Quality Assessment

Following data extraction, quality assessment was undertaken using the Integrated quality for Review of Multiple Study designs (ICROMS) tool [31] due to studies being both RCTs and non-controlled before-after studies. This tool requires certain mandatory criteria to be fulfilled for both types of study in this review (marked using an asterisk in subsequent tables), and a total score of 60 per cent is the minimum criteria for inclusion of studies. Points represent a scale from zero to two, where zero represents criterion not met, one represents an inability to conclude if criteria are met, and two identifies criteria as met.

In line with a recent systematic review by Reeve et al. [32] mandatory category 3a regarding blinding of studies was edited to a non-mandatory category, due to the impractical nature of blinding in psychological intervention research. Furthermore, studies by Goldfinger et al. [33] and Corsini-Munt et al. [29] were considered under RCT criteria due to being controlled pilot studies.

Data Analysis

Meta-analysis was intended for included papers of the same study design.

Results

Search Strategy Results

The results of the search strategy are outlined in the PRISMA diagram [34], as shown in Figure 1 below.

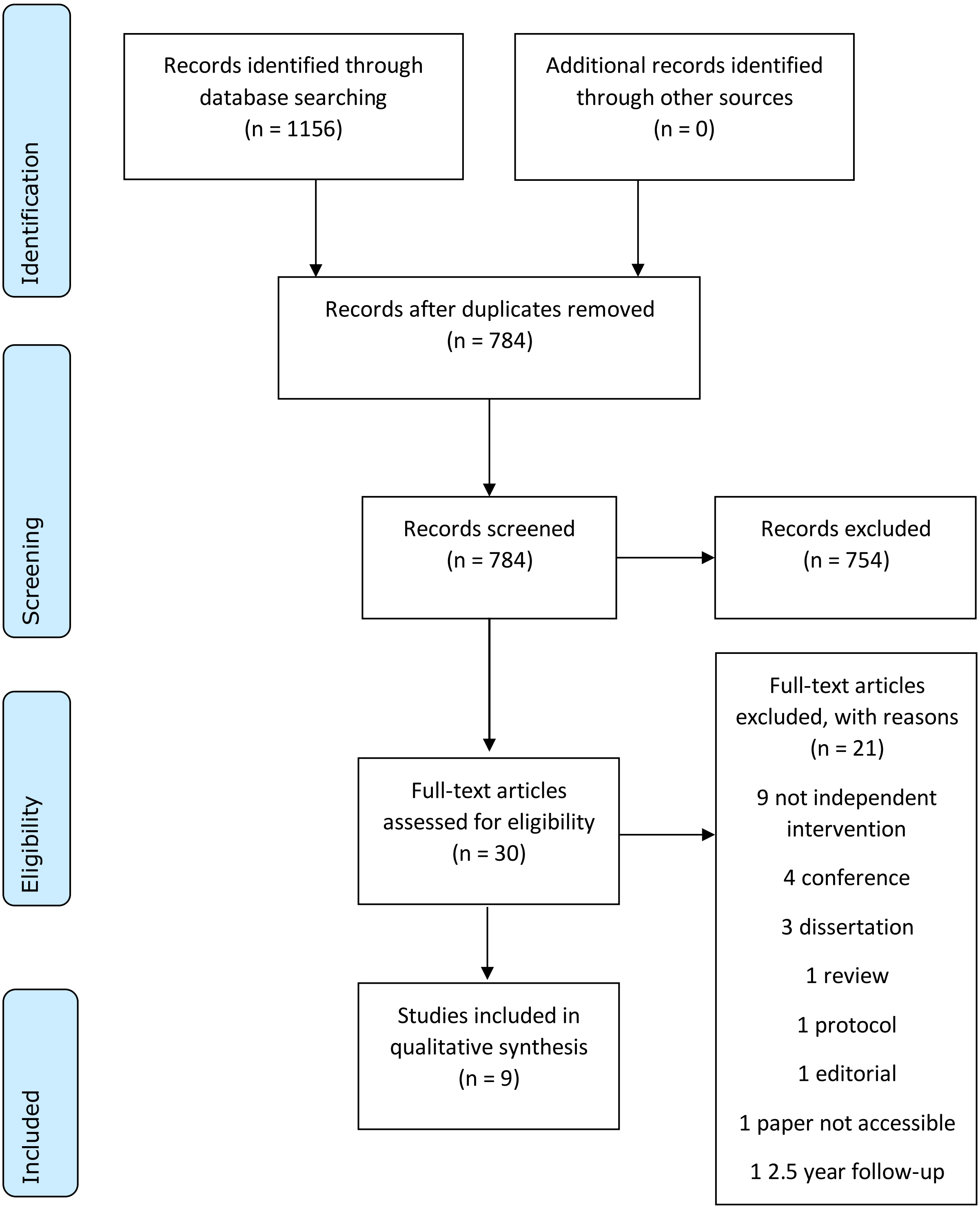

Figure 1. PRISMA 2009 diagram.

Table 1

Study Characteristics for included studies

Study ID, Author, Country	**Type of Vulvodynia**	**Study Design**	**Intervention (*n* = number randomised)**	**Comparator(s) (*n* = number randomised)**	**Pain Measures**	**Sexual Functioning Measures**	**Psych Measures**	**Key Findings**
[35] Bergeron et al. 2001 Canada	PVD	RCT	Group CBT (*n* = 28) Delivered by PhD level clinical psychologists Adherence measured by independent coding of a random sample of videotapes Manual designed by authors	(1) Vestibulectomy (*n* = 22) (2) Biofeedback (*n* = 28)	Pain index (11 point scale) Pain intensity during intercourse MPQ-PRI MPQ-Sensory	Sexual History Form Frequency of intercourse per month DSFI-Information subscale	BSI-GSI	• All three treatments had equally positive effect on sexual functioning and psychological adjustment post-treatment. This held at 6 month follow-up • Participants in the vestibulectomy condition had significantly lower pain levels than GCBT and biofeedback. This held at 6 month follow-up
[36] Bergeron et al. 2016 Canada	PVD	RCT	Group CBT (*n* = 52) Delivered by female psychologists specialising in sex and couple therapy Adherence measured by independent coding of a random sample of videotapes Manual designed by authors	Topical steroid cream (*n* = 45)	Pain index (11 point scale) MPQ-PPI PCS PISES	Frequency of intercourse per month FSFI	Nr.	• There were significant improvements in both groups from baseline to post treatment on pain, sexual functioning and measures of psychological adjustment • GCBT participants demonstrated significantly more pain reduction, improvements in sexual functioning and pain catastrophizing and pain self-efficacy post treatment
[37] Brotto et al. 2015	PVD	RCT	Group Mindfulness-based CBT (*n* = 63) Delivery nr.	Delayed treatment arm (*n* = 23)	Pain index PCS	FSDS FSFI	BDI STAI	• Brief mindfulness-based CBT was associated with significant improvements in pain self-efficacy and pain on examination,

Study ID, Author, Country	Type of Vulvodynia	Study Design	Intervention (*n* = number randomised)	Comparator(s) (*n* = number randomised)	Pain Measures	Sexual Functioning Measures	Psych Measures	Key Findings
USA			Adherence measure nr. Manual developed by first two authors		PISES PVAQ			hypervigilance and catastrophizing, and sexual distress • There was a statistically significant reduction in depression symptoms with treatment • No significant differences in anxiety symptoms were found
[38] Brown et al. 2009 USA	PVD +GVD	RCT	CBT-based self-management (*n* = 21) Delivered by a physical therapist and psychologist and nurse practitioner trained in sex therapy Adherence measure nr. Modified treatment manual by Bergeron et al. 2001 [1]	(1) Amitriptyline (*n* = 11) (2) Amitriptyline + triamcinolone (*n* = 11)	MPQ-PRI MPQ-PPI	None	None	• No significant changes between treatment groups on outcomes were found • CBT-based self-management group showed a significant improvement on total PRI score • Amitriptyline group showed a significant improvement on PPI score
[29] Corsini-Munt et al. 2014 Canada	PVD and male partners	Pilot study	Couples Group CBT (*n* = 9) Delivered by two therapists trained to use the CCBT manual Intervention checklists used for treatment reliability	None	Pain index MPQ-PRI PISES PCS	DISF-SR GMSEX	BDI-II STAI	• Significant decrease in pain during intercourse and MPQ-PRI score for women were found, as well as sexual functioning and satisfaction • Male partners reported significant increases in sexual satisfaction • Decreases in trait anxiety and large decrease in depression were reported following treatment, male partners also reported decreases in anxiety and depression • Small increases were found in sexual satisfaction

Study ID, Author, Country	Type of Vulvodynia	Study Design	Intervention (*n* = number randomised)	Comparator(s) (*n* = number randomised)	Pain Measures	Sexual Functioning Measures	Psych Measures	Key Findings
			Treatment manual adapted from Bergeron et al 2001					
[33] Goldfinger et al. 2015 Canada	PVD	Pilot study	Individual CBT (*n* = 10) Delivery nr. Adherence measure nr. Manual nr.	Physical therapy (*n* = 10)	Average pain intensity at vestibule and recent intercourse attempts Percentage of intercourse attempts involving pain, completed without termination due to pain, and of sexual/non-sexual activities resulting in vulvar pain MPQ PCS CSQ	FSFI	None	- Both groups showed significant improvements in average intercourse pain intensity, percentage of painful intercourse attempts and completed intercourse attempts, improvements in percentage of non-sexual activities results in vulvar pain, as well as significant decreases in MPQ sensory and affective pain ratings - Significant improvements in sexual functioning observed only in CBT group
[39] Lindstrom et al. 2015 Netherlands	PVD	Descriptive	Individual CBT + desensitisation exercises (*n* = 60) Delivered by one therapist Adherence measure nr. Not manualised	None	None	MFSQ	HADS	- Significant increases in satisfaction with extent of sexual activity, sexual excitement more often and increase in fantasies - Significant decreases in anxiety levels at 6 month follow-up, no significant difference in depression symptoms pre and post treatment

Study ID, Author, Country	Type of Vulvodynia	Study Design	Intervention (*n* = number randomised)	Comparator(s) (*n* = number randomised)	Pain Measures	Sexual Functioning Measures	Psych Measures	Key Findings
[40] Masheb et al. 2009 USA	PVD + GVD	RCT	Individual CBT (*n* = 25) Delivered by PhD level therapists Adherence measured by audiotaping of sessions Manual adapted from Kerns et al. 1986 chronic pain manual	Supportive Psychotherapy (SPT) (*n* = 25)	Pain index MPI MPQ	FSFI	BDI PASS	• Both CBT and SPT groups achieved statistically significant and clinically meaningful improvements in pain severity • Scores on the BDI and PASS were significantly lower from pre-to-post treatment • CBT resulted in significantly greater improvements on pain on physical exam and on sexual functioning measure
[41] Ter Kuile et al. 2006 Netherlands	PVD	Open trial	Group CBT (*n* = 67) Delivered by 7 psychologists and 2 doctors over 13 groups Adherence measured by audiotaping of sessions Not specified if manualised	None	Pain index Pain intensity during intercourse CSQ Vestibular pain and vaginal muscle tension Vaginal muscle tension	GRISS	SCL-90	• Significantly lower levels of pain during intercourse and lower scores for sexual dissatisfaction, vestibular pain, vaginal muscle tension • Significantly higher scores for perceived pain control • No significant differences in psychological distress or marital dissatisfaction

Note. Nr. = none reported. Primary conditions: PVD = Provoked Vestibulodynia; GVD = Generalised Vulvodynia. Design: Conditions using previous definitions of provoked vestibulodynia were updated and abbreviated to PVD for consistency. RCT = Randomised Controlled Trial. Intervention: CBT = Cognitive Behavioural Therapy. Measures: BDI = Beck Depression Inventory; BDI-II = Beck Depression Inventory – Version 2; BSI-GSI = Brief Symptom Inventory – Global Severity Index; CSI = Couple Satisfaction Index; CSQ = Coping Strategies Questionnaire; DISF-SR = Derogatis Interview for Sexual Functioning – Self-Report; DSFI-Information subscale = Derogatis Sexual Functioning Inventory - Sexual Information Scale; FFMQ = Five Factor Mindfulness Questionnaire; FSDS = Female Sexual Distress Scale; FSFI = Female Sexual Function Index; GMSEX = Global Measure of Sexual Satisfaction Scale; GRISS = Golombok Rust Inventory of Sexual Satisfaction; HADS = Hospital Anxiety and Depression Scale; MFSQ = McCoy Female Sexuality Questionnaire; MMQ = Maudsley Marital Questionnaire; MPI = Multidimensional Pain Inventory; MPQ-Sensory = McGill Pain Questionnaire – Sensory Scale; MPQ-PRI = MPQ - Pain Rating Index; MPQ-

PPI = MPQ – Present Pain Index; PASS = Pain Anxiety Symptom Scale; PCS = Pain Catastrophizing Scale; PISES = Painful Intercourse Self-Efficacy Scale; PVAQ = Pain Vigilance and Awareness Questionnaire; SCL-90 = Symptom Checklist 90; STAI = State Trait Anxiety Inventory.

Study Characteristics

Study characteristics of nine studies identified for review are summarised in Table 1.

Studies were conducted in Canada (*n*= 4), the USA (*n*=3) and the Netherlands (*n*=2). Five were randomised controlled trials [35-38, 40], two pilot studies [29, 33], one descriptive study [39] and one open clinical trial [41]. The number of women ranged from 9 to 97, where one study included couples [29], with a total *N* of 572 across studies. The age of women ranged from 16 to 72. Two consisted of women with provoked and unprovoked vulvodynia [38, 40], the remaining seven consisted of women with PVD, where previous terms such as 'vulvar vestibulitis' and 'vulvar vestibulitis syndrome' were used. In Table 1, samples have been summarised as either subtype of vulvodynia (PVD or PVD+GVD) for comparison purposes.

Outcome Measurement

All studies except one [39] measured pain as an outcome. Validated outcome measures for pain included the McGill Pain Questionnaire (MPQ, [43]) in seven studies [29, 33, 35-38, 40]. This measure is reported to be sensitive to pain changes in a number of clinical conditions [44]. Subscales of the MPQ included the Pain Rating Index (PRI), Present Pain Intensity (PPI), and Sensory scale. Other measures were the Pain Vigilance and Awareness Questionnaire (PVAQ, 45 [37]). Pain efficacy during intercourse and pain-catastrophizing were measured using the Pain Catastrophizing Scale (PCS, 46 [2,3,6]), and the Painful Intercourse Self-Efficacy Scale (PISES, 47 [36-37]). In two studies the PCS and PISES were identified as "psychological adjustment" [36] and "emotional functioning" outcomes" [33], whereas in one study these were used as dependent measures for "pain-related endpoints" [37]. Due to the use of the MPQ across studies, the PISES was not included in the examination of pain outcomes conducted in this review. One study [41] examined pain using the Coping Strategies Questionnaire (CSQ, 48), a common measure of coping in chronic pain conditions [49].

Outcomes for sexual functioning were included in eight of nine studies, across the following measures: Female Sexual Function Index (FSFI, 50 [33, 36-37,40]); Derogatis Sexual Functioning Inventory (DSFI, 51 [29, 35]); McCoy Female Sexuality

Questionnaire (MFSQ, 52 [39]); and the Golombok Rust Inventory of Sexual Satisfaction (GRISS, 53 [41]).

Psychological distress was examined in six studies [29, 35, 37, 39-41], in particular depression and anxiety as measured by the Beck Depression Inventory (BDI, BDI-II, 54 [29, 37,40]), State Trait Anxiety Inventory (STAI, 55 [29,37]) and Hospital Anxiety and Depression Scale (HADS, 56 [39]). Other psychological distress symptoms were examined via the Brief Symptom Inventory, Global Severity Index (BSI-GSI, 57 [35]) and Symptom Checklist 90 (SCL-90,58 [41]). Pain-related psychological distress was examined specifically in one study [40] with the Pain Anxiety Symptom Scale (PASS, 59).

Comparators

Three studies compared CBT to highly disparate medical treatments, including surgery [35], topical steroid cream [35-36] and tricyclic antidepressants [37]. One study compared CBT to supportive psychotherapy [40], one to physiotherapy [33], and the remaining four had no active control [29, 38-39, 41].

Treatment Duration, Content and Type

Five studies compared CBT to another form of treatment [33, 35-36, 38, 40] as detailed in Table 1, and one to a wait-list control [37], whereas three studies [29, 39, 41] used no comparator.

CBT treatment ranged from 4-12 sessions. There was a degree of variability in the type of CBT treatment offered. Five studies were group interventions [29, 25-27, 41] , and four were individual, including self-management [38]. Six studies used a manualised CBT treatment [29, 35-38, 40]. All reported the content of treatment which included psychoeducation around pain, sexual anatomy, breathing exercises, mindfulness, distraction techniques, coping statements, communication skills training and cognitive restructuring.

Methodological Quality of Studies

Table 2 presents the outcomes of quality appraisal for RCT criteria, and Table 3 for non-controlled before-after (NCBA) studies. All studies scored a minimum of 1 for each mandatory criteria, and met the minimum 60 per cent cut-off score. There were various methodological issues identified across the included studies as outlined below.

Inclusion and exclusion criteria were clearly defined across all studies, as were the aims of the research. Five of six RCTs minimised bias by utilising a random component for sequence generation [33, 35-36, 38, 40], with the exception of one study where sequence generation methods were not specified [37]. This same study also failed to blind primary outcome measures and was the only study where follow-up was not undertaken. None of the RCTs reported blinding methods, potentially due to the disparate nature of interventions making blinding extremely difficult. A consistent strength across both RCTs and NCBAs was the use of reliable outcome measures in all studies. However, outcome measures varied considerably, which limits meaningful comparisons between primary outcomes, particularly pain which was measured across eight studies using five different scales. The degree of control group was highly variable in RCT studies, and none of the NCBA studies provided a rationale for a lack of control group. One study [41] attempted to mitigate against the effects of no control group by examining pre-treatment group differences for dropouts and treatment completers, and this study scored the highest total quality score (80%) for NCBAs. Limitations were addressed and suggestions made for improvements in all but one study [39], the lowest scoring study in the NCBA group (60%). This study may also have introduced detection bias and threats to external validity as the therapist individualised a non-manualised treatment and collected outcome measures for the research.

There is no single gold standard tool for quality assessment, particularly where reviews combine data from multiple types of design, as in this case. Although not captured by the ICROMS tool, there are a number of further relevant methodological considerations. All studies provided a definition of the female sexual pain condition under measurement, however definitions of PVD were variable, for example some studies defined PVD as the most common form of vulvodynia [39], and others as the most frequent cause of dyspareunia [35-36]. Two studies gave an inclusive definition of vulvodynia [38, 40], with the second being a high quality study commenting on the questionable validity of disaggregating vulvodynia into subtypes. Study samples were highly variable, ranging from 9 [29], to 67 [41]. 7 studies excluded women on the basis of major psychiatric illness [29, 33, 35-39] however definitions of major psychiatric illness and the process by which this decision was made was only outlined in one study using DSM criteria [41], and one high quality study [40] utilising The Structured Clinical Interview for DSM-IV Axis 1 Disorders [42].

Table 2

Quality assessment of randomised control trials

Study ID	**ICROMS Criteria – Randomised Control Trials (RCTs)**														
	1A. Clear statement of the aims of the research*	2A. Sequence generation*	2B. Allocation concealment*	3A. Blinding (non-mandatory)	3E. Protection against detection bias: Blinded assessment of primary outcome measures	3F. Reliable primary outcome measures	4A. Follow up of subjects (protection against exclusion bias)	4C. Incomplete outcome data addressed	5A. Protection against detection bias: intervention unlikely to affect data collection	6C. Analysis sufficiently rigorous / free from bias	7A. Free of selective outcome reporting	7B. Limitations addressed	7C. Conclusions clear and justified	7D. Free of other bias	7E. Ethics issues addressed	Total score out of 30 (%)
Bergeron et al. 2001 [35]	**2**	**2**	**2**	**0**	**1**	**2**	**2**	**2**	**2**	**2**	**2**	**2**	**2**	**0**	**2**	**83**
Bergeron et al. 2016 [36]	**2**	**2**	**2**	**1**	**2**	**2**	**2**	**2**	**2**	**2**	**2**	**2**	**2**	**1**	**2**	**93**
Brotto et al 2015 [37]	**2**	**1**	**1**	**1**	**1**	**2**	**2**	**0**	**2**	**2**	**2**	**2**	**2**	**1**	**2**	**77**
Brown et al 2009 [38]	**2**	**2**	**2**	**0**	**0**	**2**	**0**	**2**	**1**	**2**	**2**	**2**	**2**	**1**	**2**	**73**
Goldfinger et al 2015 [33]	**2**	**2**	**1**	**1**	**1**	**2**	**2**	**2**	**2**	**2**	**2**	**2**	**2**	**0**	**2**	**83**
Masheb et al 2009 [40]	**2**	**2**	**1**	**1**	**0**	**2**	**2**	**0**	**2**	**2**	**2**	**2**	**2**	**2**	**2**	**80**

Table 3

Quality assessment of non-controlled before-after studies

Study ID	**ICROMS Criteria – Non-Controlled Before-After (NCBA)**															
	1A. Clear statement of the aims of the research*	1B. Adequate baseline measurement*	1C. Explanation for lack of control group	2C. Justification for sample choice*	3E. Protection against detection bias: Blinded assessment of primary outcome measures	3F. Reliable primary outcome measures	4C. Incomplete outcome data addressed	5A. Protection against detection bias: intervention unlikely to affect data collection	5D. Attempts to mitigate effects of no control	6C. Analysis sufficiently rigorous / free from bias	7A. Free of selective outcome reporting	7B. Limitations addressed	7C. Conclusions clear and justified	7D. Free of other bias	7E. Ethics issues addressed	Total score out of 30 (%)
Corsini-Munt et al 2014 [29]	**2**	**1**	**0**	**1**	**2**	**2**	**1**	**2**	**0**	**2**	**2**	**2**	**2**	**0**	**1**	**66**
Lindstrom et al 2015 [39]	**2**	**1**	**0**	**1**	**0**	**2**	**2**	**0**	**0**	**2**	**2**	**1**	**2**	**1**	**2**	**60**
Ter Kuile et al 2006 [41]	**2**	**2**	**0**	**1**	**1**	**2**	**2**	**2**	**2**	**2**	**2**	**2**	**2**	**1**	**1**	**80**

Data Analysis

Due to heterogeneity across comparators, samples and outcome measures used, meta-analysis was not considered possible, and therefore data was synthesised via narrative systematic synthesis. Effect sizes (*d*) were computed for pre- and post within-group differences in CBT treatment groups, presented in Table 4. Effect sizes for comparators were not computed due to the variability in comparators, and lack of non-active or wait-list control groups across the included studies. Descriptive commentary is given regarding outcomes for comparators where relevant.

Table 4

Effect sizes for CBT treatment groups

Study ID	CBT Intervention	Outcome Measures	Effect size for change in pre-/post-measures (d) in CBT group
[35] Bergeron et al. 2001	GCBT	**Pain**	
		MPQ-PRI	0.09
		Sexual Functioning	
		DSFI	0.03
		Psychological Distress	
		BSI-GSI	0.49
[36] Bergeron et al. 2016	GCBT	**Pain**	
		MPQ-PPI	0.47
		PCS	0.86
		Sexual Functioning	
		FSFI	0.48
[37] Brotto et al. 2015	Group Mindfulness-based CBT	**Pain**	
		PCS	0.45
		PVAQ	0.31
		Sexual Functioning	
		FSFI	0.26
		Psychological Distress	
		BDI	0.28
		STAI	0.16
[38] Brown et al. 2009	CBT-based self-management	**Pain**	
		MPQ-PRI	0.44
		MPQ-PPI	0.44
[29] Corsini-Munt et al. 2014	Couples GCBT	**Pain**	
		MPQ-PRI	0.45*
		Sexual Functioning	
		DSFI	0.71*
		Psychological Distress	
		BDI-II	1.41*

Study ID	CBT Intervention	Outcome Measures	Effect size for change in pre-/post-measures (d) in CBT group
		STAI	0.69*
[33] Goldfinger et al. 2015	Individual CBT	**Pain**	
		MPQ-Sensory	1.02*
		PCS	1.41*
		Sexual Functioning	
		FSFI	0.76*
[39] Lindstrom et al. 2015	CBT + desensitisation	**Sexual Functioning**	
		MFSQ	1.35
		Psychological Distress	
		HADS	Nr.
[40] Masheb et al. 2009	Individual CBT	**Pain**	
		MPQ	0.67
		Sexual Functioning	
		FSFI	0.59
		Psychological Distress	
		BDI	0.13
		PASS	0.12
[41] Ter Kuile et al. 2006	GCBT	**Pain**	
		CSQ	0.48
		Sexual Functioning	
		GRISS	0.31
		Psychological Distress	
		SCL-90	Ns.

*Note: Nr. = Not reported. Ns.= Non-significant. *effect sizes reported within studies.*

Efficacy of CBT for Pain

Eight studies measured pain [29, 33, 35-38, 40-41], finding significant reductions in pain in the CBT condition. Those using the MPQ [29, 33, 35-36, 28, 40] found reductions in pain with CBT, with measures of effect ranging from small to moderate for the MPQ-PRI [29, 35, 38 (*d*= 0.09 – 0.45)], and moderate for the MPQ-PPI [36, 38 (*d* = 0.44-0.45)] in CBT conditions. Of these, one high quality study [40] used the MPQ total score, finding a moderate effect (*d* = 0.67). Where the MPQ-PRI and MPQ-PPI were used [38], CBT self-management demonstrated a significant within-group improvement on the MPQ-PRI, where significant within-group improvement was demonstrated for the MPQ-PPI for amitriptyline. However, the authors identify these scores may not be clinically meaningful due to lower baseline scores across the sample. One study used the MPQ-Sensory subscale and found a large effect size of *d* = 1.02 [33], however it was unclear whether the study was free of other bias such as testing effects. Studies measuring pain catastrophizing via the PCS [36-37] yielded moderate to large effect sizes (*d* = 0.45 – 1.41), and a small effect of the PVAQ [37] (*d* = 0.31). However, treatment adherence was not measured equivalently across studies. The remaining study used the CSQ [41] with a moderate effect (*d* = 0.48). However, this study did not use comparators and there are findings to suggest the CSQ is highly related to other measures of mood [60] casting doubt on its ability to measure pain as a primary outcome.

In studies with comparators, results were highly disparate. One RCT found significant reductions in pain as measured by the MPQ Sensory subscale in the surgery group over and above CBT and biofeedback conditions [35]. This study was of good quality, where treatment was manualised, with adherence measures. However, the treatment manual was created for the purposes of this study by the authors, which may introduce bias in evaluation. Furthermore, the authors recognise that there may be a lack of representativeness of the surgery condition in this study due to differential failure in randomization of the surgery condition sample. In contrast, there were findings from another study that MPQ-PPI scores were significantly lower for the CBT condition compared to topical steroid cream [36]. Other studies found no significant differences between groups comparing medication and topical steroid cream [38], physical therapy [33] and supportive psychotherapy [40] on self-report pain outcome measures examined in this review.

Efficacy of CBT in Improving Sexual Functioning

Seven studies measured sexual functioning, four via the FSFI [33, 36-37, 40], reporting a range of effects (*d* = 0.26 – 0.76). The study reporting a small effect also did not account for incomplete outcome data, and did not report on sequence generation, allocation concealment or attempt to limit detection bias in terms of blinding of outcome measures or data collection. The second most common measure was the DSFI [29, 35] with highly disparate effect sizes (*d* = 0.03, 0.71) reported. The very small effect seen in one study [35] could be due to significant improvements being found between pre-treatment to six month follow-up in this study, where this review examines pre- to post-treatment differences. In contrast, the large effect was found in a study with no comparator or control group [29], in a small sample of $n = 10$, therefore this study may be underpowered to detect clinically meaningful changes. Remaining measures were the MFSQ [39] with a large within-group effect ($d = 1.35$) and the GRISS with a small effect ($d = 0.31$).

In terms of comparisons between treatments on sexual functioning measures examined in this review, two studies noted improvements in sexual functioning, regardless of the intervention [35-36]. One study found significant improvements only in the CBT group on sexual functioning [33] compared to physical therapy. Another study [40] reported a sharper rate of improvement on the FSFI in the CBT group compared to SPT.

Efficacy of CBT in Reducing Psychological Distress

Six studies measured psychological distress [29, 35, 37, 39-41]. Three studies measured depression using the BDI [29, 37, 40]. Effect sizes ranged from small to large [$d = 0.13 – 1.41$]. The STAI was used to measure anxiety in two studies [29, 37] with small to large effects found ($d = 0.16 – 0.69$). Large effects found in BDI and STAI difference scores were found in a study [29] with a very small sample size ($n = 9$), with no comparators and therefore should be interpreted with appropriate caution. One study measured anxiety and depression via the HADS [39], however there was no quantifiable data to calculate an effect in this study. The authors reported significant decreases in anxiety at six month follow-up, however no significant difference in scores on depression measures from pre-treatment to six month follow-up. There was no data in this study for anxiety or depression measures between pre- and post-treatment, therefore this study is limited by selective outcome reporting. One study used the SCL-90 [41] and found no significant differences from pre- to post-treatment. A study used the BSI-GSI [35], however duration of treatment was over twelve weeks, and there is evidence that the BSI-GSI has poor test re-test reliability over a period of 45 days between testing [61]. One RCT utilised a pain specific psychological distress measure, the PASS [40], finding a small effect ($d = 0.12$) for improvements on pain anxiety from pre- to post-treatment.

Two studies with active comparators measured psychological distress using the above measures [35, 40]. There were no significant differences reported between CBT and comparator treatments.

Discussion

This review sought to determine the efficacy of CBT for vulvodynia through the examination of within-group pre- to post-treatment differences on a range of validated outcome measures for pain, sexual functioning and psychological distress.

Pain

The studies included in this review indicate that CBT can achieve significant reductions in pain for women with vulvodynia, when examining PVD and GVD across a range of outcomes. Effect sizes were consistently moderate to large within CBT treatment groups across commonly used and validated outcome measures. There were inconsistencies in the use of pain catastrophizing and self-efficacy measures as measures of pain or psychological distress in included studies. There are only moderate correlations between measures such as the PCS [46] and depression and anxiety outcome measures, and evidence to suggest the PCS uniquely predicts pain intensity [46] separately from mood-related pain problems. There is also evidence that pain-related catastrophizing compared with depressed mood is related to differential outcomes, with depressed mood correlating more strongly with higher percentages of health care usage [62]. Therefore, pain itself may involve distinct psychological processes considered separate to depression or anxiety, which have in other RCTs been examined as secondary outcomes of pain [63]. Despite a modest overall effect, differences between the conceptualisation of pain and subsequent use of outcome measures, and the quality of included studies in this review, limit robust conclusions being drawn regarding the impact of CBT on pain outcomes in vulvodynia.

Sexual Functioning

There were general improvements in sexual functioning across CBT samples, however high variability was found in effect sizes across outcome measures. A number of studies examining sexual functioning did not use comparison groups, and were methodologically flawed in terms of sample size and bias. Only one study measured outcomes for couples [29], and it could be argued that self-report measures of sexual functioning are only reliable or valid in the context within which they are used [64]. In the case of this review, studies were experimental in design, and samples were women with long-term partners, therefore by virtue greater emphasis is placed on dyadic sexual functioning changes in controlled settings. Future studies may benefit from increasing representativeness by examining outcomes for couples as well as single women, to determine differences in certain types of sexual functioning, dependent on relationship status.

Psychological Distress

Small to large effect sizes were found in a limited number of studies examining psychological distress, across a variety of outcome measures, some with questionable test re-test reliability. The rationale for psychological distress measures chosen by the authors in included papers is unclear, considering the content within CBT interventions was primarily focused on pain and sexual functioning. A recent study regarding predictors of CBT outcomes for PVD [65], found that pain specific outcomes such as lower pain catastrophizing and self-efficacy were correlated with higher pain intensity following treatment, and that psychological factors did not predict outcomes for sexual functioning. Therefore, it still remains unclear which psychological distress factors are targeted and influenced by CBT, or which components of CBT are most effective relevant to these outcomes.

Limitations

The interpretation of effect sizes reported in this review is limited by the variable quality of included samples, with regard to lack of active or passive controls, missing information, and instances where bias was not accounted for. Due to the diversity in comparators, samples, and outcome measures, meta-analysis was not possible, therefore comparative efficacy was merely discussed rather than statistically determined. In a literature review by Flanagan et al. [22], the author encountered challenges in determining equivalence of outcomes in a range of psychological and medical treatments for vulvodynia. This review has attempted to move one step further towards examining the efficacy of CBT specifically, however similar methodological barriers and the requirement of this review to take a narrow focus in only examining self-report measures in studies have resulted in a need to interpret conclusions with caution.

Clinical Implications

Studies in this review examined PVD and GVD as one clinical condition: vulvodynia, and found comparable effects across all outcomes. However, drawing conclusions regarding differences in treatment outcomes between subtypes was limited by the variability in studies providing consistent definitions of vulvodynia and the heterogeneity of measures of treatment outcomes in vulvodynia. Considering there is literature calling into question the reliability of using vulvodynia subtypes [66] more effectiveness research needs to be undertaken in practice [67] to determine treatment effects in more representative samples.

Although it is difficult to determine meaningful conclusions from the available data in this review, there is evidence that CBT is efficacious in the treatment of specific pain and sexual functioning variables found in women with vulvodynia, from pre- to post-treatment. This supports findings from previous systematic reviews [21, 22]. This review found moderate effects on pain and sexual functioning for women with PVD and GVD, supporting the use of CBT therapies in vulvodynia more generally for these outcomes. More research with clearly conceptualised psychological variables is necessary to further examine the effect of CBT on psychological distress. Guidelines on the specific psychological treatment of vulvodynia do not currently exist, therefore this review may inform more specific psychological treatment recommendations in this field, as part of a multidisciplinary treatment approach.

Research Implications

Where comparators were used, one study [35] found superiority of surgery over CBT in reducing pain outcomes and improving sexual functioning. However, the authors recognised that this finding should be interpreted with caution due to differential failure in randomization. Across the remaining studies, and consistent with findings from a previous review on the topic [22], comparative efficacy of CBT was found compared to a range of medical, topical and other psychological treatments. Therefore, surgery and CBT may both be considered efficacious treatments under controlled conditions with specific samples. Further controlled trials should be undertaken comparing medical treatments and CBT in order to determine the comparative efficacy of these treatments and minimise potential harm for patients who may undergo more permanent treatments such as surgery.

Methodological limitations across studies evidence the need for more research in this area utilising robust RCT protocols. Future studies require sufficient power, and the comparison of a range of psychological treatments used in practice, in more representative samples of women with vulvodynia.

Quantitative data requires the imposition of reductionist assumptions on seemingly measurable variables, and influences the conceptualisation of constructs such as pain, sexual functioning and psychological distress. This in turn influences choice of outcome measures, of which high variability was found across studies in this review. This variability and the inconsistent use of measures across studies evidences clear challenges in the measurement of complex variables such as sexual functioning and psychological distress, which involve interpersonal and bidirectional processes. Pukall et al. [68] have made recommendations based on this challenge, for there to be further research to determine standardized outcome measures in clinical trials for vulvodynia treatments. Further qualitative research is also required examining women’s experiences of CBT treatment and management in vulvodynia, to determine the factors that they consider most important to target in this treatment, and predictors of outcomes for treatment. This in turn may help to inform future measurement of quantitative variables, and the tailoring of CBT interventions.

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Journal Paper

Title Page

Title: Creating guidelines for practitioners on communication regarding the management of the psychological and interpersonal impact of vulvodynia: A Delphi study

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Compliance with Ethical Standards

Ethics Approval

This study was performed in line with the principles of the Declaration of Helsinki. Ethical approval was granted by the University of Nottingham and the East Midlands – Leicester Central National Health Service (NHS) Research Ethics Committee. Informed consent for taking part including audio recording and use of anonymised vignettes was sought from all participants.

Consent to Participate

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

Declarations

Conflict of Interest

The authors declare that they have no conflict of interest.

Abstract

Background

Existing research highlights personal, structural and societal barriers to communication for women with vulvodynia and practitioners attempting to co-manage the psychological, interpersonal and emotional impact of vulvodynia. Patient-centred care and shared decision making are vital practitioner skills required to improve patient-practitioner interactions. This study aims to converge the views of practitioners and women with vulvodynia to co-produce a set of guidelines for practitioners to support the process of communication.

Methods

A conventional Delphi study was conducted. The expert panel was made up of seven women with vulvodynia, and seven practitioners involved in vulvodynia management. Round One consisted of semi-structured interviews to generate initial guidelines from all participants, which were then rated in terms of importance and commented on by the panel in Rounds Two and Three. An a priori consensus level was set of $\geq$70% panel agreement on guidelines scoring $\leq$2 or $\geq$6 on a 6-point Likert scale.

Results

Consensus was reached on 19 guidelines. Guidelines were organised into themes of overarching principles of good clinical practice; initial consultation including understanding symptoms, impact and mechanisms; follow-up; and future planning and long-term care. Clinical vignettes based on the experiences of participants were created for each guideline to support their application in clinical practice.

Conclusions

Practitioners play an important role in communicating with women to support the holistic management of vulvodynia, through shared decision making. Finalised guidelines provide a resource for practitioners to ensure quality of care in communication for the unique needs of this population.

Keywords: vulvodynia, communication, Delphi study, clinical practice guidelines, guidelines

Introduction

Vulvodynia is a prevalent and impactful genital pain condition (Pukall et al., 2016) characterised by idiopathic vulval pain in the absence of an identifiable cause (Arnold, Bachmann, Kelly, Rosen, & Rhoads, 2006).[3] Prevalence rates of vulval pain and vulvodynia are comparable across UK and US population-based survey samples, with the most heavily cited research from the US indicating a 25% prevalence rate (Reed et al., 2012). One UK study found a prevalence rate of 13.3% for vulval pain (Denbow & Byrne, 1998), although this study was conducted over 20 years ago and reported figures for vulval pain in general, amassing from one clinic, resulting in a lack of specificity. Unfortunately, there are no population-based or large scale studies examining the prevalence of vulvodynia in the UK, meaning there are no figures examining individual differences associated with factors such as age, ethnicity and socioeconomic status. Studies into vulvodynia in the US highlight vulvodynia as affecting all ethnic groups, with a higher percentage of Hispanic women reporting vulvodynia compared to white or African American women (Harlow & Stewart, 2003). Vulvodynia is also reported to effect predominantly women between 20-40 years of age (Reed et al., 2014).

Vulvodynia presents with considerable heterogeneity; pain can be provoked or unprovoked, or a combination, and localized or generalized (Haefner et al., 2005). Evidence regarding the aetiology of vulvodynia points toward several interdependent pathophysiological factors such as inflammation (Wylie, 2017), as well as neurological and psychopathological causes (Edwards, 2003). This guides expert opinion, but not consensus, that vulvodynia is both medical and psychiatric in aetiology (Flanagan, Herron, O'Driscoll, & Williams, 2015).

In line with other chronic pain conditions (Banks & Kerns 1996), vulval pain (the prominent symptom of vulvodynia) is linked to increased symptoms of stress (Ehrström, Kornfeld, Rylander, & Bohm-Starke, 2009), depression and anxiety (Khandker et al., 2011), sleep disturbances (Dargie, Gilron, & Pukall, 2017) and poorer sexual functioning (Bois et al., 2016).[4] Women may struggle to discuss their experiences openly (Buchan et al., 2007), resulting in feelings of guilt and shame (Sadownik, Seal, & Brotto, 2012), leading to social isolation (Seu, 2006). These factors contribute to findings that rates of mental health difficulties are significantly greater in women with vulvodynia than the general population (Mandal et al., 2010). The interactions between vulvodynia and its correlates and outcomes

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[3] See extended paper 1.1

[4] See extended paper 1.2

are linked to persistence of the condition, significantly impacting quality of life in those attempting to manage it (Ponte, Klemperer, Sahay, & Chren, 2009). In addition, the complexity, unknown cause, and variability in symptomology of vulvodynia, presents a unique challenge for practitioners attempting to find appropriate treatment or management for women (Connor, Robinson, & Wieling, 2008). This includes challenges associated with supporting women to cope with the multifactorial nature of vulvodynia management, which may encompass dealing with pain and changes in mood (Chisari & Chilcot, 2017), impact on relationships and work, and stigma (Jelovsek, Walters, & Barber, 2008).

Research around practitioner-patient interactions concerning vulvodynia focuses primarily on women's perceptions of exchanges with healthcare practitioners. Numerous studies in meta-synthesis highlight women's negative experiences of feeling dismissed and ignored (Shallcross, Dickson, Nunns, Mackenzie, & Kiemle, 2018).[5] Past research has evidenced that without adequate support and information, women may fear that recovery is not possible (Metts, 1999), or be told that their pain is psychosomatic, invalidating their condition and distress (Gottleib, 1995). This may ultimately lead to them feeling responsible for their symptoms, or that they have failed in some way (Graziottin, Castoldi, Montorsi, Salonia, & Maga, 2001). Women newly diagnosed with vulvodynia report a substantial impact of vulval pain on their lives, and perceived lack of control over their symptoms (Piper et al., 2012). The absence of adequate support coupled with uncertainty about the onset of pain, numerous barriers to seeking care, a futile search for the cause of the problem and delays in treatment have evident harmful outcomes on physical and emotional wellbeing, and sexual health and relationships (Kingdon, 2009). The recognition of deleterious outcomes as a result of difficulties managing vulvodynia highlights the importance of practitioner enquiry around the condition, and consideration of the holistic needs of women with vulval pain (Craven, Thelen, Elliott, & Lazear, 2016). Despite this, some research has shown that 80% of conversations regarding female sexual functioning difficulties in women with pre-existing sexual problems were initiated by the patient in medical consultations (Shifren et al., 2009). Research also highlights women's reluctance to seek professional advice regarding sexual issues due to embarrassment and lack of confidence in medical solutions (Donaldson & Meana, 2011), which may result in important issues not being raised at all.[6]

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[5] See extended paper 1.3

[6] See extended paper 1.4

Communication is an integral medical skill, and essential to person-centred practice (Brindley, Smith, Cardinal, & LeBlanc, 2014). Medical professionals with good communication skills have been found to identify problems more accurately (Maguire, Fairbairn, & Fletcher, 1986). Conversely, deficiencies in communication can lead to insufficient recognition of the emotional, psychological and social impact of medical problems (Maguire & Pitceathly, 2002). Basic recommendations such as giving clear instructions, asking for feedback and engaging in reflective practice can greatly improve communication (Rimmer, 2017), and resulting patient experience. As such, it is a practitioner's responsibility to develop and maintain skills in communicating effectively and for professionals to foster opportunities to improve communication.

General communication models such as the REDE model (Relationship, Establishment, Development and Engagement; Windover et al., 2014), and specific models related to sexuality such as the PLISSIT (Permission, Limited Information, Specific Suggestions, Intensive Therapy) model of communication (Annon, 1976)[7], exist to support healthcare professionals in their endeavours to work towards best practice in communication. In the case of specialist models, this may be by giving permission to communicate about sexuality and normalising the expression of sexual needs. Little is known regarding how theory translates to practice in this area, and there is evidence that some specific models such as the PLISSIT model may be interpreted differently by practitioners (Taylor & Davis, 2007), resulting in limited consistent guidance on addressing sexual issues in this population. Further, current research suggests there are barriers to effective communication by professionals on a range of issues relating to sex and sexuality in particular, including lack of knowledge, comfort, time and personal attitudes (Fennell & Grant, 2019).

Difficulties with psychological wellbeing in women with vulvodynia are rooted in chronic pain, interpersonal problems and sometimes practitioner-patient interactions associated with isolation, shame and dismissal (Nguyen, Ecklund, MacLehose, Veasley, & Harlow, 2012). Poorer mental health outcomes can result in even poorer medical and psychological outcomes for women with vulvodynia, requiring more intensive treatment and increased cost and use of resources (Goldmeier, Malik, Phillips, & Green, 2004). At present, no guidelines exist for women and practitioners to navigate the complexities of communication regarding the management of vulvodynia,[8] despite the aforementioned evidence regarding barriers to

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[7] See extended paper 1.5.1

[8] See extended paper 1.5

communication on issues central to vulvodynia, such as sexuality, psychological distress and problems in relationships.[9] As recognition grows of the importance of service users actively informing change processes, there has been a shift towards coproduction in healthcare services and research (Filipe, Renedo, & Marston, 2017).[10] As such, women's views are considered essential in developing guidelines regarding communication about the impact of vulvodynia in order to generate user-led individualised resources (Realpe & Wallace, 2010) in collaboration with and facilitated by healthcare professionals.

Current research on patient-practitioner interactions regarding vulvodynia management points towards the potential for service users and practitioners to hold contrasting views about what constitutes good practice and what is important in communication. Delphi methodology has previously been used to address similar issues in healthcare by way of synthesising perspectives to work systematically towards a consensus. The Delphi process is characterised by participant anonymity throughout the rating process (Lilja, Laakso, & Palomäki, 2011), and the ability to exchange information remotely, allowing for a wide geographical dispersion of participants and reduction of group pressure to conform to certain opinions or viewpoints (Dalkey, 1969). Further, this methodology can enable a remote dialogue between patients and practitioners which may mitigate the influence of power imbalances inherent in such interactions (Haug & Lavin, 1981), ensuring both perspectives within the patient-practitioner dyad are captured.

Practitioners in all roles that interface with women with vulvodynia require skills in communicating about the impact of vulvodynia on sexual functioning and relationship satisfaction, due to evidence that sexuality and psychological wellbeing are interconnected, particularly with vulvodynia (Merwin et al., 2017). Given that models of communication are available, it is important to consider why women with vulvodynia and their healthcare providers struggle to communicate regarding the impact of this condition on psychological, emotional and relational wellbeing.[11] Guidelines can be utilised to support practitioners to apply theory to practice. For vulvodynia management, existing guidelines provide support with medical decision making, and highlight the importance of a team approach and referral on to psychosexual therapies for women with vulvodynia (Mandal et al., 2010). However, there are no guidelines to support practitioners with communicating about the impact of

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[9] See extended paper 1.4.1

[10] See extended paper 1.6

[11] See extended paper 1.5.2

vulvodynia on complex psychosocial, psychological and sexual processes. It follows that if conversations about the impact of vulvodynia are not happening due to the aforementioned barriers, women's psychological, sexual and emotional needs may go untreated through lack of identification.

Aims

This study aimed to use a conventional Delphi method to produce a set of guidelines for practitioners communicating about the psychological, interpersonal and relational impact of managing vulvodynia. The aim of the guidelines is to offer a resource for practitioners to inform their communication regarding the impact of vulvodynia, based on consensus regarding good practice, grounded in both expert practitioner opinion and the lived experience of women with vulvodynia.[12]

Method

Procedure

The Delphi method (Linstone & Turoff, 1975) was used to generate consensus between participants according to a stepwise process. This method has applications in generating clinical practice guidelines (Boulkedid, Abdoul, Loustau, Sibony, & Alberti, 2011), including within clinical psychology (English, Tickle, das Nair, & Moore, 2020) and health research (de Meyrick, 2003). This method was chosen due to a lack of substantive research in this subject area, and evidence that this methodology can support preliminary understanding and knowledge in such a condition (Hasson, Keeney, & McKenna, 2000).[13] Delphi quality criteria proposed by Diamond et al. (2014) were adhered to within the research, in order to enhance the credibility and validity of the chosen method.[14]

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[12] See extended paper 1.7

[13] See extended method 2.1

[14] See extended method 2.8

Study Design

This research used a 'conventional Delphi' method (De Villiers, De Villiers, & Kent, e2005), consisting of three rounds.[15] The study consisted of initial interviews to generate initial guidelines, and two subsequent surveys developed as a result of data generated from the interviews to establish consensus between participants.

Interview schedules were designed by systematically reviewing the literature to identify general areas to cover in the interview. Specific interview questions were generated in supervision as a research team based on the extant literature on vulvodynia and communication. The rationale of the interviews was to elicit examples of communication and vignettes from clinical practice and experience using vulvodynia services.[16]

Based on previous Delphi studies in the field of sexual health research (Bakker et al., 2014), consensus was set *a priori* at ≥70% of the panel answers falling within the two lowest or highest Likert scale options.

Participants and Recruitment

Practitioner participants with expertise in communicating about the management of vulvodynia were recruited through the Vulval Pain Society (VPS) charity website, and via the British Society for Vulvovaginal Diseases (BSSVD) special interest group. Patient participants were women with a diagnosis of vulvodynia, recruited as 'experts by experience' through the VPS website and social media feeds (Facebook and Twitter). Participants were also invited to use snowball sampling by recommending the research to those within their professional or peer group who may meet the selection criteria. As a result, it was possible to generate a sample from a diverse range of geographical locations, services, and contexts. Participants were termed 'panellists' due to contributing to consensus agreement individually and in response to one another (Rowe & Wright, 1999).[17] Practitioners and women with vulvodynia generated consensus as a combined panel. This was to allow for the development of guidelines with the views of both stakeholders in the communicative relationship privileged with equal intent, given the communication in question is dyadic.[18]

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[15] See extended method 2.2

[16] See extended paper 2.5.1

[17] See extended paper 2.3

[18] See extended paper 2.3.1

Inclusion Criteria

Practitioners were eligible to take part if they were currently working in services in which they contribute to the management or co-ordination of clinical care related to vulvodynia. This included practitioners who had recent experience of managing vulvodynia, or experience of multiple cases of management.

Patients were eligible to take part if they were aged 18-65 years and had a diagnosis of vulvodynia.

Exclusion Criteria

Practitioners were excluded on the basis of self-reported insufficient experience of communicating with women regarding vulvodynia. An arbitrary number of cases or years of experience was not set so as not to disadvantage practitioners from applying and taking part. Patients were excluded if they had an alternative primary diagnosis of any other vulvovaginal disease.

A minimum number of ten panellists is recommended (Turoff & Linstone, 2002), with recognition that larger panel sizes may reduce consensus reliability and increase the labour intensiveness of data gathering and distribution. Attrition rates from previous research are expected of 16-28% (Hanafin & Brooks, 2005). Therefore, we aimed to recruit 14-16 panellists, allowing for up to eight from represented practitioner and patient groups.[19]

Round One

The Delphi consisted of three rounds.[20]

In Round One, demographic information was collected, and participants took part in semi-structured interviews focused on their experiences of communicating about the management of the psychological, interpersonal and relational impact of vulvodynia. Interviews were offered over the telephone, in person and on Skype with the aim to increase response rates (McKenna, 1994). At the end of the interviews, 2-3 guidelines were generated by each

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[19] See extended paper 2.4

[20] See extended paper 2.5

participant, which were transcribed verbatim where possible, and included in the Round Two survey. It is highlighted by Okoli and Pawlowski (2004) that researcher interpretations translating Round One data into the Round Two survey may compromise the validity of the process. As such, no qualitative analysis was performed on Round One contributions, and data generated through Round One interviews, in the form of guidelines, was clarified with participants at the end of each interview in order to minimise researcher bias when writing the guidelines into the Round Two survey. Interview data from Round One were later drawn on to provide vignettes to support each guideline.

Round Two

All suggested guidelines were compiled and emailed to each panellist with an invitation to rate each guideline, in terms of importance, on a 6-point Likert scale (1 = this guideline is actively unhelpful, 2 = this guideline is irrelevant, 3 = this guideline is not important, 4 = I feel neutral about this guideline, 5 = this guideline is important, 6 = this guideline is essential). A free-text comment box was provided to facilitate elaboration and rationale for responses. Guidelines with similar content were presented together in the survey to allow for commentary on preferred or combination guidelines. Panellists were given four weeks to return the survey by e-mail or post, following which non-responders were sent personalised reminder emails and given a further two weeks to return their responses.

Round Three

Participant responses to Round Two were collected, and percentage agreements for each guideline calculated. For Round Three, individualised surveys were created for each panellist, displaying their Likert scale response compared with the group percentage agreements, and all qualitative comments for each guideline displayed anonymously. Where multiple comments from different panellists indicated guidelines should be shortened or combined, the research team presented a new or amended guideline for rating by the panel in Round Three, with another option for free text commentary.

Suggestions were made by different panellists regarding the structure and organisation of the guidelines based on observed themes. Round Three provided an opportunity to comment on structuring the guidelines.

Consensus-Generating Process

Although there are no agreed recommendations on number of iterations, Walker and Selfe (1996) argue that repeated rounds may lead to respondent fatigue and attrition. Three rounds were considered acceptable, in line with other studies citing this as sufficient for consensus generation and the results of the third round (Hsu & Sandford, 2007).

In line with Mullen's (2003) guidance on obtaining normative views on a topic, percentage agreements were used as a way of displaying participant consensus within the surveys of Round Two and Three, whilst maximising clarity. In order not to bias subsequent rounds, guidelines were not removed following Round Two even if they did not reach the predetermined level of consensus. This was to ensure transparency and reduce the risk of bias in process.[21]

Final Guidelines

Guidelines that met predetermined consensus levels were included in a final set, amended in response to written feedback from panellists in Rounds Two and Three.[22] These were amended by the primary investigator in collaboration with the other authors.

For each final guideline, clinical vignettes were developed based on examples of best practice and areas for improvement in communication from Round One interviews with all participants. Vignettes were extracted from audio recordings by the primary researcher and anonymised by removing identifiers. The inclusion of vignettes was intended to enhance the applicability of the guidelines for them to be of use to professionals across a range of disciplines. Quality criteria (Diamond et al., 2014) were used to determine the quality of the Delphi methodology used.[23]

The final guidelines were disseminated directly to participants and they were asked for specific feedback regarding whether they felt the clinical vignettes identified them or anyone they had worked with, to ensure anonymity throughout the process.[24]

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[21] See extended paper 2.6
[22] See extended paper 2.7
[23] See extended paper 2.8
[24] See extended paper 2.9

Results

Demographic information of practitioners is presented in Table 5, patient demographics are presented in Table 6.[25] Figure 2 demonstrates the involvement of participants through the duration of the study.

Table 5

Practitioner demographics

Gender		Location	
Male	1	Nottingham	4
Female	6	Cambridge	2
		London	1
Years Experience in Profession		**Years Experience Specialising in Vulvodynia**	
0-10	1	0-10	4
11-15	1	11-15	2
16-20	1	16+	1
21-25	2		
26+	2		

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[25] See extended paper 3.1

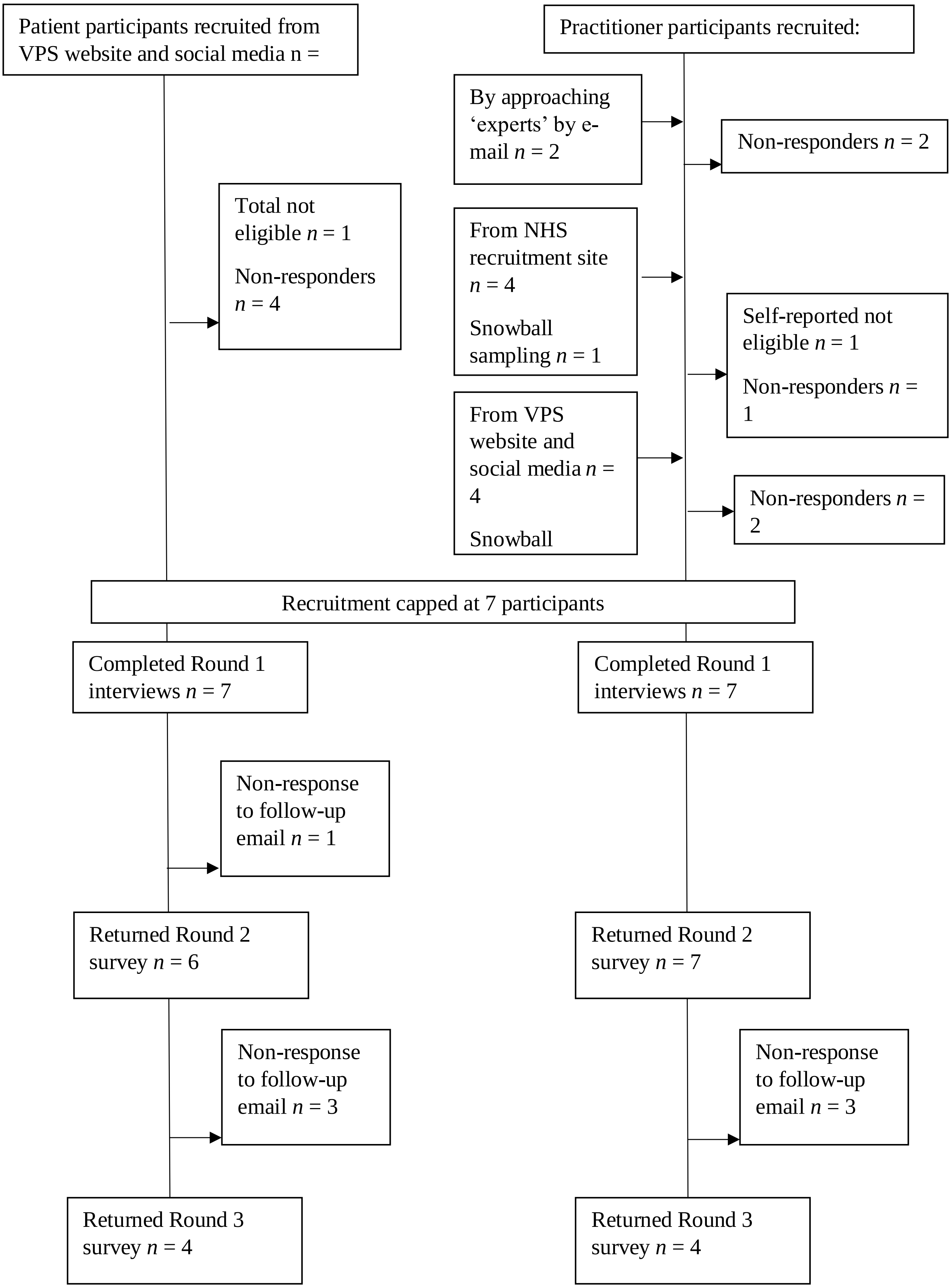
Table 6

Patient demographics

Gender		Age		Location	
Female	6	18-24	1	London	2
Gender Queer	1	25-34	2	Bristol	2
		35-44	2	Essex	1
		45-54	1	Lincolnshire	1
		55-64	1	Suffolk	1
Duration of vulval pain		Date of diagnosis		Type of vulvodynia	
0-5	2	2015-2016	2	Provoked	4
6-10	2	2016-2017	2	Generalised	1
11-15	2	2017-2018	2	Combined	1
16+	1	2018-2019	1	Unknown	1
Professionals come into contact with					
GP					7
Consultant gynaecologist / in sexual health					6
Specialist nurse					1
Sexual health clinic					1
Specialist vulvodynia clinic					2
Urologist					2
Psychosexual therapist / psychological therapist / clinical psychologist					4
Dermatologist					2
Pain clinician					1
Colposcopy professional					1
Physiotherapist					4

Figure 2

Flowchart of participant involvement



Round One

Interviews were conducted with fourteen participants, lasting between 39 and 107 min. All participants generated examples of experience of communication regarding the psychological, interpersonal and emotional impact of managing vulvodynia. At the end of the interview, participants proposed 2-3 guidelines that were extracted from the audio recordings of interviews by the primary researcher and formed into the Round Two guidelines using the participant's own language[26]. 40 initial proposed guidelines were generated and placed near other similar guidelines in the Round Two survey according to similarity of content

The first practitioner and patient participants were offered the chance to 'pilot' the interview, and provide feedback about the experience, including about the questions utilised in the process. Both stated that they did not have specific recommendations regarding changing the Round One interviews.

Round Two

The majority of participants responded to the Round Two survey and follow-up reminders (*n* = 13). One participant returned the Round Two survey having completed 31 of 40 ratings and comments (77.5%), declining to complete the remainder but expressing an interest to be included in further rounds.

Consensus agreement (≥70%) was reached on twenty-four guidelines for ratings of important or essential, with a range of 75%- 92%. No guidelines reached consensus agreement on the lowest two Likert scale ratings.

All guidelines received a minimum of one comment[27], with a range of 4-52 comments throughout the survey (*M* = 26). Of those who responded, all left a comment on at least one guideline, with a range of 1-4 comments per participant. Per guideline, there was a range of 5-14 comments (*M* = 8). Comments fell into themes around wording, specificity, additions or removal of content, similarity and merging, and applicability of the guidelines. Other comments provided were in support of the guideline.

Two participants commented that the structure of the guidelines could be grouped according to one of two options, for which a vote was provided within the Round Three survey.

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[26] See extended paper 3.2

[27] See extended paper 3.3.3

Round Three

Finalised guidelines are displayed in Table 4.

Responses to the Round Three survey were received by eight participants (57%). Consensus agreement (>70%) was reached on nineteen guidelines, with a range of consensus from 75-100%. There were eight guidelines included in the final set which reached 100% consensus from responders in Round Three. No consensus was reached on thirteen guidelines, with a range of 13-67%.

All guidelines received a minimum of one comment, with a range of 4-8 comments per guideline throughout the survey. All participants in Round Three left a comment on at least one guideline, and there was a range of 22-44 ($M = 32$) comments per panellist throughout the survey. Qualitative comments were similar to those of Round Two, with a specific focus on wording and commentary in support of guidelines or providing explanations for re-ratings.

Overlapping and Combined Guidelines

In response to panel votes on structure and organisation ($n = 5$), a combined approach was taken, and guidelines were structured according to themes and subthemes identified by the panel.[28] Where amended guidelines and original guidelines were offered together, one original guideline received no ratings, eleven ratings were offered for two original guidelines, fifteen were offered for the two amended guideline counterparts, and ten ratings were offered for both the original and amended versions.

Two guidelines were suggested to be combined in Round Two, ten votes were received to combine different guidelines, six not to combine guidelines, and two comments were made to combine some guidelines, but not others.

Qualitative commentary regarding the combining of guidelines were statements of agreement regarding similarity, proposed suggested combinations, and comments differentiating guidelines in instances where combinations were not supported.

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[28] See extended paper 3.3.1

Developing Consensus

All participants contributing to Round Three had also contributed to Round Two. Alterations and comments made by participants appeared to be evenly distributed, and there was no evidence of lack of engagement towards the end of the survey.[29] Further, Table 7 demonstrates which guidelines were combined or altered between Rounds Two and Three via the consensus generating process, with 1 guideline being split into multiple guidelines, 7 guidelines being amended, and 15 combined with other similar guidelines.

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[29] See extended paper 3.3.4

Table 7

Audit trail of consensus generation process

	Participant	Patient/Practitioner	Amended/Combined/Split	Included
Guideline 1	1	Patient	Split	Y
Guideline 2	4	Patient	Amended	Y
Guideline 3	5	Patient	Amended	Y
Guideline 4	6	Practitioner	n/a	Y
Guideline 5	8	Practitioner	Combined	Y
Guideline 6	10	Patient	Amended	N
Guideline 7	9	Practitioner	n/a	N
Guideline 8	11	Patient	Amended	Y
Guideline 9	12	Patient	Combined	Y
Guideline 10	13	Practitioner	n/a	Y
Guideline 11	14	Practitioner	n/a	Y
Guideline 12	9	Practitioner	Combined	Y
Guideline 13	11	Patient	n/a	Y
Guideline 14	4	Patient	n/a	Y
Guideline 15	10	Patient	Combined	N
Guideline 16	9	Patient	Combined	N
Guideline 17	8	Practitioner	Amended	N
Guideline 18	5	Patient	n/a	Y
Guideline 19	4	Patient	Combined	N
Guideline 20	1	Patient	Combined	N
Guideline 21	3	Patient	Combined	N
Guideline 22	10	Patient	n/a	Y
Guideline 23	11	Patient	Combined	N
Guideline 24	12	Patient	n/a	N
Guideline 25	14	Practitioner	Amended	Y
Guideline 26	1	Patient	Amended	Y
Guideline 27	3	Patient	Combined	Y
Guideline 28	14	Practitioner	Combined	N
Guideline 29	13	Practitioner	Combined	N
Guideline 30	3	Patient	Combined	N
Guideline 31	7	Practitioner	Combined	N
Guideline 32	2	Practitioner	Combined	N
Guideline 33	6	Practitioner	n/a	Y
Guideline 34	2	Practitioner	n/a	N
Guideline 35	2	Practitioner	n/a	N
Guideline 36	6	Practitioner	n/a	N
Guideline 37	8	Practitioner	n/a	Y
Guideline 38	13	Practitioner	n/a	N
Guideline 39	12	Patient	n/a	N
Guideline 40	7	Practitioner	n/a	N

There were four guidelines considered by the panel in Round Two to have similar content and messages. All participants commented on whether there was overlap between these guidelines, with variations on suggestions to combine or merge certain guidelines within qualitative commentary.[30] Consistency in a shift towards consensus was found across the two rounds (Table 8).

Table 8

Shifting consensus across rounds

	Round Two (40 Guidelines)	Round Three (36 Guidelines)
Consensus important or essential[a]	24	22
Approaching consensus important/essential[b]	8	7
No consensus[c]	8	6
Consensus not important[d]	0	0

[a]Consensus important = ≥70% on ratings 5 and 6, [b]Approaching consensus important = 60-70%, [c]No consensus = 0-60%, [d]Consensus not important = ≥70% on ratings 1 and 2.

Between Round Two and Three, there were ten opportunities to vote on guidelines which were removed due to suggestions from the panel to combine or merge these guidelines. However, three additional amended guidelines were offered alongside original guidelines to be rated, resulting in 36 opportunities to rate guidelines. There were three opportunities to vote on combining guidelines, resulting in the merging of some guidelines and a final set of nineteen guidelines.

Finalised Guidelines

There were nineteen guidelines endorsed in the final survey, organised into four themes, based on panel consensus (see Table 9). Table 10 demonstrates the practitioner-patient split

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[30] See extended paper 3.3.2

of guidelines meeting consensus to be included in the final set, with 42% (8/19) of practitioner generated guidelines and 52% (11/21) of patient generated guidelines included.

Table 9

Finalised guidelines endorsed by the panel

No.	Guideline
	Theme: Overarching good clinical practice points
1	Be aware of and work within the limits of your training, knowledge and competency. Consider the strengths of your discipline and those of other disciplines and gain an understanding of when it is appropriate to refer a PWV to another discipline, assuming the PWV supports the referral. A multi-disciplinary approach is often beneficial.
2	Demonstrate kindness and empathy in appointments. Acknowledge how alone, frustrated and confused one can feel with unexplained genital pain and how difficult it can be to share such personal information with others.
3	Alongside management, give PWV information about local pain groups and charities, such as the Vulval Pain Society or National Vulvodynia Association, books or websites. This may be a quicker way to get information and sensible ideas about non-intrusive management tactics and help PWV feel supported, and part of a wider community.
4	Be aware that vulval pain can be complex and multifaceted and it combines the physical and the mental, with various different routes and treatments available. A multidisciplinary approach is important because combination treatments need to be co-ordinated to be offered at the same time. Some PWV can feel there is no one person coordinating their treatment. Encourage PWV to discuss this with their GP, and make sure they have clear contact information to get in touch if there are problems with the referral.
5	Some practitioners feel uncomfortable discussing sex and this can prevent them asking questions that give the person permission to talk about the sexual and relationship consequence of their vulvodynia. Practitioners should be aware of their own levels of comfort and if this is an issue, consider relevant continuing professional development, e.g. spending time in a Sexual Health clinic, with gynaecologists or psychosexual therapists.
6	If possible the PWV should be seen: by the same practitioner, in an appropriate environment, e.g. private, well-lit room, on time, with sufficient time, i.e. for the appointment to not feel rushed. Making more time for an appointment will allow for specific questions about the impact of vulvodynia too.
7	People with vulvodynia should be given enough information to understand vulvodynia and its possible impacts and empowered to communicate with important others about it if it is safe and possible to do so.
8	There is a heteronormative and cisnormative approach to sex in society and touch and intimacy are not the same for everyone. Do not assume people's sexuality or gender, or assume any direct link between their sexual or gender identity and their condition.
	Theme: Initial consultation, including understanding symptoms and impact
9	Do not assume that if symptoms are not having an impact on the PWV's quality of life and relationships that they are not severe. Vulval pain can improve, but may get worse if PWV are not supported or get the wrong kind of support or advice.
10	Make time, actively listen and be responsive to what is being said in appointments. There is so much variation in symptoms of vulvodynia and the way it affects people, that the specific impact will vary for any given person. Use open questions such as "have you identified anything that makes managing vulvodynia better or worse?", "how are you coping?", "how is this affecting you?". Acknowledge that this is a difficult condition to live with.
11	Explain and give an opportunity to discuss what is going to happen in an appointment, and gain consent for all discussions, examinations and procedures at every appointment. Pain can cause hypervigilance and anxiety; therefore be open about what pain may be involved in each intervention and the possible pros and cons, to involve the PWV in the decision-making process.

12	The first appointment is really important for building up a relationship. You are likely to be fact finding and being empathetic when needed. After asking all questions to gather information, reflect back what you have heard e.g. “I am going to try and summarise...”, “My impression is...”. Try to put into a nutshell what the person has told you, so that they know you have really heard their story.
13	PWV may find it distressing to repeat their full vulvodynia story to a new practitioner and/or feel frustrated that this leaves less time to discuss the present issue. If possible, offer the PWV a choice to summarise their history themselves, or for you to summarise what you know and ask them what they specifically want to discuss in that appointment.
14	Vulvodynia is a condition which is both affected by, and can affect, people’s mental health as well as their physical health. Use open questions and active listening to explore how this might be affecting mental health and sexual relationships, while also respecting when PWV may not want to go into detail about this ‘just yet’.
15	It will be important to ask about the impact of pain on a PWV’s life and to emphasise that pain is a physiological and psychological process, which can impact on wellbeing. If you are in a position to, explain chronic pain mechanisms and how stress and anxiety can exacerbate pain. If referring to psychological or psychosexual therapy, explain that this is not a replacement for existing treatment, but that psychological support can sometimes be helpful for overall wellbeing and support.
	Theme: Follow-up
16	Validate someone’s problem as a problem worth time and thought. PWV should be supported with information regarding the prognosis of their condition and told that together you will find a way to help them with managing vulvodynia, or find a professional who can help them further.
17	For those with partners, to provide more information for partners so they can have a better understanding of how vulvodynia is impacting their lives or their partner’s lives. This may involve encouraging the partner to come to a session.
18	Once assessment results allow, give a formal diagnosis of vulvodynia (a pain syndrome) and beware of mislabelling (e.g. as dyspareunia, which is a symptom of vulvodynia). If you are in a position to, give a precise specific subset diagnosis.
	Theme: Future planning and longer-term care
19	Managing long-term expectations may involve being open and candid about vulvodynia being multifaceted and that additional support may be needed in the form of medical and/or psychological support. Explain that lots of people recover from the condition, but that for others it will be ongoing to work through, therefore a whole team approach may be required. This may include explanations of who the team is, how referral pathways work, and what kind of support exists.

Table 10

Number of guidelines per patient included across rounds

	Guideline included in Round Three	Guideline included in final set
Practitioner n=7	19	8
Patient n=7	21	11

In terms of content and organisation of the guidelines, panel members supported an approach to structuring the beginning of the guidelines with overarching good practice points[31], and the separation of subsequent guidelines into themes of initial consultation including understanding symptoms and impact, follow-up and longer-term care and future planning.

Theme 1: Overarching Good Practice Points

Inclusion of good practice points were those aspects of practice not necessarily directly linked to the management of vulvodynia, but nonetheless considered by participants to be important enough to be underscored in the guidance. Although some participants commented that these principles should be commonplace in practice, panel members also rated these guidelines highly overall in terms of consensus for inclusion in the final set.

Theme 2: Initial Contacting Including Understanding Symptoms and Impact

Guidelines in this theme clarify the need to acknowledge the emotionality of vulvodynia and its impacts, and a requirement for empathy. Common factors of patient-practitioner interactions, such as actively listening and demonstrating empathy, were identified as facilitating conversations regarding the more specific impacts of vulvodynia over and above medical symptoms such as pain.

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[31] See extended paper 4.1.1

Theme 3: Follow-up

Participants highlighted the need for practitioners to be aware of their own competence and knowledge to ensure appropriate and timely follow-up. The process of clear shared decision making, including collaboration with partners and clear communication about follow-up were identified as pertinent to managing vulvodynia and its impacts.

Theme 4: Longer-term Care and Future Planning

The guideline within this theme emphasises the need for a whole-team approach, and explanations of the types of support offered in an accessible way for women.

Clinical Vignettes

Clinical vignettes were developed out of participants descriptions of examples of good practice or difficulties in communicating, to accompany each guideline finalised by the panel (see Appendix O). Vignettes were developed out of the panel's experiences, and highlight examples of best practice, or situations in which there were concerns or difficulties with communication. Vignettes were utilised to demonstrate the applicability of each guideline in clinical practice, intended as a guide for practitioners. Panellists were sent the finalised guidelines and unsolicited informal feedback was received regarding their readability and applicability to the aims of the research.[32] Furthermore, there were no concerns addressed regarding vignettes as identifying panellists or anyone they had worked with as part of their clinical descriptions.

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[32] See extended paper 3.3.5

Discussion

Summary of Findings

This study drew on the experiences of women with vulvodynia and practitioners communicating about the psychological and interpersonal impact of vulvodynia to create a coproduced resource for use in clinical practice for any practitioners interfacing with women with vulvodynia at any level of the management process. Themes for the guidelines identified by participants are discussed in more detail below.

Theme 1: Overarching Good Practice Points

Guidance from The European Association of Urology (EAU) regarding the management of psychological issues in the treatment of chronic pelvic pain, highlights the need to provide "information that is personalised and responsive to the patient's problems, conveying belief and concern" (Fall et al., 2010 p. 55). This recommendation echoes Theme 1, which draws attention to the essential skills in communication underscored by this research. Overarching good practice points were considered by participants to be required to be commonplace in practice yet rated highly in terms of level of consensus. This conflict may mirror a process many women with vulvodynia experience with healthcare: expecting or requiring a certain degree of care, and sometimes interactions with practitioners leaving them feeling uncertain and misunderstood (LePage & Selk, 2016), or frustrated (Ponte et al., 2009). These findings emphasise the need for overarching principles of good practice in communicating with women living with vulvodynia.

In this study, panellists also highlighted the requirement for practitioners to consider their levels of comfort and ability to discuss sexual issues as part of follow-up consultations with women with vulvodynia. Research has shown that women regard exploration of sexual issues as a basic competence of practitioners, including primary practitioners such as General Practitioners (GPs; Leusink et al., 2019), although some practitioners may be reluctant to discuss sexual issues, due to personal and structural barriers such as discomfort or inexperience discussing these issues (Dyer & das Nair, 2013). These guidelines highlight the need for gynaecological and sexual knowledge to be enhanced across professions when working with vulvodynia (Pukall et al., 2016), and for continuous professional development (CPD) needs and opportunities to be identified and sought out to improve communication and patient care. This includes practitioners playing an active role in identifying how vulvodynia may impact on sexuality and understanding different approaches to sexuality outside of heteronormative and cisnormative assumptions of what sex entails, as well as addressing their own personal or service-level barriers to communicating about sex, or painful sex. This research uses the terms “women with vulvodynia” to contextualise experiences in line with descriptions in the literature, yet the panel identified that people with vulvodynia (PWV) may be a more appropriate term for the finalised guidelines, to encapsulate individuals with vulvodynia who do not necessarily identify as female. In this way, the guidelines take an important step towards recognising the diversity of vulvodynia populations, and embed within their terminology the basis for client choice regarding preferred pronouns, encouraging a culture of inquiry about these from practitioners.

Theme 2: Initial Contact Including Understanding Symptoms and Impact

It is a key finding that women on the journey towards a diagnosis of vulvodynia may have had experiences of feeling judged, invalidated or not believed regarding their pain (Marriott & Thompson, 2008). This may be due to incorrect diagnoses, and inappropriate referrals and treatments, which can bring about laboured practitioner-participant interactions (Shallcross, Dickson, Nunns, Taylor, & Kiemle, 2019). When management of vulvodynia then occurs, some women may be bringing with them a history of feeling silenced by the medical model, leading to fears regarding asserting their needs and limited knowledge regarding their condition. Hintz (2019) found that, for women with vulvodynia, positive interactions with practitioners involved them acknowledging the emotional difficulty of managing vulvodynia, and validating the process of obtaining a diagnosis, including the potential frustration women may feel. Empathy is considered key in facilitating effective communication for the management of the impact of this condition, as treatment compliance has been found to be higher in patients who note the emotional component of vulvodynia has been addressed by practitioners (Goldstein & Pukall, 2009). In particular, empathy is a key skill to support initial contact with women with vulvodynia, and research from other unexplained pain conditions with a psychosocial element indicates that a lack of empathy can result in patients feeling inhibited regarding discussing their pain and its impact (Goubert et al., 2005). The findings in this study compound findings in previous literature that human factors such as empathy, legitimization and validation of the struggles of managing vulvodynia are required for practitioners. These qualities are linked to specific outcomes of treatment adherence, level of information about the impact of vulvodynia and patient frustration and unmet need.

Theme 3: Follow-up

The finalised guidelines show the need for practitioners to be aware of their own competence and knowledge. This echoes findings that, when a lack of knowledge leads to inappropriate support options, people with vulvodynia experience detrimental outcomes including persistence of pain and psychological and sexual difficulties (Petersen, Lundvall, Kristensen, & Giraldi, 2008). Alongside management by community GPs, women with vulvodynia may have follow-up contact with a number of specialist services, particularly where presentations are more complex. Continued contact usually involves formulating a plan, and goal-setting for treatment and management, including shared decision-making. However, barriers to effective and streamlined follow-up can include long waiting times for women, and a reduced likelihood of seeing the same practitioner to develop a rapport with (Buchan, Munday, Ravenhill, Wiggs, & Brooks, 2007). There was an acknowledgement by the panel in specific comments on guidelines that resources may not necessarily always allow for the enactment of the ideal scenarios which informed the guidelines.[33] Clear decision-making and communication regarding thismay offset struggles for women and practitioners alike when managing vulvodynia in under-resourced systems.

There are challenges in operationalising patient-centred care and shared decision making, as the definition may encapsulate overall style of practice as well as specific behaviours during interactions (Mead & Bower, 2002). As a result, it is difficult to ascertain whether the finalised guidelines specifically tap into constructs of shared decision making or patient centred care. In fact, these concepts are holistic components designed to unite patients and practitioners, and may include elements of patient self-efficacy, which are likely to be expected in a sample of patients able to ‘communicate about communicating’ for the purposes of this study. Nonetheless, patient-centred communication and shared decision making are important guiding philosophies of high-quality care which should inform practitioners’ approaches to managing vulvodynia (Epstein et al., 2005).

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[33] See extended paper 4.1.2

Theme 4: Longer-term Care and Future Planning

Many women with vulvodynia experience relief or recovery from their symptoms, however for some women, involvement with services will extend across several years and involve multidisciplinary co-ordinated input, requiring consideration of ongoing and future support. For both women who recover from vulvodynia, and those for whom it persists, the psychological impact can be far reaching (Bond, Weerakoon, & Shuttleworth, 2012). Because of a lack of medical evidence for pain in vulvodynia, patients may commonly be told their symptoms are psychosomatic (Leusink et al., 2018). This guideline highlights how patients and practitioners should be working together to share knowledge about managing pain and its impact, and improving collaboration in practice and research, although there is an acknowledgement that this is not the norm across services. Practitioners may be required to be attuned to the various impacts that women with vulvodynia face and be proactive in creating relationships in which wellbeing can be discussed (Domenici & Panici, 2014).

Models of communication for sexual issues

It is important to acknowledge the barriers to practitioners communicating regarding sexual issues for this population, whilst holding in mind that genital issues should not automatically equate to sexual issues, and that the pain itself for many women is a sufficient and valid cause for distress. However, women in vulvodynia research report issues with sex and sexuality (Phillips & Bachmann, 2020), although much of the research focuses on heteronormative relationship dyads (Young & Miller, 2019), therefore a consideration of communication regarding these issues is warranted.

The extant literature identifies many barriers to communication for practitioners and women with vulvodynia when discussing sexuality. Although limited by self-report, practitioners in general report low levels of confidence and efficacy in the management of genital pain disorders (Abdolrasulnia et al., 2010). Further, systematic review evidence highlights personal and structural barriers for practitioners discussing sex such as lack of confidence, fear of causing offence, or assumptions that patients will raise what is of importance (Dyer & das Nair, 2013). The negative impact of interfacing with practitioners who lack skills, confidence and expertise discussing sex can reduce the likelihood of women raising the issue (Kaler, 2006), resulting in a vicious cycle of non-communication and unmet needs.

Communication models such as Ex-PLISSIT (Davis & Taylor, 2006) exist to aid practitioners in communicating regarding sexual issues, particularly when discussing chronic pain conditions. Components of the guidelines produced in this research converge somewhat with the principles of this model, such as permission giving for the discussion of sexual issues, and providing limited information to support signposting or referral to specialist services. Some guidelines in the final set, such as Guideline 5, go one step further to consider the research that some practitioners may feel uncomfortable discussing sex, and provide suggestions regarding how to address this in order to embody permission-giving to discuss difficult issues in their appointments. In contrast, specific to the guidelines created from this research is a capturing of the journey and unique needs of women with vulvodynia, highlighted in vulvodynia research. For example, on average women attend more than 15 appointments and wait 36 months for a diagnosis of vulvodynia (Buchan et al., 2007) and delays in specialist treatment can average 6-18 months (Connor et al., 2013). As such, women are likely to have to repeat their story to multiple practitioners and suffer undue psychological stress as a consequence. Participants in this study echoed this experience and prioritised a guideline (Guideline 13) to make suggestions on how to acknowledge and respond to this unique need in order to drive forward shared communication on important issues. This study may provide evidence of how the principles of communication as highlighted by pre-existing models, can be considered in specific contents where sexuality may be impacted.

Strengths

One strength of the Delphi method is subject anonymity in the consensus generating process. Anonymity can reduce the risks of the panel conforming to certain viewpoints, and the influence of dominant individuals (Lilja et al., 2011). However, absence of live dialogue may deprive the panel of opportunities to clarify important information, such as those pertaining to disputed commentary. The research team attempted to mitigate the effects of this by providing three rounds, and by disseminating the finalised guidelines out to the panel.

There is increasing acknowledgment of the value of coproduction in research, in which service users' views and contributions are woven through the research process.[34] This study utilised specific 'experts by experience', enabling the views of women with vulvodynia to be

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[34] See extended paper 4.2.2

inherent within the research, and creating a dialogue between patients and professionals in the first study of its kind in this field.

Limitations

The study may have been limited by attrition between Rounds Two and Three, with just over half of the overall panel contributing to the final consensus generating survey.[35] The Delphi methodology does not allow for an analysis of what results may have been obtained in the absence of attrition, and relies heavily on panel contributions. The authors guarded against the risk of attrition by sending personalised reminder e-mails and engaging each panel participant, however attrition may have biased the results in favour of the final contributors somewhat.

Consensus methods are subject to methodological issues such as bias in selection of participants. Overall, practitioner participants were fairly homogenous in terms of geographical location, although Nottingham-based clinicians spanned two NHS trusts in this region. It was also not possible to recruit nurses, pain clinicians and GPs into the panel, who may disagree with the recommended guidelines. Of particular importance is the view of GPs, who may be required to utilise the guidelines due to playing an important role in the management of vulvodynia from a primary care perspective, in the absence of a multidisciplinary team to draw upon. This affects the generalisability of the findings, in that not all of the guidelines will be relevant to other professionals. Further, the omission of key demographics such as ethnicity and sexuality is a limitation to understanding the diversity of the sample of individuals informing the guideline creation.[36] This may have implications for the guidelines themselves where specific issues related to minority groups may be overlooked in the guidelines. This would be important to explore in future research into the implementation of the guidelines.

Specific criteria were not set regarding how many cases of vulvodynia practitioners needed to have encountered in order to take part. It is possible that some participants had more experience in their field, but less contact with women with vulvodynia. However, it would have been arbitrary to impose a specific number of cases, and it is recognised that one in-

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[35] See extended paper 4.1.3

[36] See extended paper 4.1.4

depth case may generate as much data as numerous brief contacts with women with vulvodynia.

The sample of women with vulvodynia in the study was diverse in terms of length of vulval pain symptoms and duration of diagnosis. However, self-selection of participants can introduce bias, therefore there is a recognition that women with vulvodynia may have had experiences that the guidelines were unable to capture, meaning that some issues in communication were not recognised within the research. There is also evidence to suggest that many women with vulvodynia can reach a sense of empowerment through having to find out information for themselves regarding their condition, resulting in them becoming advocates (Imber-Black, 2008). Many of the sample were vocal regarding their advocacy and ability to speak out about vulvodynia, however by virtue of the methodology requiring a level of communication regarding views, women who experience the most struggles with communication may have been underrepresented in the process.

Clinical Implications

A fundamental and key skill for practitioners across all health settings is communication. As such, practitioners have an ethical and legal obligation to ensure that they are meeting best practice standards of communication within their work. The finalised guidelines of this study provide a consensus-based tool to support this endeavour in practice, and highlight the need for practitioners to consider their communication with women with vulvodynia, by providing support to practitioners to improve their communication.[37] Practitioners may wish to suggest the guidelines to colleagues who highlight learning needs in this area, use them idiosyncratically in their own practice, or revisit them when desired as a reminder to consider communication throughout their career. They may also be of benefit to new practitioners, such as trainee doctors or gynaecologists early on in their specialist training, to underscore the specific needs of this population. It would also be considered appropriate for women to be aware of the presence of the guidelines, to shape their expectations for the patient-practitioner interaction. This implication appeals to the dyadic nature of such communication.

By producing a set of guidelines, this study provides a guiding tool for how professionals can use their own practice and compare this with the experience of patients in order to better

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[37] See extended paper 4.2.3

understand what works well in practice, and what shifts or changes may be needed in communication. Guidelines are intended for use by any practitioner working with women in supporting them to manage vulvodynia, although there is a recognition that practitioners will be required to determine how best the guidelines may inform their practice based on the competencies required by their specific profession. Further, applied critically, the methodology used in this study may also be applicable to individuals who seek to improve communication in areas in which difficulties with this process are highlighted.

This research contributes to the field of clinical psychology by building on existing models of communication around sexual issues to consider other issues connected to sexuality, including psychological and interpersonal distress, in a genital pain condition population with unique needs. Lack of communication about these issues may limit the potential for psychological and interpersonal distress to be addressed because of a lack of identification and therefore appropriate referral and service provision. This study aims to provide methods to support the process of communication.

The research offers appropriate ways of bringing to light the struggles of women with vulvodynia and practitioners communicating within clinical settings, via the methodology used, and highlights the unique struggles of women with vulvodynia in communicating with professionals about impacts, as well as struggles professionals have in relation to communication, which may in part arise from their own psychological barriers to communicating openly about this subject. This research aims to bridge the theory-practice gap in order to produce a resource to navigate difficulties in communication.

Future Research

These guidelines were developed out of the direct experiences of individuals on both sides of the patient-practitioner interaction. In order to gather evidence regarding the value of the guidelines, their clinical utility should be considered, in the form of trialling their use with women and practitioners to discover how they may be of benefit within dyad interactions. The sampling strategies used allowed for prospective and snowball sampling of a range of clinicians working with vulvodynia, and women with vulvodynia, resulting in recruitment of practitioners across the UK, as well as women with varying durations of vulval pain symptoms and length of interacting with practitioners regarding vulvodynia. Lack of representativeness of all practitioners involved in vulvodynia management, in particular GPs, may limit the use of the guidelines with this population without future consultation regarding their applicability. Due to the lack of GP representation within the study, it may be useful to pilot the guidelines with a sample of GPs in order to assess their applicability to this professional role. Although attempts were made to recruit GPs through a national GP registration body, future studies may wish to consider recruitment of harder to reach practitioner groups through targeted sampling, for example by way of an advert in local GP surgery bases.

This research took a narrow focus to consider communication and practitioner care of the management of vulvodynia from a psychological, emotional and interpersonal perspective.[38] This meant that those with a diagnosis of vulvodynia were eligible to take part, and that information informing guidelines focused on the management of this condition. However, there is a wealth of evidence from women's accounts in qualitative research to suggest that the journey to diagnosis can be protracted and traumatising for many women interacting with healthcare systems (Shallcross et al., 2019). It would be beneficial for future research to obtain the views of practitioners on this journey, and to consider how women and practitioners can work together to improve patient care across various aspects of unexplained genital pain research and practice.

Implementation Plan

There is research to suggest that clinical guidelines are frequently not applied in practice, due to barriers associated with implementation and adherence (Fischer et al, 2016). Factors may be personal, guideline related or external, and structured implementation planning can improve the likelihood of their use (Beauchemin et al., 2019).

The initial step in the structured implementation plan for this research[39] is publishing the research in a peer-reviewed journal. This will aim to make the guidelines available for clinical use in settings where healthcare professionals interact with and communicate with those with vulvodynia regarding managing the impact of the condition. This step also allows peer review of the methodology and output of the research and enhances credibility.

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[38] See extended paper 4.3

[39] See extended paper 4.4

Stages associated with actioning guideline use are confirmed agreement for the guidelines to be published through the Vulval Pain Society, including on their website. One possibility may be piloting the guidelines within the NHS recruitment site for this research, as well as associated vulval pain clinics in the local area. Dissemination will include consideration of how to apply learnings from evaluation at the recruitment site to allow for widespread knowledge and adoption of the guidelines, including with individual services and clinicians. This may be possible as part of future service-based and academic research.

Conclusions

Women with vulvodynia continue to note problematic patient-practitioner dynamics, and an overemphasis on the medical components of managing vulvodynia, meaning that psychological and interpersonal needs of women may go undiscussed and unsupported. The findings in this study highlight the unique needs of women with vulvodynia, and provide an opportunity to prioritise these, with examples of best practice regarding how to identify and communicate about these needs, aided through the use of the finalised guidelines.

The co-produced guidelines expand on existing theories and models of communication to support practitioners to target the unique communicative needs of women with vulvodynia aiming to manage the impact of this condition on psychological, emotional and interpersonal factors. Guidelines highlight the importance of good clinical practice including adjustments to environments and interpersonal skills, guide conversations at initial contacts to explore the impact of vulvodynia, structure shared decision-making and person-centred care around managing impacts and consider future planning for this group.

Key Points from the Guidelines:

1 Overarching good clinical practice points: Practitioners are invited to consider how to create safe spaces for exploring impacts of vulvodynia, by considering impacts as a combination of physical and mental distress. Skills such as empathy and kindness, as well as working within the limits of your competency and giving clear information about referral routes are key. This may include consideration of your own feelings as a practitioner on discussing sex with patients, and not assuming sexual or gender identity of your patients and how this links to vulvodynia symptoms.

2 Initial consultation, including understanding symptoms and impact: These guidelines consider the importance of not assuming the impact of vulvodynia, asking specific open questions regarding the psychological/emotional impact as part of fact finding, if the patient gives consent for these conversations. Emphasise the relationship between pain and wellbeing and how difficult this can be. Make explicit the process of referral to other practitioners if needed.

3 Follow up: These guidelines emphasise the importance of instilling hope that managing vulvodynia is possible, and that collaboration to find the right support is possible. This may mean involving partners. If you are in a position to, tell patients what their formal diagnosis and subset diagnosis is and be careful not to mislabel vulvodynia e.g. as dyspareunia (painful sex).

4 Future planning and longer-term care: This pertains to managing long-term expectations that some people recover, and others need ongoing additional support in the form of a whole-team approach. Explain what support exists, what referral pathways are, and how they work.

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Extended Paper

1 Extended Introduction

1.1 Defining Vulvodynia

1.1.1 Vulvodynia: A New Area of Interest and Research. Understanding of the impact of vulvodynia has been limited by several factors over the course of the study and treatment of the condition. Vulvodynia was historically an under-researched and under-recognised female genital pain condition (Clare & Yeh, 2011), until increased patient reports of symptoms of vulvodynia in the 1970s led to the generation of discourse on its aetiology and management (Ridley, 1996), by way of the 1983 International Society for the Study of Vulvovaginal Disease (ISSVD) vulvodynia committee. Since then, increasing detection and treatment of cases have led to an expansion in research regarding the epidemiology, prevalence and impact of vulvodynia, including a revised definition (Bornstein et al., 2015).

1.1.2 Defining Vulvodynia in Order to Manage It. It is only in recent years that an accurate definition of vulvodynia has been developed, resulting in what is known as the '2015 classification' (Bornstein et al., 2015). Types of vulvar pain are considered to fall under two categories in this classification: chronic pain related to a disorder (such as inflammatory e.g. lichen sclerosus), and vulvodynia. Vulvodynia refers to idiopathic pain in the vulvar region experienced for at least three months duration (Sadownik, 2014), and is considered a 'diagnosis of exclusion' (Eppsteiner, Boardman, & Stockdale, 2014), given only when other differential diagnoses have been discounted through examination and investigation. There is also nomenclature differentiating subtypes of vulvodynia as provoked vestibulodynia (PVD) and unprovoked or generalised vulvodynia (GVD). PVD is characterised by pain at the vaginal vestibule aggravated by touch at the vestibule site (Henzell, Berzins, & Langford, 2017), whereas GVD is wide spread pain occurring in the absence of known triggers (Falsetta et al., 2017). There is lack of clarity in the research as to whether the subtypes are distinctive disorders, and debates exist as to whether PVD and GVD may exist on a continuum of the same condition (Wesselmann, Bonham, & Foster, 2014). Inconsistencies in the disaggregation of subtypes in research has resulted in an over-representation of women with PVD in research. More longitudinal research is needed to understand risk factors related to the occurrence of vulvodynia and elucidate subgroups of those affected (Pukall et al., 2016).

The long-term lack of a cohesive definition has also been linked to difficulties in vulvodynia diagnosis and management. Few randomized control trials (RCTs) have been published to review effective treatments, due to challenges operationalising outcome variables specific to vulvodynia compared with other vulvovaginal pain conditions (Corsini-Munt et al., 2017). Those that do exist are limited by variable quality of included participant samples, failures to account for bias, equivalence of outcomes and lack of follow-up data. More recent medical guidelines for the management of vulvodynia emphasise that the principles of chronic pain management should be adhered to when treating this population, and that treatment should be holistic due to the impact of the interaction between pain, lifestyle and sexual functioning for women (Mandal et al., 2010).

1.2 The Impact of Vulvodynia

As with other chronic pain conditions, the personal impact of vulvodynia is idiosyncratic, although common themes have emerged regarding the onset and maintenance of vulvodynia as influenced by biopsychosocial factors.

1.2.1 Psychological Impact. Research has established a firm connection between vulvodynia and psychological distress in the form of anxiety and low mood (Masheb et al., 2009), although this relationship is not well understood. Controlled studies have found increased rates of depression in women with vulvodynia in inpatient settings compared with asymptomatic controls (Reed et al., 2000; Reed et al., 2014), although other community studies have failed to replicate this difference (Aikens et al., 2003). Online survey results indicate women with vulvodynia experience higher rates of depressive symptoms than women without vulvodynia, although presentations of comorbid depression have been subclinical (Corsini-Munt et al., 2017). There is also evidence to suggest that psychological morbidity is similar to that of other vulvar diagnoses (Jadresic et al., 1993). However, studies are limited by overall measurement using generic screening tools that capture a wide range of difficulties. When disorder specific measures are used, vulvodynia patients score higher than healthy controls on symptoms of depression and anxiety (Stewart et al., 1994). Furthermore, there is evidence to suggest that individuals with pre-existing low mood and anxiety are four times more likely to have vulvodynia than those without, and that vulvodynia is associated with new and recurring depression and anxiety (Khandker et al., 2011). Therefore, the relationship between vulvodynia and psychological distress appears to be interactive.

Shallcross et al. (2018) used meta-synthesis on available qualitative data regarding the impact of living with vulvodynia to elucidate common themes and experiences in this population. Within this review is a recognition that quantitative data on the psychological impact of managing vulvodynia highlights the physical impact of pain and discomfort, including on activities of daily living, which are somewhat linked to psychological outcomes (Ponte et al., 2009). Methodological issues exist in converting complicated emotional and psychological processes into measurable variables, and therefore qualitative data provides a more in-depth exploration of experiences of distress in women with vulvodynia. Results of the review indicated that across seven included studies, depression was a common theme to varying degrees. Of note, sources of distress were not solely associated with pain or problems with sexual functioning, but with feelings of shame and guilt, common emotions associated with a depressive experience (Kim et al., 2011). Nonetheless, in this review, these emotions were linked specifically to vulvodynia due to shame developing from seeing the self as abnormal (Kaler, 2006), and guilt specifically linked to not feeling like a ‘real’ woman (Marriott & Thompson, 2008). Although, it is important to note that some women also report confidence and happiness despite their diagnosis and associated challenges (Ayling & Ussher, 2008).

1.2.2 The Impact of Pain. As with other chronic pain conditions, the psychological impact of experiencing pain is of key importance in vulvodynia (Giesecke et al., 2004). In an online survey by Dargie, Gilron, and Pukall (2017), women with PVD reported more symptoms of stress, depression, anxiety and sleep disturbances as a result of pain compared with pain-free controls. Chisari and Chilcot

(2017) found that for women with vulvodynia, greater psychological distress was associated with increased pain severity and interference in daily life on validated outcome measures of illness perception. These findings are in line with studies into self-efficacy, which relates to the degree people believe they can influence events or outcomes in their lives (Bandura, 2010). Desrochers et al. (2009) highlighted that lower self-efficacy, amongst other factors such as hypervigilance to pain and fear of pain, accounted for 15% of variance in intensity of pain during intercourse in a sample of 75 patients with PVD.

Although it is evident that pain and psychological distress are linked in vulvodynia, it is difficult to determine the direction of this relationship, and there are conflicting suggestions from theorists (Husted et al., 2012). The consequence hypothesis is suggestive of pain developing first and interfering with quality of life, resulting in depression or anxiety; whereas the antecedent hypothesis indicates that anxiety and depression impact on pain tolerance thresholds, increasing the risk of developing chronic pain (Fishbain et al., 1997). Longitudinal studies support a bidirectional pathway, in which mood and pain are inextricably linked, and impact on physical and mental processes (Kroenke et al., 2011).

What is clear from the evidence is that chronic pain adversely affects the psychosocial functioning of sufferers (Banks & Kerns, 1996). Qualitative research highlights feelings of disempowerment linked to chronic vulval pain as associated with feelings of shame and isolation (Nguyen, Ecklund et al., 2012). This is made worse by the unexplained nature of pain, resulting in some women concluding that they are to blame for their pain, or that pain is ‘all in their head’ (Basson et al., 2003), in the absence of a clear cause. In fact, in one study, women with generalised vulvodynia were found to experience more distress than those with vulvodynia with direct physical pain triggers such as touch (Stewart et al., 1994). Difficulty providing an explanation for pain may also result in struggles communicating with others about the qualitative experience of pain, resulting in women feeling the need to silence themselves (Leeming & Boyle, 2004). This can have a direct and interactive effect on sexual relationships with the self, and sexual or romantic relationships for those with partners, including on communication within relationships.

1.2.3 Sexual Impact. Sexuality in its basic biological form is related to an individual's capacity to experience genital excitation (Goettsch, 1989). However, there is a recognition in sociological literature that sexuality is a complex and individualised process linked to culture, power, and narratives in the society in which an individual is part of (Castelo-Branco et al., 2008). Sexuality is also linked to identity and wellbeing, through the experience and expression of pleasure, intimacy, fantasy, roles and relationships (Hyde & DeLamater, 2008). As a result, it is unsurprising that individuals who experience threats to their sexuality or impaired sexual functioning report distress and reduced quality of life (Jackson et al., 2019).

Barriers to engaging in sex for women with vulvodynia at the procedural level are associated with pain, burning or itching of the vulva or vestibule, including the insertion of anything into the vulva (Davis & Hutchinson, 1999). However, arousal is a complex process encompassing cognitive, emotional and behavioural factors which extend beyond the physical act of 'sex', in whatever form this may take. In various controlled studies over time, women with vulvodynia have been found to experience significantly less desire, satisfaction and arousal than their healthy counterparts (Desrochers et al., 2008; Meana et al., 1997). Other difficulties with sexuality in women with vulvodynia include a higher likelihood of negative attitudes toward sex, and higher levels of sexual distress (Van Lankveld et al., 2010). Few studies into sexuality in vulvodynia differentiate the experience of sexuality as an individual as separate from that within a relationship dyad. Van Lankveld, Weijenborg, and Ter Kuile (1996) found that women with vulvodynia masturbate less than ‘average’, although there are limitations to defining what ‘average’ masturbation may be, given wide variations in sexual activity and practices (Dunn, Croft, & Hackett, 2000). As a result of limited research into women’s individual sexuality, the context of findings of studies into the sexual impact of vulvodynia are mostly relational. Some researchers have made attempts to isolate specific variables related to a woman’s experience of vulvodynia on sexuality, finding general lower rates of sexual self-esteem (Bergeron et al., 2015), diminished libido and difficulties reaching orgasm (Donaldson & Meana, 2011). There is also a general finding that the majority of vulvodynia patients in research samples associate pain with sexual activity, which could contribute to reduced sexual interest (Jantos & White, 1997).

It could be hypothesised that the lack of research into women’s individual sexuality related to female genital pain is influenced by unhelpful societal constructions regarding women’s sexuality. (Shallcross et al., 2017). This includes potential narratives regarding the perceived reduced importance of female sexual experience in the absence of a male counterpart, termed the ‘coital imperative’ (McPhillips, Braun, & Gavey, 2001). Eminent researchers into vulvodynia advocate for a change in terminology, away from vulvodynia being merely thought of as a ‘sexual pain’ disorder, due to female genital pain being debilitating enough in itself, and female genitals being associated with more than sex (Dargie, Gilron, & Pukall, 2017).

Hintz (2019) used a method of intersectional analysis to consider how women with vulvodynia may exist at odds with heterosexual norms, constructions and ideological systems, affecting their self-perceptions and existing relationships. Heterosexual sex is typically most linked to sex as penetrative, whereby women are a passive recipient of a penis (Potts, 2001). Vitellone (2000) considers that when women are unable or unwilling to engage in this heteronormative process, this may be experienced as a threat to masculinity. Hintz' (2019) study found that manifestations of power in sexual relationships as a result of societal norms and constructions on sex can intersect with women's experiences of vulvodynia within the context of heteronormative expectations of sex. In a sample of 26 women with vulvodynia, themes of *'penetrative sex as a relational prerequisite', 'failing to have sex, failing as a woman'* and *'choosing painful intercourse'* emerged. These themes highlighted women's struggles with fear of their relationship ending due to the absence of penis-in-vagina sex, believing their sexual functionality defined their worth as a woman or partner, and feeling obligated to engage in penis-in-vagina sex for emotional connection (Gordon et al., 2003). Further findings were of the media reinforcing problematic sexual norms by way of inaccurate depictions of sex and stereotyping painful sex, resulting in women feeling abnormal. It is evident that societal discourse will have an impact on how sex is viewed in vulvodynia, although this is not always negative. Women with vulvodynia have noted feeling confident and happy sexually in other qualitative studies (Desrosiers et al., 2008). A further outcome of Hintz's (2019) research was that resisting the status quo can also lead to negotiating a ‘new normal’ for sex, self advocacy and empowerment.

Similar findings have occurred in studies of couples noting the impact of vulvodynia on sex. In a study by Connor, Robinson, and Wieling (2008), a diagnosis of vulvodynia was found to ease tension in some relationships, by way of an explanation for sexual functioning problems. Nonetheless, there was also evidence in this study that vulvodynia can lead to couples adopting strategies such as avoiding sex, or both parties experiencing anxiety about sex due to fear of pain. This may explain findings that partners of women with vulvodynia experience more erectile difficulties and rate lower on sex satisfaction measures (Smith & Pukall, 2014). As such, vulvodynia may put strain on relationships in differing ways, depending on couple resources and communication.

1.2.4 Impact on Relationships. Within research studies into heteronormative relationships, there is also information about the impact of vulvodynia on overall relationship satisfaction and quality. Some studies suggest that there are no differences in relationship satisfaction between women with vulvodynia and women without (Rosen et al., 2015). Women with vulvodynia have, in some studies, reported that supportive partners have been the most important coping factor for pain (Gordon, Panahian-Jan et al., 2003), although, as literature on sexual functioning has indicated, stressors associated with vulvodynia may lead to more distress for both partners in conventional dyadic relationships (Pazmany et al., 2014). As such, relationship satisfaction has been considered a moderator of distress in women with vulvodynia who are also in relationships. Rosen et al. (2014) found that increases in facilitative partner responses were correlated with decreased feelings of depression and higher relationship satisfaction, as reported by women with vulvodynia. It is likely that communication therefore plays a key role in navigating the complexities of vulvodynia with partners. This likelihood is further endorsed by research finding greater disclosure and empathic response is associated with higher relationship adjustment as measured by an outcome measure with good psychometric properties (Rosen et al., 2016). Findings are promising for the treatment of relationship factors associated with vulvodynia, for example through couple's therapy aiming to improve communication (Slowinski, 2001). Therefore, despite very few published studies on lesbian, bisexual and other sexual minority women living with vulvodynia and the ways in which they navigate partner relationships and seek support, current considerations regarding improving adjustment in relationships may be generalisable to a degree (Bond, Weerakoon, & Shuttleworth, 2012). However, more research is needed considering different types of sexuality and relationships, including polyamory and polygamy, and ways of coping with communication in the face of vulvodynia.

Vulvodynia can also impact on peer relationships and women's engagement with other women in their social network. Nguyen, MacLehose et al. (2012) found that in an online sample of women with vulvodynia, 39% were comfortable discussing it with family and 26% with female friends. This indicates that there may be significant barriers to opening up about female genital pain and vulvodynia specifically. Shame linked to self-silencing about symptoms may be one explanation for limits to disclosure, including to family, friends, and medical health professionals (Nguyen, MacLehose et al., 2012). Social support has well established links with supporting coping with long-term conditions and pain across cultures and disorders (Karayannis et al., 2019; White et al., 2019; Zhou & Gao, 2008). However, much of the available research into vulvodynia and coping focuses on women's perceptions of vulvodynia and the impact on them in terms of pain, psychological distress and dyadic relationships. More research is needed to examine the systemic factors related to vulvodynia disclosure and support seeking within social networks.

1.2.5 Financial and Economic Impact. A further consideration is of the financial and economic impact of living with and managing vulvodynia. There are no studies in the United Kingdom outlining the economic burden of vulvodynia, although studies from the United Stated (US) estimate the cost of vulvodynia to be up to 72 billion dollars a year (Xie at al., 2012) encapsulating costs of transportation, work leave and sickness. A retrospective audit of one United Kingdom (UK) clinic by Goldmeier et al. (2004) found higher expenses for the National Health Service (NHS) in the management of sexual dysfunction in women than in males. However, this study did not present results of vulvodynia samples separately, and encapsulated female sexual arousal and orgasmic disorders qualitatively different to vulvodynia. Findings indicate the prevalence of female sexual dysfunction is reportedly higher than that of males, yet remains underdiagnosed and undertreated, and therefore underfunded. Furthermore, studies also exclude the psychological burden of vulvodynia, further impacting women's ability to work, contributing to higher rates of sickness and absence and lower productivity, in line with other chronic pain conditions (Patel et al., 2012). Other chronic pain conditions such as back pain have attracted more research to inform treatment pathways and outcomes. The financial impact of back pain in the UK in 1998 equated to over £1632 million for direct health costs alone, excluding production losses and the cost of associated informal care (Maniadakis & Gray, 2000). Further research is necessary to consider the personal financial and economic costs for women and the National Health Service (NHS) and general economy when managing the impact of vulvodynia, to inform health policies and identify associated risk factors and potential for funding (Balon, 2017).

1.3 Women's Experiences of Communicating Regarding Vulvodynia

1.3.1 Diagnosis Leading to Management. The multifactorial impact of vulvodynia is underscored in the above studies, and it follows that if the impact is as significant as is highlighted, diagnosis should be timely so that management can be aided. However, there are distinct challenges with diagnosis and management of vulvodynia for practitioners and women alike.

Although not the focus of this review, there is extensive qualitative literature regarding the journey to diagnosis in vulvodynia as protracted, consisting of inappropriate referrals, long waiting times to see specialists and incorrect diagnoses (see Bond et al., 2012 for a review). Part of the reason why diagnosis and management are so difficult is because of the unknown cause of vulvodynia, and variability in symptomology (Connor et al., 2008). As a result, it may not only take women months or years to achieve a diagnosis (Reed, 2006), but several months for practitioners to identify individualised treatment plans (Ventolini, Barhan, & Duke, 2009).

There is literature to suggest that, for some women, the struggles associated with vulvodynia in the context of interacting with healthcare systems can lead to empowerment, and becoming advocates for themselves and the vulvodynia community (Connor, Brix, & Trudeau-Hern, 2013). However, for many women, difficulties with getting a diagnosis results in attempts to self-manage symptoms with little success (Donaldson & Meana, 2011). This may mean that when practitioners are in a position to support women with managing their condition, they may be interacting with women who have searched for causal attributions for pain with little success, and experienced multiple barriers seeking medical help and support (Bogliatto & Miletta, 2017). Therefore, it is important to consider the potential barriers and facilitators for women and practitioners in managing vulvodynia in line with a holistic approach.

Guidelines on the medical management of vulvodynia have been developed to consider a wide-range of potential physical treatments (Metts, 1999). Women can report negative or iatrogenic side effects of some medications (Haefner et al., 2005), although consistent specialist management can support clinical flexibility in this area. Medical guidelines have also developed in line with the evidence-base, to advocate for whole-team approaches encapsulating the physical, emotional and interpersonal needs of women with vulvodynia (Mandal et al., 2010). However, qualitative studies consistently highlight poorer mental health outcomes for women with vulvodynia, which can result in slower recovery and the need for more intensive care and resources (Eppsteiner et al., 2014), perpetuating the burden of disease of vulvodynia. Despite the likely need for mental health management, only a small percentage of women with vulvodynia are referred for psychological support, and engagement in psychological therapy can be difficult due to previous failed attempts to alleviate pain without input (Patsatsi et al., 2012). Once appropriate psychological care is accessed, women can achieve significant improvements in multiple areas such as pain, sexual functioning and psychological wellbeing through the use of Cognitive Behavioural Therapy (Hamilton et al., 2020). Therefore, deleterious mental health outcomes occurring during the management of vulvodynia may in part be related to factors associated with practitioner-patient communication.

1.4 Women's and Practitioners' Experiences of Communicating Regarding Vulvodynia in Healthcare Settings

Women with vulvodynia interact with multiple professionals, due to the need for a multidisciplinary team approach to manage vulvodynia, involving primary care in the form of general practitioners (GPs) and specialist input (Metts, 1999). Specialists may consist of consultant gynaecologists, physiotherapists, pain consultants, psychosexual counsellors, and clinical nurse specialists. Therefore, women with vulvodynia will attend multiple consultations in which communication occurs between them and practitioners. Research suggests that there may be several barriers, for practitioners and for women, to effectively communicating regarding managing vulvodynia; particularly its psychological, interpersonal and emotional impacts.

1.4.1 Barriers and Facilitators for Practitioners. One qualitative study demonstrated that 60% of practitioners agree that issues of sexuality are fundamental to holistic care, yet just 6% initiate frequent discussions on the topic (Haboubi & Lincoln, 2003), potentially due to reluctance to 'probe' for information about sexual wellness (Hintz & Venetis, 2019). Qualitative studies can be limited by small sample sizes and the researchers' interpretation of available data. Dyer & das Nair (2013) conducted a systematic review of ten studies regarding barriers and facilitators for health care professionals (HCPs) in the UK discussing sexuality with patients. The main theme emerging from this data is that sexuality is not routinely discussed by HCPs, due to several types of personal and structural barriers such as fears of causing offence, personal discomfort, fears of opening a 'can of worms', no recent experience discussing sexuality, or assumptions that the patient should raise it as an issue. One positive finding was that communication between practitioners about lack of knowledge or comfort discussing sex is a major facilitator for increasing discussions around sexuality between patients and practitioners. This underscores the value of seeking support from colleagues and specialists for practitioners who find it difficult to talk about sexual issues.

Multidisciplinary team working could also counteract feelings of incompetence and helplessness reported by many clinicians working with women with vulvodynia, particularly those in primary care (Leusink et al., 2018). The majority of GPs, and some gynaecologists, may lack specialist knowledge, skills and expertise in vulvodynia. The effects of this may be heightened by austerity and pressure in healthcare systems necessitating short consultation times, lack of continuity of care, and difficulty establishing a plan that includes follow-up.

In general, practitioners report low levels of efficacy and a lack of confidence in treating genital pain disorders (Abdolrasulnia et al., 2010). By increasing knowledge of targeted issues and seeking support to understand the management of vulvodynia, practitioners may counteract findings from studies that limited understanding of vulvodynia by GPs can lead to failures in “respecting patient legitimacy and dignity” (Hintz & Venetis, 2019, p. 107). A lack of understanding from practitioners can result in disbelief about the source of pain for women with vulvodynia, delegitimising their distress. Furthermore, practitioners feeling incompetent may be more likely to offer psychological ascriptions for vulval pain (Newton et al., 2013), perpetuating the idea that vulvodynia is ‘all in your head’ for many women.

1.4.2 Barriers and Facilitators for Women. It follows that if some practitioners seeing women for vulvodynia diagnosis and management express difficulties discussing genital pain and a lack of expertise, that women are likely to have had negative experiences of communicating about managing vulvodynia. There is evidence from meta-synthesis (Shallcross et al., 2018) to suggest that doctors’ knowledge and negative attitudes can directly worsen distress and the experience of vulvodynia for patients. This may be related to a number of factors including discourse that sex is inevitably painful for women (Kaler, 2006), and the negative experience of interfacing with multiple different practitioners who lack skills and expertise in vulvodynia. This review also only included samples of White, young, ‘educated’ women, and there is evidence to suggest outcomes may be even worse for those from Black Minority Ethnic (BME) backgrounds, older women, and individuals of minority sexuality status (Dyer & das Nair, 2013). Practitioners may be more likely to dismiss these groups if they feel exasperated by attempts to help them, in the absence of understanding their needs based on previous experience (Connor et al., 2008).

Helpfully, studies that consider facilitators of good communication have found that one buffer for lack of skills and expertise is practitioner’s willingness to address the emotional components of vulvodynia and engage in dialogue to try to speak the same ‘pain language’ (Nunns, 2016). Although, there may also be a barrier for women trying to find a way to communicate their experience of pain in a way that is accessible to the listener (Hintz & Venetis, 2019). Therefore, a dialogue needs to be co-created through effective communication. Within this process there is a risk of pain becoming the sole focus of vulvodynia management, due to the influence of women also experiencing reluctance to discuss sexuality due to embarrassment (Leusink et al., 2019). Further, women may be more invested in the physical origin of their vulvodynia if it is associated with increased hope of overcoming it (Hintz, 2019). Therefore, if practitioners lacking expert knowledge attribute pain to psychological causes, this can also result in a lack of confidence in medical care, affecting treatment adherence (Newton et al., 2013) and communication about symptoms.

Moreover, women are faced with overcoming their own and societal stigma in order to discuss complex issues associated with female genital pain. Stigma notoriously impacts on health promotion, treatment and support in a wide range of mental and physical health problems (Smith-Rosenberg, 1972). As outlined earlier in this review, due to continuous under-prioritisation of women’s health issues, it is the responsibility of organisations and individual practitioners to support women to overcome stigma through the use of communication (Monsivais, 2013).

In summary, there is a need for an increase in the frequency and duration of conversations regarding sexuality in medical settings. This applies to vulvodynia, encapsulating a need for discussions about the interaction between pain, and other factors, with psychological wellbeing and emotional outcomes. This is of particular importance considering the interaction between interfacing with the medical system and outcomes for vulvodynia. However, no evidence-based guidelines exist to support practitioners and women with this task.

1.5 The Importance of Communication

Patient-centred care and communication is a key medical skill and should be considered fundamental in supporting women and practitioners co-managing vulvodynia. Person-centred care is an approach to practice underpinned by respecting and valuing people and fostering mutual respect and understanding (McCormack et al., 2010). It encapsulates structural elements of power, responsibility and shared decision-making (Epstein et al., 2005), as well as human factors such as empathy, validation, acknowledgement and legitimising problems (Liu & Picard, 2005).

Shared decision making (SDM) is a process between patients and practitioners in which both are able to discuss concerns and views, beliefs about a condition, and agree a course of action for treatment (Godolphin, 2009). An understanding and affirmation of a patient’s journey regarding a condition is essential to this process (Newton et al., 2013). Studies examining the views of both patients and practitioners in the process of SDM can shed light on key ingredients involved. In a study by

Parsons et al. (2012), SDM counteracted the negative effects of dissonance regarding the need for psychosocial aspects of care between healthcare providers and sufferers of unexplained pain. These included practitioners supporting patients to manage expectations about obtaining causation for pain, resulting in a shift towards symptom management and realistic goal attainment. Overall, SDM is empirically linked to improved cognitive and affective outcomes for patients, although the association between SDM and health outcomes lacks evidence (Shay & Lafata, 2015). Findings from one RCT indicate that although SDM may not directly influence pain or treatment outcomes, it can result in more productive clinical encounters in which patients report feeling understood and practitioners experience less negativity towards patients (Bieber et al., 2006). It may be difficult to expect a mutual understanding to occur between patients and practitioners in vulvodynia management (Hintz & Venetis, 2019), but patient-centred communication and SDM may involve more flexibility in thinking, including the consideration of alternative healthcare options and a joint search for the right type of support. This may lead to better outcomes in the form of treatment adherence, by way of treatment agreement (Joosten et al., 2008).

SDM is intricately linked with good communication skills in medical care, although communication in dyadic practitioner-patient relationships can be difficult to study without introducing observer bias (Spano, 2005), and there is an overreliance on practitioners' views in this area (Ballard-Reisch, 1990). Nonetheless, objective secondary evidence indicates that the majority of medical complaints are related to poor communication (Kidd et al., 2005), and with this comes a recognition that sound clinical knowledge is not sufficient in the absence of communication, due to the knock-on effect on health management (McKenzie, 2002).

Although active engagement from both parties in communication is essential, practitioners are required to be particularly aware of the barriers previously discussed, especially when symptoms are unexplained and contested legitimacy may lead to interactional problems between patients and practitioners (Wileman, May, & Chew-Graham, 2002). There are also important intersections of power in medical consultations and appointments which may influence women’s feelings about disclosure, asking questions, and asserting needs.

One sample of primary practitioners encountering patients with medically unexplained symptoms reported that they felt the balance of power lay with the patient, due to the lack of identifiable medical solutions, which resulted in uncomfortable feelings (Wileman et al., 2002). However, the majority of literature exploring power in medical settings relative to vulvodynia highlights women’s experiences of patronising messages from paternalistic medical systems (Kaler, 2006; Shallcross et al., 2019). There is evidence to suggest that effective communication can stimulate questions from patients, leading to better SDM (Post, Cegala, & Miser, 2002). However, due to imbalances of power, patients may feel intimidated, fearing use of assertiveness and enquiry. Rarely in patient-practitioner interactions will a patient feel empowered to ask the doctor for the evidence for decision-making (Godolphin, 2003), and conversations can risk being punctuated with medical expertise. Reflective practice for practitioners can support the identification of barriers to communication, including personal prejudices and weaknesses in personal and professional development (Mann, Gordon, & MacLeod, 2009). Learnings can also be taken from research in which women with vulvodynia are invited to give constructive feedback, and where practitioners and women collaborate and co-operate to inform best practice (LaRosa, 1994). There have been significant shifts towards patient involvement in services and the availability of information and resources via the internet. Therefore, it is timely to update research on communication between patients and practitioners.

1.5.1 Models of Communication Health communication research and application has received growing interest over the last 10-20 years, such that the topic is integral to the training of medical professionals in the UK (Berry, 2004). Transactional theories of communication form the basis of more recent analyses of the process of communication, and offer evidence that communication is adaptable at any point of an interaction (Beattie & Ellis, 2017). Neuhauser and Kreps (2002) highlight communication as a highly complex process, particularly where the exchange of information related to the impact of a chronic pain condition is concerned, therefore factors such as demographics, educational level, culture, social support and psychosocial adjustment to the presenting problem cannot be ignored.

Specific models of communication were designed to support practitioners to address healthcare needs, including in the field of sexual health practice. For example, the PLISSIT model (Annon, 1976) highlights the importance of the following: Permission (P), Limited Information (LI), Specific Suggestions (SS) and Intensive Therapy (IT) as a graduated intervention for the gentle approach towards communicating about sexual problems. This model was extended to the Ex-PLISSIT model, highlighting the need for explicit permission-giving at all stages of communication, to review interactions with patients and for healthcare professionals to challenge their own assumptions about patient's situations (Taylor & Davis, 2007). These models of sexual communication were designed to address sexual wellbeing in those with chronic illness, although there are few studies evaluating their use in practice, and no studies to determine the use of these models with women with vulvodynia in research or clinical practice.

1.5.2 Guidelines for communication With respect to the development of specific guidelines for vulvodynia, there is a requirement to consider the unique needs of women with vulvodynia, and practitioners attempting to communicate about this issue in the context of the support available. Standard operating procedures for female genital sexual pain exist (Fugl-Meyer et al., 2013) highlighting the comorbidity of such conditions as vulvodynia with psychological distress and sexual problems, and discussing modalities for psychological assessment and treatment. However, in order for women with vulvodynia to access such resources, conversations are required between practitioners and women to elicit these impacts. Similarly, The Vulvodynia Guideline (Haefner et al., 2005) considers expert research in the area of vulvodynia, however bares no reference to communication or shared-decision making, which may present challenges to practitioners attempting to find ways to communicate holistically with patients in order to apply the expert opinion developing in the research. Further, UK National Guidelines on the management of vulval conditions (Mandal et al., 2010) note the importance of psychological support, but do not provide information or guidance to practitioners on how to discuss, assess and support women with these needs. Where general guidelines for discussing sex and sexual problems exist, little widespread application is made in the field of chronic pelvic pain practice. This is evidenced by forums outside of the academic sphere, for example The Second World Congress on Abdominal Pain in 2015 (Crowe et al., 2015), where practitioners and patients came together to highlight the need for better shared understandings of sexual needs and sexuality to inform research, care and treatment. As such, it is imperative to consider how practitioners and women with vulvodynia may influence greater understanding in this area, as well as find methods by which to bring understanding of vulvodynia-specific impacts and issues into clinical discussions and practice.

1.6 Bridging the Gap: Service User Involvement

Service user involvement is increasingly being recognised as a vital component of service development, with the power to influence professional practice (Perry et al., 2013). It is only within the last 20-25 years that service users have been involved in a top-down process of developments towards change as partners (Faulkner & Thomas, 2002). This change was driven by non-profit organisations enabling the voices of users of services, also known as ‘experts by experience’ to be heard within research and the provision of services (Wallcraft, Schrank, & Amering, 2009). However, user involvement can be subject to limitations regarding authenticity, where users of services contributing to policy and research may be unrepresentative, or the process experienced as tokenistic (Contandriopoulos, 2004). As such, the benefits and costs of involving service users in research should be carefully considered, rather than executed dogmatically.

Collaboration and consultation are dominant in service user involvement research (Fisher, 2002), and although active involvement of service users in every stage of research is not yet satisfactory, it is recommended and called for within the Research Governance Framework for Health and Social Care (DoH, 2005). In the context of vulvodynia research and practice, many women have found their personal experiences to be drivers towards activism and commitment to help others (Connor et al., 2008). This can be bourne out of difficult experiences, where women “create a meaning for the illness that promotes a sense of competence and mastery in the context of partial loss” (Rolland 1994, p. 127). This unique by-product of managing vulvodynia can be harnessed towards coproduction (Durose et al., 2017), influencing a bridge in the gap between service user involvement and leadership in women’s sexual health (Byrne, Startford, & Davidson, 2018). Service user involvement and coproduction also provide opportunities for patients and practitioners to co-create a dialogue and produce original publishable resources, grounded in the value of privileging voices of women with vulvodynia within sometimes problematic power relationships.

1.7 Specific Areas of Enquiry

In summary, models of communication and guidelines on discussing sexuality and sex exist in generalist settings, yet women’s experiences of managing vulvodynia with healthcare providers highlight consistent difficulties and barriers to communication on these issues, and issues of psychological wellbeing and any relationship impact. Given that the literature above highlights specific and unique impacts for women with vulvodynia as evidenced by qualitative research and meta-synthesis, there is a need for specific guidelines for practitioners on how to navigate conversations regarding these impacts, in order to validate women's experiences and inform best-practice for supporting and addressing them.

2 Extended Method

2.1 Selection of the Delphi Method

The value of generating consensus is relevant to a range of applied research activities, including creation of policy guidelines, correlating judgments on wide ranging and disputed topics, and determining popular opinion in order to guide future research (Iqbal & Pipon-Young, 2009). Consensus generating methods seek to counteract inherent disadvantages of less-structured approaches such as committees, whereby the views of one individual may be privileged, or results may be influenced by stakeholder coalitions and vested interests (Jones & Hunter, 1995).

The two most highly utilised techniques for driving consensus are The Delphi method and nominal group technique (McMillan, King, & Tully, 2016). These techniques are similar in that they both use structured information gathering processes to generate expert opinion, and ‘rounds’ provide opportunities for all experts, termed ‘panellists’, to rate and comment on items or questions. Both techniques support the premise that it is both possible and valuable to work towards a consensus (Fish & Busby, 2005). Nonetheless, the nominal group technique differs to the Delphi method in that it occurs over the course of a live meeting, whereas the Delphi method can be utilised remotely over the course of a planned process. This has the advantage of allowing participants time to consider answers and equal opportunity to contribute.

The Delphi method was also constructed as a decision-making tool for use in areas where there is insufficient and contradictory information on a topic (Jones & Hunter, 1995). This method has amassed evidence in exposing underlying assumptions and seeking new perspectives among multiple respondents (Rodríguez-Mañas et al. 2013). There is also no clear research evidence that meeting-based methods such as the nominal group technique are theoretically superior to the Delphi method. Although both approaches were considered in approaching this research project, the Delphi method was chosen due to the evidence-base around its use in clinical psychology (Bolger & Wright, 2011), as well as the pragmatic value of its remote use with a smaller panel of participants.

Limited research into practitioner communication about the psychological, emotional and interpersonal impact of managing vulvodynia provides a rationale for correlating judgments on this topic, in a setting which is anonymous and allows for a wider geographical scope, increasing inclusivity (Fletcher & Marchildon, 2014). Further, the Delphi approach is replicable for future research in this or similar topic areas.

2.2 The Delphi Method

Comprising of three rounds, including semi-structured interviews and tailored survey instruments, the Delphi method was used to drive consensus based on agreement at two levels. Agreement is defined as the extent to which panellists agree with the issue under consideration on a categorical scale, as well as the extent to which respondents agree with each other, termed consensus, calculated through measures of average responses (Jones & Hunter, 1995). Qualitative information is also given across surveys to contextualise responses and facilitate structured communication between participants (Brady, 2015).

There is a lack of agreement regarding how much data should be collected within a Delphi study, and how many rounds to conduct (Green et al, 1999), although literature indicates that three to five is the most common number of iterations, due to difficulty driving consensus further over and above this (Custer, Scarcella, & Stewart, 1999; Cyphert & Gant, 1970). Therefore, the study was conducted over three rounds to minimise participant and data fatigue (Thangaratinam & Redman, 2005).

2.3 Group Effects in Delphi Studies

There is mixed evidence regarding the value of interacting groups versus expert opinion from individuals being used in decision-making process research. Studies have found that individual judgment is rarely superior to aggregated opinion through group techniques (Dalkey & Helmer, 1963), and where groups are utilised, anonymity is now considered a key factor to offset influences of group conformity (Gordon, 1994), often associated with dominant opinions of individuals in groups. The Delphi aims to “overcome the undesirable effects of group interaction while retaining the positive aspects of interacting group judgments” (Nelms & Porter, 1985, pg. 46).

It is important to consider group dynamics within consensus generating methodologies, including interactions and influences of the panel in relation to their role within the study. Power imbalances can inherently exist within patient-practitioner dynamics (Quill & Brody, 1996) and between practitioners of different disciplines, which may influence contributions within a face to face meeting forum. The Delphi method in this study was chosen as an anonymous forum to explore statements of position from a whole group on a specific topic area, from both sides of this dynamic. The panel are united by their individual and shared knowledge, which is converged into consensus on the identified issue as a result of the method (Keeney, McKenna, & Hasson, 2011). Nonetheless, practitioners and patients within the study were tasked with co-creating a set of guidelines about communication, which involves high task and social complexity. Task complexity is the dispersion of facts and skills among group members, whereas social complexity relates to the investment in members regarding the outcome (Nelms & Port, 1985). The use of a primary facilitator (the author) for the Delphi method, embedded within a research team, provided opportunities to consider survey content across a range of experiences, responses and investment, in an attempt to counteract potential hidden group effects such as these.

2.3.1 Coproduction in the Delphi method A primary premise of the Delphi technique is that group opinion on a topic with limited existing knowledge or consensus is more valid than individual opinion (Bolger et al., 2020). There is also an overarching aim of generating consensus through the use of the Delphi, although consensus is not always achieved, which can be informative in and of itself. There are risks associated with a heterogenous sample, such as the potential to fail to reach consensus, therefore it was essential to predetermine consensus levels for this study based on previous research. It was considered that a combined panel of women with lived experience of vulvodynia, and practitioners encountering vulvodynia in their practice, would be most representative of the patient-practitioner communicative dyad. This hoped to limit the opportunity of bias entering the data through only exposing practitioners or women with vulvodynia to each other's views without the opportunity for collective dialogue influencing overall consensus.

2.4 The Delphi Expert Panel

A key component of the Delphi method is the selection of panellists based on their expertise in the topic of interest. Sumison (1998) identifies that due to a lack of definition of the notion of an 'expert', the responsibility falls to the researcher to choose the most appropriate experts. Some argue that experts are any individuals with relevant knowledge and experience on a particular topic (Cantrill, Sibbald, & Buetow, 1996), however this definition is contingent on the setting and objectives and aims of the research. As a result, random sampling is not appropriate, and selection of participants is of the utmost importance because it relates to the quality of generated results (Baker, Lovell, & Harris, 2006).

The definition and selection of standards for experts have remained ambiguous, and choosing those knowledgeable on a target issue is not sufficient (Oh, 1974). The researchers decided how to conceptualise and define experts, including any women with a diagnosis of vulvodynia based on being 'experts by experience' (Hardy et al., 2004). Practitioners were experts in their professional field, and an informed decision was made to seek qualified professionals from special interest groups and to solicit experts in the target group of vulvodynia expertise. However, the aims of this research did not completely necessitate practitioner expertise in vulvodynia, as practitioners were required to have managed vulvodynia, and through this will have utilised skills in communication regarding this management. This was based on research that a minority or differing perspective (for example of general practitioners) should be actively sought in recruiting to the panel (Linstone & Turoff, 2002).

A study by Baker et al. (2006) provides a research aid for the conceptualisation of ‘experts’, including considerations of the type of Delphi utilised, sampling, inclusion and exclusion criteria, definitions of knowledge and experience and the featuring of service users within the study. In line with this guidance, the rationale for the inclusion criteria of this research was not to actively select for experts in vulvodynia, or those with excellent communication skills, but individuals who have experience of communicating regarding the management of vulvodynia, at any area of triaging management. Due to the heterogeneous sample, it was considered most appropriate to use a conventional Delphi method (Webler et al., 1991), and snowball sampling provided the opportunity to increase the validity of findings (Mead & Moseley, 2001). It was a deliberate decision not to rely on arbitrary thresholds such as years of experience in a field, as it would be a tenuous conclusion to suggest this is tied to expertise. Further, credibility was increased by the inclusion of patient participants (Walker, 1994). Critically considering these specific characteristics allowed for an informed decision regarding practitioner expertise in particular, for example the inclusion of GPs. Although GPs are not classified as 'experts' in the field of vulvodynia, they are the likely gatekeepers for referrals to specialists in diagnosis and treatment, and therefore involved in communication with women about vulval pain, and in the management of the initial response.

No optimal number of panellists has been decided upon within Delphi research (Delbecq, Van de Ven, & Gustafson, 1975). To recruit a representative pool of participants whilst considering the information processing capabilities of the group and research team, the intended total panel number was set at sixteen experts. This is in line with empirical evidence that a minimum panel size of seven should be sought (Linstone & Turoff, 2011) and that >10 participants should be sought if a group is not homogenous, for example experts are from different disciplines (Ludwig, 1997). In this research, a combination of those most affected by the production of the guidelines, patients and practitioners within core aspects of the management process, were key to the research being driven by its primary stakeholders. Credibility was of consideration in this study due to a higher proportion of physiotherapists representing the practitioner panel (57%). This was mitigated by a wide geographic range from which physiotherapists were recruited, as well as the rest of the panel being considerably heterogeneous.

2.5 Design of Delphi Rounds

It is considered that three iterations of consensus generation are often sufficient in a Delphi study (Custer et al. 1999). Guidance suggests Round One should be used to elicit specific information regarding the content area, often in an open-ended manner. However, recent Delphi research has moved to creating surveys based on available information from current literature on the topic area (Fry & Burr, 2001). This study chose to converge the opinions of women and practitioners in the field of vulvodynia, due to no existent research having attempted this task. As a result, open-ended interviewing with a specific focus on the aims of the research was utilised, in order to prevent researcher bias and compromising the validity of the method. The Delphi method also provides an opportunity to develop knowledge and drive consensus on topics with little extant literature (Martino, 1993). Round One sought to bring together the views of patients and practitioners around the personal and sensitive topic of communicating regarding psychological, emotional and interpersonal aspects of managing a chronic genital pain condition. Due to no research study having attempted to bring together the views of vulvodynia professionals and patients, and existing sparse research pointing towards women feeling isolated, alone and unheard in consultations with professionals (Nguyen, Ecklund et al., 2012), Round One interviews were decidedly the most appropriate method of gathering initial commentary.

2.5.1. Interview Schedule Design Decisions regarding designing the interview schedule for Round One interviews were made based on previous Delphi studies into areas where there was little established literature (Taylor, 2020). Although some Delphi studies choose to develop Round One surveys based on a review of the current literature, it was thought that the creation of new knowledge would be limited by choosing to develop a questionnaire on the topic area in question, where there is little extant literature into communication with this client group. One aim of the study was to bring together the expertise and experiences of women with vulvodynia and practitioners managing vulvodynia to produce practice-based guidelines to address communication regarding the impact of this condition. Due to the current literature failing to address how this may be done, Round One was used to gather this information from panellists themselves. As such, interview questions were discussed as a research team, and made opened ended, general in terms of the area of enquiry (see Appendices J and K) and explorative, centred around examples of difficulties and barriers to communication, and best practice in this area elicited from panellists' experiences.

Literature on the Delphi method lacks guidance and agreed standards of interpreting and analysing results (McPherson, Reese, & Wendler, 2018). In some circumstances, Round One data gathering processes are subject to qualitative content analysis in the structure of Round Two surveys. Due to the emerging nature of the knowledge on this topic, the researchers decided to make explicit all guidelines created by panellists in the first round, with attempts to adhere to participants own language as best as possible, through re-listening to audio recorded interviews. This was in an attempt not to bias the data in its early stages, although it may be argued this can result in the study being less methodologically robust. However, there is limited consensus regarding robustness or adherence to any protocol in Delphi studies, due to high variability across existing Delphi research (Hasson, Keeney, & McKenna, 2000).

2.6 Removing Items Using the Delphi Method

Items were not removed between Round Two and Three surveys, despite some guidelines not meeting the set consensus percentage agreement. Conventional Delphi methods consider the removal of items can be helpful for driving consensus, however these decisions tend to be arbitrary, and there are no existing guidelines from which to base such decisions. Concerns were that opinions on subsequent items could be unnecessarily biased by the removal of data between rounds (Hasson et al., 2000). To counteract this, particular consideration was given to content analysis of qualitative commentary, and the development of merged or combination guidelines for commentary and re-rating for preference. This is supported by research by Murphy et al. (1998) which found that including all information throughout the process supports the accuracy of final results. Further, Delphi research can be criticised for misusing experts, in circumstances where they are asked to fit their knowledge into questions designed by less knowledgeable others, such as those outside of their field or area of expertise. This can result in participant dropout, and can occur in situations in which there is limited opportunity to interact with other panellists (Altschuld & Thomas, 1991). In an attempt to counteract this, opportunities for rewording and incorporating relevant facts into the judgment process were available within Round Three by limiting the removal of items.

2.7 Defining Consensus

Although the Delphi method has been designed to generate consensus, defining consensus is subject to interpretation, and highly variable across Delphi research (Hsu & Sandford, 2007). As a general rule, if a certain percentage of votes falls within a prescribed range it is considered to be consensus (Miller, 2006). However, this is a somewhat arbitrary number and therefore one argument against use of the Delphi is that it overlooks reliability measurement (Dodge & Clark, 1977). However, the Delphi is often applied in situations where no evidence is available, hence the use of an expert panel. These limitations can be overcome by using robust rationale to justify chosen consensus levels, determined a priori based on similar research in the subject area, to reduce bias and ensure systematic consensus generating procedures. The most common consensus level as determined in a systematic review of Delphi studies by Diamond et al. (2014) is 75% agreement. This falls in line with research by Ulschak (1983) recommending that 80% of subject votes fall within two categories at either extremes of a chosen scale. Due to this being the first Delphi study of it’s type, consensus was set based on a study by Bakker et al. (2014) using the Delphi method in sexual rehabilitation research, within which consensus was determined as 70% agreement on either extremes of included Likert scales. In this research, consensus was therefore ≥70% of participant answers falling within the two highest or lowest categories on a Likert scale.

2.8 Quality Criteria

Diamond et al. (2014) conducted a systematic review of 100 Delphi studies to determine quality criteria for this methodology. Table 11 documents the current study against this criteria.

Table 11

Delphi quality criteria (Diamond et al., 2014).

Criteria	This study
Study objective	
Does the Delphi study aim to address consensus?	Yes
Is the objective of the Delphi study to present results (e.g. a list of statements) reflecting the consensus of the group, or does the study aim to merely quantify the level of agreement?	The group were required to determine which guidelines were important and warranted endorsement in the final set
Participants	
How will participants be selected or excluded?	Inclusion criteria: Practitioners working in services in which they contribute to

	the management of vulvodynia. Patients aged 18-65 with a diagnosis of vulvodynia Exclusion criteria: Practitioners self-reporting insufficient experience of working with vulvodynia. Patients with no diagnosis or primary diagnoses of other vulvovaginal diseases
How will the consensus be defined?	≥70% agreement that an item is essential or important
If applicable, what threshold value will be required for the Delphi to be stopped based on the achievement of consensus?	N/A
What criteria will be used to determine when to stop the Delphi in the absence of consensus?	The Delphi will be stopped after three rounds
Delphi process	
Were items dropped?	Yes, occurring after Round Three
What criteria will be used to determine which items to drop?	If there is no consensus regarding the item as essential or important, or consensus that the guideline is harmful or not important
What criteria will be used to determine whether to stop the Delphi process or will the Delphi be run for a specific number of rounds only?	Three rounds were predetermined for the Delphi

2.9 Member Checking

To establish credibility in Delphi studies, ‘member checking’ can be used internally and externally in the overall process (Lincoln & Guba, 1985). This process involves participants reviewing the content and interpretation of final guidelines for accuracy. Delphi studies can be at risk of failing to summarise and present the group response accurately (Linstone & Turoff, 2002), therefore participants were able to distinguish their own response relative to the group response throughout all stages. Member checking was not used within this study, due to concerns that this would be equivocal to providing a further survey round. However, the final guidelines were disseminated to participants, which elicited informal feedback volunteered by panellists. Efforts were made to ensure clinical vignettes were generalised and that any nuanced information was taken out to protect individuals’ anonymity. Participants were specifically asked whether they had concerns that they or anyone they had worked with were identifiable by the clinical vignettes used.

2.10 Ethical Approval

Ethical approval was granted by the University of Nottingham and the East Midlands – Leicester Central National Health Service (NHS) Research Ethics Committee. Informed consent for taking part including audio recording and use of anonymised vignettes was sought from all participants.

3 Extended Results

3.1 Demographics

There was geographical representation from across the UK in terms of patient and practitioner involvement in the research. The majority of participants identified as female, with one patient participant identifying as gender queer, and one male practitioner participant taking part in the study.

3.1.1 Practitioners. The finding that over half of practitioner participants were made up of NHS staff from Nottingham is unsurprising considering active recruitment occurred at a specific NHS site and snowball sampling was encouraged. This group was further homogenous in terms of job title, consisting of 57% physiotherapists. The remainder were consultants in sexual health and a psychosexual therapist. Therefore there was limited diversity and representation in professional roles. Attempts were made to recruit general practitioners (GPs) by advertising the study through the Royal College of General Practitioners, by way of an advert in their Research Opportunities Newsletter. However, no GPs came forward to take part in the research, whereas five physiotherapists showed interest, therefore it was considered that accepting interested participants into the study would be most inclusive,

Practitioner years of experience in their profession ranged from 6-36, and all consulted with patients with vulvodynia within the context of NHS services, with one also working privately. Two participants did not note how many years of their experience was specific to vulvodynia practice, although remaining participants had accumulated 10-25 years of specific experience working with vulvodynia. Furthermore, of the four practitioners who cited the frequency of seeing vulvodynia patients, this ranged from three to seven times per week.

Practitioners were also asked whether they themselves had experience of vulvodynia as a patient or carer, in order to ascertain the context of their experiences. One participant noted specific women’s health issues unrelated to vulvodynia, and another stated that they had experienced female genital pain previously. Both noted that their experiences had influenced their practice and vice versa, in that one was able to approach consultations with practitioners as a patient with their own knowledge, and another noting that their experience of pain had informed their working practice with vulvodynia patients.

3.1.2 Patients. Patients ranged from 22-55 years of age, and there was diversity in terms of the duration of vulval pain in this sample, with a range of 4-22 years. Of note, the earliest date of diagnosis in this sample was in 2015, and all participants had been diagnosed with vulvodynia in the last four years. Patients had come into contact with a wide range of professionals as part of and following diagnosis, and all of those who had a specific diagnosis of provoked vulvodynia had had contact with a mental health professional (psychological therapist, couples counsellor, clinical psychologist or psychosexual counsellor), whereas those with mixed and generalised vulvodynia did not cite contact with psychological therapies practitioners for vulvodynia-related support. The majority of participants mentioned having had contact with the Vulval Pain Society, a vulvodynia charity, as part of the management of their condition.

3.2 Guideline Creation

Round One interviews concluded with the generation of 2-3 guidelines by participants. Interviews were not analysed for themes as this is not in line with the Delphi method. To reduce research bias, the primary researcher did not select items for inclusion in the Round 2 survey. Guidelines were spoken aloud or crafted by participants at the end of Round One interviews, facilitated by the primary researcher. Round One interview data is presented in Table 12 below.

Table 12

Results of round one interviews

Participant No	Patient/ practitioner	Guideline	Quote from interview
1	Patient	Tell patients about the existence of charities and local pain groups such as the Vulval Pain Society, or Vulval Pain Groups. This may be a quicker way for information to be given. They may stop people feeling isolated and have sensible ideas about basic non-intrusive management tactics, and can help patients to start unpicking ideas about being a woman, genitals and sex	1:01:31 My advice would be, tell them that there is a vulval pain society and there may also be local pain groups. They really really can make a difference, they will stop people feeling isolated, they usually have some sensible ideas about, you know, basic non-intrusive management tactics, so they will start helping you to unpick whatever ideas you've got about women, genitals, sex 1:02:03 You might end up seeing like, because um, I don't know if you've ever done any of the vulval pain society things but they do do like, they do whole days or weekends 1:02:27 One of the day long conferences, when you're like, new to having vulvodynia, is going to be so much faster, like, it's intense…everything you need to know in a one day course rather than like, you could be waiting months to see someone

	There is a heteronormative approach to sex in society and touch and intimacy are not the same for everyone. How you define your womanhood and how you define sex have a direct relationship to how distressing you will find vulvodynia. You need to be aware that those concepts are an issue and that it’s helpful to understand your patients perspectives on this e.g. to make an appropriate referral to psychosexual therapy	1:06:45 I mean generally, my experience has been it’s getting better but my experience has been that there’s definitely I would call it a heteronormative approach to sex. To be fair that’s also true in the Vulval Pain groups, but there is an argument about it happening there but there is not necessarily an argument happening about it amongst the professionals. 1:07:33 Basically, in my experience, how you define your womanhood and how you define sex have a really really really direct relationship to how distressing you will find vulvodynia. So you need to be able to assess, you need to at least be aware that those concepts are an issue and that it’s helpful to understand where your vulvodynia person is at with that. Then you can be like does this person need to see a psychosexual therapist 1:10 And then also the idea that like, uh, that touch and intimacy are the same thing, and I’m like, that’s not true for everyone
	Be aware of what you’re competent in, and if not then refer it on. There can be an assumption that unless a woman is having problems working, with poor relationship outcomes and a very poor quality of life, then symptoms are “not that serious”. However, consequences can be severe if you’re not competent in this specific area	1:13:38 For me a guideline about please be aware of what you’re competent in, and if you’re not competent in it, for gods sake refer it on 1:14:23 I think there’s an assumption that like, because it’s vulval pain, and at the end of the day you can manage it with a lot of life stuff, um, and you know like, it doesn’t generally unless it’s very very severe…so like, and I think the assumption is unless it’s having problems working or screwing up your relationship its not really that serious and if there’s bits of it you haven’t attended to then it’s not really that important but actually you know if you’re not competent in it in a particular area and you haven’t picked up on it, actually the consequences can be pretty severe

2	Practitioner	For health professionals to monitor moods beliefs and expectations with patients. Questions around moods may include ‘how does it make you feel?’. It is helpful for patients to understand their ability to cope with day to day mood and stress influences. Recognising how well or not they cope with stress, anxiety and depression can help them prevent a severe negative shift. Such severe shifts can influence their ability to cope with pain. Practitioners may ask ‘what do you think caused it?, what do you think will make it better?’, what do you think is going on down there?’ in order to understand the patient’s beliefs and offer alternative understandings. Ask patients about their expectations with questions such as ‘what kind of treatments are you expecting?, what improvements are you expecting’, to understand and manage expectations	So like moods, how does it make you feel, and you know, I notice that if they say I am angry, from observation they have to lose that anger in order to be able to move forward. I notice that anger will hold them in that pain state and prevent progression, so we work a lot on that 1:09:58 So beliefs are about what do you think caused it, what do you think would make it better, what do you think is going on down there 1:12:11 What kind of treatments they’re expecting, and what improvements they’re expecting, so managing about chasing a cure or about you know to be completely pain free super fast

	Goal setting can be done by all professions as part of the treatment plan, and should be done in detail. If a patient has a specific goal, ask them ‘what does that look like on a day to day?’, ‘how will you achieve your goal?’, ‘what will you do whilst you are there to manage flare ups of pain’? Specific, Measurable, Achievable, Realistic and Time-bound (SMART) goals may be set by different professions depending on the treatment plan	1:05:00 My key things are mood beliefs and expectations, and you mentioned goal setting that’s massive. I do spend a lot of sessions on goal setting, I find that’s almost part of the treatment getting everything started with looking at what we are going to do and how we are going to do it 1:05:45 It has to be done in great detail…what does that look like on a day to day, almost the goals are your treatment plan…how are you going to achieve being able to go to the restaurant with your friend for lunch, we need to practice sitting on the chair everyday and think about what you’re going to eat or drink, some patients have strong feelings that certain foods flare up their vulvodynia so there’s all of those perspectives as well

		A holistic approach can include supportive conversation with patients to think about who is on their "team" in their social network, and who they may be able to confide in. Chronic pain patients may find it helpful to be supported to find ways to get their hobbies back, or a sense of joy or happiness. Use of the "Pain Toolkit" (https://www.paintoolkit.org/) with patients can help to explore themes about anger and acceptance of pain, as well as moving forward	1:16:10 I don't know if you've ever read the Pete Moore toolkit, so I give that to a lot of patients and my successful patients quote that back to me on a regular basis…they take different things…that first bit is about acceptance and that can seem quite harsh…we are saying work out the anger and leave that anger there and move forward type thing. But there's something as well around getting your team, whose going to a be a good supportive team….confiding in them. 1:18:28 The other thing I think is really important for the chronic pain patients is getting their hobbies back…what would bring you joy, what would bring you happiness?
3	Patient	There can be a misconception about vulvodynia being "all in your head". If you are referring a patient to a psychological service, provide clarity about why this is happening e.g. key information may be "this is to help you", that it is not a replacement for existing treatment, and that a condition such as vulvodynia can be hard to come to terms with, therefore psychological support can be helpful	1:14:15 I think there's an issue in general with the women feeling the pain isn't being taken seriously and that happens with vulvodynia and other things like endometriosis. I think the worry for women then is to not be taken seriously and I think there is a misconception about the mental wellbeing side of things, because there's the risk that it is present as "it's all in your head". 1:16:00 Any kind of referral really make it clear why. 1:17:36 Phrasing in terms of "this is to help you". Not fobbing you off to someone else, the way it was presented to me was in the context of I was having other treatment at the same time, it wasn't going to be a replacement. It was more about the fact that, well, it is a condition that can be difficult to come to terms with and psychological support can be really helpful

		When women have been diagnosed with vulvodynia, it can be important to emphasise that pain is a physiological process, which can impact on wellbeing, and that this does not mean it is “in your head”. An explanation regarding how chronic pain works e.g. parasympathetic / sympathetic nervous systems, can support these conversations	1:20:18 The booklet that I had…the first part of it was a general explanation of how chronic pain works, so the actual, sympathetic and parasympathetic nerve and what happens with vulvodynia, the actual process…it is very clearly a physiological process, there isn’t necessarily anything underlying than the nerves themselves but that doesn’t mean there isn’t anything wrong
		To signpost patients to more information, in order for them to understand vulvodynia more generally. Organisations such as the National Vulvodynia Association and the Vulval Pain Society can provide up to date information on local support groups and provide information about seeking support	1:21:53 I think what I found helpful would have been signposted to more information, being able to read things for myself. When I access psychological services I knew exactly why it is that it would benefit me, to understand vulvodynia more generally. Information on NVA, this is where they have up to date information, Vulval Pain Society, local support groups
4	Patient	Have a smile on your face but have empathy. Try to consider the aloneness a patient may be feeling when they have vulvodynia e.g. imagine having unexplained genital pain that is hard to describe to others	1:29:41 I think first of all, have a smile on your face. 1:34:54 I think empathy, I think vulvodynia is very lonely...I think it can make you very very lonely because, it is very hard to describe vulval pain to someone who doesn’t know what it’s like

	Ask specific questions about the mental / emotional impact of vulvodynia. These may be questions such as: “how are your relationships going? How are you coping with your partner? How are you both coping with pain?”	1:31:16 I think we all know the physical side is the pain, is has to be more, if they say how are you feeling today, it’s got to probably be more on the mental side, because the mental side can eat away more than the physical pain 1:31:42 Once you get the diagnosis, physical pain is the same in everything I guess, how are you relationships going How are you coping with your partner. Because I think going to the support group, a lot of them suffer with relationship problems 1:33:09 You feel so lonely, so alone to have a companion of the opposite sex because of this condition and I think that could probably mentally, I think we can all probably cope with the pain, it’s the mental problem of coping without a partner because of the pain
	Help the patient not to feel rushed. It may take more time for the patient to sit down because of pain. Making more time for an appointment will allow for specific questions about the impact of vulvodynia too	1:30:33 You don’t feel rushed, I think with vulvodynia you can’t get away with a five minute appointment…it take times because you’re moving a bit slower, it’s probably more uncomfortable to sit down for a start

5	Patient	Make time and actively listen and be responsive to what is being said in appointments. There is so much variation in symptoms of vulvodynia and the way it effects women, that the specific impact will vary for any given person. Use open questions such as “have you got any other issues that effect this issue”, “how are you coping?”, “how is this affecting you?”. Make attempts to acknowledge that it must be difficult	50:20 Even if they haven’t got the time…to actually say would you like to talk to someone about the wider impact of this condition? I think they’re scared of that question because that’s going to take at least another 20 minutes 51:12 Just somebody saying how is this effecting you, how are you coping? Simple as that. Acknowledging that that must be difficult, how are you coping? 53:15 It’s easy to assume how people are affected by it, and we’re all effected by it so differently
		Ask about the impact on relationships, in order to support women early enough to explore the best options for their relationships. This may involve asking if the women or her partner wishes to talk to someone about the wider impact of this condition, and a referral on for support	54:20 Asking that particular woman, delving and finding out what is going on, what her reality is. Listen to the answers and respond to them 56:13 Catch women early enough to explore the best option for relationships…

6	Practitioner	Explain the vulvodynia diagnosis thoroughly to the patient. This may involve an explanation about the physiology of pain, so that the patient knows why it is happening	53:05 The first thing I think is really important. The professional needs to know why it's happening. They need to take a really thorough subjective history to understand when and why it happened. They need to understand the pathophysiology and communicate that to the patient
		Approach topics sensitively and gain consent for all discussions, examinations and procedures, as well as offer explanations for why they are happening. Pain can cause hypervigilance and anxiety, therefore it is important to be open and transparent about what examinations or treatments may increase or aim to decrease pain, and what the pros and cons are for each intervention	53:50 The other really important thing with this is they need loads of consent. They're obviously in pain and are going to be anxious and hypervigilant. You need lots of, you need to really ask consent for everything you do…would you like me to do this treatment…the pros of me doing this is it might reduce your pain but the cons are it may increase your pain, so I think having a really trustworthy open transparent conversations throughout the whole

	Managing long-term expectations may involve being open and candid about vulvodynia being multifaceted and that additional support may be needed in the form of medical / psychological intervention. Explaining that this is not a quick fix, and it will be ongoing to work through, therefore a whole team approach may be required	54:38 The other thing that's really important is managing the expectations of the condition. And setting realistic SMART goals so, you might not be able to say it's 100 percent/;; better but we are aiming for a 50 percent improvement within six months, whatever you think is realistic…being really open and candid about its multifaceted and they might need additional support in the form of psychology or medical intervention 58:06 They need to approach sensitively 59:05 Asking consent all the way through, explaining all procedures and explaining pros and cons of everything. Because if you get the to go away and do something they might end up with pain. The other one I think is really important is managing long-term expectations, knowing it's not a quick fix and this will be an ongoing thing to work through and it might require an MDT approach

7	Practitioner	Identify treatment goals with patients by finding out how vulvodynia is affecting their life and what their realistic hope is, to target a solution. Establish how best to manage that hope e.g. with physical / pharmacological / psychological/ sexual aspects of treatment. When you have established what the pathways and goals are, you can address the path to get there. Review this at each visit to reinforce to the woman it has been taken seriously	47:38- Treatment goals, identify what the patient's goals are. And have that discussion, you know so, if you find our how it's affecting their life, and what their hope is, what their target solution, and a realistic one…and then it's establishing how best to manage that…cause like I say the physical aspect, the pharmacological aspect and maybe the psychological aspect, and then within that the sexual aspect. Until you know what the goal is, you can't address the path to get there…once you've stablished what those pathways are and the goals you can then review that at each visit… 49:31 It reinforces to the woman that that's been taken seriously
		Give patients permission to discuss relationships and other stressors in life including money, other relationships and health. Revisit questions that have been asked before, especially if you are seeing the same person, as you may get a different answer. This can be supported by seeing a familiar clinician each time	50:43 Give patients permission to talk about it, in any consultation that's what you're doing, you're giving that patient opportunity to discuss things 52:15 Relationships, and other stressors in life…most people have busy lives so there will be stressors they have, money, relationships, health. There's things they may be concerned about but in your quick discussion "is there anything?", most patients reaction is "everything's fine." Revisiting the questions that have been asked before, especially if it's the same person, - you know "we talked about this last time…have you noticed anything"…it's helpful to see a familiar clinician in that sense, rapport has been established then

8	Practitioner	Be aware of and triage layers of management and consider resources e.g. Vulval Pain Society website, where drug therapy is required, whether access to talking based therapy may be helpful, or information about washing practices	42:34 Being aware of the resources, the Vulval Pain website, the triage layers of management with drug therapy is required, clinical psychology…washing practices
		Be careful not to mislabel vulvodynia, treat it as a proper diagnosis	43:53 Not mislabelling it. Try not to feed into false belief. Treat it as a proper diagnosis, to diagnose it clearly
		Know to ask certain questions, a pro forma can help with this. Five things to cover may be: 1) What do you think is wrong? 2) What do you think is going to happen? 3) What do you think would help? 4) What do you feel is the impact on your relationship? 5) How do you think your partner feels about it?	45:59 To know to ask certain questions, what sort of impact is this having on your life…what do you think is wrong? What do you think is going to happen? What do you think would help? Maybe just some questions to ask, one of the things we do, we have these pro formas…actually it is quite..even though it's irritating…it reminds you to ask things…maybe just a series of 5 questions which might then…and then once you've asked the question you can deal with that…you can take it from there 47:25 What do you think is the impact on your relationship and how do you think your partner feels about it?

9	Practitioner	Outcome measures or tools can be really useful to prioritise conversations and improve communication. These may be service specific and measure risk, anxiety and depression (e.g. Generalised Anxiety Disorder (GAD-7) and Patient Health Questionnaire (PHQ-9) questionnaires) chronic pelvic pain, bladder and quality of life (e.g. Female NIH-Chronic Prostatitis Symptom Index – NIH-CPSI), or others. This may support assessment to be more targeted, to spend more time on what is bothering the patient the most, to work out what their needs are, so that they can see the right person to address the most bothersome issue to begin with	46:37 There are outcome measures that can be really useful. So your general anxiety scores. And your PHQ. Those sort of questionnaires have on hand, as well as the more specific ones about chronic pelvic pain [discussed earlier in interview]. If from the outset those outcome measures can be used, you assessment can be more targeted, you can spend a bit more time on the things that are bothering the patients the most. They could either be things that happen in clinic or things that are filled in by the patient before they come to clinic…working out what their needs are first, so that patient is seeing the right person to address their most bothersome issue to begin with 50:17 It is the Female NIH-Chronic Prostatitis, I know females haven't got a prostate, Symptom Index…it is pain, bladder, quality of life
		If possible, it is important to see the same practitioner in the right environment e.g. in a private, well lit room. Patients should be seen on time as much as possible, and the appropriate amount of time given to them	48:18 Needs to be the same practitioner that sees that person repeatedly, in the right kind of environment that isn't a room off a busy corridor, and that, again dream world, that patients are seen on time and have the appropriate amount of time given to them

		Ask the patient, “what bothers you the most?”. What bothers the patient the most may be different to what you expected, and asking this question can ensure treatment is targeted towards that particular issue	52:20 The other issue is the thing that bothers the patient the most. That can be totally different to what you’re thinking. So treatment is targeted at that particular issue
10	Patient	Making people aware that just because they have vulvodynia it doesn’t make them “not normal”, and that it can impact their psychological wellbeing. Many people might not know/realise this early on after diagnosis	42:54 Making people aware that just because they have this condition, it doesn’t make them not normal, and that yes I think obviously, they need to make people aware that it can impact their psychological wellbeing. Many people may not realise that early on
		To provide more information for partners so they can have a better understanding of how vulvodynia is impacting their lives or their partners lives	43:19 Maybe more information for their partners to that they can have a better understanding as well, of how this is impacting their lives of their partners lives
		Exploring different areas to get help i.e. physiotherapy, psychosexual counselling. Further, a combination may be better than one of those options on its own	43:33 Exploring different areas of where you can get help i.e. physiotherapy, psychosexual counselling, or doing all of them together might be better rather than one of those options on its own

11	Patient	Validate someone’s problem as a problem worth time and thought. For example, letting someone know that they may have to live with it, but together you will try to find a way to help them live with it easier, and that as a practitioner you will support them to try everything before ‘giving up’	1:13:32 Validating their problem as a problem worth time and I dunno like, a problem work thinking about I guess! Because there are some things that you have that are wrong with you that you just live with, and I think what you get, what I’ve had from those singular moments with that particular GP what I got from her I that you shouldn’t have to live with this, you may have to live with this, but if we can find a way to help you to live with it easier then that is really important, like we should try everything first before we give up.

	Have an awareness of the psychological impact of a woman repeating their vulvodynia story to a new practitioner each time, and how repeating can also impact on how much time is left to deal with the present issues. For example, if you are inheriting a case, consider prefacing initial contact with a sentiment such as “this may be difficult to talk about again, but it would really help me to know [x, y, z], to know how we can help move forward.” If there are clinical notes, it may also be possible to summarise what you have read e.g. “I can see on the notes that this began from [e.g. difficult or traumatic relationship], we do not need to talk about that today, but we can if you want to”. This may help the narrative of the story whilst giving the patient choice to discuss what is important that day e.g. symptoms	1:18:19 Maybe something around the awareness of the psychological impact of repeating the story to a new practitioner each time, and that if they are inheriting the case…to just, even if it’s just, and I get that they probably need to hear it for themselves but, to preface with.. “I’m aware that you’ve told a colleague and this might be difficult to talk about again, but it would really help me to know [x,y,z]”. It helps it just feel like, yeah 1:19:39 Part of me is like, why did I have to go over it again if it’s on the notes. Can they say “I can see on the notes that this began from a difficult and traumatic relationship, we don’t need to talk about that today but we can if you want to”. So it’s like, I’m a bit on the story, I can see some of it. Going over the whole narrative is exhausting and sometimes means you don’t have time to talk about what is happening in the present

		Signpost to other places that a patient can find support. This may include recommending a helpful book or website. For a patient this may help them feel like they can help themselves a bit, if there is somewhere they can go	1:22:24- I wanted to say signposting to other places you can find support, or even like recommending a book, or like something else. I've never had that and I think it can be, it can just help you feel like you can help yourself a bit. I mean, a GP did tell me about the Vulval Pain Society, but it feels to me more like research. There are a couple of support groups but there isn't one in my area…making people feel like…it makes you feel like you're not alone and there are things that can be done, I think that's the thing
12	Patient	Be aware that vulval pain is complex and multifaced and it combines the physical and the mental, and has various different routes and potential treatments. Check in through the process, schedule a phone call (e.g. 10 minutes) after someone has gone down one of the referral routes such as psychosexual therapy, in order to steward the person	47:06 Maybe rather than framing it as a negative…vulval pain is complex and multifaceted, it combines the physical and the mental, and has various different routes and potential cures that can help… 48:10 Checking in through the process is so important, it's so easy to get demoralised, having like a phone call scheduled in, like a ten minute phone call after someone has gone down the routes e.g. if someone says lets try psychosexual therapy, then have a call to see if you want to continue…having a kind of like, really stewarding the person..[laughs] I'm sure there's no resource for that

	Take women seriously when they come to you about vulvodynia. That doesn’t necessarily mean ‘be serious’. Having a human face alongside your professional one means being open to hearing people’s story and accepting that people’s stories are different. This includes believing what people say	49:59 Take women seriously when they come to you about vulvodynia. That doesn’t necessarily mean be serious [laughs]. You can take someone seriously while still being, having that human face alongside your professional one… 50:40 Being open to hearing people’s story and sort of, accepting that people’s stories are kind of different, believing what people say a lot of the time we don’t really feel believed and heard
	If you don’t know the answer, don’t overprescribe and signpost without knowing. It is better to wait and call the person back once you know more. Make the journey shorter by trying to figure things out, so that the person you refer them onto can really help them. This may include using a range of resources that are available to understand vulval pain e.g. organisations/specialists private/NHS, and giving them to patients to reach out to	51:40 If you don’t know the answer, don’t overprescribe and don’t like, signpost without knowing. If that makes sense. Like, it’s better to wait and say I’ll call you back once I know more, rather than just send you to someone else who may send you to someone else. Make the journey shorter by trying to figure things out. When someone comes to you, try to be the last person that person sees, or at least the second last person. Make sure the person you refer them is the person that can really help them 54:12 I think I just had another thought just at the end, but I can’t remember what it was… 55:05 I just remembered it! So I think um, just to build on the third one. To be, to think about the range of resources that are available to them to help them understand vulval pain, thinking about the organisations they can reach out to, and the specialists they can reach out to both private and NHS, there are so many people out there screaming about this, once you find them you just keep finding them

13	Practitioner	Sexual wellbeing and relationships have such a huge impact on general wellbeing and relationships. Practitioners should be aware of their unease in talking about sex and find ways to address it as a professional responsibility to become more comfortable. This could include identifying this as an area of training and may involve spending time in the GU clinic or with gynaecologists	30:00 Your sexual wellbeing has such a huge impact on your wellbeing. What is going on in your sexual relationship can have such a huge impact on what is going on in your general wellbeing. Part of this reason why this may be difficult is because we are not just talking about pain, we are talking about sexual pain 32:02 I think its about the practitioner being away of this unease or disease in talking about sex. I think that's the key thing there. And there are some people who are very comfortable and some people who are not so it's about recognising where you are in that and addressing it. We have a professional responsibility to address it we owe it to our clients and patients to become more comfortable. Identifying it as n area of training or going and spending time in GU clinic or with gynaecologists
		In communication, it is helpful to be aware that asking a question is permission giving, and that by asking something you are giving a client permission to talk about it	33:55 Asking the question gives the client permission to talk about it
		Explicitly ask a woman or couple "what is the impact of 'the pain' in your life?", and "what effect does that pain have in your life?"	35:35 It's about the impact. What's the impact of the pain? So, you might ask the question might be so a woman might come and say sex is painful, and so the practitioner might then go down the well where is the pain, what type of pain is it, which are all valid questions, but you know another really important question is what is the impact of that pain, where do you notice that pain, what effect does that pain have in your life?

14	Practitioner	The first appointment is really important for building up a relationship with a patient. You are likely to be fact finding and being empathetic when needed. After asking all questions to gather information, reflect back what you have heard e.g. “I am going to try and summarise...”, “My impression is...”. Try to put into a nutshell what the patient has told you, so that they know you have really heard their story	51:12 I think your first appointment is really important for building up a relationship with that patient, um where you’re fact finding but you’re also being hugely empathetic when you need to be empathetic. Um, the other skill that I tend to use after I’ve asked all my questions is I reflect back what I’ve heard, so I will say like my impression, I’m going to try and summarise,, because they’re obviously quite convoluted topics, so your problem started here an this is what your experiencing…and really just reflect back what I’ve heard but try and put it into a nutshell so that patient knows you’ve really heard their story, so I always do that…

	Try to explain chronic pain mechanisms in relation to vulvodynia, using information heard from the patient’s own examples and problems. This includes showing them how the physiology of the limbic nervous system impacts on their pain, and providing user friendly techniques like mindfulness, breathing exercises and stretches, including how they can redress the balance of the parasympathetic and sympathetic nervous system. Metaphors may be helpful e.g. a “volume button” to show anything pain impacts on (e.g. sex and relationships, mood, how patient feels about themselves, taking medication, holidays or increased personal time), will probably turn the pain volume up. Conversations about stress and anxiety are important here because they are a big exacerbator of pain	53:59 Try to explain chronic pain mechanisms in relation to vulvodynia, or in relation to that patients own problems. Showing them how the physiology of the limbic nervous system impacts on their pain. And then, um, using um, giving them user friendly sort of techniques like mindfulness, breathing exercises, stretches etc, showing them how they fit into the physiology to help um redress the balance of the sympathetic and parasympathetic nervous system. 55:07 I think the whole volume button bit in there as well is really important, it’s showing them how anything the pain impacts on, so often with these patients its sex and relationships, how they feel about themselves, it’s lots of mood, often taking medications, what else, sometimes holidays they don’t want to go away because it’s more personal time…will probably turn the pain volume up and they need to address their thoughts on those…and this is where you can bring in how stress and anxiety is one of the big exacerbators of pain

	It is important to empower the patient to feel confident to communicate with their partner about how pain physiology impacts on vulvodynia	57:01 The other real big thing is about trying to empower the woman to be able to go back and talk to their partners, to open up that whole conversation level with their partners again. I always draw out the pain cycle for them so they can take it home to show their other half and try and explain it…

3.3 Feedback on Guidelines

3.3.1 Structure and Organisation. General Round Two comments were received by three participants. Two participants made suggestions regarding the structure and organisation of the guidelines, suggesting that they be grouped into stages of consultation (see Figure 3).

Figure 3

Suggestions regarding structure and organisation of guidelines

Suggestion 1	*Suggestion 2*
1. Good clinical practice 2. Unpacking symptoms and impact 3. Explanation of mechanisms + plan of actions 4. Future plan – recognition of onward referral	1. Initial consultation 2. Follow-up appointment 3. Long-term treatment

Participants were given the opportunity in the Round Three survey to comment on whether they felt the guidelines should be organised in either or both of the following ways suggested by the panel, or to provide other commentary on their grouping. One participant also stated that they felt two sets of guidelines should be created, one for primary clinicians and another for specialists. Within Round Three guidelines, the researchers provided a response in the form of a comment, stating that the acknowledged intention of the research is to develop guidelines for all clinicians in the management process. Within this was a recognition that specific guidelines may refer to multidisciplinary practice and/or individual disciplines as appropriate.

Based on comments to the Round Two survey, seven guidelines were amended according to feedback and participants were given the opportunity to rate and comment on the amended versions. Eight guidelines had minor wording amendments, and suggestions for combined guidelines were given for three guidelines, where re-rating of the original guideline was offered if the panel did not agree with the combination guideline. Four guidelines were presented as similar or linked to other guidelines, and participants provided commentary or suggestions to combine or merge two guidelines, and two suggested combination guidelines were offered for ratings and commentary. Finally, a question on whether one guideline could replace another guideline was given.

In Round Three, five participants voted on the structure and organisation of the guidelines proposed by the panel in Round Two. Two participants voted for Suggestion 1, two participants voted for a combined approach (Suggestion 1 and 2), and one participant suggested several categories and matched their chosen guidelines to each category. Guidelines were therefore structured according to good clinical practice; initial consultation including understanding symptoms and impact; follow-up; and future planning and longer-term care.

3.3.2 General Comments. In Round Two, general comments were provided by three participants. One was of the opinion that the guidelines were heavily influenced by a participant pool of individuals with protracted time to diagnosis, and higher duration and severity of vulvodynia, which included a high proportion of negative communicative experiences with professionals. This was addressed by way of a comment in the Round Three guidelines stating that consideration regarding the influence of participant experiences on guidelines will be considered in the introduction to the finalised guidelines. A statement was added to the finalised guidelines to note that consideration should be given to the influence of the guidelines based on experiences of the panel, influencing their contents in line with participant context and experiences.

A further general comment was offered that comprehensive statements could be added as an appendix to the guideline, in order to explain more detailed clinical guidelines. A response was provided in the Round Three survey that the function of the clinical vignettes in the finalised guidelines is to support the contextualisation of guidelines in real world examples.

Another general comment received was that many of the guidelines are similar, which was also incorporated throughout the feedback in comments on specific guidelines. It was noted by the researchers that the process of generating consensus between panel members hopes to filter out guidelines which feel repetitive or inappropriate, through the process of rating and commenting, and privilege more helpful guidelines. Attention was also drawn to the fact that similar guidelines have been placed next to one another in the guidelines, and that the Round Three survey provides opportunities to vote and comment on similar guidelines.

3.3.3 Specific Comments. Specific comments on each guideline fell into themes, depicted in Table 13, with accompanying examples from Round One. Comments about wording included suggestions for rewording, for example where terminology was confusing, vague, or deemed inappropriate, and seeking clarification on wording through the use of specific questions. There were also comments regarding the inclusivity of wording e.g. ensuring assumptions were not made regarding participant gender or relationship status. Specificity related to comments regarding guidelines being too specific or general. Some participants felt that additions would endorse guidelines further, whereas others suggested removal of words or concepts in order to reduce the cognitive load of reading the guideline. Applicability related to comments regarding concerns about the use of guidelines in the context of time constraints, funding and resources.

Table 13

Examples of Qualitative Commentary from Round One Survey

Feedback theme	**Example**
Wording	Don't use the term 'down there'. I would use professional language.. 'your vulva / vagina'
Specificity	This is about competency + getting it right first time. I assume this refers to GPs. It is important however does not just relate to vulvodynia
Supportive of the guideline	This is useful. Let's get info right for patient's first
Unsupportive or uncertain of the guideline	Why on earth would parasympathetic/sympathetic be relevant to chronic pain?
Additions to the guideline	Also important to emphasise that the treatment goals do not necessarily lead to a cure.
Similarity and merging	Links with guideline 5 don't need both
Applicability	My only concern would be, within the current system, that some doctors might forget to call back, or there might be lengthy delays in waiting for more information

In Round Three, the majority of comments were regarding whether panellists agreed with the new wording or amendments made to guidelines. Wording commentary in Round Three was more positive and in support of guidelines rather than asking for re-wording of the guidelines. Some suggestions were made to shorten or re-word some parts of guidelines. There were also several comments regarding how some guidelines should be standard or good practice for practitioners. Guidelines identified as good clinical practice were also those rated as important or essential, and achieved consensus.

3.3.4 Consensus. Participants in Round Three re-rated original and new combined or amended guidelines (see Appendix N). The panel evidenced that they responded to new information by commenting on preference of re-wording of guidelines, and by replying to participant commentary in the Round Two survey. The panel engaged well in the process by virtue of the amount of comments provided, with participants offering comments on the majority of guidelines throughout Round Three.

3.3.5 Feedback on Finalised Guidelines. Participants commented that they found the guidelines to be a helpful resource overall, and responses to the finalised guidelines were to express positive overall messages about them. One participant noted that they were able to identify themselves through a clinical vignette, but that they did not think this made them identifiable to others, and that they found seeing their example in the guidelines empowering. One participant provided clarification on where she had sought shadowing opportunities to improve her clinical practice.

3.3.6 Evaluating the Guidelines. In order to begin to evaluate the finalised guidelines, they were sent to a local consultant gynaecologist specialising in vulvodynia management, with a request for general commentary and feedback on their applicability for use in practice. Dr David Nunns provided specific commentary on wording within the first four pages of the guidelines, and comments about specificity and applicability (see Appendix O).[40] Due to the wording of guidelines being structured and voted on by the panel, specific changes were not made to the wording in the finalised guidelines document. Dr Nunns noted that most gynaecologists may not be aware of the terms “heteronormative and cisnormative”, therefore a glossary was added to the finalised guidelines. Furthermore, Dr Nunns suggested including the British Society for the Study of Vulval Disease (BSSVD) guidelines on vulvodynia management, as well as a reference list. In response to this feedback, some key readings on the experiences of women and practitioners in managing communication regarding vulvodynia, and the BSSVD guidelines, were included in the final set, under ‘further reading’.

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[40] Consent was obtained from Dr David Nunns for his name and feedback to be included in the extended paper of this thesis

4 Extended Discussion

4.1 Further Exploration of Themes

4.1.1 Good Clinical Practice Points. The process of this research highlighted tensions around how best practice in communicating about managing vulvodynia should be represented within the guidelines. Some members of the panel considered that best practice should be a prerequisite of all clinical care and need not be reiterated to practitioners. However, patient participants highlighted a need for aspects of good clinical care to be underscored in written form, based on their experiences. This may demonstrate a disparity between the experiences of practitioners and patients in terms of considerations of what is important. The need for these basic tenets of communication to be highlighted may echo the requirement for acknowledgement of basic good practice skills. This conflict was highlighted with many participants rating guidelines as essential, whilst simultaneously commenting that they were general principles of good practice. Best practice in this research related to shared decision making, and human factors such as empathy, active listening and information gathering by way of asking open questions to elicit information in a non-threatening or non-intrusive way.

Eppsteiner et al. (2014) noted the critical need for a good working relationship with patients with vulvodynia, facilitated by explaining diagnosis and realistic treatment goals. This links to good clinical practice in the context of shared decision making (SDM), whereby patients are given choice about how information is acted on, and how treatment aligns to their preferences. However, there is no guidance in existing literature on how to navigate conversations regarding the impact of vulvodynia on wellbeing. This may mean clinicians rely on psychosomatic explanations for pain, resulting in women feeling that their problems have not been listened to (Cantin-Drouin, Damant, & Turcotte, 2008). This could explain why a large amount of qualitative literature highlights women with vulvodynia experiencing medical professionals as dismissive of their overall difficulties, resulting in them trying to find solutions to their pain and the impacts of this on their own (Goldstein et al., 2016). These findings underscore the need for clinical vignettes to isolate the specific experiences of women with vulvodynia. Although experiences are wide-ranging and varied, the guidelines offer an opportunity to prompt and guide practitioners, embedding experiences within a context which can be used in practice.

4.1.2 Structural and Organizational Contexts. Many practitioners and women reported within their comments that the current set-up of systems within NHS services does not always allow for women with vulvodynia to access time, space and the right environment to discuss the impact of managing their condition. Research has highlighted the impact of financial austerity on practitioners and patients alike, with patient-centred care, including patient choice, suffering as a result of immense pressure on primary care services to function in the presence of cuts to general practice budgets (Malin, 2020). Furthermore, practitioners experiencing increased demands may not be in a position to devote sufficient time to patients with complex needs, which may result in a lack of perceived empathy, and frustration on the part of practitioner (Byth, 1998). Practitioner participants' views on the importance of guidelines that tap into the need for structural consistency and endorsement of the more practical aspects of patient care may be influenced by the particular stance their profession takes on the cause and solutions of problems. Although all practitioners will be working within an evidence-based practice framework, the majority of the practitioner sample was made up of physiotherapists, who are likely to have extensive experience of working with biological problems that cannot always be seen. This may make room for a more in-depth assessment of biopsychosocial factors influencing pain (Nicholls & Gibson, 2010), as was reported by the physiotherapists in the panel. As a result, the importance of allowing sufficient time may have been privileged in the guidelines, over and above the reality of some professions, for example GPs, being able to apply this in practice.

4.1.3 Attrition. The majority of participants responded to the Round Two survey (*n* = 13) and over half of participants responded to the Round Three survey (*n* = 8). In line with recommendations regarding the Delphi methodology, efforts were made to engage participants by way of personalised e-mails and by allowing sufficient time for the panel to return survey responses (six weeks in total). Non-response bias was not considered to be high despite the low response rate between the surveys, due to Round Three respondents being made up of four practitioners and four patients, evenly representing both participant pools. The aim of conducting two surveys was to reduce demand on participants and the likelihood of attrition (Rayens & Hahn, 2000). However, a number of participants did not respond to the Round Three survey. One participant commented on the lengthy nature of the Round Three survey, therefore attrition may have been reduced by removing some guidelines down rated by the panel between the Round Two and Three survey. However, it was considered important to offer participants opportunities to rate the guidelines they felt were most representative, and not to bias results between rounds as a research team by removing guidelines if they did not reach consensus. By anticipating participants' time, effort and engagement required, the research team attempted to counteract the effects of attrition. Although a participant noted the resource-intensive nature of the guidelines, they were able to contribute to re-rating all guidelines in the survey to contribute towards consensus.

One positive factor in reducing attrition can be meeting the research team (Hasson et al., 2000). However, this recommendation does not account for attrition in this study, as of the two participants the researcher met face to face, one responded to the Round Three survey and one did not. The ability to complete rounds by electronic mail is likely to have made the Delphi process easier for some participants, reducing attrition to a degree. The personal relationship between the panel and the researcher may also be of value in explaining attrition, including through commitment to the broader enquiry and a desire to develop the guidelines in line with the methodology (Toronto, 2017). Participants who responded to the Round Three survey engaged well with the process, offering in-depth commentary and ratings of guidelines, suggesting motivation and engagement with the entire methodology. Furthermore, many participants who did not take part in the Round Three survey provided positive comments on the finalised guidelines, citing them as helpful and accessible as a resource.

4.1.4 Demographic variables There are key participant variables that will have led to a greater appreciation of the representativeness and diversity of the sample. Information was collected on gender identity, age, location, and lived experience of vulvodynia in both women and practitioners where relevant. However, the omission of variables such as ethnicity and sexuality is a limitation of the study which means valuable inferences and reflections may have been overlooked in the analysis.

Where sexuality is concerned, there is a sparsity of research examining the experiences of those from LGBTQIA+ communities within vulvodynia literature. The utilization of healthcare services by those in the LGBTQIA+ community are adversely affected by marginalisation and stigma (Bjorkman & Malterud, 2009). Barriers may include fear of disclosing sexual orientation due to stigma, and lack of specific healthcare professional knowledge around the specific needs of non-heterosexual patients (Krehely, 2009). These factors are likely to worsen the impact of vulvodynia over and above those existing for the general population, and future research should consider how to incorporate the views of marginalised groups into healthcare policy, to create safe spaces for communication (Quinn et al., 2015).

Ethnicity can be a significant barrier to accessing healthcare, particularly in the field of sexual and genital health, where emotional distress and fear of pain have been found to be significant barriers to seeking help for pelvic pain for racial/ethnic minority groups (Hoyo et al., 2005). There is currently no evidence from UK studies regarding ethnic disparities in seeking help regarding vulvodynia, despite much of the literature recommending such studies (Byrd et al., 2007). As such, this study would have been greatly improved by actively seeking out more diverse participant samples as has been recommended in vulvodynia research since its commencement.

It could be considered that those recruited into the study via the methods used were those most able to access the research due to being English-speaking individuals with a certain level of communicative ability to put themselves forward for involvement. By failing to capture the individual differences in the sample as well as the similarities, there are risks of not drawing attention to the ongoing need for critical thinking about how to engage hard-to-reach groups in research and clinical practice. This limits opportunities to consider how to change the status quo of overrepresentation of well-educated, white, English-speaking heterosexual women in vulvodynia research.

4.2 Implications for Clinical Practice

4.2.2 A User-Led Resource. Literature on this research topic area has consistently highlighted the experiences of women with vulvodynia as consisting of struggles communicating with practitioners regarding wellbeing. This was influenced by barriers faced by women and practitioners alike in having helpful conversations. The focus on the area of communication in medically unexplained symptoms is continually expanding (den Boeft et al., 2017), and more research is required to make an evidence-based case for the need for medical practitioners to better understand some of the struggles women may have had or are having in getting their communication needs met related to vulvodynia. Identifying specific needs can then support good practice and identify gaps in current practice. This research goes one step beyond qualitative accounts and correlational studies into the relationship between vulvodynia and various problems with psychological wellbeing, to provide an accessible resource for practitioners to navigate communication with this population.

4.2.3 Underscoring Communication. This research takes a specific focus on communication between patients and practitioners. It is only in recent years that publications regarding vulvodynia have begun to underscore the value of considering communication, including how it can influence and be influenced by concepts of power, resistance and reflexivity (Hintz, 2019). The few papers that explicitly focus on communication are from the perspective of women with vulvodynia. Communication in patient-practitioner interactions commonly takes the form of a dyad, in which communication is expected to be bidirectional in some way. However, Hintz and Scott (2020) highlight the burden on patients with vulvodynia to communicate in a way that enables a clearer understanding of their problems in the absence of an identifiable cause for their pain. In response to women's voices in existing research, this research project and its output places the focus on practitioners as the agents of change, in order to improve experiences for women by considering and adapting communication. Through submission for publication in a peer-reviewed journal, there is an expectation that this study will contribute to the field of communication in vulvodynia, and influence practitioners and researchers to consider the value of applying theory to practice in communication.

4.3 Future Research.

The combined patient and participant panel has created opportunities for user-led research, adding validity and credibility to women's accounts, and identifying areas for change and development. In this way, the views of practitioners and women have been privileged with equal intent, allowing those reading the guidelines and vignettes to consider how women and practitioners may feel and respond in certain situations and what could be beneficial. Without testing of the guidelines in practice, there is little way to measure their ability to support communication in patient-practitioner interactions. Gathering practitioner and patient views on the helpfulness of the finalised guidelines, particularly those not represented in the participant pool (such as GPs) may support an analysis of their potential effectiveness. Furthermore, opportunities for practitioners to pilot the guidelines with women with vulvodynia will shed light on their usability in clinical practice.

4.4 Implementation Plan

Implementation science considers the principles likely to enhance the use of clinical guidelines in practice as well as barriers and facilitators to adoption of new or different ways of working (Bauer et al., 2015).

The following implementation plan (Table 14) was produced to ensure translation of research to practice is developed and actioned. This plan was in line with a published content analysis (Beauchemin et al., 2019) which produced a framework for iterative guideline implementation in healthcare settings.

Table 14 Implementation plan

Attribute of guideline implementation	Definition	Application in this research
Current practice and policy	Determining common practices, published evidence, standard procedures	Literature review and initial Round 1 interviews with all participants
New evidence/innovation	Innovation which supports best practice or demonstrates efficiency of alternative practices	Creation of final guideline document through Delphi rounds two and three

Introduction of new practice or new evidence	Assessment of integration of guidelines into practice in healthcare setting Includes institutional assessment, individual clinician assessment, patient involvement in new practice	Future publishing of guidelines as agreed in collaboration with Vulval Pain Society and host university of the research (see Appendix R). Future review by recruitment site genitourinary medicine clinic to consider application in practice (Appendix R).
Practice change	Active implementation phase	To be determined through future implementation projects
Reassessment and evaluation plan	Follow-up of effectiveness	To be determined through future implementation projects Guidelines would not be automatically altered, as they are consensus guidelines co-produced through specific methodology. If limitations to their applicability were identified, it may be important to update the guidelines to reflect this

The overarching goal of clinical guidelines is to produce and disseminate up-to-date, high quality evidence-based recommendations to improve patient care (Watkins et al., 2015). However, there is evidence that published guidelines translate into changes in practice in limited numbers of cases (Rauh et al., 2018). As such, considering principles of implementation science and strategies to bridge the theory-practice gap are essential to enhance the adoption of guidelines in clinical practice.

The current research output contributes to incorporating current practice and policy to produce new evidence in the form of the guidelines. Subsequent steps include the introduction of the guidelines to a specific targeted service and vulval pain charity, to allow for practice change and evaluation to be iteratively considered. Future research may allow for an examination of the active implementation phase and follow-up of the effectiveness of the guidelines for meeting their aims.

There is variance within and between studies on implementation strategies. Several authors have described mapping processes for implementing guidelines which incorporate broadly similar themes around assessment, objectives and integration of theory, practical strategies and adoption and evaluation of the guidelines in settings (Fischer et al., 2016). There is need for further research regarding effectiveness of guideline implementation strategies and often studies in this field are heterogenous (Bekkering et al., 2005).

Implementation of guidelines should also proactively consider potential barriers and facilitators to their implementation. Guidelines are directed towards reducing harmful or unsuitable variability in practice (Gunderson, 2000) and provide a valuable tool in areas where scientific evidence is limited, as is the case for communication regarding managing vulvodynia. There is evidence that patient involvement increases focus on patient-relevant outcomes (Rauh et al., 2018), and so involvement from patients in the production of the guidelines may offset some initial barriers in the form of relevance.

A systematic review identified three main barriers to adoption of guidelines by practitioners in the form of physician knowledge or awareness and familiarity, attitudes pertaining to motivation and agreement with the content, and external barriers such as the environment within which their work is situated (Cabana et al., 1999). Knowledge and awareness may be increased through dissemination and education, including through publishing the guidelines via the Vulval Pain Society website to provide a reputable endorsement and increase awareness. The plausibility of the guidelines was considered by participants; however, it may be that audit and feedback in initial pilot areas will provide further information regarding how they are received by professions, including those not included in the study such as GPs. This may be aided by a short and user-friendly version of the guidelines in the form of a leaflet. In terms of environmental implantation, consideration will need to be given to how the guidelines fit with existing protocols on a service or organisational level. There will be feedback from the NHS recruitment site used in this research, and one component that may foster implementation is the use of a multi-professional sample to create the guidelines. However, because some disciplines were not represented, there may be some environments where implementation and generalisability may be a barrier to be considered.

One suggestion to overcome generalisability concerns may be to disseminate the guidelines to different practitioner groups in the form of written materials, presentations, and interactive conferences, such as small group training sessions or through outreach visits. Further, someone who has used the guidelines in practice, such as an opinion leader, may be consulted upon to support this process.

5 Critical Reflections

5.1 Epistemological Position

There is a requirement for those involved in healthcare professions and research to make explicit their value judgments, particularly considering that all empirical evidence requires a certain degree of interpretation. Therefore, in order to conduct this research, a consideration of my ontological commitment is warranted.

This research focuses on the experiences of those closely involved in the management of vulvodynia, through living with the condition as patients and managing it as practitioners. A critical realist stance (Bhaskar, 1975) has therefore informed thinking that experiences cannot be separated from the contexts in which they have developed. Critical realism can be difficult to define, as it is considered a post-positivist position, bridging ideas of positivism and interpretivism, to acknowledge the existence of objective realities through an interpretative lens (Dean, 2006). Archer et al. (2016) outline the principles of critical realism, which include acceptance that knowledge is relative to what one is and what one does, and that what we consider as true facts can be subjectively perceived. In this research, the practicality of this epistemological position offers the opportunity for debate over how life is and should be, which is inherent in the back-and-forth debate offered by way of the Delphi methodology, including the integration of practitioner and patient values to inform the synthesis and generation of knowledge.

The Delphi method is heterogenous in nature and straddles the divide between qualitative and quantitative research and interpretation. As such, it is not tied to a particular epistemological position, which may be considered a limitation by way of a lack of specificity. There is ongoing debate regarding the type of knowledge that the Delphi method attempts to seek and construct (Keeney et al., 2010). Because of a lack of specificity, critical realism is not linked to a specific procedure for conducting research in clinical psychology or social science. However, due to the flexibility of the Delph method, it is possible to apply it critically and flexibly, with the assumption that knowledge in a particular field may still be advanced even with a recognition of knowledge as fragile and open to interpretation. Therefore, critical realism can be criticised for its existence as a meta-theory (Scott, 2005), but this also makes room for interpretation of its application in practice.

As applied to service user involvement in research and the co-production of guidelines, critical realism offers an alternative to understanding the perspectives of those most invested in vulvodynia outcomes. The writings of Foucault (1972) inform this stance, in that discourses are seen as comprising of both power and knowledge. Professional language may exclude individuals who have not been exposed to this language, meaning those most in need of changes to policy and practice may be rendered institutionally powerless. As seen in this study and in vulvodynia research, service users have been required to learn the language of dominant discourses in order to approach involvement and effect change. Critical realism provides a stance that recognises services users may and can establish a position of power outside of the dominant discourses of archetypal power and control in existing UK healthcare systems (Stickley, 2006). This research attempts to provide those opportunities, through transparent sharing of experiences and interpretations by way of the methodology, and opportunities to co-construct causal change through a critical realist lens.

5.2 Challenges and Decisions

5.2.1. Holding a Dual Identity Within the Research*.* Considering choices, options, and decision-making processes for this research, and utilising supervision from a research team, has been vital for formulating thinking about how my holding a dual identity as a researcher and a woman with vulvodynia may influence these processes, and ultimately the generation of new knowledge.

In the initial stages of developing a research question, I was drawn to the topic of communicating about the psychological impact of vulvodynia for women. I myself have had experiences of communicating with practitioners regarding managing vulvodynia which reflect examples of good and bad practice. Because of this, I also identify with many experiences of women within the literature, of feeling dismissed, frustrated and isolated (Shallcross et al., 2018). However, the literature that I have most identified with is that which highlights a sense of empowerment for women who do not feel that their vulvodynia care journey has been adequate, and as a result have become vocal activists about challenges and hopes for change (Imber-Black, 2008).

At the design stage of the research, I had not considered that my driving motivator for conducting this research was in part a personal one, but rather felt compelled to explore a topic which I felt knowledgeable around and took a professional interest in. I now consider that unconscious driving forces for conducting this specific research may have been hopes for reparation of my own experiences, and for providing an opportunity for change for those who may be at risk of having similar experiences to myself. I was required to confront my thoughts and feelings regarding myself as a researcher and patient when a Consultant Gynaecologist I had seen as a patient responded to a request I had made to advertise the study through a professional vulvodynia specialist interest group. By keeping a reflective research journal (see Appendix Q), I was able to record my feelings of uncertainty about holding a dual role as a researcher and someone with lived experience, which prompted discussions with research supervisors regarding disclosure of my experience to patients and practitioners, and how this may impact on gathering data throughout the research process.

When considering the requirement to create a space to elicit practitioners' views and experiences with as much authenticity as possible, it was felt that by disclosing my identity as a patient I may risk re-creating a patient-practitioner dynamic, which may result in less reflexivity on the part of the practitioner to recall or speak about struggles with communication. One practitioner was recruited via snowball sampling, and there was a requirement for me to disclose my status as patient and researcher to this participant due to being involved with them as a patient previously. This may highlight one difficulty with researching a topic area in a locality in which you have received care, although should not be seen as a barrier to those attempting to conduct research. I have not considered that my position or identity is of a patient-researcher within this research, but rather that my dual identity is important to be recognised to inform processes. This was also reflected with patient participants, whom I made a decision to disclose my status to, in order to allow openness rather than assume shared understanding. The decision was made in the hope that this would enhance my role as researcher, and create opportunities for patients to communicate with me with the removal of some of the potential power imbalances inherent within researcher and participant dynamics.

5.2.2 Specific Delphi Decisions*.* There is a strength inherent in the Delphi method in that it allows for flexibility in its application. However, because of a lack of an agreed-upon approach to the methodology, it necessitated the research team making decisions about how to use the data it generated, including justifications for these decisions.

Initial decisions were around extracting relevant data from Round One interviews, in order to form initial guidelines. Commonly in the Delphi method, initial interview transcripts are analysed qualitatively through content or thematic analysis (Brady, 2015). However, due to the overarching aim of the research being to generate guidelines for use in practice, it could be considered as unnecessarily biasing the data to analyse it in this way. Panel members were asked to generate their own guidelines at the close of the interviews, and this allowed for the linking of guidelines with qualitative accounts of experiences described in earlier parts of the interview to create clinical vignettes later in the process. When clinical vignettes were developed, we ensured that these adhered to the truest possible description provided by panel members. In some circumstances, participant experiences were similar, and therefore it was considered that the combination of more than one vignette would elucidate a better description of an example of best practice or area for change.

Some researchers utilising the Delphi method consider it appropriate to remove items between the Round Two and Three surveys which have not reached the consensus threshold (Berk et al., 2011). However, due to this study being the first of its kind in the field of vulvodynia, it was considered that removal of items would force consensus and potentially bias the data towards certain guidelines without the opportunity for panellists to correct or improve them. As such, a decision was made to include all guidelines and amended guidelines in the Round Three survey (see Appendix N).

In order for the Delphi to be valid and reliable, it is important to set a consensus level a priori. Although higher levels of consensus would be preferable for more widely researched topic areas (Rayens & Hahn, 2000), the authors drew upon studies of similar topics in this field, to predetermine a moderate level of consensus (≥70%). Because of the flexibility of the methodology, decisions could at times feel arbitrary, for example whether to change or edit guidelines based solely on commentary, where consensus was not achieved. Frequent research supervision and recording of research decisions via supervision logs allowed a critical approach to be taken by the researcher with the support of researcher supervisors who could provide a fresh perspective on the data in order for difficult decisions to be made.

When it came to deciding how to present the guidelines, participants were provided with a vote during Round Three, based on commentary in Round Two that guidelines may be best structured in two different ways. The decision on how to group the guidelines was based on the panel consensus, which supported a combined approach for the grouping into different themes. Although there were other more comprehensive suggestions offered by the panel, the usability of the guidelines was considered an important component when making decisions on how to present the final output of the research. Therefore, guidelines were organised into themes based on panel consensus and as a result of a research decision to adhere to the aims of producing accessible guidelines for practitioners.

5.2.3. Personal Reflections on Terminology

Participants in the research highlighted preferred gender terms within their general and specific commentary on guidelines, which allowed for an exploration of my thinking around use of terminology within the research and the finalised guidelines. I have chosen to use the term ‘women’ when referring to those with vulvodynia throughout the research, based on previous research in this area utilising similar terminology. This is also a default position language-wise, as an inherent assumption of writing about and researching vulvodynia may be that those with vulvas are likely to identify or be identified as women. However, not all of the panellists in this research use the term woman to describe their gender identity. A specific request was made by the panel to use the term ‘people with vulvodynia’ in the finalised guidelines, to highlight that those who experience vulvodynia may not necessarily identify as women. This has given me more insight into how my assumptions may effect my use of terminology and vice versa, and informed a decision to use the term people with vulvodynia in the finalised guidelines, to offer readers an opportunity to challenge their own assumptions. My reflections also informed a decision to use the term penis-in-vagina sex rather than penetration. The research has been guided by feminist discourse, in that it felt important to outline that vulvodynia does not solely effect sexual relationships, and that impacts can also exist on an individual woman’s sexuality, regardless of her relationship status. Vulvodynia is frequently mislabelled as a sexual pain disorder, the implications of which may be that genital pain is a concern to healthcare providers, because it is linked to heteronormative sex. Women’s health problems may be at risk of being seen as important only in the context of their impact on women as sexual objects, and as such, women may be at risk of being positioned as passive recipients of sex, through the use of terms such as ‘penetration’. Although individuals will have their own preferred terms, one panellist suggested penis-in-vagina sex as an alternative to the dominant language used to describe this act or experience, which aligned more with the intention of the research to privilege the views and experiences of those with vulvodynia, regardless of their sexuality.

5.3 Challenges

A point of reflection exists regarding the engagement of participants in the process, thought to be evidenced through the emotionality of their feedback. The anonymity of the Delphi process appears to have provided a forum for participants to communicate about concerns and struggles in an open way, which presents its own risks and challenges as well as benefits. Many participants noted the importance of the topic in their comments and feedback, by way of positive expressions in support of guidelines, or concerns about how the implementation of guidelines may make women or practitioners feel. One panel participant contacted the research team following the Round Two survey expressing that they had been really affected by the comments of another panellist, highlighting them as “attacking”. These were comments related to guidelines others had made such as “get over it” and “you’re expecting too much”. I shared the affected participant’s response in that I also noted the emotionality of reading one panellist’s less positive comments regarding guidelines, and this was also echoed by the research team when they read the Round Two survey. As a team we had considered the risks and benefits of including these comments in the Round Three survey to go out to all participants. It was ultimately considered that by removing the comments we may bias the data away from critical commentary, and that all panellists would not have been represented within the data. However, there was also a recognition of the potential for distress as a result of certain comments from the panel. It could be viewed as a strength of the research process and the relationship built with participants that panellists were able to give honest and open feedback on the guidelines and the process, freely asserting their feelings and concerns to the author. Furthermore, research regarding women's experiences of managing a difficult chronic genital pain condition is likely to evoke emotions in panellists and researchers alike. This process highlighted the importance of the topic in the research including the commitment and personal investment from the panel, and the need for the research not to take any component part of this process for granted, in the hope that participants and researchers can learn from each other regarding the experience.

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Appendices

Appendix A

Ethical Approval from University of Nottingham Ethics Committee

RE: Sponsor Ref: 19044

BB-sponsor <BB-sponsor@exmail.nottingham.ac.uk>

Thu 13/06/2019 14:02

To: Zoe Hamilton <msxzh3@exmail.nottingham.ac.uk>

3 attachments (937 KB)

Email_Template_share_UK_Local_Information_Pack__non-commercial_Eng_Wales_V2-0.docx; Sponsor Letter HRA REC v3.0.pdf; 2018 To Whom It May Concern - EL PL PI.pdf;

Application Authorised:

Make sure you add @nhs.net to your 'Never Block Sender's Domain' list (accessed from the Junk menu) in Outlook to prevent responses going into your Junk file.

Please read this email in full as it provides you with guidance on the submission process, along with guidance which should be followed during your study and once your study is complete.

Your application has been e-authorised in IRAS by the sponsor – please do not make any amendments to your authorised IRAS forms (even clicking on a question will invalidate the authorisation – you can add the REC reference (if applicable) but that is all).

Please ensure that you have attached all study related documents to your IRAS checklist (inc. Statement of Activities and Schedule of Events) otherwise it will not be deemed a valid application

Please if you haven't already send us the version of ALL study documents you are submitting to the HRA – ensuring that all comments are deleted and all tracked changes are accepted. Once you have received full HRA/ethics approval please send me a copy of all Final Version 1.0 documents

Sponsor letter and Certificate of Insurance

Please find attached your sponsor letter and certificate of insurance which is required for your HRA Approval submission. **Please upload these to your checklist.**

How to book your application for HRA Approval

- You will need to telephone the Central Booking Service to book your application. You will need to provide the IRAS Project ID and key information about your project.
- Phone the Central Booking Service (CBS) on 0207 104 8000.
- Confirmation of your booking will be provided via email – please forward a copy of this to the sponsor (if we have not already been copied in to the email sent)

***IMPORTANT: Booking and submission must be completed on the same day ***

- As soon as you have your booking confirmation you need to electronically submit your application

- Firstly add your ethics committee booking information to page 1 of the IRAS form the click “E-submit application” (on the submission tab in IRAS)
  This will electronically submit your form and supporting documents uploaded to the checklist.
  Note: The submission history (on submission tab) provides a record of your submission and updates on its status.
- We suggest Checking these status updates to ensure that your application has been accepted for processing.
- The ‘E-submit application’ button will be disabled when your application has been submitted and/or it is being processed.
- After you have submitted your application

Please contact the HRA, if you have:

  - Made a mistake and/or need to withdraw your application;
  - Need to supply additional supporting documents;
  - Need to submit a response to a request from HRA. Refer to HRA Website for guidance.

Agreements:

I will shortly sent the sponsor/chief investigator agreement and non-commercial research agreement (if applicable) in the mail to you at the address given for the chief investigator in the protocol.

Final Version of Study Documents:

As sponsor we **must** keep a copy of the documents submitted to the ethics committee, if you haven’t already, please send me the **final clean version** of your documents. You also need to send me a copy of the fully authorised and submitted IRAS form (these may be found in ‘Submission History’ which is under the ‘e-submission’ tab of your IRAS form and ‘Submission History’).

HRA Initial Assessment/Ethics changes (provisional opinion):

Please note that if the HRA initial assessment or HRA ethics committee requests any changes to any documents these should also be sent to sponsor@nottingham.ac.uk as we must keep a record of the final ethics committee approved version of your study documents you will also need to update your ‘local document package’ accordingly.

Amendments (after HRA Approval): See Sponsor SOP TA013 Amendments

Should there be any subsequent amendment to any of the study documents please refer to SOP TA013 Protocol Amendments, available on the RGS webpage. Copies of amendments including the Notification of Substantial Amendment (found in IRAS) should be submitted to sponsor@nottingham.ac.uk for sponsor review and sign off prior to submission to the HRA and HRA ethics.

R&D submission:

I have also provided guidance in relation to the R&D approval process in more detail below:

Once you have received confirmation that your ethics application is valid, you can now apply for R&D approval as well. It is best to try to submit to the HRA and R&D at the same time to help speed up the process.

For your R&D application you will need collate your ‘local information pack’
This should comprise the same documents that have been added to the IRAS form checklist in IRAS. Once you have received any correspondence from the HRA (for HRA approval) this should also be added to your local document package.

You will then need to email your ‘local information pack’ to the relevant R&D department for them to begin their review (this can be done simultaneously with your ethics application to save time). Please use the HRA email template attached. You may need to forward any additional correspondence from HRA/HRA ethics once this is received
Please copy me in

Progress Reports:

It is a condition of your ethical approval that a progress report is submitted to ethics yearly on the anniversary of your ethics approval date (not first participant recruited). Failure to do this, may result in a suspension of your favourable opinion by the ethics committee. Please ensure that you complete your progress report and also send a copy to the sponsor representative (me) and any R&D departments.

End of Study Declaration:

Once your study is complete you MUST notify the sponsor, ethics committee, NOMS (if appropriate) and all R&D departments involved with your study.
To do this you MUST complete a copy of the end of study declaration (within 90 days of the data collection period completing (including any follow-up)) and submit a final

report (within 12 months of notifying that the study is complete). If you have any queries regarding this please do not hesitate to contact me.

The form may be accessed here:

http://www.hra.nhs.uk/resources/during-and-after-your-study/end-of-study-notification-studies-other-than-clinical-trials-of-investigational-medicinal-products/

You can also use this form for notifying UoN ethics committees

See also Sponsor SOP QA005 Archiving – for archiving of your study documents

All **Sponsor SOPs, Record Forms and Work Instructions** may be found here:

https://workspace.nottingham.ac.uk/display/ResG/SOPs%2C+Record+Forms+and+Work+Instructions

Please note that this is only accessible to University of Nottingham staff, if you are student, your academic supervisor will need to access these documents for you

Please ensure that you submit your application to the HRA within 2 working days, you must also submit to any R&D departments at the SAME time. Please do not delay submitting your applications.

Any queries please do not hesitate to contact me

Sandip Stapleton

Research Governance Officer

Research and Innovation.

East Atrium

Jubilee Conference Centre

Triumph Road

Nottingham

NG8 1DH

Tel: **0115 8467103**

Fax: 0115 9513633

sponsor@nottingham.ac.uk

https://workspace.nottingham.ac.uk/display/ResG/Introduction

Appendix B

Ethical Approval from the Leicester Central Health Research Authority Ethics Committee

IRAS 260778. HRA & HCRW Approval issued

nrescommittee.eastmidlands-leicestercentral@nhs.net <noreply@harp.org.uk>

Wed 18/09/2019 10:16

To:

- Danielle De Boos <mczdcd@exmail.nottingham.ac.uk>;
- Zoe Hamilton <msxzh3@exmail.nottingham.ac.uk>;
- Danielle De Boos <mczdcd@exmail.nottingham.ac.uk>

Cc:

- sponsor@nottingham.ac.uk <sponsor@nottingham.ac.uk>

1 attachments (179 KB)

260778 Letter_of_HRA_Approval 18092019.pdf;

Dear Dr De Boos

RE: IRAS 260778 Guidelines for communication in psychological management of vulvodynia. HRA & HCRW Approval issued

Please find attached your HRA and HCRW letter of Approval.

You may now commence your study at those participating NHS organisations in England and Wales that have confirmed their capacity and capability to undertake their role in your study (where applicable). Detail on what form this confirmation should take, including when it may be assumed, is provided in the HRA and HCRW Approval letter.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

If you have any queries please do not hesitate to contact me.

Kind regards

Barbara Cuddon

Approvals Specialist

Health Research Authority

The Old Chapel | Royal Standard Place | NG1 6FS

T. 0207 972 2568

E. nrescommittee.eastmidlands-leicestercentral@nhs.net

Appendix C

Study Advertisement - Patients

(Final Version 1.0: 26/07/2019)

Do you have a diagnosis of vulvodynia?

Would you be interested in taking part in research supporting practitioners to improve communication around the psychological aspects of this condition?

What is the aim of the study?

The aim of this research is to understand the views of women and practitioners in communicating regarding the impact of this condition on wellbeing and relationships, in order to produce a set of guidelines to support practitioners in their communication.

What will happen if I choose to take part?

Taking part in the study involves an audio-recorded individual interview, lasting up to 1 hour. You will then be asked to take part in two separate surveys by e-mail or post at later dates which will support the creation of the guidelines. As a result, your involvement in the study would span approximately nine months, requiring up to 150 minutes of your time.

Those who participate in the research will have the option of a £10 Amazon voucher or an equivalent donation to the National Vulvodynia Association, or an alternative vulvodynia charity of their choice.

I am interested in taking part, what next?

If you would like to take part in the study, or would like to know more, please contact Zoe Hamilton, primary investigator at the details below:

E-mail: zoe.hamilton@nottingham.ac.uk

Tel: [Researcher's telephone number]

Appendix D

Study Advertisement - Practitioners

(Final Version 2.0: 26/07/2019)

Are you a practitioner working with women with vulvodynia, either in the management of the condition or by referring on to specialist services?

Would you be interested in taking part in research supporting practitioners to improve communication around the psychological aspects of this condition?

What is the aim of the study?

The aim of this research is to understand the views of women and practitioners in communicating regarding the impact of this condition on wellbeing and relationships, in order to produce a set of guidelines to support practitioners in their communication.

What will happen if I choose to take part?

Taking part in the study involves an audio-recorded individual interview, lasting up to 1 hour. You will then be asked to take part in two separate surveys by e-mail or post at later dates which will support the creation of the guidelines. As a result, your involvement in the study would span approximately nine months, requiring up to 150 minutes of your time.

Those who participate in the research will have the option of a £10 Amazon voucher or an equivalent donation to the National Vulvodynia Association, or an alternative vulvodynia charity of their choice.

I am interested in taking part, what next?

If you would like to take part in the study, or would like to know more, please contact Zoe Hamilton, primary investigator at the details below:

E-mail: zoe.hamilton@nottingham.ac.uk

Tel: [Researcher's telephone number]

Appendix E

Study Invitation Letter

PARTICIPANT ADDRESS

IRAS Project ID: 260778

Title of Study: Creating guidelines for practitioners on communication regarding the management of the psychological and interpersonal impact of vulvodynia: A Delphi study

Dear [PARTICIPANT NAME]

Thank you for expressing an interest in taking part in our study.

Please find enclosed an **Information Sheet** which includes all relevant study information for your consideration. This information is for you to keep to refer back to.

Two copies of the **Consent Form** and a prepaid envelope is also provided. Should you wish to take part in the study, please could you return one of these forms via post. One copy is for you to keep. Following this, a member of the research team (Zoe Hamilton, Primary Investigator) will be in touch to discuss the information enclosed in this letter, as well as the next steps for taking part.

If you have any questions or queries regarding any of this information upon receiving it, or would like to clarify any information before returning a consent form, please do not hesitate to get in touch using the following details:

E-mail: zoe.hamilton@nottingham.ac.uk

Telephone: 07749493567

Kind regards,

Zoe Hamilton Primary Investigator
Trainee Clinical Psychologist (research in partial fulfilment of Doctorate in Clinical Psychology (DClinPsy)
Trent Doctorate in Clinical Psychology, University of Nottingham
Yang Fujia Building, B Floor, Jubilee Campus, Wollaton Road, Nottingham, NG8 1BB
Enc. Information Sheet, Consent Form, Prepaid Envelope

Appendix F

Participant Information Sheet - Patients

Participant Information Sheet- Patients

(Final Version 3.0: 02/09/2019)

IRAS Project ID: 260778

Title of Study: Creating guidelines for practitioners on communication regarding the management of the psychological and interpersonal impact of vulvodynia: A Delphi study

Name of Chief Investigator: Dr Danielle De Boos

Local Researcher(s): Miss Zoe Hamilton (primary investigator), Dr Anna Tickle, Dr Sanchia Biswas

You are invited to take part in our research study. This study is being undertaken towards the qualification of Doctorate in Clinical Psychology (DClinPsy).

Before you decide we would like you to understand why the research is being done and what it would involve for you. One of our team will go through the information sheet with you and answer any questions you have. Talk to others about the study if you wish. Ask us if there is anything that is not clear.

What is the purpose of the study?

Research into communication between women and practitioners regarding the management of vulvodynia highlights a struggle for both groups and women can be left feeling they have to manage alone. This can result in psychological and emotional distress, making the condition even harder to manage without adequate information, support and guidance. The intensive nature of treatment requires a team approach that recognises the psychological and interpersonal needs of women with this condition. However, there are few resources that support women and practitioners to communicate regarding managing the psychological and interpersonal impact of vulvodynia.

The aim of the research is to use a method of generating consensus (the Delphi method) to create guidelines for practitioners in communicating regarding the management of the psychological and interpersonal impact of vulvodynia.

Why have I been invited?

You are being invited to take part because you are a woman with personal experience of vulvodynia. We are inviting 8 women to take part in order to offer expertise through their lived experiences.

We are also inviting 8 practitioners from a range of disciplines who come into contact with vulvodynia in their practice to take part.

Do I have to take part?

It is up to you to decide whether or not to take part. If you decide to participate you can keep this information sheet and will be asked to sign a consent form. If you decide to take part, you are still free to withdraw at any time and without giving a reason. This would not affect your legal rights.

What will happen to me if I take part?

The research will last approximately one year and consist of the following involvement:

You will be invited to participate in an audio-recorded individual interview with the primary investigator of this study, lasting approximately 1 hour. Interviews will be recorded via Dictaphone. Digital recordings of interviews will be transferred to a password-protected laptop and deleted from the Dictaphone. Identifiable data will be anonymised. The interview will be arranged for a time and place that is convenient for you between September 2019 and October 2019, and can take place in person, over the phone or by Skype.

You will then be asked to take part in two separate surveys which you will receive via e-mail or post and invited to return the surveys within four weeks of receiving them. The first survey will be distributed around December 2019 2019 and the second around February 2020. Each survey will require approximately 30 minutes of your time.

You will not be required to meet the primary researcher following your initial interview.

It is intended that the interview data will also be retained for secondary analysis by the research team. This would be to optimise learning from the data collected by answering the question ‘What are practitioners’ and women’s experiences of communication in the management of vulvodynia’. However, this analysis is not required as part of the Delphi methodology.

Expenses and payments

You will not be paid to participate in the study, but the option of a £10 Amazon voucher or an equivalent donation to the National Vulvodynia Association, or an alternative vulvodynia charity of your choice, will be offered for every person that participates. Travel expenses and postal costs will be offered for any visits incurred as a result of participation.

What are the possible disadvantages and risks of taking part?

By being part of this research, you will be required to give up approximately 120 minutes of your time. Since the subject matter is about chronic female genital pain and the potential associated psychological and interpersonal impact, some participants may feel mild discomfort in discussing this with the researcher at the interview stage.

We recognise the sensitive nature of the research and talking about your experiences may be difficult at times. It will be possible to take breaks throughout interviews or resume at a later date. You are also free to withdraw from the research at any time.

What are the possible benefits of taking part?

We cannot promise the study will help you but the information we get from this study may help you in communicating regarding managing the psychological and interpersonal impact of vulvodynia. The guidelines produced may help to inform practitioners and women around the issue in question based on the experiences and expertise of women with vulvodynia and professionals in this field.

In addition to the Delphi process, ‘secondary analysis’ of all interviews may be used by members of the research team to identify common themes in relation to communication between women and practitioners in the management of vulvodynia. This would be written up as a separate study or in future research and may include the use of anonymous quotes, shared anonymously with other research.

What happens when the research study stops?

Upon completion of the study, the proposed guidelines will be disseminated to participants as part of the Delphi process once they are finalised, with accompanying anonymous vignettes (examples to illustrate each guideline) to allow for translation of guidelines into practice, to improve accessibility and application. We will ask for your consent to hold your contact details for up to three months following the end of the study in order to circulate the proposed guidelines to all participants.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. The researchers' contact details are given at the end of this information sheet. If you remain unhappy and wish to complain formally, you can do this by contacting Sherwood Forest Hospitals NHS Foundation Trust Patient Experience Team on 01623 672222, or by e-mail at sfh-tr.pet@nhs.net. You can also write to: Patient Experience Team, Sherwood Forest Hospitals NHS Foundation Trust, King's Mill Hospital, Mansfield Road, Sutton-in-Ashfield, Notts, NG17 4JL.

In the event that something does go wrong and you are harmed during the research and this is due to someone's negligence then you may have grounds for a legal action for compensation against the University of Nottingham but you may have to pay your legal costs. The normal National Health Service complaints mechanisms will still be available to you.

Will my taking part in the study be kept confidential?

The responses of all participants will be made known to all other participants and will be documented on the copies of the surveys received, but all responses will be anonymised. The names of those contributing will remain confidential both during and after the study.

We will follow ethical and legal practice and all information about you will be handled in confidence.

If you join the study, we will use information collected from you during the course of the research. This information will be kept strictly confidential, stored in a secure and locked office, and on a password protected database at the University of Nottingham. Under UK Data Protection laws the University is the Data Controller (legally responsible for the data security) and the Chief Investigator of this study (named above) is the Data Custodian (manages access to the data). This means we are responsible for looking after your information and using it properly. Your rights to access, change or move your information are limited as we need to manage your information in specific ways to comply with certain laws and for the research to be reliable and accurate. To safeguard your rights we will use the minimum personally – identifiable information possible.

You can find out more about how we use your information and to read our privacy notice at:

https://www.nottingham.ac.uk/utilities/privacy.aspx.

The data collected for the study will be looked at and stored by authorised persons from the University of Nottingham who are organising the research. They may also be looked at by authorised people from regulatory organisations to check that the study is being carried out correctly. All will have a duty of confidentiality to you as a research participant and we will do our best to meet this duty.

Your contact information will be kept by the University of Nottingham for three months after the end of the study so that we are able to contact you about the findings of the study and possible follow-up studies (unless you advise us that you do not wish to be contacted). This information will be kept separately from the research data collected and only those who need to will have access to it. All other data (research data) will be kept securely for 7 years. After this time your data will be disposed of securely. During this time all precautions will be taken by all those involved to maintain your confidentiality, only members of the research team given permission by the data custodian will have access to your personal data.

For patient participants recruited from NHS sites, an information sheet and signed consent form will be stored in health records, and it will be documented that these study forms have been discussed.

In accordance with the University of Nottingham's, the Government's and our funders' policies we may share our research data with researchers in other Universities and organisations, including those in other countries, for research in health and social care. Sharing research data is important to allow peer scrutiny, re-use (and therefore avoiding duplication of research) and to understand the bigger picture in particular areas of research. Data sharing in this way is usually anonymised (so that you could not be identified) but if we need to share identifiable information we will seek your consent for this and ensure it is secure. You will be made aware then if the data is to be shared with countries whose data protection laws differ to those of the UK and how we will protect your confidentiality.

Although what you say to us is confidential, should you disclose anything to us which we feel puts you or anyone else at any risk, we may feel it necessary to report this to the appropriate persons. With regards to practitioner involvement, if anything is disclosed that is considered a breach of professional guidelines, then it may be necessary for action to be taken in this instance.

What will happen if I don't want to carry on with the study?

Your participation is voluntary and you are free to withdraw at any time, without giving any reason, and without your legal rights being affected. If you withdraw we will no longer collect any information about you or from you but we will keep the information about you that we have already obtained as we are not allowed to tamper with study records and this information may have already been used in some analyses and may still be used in the final study analyses. To safeguard your rights, we will use the minimum personally-identifiable information possible.

For patient/women participants, you have a right to withdraw from the study without your current or future care being affected in any way.

What will happen to the results of the research study?

This research will be submitted in partial fulfilment of the requirements for the Trent Doctorate in Clinical Psychology (DClinPsy).

The proposed guidelines will be disseminated to participants as part of the Delphi process, and once they are finalised, with accompanying vignettes to allow for translation of guidelines into practice, to improve accessibility and application.

This study will be submitted for publication in a peer-review journals as separate publications. An example of potential journals for publication are The Journal of Pain Research, The Journal of Sexual Medicine, or Archives of Sexual Behaviour. Other potential organisations for dissemination are the National Vulvodynia Association where guidance around vulvodynia is published on their website.

Who is organising and funding the research?

This research is being organised by the University of Nottingham and is being funded by Health Education England as part of Doctorate in Clinical Psychology (DClinPsy) training.

Who has reviewed the study?

All research in healthcare is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by East Midlands – Leicester Central Research Ethics Committee.

Thank you very much for your time.

Further information and contact details

Chief investigator: Dr Danielle De Boos (primary research supervisor)

Assistant Professor

Trent Doctorate in Clinical Psychology

University of Nottingham

Yang Fujia Building, B Floor

Jubilee Campus

Wollaton Road

Nottingham

NG8 1BB

Tel: 01158466696

E-mail: Danielle.Deboos@nottingham.ac.uk

Co-investigators: Zoe Hamilton (doctoral student)

Trainee Clinical Psychologist (research in partial fulfilment of Doctorate in Clinical Psychology (DClinPsy)

Trent Doctorate in Clinical Psychology

University of Nottingham

Yang Fujia Building, B Floor

Jubilee Campus

Wollaton Road

Nottingham

NG8 1BB

E-mail: zoe.hamilton@nottingham.ac.uk

Dr Anna Tickle (research supervisor)

Research Tutor

Trent Doctorate in Clinical Psychology

University of Nottingham

Yang Fujia Building, B Floor

Jubilee Campus

Wollaton Road

Nottingham

NG8 1BB

Tel: 07971 990 371

E-mail: anna.tickle@nottingham.ac.uk

Dr Sanchia Biswas (field supervisor)

Clinical Psychologist

Kingsmill Hospital, Clinic 9
Mansfield Road
Sutton in Ashfield
Nottinghamshire
NG17 4JL
Tel: 01623 622515 Ext 6692
E-mail: Sanchia.Biswas@nottshc.nhs.uk

Study Coordinating Centre: Division of Psychiatry & Applied Psychology
School of Medicine
Jubilee Campus
The University of Nottingham
Nottingham, NG8 1BB

Appendix G

Participant Information Sheet – Practitioners

Participant Information Sheet - Practitioners

(Final Version 3.0: 02/09/2019)

IRAS Project ID: 260778

Title of Study: Creating guidelines for practitioners on communication regarding the management of the psychological and interpersonal impact of vulvodynia: A Delphi study

Name of Chief Investigator: Dr Danielle De Boos

Local Researcher(s): Miss Zoe Hamilton (primary investigator), Dr Anna Tickle, Dr Sanchia Biswas

You are invited to take part in our research study. This study is being undertaken towards the qualification of Doctorate in Clinical Psychology (DClinPsy).

Before you decide we would like you to understand why the research is being done and what it would involve for you. One of our team will go through the information sheet with you and answer any questions you have. Talk to others about the study if you wish. Ask us if there is anything that is not clear.

What is the purpose of the study?

Research into communication between women and practitioners regarding the management of vulvodynia highlights a struggle for both groups and women can be left feeling they have to manage alone. This can result in psychological and emotional distress, making the condition even harder to manage without adequate information, support and guidance. The intensive nature of treatment requires a team approach that recognises the psychological and interpersonal needs of women with this condition. However, there are few resources that support women and practitioners to communicate regarding managing the psychological and interpersonal impact of vulvodynia.

The aim of the research is to use a method of generating consensus (the Delphi method) to create guidelines for practitioners in communicating regarding the management of the psychological and interpersonal impact of vulvodynia.

Why have I been invited?

You are being invited to take part because you are a professional coming into contact with women with vulvodynia in your practice. We are inviting 8 practitioners from a range of disciplines to take part in the study.

We are also inviting 8 women to take part in the study in order to offer expertise through their lived experiences.

Do I have to take part?

It is up to you to decide whether or not to take part. If you decide to participate you can keep this information sheet and will be asked to sign a consent form. If you decide to take part, you are still free to withdraw at any time and without giving a reason. This would not affect your legal rights.

What will happen to me if I take part?

The research will last approximately one year and consist of the following involvement:

You will be invited to participate in an audio-recorded individual interview with the primary investigator of this study, lasting approximately 1 hour. Interviews will be recorded via Dictaphone. Digital recordings of interviews will be transferred to a password-protected laptop and deleted from the Dictaphone. Identifiable data will be anonymised. The interview will be arranged for a time and place that is convenient for you between September 2019 and October 2019, and can take place in person, over the phone or by Skype. As part of the interview you will be asked if you have personal experience of vulvodynia e.g. personal direct experience/caring for someone with vulvodynia, in order to clarify if you are an expert by experience, by profession or both.

You will then be asked to take part in two separate surveys which you will receive via e-mail or post and invited to return the surveys within four weeks of receiving them. The first survey will be distributed around December 2019 and the second around February 2020. Each survey will require approximately 30 minutes of your time.

You will not be required to meet the primary researcher following your initial interview.

It is intended that the interview data will also be retained for secondary analysis by the research team. This would be to optimise learning from the data collected by answering the question ‘What are practitioners’ and women’s experiences of communication in the management of vulvodynia’. However, this analysis is not required as part of the Delphi methodology.

Expenses and payments

You will not be paid to participate in the study, but the option of a £10 Amazon voucher or an equivalent donation to the National Vulvodynia Association, or an alternative vulvodynia charity of your choice, will be offered for every person that participates. Travel expenses and postal costs will be offered for any visits incurred as a result of participation.

What are the possible disadvantages and risks of taking part?

By being part of this research, you will be required to give up approximately 120 minutes of your time. Since the subject matter is about chronic female genital pain and the potential associated psychological and interpersonal impact, some participants may feel mild discomfort in discussing this with the researcher at the interview stage.

We recognise the sensitive nature of the research and talking about your experiences may be difficult at times. It will be possible to take breaks throughout interviews or resume at a later date. You are also free to withdraw from the research at any time.

What are the possible benefits of taking part?

We cannot promise the study will help you but the information we get from this study may help you in communicating regarding managing the psychological and interpersonal impact of vulvodynia. The guidelines produced may help to inform practitioners and women around the issue in question based on the experiences and expertise of women with vulvodynia and professionals in this field.

In addition to the Delphi process, ‘secondary analysis’ of all interviews may be used by members of the research team to identify common themes in relation to communication between women and practitioners in the management of vulvodynia. This would be written up as a separate study or in future research and may include the use of anonymous quotes, shared anonymously with other researchers.

What happens when the research study stops?

Upon completion of the study, the proposed guidelines will be disseminated to participants as part of the Delphi process once they are finalised, with accompanying anonymous vignettes (examples to illustrate each guideline) to allow for translation of guidelines into practice, to improve accessibility and application. We will ask for your consent to hold your contact details for up to three months following the end of the study in order to circulate the proposed guidelines to all participants.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. The researchers' contact details are given at the end of this information sheet. If you remain unhappy and wish to complain formally, you can do this by contacting Sherwood Forest Hospitals NHS Foundation Trust Patient Experience Team on 01623 672222, or by e-mail at sfh-tr.pet@nhs.net. You can also write to: Patient Experience Team, Sherwood Forest Hospitals NHS Foundation Trust, King's Mill Hospital, Mansfield Road, Sutton-in-Ashfield, Notts, NG17 4JL.

In the event that something does go wrong and you are harmed during the research and this is due to someone's negligence then you may have grounds for a legal action for compensation against the University of Nottingham but you may have to pay your legal costs. The normal National Health Service complaints mechanisms will still be available to you.

Will my taking part in the study be kept confidential?

The responses of all participants will be made known to all other participants and will be documented on the copies of the surveys received, but all responses will be anonymised. The names of those contributing will remain confidential both during and after the study.

We will follow ethical and legal practice and all information about you will be handled in confidence.

If you join the study, we will use information collected from you during the course of the research. This information will be kept strictly confidential, stored in a secure and locked office, and on a password protected database at the University of Nottingham. Under UK Data Protection laws the University is the Data Controller (legally responsible for the data security) and the Chief Investigator of this study (named above) is the Data Custodian (manages access to the data). This means we are responsible for looking after your information and using it properly. Your rights to access, change or move your information are limited as we need to manage your information in specific ways to comply with certain laws and for the research to be reliable and accurate. To safeguard your rights we will use the minimum personally – identifiable information possible.

You can find out more about how we use your information and to read our privacy notice at:

https://www.nottingham.ac.uk/utilities/privacy.aspx.

The data collected for the study will be looked at and stored by authorised persons from the University of Nottingham who are organising the research. They may also be looked at by authorised people from regulatory organisations to check that the study is being carried out correctly. All will have a duty of confidentiality to you as a research participant and we will do our best to meet this duty.

Your contact information will be kept by the University of Nottingham for three months after the end of the study so that we are able to contact you about the findings of the study and possible follow-up studies (unless you advise us that you do not wish to be contacted). This information will be kept separately from the research data collected and only those who need to will have access to it. All other data (research data) will be kept securely for 7 years. After this time your data will be disposed of securely. During this time all precautions will be taken by all those involved to maintain your confidentiality, only members of the research team given permission by the data custodian will have access to your personal data.

For patient participants recruited from NHS sites, an information sheet and signed consent form will be stored in health records, and it will be documented that these study forms have been discussed.

In accordance with the University of Nottingham's, the Government's and our funders' policies we may share our research data with researchers in other Universities and organisations, including those in other countries, for research in health and social care. Sharing research data is important to allow peer scrutiny, re-use (and therefore avoiding duplication of research) and to understand the bigger picture in particular areas of research. Data sharing in this way is usually anonymised (so that you could not be identified) but if we need to share identifiable information we will seek your consent for this and ensure it is secure. You will be made aware then if the data is to be shared with countries whose data protection laws differ to those of the UK and how we will protect your confidentiality.

Although what you say to us is confidential, should you disclose anything to us which we feel puts you or anyone else at any risk, we may feel it necessary to report this to the appropriate persons. With regards to practitioner involvement, if anything is disclosed that is considered a breach of professional guidelines, then it may be necessary for action to be taken in this instance.

What will happen if I don't want to carry on with the study?

Your participation is voluntary and you are free to withdraw at any time, without giving any reason, and without your legal rights being affected. If you withdraw we will no longer collect any information about you or from you but we will keep the information about you that we have already obtained as we are not allowed to tamper with study records and this information may have already been used in some analyses and may still be used in the final study analyses. To safeguard your rights, we will use the minimum personally-identifiable information possible.

For patient/women participants, you have a right to withdraw from the study without your current or future care being affected in any way.

What will happen to the results of the research study?

This research will be submitted in partial fulfilment of the requirements for the Trent Doctorate in Clinical Psychology (DClinPsy).

The proposed guidelines will be disseminated to participants as part of the Delphi process, and once they are finalised, with accompanying vignettes to allow for translation of guidelines into practice, to improve accessibility and application.

This study will be submitted for publication in a peer-review journal as separate publications. An example of potential journals for publication are The Journal of Pain Research, The Journal of Sexual Medicine, or Archives of Sexual Behaviour. Other potential organisations for dissemination are the National Vulvodynia Association where guidance around vulvodynia is published on their website.

Who is organising and funding the research?

This research is being organised by the University of Nottingham and is being funded by Health Education England as part of Doctorate in Clinical Psychology (DClinPsy) training.

Who has reviewed the study?

All research in healthcare is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by East Midlands – Leicester Central Research Ethics Committee.

Thank you very much for your time.

Further information and contact details

Chief investigator: Dr Danielle De Boos (primary research supervisor)

Assistant Professor

Trent Doctorate in Clinical Psychology

University of Nottingham

Yang Fujia Building, B Floor

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Study Coordinating Centre: Division of Psychiatry & Applied Psychology
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Appendix H

Participant Consent Form

CONSENT FORM

(Final Version 2.0: 26/07/2019)

Title of Study: **Creating guidelines for practitioners on communication regarding the management of the psychological and interpersonal impact of vulvodynia: A Delphi study**

IRAS Project ID:	260778
Name of Researcher:	Miss Zoe Hamilton
Local Researcher(s):	Dr Danielle De Boos (chief investigator) Dr Anna Tickle Dr Sanchia Biswas

Please initial box

Name of Participant:

1. I confirm that I have read and understand the information sheet version number 3.0 dated 02/09/2019 for the above study and have had the opportunity to ask questions. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, and without my legal rights and current or future care, if applicable, being affected. I understand that should I withdraw then the information collected so far cannot be erased and that this information may still be used in the project analysis. ☐

3. I understand that should I choose not to respond to surveys that I will be sent further surveys as part of the research unless I actively withdraw from the study by contacting a member of the research team. ☐

4. I understand that data collected in the study may be looked at by authorised individuals from the University of Nottingham, the research group and regulatory authorities where it is relevant to my taking part in this study. I give permission for these individuals to collect, store, analyse and publish information obtained from my participation in this study. I understand that my personal details will be kept confidential. ☐

5. I understand that the interview will be recorded and that anonymous direct quotes from the interview may be used in the study reports and written up as examples of good practice in communication and sent to other participants as part of surveys associated with the research. ☐

6. I understand that the information collected about me will be used to support other research in the future, and may be shared anonymously with other researchers. ☐

7. I understand that should I disclose any information which the research team feel puts me or anyone else at risk, or where applicable is considered unethical practice, then it may be necessary to report this to the appropriate persons. ☐

8. I agree to take part in the above study. ☐

________________________	________________	________________________
Name of Participant	Date	Signature

______________________________	________________	_________________________
Name of Person taking consent	Date	Signature

2 copies: 1 for participant, 1 for the project notes

Appendix I

Interview Schedule – Patients

Draft Semi-Structured Interview Schedule – Women

Study Title: Creating guidelines for practitioners on communication regarding the management of the psychological and interpersonal impact of vulvodynia: A Delphi study

(Final Version 1.0: 13/06/2019)

Opening statement: Thank you for agreeing to be interviewed today to discuss your experiences of working with women in communicating regarding the management of the psychological and interpersonal impact of vulvodynia. Today we will have up to an hour to discuss some of the key issues and areas of best practice in this area, and finish by generating some examples of potential guidelines for future practice. If you would like to take a break at any point in the process please let me know and we can facilitate this. If you are finding any issues uncomfortable to discuss then please let me know. Just to confirm I will be audio-taping today's interview, can you confirm you are happy for me to go ahead with this?

Demographic and role-based questions:

- Gender
- Date of birth
- How long have you been experiencing symptoms of vulvar pain?
- When were you diagnosed with vulvodynia?
- What type of vulvodynia have you been diagnosed with (if known)?
- What professionals have you had contact with relative to vulvodynia?

Within this draft semi-structured interview there will be opportunities to expand on and follow up answers to questions to elicit further information, seen here in italics.

Question One:

Tell me about your experience of communicating with professionals/practitioners about managing the impact of vulvodynia.

Follow up: What are your views on current communication between women and practitioners regarding managing the impact of vulvodynia?

Follow up: What are your views on communication between women and practitioners regarding managing the psychological impact?

Follow up: What are your views on communication regarding managing the interpersonal impact?

Question Two:

Drawing on your experiences, what do you think are the key concerns or barriers to communication for *women* when discussing managing the psychological/interpersonal impact of vulvodynia?

Follow up: How do you feel these barriers impact on managing the psychological and interpersonal impact of vulvodynia?

Question Three:

Drawing on your experience, what do you think are the key concerns or barriers to communication for *practitioners* when discussing managing the psychological/interpersonal impact of vulvodynia?

Follow up: What do you feel are the key important concerns in terms of emotional and psychological wellbeing?

Follow up: What do you feel the important considerations are for interpersonal relationships for women?

Follow up: What are your views on the impact of managing vulvodynia on female sexuality?

Question Four:

Tell me about a time when there have been difficulties in communication regarding the management of the psychological/interpersonal impact of vulvodynia?

Follow up: What has been the impact of this on you?

Follow up: What do you believe has been the impact of this for the practitioner?

Follow up: What specifically did you find did not go well in terms of communication? Can you give an example of this?

Question Five:

Tell me about a time from your experiences where you feel that communication regarding the management of the psychological/interpersonal impact of vulvodynia has been successful for you or the practitioner?

Follow up: Can you give an example?

Follow up: How about the successful management of immediate emotional and psychological distress for you?

Follow up: What do you think went well in terms of practitioner input here? Can you give a specific example of this?

Question Six:

What do you think is important in order to make communication work well between women and practitioners in relation to managing vulvodynia?

Question Seven:

Based on your experiences, can you suggest three potential guidelines for practitioners that could support them in improving or working towards best practice in this process?

Follow up: Can you give examples relative to these guidelines?

Appendix J

Interview Schedule – Practitioners

Draft Semi-Structured Interview Schedule – Practitioners

Study Title: Creating guidelines for practitioners on communication regarding the management of the psychological and interpersonal impact of vulvodynia: A Delphi study

(Final Version 2.0: 26/07/2019)

Opening statement: Thank you for agreeing to be interviewed today to discuss your experiences of working with women in communicating regarding the management of the psychological and interpersonal impact of vulvodynia. Today we will have up to an hour to discuss some of the key issues and areas of best practice in this area, and finish by generating some examples of potential guidelines for future practice. If you would like to take a break at any point in the process please let me know and we can facilitate this. If you are finding any issues uncomfortable to discuss then please let me know. Just to confirm I will be audio-taping today’s interview, can you confirm you are happy for me to go ahead with this?

Demographic and role-based questions:

- Gender
- Do you have personal experience of vulvodynia as a patient or carer, as well as professional experience of working with this condition?
- How long have you been practicing in your profession?

- How have you come into contact with the management of vulvodynia in your professional role?

Within this semi-structured interview there will be opportunities to expand on and follow up answers to questions to elicit further information, seen here in italics.

Question One:

Tell me about your experience of communicating with women about managing the impact of vulvodynia.

Follow up: What are your views on current communication between women and practitioners regarding managing the impact of vulvodynia?

Follow up: What are your views on communication between women and practitioners regarding managing the psychological impact?

Follow up: What are your views on communication regarding managing the interpersonal impact?

Question Two:

Drawing on your experience of clinical practice, what do you think are the key concerns or barriers to communication for *practitioners* when discussing managing the psychological/interpersonal impact of vulvodynia?

Follow up: How do you feel these barriers impact on managing the psychological impact of vulvodynia?

Question Three:

Drawing on your experience of clinical practice, what do you think are the key concerns or barriers to communication for *women* when discussing managing the psychological/interpersonal impact of vulvodynia?

Follow up: What do you feel are the key important concerns in terms of emotional and psychological wellbeing?

Follow up: What do you feel the important considerations are for interpersonal relationships for women?

Follow up: What are your views on the impact of managing vulvodynia on female sexuality?

Question Four:

Tell me about a time when there have been difficulties in communication regarding the management of the psychological/interpersonal impact of vulvodynia in your practice?

Follow up: What has been the impact of this for you as a practitioner?

Follow up: What do you believe been the impact of this for the patient?

Follow up: What specifically did you find did not go well in terms of communication? Can you give an example of this?

Question Five:

Tell me about a time from your practice where you feel that communication regarding the management of the psychological/interpersonal impact of vulvodynia has been successful for women and yourself as a practitioner?

Follow up: Can you give a specific example of this from clinical practice?

Follow up: How about the successful management of immediate emotional and psychological distress for women?

Follow up: What do you think went well in terms of your input here? Can you give a specific example of this?

Question Six:

What do you think is important in order to make communication work well between women and practitioners in relation to managing vulvodynia?

Question Seven:

Based on your experiences, can you suggest two potential guidelines for practitioners that could support them in improving or working towards best practice in this process?

Follow up: Can you give examples relative to these guidelines?

Appendix K

Participant Debrief Form

Participant Debrief Sheet

(Final Version 1.0: 13/06/2019)

Title of Study: Creating guidelines for practitioners on communication regarding the management of the psychological and interpersonal impact of vulvodynia: A Delphi study

Name of Researchers: Zoe Hamilton (primary investigator)

Dr Danielle De Boos

Dr Anna Tickle

Thank you for taking part in this study.

What is the purpose of the study?

The aim of the research is to draw on the experience of practitioners, and women with vulvodynia in communicating regarding the psychological and interpersonal management of vulvodynia to identify guidelines for good practice.

The purpose of the research is to produce a set of guidelines that will aim to improve practitioner communication regarding the psychological and interpersonal management of the condition in the future.

The research has used the “Delphi method”, where interviews were conducted with practitioners with experience of working with women with vulvodynia, and women with vulvodynia, to elicit important issues in communicating regarding the psychological and interpersonal management of the condition.

During the interview you provided information and examples of your experience and suggested guidelines for practitioners in relation to communicating with women in the management of vulvodynia.

The guidelines were collated by the primary researcher and sent out to participants in the form of two surveys, where guidelines were considered in terms of importance, and then again in terms of importance relative to the other participants responses.

As a result of this process, the guidelines that reached the highest level of consensus were selected and finalised. Each guideline has the addition of a “clinical vignette”. These vignettes are examples of how to use the guidelines in practice and are borne out of your experiences of the management of vulvodynia, as well as the experiences of the other participants contributing to the research.

These guidelines will be offered as practice-based approaches to help support practitioners in communicating regarding the psychological and interpersonal management of the condition. It is intended that this set of guidelines will be used in future research to ascertain how they may be best used in practice, and what the outcomes of their use may be for women and practitioners. Anonymous information from interviews may also be used in further qualitative research.

If you have a concern about any aspect of this study, you can contact the research team, whose contact details are provided. If you wish to complain formally about any aspect of the process, you can do this by contacting The Research Innovation

Services, King's Meadow Campus, Lenton Lane, Nottingham, NG7 2NR. Tel: 0115 8467408.

Thank you for your time and contribution to this research.

Further information and contact details

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Appendix L

Introduction to Round Three Survey Including Voting on Structure and Organisation and Responses to Participant General Comments

Round Three Guidelines: Creating guidelines for practitioners on communication regarding the management of the psychological and interpersonal impact of vulvodynia: A Delphi study

Thank you very much to everybody who completed ratings and made comments on the Round Two guidelines. Your responses have contributed to the consensus generating process, and the next part of the study is to rate Round Three guidelines.

For Round Three, comments have been collated (made by participants who have responded to Round Two), and percentage agreement calculations (how much the panel of participants have agreed on each item) have been made for each rating option (1-6) on the scales provided.

Below, you will find Round Three Guidelines. These are comprised of all 40 suggested guidelines from the panel: consisting of 7 women with vulvodynia and 7 practitioners participating within this study, complete with the percentage agreement from the panel and all comments generated for each guideline.

Please note that comments and guidelines have been generated exclusively by the panel and not the researcher, and Round Three is an opportunity to comment on the panel's ratings as well as provide further comments to drive consensus further.

The following general comments about the structure and organisation of the guidelines have been made by participants, summarised below:

General comments from participants regarding structure and organisation:

One participant said:

"I think they come into 3 categories – maybe 4…

1. Good clinical practice – applicable for all areas of work
2. (possible extra point – could be included in 1. – important to read all previous consultations when seeing a patient so information doesn't have to be repeated
3. Unpacking of symptoms and impact on person's life, including relationship/partner – as particular to vulvodynia
4. Explanation of mechanisms, plan of actions
5. Future plan: resources available, recognition of need for onward referral."

Another participant suggested:

"Maybe they need dividing into: Initial consultation, follow-up appointment, long-term treatment"

General comments have been addressed by the researcher in the following way:

Below is the opportunity to comment regarding the structure and organisation of the guidelines in the final set, based on categories suggested by participants in Round 2.

Voting on Structure and Organisation

Please provide commentary on whether you feel the guidelines should be organised in either or both of the following ways suggested by the panel. You may prefer one option, a combination, or have other commentary on structure and organisation.

Suggestions regarding structure and organisation of guidelines	
5. Good clinical practice 6. Unpacking symptoms and impact 7. Explanation of mechanisms + plan of actions 8. Future plan – recognition of onward referral	4. Initial consultation 5. Follow-up appointment 6. Long-term treatment
Comment:	

One participant also stated:

"Overall I come away with the impression that possibly I would want one set of guidelines for primary clinicians and another for the more specialist ones"

In response to this comment, the researcher acknowledges that the intention of the research is to develop guidelines for all clinicians coming into contact with women with vulvodynia in their practice. With this is a recognition that people of one discipline may be involved in different ways throughout the process. Specific guidelines do refer to multidisciplinary practice and/or individual disciplines as appropriate.

General comments from participants regarding the guidelines:

Other general comments include the following:

"…and that the guidelines proposed have been heavily influenced by being answered by people who had significantly worse than average time to diagnosis, duration and severity of the illness, and bad treatment by professionals. I get a strong impression that a lot of it could have been avoided by a good therapist familiar with vvd and pain issues!"

"My general comment is that many of the guidelines are very similar"

"Maybe you could include many of those more comprehensive statements in an appendix to the guideline? I guess I am thinking that a guideline would have some short summary guidelines and then perhaps an explanatory section below which could include some of the longer, more detailed and comprehensive clinical guidance outlined in the guidelines towards the end of the list."

These have been addressed by the researcher in the following ways:

- Consideration regarding the influence of participant experiences on guidelines will be considered in the introduction to the finalised guidelines. For example, a statement will be provided that the guidelines have been produced by a panel of seven women with vulvodynia and seven professionals from a range of disciplines, which influences their contents in line with participant context and experiences.
- The process of generating consensus between panel members hopes to filter out guidelines which feel repetitive or inappropriate, through the process of rating and commenting, and privilege more helpful guidelines.

- Many of the guidelines which are similar have been placed after or before one another in the guidelines. Comments have been extremely helpful from the panel regarding which guidelines they feel are similar, and there are amendments, and options to vote in this round on which guideline may be chosen within a group of similar guidelines.
- Once Round Three is complete, a final set of guidelines will be produced, and these will be accompanied by clinical vignettes, based on information gathered in the initial interviews every participant took part in. These will be based on questions asked such as “tell me about a time when…” to generate examples of best practice. This should support guidelines to be contextualised in real world examples.

Thank you very much for all your suggestions, comments and ratings, and time taken to complete the initial Round 2 guidelines. Below is an individualised summary tailored to each participant, with your rating compared with the panel’s rating. There are also comments on each guideline from the panel.

For Round Three, please consider the below amended guidelines, and re-rate and comment on your re-ratings in order to drive consensus further.

Please could you return Round Three guidelines by **Monday 20th April 2020.**

Thank you again for your continued involvement in the research and towards driving the guidelines toward consensus.

If you have any questions or queries, please do not hesitate to contact me at zoe.hamilton@nottingham.ac.uk

Appendix M

All Delphi Responses and Feedback

General Comments from the Panel: Round Two

"I think they come into 3 categories – maybe 4…

6. Good clinical practice – applicable for all areas of work
7. (possible extra point – could be included in 1. – important to read all previous consultations when seeing a patient so information doesn't have to be repeated
8. Unpacking of symptoms and impact on person's life, including relationship/partner – as particular to vulvodynia
9. Explanation of mechanisms, plan of actions
10. Future plan: resources available, recognition of need for onward referral."

"Maybe they need dividing into: Initial consultation, follow-up appointment, long-term treatment"

"Overall I come away with the impression that possibly I would want one set of guidelines for primary clinicians and another for the more specialist ones"

"…and that the guidelines proposed have been heavily influenced by being answered by people who had significantly worse than average time to diagnosis, duration and severity of the illness, and bad treatment by professionals. I get a strong impression that a lot of it could have been avoided by a good therapist familiar with vvd and pain issues!"

"My general comment is that many of the guidelines are very similar"

"Maybe you could include many of those more comprehensive statements in an appendix to the guideline? I guess I am thinking that a guideline would have some short summary guidelines and then perhaps an explanatory section below which could include some of the longer, more detailed and comprehensive clinical guidance outlined in the guidelines towards the end of the list."

Comments on Structure and Organisation: Round Three

"Personally I would support a combined approach. Good practice points could be an overarching section, but I would then be tempted to utilise the initial/follow-up/longer-term strategy. My reasoning behind this would be to practically support those clinicians who do not regularly see such patients as it could be a more pragmatic guide in ensuring appropriate management is achieved at each stage. Non-specialists want go-to guidelines that clearly outline what needs to be done for a patient and when this needs to be done."

"I think the first option is a possibility, but don't think the second works. However, I have thought about structure and organisation as I have looked through this round and think the guidelines fit into the following categories (some of which are the same/similar to the first above) - I have included the corresponding guideline number in brackets:

1. Effective communications skills (good clinical practice)
    a. Building a relationship (2)

    b. Active listening and effective questioning (2)
    c. Empathy (2)
    d. Informed consent (4)
    e. Preventing patient feeling abandoned (9)
    f. Summarising/reflecting back (2)
    g. Woman's comfort
        i. Appointment practicalities (12)
        ii. Sufficient time (13)
        iii. Minimising distress (13)
2. Clinician competence
    a. Onward referral (1a)
        i. Ongoing assessment of need for onward referral (34a)
    b. Comfort in discussing sex (10)
    c. Awareness of diversity (26)
3. Assessment
    a. Symptom severity (1b)
    b. Woman's priority (16)
    c. Specific questions
        i. Re mental/emotional impact (14)
        ii. Re impact on sex and relationships (18)
    d. Pro forma (17)
    e. Impact of pain (27a)
4. Diagnosis (37)
5. Treatment
    a. Identifying goals (31)
    b. Challenging beliefs and expectations (34b)
    c. Chronic pain-management techniques (35)
6. Information-giving
    a. Signposting (5)
    b. Normalising (6)
    c. Re psychological impact (6)
    d. Prognosis (8)
    e. For partners (22)
    f. Re vulvodynia and pain (27b)"

"Suggestion 1 sounds good - prefer this to suggestion 2"

"I think a combination of the two ways would work. I think good clinical practice should be the first one, followed by initial consultation (which should then include unpacking of symptoms/impact, explanation of mechanisms, and at least some indication of a future plan). It might not be possible at the first consultation to necessarily have a detailed future plan if the purpose of the appointment is to get a diagnosis. Then, in the follow-up appointment, a more detailed plan of action should be given, which will then lead to 3.Long-term treatment."

"I like the 3 options better than the 4. I don't think "unpacking of symptoms and impact" sounds good"

Guideline 1: Be aware of what you're competent in, and if not then refer it on. There can be an assumption that unless a woman is having problems working, with poor relationship outcomes and a very poor quality of life, then symptoms are "not that serious". However, consequences can be severe if you're not competent in this specific area.

Participant Ratings and Shift

Guideline 1 was amended and expanded to Guidelines 1a and 1b:

Guideline 1a: Be aware of and work within the limits of your training, knowledge and competency. Be aware of the strengths of your discipline and those of other disciplines and gain an understanding of when it is appropriate to refer a patient to another discipline, assuming the patient supports the referral.

Guideline 1b: Do not make assumptions about the severity of symptoms and be aware that the current impact of vulval pain may get worse if they are not supported or get the wrong kind of support or advice.

Key: Guideline 1 ratings shown in **black**. Guideline 1a ratings shown in **green.** Guideline 1b ratings shown in **pink.**

Participant Number	1	2	3	4	5	6	Shift
1						X	
2					X		
3						X X	0
4					X	X X	+1, +1
5						X	
6		X		X	X		+1, -2
7					X X X		0, 0
8				X			
9					X X	X	+1, 0
10							
11		X		X	X		-2, -1
12					X X	X	+1, 0
13					X X	X	+1, 0
14					X		
Percentage Agreement and Number of Ratings	1	2	3	4	5	6	Total
% agreement Round Two 1 (*n*=13)	0%	0%	0%	15%	62%	23%	85%

% agreement Round Three 1a (*n*=8)	0%	13%	0%	0%	63%	88%	88%
% agreement Round Three 1b (*n*=7)	0%	14%	0%	14%	57%	14%	71%

Participant Comments:

Key:

Round 2 comments shown in **black**. Round 3 comments on Guideline 1a shown in **green.** Round 3 comments on Guideline 1b shown in **pink.**

- GPs need to be honest and refer appropriately - however there is concern that budgetary restrictions will negatively impact this.
- There are 2 different statements in this guideline. Clinicians knowledge. Clinicians measure of severity
- Although often a ‘given’, it is important to remind clinicians that “one should always work within one’s sphere of competence”. This is what is being said in the guideline, but could be more phrased in a more succinct manner.
- I think that this guideline applies to all aspects of clinical practice so is not specific for vulvodynia – therefore does it need to be included?
- The wording of this seems quite confrontational.
- Moreover ‘the consequences can be severe’ didn’t feel quite right. Could ‘consequences’ be replaced by ‘impact’ – that feels somehow better.
- Work within realms of competency and have good multi-disciplinary team to refer onto/seek support from
- I don’t like how this is worded.
- I don’t think ‘refer it on’, maybe it should say… To be aware of your skills competancy and ask for help in your field if you are unsure and gain backup that you need onward referral for the issue. Otherwise if they DO need physio then you refer on they may lose faith in physiotherapy.
- If something needs further invesitgation then you will need to refer on.
- Think the wording of the guideline can be perceived as accusatory - would want it framed in a way that people can hear it. I’d also emphasise different things (see below point) - Would frame this more as ‘be aware of the strengths of your discipline and of the strengths of other disciplines. Gain an understanding of when it’s the right time to refer someone onto another, but ensure this process is one that the patient is comfortable with and supportive of. Ensure they are actually in someone else’s care once you refer them on.’ - If we don’t have this framing then I think this guideline could be unhelpful – we don’t want the perpetuation of people being referred on and on which is a separate issue.
- Also feels like there are two guidelines here: (1) be aware of the strengths of your discipline etc… (2) Recognise that, however much someone’s vulval pain is currently impacting their life, things could get worse if they’re unsupported, or if they get the wrong kind of support or advice.
- This should be linked to adequate training, because a health care professional needs to know what their role in vulvodynia management is. I’m wondering whether there’s an issue with some doctors not being competent, but also not realising that they are not competent.
- Rewording: Ensure you have the correct knowledge skills and training to enable competency when dealing with this vulnerable patient group with a diagnosis of vulvodynia.
- The wording is much improved for the recipient to work positively.
- This should be standard practice for all GPs surely.

- Much better phrased, a good over aching statement
- This should be standard in any clinical care setting not just vulvodynia
- I think this is about competence in onward referral (1a). I think it is similar to 15 and could be merged to read: Be aware of and work within the limits of your training, knowledge and competency. Be aware of the strengths of your discipline and those of other disciplines and gain an understanding of when it is appropriate to refer a patient to another discipline, assuming the patient supports the referral. A multi-disciplinary approach is often beneficial.
- This is much better!
- Would there be resources available to practitioners on how to ‘gain an understanding’? Might be good to be able to signpost practitioners to appropriate resources.
- At this stage patients already feel at the end of their tether and feel isolated and in severe need of both physical and psychological easement.
- Again, on reflection this seems like obvious practice for any GP
- Much better phrased, a good over aching statement
- Also be aware some pain improves, its doesn’t always get worse.
- I think this is about assessment of symptom severity (1b). I don’t think the guideline above fully reflects the sentiment in the original one. I suggest the following: Do not assume that if symptoms are not having an impact on the woman’s quality of life and relationships that they are not severe.
- Could this be merged with the guideline above? Given that a poor understanding of vulvodynia would probably lead to wrong advice and support.
- I don’t think you need the second

Guideline 2: Have a smile on your face but have empathy. Try to consider the aloneness a patient may be feeling when they have vulvodynia e.g. imagine having unexplained genital pain that is hard to describe to others.

Participant Ratings and Shift

Guideline 2 was amended to Amended Guideline 2:

Guideline: Be kind and empathic. Acknowledge how ‘alone’ one can feel with unexplained genital pain and how difficult it can be to share such personal information with others.

Key: Guideline 2 ratings shown in **black**. Round Three Guideline 2 ratings deviating from the original rating shown in **red**. Amended Guideline 2 ratings shown in **green.**

Participant Number	1	2	3	4	5	6	Shift
1		X					
2			X				
3						XX X	0, 0
4					X X	X	-1, -1
5					X		
6				X	X X		-1, 0
7				XX	X		0, +1
8				X			
9					XX	X	0, +1
10							
11						X X	0
12			X			X X	-3, 0
13					X	X	+1
14					X		
Percentage Agreement and Number of Ratings	1	2	3	4	5	6	Total
% agreement Round Two 2 (*n*=13)	0%	7.7%	7.7%	15.4%	38.5%	30.8%	69.3%
% agreement Round Three 2 (*n*=6)	0%	0%	17%	33%	33%	17%	50%
% agreement Round Three Amended 2 (*n*=8)	0%	0%	0%	0%	30%	63%	100%

Participant Comments:

Key:

Round 2 comments on Guideline 2 shown in **black**. Round 3 comments on Guideline 2 shown in **red.** Round 3 comments on Amended Guideline 2 shown in **green.**

- Reassurance here is essential.
- I would prefer my doctors be competent than that they worry about their facial expressions - and this guideline feels vague. Is a smile always appropriate? what does it have to do with empathy?
- Empathy 'yes', but unsure about the smile on one's face – might come across as a little creepy and insincere while talking about a patient's genital area
- As for guideline 1 – important for all aspects of clinical practice
- Sounds again a little patronising to healthcare professionals but I don't know what these guidelines are like!
- Do not skirt around issues. Be bold and brave, and empathetic when asking questions; maintain a "you can't shock me" face too
- Prefer wording like ' Treat each patient with kindness and empathy. A smile may not be appropriate depending on the patient.
- Would say 'and' have empathy in first line.
- Not just aloneness, also the difficulty in being able to describe it using appropriate terminology – e.g. many women don't know the difference between the vulva and vagina, making it more difficult to adequately describe the pain.
- Rewording- Be kind and empathic with this patient group. Acknowledge how 'alone' one can feel with this diagnosis as it is such personal information to share.
- I still have the issues the reference to 'smiling' as raised in Round Two, so feel neutral about this as it currently stands. Empathy is essential, facial expressions should be dependent on the mood of the consultation so as not to come across inappropriate.
- Have put it as not important in light of seeing the amended version, which is much better thank you!
- I agree now that no comment should be made about smile, but maybe – think about demonstrating empathy and consider how the patient may be feeling with this diagnosis.

- Agree with improved wording. A good point to avoid being condescending to health professionals
- Amended version is great.
- Much better phrased
- Not just 'alone' its about feeling daunted, frustrated and confused. Alone isn't quite the right word – too narrow an emotion
- I think this is about the effective communication skill of empathy. However, the woman may not be feeling alone or have difficulty sharing. I think it fits well with the effective communication skills of: building a relationship (11a); listening and questioning (guideline 3); summarising / reflecting back (11b). I suggest combining them: Guideline 2: Remember basic effective communication skills. Consider how to build a relationship, particularly in the first appointment. Be kind and empathic. It may be appropriate to acknowledge how 'alone' one can feel and how difficult it can be to share such personal information with others. Make time, ask appropriate questions, actively listen and be responsive to what is being said. At the end reflect back what you have heard.
- Would remove quotation marks from around alone – makes it feel a bit patronising / like we don't actually feel alone (when we do!).

- I agree with the rewording – it’s not so much about having a smile on your face but rather just being empathetic.
- “Demonstrate kindness and empathy throughout assessment”

Guideline 3: Make time and actively listen and be responsive to what is being said in appointments. There is so much variation in symptoms of vulvodynia and the way it effects women, that the specific impact will vary for any given person. Use open questions such as “have you got any other issues that effect this issue?”, “how are you coping?”, “how is this affecting you?”. Make attempts to acknowledge that it must be difficult.

Guideline 3 was amended to Amended Guideline 3:

Amended Guideline 3: Make time, actively listen and be responsive to what is being said in appointments. There is so much variation in symptoms of vulvodynia and the way it affects women, that the specific impact will vary for any given person. Use open questions such as “have you got any other issues that affect this issue?”, “how are you coping?”, “how is this affecting you?”. Acknowledge that this is a difficult condition to live with. Check if they also need a referral for the impact on mental health, sex, relationships or occupation.

Key: Guideline 3 ratings shown in **black**. Amended Guideline 3 ratings shown in **green.**

Participant Number	1	2	3	4	5	6	Shift
1				X			
2				X			
3						X X	0
4						X X	0
5					X		
6					X X		0
7						X X	0
8					X		
9						X X	0
10							
11						X X	0
12						X X	0
13	X				X		-4
14						X	
Percentage Agreement and Number of Ratings	1	2	3	4	5	6	Total
% agreement Round Two 3 (*n*=13)	0%	0%	0%	15.4%	30.8%	53.8%	84.6

% agreement Round Three Amended 3 (*n*=8)	13%	0%	0%	0%	13%	75%	88%

Participant Comments:

Key:

Round 2 comments on Guideline 3 shown in **black**. Round 3 comments on Amended Guideline 3 shown in **green.**

- Time may not be available at initial visit (depending on clinical setting/presentation), but patients being reviewed at follow-up need to not feel rushed and feel they are being listened to.
- Important – to encourage unpacking vulvodynia
- Grammar – ‘effects’ should be ‘affects’ ☺
- Active listening and open questions are vital
- First line would change to: ‘Make time, actively listen, and be responsive to what is being said in appointments’
- Would change ‘effects’ in second sentence and ‘effect in penultimate sentence to ‘affects’ and ‘affect’ respectively
- ‘Acknowledge that this is a difficult condition to live with’ rather than ‘Make attempts to acknowledge that it must be difficult’. Has more oomf and sounds more validating to me.
- This guideline feels like 3 in one! Hard to say how I feel about it (last sentence feels like an
- extension of guideline 2). But largely would say all of it is essential.
- The attempts to acknowledge the difficulty is important as a way to show empathy.
- Rewording - Make time and actively listen and reflect back information to make sure of understanding. Communicate using open questions such as “have you got any other issues that effect this issue?”, “how are you coping?”, “how is this affecting you?”.
- I think this very much depends on which level of care you’re at. A GP isn’t going to know the difference. A specialist obviously should. It also seems like a guideline that is attempting to say “check if they also need a referral for the impact on mental health or sex or relationships or occupation etc” but doesnt clearly say it.

- Agree with new wording
- Much better after amendments. Although it’s a bit lengthy isn’t it?
- I don’t think it is necessary to explain what open questions are
- As stated above, I think this is about the communication skills of active listening and effective questioning and should be combined with 2. I would not include the last 2 sentences, which I think are about empathy (“Acknowledge that this is a difficult condition to live with”) and onward referral (“Check if they also need a referral for the impact on mental health, sex, relationships or occupation”).
- The last sentence isn’t needed so long as we keep guideline 1 – and could perhaps be added to the end of guideline 1. The rest is essential.
- I think that “have you got any other issues that affect this issue?” should be rephrased since the word ‘issue’ is repeated twice. Maybe ask if the patient has identified anything that makes the pain worse (or better). Also a patient might not necessarily know they have something else going on that affects vulvodynia and that might be something that a doctor needs to explain to them.
- Better wording here well done.

Guideline 4: Approach topics sensitively and gain consent for all discussions, examinations and procedures, as well as offer explanations for why they are happening. Pain can cause hypervigilance and anxiety; therefore it is important to be open and transparent about what examinations or treatments may increase or aim to decrease pain, and what the pros and cons are for each intervention.

Key: Guideline 4 ratings shown in **black**. Re-rated guideline 4 ratings shown in **red.**

Participant Number	1	2	3	4	5	6	Shift
1						X	
2				X			
3						X X	0
4					X	X	+1
5				X			
6				X		X	+2
7						X X	0
8					X		
9				X		X	+2
10							
11				X		X	+2
12					X	X	+1
13					X	X	+1
14						X	
Percentage Agreement and Number of Ratings	1	2	3	4	5	6	Total
% agreement Round Two 4 (*n*=13)	0%	0%	0%	15.4%	7.7%	76.9%	84.6
% agreement Round Three 4 (*n*=8)	0%	0%	0%	0%	0%	100%	100%

Participant Comments:

Key:

Round 2 comments on Guideline 4 shown in **black**. Round 3 comments on Guideline 4 shown in **red.**

- This should already be happening.

- As for 1 & 2 – all aspects clinical practice should reflect this
- Great!
- SO MUCH YES.
- This just reminded me of my first gyne appointment (with a non-vulvodynia specialist) who in a gyne examination said: " You don't look normal. Do you always look like that?" ... Not great! A sensitive approach would have helped!
- This is also an important aspect of obtaining informed consent in medicine in general – doctors should always be providing the necessary information in order for the patient to give informed consent.
- Rewording - Explain and give an opportunity to discuss what is going to happen in an appointment, then gain consent for all discussions, examinations and procedures at every appointment.

- Views seem to be consistent
- I think this is about informed consent. It is quite wordy. I don't understand the last sentence - surely all treatments aim to decrease pain. I suggest: It is important to obtain informed consent, i.e. offer explanations for discussions, examinations and treatments; then gain consent. Be open about what pain may be involved in each intervention and the possible pros and cons.
- I do like the wording 'Explain and give an opportunity to discuss what is going to happen in an appointment, **and** gain consent for all discussions, examinations and procedures at every appointment'. Instead of the first sentence here. But both are okay!
- Could add something along the lines of involving the patient in the decision-making process as much as possible – which is something that happens in medicine already.
- Brilliant guideline yes.

Guideline 5: Be aware of and triage layers of management and consider resources e.g. Vulval Pain Society website, where drug therapy is required, whether access to talking based therapy may be helpful, or information about washing practices.

In Round Two, the panel proposed Guideline 5 was similar to Guidelines 20, 21 and 23. A suggested alternative Combined Guideline 5 was offered based on panel comments:

Combined Guideline 5: Signpost patients to local pain groups and charities, such as the Vulval Pain Society or National Vulvodynia Association, as well as helpful books or websites. This may be a quicker way to get information and sensible ideas about non-intrusive management tactics and stop people feeling isolated. This is a first step in triage, before considering use of other resources, such as drug therapy or talking therapy.

Key: Guideline 5 ratings shown in **black**. Combined Guideline 5 ratings shown in **green.**

Participant Number	1	2	3	4	5	6	Shift
1				X			
2			X				
3					X	X	-1
4					X	X	+1
5				X			
6				X	X		+1
7						X X	0
8					X		
9				X		X	+2
10							
11				X X			0
12					X	X	+1
13					X	X	+1
14						X	
Percentage Agreement and Number of Ratings	1	2	3	4	5	6	Total
% agreement Round Two 5 (*n*=13)	0%	0%	7.7%	38.5%	30.8%	23.1%	53.9%
% agreement Round Three Combined 5 (*n*=8)	0%	0%	0%	13%	25%	63%	88%

Participant Comments:

Key:

Round 2 comments on Guideline 5 shown in **black**. Round 3 comments on Combined Guideline 5 shown in **green.**

- Data/information is readily available .
- I'm just confused by this. I dont really understand it.
- Not sure I would instantly understand the phrase "triage layers of management" when used in a guideline.
- Important – specific to vulval pain
- Guidelines 5 + 20 + 21 + 23 all about signposting to trusted sources of help. Essential + useful for patients
- Better wording 'Consider other appropriate resources which may be helpful'
- Would also add physiotherapy and hypnotherapy, or else wouldn't list so many things
- It would be helpful if they prepared their own booklets with information and signposting to further resources
- Rewording- Ensure an up to date resource list is available for patient with information that may relate to their problem, for example websites, podcasts and relevant books.

- Agree with comments and yes appropriate to avoid repetition of guidelines.
- I don't like the phrasing 'this is a first step in triage' because it's not really a step, it is something that can support while the other steps are followed.
- Clear and succinct. Would consider replacing 'drug therapy' with 'medication'; medication is a more supportive term whereas drugs could suggest negative implications
- Completely agree with this
- I think this is about information-giving by signposting. It is very wordy. I would expect practitioners to tell women about non-invasive management tactics as a first line of treatment. I suggest: Signpost women to local and national resources, e.g. the Vulval Pain Society, National Vulvodynia Association, books, websites.
- Reword – '…sensible ideas about non-intrusive management tactics and **help patients feel supported, and part of a wider community'**. As a general point, I try to word things with the positive in mind rather than the negative – it helps envision what's meant by moving conversation away from there being a 'lack of a negative thing', and towards a concrete positive vision.
- I don't think this should be a first step in triage before considering other resources – the VPS and NVA have useful information but are not a substitute for treatment, and using it as a first step could risk women feeling fobbed off. This is especially the case if they then read all of those resources that mention the types of first-line treatment available, yet they weren't offered those treatments. Rather it should be something that is done alongside treatment so that women feel less isolated and more informed, and useful for when first-line treatments don't help.
- Better to group.

Guideline 6: Make people aware that just because they have vulvodynia it doesn't make them "not normal", and that it can impact their psychological wellbeing. Many people might not know/realise this early on after diagnosis.

Guideline 6 was amended to Amended Guideline 6:

Amended Guideline 6: Educate the patient about the effects of vulvodynia and its impact on psychological wellbeing. Ensure patients are aware that having vulval pain is common and does not make them abnormal. Ensure they are aware of psychological support that is available to them alongside other support with more physical aspects of the condition.

Key: Guideline 6 ratings shown in **black**. Amended Guideline 6 ratings shown in **red.**

Participant Number	1	2	3	4	5	6	Shift
1					X		
2			X				
3	X				X		+4
4					X X		0
5				X			
6				X X			0
7					X X		0
8				X			
9				X			
10							
11				X		X	-2
12	X X						0
13					X	X	+1
14					X		
Percentage Agreement and Number of Ratings	1	2	3	4	5	6	Total
% agreement Round Two 6 *n*=13)	15.4%	0%	7.7%	30.8%	38.5%	7.7%	46.2
% agreement Round Three Amended 6 (*n*=7)	14%	0%	0%	29%	43%	14%	57%

Participant Comments:

Key:

Round 2 comments on Guideline 6 shown in **black**. Round 3 comments on Amended Guideline 6 shown in **green.**

- You’d hope medical health professionals would already be aware not to stigmatise conditions and to always consider the mental health impact but I guess we have to say so?!
- As for 1,2 & 4
- It’s “not normal” to have vulvodynia. Good to link the psychological well-being as a concept early.
- Better wording around the support you need to show for your patient.
- I don’t like the wording ‘make people aware’.. would prefer ‘ educate patient about the effects of vulvodynia and its impact on psychological wellbeing’.
- In its current form this feels unhelpful, particularly because most medical professionals are all too aware that vulval pain is linked up with mental health and all too ready to refer people onto psychosexual counselling.
- Would rephrase so it’s positive rather than negative. “Ensure patients are aware that having vulval pain is really common and doesn’t make them abnormal. Ensure they’re also aware of psychological support that is available to them alongside other support with
- more physical aspects of the condition’
- Difficult to balance this with "not in your head"...
- I’m not sure if this guideline is necessary – I would merge it with reassurances that it’s not all in their head but that psychological interventions may be helpful. Also I’m wondering if it’s actually unhelpful to be told that you’re normal, part of the point of being diagnosed is a recognition and validation that the pain isn’t normal.
- Rewording - There is usually a psychological component with a patient who has vulvodynia, it is important to explain the links.

- It is not normal to have pain but patients are not a normal for having it.
- I’m still unsure about this ‘abnormality’ reference. Being told that the pain is common and normal can force people to feel more isolated in their distress, like it’s something they just have to put up with.
- I think there are 2 information-giving aspects to this guideline that should be separated out: normalising and informing re the psychological impact. I suggest: a) Although vulval pain is abnormal and needs addressing, it is a recognised and common condition b) Vulvodynia can impact psychological well-being and psychological support is avaiable
- Better phrased, still important.
- Well worded, much better
- The second and third sentences are helpful, but the first sentence is unhelpful. Vulvodynia can be caused in part due to mental health problems. However vulvodynia doesn’t necessarily need to have a super bad impact on wellbeing – that part is socially constructed. We’re striving to heal, but that healing process would only negatively impact our mental health because of traumatic experiences we’ve faced with partners, peers, or medical professionals (which, in a more socially just world would be more or less eradicated). If a medical professional were to tell me that vulvodynia negatively impacts patients’ wellbeing then I’d be much more likely to develop bad mental health around it. Being aware that psychological support is there is good, being aware of how vulvodynia can be caused by tension and responses to stress, fight or flight etc is good. Being told how I supposedly feel is unhelpful though!
- This is better than the original guideline but it might be worth emphasising that whilst vulval pain is common, it doesn’t mean it’s something that they should be putting up with.

- I think that this would only be necessary if they had psychological issues, then support would be needed to explain that vulvodynia is more common than they think.

Guideline 7: Outcome measures or tools can be really useful to prioritise conversations and improve communication. These may be service specific and measure risk, anxiety and depression (e.g. Generalised Anxiety Disorder (GAD-7) and Patient Health Questionnaire (PHQ-9) questionnaires) chronic pelvic pain, bladder and quality of life (e.g. Female NIH-Chronic Prostatitis Symptom Index – NIH-CPSI), or others. This may support assessment to be more targeted, to spend more time on what is bothering the patient the most and to work out what their needs are, so that they can see the right person to address the most bothersome issue to begin with.

Key: Guideline 7 ratings shown in **black**. Re-rated guideline 7 ratings shown in **red**

Participant Number	1	2	3	4	5	6	Shift
1	X						
2						X	
3					X	X	-1
4						X X	0
5				X			
6						X	
7					X X		0
8				X			
9					X		
10							
11				X X			0
12				X			
13	X				X		-4
14	X					X	-5
Percentage Agreement and Number of Ratings	1	2	3	4	5	6	Total
% agreement Round Two 7 (*n*=13)	7.7%	0%	0%	30.8%	23.1%	38.5%	61.6
% agreement Round Three 7 (*n*=6)	33%	0%	0%	17%	33%	17%	50%

Participant Comments:

Key:

Round 2 comments on Guideline 7 shown in **black**. Round 3 comments on Guideline 7 shown in **red.**

- Above guideline was a bit too wordy for me.
- I really don’t want people who aren’t trained administering psych tests.
- DASS 21, CSI – central sensitisation inventory
- Not all clinicians are familiar with using such questionnaires, so would need be appropriate for the individual’s “sphere of competence”. Could this include “referral to a clinical psychologist” for appropriate assessment via such questionnaires as part of recommended management?
- Not sure that these are helpful. Can be non-specific, I prefer more attention to guideline 3.
- Finding a way to ensure pts receive outcome measures open to ?? is an ongoing challenge
- I’m not sure what this is. This feels like a more tangible action rather than a guideline, but I’m all up for the principle of having a patient-centred approach and figuring out what is priority for the patient before proceeding.
- Possibly later in the process. Can be overwhelming to include too much early on!
- I think it would be useful for there to be a pain questionnaire to fill in beforehand.
- I agree the above guideline is wordy but the fundamental point is still valid.
- I also agree maybe a pain questionnaire would be useful.
- The whole purpose of a validated questionnaire is that is can be used by ‘non-experts’ to assess psychological impact before and after an intervention. Almost tempted to push this from important into the essential category, although this might result in earlier escalation of referral if clinicians are uncomfortable with administering such questionaires.
- we absolutely need outcomes measures to guide treatment and see ifs effectiveness. The wording of this guideline needs more thought and there will be different questionnaires applicable to different healthcare settings.
- I think this is about assessing the woman’s priorities. My answer this round is very different to last round! I now think this is wordy and raises questions: Who will administer these tools? When? What will they do with the outcomes? I think this could be replaced with guideline 16.
- Seeing comments that this requires certain training/competency has made me think this is too specific to be a guideline. However we should definitely have a guideline around having a patient-centred approach and figuring out what is a priority for the patient before proceeding.
- I think a patient health questionnaire/ pain questionnaire should be prioritised over the GAD-7 one, the former could be helpful to give some background information before the first appointment, whilst the GAD-7 could be a bit too much for a first appointment and could even fuel distrust if it makes the patient feel like the doctor is assuming that it’s all in their head, even though in practice, of course, vulval pain impacts mental health and vice versa.

Guideline 8: Validate someone's problem as a problem worth time and thought. For example, letting someone know that they may have to live with it, but together you will try to find a way to help them live with it easier, and that as a practitioner you will support them to try everything before 'giving up'.

Guideline 8 was amended to Amended Guideline 8:

Amended Guideline 8: Validate someone's problem as a problem worth time and thought. Women should be supported with information regarding the prognosis of their condition and told that together you will try and find a way to help them with their symptoms.

Key: Guideline 8 ratings shown in **black**. Amended Guideline 8 ratings shown in **green.**

Participant Number	1	2	3	4	5	6	Shift
1				X			
2				X			
3					X X		0
4						X X	0
5					X		
6					X	X	-1
7					X X		0
8				X			
9					X X		0
10							
11					X	X	-1
12	X					X	+5
13						X X	0
14					X		
Percentage Agreement and Number of Ratings	1	2	3	4	5	6	Total
% agreement Round Two 8 (*n*=13)	7.7%	0%	0%	23.1%	38.5%	30.8%	69.3
% agreement Round Three 8 (*n*=8)	0%	0%	0%	0%	63%	38%	100%

Participant Comments:

Key:

Round 2 comments on Guideline 8 shown in **black**. Round 3 comments on Amended Guideline 8 shown in **green.**

- This will reap dividends in the patient's wellbeing.
- Also vague and confusing. Most people recover completely so won't need this.
- Patients need to be educated on their condition, and certainly need to be aware of the prognostic expectations in conditions which are not easy to manage.
- As for 1,2,4
- Yes yes yes – love this so much
- Validation of symptoms is very important.
- Don't like the giving up wording but the rest is great. Again, though they must give this information within their scope of practice, they cannot give them hope if the patient isnt going to improve.
- First sentence is really important - up for that being a guideline. Worried about the example given though as practitioners are still now at the stage of telling patients that they'll have to live with their condition when most of us don't! So this part I think is really unhelpful as an example.
- I'm not sure that giving up is the best terminology to use as it sounds a bit too negative. Also I would add that women should be told that it is going to take time for things to get better and that's normal.
- I still think this guideline is still essential. Noting some of the comments, though some women may be cured, and some women may find their pain decreases, there are still a lot of women from the Support Groups who have lived with this for 20 years.
- It's definitely better worded now.
- Better phrased
- I think this is about giving information about the prognosis and I don't like the first sentence because it is not in line with this. I suggest it is combined with guideline 33.
- This does feel like two separate guidelines. First sentence is essential. Second and third is less essential, but still important. Something about 'try to find a way' sounds quite negative – most people with vulval pain can heal fully, so rewording could be 'together you will find a way to help them with their symptoms, or a referral partner who can help further if not'. Given research is constantly evolving I wouldn't want anyone to feel like their condition is permanent just because one professional couldn't help them!
- This is good, more optimistic than the first version.
- Worded so much better. More succinct.

Guideline 9: Be aware that vulval pain is complex and multifaced and it combines the physical and the mental, and has various different routes and potential treatments. Check in through the process, schedule a phone call (e.g. 10 minutes) after someone has gone down one of the referral routes such as psychosexual therapy, in order to steward the person.

The panel suggested combining Guidelines 9 and 15 as follows:

Combined Guideline 9/15: Be aware that vulval pain is complex and multifaceted and it combines the physical and the mental, with various different routes and treatments available. A multidisciplinary approach is important because combination treatments need to be co-ordinated to be offered at the same time.

Key: Guideline 9 ratings shown in **black**. Re-rated Guideline 9 shown in **red.** Combined Guideline 9/15 ratings shown in **green.**

Participant Number	1	2	3	4	5	6	Shift
1	X						
2				X			
3				X	X	X	-1, +1
4					X X		0
5				X			
6					X	X	-1
7				X X		X	0, +2
8					X		
9				X	X	X	+1, +2
10							
11					X X	X	-1, -1
12					X	X X	-1, 0
13	X			X	X		-4, +1
14			X				
Percentage Agreement and Number of Ratings	1	2	3	4	5	6	Total
% agreement Round Two 9 (*n*=13)	7.7%	0%	7.7%	38.5%	23.1%	23.1%	46.2%
% agreement Round Three 9 (*n*=6)	0%	0%	0%	33%	67%	0%	67%

% agreement Round Three Combined 9/15 (*n*=8)	13%	0%	0%	0%	38%	50%	88%

Participant Comments:

Key:

Round 2 comments on Guideline 9 shown in **black**. Round 3 comments on Guideline 9 shown in **red.** Combined Guideline 9/15 shown in **green.**

- Who is this directed at? Should the GP be the "steward"?
- The totality of our requests need to balance the GPs time constraints - being realistic.
- This level of handholding is absolutely ridiculous to expect. You don't even get it paying privately. If you're not competent to chase up your own referrals you have bigger issues than vulvodynia.
- "Multifaced" or "multifaceted"? As in number 8, I am all for educating patients on their condition, but not convinced that services are flexible enough to schedule phone calls to patients at each step their management plan.
- Important – specific to vulval pain
- Wow, I wish I got a phone call!
- This suggests that there is one person "overseeing" the patients care. Is this what is meant? The reality of scheduling a 10 min phonecall is extremely challenging and difficult to organise across NHS Trusts/care pathways
- YES YES YES.
- This is two guidelines - (1) vulvodynia is multifaceted etc. and (2) provide ongoing support and ensure people aren't left unsupported
- I would say both are essential
- Limited resources: Is this realistic?
- I agree this is complex and multifaceted but I think that getting help from one practitioner initially will lead to follow on referrals if that practitioner feels that other facets of the MDT would be helpful for this person. From a physio perspective our initial assessment would pick this up.
- Better put in guideline 15
- I still think this guideline is still essential. Noting some of the comments, though some women may be cured, and some women may find their pain decreases, there are still a lot of women from the Support Groups who have lived with this for 20 years.
- Remain neutral. Agree with comments that NHS not flexible enough for this level of service. I suspect the division in comments above shows the patient expectation and NHS reality.
- Comment:the reality of having one person coordinate care is unrealistic at present, whether private or nhs
- I think this is about the communication skill of preventing the woman feeling abandoned when being referred on, often multiple times (the phrase "from pillar to post" is applicable in some cases - or perhaps "from physio to PST"!). Ideally there would be one professional as the anchor/steward/coordinator; most logically the GP. However, I recognise it is probably unrealistic to expect them to regularly check-in. I suggest: Because vulvodynia is complex and multifaceted and treatment may involve several approaches and professionals, women can feel there is no one person coordinating their treatment. Encourage women to discuss this with their GP.

- Sentence #1 is essential and works well in below amendment . Happy to not include second sentence given comments about realistic nature of this (though it should still be an ideal our health sector should work towards). The comment 'If you're not competent to chase up your own referrals you have bigger issues than vulvodynia' however was incredibly unfeeling and I think this could have been hidden from patients. Vulvodynia is a condition which often derives from trauma. We face difficulty with our interactions with medical practitioners – it's not easy to chase up referrals when you've been treated badly by some practitioners. There should be something about ensuring patients don't fall through a gap and get forgotten about however. Perhaps a call from their GP if a patient hasn't seen anyone within the NHS about their condition for the last year? Just to check in. Surely that shouldn't take a huge amount of resource!
- I think is important but it is a bit unclear who is responsible for this, and I'm not sure 'stewarding' the person is necessary, rather it's more just to check that the referral was helpful. A phone call might be a bit too much for some people, email should be an option. Or, given logistical constraints in practice, maybe it should be more about making sure that patients have clear contact information to get in touch if there are problems with the referral, rather than scheduling a phone call with each patient.
- Fully agree. New guideline more appropriate .
- Yes I like this better.
- Sensible and realistic statement.
- I do not think 9 and 15 should be combined as 15 is about the clinician's competence in onward referral and I have already suggested it should be combined with 1a.
- This is good. There should still be something about ensuring patients don't fall through a gap and get forgotten about however (see above comment). Might also add: 'a multidisciplinary approach **which particularly includes physiotherapy** is important…' given how successful physiotherapy is at healing vulval pain.
- I think combining 9 and 15 is a good idea! I prefer this one to the one above which I've interpreted as being more about the doctor checking in with the patient.
- Vulval pain "can be" multifaceted and complex – not always. "Consider a MDT approach"

Guideline 10: Sexual wellbeing and relationships have such a huge impact on general wellbeing. Practitioners should be aware of their unease in talking about sex and find ways to address it as a professional responsibility to become more comfortable. This could include identifying this as an area of training and may involve spending time in a Sexual Health clinic, with gynaecologists or psychosexual counsellors.

Key: Guideline 10 ratings shown in **black**. Re-rated guideline 10 ratings shown in **red**

Participant Number	1	2	3	4	5	6	Shift
1					X		
2					X		
3						X X	0
4					X	X	-1
5					X		
6					X X		0
7					X X		0
8				X			
9					X X		0
10							
11					X X		0
12					X X		0
13						X X	0
14					X		
Percentage Agreement and Number of Ratings	1	2	3	4	5	6	Total
% agreement Round Two 10 (*n*=13)	0%	0%	0%	15.4%	61.5%	23.1%	84.6%
% agreement Round Three 10 (*n*=8)	0%	0%	0%	0%	75%	25%	100%

Participant Comments:

Key:

Round 2 comments on Guideline 10 shown in **black**. Round 3 comments on Guideline 10 shown in **red.**

- Research is showing this to be a high value target for overall wellness.
- Mixed - i think its important for all professionals to understand their issues with sex and how that limits their practise, but the notion that they should go train with

gynaes etc . . . no. It’s unreasonable to expect all healthcare professionals to be perfect at everything.

- Add…or psychosexual counsellors
- The term ‘GU Medicine’ is being used less – perhaps use the term ‘Sexual Health’ instead?
- Good comment but non-specific
- Practitioners talking about sex need to be comfortable talking about it and especially so different types of sexual activities
- This would not be an area I would expect someone to be treating in with no expertise in treating pelvic health conditions.
- This links to guideline 1 about competency
- This is therapy, not medicine. Stop expecting your doctors to be therapists.

- I agree with the above comments. The key issue is to be aware and not have expertise.
- Nobody expects all health care professionals to be experts in everything (as suggesting in comments) but, should an individual identify an area that they are uncomfortable discussing, then this should be an area they consider exploring as part of their expected continuing professional development
- I think this was one of my guidelines, but re-reading it alongside the comments, I don’t think it conveys my underlying message, which is about the clinician’s competence in terms of comfort discussing sex. I now suggest combining it with 38 as follows: Some practitioners feel uncomfortable discussing sex and this can prevent them asking questions that give the patient permission to talk about the sexual and relationship consequence of their vulvodynia. Practitioners should be aware of their own levels of comfort and if this is an issue, consider relevant continuing professional development, e.g. spending time in a Sexual Health clinic, with gynaecologists or psychosexual therapists.
- Just regarding the comment ‘This is therapy, not medicine…’: I’m not expecting doctors to be therapists. I’m hoping that doctors can competently and compassionately ask questions about and discuss basic topics on sexual health and relationships as part of their wider treatment. I’m not asking for psychological analysis as this would be too much to ask, as well as being unhelpful to receive from someone who’s not trained in this area. There’s room for observing the link between the physical and mental more here.
- I agree with the rewording.

Guideline 11: The first appointment is really important for building up a relationship with a patient. You are likely to be fact finding and being empathetic when needed. After asking all questions to gather information, reflect back what you have heard e.g. “I am going to try and summarise...”, “My impression is...”. Try to put into a nutshell what the patient has told you, so that they know you have really heard their story.

Key: Guideline 11 ratings shown in **black**. Re-rated guideline 11 ratings shown in **red**

Participant Number	1	2	3	4	5	6	Shift
1	X						
2				X			
3						X X	0
4					X X		0
5					X		
6					X	X	-1
7					X X		0
8				X			
9						X X	0
10							
11					X	X	-1
12				X	X		-1
13	X					X	-5
14						X	
Percentage Agreement and Number of Ratings	1	2	3	4	5	6	Total
% agreement Round Two 11 (*n*=13)	7.7%	0%	0%	15.4%	30.8%	46.2%	77%
% agreement Round Three 11 (*n*=8)	0%	0%	0%	40%	40%	20%	60%

Participant Comments:

Key:

Round 2 comments on Guideline 11 shown in **black**. Round 3 comments on Guideline 11 shown in **red.**

- This should be the basic strategy for all conditions.
- An important good practice point for consultations with patients.

- Important but general guidelines, as for 1,2,4
- Always a danger with summarising that what is a challenging story gets reduced to one thing. I would add to this ‘making sure to capture how the patient feels about this issue’ but that may be a bit too much.
- Would frame this more as a general ‘active listening’ guideline, with the first appointment
- being an example of how the guideline could be put in place
- I think this is important although my only concern is whether there are time constraints on this, particularly within the NHS.

- Agree with above comments.
- Too general
- If attending privately, you will get what you pay for, but ideal situations are rarely achieved in any aspect of NHS medicine. Need to be re-badged as an important ‘good practice point’
- I prefer it combined with 19
- ‘It’s the NHS, deal with it’ – these sorts of comments really could’ve been hidden from patients - it lands as quite aggressive for me. I understand the general sentiment that this is a wider systemic issue that has to be tackled, and we can’t expect the guidelines to be able to resolve these issues alone.
- This should be a basic part of ALL NHS appointments.

Guideline 12: If possible, it is important to see the same practitioner in the right environment e.g. in a private, well lit room. Patients should be seen on time as much as possible, and the appropriate amount of time given to them.

The panel suggested combining Guidelines 12 and 19 as follows:

Amended Guideline 12: If possible, it is important to see the same practitioner in the right environment e.g. in a private, well lit room. Patients should be seen on time as much as possible, and the appropriate amount of time given to them. Help the patient not to feel rushed. It may take more time for the patient to sit down because of pain. Making more time for an appointment will allow for specific questions about the impact of vulvodynia too.

Key: Key: Guideline 12 ratings shown in **black**. Re-rated Guideline 12 shown in **green.** Combined Guideline 12/19 ratings shown in **red.**

Participant Number	1	2	3	4	5	6	Shift
1	X						
2				X			
3						X X	0
4						X X	0
5					X		
6				X	X	X	-2,-1
7					X X X		0, 0
8				X			
9						X X	0
10							
11				X	X	X	-1, -2
12				X X	X		-1,-1
13					X X		0
14						X	
Percentage Agreement and Number of Ratings	1	2	3	4	5	6	Total
% agreement Round Two 12 (*n*=13)	7.7%	0%	0%	15.4%	30.8%	46.2%	77%
% agreement Round Three 12 (*n*=5)	0%	0%	0%	40%	40%	20%	60%

% agreement Round Three Combined 12/19 (*n*=7)	0%	0%	0%	29%	43%	29%	71%

Participant Comments:

Key:

Round 2 comments on Guideline 12 shown in **black**. Round 3 comments on Combined Guideline 12/19 shown in **green.**

- Again - basic requirements for all.
- It's the NHS, deal with it. Everyone tries to do this, no-one manages it, it's rarely about you and it has nothing to do with vvd specifically
- An important good practice point for consultations with patients.
- Second part of this should go to guideline 19
- Ideally 60 mins for a new patient and 45 for follow ups

- Agree with combination of 12/19. Again the reality against NHS appointment times. 60 minutes seems unrealistic.
- Much better
- I think this is about good clinical practice and attending to patient comfort in respect to the appointment practicalities. I suggest making it clearer as follows: If possible the woman should be seen: by the same practitioner, in an appropriate environment, e.g. private, well-lit room, on time, with sufficient time, i.e. for the appointment to not feel rushed
- Neutral because of the first part – as above. Think guideline 19 is still important however.
- Combining these guidelines makes sense, I prefer it to the standalone guideline.
- I prefer the one above.

Guideline 13: Guideline 13: Be aware of the psychological impact of a woman repeating their vulvodynia story to a new practitioner each time, which can also limit time to deal with the present issues. For example, if you are inheriting a case, consider prefacing initial contact “this may be difficult to talk about again, but it would really help me to know [x, y, z], to know how we can help move forward.” If there are clinical notes, it may also be possible to summarise e.g. “I can see on the notes that this began from [x, y, z] we do not need to talk about that today, but we can if you want to”.

Minor wording amendments were made to Guideline 13:

Guideline 13: ~~Have an awareness~~ Be aware of the psychological impact of a woman repeating their vulvodynia story to a new practitioner each time, ~~and how repeating can also impact on how much time is left~~ which can also limit time to deal with the present issues. For example, if you are inheriting a case, consider prefacing initial contact ~~with a sentiment such as~~ “this may be difficult to talk about again, but it would really help me to know [x, y, z], to know how we can help move forward.” If there are clinical notes, it may also be possible to summarise ~~what you have read~~ e.g. “I can see on the notes that this began from [x, y, z] we do not need to talk about that today, but we can if you want to”. ~~This may help the narrative of the story whilst giving the patient choice to discuss what is important that day e.g. symptoms.~~

Key: Guideline 13 ratings shown in **black**. Amended Guideline 13 ratings shown in **red.**

Participant Number	1	2	3	4	5	6	Shift
1	X						
2					X		
3						X X	0
4				X	X		+1
5				X			
6					X X		0
7					X X		0
8					X		
9						X X	0
10							
11						X X	0
12					X	X	-1
13						X X	0
14				X			
Percentage Agreement and Number of Ratings	1	2	3	4	5	6	Total

% agreement Round Two 13 (*n*=13)	7.7%	0%	0%	23.1%	30.8%	38.5%	69.3%
% agreement Round Three 13 (*n*=5)	0%	0%	0%	0%	50%	50%	100%

Participant Comments:

Key:

Round 2 comments on Guideline 13 shown in **black**. Round 3 comments on Guideline 13 shown in **red.**

- There are no illnesses where you dont get asked over and over, its not about vvd or us, its about resources. Take a written summary with you if this is a problem.
- An important good practice point for most consultations with patients. Essentially this is the follow on from point 12 “where the patient is not seeing the same practitioner, the psychological impact can be ameliorated by ….”
- Important point for those difficult conditions where need to re-cap can be tedious/distressing. Perhaps applies more where sexual assault/abuse has been in the background
- WONDERFUL
- Repetition is not helpful, summarising and moving forwards is I think it’s especially important, if inheriting a case, to make it clear to the patient what they know about the case. That way the patient doesn’t have to repeat their entire story, which saves time and is also less upsetting.
- Good to acknowledge but rather long winded! Continuity of practitioner is essential in the correct environment, well lit room with sink and privacy.

- The relevant point is to balance the waste of time through repetition against the confidence of the patient in giving reassurance that together we are moving forward.
- Irritated by the first comment above – the repetition is damaging psychologically. It’s not the same as other health conditions as it can be prompted by trauma in a way that many other long term conditions are not. Taking a written summary of ones trauma is not viable for most people.
- This is important for all long term conditions not just vulvodynia
- I think this is about two things: good clinical practice of creating patient comfort by (i) making sure there is sufficient time to discuss the present issue(s); (ii) minimising distress from multiple re-telling of history. I know that patients are often asked the same things by multiple professionals, but I think women with vulvodynia might see more than the average number of professionals and find it more than averagely distressing to tell their story. Conversely, some may find it easier the more they tell it; however, this leaves less time to discuss the present issues. I suggest: Women may find it distressing to repeat their full vulvodynia story to a new practitioner and/or feel frustrated that this leaves less time to discuss the present issue. If possible, summarise what you know and ask the woman what she specifically wants to discuss in that appointment.
- This is a quick win, even when allowing limited time and human resourcing. It doesn’t take a huge amount to summarise what’s in clinical notes, and ask if there’s anything the patient wants to add, so you can spend more time on the present and moving the treatment forward. I think this could still be shortened to something more concise – a more general point about allowing patients to summarise their history themselves if they’d like to, but also offering to summarise it yourself.

- I agree with the amendments – this guideline is good because it acknowledges the psychological impact of repetition but also just the practical issues (in terms of time limits) with it. Repetition is inevitable (and sometimes necessary) but it's helpful to be told why you have to repeat yourself again. I don't think that repetition being common in the NHS is an excuse, and I think talking about vulvodynia, due to the fact that it impacts women in such a personal way, is different from talking about other chronic pain conditions, or other conditions in general. Also I've taken written summaries before and sometimes they'd get acknowledged and at other times completely ignored.
- I think as long as they have the same practitioner for the duration of their symptoms then the patient will not need to repeat again and again.

Guideline 14: Ask specific questions about the mental / emotional impact of vulvodynia. These may be questions such as: “how are your relationships going? How are you coping with your partner? How are you both coping with pain?”.

The panel proposed that Guideline 14 was similar or linked to Guidelines 3, 10 and 18. Participants were asked to provide commentary on whether they thought the guidelines were similar or linked, and whether they had a preferred Guideline or would consider a combination of most benefit.

As such, Guideline 14 was not re-rated.

Key: Guideline 14 ratings shown in **black**.

Participant Number	1	2	3	4	5	6	Shift
1						X	
2					X		
3						X	
4						X	
5					X		
6						X	
7						X	
8				X			
9					X		
10							
11					X		
12					X		
13						X	
14						X	
Percentage Agreement and Number of Ratings	1	2	3	4	5	6	Total
% agreement Round Two 14 (n=13)	0%	0%	0%	7.7%	38.5%	53.8%	92.3%

Participant Comments:

Key:

Round 2 comments on Guideline 14 shown in **black**. Round 3 comments on Guideline 14 shown in **red.**

- This area is linked to Guideline 10 .

- Don't forget single people exist. It's as important that you experience pleasure in your body for yourself as for a partner.
- Patient needs to be aware that the partner needs to be involved/informed of the condition as they will be affected (albeit differently) by the issues that the patient is experiencing.
- I think this was included in Guideline 3
- The practitioner asking these questions needs to have the right tools/pathways to manage/signpost the response
- It's important to gauge the boundaries of the patient with this though and not push if someone doesn't want to share. And to ensure it's not done in an othering or
- pidgeonholing way that equates vulval pain with sexual dysfunction.
- Preface with 'are you sexually active- then its easy to continue to ask questions about the relationship.
- Links with guideline 18

- Combine 3,10,14 and 18

- Yes linked. Guideline 14 probably the best but some of 18 is good too. Combination
- Similar, but not the same. Mental and emotional aspects of a health issues in an individual may (or may not) overlap with any relationships they might have. Also these relationships may (or not) be sexual in nature. Perhaps clarification and questioning on the effects of patients
- own wellbeing/mental health
- partner's wellbeing/mental health, and strength of relationship/support
- effects on sexual relationship

- They have have a similar theme. It is not necessary to be direct. Need to maintain a wide elemnt of sexual dysfunction but also be aware that not everyone experiences this and also that sex isn't important to everyone. Definitely guideline 10. This is much better wording.
- I think 14 is about assessment and asking specific questions about the mental/emotional impact of vulvodynia. 3 is about the general communication skill of active listening and effective questioning, and therefore different. 10 is about the practitioner's competence discussing sex, and therefore different. However, I think 14 and 18 are similar.
- I would prefer to keep 3 and 10 separate, but combine 14 and 18, but distinguish between individual vs couple experience, and if in a relationship, impact on general vs sexual relationship. I suggest the following, although realise it is very long-winded and would lend itself to a decision-tree/flowchart:

Ask the following specific questions:

- Are you sexually active, either alone and/or with a partner/partners? (Because may have multiple partners, e.g. casual or polyamory)
- If so, does the vulvodynia affect your sexual experience?
- If so, is it a problem for you?
- If so, in what way?
- Are you in a significant relationship/relationships?
- If so, does the vulvodynia affect your relationship generally and/or sexually?
- If so, is it a problem for you and/or your partner(s)?
- If so, in what way?

Refer on as required.

- Yes they are similar. Suggested combination - ‘Vulvodynia is a condition which is both affected by, and can affect, patients’ mental health as well as their physical health. Use open questions and active listening to explore how this might be affecting patients’ mental health and sexual relationships, while also respecting when patients may not want to go into detail about this just yet’. Other parts of this are perhaps too detail-oriented (e.g. identifying area of training, specific recommended questions etc.)
- I think these linked to guideline 14 because they are all related to the mental or emotional impact of it, though guideline 3 perhaps less so as that one is more to do with active listening. A combination of 14, 10, and 18.
- All similar. I prefer 14. I like the guidelines being succinct.

Guideline 15: Be aware of the psychological impact of a woman repeating their vulvodynia story to a new practitioner each time, which can also limit time to deal with the present issues. For example, if you are inheriting a case, consider prefacing initial contact “this may be difficult to talk about again, but it would really help me to know [x, y, z], to know how we can help move forward.” If there are clinical notes, it may also be possible to summarise e.g. “I can see on the notes that this began from [x, y, z] we do not need to talk about that today, but we can if you want to”.

Guideline 15 was combined with Guideline 9 in the Round Three survey, therefore there was no opportunity to re-rate Guideline 15.

Key: Guideline 15 ratings shown in **black**.

Participant Number	1	2	3	4	5	6	Shift
1						X	
2				X			
3						X	
4					X		
5						X	
6						X	
7						X	
8					X		
9					X		
10							
11					X		
12						X	
13						X	
14							
Percentage Agreement and Number of Ratings	1	2	3	4	5	6	Total
% agreement Round Two 15 (*n*=12)	0%	0%	0%	8.3%	33.3%	58.3%	91.6%

Participant Comments:

Key:

Round 2 comments on Guideline 15 shown in **black**. Round 3 comments on Guideline 15 shown in **red.**

- isn’t this already in NICE?
- I disagree with a combination running simultaneously. I recommend a patient to see one at a time. To put their energy and time into one programme. A little crossover may work but not 2 health professionals at the same time for one whole time. How do you know what is helping / hindering?
- Finding the right combination is tricky. We don’t have all the clinical evidence yet either
- ‘Consider MDT approach’
- I would combine this with the first part of guideline 9 (think I said guideline 9 and I’d be happy for them to be combined as they sound like the same thing)
- The combination is important – these need to be coordinated to be offered at the same time.
- Not really a guideline- an MDT approach is important so in essence if it was written as a guideline it would be important

- As already mentioned, I think 9 is about the patient not feeling abandoned. I think 15 I much more like 1a and have made a suggested change there. I agree with the above comments about it not being clear whether it is helpful to be regularly working with more than one practitioner at a time; but hopefully having a coordinator (9) would help discover this.

Guideline 16: Ask the patient, “what bothers you the most?”. What bothers the patient the most may be different to what you expected, and asking this question can ensure treatment is targeted towards that particular issue.

The panel proposed that Guideline 16 could be merged with Guideline 3. Participants were asked to provide commentary on whether they thought the guidelines were similar or could be merged.

The panel proposed Guideline 16 could replace Guideline 7. Participants were asked to provide commentary on whether they thought Guideline 16 should replace Guideline 7, or if Guideline 7 should be used as an example.

As such, Guideline 16 was not re-rated.

Key: Guideline 16 ratings shown in **black**.

Participant Number	1	2	3	4	5	6	Shift
1						X	
2					X		
3						X	
4						X	
5						X	
6						X	
7					X		
8					X		
9						X	
10							
11				X			
12						X	
13						X	
14						X	
Percentage Agreement and Number of Ratings	1	2	3	4	5	6	Total
% agreement Round Two 16 (*n*=13)	0%	0%	0%	7.7%	23.1%	69.2%	92.3%

Participant Comments:

Key:

Round 2 comments on Guideline 16 shown in **black**. Round 3 comments on Guideline 16 shown in **red.**

- Good for reassurance
- This will help formulate a personal targeted management plan for the patient – provided it is within the prognostic expectations of the condition. Don't promise to achieve the unexpected.
- Important – but again – I think could be part of guideline 3
- Hmm. Not sure because it can feel like a web of problems. Might feel reductionist. This can replace guideline 7 for me (or combine with the last sentence of it). Then the rest of guideline 7 can be an example
- This is important to know what treatment to prioritise.

- Though similar they are not the same. Guideline 16 would be actioned not as an initial question but later when drilling down.

- Yes, merge them.

- Similar but not the same. In other aspects of medicine, a patient may present with a myriad of issues, but identifying the main issue (to the patient) may help the clinician to best direct their management to achieve the most appreciated resolution
- Merged
- I do not think they could be merged or are similar. I think 16 is about assessing the woman's priorities.
- Yes they are similar. Suggested combination – 'Use a collaborative, patient-centred approach to explore what is most important for patients, and how their condition is affecting them. Ask open questions and actively listen, while also making clear that patients can opt out of these discussions if they're not yet ready to have them.'
- I think these two could be merged though I think the 'make attempts to acknowledge that it must be difficult' can be left out, it should already be covered under being empathetic.
- Can be merged

Guideline 17: Know to ask certain questions, a pro forma can help with this. Five things to cover may be: 1) What do you think is wrong? 2) What do you think is going to happen? 3) What do you think would help? 4) What do you feel is the impact on your relationship? 5) How do you think your partner feels about it?

Guideline 17 was amended to Amended Guideline 17:

Amended Guideline 17: Develop a pro forma to support structured assessments using open questions to seek information relevant to your discipline that takes account of what is important to the patient.

Key: Guideline 17 ratings shown in **black**. Amended Guideline 17 ratings shown in **green.**

Participant Number	1	2	3	4	5	6	Shift
1	X						
2				X			
3						X X	0
4				X	X		+1
5					X		
6			X			X	-3
7					X	X	-1
8				X			
9			X			X	+3
10							
11				X	X		-1
12			X	X			-1
13			X		X		+2
14				X			
Percentage Agreement and Number of Ratings	1	2	3	4	5	6	Total
% agreement Round Two 17 (*n*=13)	0%	0%	0%	23.1%	38.5%	38.5%	77%
% agreement Round Three Amended 17 (*n*=8)	0%	0%	25%	13%	38%	25%	63%

Participant Comments:

Key:

Round 2 comments on Guideline 17 shown in **black**. Round 3 comments on Amended Guideline 17 shown in **green.**

- I think a pro forma is a good idea but these questions do not cover important aspects of the woman's psychological well-being, i.e. the questions above are very symptom and relationship focussed.
- Questions 1 -3, the patient is probably at the last resort and may not want to hear when seeking help.
- Loving how everyone assumes all vvd folks are in a conventional relationship. A standardised assessment seems handy - but this one is more into therapy land, q 3 is going to confuse folks who dont know what options are available and 4 and 5 would be really offputting for many.
- Proforma – can be helpful – encourages not to miss points and makes it easier to recap a history quicker from reading – tends to make for structured note taking.
- I don't think it can be summarised to 5 things at all – a proforma of some sort is useful
- Agree with the general principal of asking open questions, I'm not set on giving practitioners this set of questions to ask though as I don't know well enough to say
- Each profession probably has their own developed proforma- in physio we have many more sections to cover

- A much improved guideline - supported.
- I think on reflection that I feel this should be standard procedure anyway.
- Maybe "specialties to consider developing" a proforma……
- Yes lovely
- I think this is about assessing using a pro forma. I don't think a pro forma requires all open questions. It might be helpful to include example questions from 14, 16 and 17.
- Think the principal of open questions is the guideline - this pro forma can be an example. Seems like the questions asked would depend on the role.
- Depending on the skill and experience of the practitioner a proforma may not be helpful.

Guideline 18: Ask about the impact on relationships, in order to support women early enough to explore the best options for their relationships. This may involve asking if the woman or her partner wishes to talk to someone about the wider impact of this condition, and a referral on for support.

In Round Two, the panel proposed Guideline 18 was similar to Guidelines 3, 10, 14, 15 and 17. A suggested alternative Combined Guideline 18 was offered based on panel comments:

Combined Guideline 5: Sexual wellbeing and relationships have a huge impact on general wellbeing. Ask specific questions about the impact of vulvodynia on their sexuality and relationships, to support women to explore the best options to support coping, e.g. referral to psychosexual counselling.

Key: Guideline 18 ratings shown in **black**. Combined Guideline 18 ratings shown in **green.**

Participant Number	1	2	3	4	5	6	Shift
1						X	
2					X		
3						X X	0
4						X X	0
5				X			
6			X	X			-1
7					X	X	-1
8					X		
9						X X	0
10							
11					X	X	+1
12					X X		0
13					X	X	-1
14					X		
Percentage Agreement and Number of Ratings	1	2	3	4	5	6	Total
% agreement Round Two 18 (*n*=13)	0%	0%	0%	23.1%	38.5%	38.5%	77%
% agreement Round Three Combined 18 (*n*=8)	0%	0%	0%	0%	38%	63%	100%

Participant Comments:

Key:

Round 2 comments on Guideline 18 shown in **black**. Round 3 comments on Combined Guideline 18 shown in **green.**

- Refers back to overall well-being Guideline 10.
- Yes, everyone should get offered talk/sex therapy if they want it.
- Not all clinics will have the time to address this themselves so referral to a clinical psychologist would certainly support this aspect of management.
- I think included in Guidelines 3 and in Guideline 15
- Holistic care is vital
- This is really really important. Don't want to say it's essential only because there are things on here that are even more important to me.
- Also to emphasise again this must be done well and without pidgeonholing as above
- This could be integrated with guideline 17.
- Links with guideline 14

- Fully uphold the combination of above into this succinct guideline.
- Yes, much much better to combine them all like this.
- Lovely
- I do not think 3,10,14,15,17 and 18 can be combined to produce this; but I like the succinctness of this! I have already made my suggestion of combining with just 14.
- This works as a combination - I'd want active listening to still be in the guidelines somewhere however.
- This is a good, concise guideline.
- Much better and much more succinct.

Guideline 19: Help the patient not to feel rushed. It may take more time for the patient to sit down because of pain. Making more time for an appointment will allow for specific questions about the impact of vulvodynia too.

Guideline 19 was combined with Guideline 12 to produce Guideline 12/19. Participants were given the opportunity to re-rate Guideline 19 as a stand-alone Guideline, or to leave it blank if they had voted and commented on Guideline 12/19.

Key: Guideline 19 ratings shown in **black**. Re-rated guideline 19 ratings shown in **red.**

Participant Number	1	2	3	4	5	6	Shift
1	X						
2			X				
3					X		
4					X		
5				X			
6					X X		0
7					X X		0
8				X			
9					X		
10							
11						X	
12				X		X	-2
13					X		
14				X			
Percentage Agreement and Number of Ratings	1	2	3	4	5	6	Total
% agreement Round Two 19 (*n*=13)	7.7%	0%	7.7%	23.1%	46.2%	15.4%	61.6%
% agreement Round Three 19 (*n*=3)	0%	0%	0%	33%	67%	0%	67%

Participant Comments:

Key:

Round 2 comments on Guideline 19 shown in **black**. Round 3 comments on Guideline 19 shown in **red.**

- Again - this is a resource issue for the most part, its not specific to vvd, expecting special treatment is a bit silly.
- An important good practice point for consultations with patients.
- General good practice point
- However we also know patients only absorb 20% of information/education. Telling about symptoms is exhausting. No more than 45 mins – 1 hour
- As above, part of guideline 12 can come here
- This could probably be merged with the other guidelines concerning asking questions about the impact of vulvodynia
- Same comment as above - if attending privately, you will get what you pay for, but ideal situations are rarely achieved in any aspect of NHS medicine. Need to be re-badged as an important ‘good practice point’
- I understand the resource related concerns. Perhaps there could still be something about ensuring patients don’t feel rushed as much as you can within the timeframe you have. If you’re short of time, you can, for example, be gentle and clear about the amount of time you at the beginning of an appointment and gently bring conversation to a close at the end.
- Maybe better worded as something like.. Take time to patiently address all needs in the session without rushing. I don’t like the flow of the words.

Guideline 20: Tell patients about the existence of charities and local pain groups such as the Vulval Pain Society, or Vulval Pain Groups. This may be a quicker way for information to be given. They may stop people feeling isolated and have sensible ideas about basic non-intrusive management tactics, and can help patients to start unpicking ideas about being a woman, genitals and sex.

Guideline 20 was combined with Guideline 5 to produce Combined Guideline 5. Participants were given the opportunity to re-rate Guideline 20 as a stand-alone Guideline, or to leave it blank if they had voted and commented on Combined Guideline 5.

Key: Guideline 20 ratings shown in **black**. Re-rated guideline 20 ratings shown in **red.**

Participant Number	1	2	3	4	5	6	Shift
1						X	
2				X			
3					X		
4						X	
5					X		
6						X X	0
7						X	
8					X		
9						X	
10							
11					X		
12						X	
13						X	
14				X			
Percentage Agreement and Number of Ratings	1	2	3	4	5	6	Total
% agreement Round Two 20 (*n*=13)	0%	0%	0%	15.4%	30.8%	53.8%	84.6%
% agreement Round Three 20 (*n*=1)	0%	0%	0%	0%	0%	100%	100%

Participant Comments:

Key:

Round 2 comments on Guideline 20 shown in **black**. Round 3 comments on Guideline 20 shown in **red.**

- be aware not all areas have such local groups.
- this and 21 look identical.
- Guideline 21 is similar and better
- Needs to be supported by clearly written/visual presented, evidence-based educational leaflets which dovetail into a clear clinical pathway for vulvodynia.
- Helpful and specific – could be last item on a proforma – 'what information/website/ other services have been highlighted to the patient?'
- Guidelines 5 + 20 + 21 + 23 are the same thing
- The only thing worth noting is that not all areas have vulval pain support groups. Doctors could perhaps play a role in setting these up.
  Links with guideline 5 don't need both
- Voted for amended guideline 5
- "Inform patients" sounds better, or "sign post"

Guideline 21: To signpost patients to more information, in order for them to understand vulvodynia more generally. Organisations such as the National Vulvodynia Association and the Vulval Pain Society can provide up to date information on local support groups and provide information about seeking support.

Guideline 21 was combined with Guideline 5 to produce Combined Guideline 5. Participants were given the opportunity to re-rate Guideline 21 as a stand-alone Guideline, or to leave it blank if they had voted and commented on Combined Guideline 5.

Key: Guideline 21 ratings shown in **black**. Re-rated guideline 21 ratings shown in **red.**

Participant Number	1	2	3	4	5	6	Shift
1						X	
2						X	
3						X	
4						X	
5					X		
6						X X	0
7						X	
8				X			
9						X	
10							
11			X				
12						X	
13						X	
14					X		
Percentage Agreement and Number of Ratings	1	2	3	4	5	6	Total
% agreement Round Two 21 (*n*=13)	0%	0%	7.7%	7.7%	15.4%	69.2%	84.6%
% agreement Round Three 21 (*n*=1)	0%	0%	0%	0%	0%	100%	100%

Participant Comments:

Key:

Round 2 comments on Guideline 21 shown in **black**. Round 3 comments on Guideline 21 shown in **red.**

- Needs to be supported by clearly written/visual presented, evidence-based educational leaflets which dovetail into a clear clinical pathway for vulvodynia.
- This seems to me to be part of Guideline 20
- Prefer the one before.
- Guidelines 5 + 20 + 21 + 23 are the same thing
- This can be combined with guideline 20 and other similar guidelines to a general: ‘gain an awareness of the variety of support that’s available and share this information with patients, putting particular emphasis on the Vulval Pain Society and London Vulval Pain
- Support Group’
- I’m wondering if guideline 20 and 21 should be merged together.
  Link with guideline 5 and 20
- Again agree with combined Guidelines as to Guideline 20
- Voted for amended guideline 5
- This can be combined with 21

Guideline 22: For those with partners, to provide more information for partners so they can have a better understanding of how vulvodynia is impacting their lives or their partner's lives.

Minor wording amendments were made to Guideline 22:

Guideline 22: For those with partners, to provide more information for partners so they can have a better understanding of how vulvodynia is impacting their lives or their partner's lives.

Key: Guideline 22 ratings shown in **black**. Re-rated guideline 22 ratings shown in **red.**

Participant Number	1	2	3	4	5	6	Shift
1				X			
2					X		
3			X	X			+1
4						X X	0
5					X		
6					X	X	-1
7						X X	0
8				X			
9					X X		0
10							
11					X X		0
12					X	X	-1
13				X	X		-1
14					X		
Percentage Agreement and Number of Ratings	1	2	3	4	5	6	Total
% agreement Round Two 22 (*n*=13)	0%	0%	7.7%	15.4%	46.2%	30.8%	77%
% agreement Round Three 22 (*n*=8)	0%	0%	0%	25%	50%	25%	75%

Participant Comments:

Key:

Round 2 comments on Guideline 22 shown in **black**. Round 3 comments on Guideline 22 shown in **red.**

- Maybe when a patient has been diagnosed the patient is encouraged to bring their partner
- Honestly if your partner wasn't interested to start with you've got bigger problems and an info leaflet probably isn't going to fix them.
- Yes but were is the information for partners? There is a podcast of VPs but I think this is quite old
- Patient needs to be aware that the partner needs to be involved/informed of the condition as they will be affected (albeit differently) by the issues that the patient is experiencing
- Repeat of Guideline 20
- I quite like this although I think a working group will have to write it!
- This is useful. Let's get info right for patient's first
- I'm not sure this is as important – if enough information is provided to the woman herself, then this information can be given to the partner as well.
- Offer an opportunity for partner to be involved in treatment sessions if they feel they would like this.

- Do not underestimate the value of a partner hearing for him/herself the reality of the symptoms from an HP
- I still feel this would have value but we'll have to write it first! I never received a leaflet about my condition until I got to the specialist gynae.
- I think this is about giving information for partners, which is great in theory, but as the comments above reflect, I am not sure what is available in practice.
- Still think this is important - perhaps guidelines for patients first are more important.
- I think the amendment is good though I think information for the woman is more important than specific information for the partner.
- If they have a partner I may encourage the partner to come to a session, its always good to get the partner onboard with the seriousness of the treatment

Guideline 23: Signpost to other places that a patient can find support. This may include recommending a helpful book or website. For a patient this may help them feel like they can help themselves a bit, if there is somewhere they can go.

Guideline 23 was combined with Guideline 5 to produce Combined Guideline 5. Participants were given the opportunity to re-rate Guideline 23 as a stand-alone Guideline, or to leave it blank if they had voted and commented on Combined Guideline 5.

Key: Guideline 23 ratings shown in **black**. Re-rated guideline 23 ratings shown in **red.**

Participant Number	1	2	3	4	5	6	Shift
1						X	
2			X				
3						X	
4						X	
5					X		
6					X	X	-1
7						X	
8					X		
9						X	
10							
11				X			
12						X	
13						X	
14					X		
Percentage Agreement and Number of Ratings	1	2	3	4	5	6	Total
% agreement Round Two 23 (*n*=13)	0%	0%	7.7%	7.7%	23.1%	61.5%	84.6%
% agreement Round Three 23 (*n*=1)	0%	0%	0%	0%	100%	0%	100%

Participant Comments:

Key:

Round 2 comments on Guideline 23 shown in **black**. Round 3 comments on Guideline 23 shown in **red.**

- see 20/21

- In many conditions, NHS resources cannot address all of a complex patient's needs. We seem to live in a society where individuals expect health services to do everything for them. It is therefore essential that patients engage with the advice from professionals and actively attempt to improve their own health, whether this be smoking cessation, healthy eating, exercise (for many physical conditions), or mindfulness and meditation (to facilitate relaxation).
- Guideline 20
- Prefer others.
- Guidelines 5 + 20 + 21 + 23 are all the same
- See comment under guideline 21
- This could perhaps be merged with guidelines 20 and 21. Perhaps if doctors provided a booklet about vulvodynia, which I'm aware some doctors do, these booklets can include signposting to places where women can get more information.
  Link to 5
- Voted for amended guideline 5.
- This is very similar to the other guideline about the signposting to support so merge this.

Guideline 24: If you don’t know the answer, don’t overprescribe and signpost without knowing. It is better to wait and call the person back once you know more. Make the journey shorter by trying to figure things out, so that the person you refer them onto can really help them. This may include using a range of resources that are available to understand vulval pain e.g. organisations/specialists private/NHS, and giving them to patients to reach out to.

Key: Guideline 24 ratings shown in **black**. Re-rated guideline 24 ratings shown in **red**

Participant Number	1	2	3	4	5	6	Shift
1	X						
2					X		
3					X X		0
4						X X	0
5					X		
6					X	X	-1
7					X		
8				X			
9				X X			0
10							
11			X				
12					X	X	-1
13		X			X		-3
14				X			
Percentage Agreement and Number of Ratings	1	2	3	4	5	6	Total
% agreement Round Two 24 (*n*=13)	7.7%	0%	7.7%	23.1%	38.5%	23.1%	
% agreement Round Three 24 (*n*=6)	0%	17%	0%	17%	50%	17%	67%

Participant Comments:

Key:

Round 2 comments on Guideline 24 shown in **black**. Round 3 comments on Guideline 24 shown in **red.**

- This is DANGEROUS. Pain conditions left untreated tend to get worse and develop complications and become harder to treat, AND, genital health symptoms can be indicative of all sorts of things including various forms of cancer, skin conditions that can leave permanent damage, etc etc. It is MUCH better to refer on when you're out of your competency area than to wait and see (especially as no GP has the time to research and many patients won't)
- A clear clinical pathway for vulvodynia is long overdue which results in a lottery as to whether patients are managed well.
- Repeat of the above
- This is about competency + getting it right first time. I assume this refers to GPs. I tis important however does not just relate to vulvodynia
- YES YES YES
- The key thing would also to be upfront with the patient that they don't know. My only concern would be, within the current system, that some doctors might forget to call back, or there might be lengthy delays in waiting for more information.
- This links with 1 competancy and 5 resources guidelines

- Signposting must be credible and not used liberallly.
- I don't know how I feel about this one sorry.
- Given the comments, this appears to be a divisive guideline – are respondents interpreting it differently? Does it require a list of practical steps to exclude other differential diagnoses, such as examining the skin and performing genital infection screen, and awaiting these without prescribing, then signposting with a better level of knowledge? Highlighting that certain steps need to be performed is different than suggesting "waiting", without an aim/purpose.
- I don't think this really adds anything or is specific enough for vulval pain.
- I think this is about competence in onward referral and is therefore included in 1a. I disagree with the first comment above - the guideline does not suggest "wait and see". However, I agree with the other comment that busy practitioners may forget to research and call back.
- Still think this is important. I understand the concerns about waiting too long however. I think if a practitioner is fairly sure of the appropriate next step for the patient then it's fine to refer on. This is more about if a practitioner is really unsure what to suggest for the patient. Always better to say you're not sure and to come back to them rather than to refer on or to say this is the end of the road. And we've got to be able to assume that practitioners will remember to get back in touch with patients.
- I'm concerned about patients getting lost in the system and not being called back, and I think this could be linked to a more general competency point – need to know when and where to refer and have clear reasoning behind it. I agree with the point in this guideline about making the journey shorter and not referring for the sake of it. At the same time they should err on the side of caution and refer rather than not refer if in doubt.

  Important but you have also duplicated yourself, I think that this is also somewhere else, to treat within your scope of practice and refer on when needed.

Guideline 25: It is important to empower the patient to feel confident to communicate with their partner about how pain physiology impacts on vulvodynia.

Guideline 25 was amended to Amended Guideline 25:

Amended Guideline 25: Women with vulvodynia should be given enough information to understand how pain physiology impacts on vulvodynia, and empowered to communicate with important others about it.

Key: Guideline 25 ratings shown in **black**. Amended Guideline 25 ratings shown in **green.**

Participant Number	1	2	3	4	5	6	Shift
1					X		
2					X		
3			X		X		+2
4						X	
5				X			
6						X X	0
7						X X	0
8					X		
9					X	X	+1
10							
11				X	X		+1
12						X X	0
13	X					X	-5
14						X	
Percentage Agreement and Number of Ratings	1	2	3	4	5	6	Total
% agreement Round Two 25 (*n*=13)	0%	0%	7.7%	15.4%	30.8%	46.2%	77%
% agreement Round Three Amended 25 (*n*=7)	14%	0%	0%	0%	29%	57%	86%

Participant Comments:

Key:

Round 2 comments on Guideline 25 shown in **black**. Round 3 comments on Amended Guideline 25 shown in **green.**

- Partner/partners/people they are casually fucking. . .
- Yes, but this isn’t a job for the average GP so who are these guidelines for?
- Full stop after partner then new sentence. This could include pain biology in vulvodynia diagnosis.
- Patient needs to be aware that the partner needs to be involved/informed of the condition as they will be affected (albeit differently) by the issues that the patient is experiencing
- I think this is important - more a management ending guideline
- Communication between patient/partners is important but it doesn’t need to be down to the detail of pain physiology – depends on the pt/partners
- I’m not 100% sure that it’s necessary as separate guideline – the starting point should be that the woman herself should be given enough information to understand how pain physiology impacts on vulvodynia, thus empowering her to communicate with others about it.

- Maybe consider combining with Guideline 22. Some partners may not fully comprehend or accept how real the pain can be and could this situation lead into abuse?
- Yes much better.
- Hopefully the term “important others” is more acceptable than the word “partner” to certain respondents!
- Lovely
- I don’t think this needs to be specifically about pain physiology, i.e. could say “…to understand vulvodynia and its possible impacts”. Apart from being given the information (which is covered in other guidelines), how will the women be empowered to communicate with others? This could be replaced with …”and encouraged to communicate with important others”; but is that always appropriate? I have too many questions about this guideline to think it could be helpful.
- Not women - ‘people with vulvodynia’. As you can have non-binary, agender, gender queer and trans men with vulvodynia too.
- I like this amendment – short and to the point. Information is empowering.
- Love it how it is

Guideline 26: There is a heteronormative approach to sex in society and touch and intimacy are not the same for everyone. How someone defines their womanhood and how they define sex have a direct relationship to how distressing they will find vulvodynia. You need to be aware that those concepts are an issue and that it's helpful to understand your patients' perspectives on this e.g. to make an appropriate referral to psychosexual therapy.

Guideline 26 was amended to Amended Guideline 26:

Amended Guideline 26: There is a heteronormative approach to sex in society and touch and intimacy are not the same for everyone. It is important not to assume patients' sexuality or gender, or assume any direct link between their sexual or gender identity and their condition.

Key: Guideline 26 ratings shown in **black**. Amended Guideline 26 ratings shown in **green.**

Participant Number	1	2	3	4	5	6	Shift
1					X		
2				X			
3					X	X	+1
4		X		X			-2
5				X			
6					X X		0
7					X	X	-1
8				X			
9					X	X	-1
10							
11					X X		0
12	X					X	+5
13						X X	0
14				X			
Percentage Agreement and Number of Ratings	1	2	3	4	5	6	Total
% agreement Round Two 26 (*n*=13)	7.7%	0%	0%	38.5%	30.8%	23.1%	53.9%
% agreement Round Three Amended 26 (*n*=8)	0%	13%	0%	0%	50%	38%	88%

Participant Comments:

Key:

Round 2 comments on Guideline 26 shown in **black**. Round 3 comments on Amended Guideline 26 shown in **green.**

- Never was referred so not sure how to answer.
- On reflection after saying this I think it's only relevant for the more specialised workers - not sure the average GP needs to think about these things.
- Included in 3
- Guidelines 10 + 26 are the same
- Link to guideline 1 about skills and training
- Started off like a good guideline but was confused by the end! I think this (without meaning to) gives the impression that people with vulvas who are gender queer or queer in their sexuality are more likely to find vulvodynia distressing. I don't know if this is necessarily true. As someone who's both gender queer and queer in their sexuality, I'd prefer something along the lines of 'to not assume patients' sexuality or gender, or assume any direct link between their identity and their condition. Instead, (if you are a psychological practitioner) to explore with the patient how their condition impacts their relationship with their bodies and their relationship with others, and offer support based on their responses'. This feels more positive to me and more in keeping with queer liberation'
- It's also important to understand when it's appropriate to refer to psychosexual therapy vs psychological therapy.

- You have either got a vulva or you haven't. Gender identity and sexual orientation doesn't matter
- Yeah, better.
- Better phrased, more succinct.
- This is true but it is not about vulvodynia
- I think this is about competency in being aware of diversity. I don't think "and touch and intimacy are not the same for everyone" is required. Also I suggest "Do not assume…" (less wordy).
- This is much, much better. I'd also add - 'heteronormative and cisnormative approach...'. Cisnormative = assuming everyone identifies with the gender they were assigned at birth.
- BUT its very similar to other guidelines, could be condensed and more succinct.

Guideline 27: There can be a misconception about vulvodynia being “all in your head”. If you are referring a patient to a psychological service, provide clarity about why this is happening e.g. key information may be “this is to help you”, that it is not a replacement for existing treatment, and that a condition such as vulvodynia can be hard to come to terms with, therefore psychological support can be helpful.

In Round Two, the panel proposed Guideline 27 was similar to Guidelines 28, 29 and 30. A suggested alternative Combined Guideline 27 was offered based on panel comments:

Combined Guideline 27: It will be important to ask about the impact of pain on a woman’s life and to emphasise that pain is a physiological process, which can impact on wellbeing, and that this does not mean it is “in your head”. If you are in a position to, explain chronic pain mechanisms and how stress and anxiety can exacerbate pain. If referring to psychological or psychosexual therapy, explain that this is not a replacement for existing treatment, but that psychological support can sometimes be helpful for overall wellbeing and support.

Key: Guideline 27 ratings shown in **black**. Combined Guideline 27 ratings shown in **green.**

Participant Number	1	2	3	4	5	6	Shift
1						X	
2				X			
3						X X	0
4						X X	0
5					X		
6					X X		0
7						X X	0
8				X			
9					X	X	+1
10							
11						X X	0
12						X X	0
13						X X	0
14					X		
Percentage Agreement and Number of Ratings	1	2	3	4	5	6	Total
% agreement Round Two 27 (*n*=13)	0%	0%	0%	15.4%	30.8%	53.8%	84.6%

% agreement Round Three Combined 27 (*n*=8)	0%	0%	0%	0%	13%	88%	100%

Participant Comments:

Key:

Round 2 comments on Guideline 27 shown in **black**. Round 3 comments on Combined Guideline 27 shown in **green.**

- It is essential to stress that this is an additional support for the primary problem and not a replacement for it.
- It comes back to the practitioner understanding pain biology. Pain is an output of the brain…
- Not sure that this is a guideline – more a philosophical point
- With good explanation of how psychology helps, that is treatment in itself
- Also worth emphasising to the patient that the brain plays a crucial role in mediating the experience of pain – thus psychological interventions can help to dial down the pain.
- Much better to describe as in guideline 28 than put the thought of all in the head up front!
- Better to explain the whole pain concept properly
- This is a two pronged approach and essential that it is pointed out and is additional and not a replacement treatment.

- Yes this is great at summarising all of the above. It's quite lengthy though. Does that matter?
- This is good!
- Lovely
- I think the suggested amended 27 includes 2 elements: a) assessing the impact of the pain b) giving information to explain the pain. I therefore suggest this is split into 2 separate guidelines. I see pain as a physiological AND psychological process and think both aspects need to be addressed.
- I like this – it's really important to emphasise that it's not in your head.
  Can be more succinct – don't like in your head – explaining pain in all chronic pain conditions is a must – but having it in there would be good. Emphasising the biopsychosocial model is important

Guideline 28: Try to explain chronic pain mechanisms in relation to vulvodynia, using information heard from the patient’s own examples and problems. This includes showing them how the physiology of the limbic nervous system impacts on their pain, and providing user friendly techniques like mindfulness, breathing exercises and stretches, including how they can redress the balance of the parasympathetic and sympathetic nervous system. Metaphors may be helpful e.g. a ‘volume button’ to show anything pain impacts on (e.g. sex and relationships, mood, how patient feels about themselves, taking medication, holidays or increased personal time), will probably turn the pain volume up. Conversations about stress and anxiety are important here because they are a big exacerbator of pain.

In Round Two, the panel proposed Guideline 28 was similar to Guidelines 27, 29 and 30. A suggested alternative Combined Guideline 27 was offered based on panel comments, therefore participants did not re-rate Guideline 28.

Key: Guideline 28 ratings shown in **black**.

Participant Number	1	2	3	4	5	6	Shift
1				X			
2						X	
3						X	
4						X	
5				X			
6						X	
7					X		
8				X			
9						X	
10							
11						X	
12					X		
13						X	
14						X	
Percentage Agreement and Number of Ratings	1	2	3	4	5	6	Total
% agreement Round Two 28 (*n*=13)	0%	0%	0%	23.1%	15.4%	61.5%	76.9%

Participant Comments:

Key:

Round 2 comments on Guideline 28 shown in **black**.

- This will be an investment for the patient’s understanding and acceptance of the journey as Vulvodynia is not a quick fix.
- Again, who are these for? cos yes I would expect this from people specialised in vvd or pain conditions but for GP’s etc probably not?
- Not all clinicians are familiar with using such techniques, so would need be appropriate for the individual’s “sphere of competence”. Could this include “referral to a clinical psychologist” for appropriate advice as part of recommended management?
- This is part of management – and good history taking – not sure that all this detail is helpful in a guideline
- I only learnt about this from my support group. Never heard this from a clinician and wish I had.
- If it is appropriate to talk about chronic pain as they may not have chronic pain at this point, but it is likely.
- This to me feels like more of an ‘action’ as it’s too detailed. The more general guideline feels like ‘to learn about chronic pain, keep updated with pain science, and, if the patient has anxiety, offer to explore techniques with them e.g.mindfulness’
- I feel like **these guidelines really need to be topline** otherwise I fear that they both won’t be applicable for the majority of patients, and that practitioners won’t take them in
  Essential so that the woman adequately understands what is going on, and also helps her communicate what is going on to other people (e.g. partners).

Guideline 29: Explicitly ask a woman or couple “what is the impact of ‘the pain’ in your life?”, and “what effect does that pain have in your life?”.

In Round Two, the panel proposed Guideline 29 was similar to Guidelines 27, 28 and 30. A suggested alternative Combined Guideline 27 was offered based on panel comments, therefore participants did not re-rate Guideline 29.

Key: Guideline 29 ratings shown in **black**.

Participant Number	1	2	3	4	5	6	Shift
1					X		
2						X	
3						X	
4						X	
5					X		
6						X	
7					X		
8				X			
9						X	
10							
11					X		
12					X		
13				X			
14						X	
Percentage Agreement and Number of Ratings	1	2	3	4	5	6	Total
% agreement Round Two 29 (*n*=13)	0%	0%	0%	15.4%	38.5%	46.2%	84.7%

Participant Comments:

Key:

Round 2 comments on Guideline 29 shown in **black**.

- Not sure the difference between these 2 questions
- This is tremendously essential. From my own experience I had some very dark days.
- I think this is the same as several of the other guidelines really.
- “How is this effecting your day to day?”

- Already included in the above
- Covered above I think but yes, this kind of thing.
- Need to gain good understanding of impact of pain
- This could be merged with other guidelines on asking questions about the impact of vulvodynia

Guideline 30: When women have been diagnosed with vulvodynia, it can be important to emphasise that pain is a physiological process, which can impact on wellbeing, and that this does not mean it is “in your head”. An explanation regarding how chronic pain works e.g. parasympathetic / sympathetic nervous systems, can support these conversations.

In Round Two, the panel proposed Guideline 30 was similar to Guidelines 27, 28 and 29. A suggested alternative Combined Guideline 27 was offered based on panel comments, therefore participants did not re-rate Guideline 30.

Key: Guideline 30 ratings shown in **black**.

Participant Number	1	2	3	4	5	6	Shift
1					X		
2					X		
3						X	
4						X	
5						X	
6					X		
7						X	
8				X			
9						X	
10							
11						X	
12					X		
13						X	
14						X	
Percentage Agreement and Number of Ratings	1	2	3	4	5	6	Total
% agreement Round Two 30 (*n*=13)	0%	0%	0%	7.7%	30.8%	61.5%	92.3%

Participant Comments:

Key:

Round 2 comments on Guideline 30 shown in **black**.

- This understanding will reassure and build confidence.
- seems like a mix of the other guidelines (so see 28)

- Why on earth would parasympathetic/sympathetic be relevant to chronic pain?
- I am not keen on this [“how chronic pain works”], I’d rather that we understand pain as a diagnosis in it’s own entity. It’s not always a problem of the local issues but a problem of the nervous and immune system. Chronic means >3 months. Some patients misinterpret chronic to mean severe therefore I quite like the term persistent.
- Needs to be supported by clearly written/visual presented, evidence-based educational leaflets which dovetail into a clear clinical pathway for vulvodynia.
- Already covered
- This is potentially better wording than the one above but definitely should be a guideline on this somewhere that mentions things being ‘all in your head’ as this is an important patient perspective that needs to be communicated.
- A good understanding of pain mechanisms is vital
- Similar to guideline 28
- This can be combined with other similar guidelines around not perpetuating the ‘it’s in
- your head’ narrative
- So many are worried that professionals (and others) think it's all in the patient's head.
- I think this could be merged with guideline 27 and 28.
- Reframed as guideline 28

Guideline 31: Identify treatment goals with patients by finding out how vulvodynia is affecting their life and what their realistic hope is, to target a solution. Establish how best to manage that hope e.g. with physical / pharmacological / psychological/ sexual aspects of treatment. When you have established what the pathways and goals are, you can address the path to get there. Review this at each visit to reinforce to the woman it has been taken seriously.

In Round Two, the panel proposed Guideline 31 was similar to Guideline 32. Combined Guideline 31 was offered for rating and commentary, therefore participants did not re-rate Guideline 31.

Key: Guideline 31 ratings shown in **black**. Combined Guideline 31 ratings shown in **green.**

Participant Number	1	2	3	4	5	6	Shift
1		X					
2					X		
3						X X	0
4						X X	0
5						X	
6					X	X	-1
7					X	X	+1
8				X			
9						X X	0
10							
11				X	X		-1
12			X			X	-3
13				X	X		-1
14					X		
Percentage Agreement and Number of Ratings	1	2	3	4	5	6	Total
% agreement Round Two 31 (*n*=13)	0%	7.7.%	0%	7.7%	38.5%	46.2%	84.7%
% agreement Round Three Combined Guideline 31 (*n*=8)	0%	0%	13%	25%	13%	50%	63%

Participant Comments:

Key:

Round 2 comments on Guideline 31 shown in **black**. Round 3 comments on Combined Guideline 31 shown in **green.**

- The setting of goals and a genuine plan must be agreed at an initial/early stage.
- So, some of these guidelines seem to have come from people who have unusually long lasting/persistent issues - which, I am one, but I'm very aware that 65-85% of people recover completely so why do we need to have elaborate guidelines about hope and long term etc? This stuff is only relevant if you're a long term patient and frankly even then I'd not be thrilled by it being this systematised. Also, at the start, a specialist is going to have a MUCH better notion of what the priority is. I mean I had no idea my labia were disappearing due to LS when I was first diagnosed.
- Already covered
- So many of these are so similar… I'm not sure which is best!
- + 32 is similar. Be specific goals help to direct the of most bothersome features
- Really good framing of something that's cropped up in different places above
- Also important to emphasise that the treatment goals do not necessarily lead to a cure.
- Agree with the new combined guideline.
- It's a bit heavy handed somehow.
- Happy to merge
- I know SMART goals are important generally – is it necessary to state this? Sounds a bit like college.
- I think this is about an aspect of treatment - identifying goals.
- I've never had this type of treatment but I feel it wouldn't work for me. I think this is too specific to be a guideline, but could perhaps be an example about how to make treatment patient-centred.
- I'm slightly unsure about the SMART goals – whether it would be too overwhelming if there are too many of them, or if certain goals aren't hit by the time set. I do think that identifying treatment goals overall is important at each visit.
- SMART goals are important, maybe do not need to revisit at every apt as sometimes I have patients coming for more than a year, may get repetitive.

Guideline 32: Goal setting can be done by all professions as part of the treatment plan, and should be done in detail. If a patient has a specific goal, ask them 'what does that look like on a day to day?', 'how will you achieve your goal?', 'what will you do whilst you are there to manage flare ups of pain'? Specific, Measurable, Achievable, Realistic and Time-bound (SMART) goals may be set by different professions depending on the treatment plan.

In Round Two, the panel proposed Guideline 32 was similar to Guideline 31. A suggested alternative Combined Guideline 31 was offered based on panel comments, therefore participants did not re-rate Guideline 32.

Key: Guideline 32 ratings shown in **black.**

Participant Number	1	2	3	4	5	6	Shift
1	X						
2					X		
3				X			
4						X	
5					X		
6						X	
7					X		
8							
9						X	
10							
11			X				
12	X						
13					X		
14						X	
Percentage Agreement and Number of Ratings	1	2	3	4	5	6	Total
% agreement Round Two 32 (*n*=12)	16.7%	0%	8.3%	8.3%	33.3%	33.3%	66.6%

Participant Comments:

Key:

Round 2 comments on Guideline 32 shown in **black**.

- As in Guideline 31

- This person needs a cognitive behavioural therapist, not a doctor.
- Patients should have realistic expectations with respect to their management and prognosis.
- Smart goals useful but not sure this is necessary.
- + 31. Be specific goals help to direct ??? of most bothersome features
- Think this really depends on the individual e.g. for me, this approach would be quite
- unhelpful.
- I think it should definitely be an option for patients and part of a wider ‘tailor your care to your patient’ type guideline (as an action one might take if a patient requests concrete next steps/a path to follow)

Guideline 33: Managing long-term expectations may involve being open and candid about vulvodynia being multifaceted and that additional support may be needed in the form of medical / psychological intervention. Explaining that this is not a quick fix, and it will be ongoing to work through, therefore a whole team approach may be required.

Minor wording amendments were made to Guideline 33:

Guideline 33: Managing long-term expectations may involve being open and candid about vulvodynia being multifaceted and that additional support may be needed in the form of medical / psychological intervention. Explain that lots of people recover from the condition, but that ~~this is not quick fix, and~~ for others it will be ongoing to work through, therefore a whole team approach may be required. This may include explanations of who the team is, how referral pathways work, and what kind of interventions exist.

Key: Guideline 33 ratings shown in **black**. Re-rated guideline 33 ratings shown in **red.**

Participant Number	1	2	3	4	5	6	Shift
1	X						
2					X		
3						X X	0
4						X X	0
5				X			
6						X	
7						X X	0
8							
9					X	X	-1
10							
11				X X			0
12	X				X		+4
13						X X	0
14					X		
Percentage Agreement and Number of Ratings	1	2	3	4	5	6	Total
% agreement Round Two 33 (*n*=12)	16.7%	0%	0%	16.7%	16.7%	50%	66.7%
% agreement Round Three 33 (*n*=7)	0%	0%	0%	14%	29%	57%	86%

Participant Comments:

Key:

Round 2 comments on Guideline 33 shown in **black**. Round 3 comments on Guideline 33 shown in **red.**

- Again only relevant for a minority, why scare people.
- Patients should have realistic expectations with respect to their management and prognosis.
- In my experience this is something professionals are already too good at. I wish I'd heard more about how a lot of people recover from the condition - this can help change one's mindset around it too. That's not to say that this isn't important. It is important to manage peoples' expectation. But I think in this climate (where the majority of healthcare professionals are saying that it's uncurable and that we'll have to live with it), it's not what I'd want to recommend practitioners to do more of
- Also it would be helpful if it's clear who the team is – how do the referral pathways work, what kind of interventions exist in that particular vulval clinic, etc.
- This will be covered in explain pain properly

- I note some of the comments but false hope mustn't be given to avoid loss of trust.
- I think this is about giving information about prognosis, and similar to 8. I suggest they are combined as follows: Explain that vulvodynia is usually a short-term condition *(if there is statistical evidence of %, then quote this)* but may be longer term and require a multi-disciplinary approach. This sounds to me like an early intervention and so at this stage it may be information overload to go into details of referral pathways etc.
- Much better thank you. Wouldn't want the word 'intervention' though - this sounds aggressive and intrusive. I'd recommend 'medical or psychological **support'**.
- I agree with the amendments.

Guideline 34: For health professionals to monitor moods beliefs and expectations with patients. Questions around moods may include ‘how does it make you feel?’. It is helpful for patients to understand their ability to cope with day to day mood and stress influences. Recognising how well or not they cope with stress, anxiety and depression can help them prevent a severe negative shift. Such severe shifts can influence their ability to cope with pain. Practitioners may ask ‘what do you think caused it?, what do you think will make it better?’, what do you think is going on down there?’ in order to understand the patient’s beliefs and offer alternative understandings. Ask patients about their expectations with questions such as “what kind of treatments are you expecting?, what improvements are you expecting?”, to understand and manage expectations.

Minor wording amendments were made to Guideline 34:

Guideline 34: For health professionals to monitor moods, beliefs and expectations with patients. Questions around moods may include ‘how do you feel about it~~does it make you feel~~?’. ~~It is helpful for patients to understand their ability to cope with day to day mood and stress influences. Recognising how well or not they cope with stress, anxiety and depression can help them prevent a severe negative shift. Such severe shifts can influence their ability to cope with pain.~~ Practitioners may ask ‘what do you think caused it?, what do you think will make it better?’~~, what do you think is going on down there?’~~ in order to understand the patient’s beliefs, ~~and offer alternative understandings.~~ Ask patients about their expectations with questions such as “what kind of treatments are you expecting?, what improvements are you expecting?”, to understand ~~and manage~~ expectations.

Key: Guideline 34 ratings shown in **black**. Re-rated guideline 34 ratings shown in **red.**

Participant Number	1	2	3	4	5	6	Shift
1	X						
2					X		
3				X		X	-2
4				X			
5				X			
6				X		X	-2
7					X X		0
8							
9				X		X	-2
10							
11	X			X			+3
12			X X				0
13				X	X		-1

14					X		
Percentage Agreement and Number of Ratings	1	2	3	4	5	6	Total
% agreement Round Two 34 (*n*=12)	16.7%	0%	8.3%	16.7%	33.3%	25%	58.3%
% agreement Round Three 34 (*n*=7)	0%	0%	17%	67%	17%	0%	17%

Participant Comments:

Key:

Round 2 comments on Guideline 34 shown in **black**. Round 3 comments on Guideline 34 shown in **red.**

- This could infuriate the patient because they are probably at their wits end with discomfort and pain and the last thing she would want to hear would be the above along the lines of ....”what kind of treatment/improvement are you expecting?”
- Again - cognitive behavioural therapist, not a doctor
- Patients with any condition will have their own pre-conceptions around their condition and it is always important to explore these and then address any false/incorrect assumptions.
- Don’t like phrasing of some of this.
- How does it make you feel? Very disempowering “how do you feel about it?’ more empowering. What do you think caused it? Also potentially tricky as do they have time for the answer?
- Relates to guideline 28
- Don’t use the term ‘down there’. I would use professional language.. ‘your vulva / vagina’.
- This feels quite specific again - this wouldn’t be something I’d find helpful personally so I wouldn’t want it to be a general guideline. I can see why it’d be helpful for others though and I don’t mean at all to diminish the importance of that.
- This may lead the patient to believe that it is being implied that it's no physiological.
  As for expectations: surely improvement/cure applies to all patients.
  Vvv wordy as a guideline

- Previously put neutral but looking at comments maybe it should be removed ?
- It feels like it’s been covered in the others above.
- Feels a bit vague
- I think this includes 2 aspects: a) the clinician’s competence in ongoing assessment of need for onward referral b) the treatment strategy of challenging beliefs and expectations. I would therefore suggest if this guideline is retained, it is divided into 2.
- I think there are more important guidelines - psychological practitioners will be great at doing this anyway. And I think for other practitioners it’s probably not the most important thing, and a difficult thing to do well / make use of without psychological training I’d imagine. Also it can be unhelpful to fixate on the ‘cause’ of one’s condition so I wouldn’t want to be repeatedly asked about that.

- I’m not sure, on reflection, if this needs to be a separate guideline. I do think the amendments are good but it relates to some of the other guidelines on active listening and could be merged with guideline 3.

Guideline 35: A holistic approach can include supportive conversations with patients to think about who is on their ‘team’ in their social network, and who they may be able to confide in. Chronic pain patients may find it helpful to be supported to find ways to get their hobbies back, or a sense of joy or happiness. Use of the “Pain Toolkit” (https://www.paintoolkit.org/) with patients can help to explore themes about anger and acceptance of pain, as well as moving forward.

Key: Guideline 35 ratings shown in **black**. Re-rated guideline 35 ratings shown in **red.**

Participant Number	1	2	3	4	5	6	Shift
1	X						
2						X	
3			X	X			+1
4					X X		0
5				X			
6					X X		0
7					X X		0
8							
9				X		X	-2
10							
11					X		
12						X X	0
13				X	X		-1
14					X		
Percentage Agreement and Number of Ratings	1	2	3	4	5	6	Total
% agreement Round Two 35 (*n*=12)	8.3%	0%	8.3%	8.3%	50%	25%	75%
% agreement Round Three 35 (*n*=7)	0%	0%	0%	43%	43%	14%	57%

Participant Comments:

Key:

Round 2 comments on Guideline 35 shown in **black**. Round 3 comments on Guideline 35 shown in **red.**

- No objection to suggesting the pain toolkit, but again, most people aren't going to be chronic. most people get better.
- Not something I was aware of but if the evidence is there the important to include.
- I like this.
- The whole package about pain is key
- Big thumbs up to a holistic approach (this could perhaps be combined with an above guideline around acknowledging the importance of different disciplines
- I think the pain toolkit is useful but I don't think it replaces adequate psychological interventions.
  Again linked to resources guideline no 5 all about the virtual MDT
- Will need to respect patient preference and leave this to the HP's judgement in application.
- Whole package of care is important
- I think this is about treatment and includes general chronic pain-management techniques.
- This is important but could be combined with the guideline around having a holistic approach and directing people to resources, and used as a practical example.
- I think the usefulness of this guideline depends on who uses it – if it's a practitioner who regularly works with the pain toolkit it would be more helpful than if it's a practitioner who's heard of it but isn't very familiar with it.
  Always best for a holistic approach.

Guideline 36: Explain the vulvodynia diagnosis thoroughly to the patient. This may involve an explanation about the physiology of pain, so that the patient knows why it is happening.

Minor wording amendments were made to Guideline 36:

Guideline 36: Explain ~~the~~ the current understanding of a vulvodynia diagnosis ~~thoroughly~~ to the patient. This ~~may~~ will involve an explanation about the physiology of pain, so that the patient ~~knows~~ understands why they are experiencing pain. ~~it is happening.~~

Key: Guideline 36 ratings shown in **black**. Re-rated guideline 36 ratings shown in **red.**

Participant Number	1	2	3	4	5	6	Shift
1				X			
2					X		
3			X			X	+3
4						X X	0
5						X	
6					X	X	-1
7						X X	0
8							
9					X	X	-1
10							
11					X	X	+1
12	X					X	+5
13		X				X	-4
14						X	
Percentage Agreement and Number of Ratings	1	2	3	4	5	6	Total
% agreement Round Two 36 (*n*=12)	8.3%	0%	8.3%	8.3%	16.7%	58.3%	75%
% agreement Round Three 36 (*n*=7)	0%	14%	14%	0%	0%	71%	71%

Participant Comments:

Key:

Round 2 comments on Guideline 36 shown in **black**. Round 3 comments on Guideline 36 shown in **red.**

- Do we think it isnt being explained or do we think people arent in a state to grasp it in an appointment? also again this is two things in one.
- ["Thoroughly"] – is this possible?, ["may"] – will, ["knows"] - understands
- Explain our "current understanding of vulvodynia" thoroughly to the patient. There remains gaps in our own understanding of the causes and management.
- This or one of the above. All very good.
- Totally
- Must explain the WHY they are getting pain to every patient.
- Up for explaining the diagnosis thoroughly being a guideline and explaining basic pain science along with that but I think it's unhelpful to ask practitioners to see their explanation as 'why it's happening', because, ultimately that is different for different people, and only the patient can really know that
- I feel like this guideline isn't necessary given that there are more detailed ones already discussed above that pretty much mention the same thing.
  link to no 28 explain pain

- I agree with the comments above and that this guideline can be combined as this has been covered.
- Yes this is still strong – I never received an explanation around pain at the GP (or even at the specialist!), only found out about it through my support group & then reading up on it. It has helped me understand my symptoms much better.
- Patient education is essential.
- I think this is information-giving about vulvodynia/pain and is covered in 27b.
- Much better thank you. Though this can be combined with similar guidelines around explaining the physiology of pain / pain science.
- I think it is similar to other guidelines and should be combined. The actual explanation of pain physiology is important, just not this particular guideline as a standalone guideline.
- Perfect!

Guideline 37: Be careful not to mislabel vulvodynia, treat it as a proper diagnosis.

Minor wording amendments were made to Guideline 37:

Guideline 37: Be careful not to mislabel vulvodynia, which is a pain syndrome; treat it as a proper diagnosis. If you are in a position to, give a precise specific subset diagnosis.

Key: Guideline 37 ratings shown in **black**. Re-rated guideline 37 ratings shown in **red.**

Participant Number	1	2	3	4	5	6	Shift
1						X	
2					X		
3						X X	0
4						X X	0
5					X		
6					X	X	-1
7						X X	0
8							
9				X	X		+1
10							
11					X	X	+1
12						X X	0
13		X				X	+4
14				X			
Percentage Agreement and Number of Ratings	1	2	3	4	5	6	Total
% agreement Round Two 37 (*n*=12)	0%	8.3%	0%	16.7%	25%	50%	75%
% agreement Round Three 37 (*n*=8)	0%	0%	0%	0%	25%	75%	100%

Participant Comments:

Key:

Round 2 comments on Guideline 37 shown in **black**. Round 3 comments on Guideline 37 shown in **red.**

- I do not understand what the mislabelling might be.
- I dread to think what was said to this person.

- Add: “which is a pain syndrome”.
- Don’t just write it on the medical notes! (lol)
- This does not add anything to a guideline at all
- Would add particularly misdiagnosing it as ‘dyspareunia’, which is so so common. Sidenote: dyspareunia ultimately feels like a symptom to me and we need professionals to know that. I’m not a health professional so maybe I’m wrong here but I don’t see how it’s a diagnosis
  Also make sure to give a precise diagnosis – e.g. neuroproliferative vestibulodynia, hormonally-mediated, provoked or spontaneous pain. Sometimes vulvodynia can be a bit too broad of a diagnosis without the specific subset diagnosis.

- I would agree with the statement it is Vulvodynia as the primary diagnosis and then work on the subset.
- Really encouraged to read people’s feedback on this but would agree about the danger of seeing dyspareunia as a diagnosis rather than a symptom. While a diagnosis can be labelling, it can also help the patient know where to find support and enable them to feel better understood and validated.
- I think this is about diagnosis; however I don’t like the phrase “treat it as a proper diagnosis”. I suggest: Once assessment results allow, give a formal diagnosis of vulvodynia (a pain syndrome) and beware of mislabelling (e.g. as dyspareunia, which is a symptom of vulvodynia). If you are in a position to, give a precise specific subset diagnosis.
- Would also add to be aware that conditions that may be referred to as dyspareunia or vaginismus are often vulvodynia which haven’t been diagnosed correctly.
- Good!
- I feel vulvodynia is a proper diagnosis. But can be more specific like primary provoked vulvodynia. Or secondary unprovoked vulvodynia. Or Vulvodynia secondary to recurrent thrush / BV. Just need to be very specific if possible as this will guide treatment and make it clear for the another professional picking their treatment up.

Guideline 38: It is helpful to be aware that asking a question is permission giving, and that by asking something you are giving a client permission to talk about it.

Key: Guideline 38 ratings shown in **black**. Re-rated guideline 38 ratings shown in **red.**

Participant Number	1	2	3	4	5	6	Shift
1	X						
2				X			
3			X X				0
4			X			X	-3
5					X		
6				X	X		-1
7				X	X		-1
8							
9					X X		0
10							
11				X X			0
12		X		X			+2
13		X			X		-3
14				X			
Percentage Agreement and Number of Ratings	1	2	3	4	5	6	Total
% agreement Round Two 38 (*n*=12)	8.3%	8.3%	8.3%	25%	41.7%	8.3%	50%
% agreement Round Three 38 (*n*=8)	0%	13%	25%	50%	13%	0%	13%

Participant Comments:

Key:

Round 2 comments on Guideline 38 shown in **black**. Round 3 comments on Guideline 38 shown in **red.**

- Can be useful to allow the patient to open up.
- Yet again vague and also very much a therapy idea not a medical doctor thing.
- An important good practice point for consultations with patients.
- This is surely part of the etiquette of a consultation non-specific to vulvodynia

- I’m not sure what this means? Are we saying ‘give clients space to talk about things in as
- much detail as they’d like’ or are we saying ‘give clients space to take your question in a
- direction they need to’ or something else?
- Think we need to nail down what this means before taking a vote on it as people will likely
- interpret it differently
  I’m not sure this needs to be a standalone guideline – perhaps integrated with some of the others to do with talking to patient.
- Downrated on the basis that this is included in normal practice.
- Just feels so general and slightly patronising. I worry that if there are patronising guides in this guideline, GPs will dismiss it.
- More of a general principle rather than a guideline
- I think this is one of mine, but actually I now would prefer to include it with 10 (I meant that asking questions about sex and relationships gives a woman permission to talk about these subjects).
- I think this could be added to other guidelines around asking open questions and actively listening. My understanding of the key message with this around giving patients space to answer questions and actively listening to their responses.
- I don’t think this should be a separate guideline – it’s quite vague and either needs to be merged or rephrased. I feel like this has more to do with understanding that vulvodynia can be a difficult topic to talk about – especially when it comes to the impact of it on things like sex – so for example when a healthcare practitioner specifically brings up the question of how does vulvodynia impact your sex life, this encourages the patient to talk about when they otherwise might not have said anything or not in a lot of detail.
  Sorry changed my mind, I don’t think you need this, its vague.

Guideline 39: Take women seriously when they come to you about vulvodynia. That doesn’t necessarily mean ‘be serious’. Having a human face alongside your professional one means being open to hearing people’s story and accepting that people’s stories are different. This includes believing what people say.

Key: Guideline 39 ratings shown in **black**. Re-rated guideline 39 ratings shown in **red.**

Participant Number	1	2	3	4	5	6	Shift
1	X						
2						X	
3				X	X		-1
4					X		
5					X		
6				X	X		-1
7						X X	0
8							
9					X X		0
10							
11				X		X	-2
12						X X	0
13		X				X	-4
14				X			
Percentage Agreement and Number of Ratings	1	2	3	4	5	6	Total
% agreement Round Two 39 (*n*=12)	8.3%	0%	0%	8.3%	41.7%	41.7%	83.4%
% agreement Round Three 39 (*n*=7)	0%	14%	0%	43%	14%	29%	43%

Participant Comments:

Key:

Round 2 comments on Guideline 39 shown in **black**. Round 3 comments on Guideline 39 shown in **red.**

- There seem to be 4 different parts to one guideline which is way too many. Also this is generically true for all health issues.
- An important good practice point for consultations with patients.

- + 2
- This should be known by health professionals.
- 100%
- This shouldnt need a guideline – its how all professionals should treat everyone

- Have noted comments and would remove guideline.
- Changed how I feel about this one – it should be standard practice.
- Essential statement, but more of a general principle for all aspects of medicine rather than a guideline
- I think this is covered by previous guidelines.
- On reflection I'm not sure that this guideline is that important to have a standalone guideline. It seems to be linked to being empathetic.
  This should be a given now.

Guideline 40: Give patients permission to discuss relationships and other stressors in life including money, other relationships and health. Revisit questions that have been asked before, as you ay get a different answer, whilst asking the patient if they are comfortable to be asked that question again. This can be supported by seeing a familiar clinician each time.

Minor wording amendments were made to Guideline 40:

Guideline 40: Give patients permission to discuss relationships and other stressors in life including money, other relationships and health. Revisit questions that have been asked before, as you may get a different answer, whilst asking the patient if they are comfortable to be asked that question again. ~~*especially if you are seeing the same person.*~~ *This can be supported by seeing a familiar clinician each time.*

Key: Guideline 40 ratings shown in **black**. Re-rated guideline 40 ratings shown in **red.**

Participant Number	1	2	3	4	5	6	Shift
1			X				
2				X			
3					X X		0
4				X			
5				X X			0
6				X	X		-1
7					X X		0
8							
9					X X		0
10							
11				X X			0
12					X X		0
13		X			X		-3
14					X		
Percentage Agreement and Number of Ratings	1	2	3	4	5	6	Total
% agreement Round Two 40 (*n*=12)	0%	0%	8.3%	33.3%	58.3%	0%	58.3%
% agreement Round Three 40 (*n*=8)	0%	14%	0%	43%	14%	29%	50%

Participant Comments:

Key:

Round 2 comments on Guideline 40 shown in **black**. Round 3 comments on Guideline 40 shown in **red.**

- Again, who is this for, because I for one do not want to be discussing my finances with my GP, and in terms of same clinician, again, this doesn't happen anywhere for anything in the NHS. Again this sounds like someone who needs to see some sort of social worker of therapist not a doctor.
- There are similar guidelines to this statement
- Definitely good to bridge the gap between physical and mental and ensure a holistic approach is being taken - this matches up with some other guidelines above
- A caveat to revisiting questions would be to make sure to ask the patient if they are okay with discussing that particular question again.
- The familiar clinician is key here – otherwise revising the same questions is just an annoyance.
- Explain pain done well will open dialogue into all aspects of a patients life and show how different issues can link to pain link to 28
- The key here would be for the familiar clinician but could be taken mistakenly by the patient as trying to divert to a different cause e.g. "this is probably a symptom of being unhappy with partner, or money worries."
- Just not miss the point of being holistic but again this is covered in other Guidelines.
- How would there ever be time for this at the GP?
- Could be combined with guideline 3 or other similar guidelines.
- I'm not 100% sure if this needs to be a separate guideline but I do agree with the holistic approach, and I think the point about revisiting questions because you might get a different answer is good.
  I feel this has been covered in other guidelines. Also as a clinician, we know that pain is exacerbated by stress / anxiety and depression so should be autonomously screening for this in our initial assessment.

Appendix N

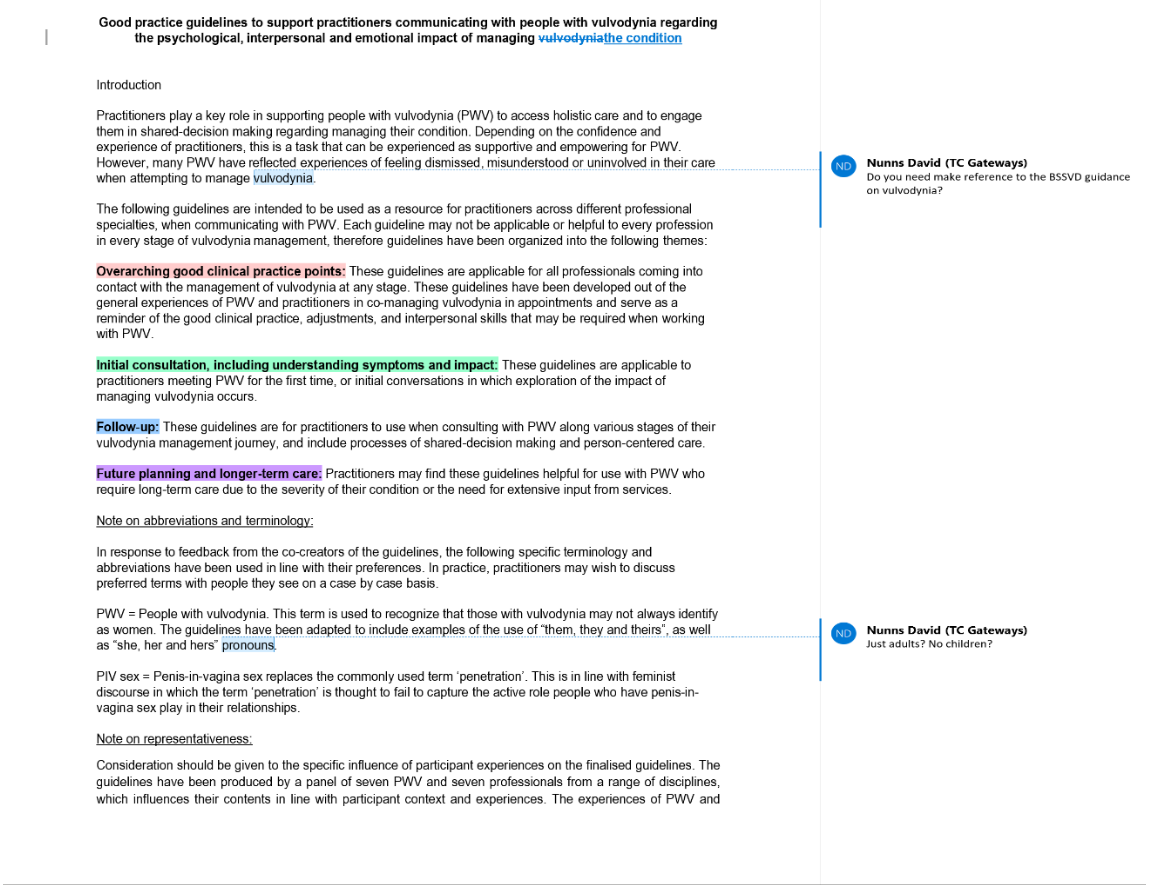
Feedback from a Vulvodynia Specialist Practitioner on the Finalised Guidelines

E-mail feedback

From: Nunns David (TC Gateways) <David.Nunns@nuh.nhs.uk>
Sent: 27 May 2020 14:55
To: Zoe Hamilton <msxzh3@exmail.nottingham.ac.uk>
Subject: RE: Guidelines for practitioners communicating with women with vulvodynia

Thanks and well done. Comments tracked
Do you need a reference list?
How will you disseminate the results?
Regards
David

Feedback on document with track changes



Good practice guidelines to support practitioners communicating with people with vulvodynia regarding the psychological, interpersonal and emotional impact of managing ~~vulvodynia~~the condition

Introduction

Practitioners play a key role in supporting people with vulvodynia (PWV) to access holistic care and to engage them in shared-decision making regarding managing their condition. Depending on the confidence and experience of practitioners, this is a task that can be experienced as supportive and empowering for PWV. However, many PWV have reflected experiences of feeling dismissed, misunderstood or uninvolved in their care when attempting to manage vulvodynia.

Nunns David (TC Gateways)
Do you need make reference to the BSSVD guidance on vulvodynia?

The following guidelines are intended to be used as a resource for practitioners across different professional specialties, when communicating with PWV. Each guideline may not be applicable or helpful to every profession in every stage of vulvodynia management, therefore guidelines have been organized into the following themes:

Overarching good clinical practice points: These guidelines are applicable for all professionals coming into contact with the management of vulvodynia at any stage. These guidelines have been developed out of the general experiences of PWV and practitioners in co-managing vulvodynia in appointments and serve as a reminder of the good clinical practice, adjustments, and interpersonal skills that may be required when working with PWV.

Initial consultation, including understanding symptoms and impact: These guidelines are applicable to practitioners meeting PWV for the first time, or initial conversations in which exploration of the impact of managing vulvodynia occurs.

Follow-up: These guidelines are for practitioners to use when consulting with PWV along various stages of their vulvodynia management journey, and include processes of shared-decision making and person-centered care.

Future planning and longer-term care: Practitioners may find these guidelines helpful for use with PWV who require long-term care due to the severity of their condition or the need for extensive input from services.

Note on abbreviations and terminology:

In response to feedback from the co-creators of the guidelines, the following specific terminology and abbreviations have been used in line with their preferences. In practice, practitioners may wish to discuss preferred terms with people they see on a case by case basis.

PWV = People with vulvodynia. This term is used to recognize that those with vulvodynia may not always identify as women. The guidelines have been adapted to include examples of the use of "them, they and theirs", as well as "she, her and hers" pronouns.

Nunns David (TC Gateways)
Just adults? No children?

PIV sex = Penis-in-vagina sex replaces the commonly used term 'penetration'. This is in line with feminist discourse in which the term 'penetration' is thought to fail to capture the active role people who have penis-in-vagina sex play in their relationships.

Note on representativeness:

Consideration should be given to the specific influence of participant experiences on the finalised guidelines. The guidelines have been produced by a panel of seven PWV and seven professionals from a range of disciplines, which influences their contents in line with participant context and experiences. The experiences of PWV and practitioners communicating with PWV is wide ranging, and therefore guidelines should be considered as a guiding tool, and their application considered on a case by case basis.

Overarching good clinical practice points

Be aware of and work within the limits of your training, knowledge and competency. Consider the strengths of your discipline and those of other disciplines and gain an understanding of when it is appropriate to refer a PWV to another discipline, assuming the PWV supports the referral. A multi-disciplinary approach is often beneficial.

Clinical Vignettes:
Ally (PWV) had received inappropriate referrals for problems with vulvodynia and lichen sclerosuis, an inflammatory skin ~~vulval pain~~ condition that can predispose vulval cancer in ~~some~~ around 5% of cases. Ally reflected that they would much rather a practitioner say they did not know about something, or were not competent in a particular area, due to the potential severe consequences of not getting the right treatment.

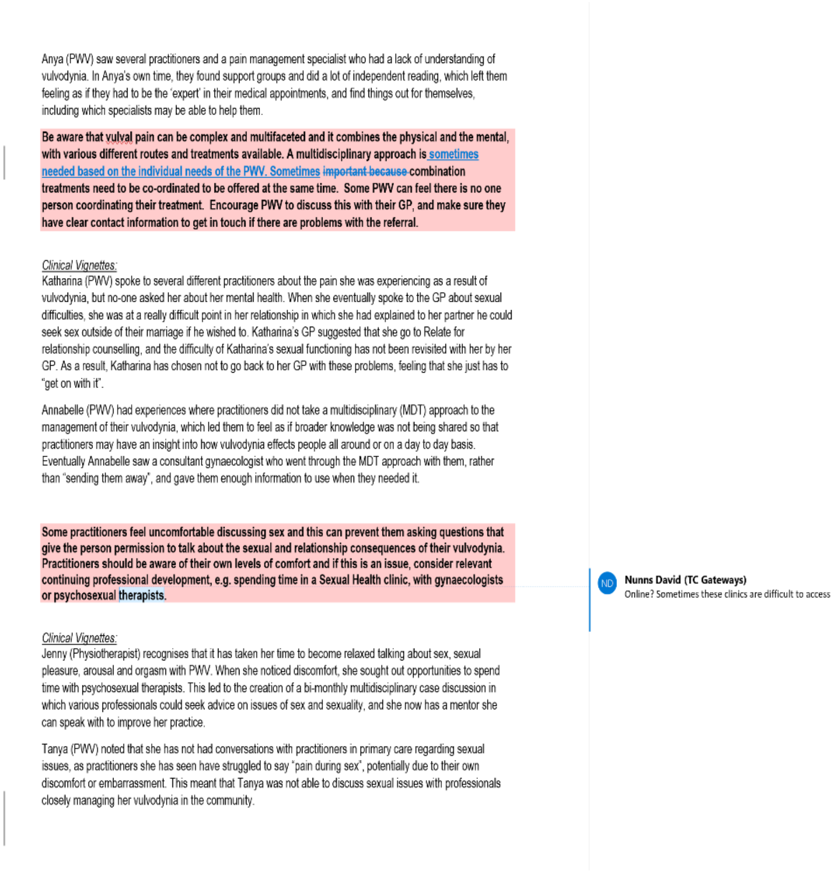
Jordan (Physiotherapist) noted that in the early stages of her career she did not know a great deal about different treatment pathways for PWV experiencing difficulties with their relationships, psychological wellbeing and sexuality. As a result, Jordan would not have conversations about different types of treatment with PWV, and noted that the content felt personal, sensitive and emotional which acted as a barrier. By speaking with multidisciplinary colleagues and attending psychosexual lectures, Jordan built up her knowledge base and ability to speak about holistic options with PWV.

Demonstrate kindness and empathy in appointments. Acknowledge how alone, frustrated and confused one can feel with unexplained genital pain and how difficult it can be to share such personal information with others.

Clinical Vignettes:
Following a consultation regarding vulvodynia, which included an examination, Jennifer (PWV) was seen by a nurse who reflected that it was really difficult to see Jennifer in so much pain during the examination. Jennifer was asked by the nurse how vulvodynia was affecting her and how she coped, making her feel like “a human being rather than a batch of symptoms”.

Orla (PWV) was referred for specialist vulvodynia management by her General Practitioner (GP) due to painful sex associated with vulvodynia. During their consultation, Orla reflected to their GP that they felt “silly, because it's not a big thing”. The GP had told them that nearly all of us are sexual beings and it is a hugely important part of how we feel in ourselves, so it is really important to be able to enjoy that thing. Orla was left feeling as if it was not indulgent to want pain free sex, and that they were given permission by the GP to make a fuss about it, counteracting other previous dismissive messages they had received from healthcare professionals.

Alongside management, give PWV information about local pain groups and charities, such as the Vulval Pain Society or National Vulvodynia Association, books or websites. This may be a quicker way to get information and sensible ideas about non-intrusive management tactics and help PWV feel supported, and part of a wider community.



Anya (PWV) saw several practitioners and a pain management specialist who had a lack of understanding of vulvodynia. In Anya's own time, they found support groups and did a lot of independent reading, which left them feeling as if they had to be the ‘expert’ in their medical appointments, and find things out for themselves, including which specialists may be able to help them.

Be aware that vulval pain can be complex and multifaceted and it combines the physical and the mental, with various different routes and treatments available. A multidisciplinary approach is sometimes needed based on the individual needs of the PWV. Sometimes ~~important because~~ combination treatments need to be co-ordinated to be offered at the same time. Some PWV can feel there is no one person coordinating their treatment. Encourage PWV to discuss this with their GP, and make sure they have clear contact information to get in touch if there are problems with the referral.

Clinical Vignettes:
Katharina (PWV) spoke to several different practitioners about the pain she was experiencing as a result of vulvodynia, but no-one asked her about her mental health. When she eventually spoke to the GP about sexual difficulties, she was at a really difficult point in her relationship in which she had explained to her partner he could seek sex outside of their marriage if he wished to. Katharina's GP suggested that she go to Relate for relationship counselling, and the difficulty of Katharina's sexual functioning has not been revisited with her by her GP. As a result, Katharina has chosen not to go back to her GP with these problems, feeling that she just has to “get on with it”.

Annabelle (PWV) had experiences where practitioners did not take a multidisciplinary (MDT) approach to the management of their vulvodynia, which led them to feel as if broader knowledge was not being shared so that practitioners may have an insight into how vulvodynia effects people all around or on a day to day basis. Eventually Annabelle saw a consultant gynaecologist who went through the MDT approach with them, rather than “sending them away”, and gave them enough information to use when they needed it.

Some practitioners feel uncomfortable discussing sex and this can prevent them asking questions that give the person permission to talk about the sexual and relationship consequences of their vulvodynia. Practitioners should be aware of their own levels of comfort and if this is an issue, consider relevant continuing professional development, e.g. spending time in a Sexual Health clinic, with gynaecologists or psychosexual therapists.

Nunns David (TC Gateways)
Online? Sometimes these clinics are difficult to access

Clinical Vignettes:
Jenny (Physiotherapist) recognises that it has taken her time to become relaxed talking about sex, sexual pleasure, arousal and orgasm with PWV. When she noticed discomfort, she sought out opportunities to spend time with psychosexual therapists. This led to the creation of a bi-monthly multidisciplinary case discussion in which various professionals could seek advice on issues of sex and sexuality, and she now has a mentor she can speak with to improve her practice.

Tanya (PWV) noted that she has not had conversations with practitioners in primary care regarding sexual issues, as practitioners she has seen have struggled to say “pain during sex”, potentially due to their own discomfort or embarrassment. This meant that Tanya was not able to discuss sexual issues with professionals closely managing her vulvodynia in the community.

If possible the PWV should be seen by the same practitioner, in an appropriate environment, e.g. a private, well-lit room, on time, with sufficient time, i.e. for the appointment to not feel rushed. Making more time for an appointment will allow for specific questions about the impact of vulvodynia too.

Clinical Vignettes:
Rita's (PWV) vulvodynia was being managed by primary clinicians in the community, although they would rarely see the same practitioner more than once. Practitioners had received written information about their use of vibrators in attempting to overcome symptoms of vulvodynia, and had enquired about this with Rita. Rita felt there were barriers to discussing personal details such as this with a new practitioner each time, as the practitioner did not have a context of how things had been for them during their vulvodynia journey. As a result, Rita did not feel able to be open and honest with the practitioner.

Phillipa (PWV) had been seeing the same physiotherapist for support managing her vulvodynia. The physiotherapist was able to anticipate times Phillipa may be sitting more, for example during exams or when she was due to attend a work event. This enabled the physiotherapist to support her to attend to her pelvic floor during these times, and also supported Phillipa to feel thought about.

People with vulvodynia should be given enough information to understand vulvodynia and its possible impacts and empowered to communicate with important others about it if it is safe and possible to do so.

Clinical Vignettes:
Gina (Physiotherapist) worked with a PWV who shared that their partner would not have intercourse until they were pain free. Their partner was not willing to attend appointments, so Gina spent some time discussing how to broach and communicate the recovery journey in a way that the partner may identify with. The PWV's partner enjoyed playing sport, therefore they discussed how to share an analogy of the healing of a sporting injury, and the various adjustments that may need to be made, in order for the partner to be able to gain an understanding of the management journey of vulvodynia.

There is a heteronormative and cisnormative approach to sex in society and touch and intimacy are not the same for everyone. Do not assume people's sexuality or gender, or assume any direct link between their sexual or gender identity and their condition.

ND **Nunns David (TC Gateways)**
Most gynae docs will not know what this means!

Clinical Vignettes:
Katie (PWV) was experiencing painful sex due to vulvodynia, which resulting in vaginal tearing, which was not visible when she was examined by the GP. Katie had to bring a photograph along to the GP and was repeatedly asked if she was having "rough sex", despite her communicating this was not the case. Katie felt humiliated, and that her explanations of pain alone did not lead to useful support.

Andy (Physiotherapist) met with a PWV who was struggling with a sexual relationship in which them and their partner needed to use dildos. Andy recognised that this challenged her assumptions about heteronormative sex. She took the time to ask questions and recognised what she didn't know, reflecting to the PWV that she would be happy to find out for them if she wasn't able to answer questions right away.

Initial consultation, including understanding symptoms and impact

Do not assume that if symptoms are not having an impact on the PWV's quality of life and relationships that they are not severe. Vulvar pain can improve, but may get worse if PWV are not supported or get the wrong kind of support or advice.

ND **Nunns David (TC Gateways)**
The HP can ask about function?

Appendix O

Finalised Guideline Document

Final guideline document with vignettes

Good practice guidelines to support practitioners communicating with people with vulvodynia regarding the psychological, interpersonal and emotional impact of managing vulvodynia

Introduction

Practitioners play a key role in supporting people with vulvodynia (PWV) to access holistic care and to engage them in shared-decision making regarding managing their condition. Depending on the confidence and experience of practitioners, this is a task that can be experienced as supportive and empowering for PWV. However, many PWV have reflected experiences of feeling dismissed, misunderstood or uninvolved in their care when attempting to manage vulvodynia.

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Note on abbreviations and terminology:

In response to feedback from the co-creators of the guidelines, the following specific terminology and abbreviations have been used in line with their preferences. In practice, practitioners may wish to discuss preferred terms with people they see on a case by case basis.

Abbreviations:

PWV = People with vulvodynia. This term is used to recognize that those with vulvodynia may not always identify as women. The guidelines have been adapted to include examples of the use of “them, they and theirs”, as well as “she, her and hers” pronouns.

PIV sex = Penis-in-vagina sex replaces the commonly used term ‘penetration’. This is in line with feminist discourse in which the term ‘penetration’ is thought to fail to capture the active role people who have penis-in-vagina sex play in their relationships.

Glossary:

Cis = A person whose gender identity matches their assigned sex at birth.

Cisnormative = The assumption that “cis” people are “normal” and therefore people identifying with other gender descriptions are “abnormal”.

Heteronormative = The assumption that heterosexuality is the norm, and that sex is defined by penis-in-vagina sex.

For further definitions, please see Holleb, M. L. E. (2019). *The AZ of Gender and Sexuality: From Ace to Ze*. Jessica Kingsley Publishers.

Note on representativeness:

Consideration should be given to the specific influence of participant experiences on the finalised guidelines. The guidelines have been produced by a panel of seven PWV and seven professionals from a range of disciplines, which influences their contents in line with participant context and experiences. The experiences of PWV and practitioners communicating with PWV is wide ranging, and therefore guidelines should be considered as a guiding tool, and their application considered on a case by case basis.

Further Reading:

Guidelines for Vulvodynia Management:

- Mandal, D., Nunns, D., Byrne, M., McLelland, J., Rani, R., Cullimore, J., ... & British Society for the Study of Vulval Disease (BSSVD) Guideline Group. (2010). Guidelines for the management of vulvodynia. *British Journal of Dermatology*, *162*(6), 1180-1185.

Women's Experiences of Living with Vulvodynia:

- Shallcross, R., Dickson, J. M., Nunns, D., Mackenzie, C., & Kiemle, G. (2018). Women's subjective experiences of living with vulvodynia: a systematic review and meta-ethnography. *Archives of sexual behavior*, *47*(3), 577-595.

Women's Experiences of Management of Vulvodynia by General Practitioners:

- Leusink, P., Steinmann, R., Makker, M., Lucassen, P. L., Teunissen, D., Lagro-Janssen, A. L., & Laan, E. T. (2019). Women's appraisal of the management of vulvodynia by their general practitioner: a qualitative study. *Family practice*, *36*(6), 791-796.

Patient-practitioner Interactions in Vulvodynia Management:

- Hintz, E. A., & Venetis, M. K. (2019). Exploring the effects of patient-provider communication on the lives of women with vulvodynia. *Narrating patienthood: Engaging diverse voices on health, communication, and the patient experience*, 99-116.

Guidelines

Overarching good clinical practice points

Be aware of and work within the limits of your training, knowledge and competency. Consider the strengths of your discipline and those of other disciplines and gain an understanding of when it is appropriate to refer a PWV to another discipline, assuming the PWV supports the referral. A multi-disciplinary approach is often beneficial.

Clinical Vignettes:
Ally (PWV) had received inappropriate referrals for problems with vulvodynia and lichen sclerosis, a vulval pain condition that can predispose vulval cancer in some cases. Ally reflected that they would much rather a practitioner say they did not know about something, or were not competent in a particular area, due to the potential severe consequences of not getting the right treatment.

Jordan (Physiotherapist) noted that in the early stages of her career she did not know a great deal about different treatment pathways for PWV experiencing difficulties with their relationships, psychological wellbeing and sexuality. As a result, Jordan would not have conversations about different types of treatment with PWV, and noted that the content felt personal, sensitive and emotional which acted as a barrier. By speaking with multidisciplinary colleagues and attending psychosexual lectures, Jordan built up her knowledge base and ability to speak about holistic options with PWV.

Demonstrate kindness and empathy in appointments. Acknowledge how alone, frustrated and confused one can feel with unexplained genital pain and how difficult it can be to share such personal information with others.

Clinical Vignettes:
Following a consultation regarding vulvodynia, which included an examination, Jennifer (PWV) was seen by a nurse who reflected that it was really difficult to see Jennifer in so much pain during the examination. Jennifer was asked by the nurse how vulvodynia was affecting her and how she coped, making her feel like “a human being rather than a batch of symptoms”.

Orla (PWV) was referred for specialist vulvodynia management by her General Practitioner (GP) due to painful sex associated with vulvodynia. During their consultation, Orla reflected to their GP that they felt “silly, because it’s not a big thing”. The GP had told them that nearly all of us are sexual beings and it is a hugely important part of how we feel in ourselves, so it is really important to be able to enjoy that thing. Orla was left feeling as if it was not indulgent to want pain free sex, and that they were given permission by the GP to make a fuss about it, counteracting other previous dismissive messages they had received from healthcare professionals.

Alongside management, give PWV information about local pain groups and charities, such as the Vulval Pain Society or National Vulvodynia Association, books or websites. This may be a quicker way to get information and sensible ideas about non-intrusive management tactics and help PWV feel supported, and part of a wider community.

Clinical Vignettes:
Karen (Consultant Gynaecologist) works with PWV and routinely refers PWV to the National Vulvodynia Association and Vulval Pain Society websites, giving them a concrete place to find out information about vulvodynia and validating their condition as ‘real’ enough for a website to exist on it.

Anya (PWV) saw several practitioners and a pain management specialist who had a lack of understanding of vulvodynia. In Anya’s own time, they found support groups and did a lot of independent reading, which left them feeling as if they had to be the ‘expert’ in their medical appointments, and find things out for themselves, including which specialists may be able to help them.

Be aware that vulval pain can be complex and multifaceted and it combines the physical and the mental, with various different routes and treatments available. A multidisciplinary approach is important because combination treatments need to be co-ordinated to be offered at the same time. Some PWV can feel there is no one person coordinating their treatment. Encourage PWV to discuss this with their GP, and make sure they have clear contact information to get in touch if there are problems with the referral.

Clinical Vignettes:
Katharina (PWV) spoke to several different practitioners about the pain she was experiencing as a result of vulvodynia, but no-one asked her about her mental health. When she eventually spoke to the GP about sexual difficulties, she was at a really difficult point in her relationship in which she had explained to her partner he could seek sex outside of their marriage if he wished to. Katharina’s GP suggested that she go to Relate for relationship counselling, and the difficulty of Katharina’s sexual functioning has not been revisited with her by her GP. As a result, Katharina has chosen not to go back to her GP with these problems, feeling that she just has to “get on with it”.

Annabelle (PWV) had experiences where practitioners did not take a multidisciplinary (MDT) approach to the management of their vulvodynia, which led them to feel as if broader knowledge was not being shared so that practitioners may have an insight into how vulvodynia effects people all around or on a day to day basis. Eventually Annabelle saw a consultant gynaecologist who went through the MDT approach with them, rather than “sending them away”, and gave them enough information to use when they needed it.

Some practitioners feel uncomfortable discussing sex and this can prevent them asking questions that give the person permission to talk about the sexual and relationship consequences of their vulvodynia. Practitioners should be aware of their own levels of comfort and if this is an issue, consider relevant continuing professional development, e.g. spending time in a Sexual Health clinic, with gynaecologists or psychosexual therapists.

Clinical Vignettes:
Jenny (Physiotherapist) recognises that it has taken her time to become relaxed talking about sex, sexual pleasure, arousal and orgasm with PWV. When she noticed discomfort, she sought out opportunities to spend time with psychosexual therapists. This led to the creation of a bi-monthly multidisciplinary case discussion in which various professionals could seek advice on issues of sex and sexuality, and she now has a mentor she can speak with to improve her practice.

Tanya (PWV) noted that she has not had conversations with practitioners in primary care regarding sexual issues, as practitioners she has seen have struggled to say “pain during sex”, potentially due to their own discomfort or embarrassment. This meant that Tanya was not able to discuss sexual issues with professionals closely managing her vulvodynia in the community.

If possible the PWV should be seen: by the same practitioner, in an appropriate environment, e.g. private, well-lit room, on time, with sufficient time, i.e. for the appointment to not feel rushed. Making more time for an appointment will allow for specific questions about the impact of vulvodynia too.

Clinical Vignettes:
Rita’s (PWV) vulvodynia was being managed by primary clinicians in the community, although they would rarely see the same practitioner more than once. Practitioners had received written information about their use of vibrators in attempting to overcome symptoms of vulvodynia, and had enquired about this with Rita. Rita felt there were barriers to discussing personal details such as this with a new practitioner each time, as the practitioner did not have a context of how things had been for them during their vulvodynia journey. As a result, Rita did not feel able to be open and honest with the practitioner.

Phillipa (PWV) had been seeing the same physiotherapist for support managing her vulvodynia. The physiotherapist was able to anticipate times Phillipa may be sitting more, for example during exams or when she was due to attend a work event. This enabled the physiotherapist to support her to attend to her pelvic floor during these times, and also supported Phillipa to feel thought about.

People with vulvodynia should be given enough information to understand vulvodynia and its possible impacts and empowered to communicate with important others about it if it is safe and possible to do so.

Clinical Vignettes:
Gina (Physiotherapist) worked with a PWV who shared that their partner would not have intercourse until they were pain free. Their partner was not willing to attend appointments, so Gina spent some time discussing how to broach and communicate the recovery journey in a way that the partner may identify with. The PWV's partner enjoyed playing sport, therefore they discussed how to share an analogy of the healing of a sporting injury, and the various adjustments that may need to be made, in order for the partner to be able to gain an understanding of the management journey of vulvodynia.

There is a heteronormative and cisnormative approach to sex in society and touch and intimacy are not the same for everyone. Do not assume people's sexuality or gender, or assume any direct link between their sexual or gender identity and their condition.

Clinical Vignettes:
Katie (PWV) was experiencing painful sex due to vulvodynia, which resulting in vaginal tearing, which was not visible when she was examined by the GP. Katie had to bring a photograph along to the GP and was repeatedly asked if she was having "rough sex", despite her communicating this was not the case. Katie felt humiliated, and that her explanations of pain alone did not lead to useful support.

Andy (Physiotherapist) met with a PWV who was struggling with a sexual relationship in which them and their partner needed to use dildos. Andy recognised that this challenged her assumptions about heteronormative sex. She took the time to ask questions and recognised what she didn't know, reflecting to the PWV that she would be happy to find out for them if she wasn't able to answer questions right away.

Initial consultation, including understanding symptoms and impact

Do not assume that if symptoms are not having an impact on the PWV's quality of life and relationships that they are not severe. Vulvar pain can improve, but may get worse if PWV are not supported or get the wrong kind of support or advice.

Clinical Vignette:
Tina (PWV) received a referral to a gynaecologist regarding severe vulval pain. She described having an examination and the gynaecologist noting that they could not see anything wrong with her, being told it was her age and it was likely the menopause. She was subsequently discharged from the service. Tina had to give up her job because of constant pain, and was feeling as if life was not worth living, describing herself as "resenting life".

Make time, actively listen and be responsive to what is being said in appointments. There is so much variation in symptoms of vulvodynia and the way it affects people, that the specific impact will vary for any given person. Use open questions such as “have you identified anything that makes managing vulvodynia better or worse?”, “how are you coping?”, “how is this affecting you?”. Acknowledge that this is a difficult condition to live with.

Clinical Vignettes:

Priya (Psychosexual Therapist) noted that her initial management of PWV involves further assessment, and that through assessment PWV can become more aware of different things that can be going on for them, creating a multifactorial understanding of the nature of vulvodynia. This involves Priya being curious in the beginning of her work regarding what the PWV’s symptoms are, and not always taking medical referrals on ‘face value’.

Tammy (PWV) was referred to a physiotherapist for vulvodynia treatment and management. Tammy also suffered from fibromyalgia and other long-term health conditions. The physiotherapist reflected that Tammy’s general health is likely to impact on vulvodynia, and that this may be making life in general really hard. Tammy left the consultation feeling that their problem was acknowledged and that the physiotherapist had been sympathetic.

Explain and give an opportunity to discuss what is going to happen in an appointment, and gain consent for all discussions, examinations and procedures at every appointment. Pain can cause hypervigilance and anxiety; therefore be open about what pain may be involved in each intervention and the possible pros and cons, to involve the PWV in the decision-making process.

Clinical Vignettes:

Stevie (Physiotherapist) saw a PWV in clinic who said they were ‘terrified’ about being examined. Stevie asked them to grade their anxiety from 0-5 regarding the examination, and they stated that it was a 4/5. Initial appointments involved breathing exercises in the examination room, and shared-decision making with the PWV about them having a session on the examination table with a blanket over them, in the absence of an examination. In this way, the PWV and Stevie were able to work up to the examination in a graded way, and Stevie supported the PWV to recognise their anxiety about the process, and leave each appointment feeling as if they had moved forward in some way.

Megan (Physiotherapist) worked with a PWV who was feeling really anxious during appointments and struggling to take on board new information. Megan revisited information with the PWV at different times during the consultation, phrasing this information in different ways in order to find something that they connected with, opening up avenues of conversation and communication.

Gigi (PWV) attended an appointment with a dermatologist who told Gigi that a junior doctor would like to observe their examination for their learning. The dermatologist explained that it was Gigi's choice if she wanted the doctor to attend or not, and gave them reasons why they could say no to this request. The dermatologist also gave them an opportunity to change their mind right before the consultation began. Gigi noted this felt empowering and counteracted previous experiences they had of consent for observations being assumed rather than asked about.

The first appointment is really important for building up a relationship. You are likely to be fact finding and being empathetic when needed. After asking all questions to gather information, reflect back what you have heard e.g. "I am going to try and summarise...", "My impression is...". Try to put into a nutshell what the person has told you, so that they know you have really heard their story.

Clinical Vignettes:

Helen (Physiotherapist) saw a PWV who had experienced symptoms of vulvodynia for a long-time before management at a vulval clinic was explored, leading the PWV to feel frustrated. Helen reflected back this experience in their own words, acknowledging their frustration and instilling hope that together they will find a way forward.

Anne works with PWV as a Physiotherapist. When issues of distress are raised in initial appointments, Anne asks how the PWV would like to proceed in talking about issues, so that they feel in control of what they are talking about. At the end of the person's descriptions, she will ask "is there anything else", and reflect back what she has heard, also asking if there is anything that she has missed in her summary.

PWV may find it distressing to repeat their full vulvodynia story to a new practitioner and/or feel frustrated that this leaves less time to discuss the present issue. If possible, offer the PWV a choice to summarise their history themselves, or for you to summarise what you know and ask them what they specifically want to discuss in that appointment.

Clinical Vignettes:

Amy (Physiotherapist) works with a lot of PWV who have not had the opportunity to tell their story properly, due to seeing different practitioners each time they visit the GP, and only being allocated 10 minutes per appointment. Amy has created time and space for PWV to talk about the impact of managing vulvodynia, and asking them what their view of their problems are. PWV working with Amy have noted to her that they often feel better if they have been listened to and have had time to discuss their main concerns.

When working with PWV, Colette (Psychosexual Therapist) recognises that having therapy may follow a long history seeing several different medical professionals, including lots of physical assessments which can be very traumatic. Communication has gone well when PWV have felt safe and comfortable enough to open up about things they may not have voiced to anyone before, and given the opportunity to summarise for themselves what is important.

Vulvodynia is a condition which is both affected by, and can affect, people's mental health as well as their physical health. Use open questions and active listening to explore how this might be affecting mental health and sexual relationships, while also respecting when PWV may not want to go into detail about this 'just yet'.

Clinical Vignettes:

Abhi (PWV) has experienced a significant impact on her psychological wellbeing and on current and previous relationships as a result of managing vulvodynia. However, no practitioner has specifically enquired about the impact with her, resulting in Abhi having to bring these difficult topics up in appointments.

In his practice as a physiotherapist, Jared saw a PWV who found discussing mental wellbeing and relationships distressing. In response to this, Jared asked them if they would like to carry on with discussions or talk about something else, in order to give them some control over what they were talking about. At the end of the discussion, Jared reflected back the PWV's difficulties and concerns, and asked "is there anything else that we haven't covered?", to invite them to discuss what is important to them.

Bernadine (Physiotherapist) saw a PWV who "clamped up" when trying to talk about relationships. By giving them choice about what to discuss, Bernadine planted the seed for future discussions on this topic. The PWV returned and disclosed in subsequent appointments about what they felt was not right in their relationship and how vulvodynia effected it, enabling them to jointly explore support for this.

It will be important to ask about the impact of pain on a PWV's life and to emphasise that pain is a physiological and psychological process, which can impact on wellbeing. If you are in a position to, explain chronic pain mechanisms and how stress and anxiety can exacerbate pain. If referring to psychological or psychosexual therapy, explain that this is not a replacement for existing treatment, but that psychological support can sometimes be helpful for overall wellbeing and support.

Clinical Vignettes:

Elizabeth (Physiotherapist) worked with a PWV who was standing the majority of the time due to pain, including at home with her family. Elizabeth had discussions with the person about the 'threat' that chairs posed in terms of anxiety, as if they were all going to bring about her pain. Subsequent sessions involved working with them to think more positively about chairs, in line with education about the sympathetic and parasympathetic nervous system and how they operate to produce pain. The PWV was able to sit on a chair for 10 minutes in the next session, and eventually to sit with her family and have dinner, as well as consider going to the cinema.

Experiences Stevie (PWV) had of being asked about their wellbeing by practitioners focused on the importance of psychological input as an adjunct to current treatment. When practitioners shared information on the likely relationship between pain and mental wellbeing, Stevie was able to consider how vulvodynia affects their wellbeing, and felt as if it was not “all in their head”. They also felt that any psychological input offered was not instead of other treatment.

Follow-up

Validate someone’s problem as a problem worth time and thought. PWV should be supported with information regarding the prognosis of their condition and told that together you will find a way to help them with managing vulvodynia, or find a professional who can help them further.

Clinical Vignettes:
Claire (PWV) described appointments with practitioners regarding vulvodynia as largely negative, where GPs and gynaecologists had examined her and told her there was “nothing there”, with a lack of follow-up. This was experienced by Claire as dismissive and derogatory.

Dina (PWV) had been to visit several different GPs regarding vulvodynia, although most had not heard of the condition, meaning that they did not have knowledge on it’s management. Dina noted how GPs could struggle to relate to how it may impact on their life, as it was not a physical disability that you could see. These experiences were associated with them having lot of struggles with their psychological wellbeing as a result of vulvodynia, yet not being asked about their mental health, wellbeing and relationships.

For those with partners, to provide more information for partners so they can have a better understanding of how vulvodynia is impacting their lives or their partner’s lives. This may involve encouraging the partner to come to a session.

Clinical Vignettes:
Daniel (Consultant Gynaecologist) met with a PWV who felt distressed due to being unable to have sex as a result of vulvodynia. Daniel met with the PWV and their partner, and they both agreed that if the PWV had a bad case of thrush then they would not be having sex, which normalized sexual difficulties with vulvodynia and gave legitimacy to

their concerns. This led onto conversations about what other sexual activities the PWV and their partner could try besides PIV sex, and the PWV and their partner being given initial homework to discuss and trial this.

Ruth (Physiotherapist) came to learn that touch between a PWV and her partner had been completely absent, due to fear about intimacy in the form of touch leading to sex. The PWV was impacted psychologically due to the feeling of having to repeatedly say no to their partner in response to sexual advances, making them feel as if they were rejecting them. She would 'dread' going on holiday due to the increased time and expectations to be sexually intimate, therefore her relationship and sense of enjoyment was also effected. Ruth spoke with the PWV and their partner about ways to explore increasing their joy and intimacy in other areas of life, as well as how to have conversations about types of sex that did not involve PIV sex.

Once assessment results allow, give a formal diagnosis of vulvodynia (a pain syndrome) and beware of mislabelling (e.g. as dyspareunia, which is a symptom of vulvodynia). If you are in a position to, give a precise specific subset diagnosis.

Clinical Vignettes:

Hannah (PWV) saw a physiotherapist after diagnosis who told her that she did not think she had vulvodynia, but that she had dyspareunia caused by various other physical issues. Hannah noted this experience as having a negative effect on her general wellbeing, where she started seeing every muscular problem she had, such as shoulder pain, as linked to her vulvodynia. This had a knock on effect of resulting in more reminders of her vulvodynia, for example when her shoulder hurt. Hannah eventually stopped going to physiotherapy sessions, as she felt that the focus on many physical issues made her feel as if she was "sick".

Eleanor (PWV) met with a dermatologist for the first time three years into their vulvodynia management journey, and received a specific diagnosis. The dermatologist reflected back Eleanor's experiences: that they had heard it was "all in their mind", hormones or the menopause. Eleanor was given reassurance that they were not the first person who the dermatologist has had to say this to, and this diagnosis and experience helped Eleanor to feel they were not "going mad", and that there was someone who believed them.

Future planning and longer-term care

Managing long-term expectations may involve being open and candid about vulvodynia being multifaceted and that additional support may be needed in the form of medical and/or psychological support. Explain that lots of people recover from the condition, but that for others it will be ongoing to work through, therefore a whole team approach may be required. This may include explanations of who the team is, how referral pathways work, and what kind of support exists.

Clinical Vignettes:

In managing expectations with a PWV, Terri (Physiotherapist) explained that although symptoms were not likely to fully resolve, they can find a way to manage them together. This involved explanations about the need for different levels of intervention over time, due to the multifaceted nature of vulvodynia, and discussions about how stress may mean vulvodynia can flare up at times.

Rory (Physiotherapist) treated a PWV who had experienced vulvodynia secondary to a bout of thrush, and was unable to sit down or walk. Rory shared with the PWV that she had seen several people with a similar presentation and that they had got better, therefore Rory told the PWV she was not concerned about the prognosis. The PWV engaged well with physiotherapy and her symptoms of vulvodynia resolved.

Appendix P

Excerpts from Reflective Research Journal

Date	Context	Reflections
18.09.2019	E-mail from BSSVD consultant gynaecologist in response to study advert	After receiving an e-mail regarding the study from a consultant gynaecologist I had seen as a patient, I felt uncertainty about holding a dual role as researcher and someone with lived experience in the research. It felt timely to consider my position on this issue with research supervisors, and this prompted discussions regarding disclosure to patients or practitioners and how this may influence information elicited.
26.09.2019	Initial interview with participant for research	I had experiences of feeling moved by the responses of women to the study advert, and hearing stories of difficult journeys towards diagnosis and appropriate management. It felt difficult to disentangle my therapist role with that of a researcher or even peer in this process. Statements from the participant such as “if I had been given this information then…”, echoed my own frustrations and grief regarding the process of seeking appropriate treatment and diagnosis.
05.10.2019	Attendance at Vulval Pain Society conference	Further considerations were warranted regarding holding a dual role of researcher and woman with vulvodynia experience. Women at the conference expressed interest in taking part in the study, and this resulted in indirect disclosure of my experiences by virtue of being a researcher with lived experience at the conference. This supported my empowerment and offered more comfortability with both identities.
23.01.2020	Conversation with research supervisor	Discussions were had regarding the overlap between patient and researcher, and the emotionality of discussions with patients, as well as themes of power imbalance that may be enacted in my conversations with practitioners. This supported me to be aware of when I felt like the ‘patient’ in the practitioner dyad, even in the absence of disclosing my patient status to practitioners.
31.01.2020	Listening back to audio files for creation of guidelines	One participant had noted that they would have liked intervention for their vulvodynia earlier so that their relationships did not break down. This resonated with me on a personal level, and may have resulted in my avoidance in shaping up this guideline until later on in the process. Creating the space to do so allowed me to reflect on and package my own emotional reaction to the content, in order to re-approach the task through the lens of a researcher.

Appendix Q

Correspondence Related to Implementation Plan and Dissemination of the Guidelines

From: Nunns David (TC Gateways) <David.Nunns@nuh.nhs.uk>
Sent: 7 October 2020 08:41
To: Zoe Hamilton <msxzh3@exmail.nottingham.ac.uk>

Hello,
Very interesting. We have discussed this at the VPS and we would like to have the document on the site. Would it be worth waiting until it is published and then it can be a link?

As for medics then I could trial this with local docs. Kay suggested a leaflet or shortened version?
Thanks
David

On 21 Sep 2020, at 14:34, Zoe Hamilton <Zoe.Hamilton@nottingham.ac.uk> wrote:

Hi David,

I hope you are well, thank you very much for your e-mail.

I was awaiting the results of my viva for my doctorate in clinical psychology before I got back to you, as my thesis being the study these results are based on. I am pleased to say the viva has been passed and I am in the process of making amendments.

I have a draft final set of guidelines and will be ready to submit the study to an academic journal in the next couple of months.

I wonder whether the VPS or BSSVD would be interested in making the guidelines freely available for practitioners, or if you have any advice regarding dissemination, particularly to GPs or other non-specialist practitioner groups?

I have attached the draft final guidelines, the output of this study, for your interest.

Kindest regards and thank you so much for your ongoing interest in this research.

Zoe Hamilton

From: Biswas Sanchia - Clinical Psychologist <Sanchia.Biswas@nottshc.nhs.uk>
Sent: 12 October 2020 11:17

To: Zoe Hamilton <msxzh3@exmail.nottingham.ac.uk>

Hi Zoe,

Thanks for your email and that’s great about thesis and new job – I hope all is well 😊

Oh that’s brilliant! Yes, send it over. I’m not sure if now is the right time to discuss with the team as everything is up in the air as you can imagine. However, if you email it across I can take a look and keep it in mind to share with the team once things settle down. Is there anything else you need me to do in relation to publishing the guidelines?

Kind regards,

Dr Sanchia Biswas
Clinical Psychologist

Poster

Creating guidelines for practitioners on communication regarding the management of the psychological and interpersonal impact of vulvodynia: A Delphi study

Zoe Hamilton, Dr Anna Tickle, Dr Danielle De Boos, Dr Sanchia Biswas

Background

- Vulvodynia has wide-ranging impacts on psychological wellbeing[1], sexuality[2] and relationships[3]
- There are personal, structural and societal barriers for women and practitioners communicating about these impacts, and no existing guidelines to support them to navigate the process
- Good communication is linked to better treatment outcomes in pain conditions

Aims

Use a Delphi method to produce guidelines for practitioners communicating about the impact of managing vulvodynia, based on the views of practitioners and women with vulvodynia

Method

- The Delphi method[4] was used to generate consensus
- Participants (termed panellists) were seven women with vulvodynia and seven practitioners with experience of managing vulvodynia
- Recruitment occurred through social media and adverts through the Vulval Pain Society, and a specified NHS Trust recruitment site

Round One

- Individual interviews discussing experiences of communication
- Panellists suggested two to three guidelines

Round Two

- Suggested guidelines were made into a survey and sent to the panel
- The panel rated (on a 6-point scale) and commented on guidelines

Round Three

- All suggested guidelines with percentage ratings sent back to the panel for further ratings

Results

- Practitioners were four physiotherapists, two consultant gynaecologists and one psychosexual therapist. Women were aged between 23-54, with a mix of provoked, unprovoked and mixed vulvodynia subtypes
- Nineteen guidelines reached consensus (available on request)

Finalised Guidelines

Clinical vignettes were created for each guideline to illustrate their applicability in practice. Themes of the guidelines were: Overarching good clinical practice points; Initial consultation, including understanding symptoms and impact; Follow-up; Future planning and longer-term care

Discussion

- Practitioners play a vital role in supporting women to communicate regarding the impact of managing vulvodynia
- Shared decision making is a key part of this process
- Guidelines provide a user-led and coproduced resource for use in clinical practice

References

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Small Scale Research Project

Title: An Evaluation of the Influence of Cognitive Analytic Therapy (CAT) Personal Reformulations (PRs) on Reflective Capacity in Trainee Clinical Psychologists

Short running title: Evaluating CAT personal reformulations

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Abstract

Introduction: Cognitive Analytic Therapy (CAT) 'personal reformulations' (PRs) have been offered at some Doctorate in Clinical Psychology (DClinPsy) programmes as an opportunity for continuing personal and professional development. There is partial evidence for improved reflective capacity following CAT PRs, although no published research on reflective capacity and CAT PRs exists. **Aims:** This service evaluation aimed to evaluate the effectiveness of CAT PRs on reflective capacity and to understand how they were experienced by trainees. **Methods:** A mixed methods approach was used. The quantitative Reflective Practice Questionnaire was administered pre- and post-CAT PRs, and thematic analysis was used on qualitative data collected in an online survey. **Results:** Twenty trainees participated. There were no significant group-level differences between pre- and post-CAT PR scores on components of reflection. Reliable Change Index (RCI) calculations indicated some individual-level improvements on nine sub-scales, although a mixed picture is found. Qualitative data suggests the experience was helpful for personal and professional development for some trainees, although issues with timing and the content of sessions were identified. **Conclusions:** There is partial evidence that CAT PRs can lead to some change in reflective capacity in trainees. However, data does not support CAT PRs as the specific mechanism for change, and only a small number of participants indicated how changes in reflection would translate to practice. There are inherent challenges in disentangling influences of CAT PRs from other learning occurring through academic and placement-based training.

Keywords: *Cognitive Analytic Therapy, personal reformulation, reflective capacity, trainee clinical psychologist*, reflective practice.*

Introduction

Background

The Health and Care Professions Council (HCPC) Standards of Proficiency (HCPC, 2019), and the British Psychological Society (BPS) practice guidelines (BPS, 2017) outline the importance of developing reflective skills in clinical psychology training. Doctorate in Clinical Psychology (DClinPsy) training programmes have embedded a ‘reflective-practitioner’ stance in training criteria (Galloway, Webster, Howey, & Robertson, 2003), whereby emphasis is placed on synthesising technical and reflective skills to enable self-awareness and reflective capacity. However, there is a lack of empirical support for reflection directly improving practitioner outcomes (Lavender, 2003), which may be due to challenges in experimentally studying reflective capacity without a unified definition (Lyons, Mason, Nutt, & Keville, 2019).

Several definitions of reflective capacity and models of reflective processes have been developed and applied to training and practice. Reflection is considered by some as a deliberate and conscious act of attending to assumptions and beliefs (Schön, 1987), occurring after (on action), or during (in action), an event. Other theorists consider reflection as a process or cycle of doing, reviewing, concluding and planning, influencing skills and discovery (Kolb, 1984) and change (Gibbs, 1998). However, a challenge amongst existing definitions is that proposed reflective processes are highly variable and difficult to operationalise, resulting in heterogeneity in attempts to measure and observe reflection (Gillmer & Marckus, 2003).

One commonality in the literature is of reflection as an internal process, therefore it could be argued that attempting to evaluate the properties of an atheoretical concept using pre-defined outcomes is reductionist (Galloway et al., 2003). Nonetheless, evidence-based practice necessitates the critical evaluation of practices widely used in healthcare professions. Further rationale for studying reflective capacity in healthcare professions comes from evidence of the benefits of reflective practices, including reducing practitioner burnout (Nielsen & Tulinius, 2009), and improved practitioner empathy for clients (Spendelow & Butler, 2016). This is of importance for trainees who face profession-specific demands that increase vulnerability to distress (Dunning, 2006), such as professional self-doubt and long clinical hours (Gilroy, Carroll, & Murra, 2002).

Measuring Reflective Capacity

Opportunities to increase reflective capacity can be facilitated via numerous processes and therapeutic modalities, and through self and peer exercises and reflective practice groups. Bennett-Levy and Lee (2014) found such exercises can enhance self-reported reflective capacity, although the focus as applied here was on reflection in Cognitive Behavioural Therapy specifically. Where opportunities for personal and professional development using therapeutic modalities are available in DClinPsy training, they are oftentimes extracurricular (Wigg, Cushway, & Neal, 2011). This renders reflection a challenge to routinely evaluate and to determine the impact on client outcomes.

Evaluating Reflective Capacity

Research to date on reflective capacity has been qualitative and has evaluated appraisal of reflective capacity, rather than the development of reflective skills (Moon, 2013). Quantitative studies using valid and reliable measurement tools and a pre-post design may be used to demonstrate whether reflective practices influence reflective capacity more robustly than qualitative studies. The Reflective Practice Questionnaire (RPQ; Priddis & Rogers, 2017) was developed as a direct measure of reflective capacity and associated psychological constructs. Research has demonstrated the utility of this measure to evaluate the acquisition of reflective skills (Rogers et al., 2019), making it useful in programme and training evaluations.

Cognitive Analytic Therapy (CAT) and Reflective Capacity

Cognitive Analytic Therapy (CAT) is a time-limited structured psychotherapy, emphasising active collaboration on a sequential diagrammatic reformulation (map) of sequences of external, mental and behavioural events, and their repetition in self-management and relationships (Ryle & Kerr, 2003). This process can be adapted to 'map' personal patterns of relating, relevant to their impact on work roles (Cartwright, 2011), a process named 'personal reformulation' (PR). During CAT PRs, a visual representation of procedural patterns and sequences of actions is created, including consideration of the impact of and potential responses to these.

CAT PRs, considered a tool of CAT therapy, have demonstrated the ability to support staff teams to reflect, and increase practitioner skills and confidence as part of training in a clinical setting (Thompson et al., 2008). An unpublished service evaluation report on CAT PRs with trainees at one DClinPsy programme highlights their potential to improve self-reported personal understanding and awareness, and discovery of the potential experience of clients (Davies, 2018). However, no robust published research exists regarding the impact of PRs on trainee clinical psychologists, despite several courses offering extracurricular CAT PRs.

Service

The Trent Doctorate in Clinical Psychology programme (Universities of Lincoln and Nottingham) is one of 30 HCPC approved and BPS accredited professional clinical psychology training courses in the United Kingdom.

The programme places emphasis on the development of reflective skills via multiple methods including reflective practice groups, supervision, and written reflective assignments (Clearing House for Postgraduate Courses in Clinical Psychology, 2019). Continuous professional development (CPD) is also outlined in the Trent programme handbook (Trent

Doctoral Training Programme in Clinical Psychology, 2019) as a key requirement to equip trainees with the competencies, skills and knowledge to enhance wellbeing at work and prevent burnout and stress.

Aims

This service evaluation examined outcomes for trainee clinical psychologists who completed a CAT personal reformulation, with specific aims to:

- Aim 1: Evaluate the effectiveness of CAT PRs as a tool to improve reflective capacity of trainees.
- Aim 2: Gain an understanding of how CAT PRs were experienced by a group of trainees, including how they have impacted on practice.

Method

Design

The service evaluation employed a mixed-methodology design. Data was collected in the form of paper-based quantitative Likert scale surveys, and a qualitative online survey. As a service evaluation, the project was exempt from ethical review.

Participants

First-and-second year trainee clinical psychologists from the Trent programme (*n* = 31) were invited to complete a validated measure of reflective capacity before and after CAT PRs, and an online survey four weeks later.

Outcome Measures

Reflective Practice Questionnaire (RPQ). The RPQ (Priddis & Rogers, 2017)[41] is a 40-item self-report measure designed to evaluate components of reflective practice. It comprises ten 4-item sub-scales used for reflecting on aspects of clinical practice. The first four sub-scales: Reflective-in-action (RiA), Reflective-on-action (RoA), Reflection with others (RO) and Self-appraisal (SA) comprise 16 items in total and measure reflective capacity. Related constructs named Desire for improvement (DfI), Confidence – General (CG), Confidence - Communication (CC), Uncertainty (Unc), Stress interacting with clients (SiC), and Job satisfaction (JS) are also measured. Responses are given on a Likert scale of 1-6 (1= not at all, 6 = extremely). Sub-scale scores are calculated by summing and averaging the four items in each sub-scale. Priddis and Rogers (2017) report good internal consistency (α = > .82) of survey items and reliability of this questionnaire to measure reflective capacity across public, mental health practitioner and student samples (Rogers et al., 2019).

CAT reformulation evaluation questionnaire. An online survey[42] was constructed by the first and second authors based on a previous unpublished service evaluation (Cooper, 2018). JISC online survey software was used to create Likert scales and comment boxes in response to statements and questions. Reflective practice questions utilised in previous research (Bennett-Levy, Thwaites, Chaddock, & Davis, 2009) were included and adapted for a specific CAT focus:

1. Observe the experience (e.g. how did I feel during the process, what did I notice?).
2. Clarify the experience (e.g. was it helpful, what changed?).
3. Implications of the experience for clinical practice (e.g. for individual therapy, supervision, consultation).

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4. Implications of the experience for how I see myself as a person or therapist.
5. Implications of the experience for understanding of CAT therapy and theory.

Procedure

Phase 1. All trainees undertaking CAT PRs were provided with a hard copy of the RPQ in their university in-tray, and prompted by e-mail to complete this prior to the CAT PR and return it in a numbered envelope for anonymity. Hard copies of the RPQ were provided due to the measure being standardised, and for anonymity for the researcher to match RPQs before and after CAT PRs. Trainees were informed in e-mails that by engaging in the study they were giving informed consent to participate. Trainees then completed CAT PRs.

CAT PRs

Individual CAT PRs were facilitated by one of two external CAT practitioners. Sessions consisted of an initial two-hour session and a one-hour follow up session approximately one month later, to allow time for strategies identified in the first session to be utilised. The focus of the initial session was on a method of ‘mapping’ relational (or reciprocal) roles, the feelings that occur during engagement with these roles, and how these are managed. The ‘map’ serves as a tool of recognition and trainees were encouraged to take the map away. The initial session finished with reflective conversation about the map and active strategies to work on, such as adaptation of unhelpful patterns, and ‘exits’ from these. The follow up session provided a space to review the ‘map’ and any attempted behaviour change, and to reflect on the experience of the process. CAT PRs were funded by the DClinPsy programme.

Phase 2. Two weeks after the follow-up CAT PR, trainees were requested by e-mail to collect a follow-up RPQ from a university site, which was labelled with their participant number. The second author held a master copy of names corresponding to numbers in a locked cabinet and office, to protect participant anonymity. A follow-up reminder e-mail was circulated a week later, with the RPQ attached for completion.

Phase 3. The anonymised remote online survey was distributed via e-mail four weeks following the second CAT PR. Trainees were informed they would have up to four weeks to complete this, and that they would not be identifiable by their contributions.

Analysis

Analysis of Quantitative Data

The lead author entered anonymised data from outcome measures into an Excel spreadsheet. IBM SPSS Statistics for Windows, Version 24 was used for analysis. Data did not meet assumptions for parametric tests; therefore, Wilcoxon Signed Ranks tests were conducted. Reliable Change Index (RCI) criterion were utilised to conduct individual-level analysis on quantitative data.

Analysis of Qualitative Data

Long answer questionnaire responses to questions 3, 5-9, and 23 were analysed using inductive thematic analysis (TA), utilising the process outlined by Braun and Clarke (2006). Data was read and re-read, and semantic codes were generated and mapped into themes in relation to the research question. Inductive TA was chosen due to the absence of empirical research into CAT PRs. TA was used to address the second aim to gather first person textual data, allowing for the mapping of broad common themes and conflicting data across the entire data set.

Results

Of those invited to take part (*n* = 31), 16 (52%) were in the first year of DClinPsy training and 15 (48%) were in the second year. Pre and post RPQ questionnaires were returned by 20 trainees (64%). Four participants returned pre- and two returned follow-up RPQs only, totalling 26 participants (83% response rate). Over two thirds of participants (64%) responded to the online survey. Nine (45%) were in their second year and 11 (55%) in their first year of DClinPsy training on the Trent programme.

RPQ Results

Table 15 reports descriptive statistics and demonstrates the results of within-group difference calculations for pre- and post-CAT reformulation RPQ scores.

Table 15

Results of Wilcoxon Signed Rank Tests for pre- and post-CAT reformulation RPQ scores

RPQ sub-scale	Pretest median (IQR)	Posttest median (IQR)	*Z*	*p* value
Reflective in action (RiA)[b]	4.25 (3.44 – 4.5)	4 (3.25 – 4.25)	-.966	.319
Reflective on action (RoA)[a]	4.50 (4.19 – 5)	4.75 (3.88 – 5.06)	-.196	.845
Reflective with others (RO)[b]	5 (4.5 – 5.31)	4.75 (4.18 – 5.25)	-.954	.340
Self-appraisal (SA)[b]	4.25 (4 – 4.5)	4.25 (3.62 – 4.75)	-.745	.456
Desire for improvement	5.62 (5 – 6)	5.37 (4.44 – 5.75)	-1.54	.123
Confidence – general (CG) [a]	2.12 (1.25 – 2.56)	2.12 (1.56 – 3.25)	-.619	.536
Confidence – communication (CC)[a]	4.25 (4 – 4.5)	4.5 (3.69 – 5)	-.732	.464
Uncertainty (Unc)[b]	3.62 (3 – 4.06)	3 (2.44 – 3.87)	-1.61	.105
Stress interacting with clients (SiC)[b]	3.38 (2.62 – 3.75)	3.12 (2.19 – 3.56)	-1.60	.109
Job satisfaction (JS)[b]	5.12 (4.43 – 5.75)	4.87 (2.06 – 5.75)	-.385	.700
Reflective Capacity (RC)[b]	4.44 (4.17 – 4.64)	4.44 (3.97 – 4.78)	-5.18	.605

Note. RPQ = Reflective Practice Questionnaire, IQR = Interquartile range. RPQ sub-scales were scored on a range from 1-6, where higher scores indicate higher self-reported ratings. One RPQ item (number 37) was reverse scored prior to analysis.
[a] Based on negative ranks
[b] Based on positive ranks

As demonstrated by Table 15, at the group level, there were no significant pre-post differences in RPQ scores on any subscales.

Following group-level analysis, reliable change calculations were computed at the level of individual pre- and post-RPQ mean scores, according to the method summarised in Evans, Margison, and Barkham (1998). Criterion values were computed based on test-retest reliability values (Cronbach’s alpha), and standard deviations for each sub-scale as presented in Priddis and Rogers (2017). Changes of greater magnitude than the criterion were considered to indicate reliable change.

Table 16 summarises reliable change calculations in this sample. In order to determine reliable change, participants who did not provide pre-measures (*n* = 2) or post-measures (*n* = 4) were excluded from further analysis, leaving 20 (64%) participants.

Table 16

Reliable Change Index Summary Statistics for RPQ sub-scales

	Reliable Change Criterion*	Reliable deterioration		Uncertain change		Reliable improvement	
RPQ sub-scale		*n*	%	*n*	%	*n*	%
RiA	1.25	0	0	20	100	0	0
RoA	1.16	0	0	18	90	2	10
RO	0.56	3	15	14	70	3	15
SA	0.68	2	10	17	85	1	5
DfI	0.54	4	20	14	70	2	10
CG	0.61	2	10	11	55	7	35
CC	0.55	2	10	13	65	5	25
Unc**	0.56	1	5	13	65	6	30
SiC**	0.66	2	10	13	65	5	25
JS	0.66	3	15	14	70	3	15

Note. RPQ = Reflective Practice Questionnaire, RiA = Reflective-in-action, RoA = Reflective-on-action, RO = Reflective with others, SA = Self-appraisal, DfI = Desire for improvement, CG = Confidence – general, CC = Confidence – communication, Unc = Uncertainty, SiC = Stress interacting with clients, JS = Job satisfaction.
*Reliable Change Criterion = minimum change score needed for change to be statistically reliable
**Lower score = improvement

Most scores fell under the category of uncertain change (73.5%), indicating difficulty detecting reliable change between the two time points on the RPQ. Across all ten sub-scales, 19 scores showed a reliable deterioration, and 34 demonstrated a reliable improvement. No reliable change was indicated for ‘Reflective-in-action’. ‘Reflective with others’ demonstrated equal percentage deterioration (15%) to improvement (15%), as did the ‘Job Satisfaction’ sub-scale. Only a very small proportion (2%) demonstrated a reliable improvement on ‘’Reflective-on-action’. Highest reliable improvements were demonstrated for ‘Confidence – general’

(35%), ‘Uncertainty’ (30%) ‘Confidence – communication’ (25%), and ‘Stress interacting with clients’ (25%). Deterioration percentages on these four sub-scales ranged from 5-10%. The highest reliable deterioration was found for the ‘Desire for Improvement’ sub-scale (20%), although 10% of scores also improved for this measure.

Online Survey Results

Likert scale data from the online CAT PR survey for questions 16-20 (Table 17) were used to consider the effectiveness of the CAT PRs on reflective capacity and associated psychological constructs.

Table 17

Likert scale data for CAT reformulation survey questions 16-20 from online survey

Questionnaire item	Not at all (1)	Slightly (2)	Moderately (3)	Very much (4)	A lot (5)
Did the CAT reformulation session increase your personal awareness of yourself?	0% (*n*=0)	10% (*n*=2)	15% (*n*=3)	60% (*n*=12)	15% (*n*=3)
Did the CAT reformulation session increase your awareness of how your own emotions affect your behaviour?	0% (*n*=0)	10% (*n*=2)	15% (*n*=3)	65% (*n*=13)	30% (*n*=6)
Did the CAT reformulation session increase your awareness of how your emotions affect others?	10% (*n*=2)	30% (*n*=6)	15% (*n*=3)	40% (*n*=8)	5% (*n*=1)
Did the CAT reformulation session increase your knowledge of what helps your job performance or what may hinder it?	0% (*n*=0)	0% (*n*=0)	25% (*n*=5)	60% (*n*=12)	15% (*n*=3)
Do you feel that the CAT reformulation session has or will increase your ability to work with clients?	5% (*n*=1)	15% (*n*=3)	40% (*n*=8)	30% (*n*=6)	30% (*n*=6)

As seen in Table 17, most respondents rated above the mid-way point on Likert scales on the CAT PR’s impact on ability to work with clients, increase knowledge and awareness of emotions on self, others and behaviour, and on increasing overall personal awareness. Mixed results were found for CAT PRs' ability to increase awareness of how respondent's own emotions might affect others, and ability to work with clients.

Of the long-answer questions examined, all 20 participants gave answers to questions three, five, six and eight, 19 responded to questions 9 and 23, and 18 to question seven. Thematic analysis (TA; Braun & Clarke, 2006) led to the identification of four themes, with subthemes, relating to a range of ways in which trainees used their learning. Gender neutral pseudonyms were created for participants.

Seeing the unseen. Some identified CAT PRs as allowing for recognition of factors that may have otherwise gone unexamined.

Self. Five trainees identified the process as affording opportunities for self-discovery that may have previously been absent. One participant had taken reflections forward into placement: *"Without this map I think I would not have reflected on this experience with my clinical supervisor"* (Mo). For all five there was an acknowledgement that the CAT PR was linked to self-reflection they *"may not have pursued otherwise"* (Sasha).

Self in relation to clients. Five of six trainees felt CAT PRs were helpful for reflecting on their own experiences in session with clients, with one recognising *"my responses can be unhelpful for clients"* (Alex). The remaining participant reported more clarity about their client's relational patterns than their own following CAT PR.

Self as client. Six trainees noted the experience as offering insight into client experience, for example "*a better understanding of how our client's feel"* (Ziggy). Although, these trainees did not report specific details of this insight or how it impacted them and their work.

Application and use. Most trainees identified going into the process with an intent to use it as a personal or professional development experience, and there was some evidence that they made use of their learning after the CAT PRs.

Recognising patterns. A key theme was increased awareness of personal patterns of relating. For some, greater awareness was hoped for in *"interactions with clients and other professionals"* (Yoshi), and for others to reflect on patterns *"with clients and supervisors"* (Sasha). However, there was no indication that new awareness necessarily led to behavioural change, with only two participants linking recognising patterns with utilising exits, as per the intent of CAT PRs. Further, contradictory information from Max noted: *"I have not changed my behaviour because of the reformulation because it did not address my readiness for change",* highlighting limitations of potential increased awareness on application to practice.

Intent to apply. Fifteen trainees identified intent to use recognition of patterns, for example to *"be more open with colleagues"* (Ainsley), use CAT "*effectively in therapy"* (Jude), and *"reflect with my supervisor about a difficult experience"* (Mo). One third of these trainees spoke of benefitting from using the CAT 'map' specifically with supervisors and for one participant with their mentor, although how this was used was not specified.

Experience of the process. Trainees identified factors relevant to relational and practical elements of CAT PRs.

Safe space. Seven trainees identified the experience as validating and therapeutic, including *"feeling like someone understood"* (Reine). However, only one trainee related these feelings specifically to the use of CAT PRs: "*It helps in normalising that we all have relational patterns and reciprocal roles"* (Jude). For others, a validating space was beneficial but not necessarily because of the use of CAT. A small number of participants valued an external facilitator due to *"absence of scrutiny from the course".*

Discomfort and benefit. Eight trainees regarded the process as emotionally difficult, with some participants reporting feeling *"vulnerable"* (Ziggy), and *"initially overwhelmed"* (Jamie). Nonetheless, no participants suggested these feelings were associated with aversive outcomes, and some suggested they *"later felt empowered"* (Jamie), or that the facilitator created a space that was *"challenging but comfortable"* (Oli).

Timing and clarity. Three trainees identified issues with the timing of the CAT PRs as inconvenient relative to placements, resulting in less opportunities to apply learning. However, one participant directly contradicted views on the length, reporting timing as *"really helpful to give you space to reflect upon it"* (Alex). Two trainees indicated a desire for more time between CAT PRs in order to *"think about some exits I may use"* (Ziggy), and another saying, *"it felt a bit like a taster and not a proper session"* (Prince). Although a small number raised this as an issue, comments regarding timing were highly varied and therefore salient. Relative to clarity, there was an expression of confusion by a small number of participants who had expectations of focusing *"on relevant personal patterns of relating"* (Max), yet sessions were *"framed as not being personal therapy"* (Jude), yet for some *"it was really difficult at times not to move into my personal life"* (Alex). Contracting regarding the use of a therapeutic process for professional development is worth consideration.

Personal professional development.

Becoming a better therapist. Over half of participants noted that they thought the process would help them to develop as therapists. This was linked to CAT for some, for example Alex said, *"I feel I am now more able to notice when I am being drawn into unhelpful patterns with particular clients"*. The majority talked about developing clinical and personal skills in a way that was not CAT specific, for example feeling able to *"be a more effective therapist"* (Gurpreet). Increased awareness was identified by most participants in this subtheme, with only one identifying a specific CAT-related change in *"the way I offer endings to clients and colleagues"* (Stevie).

Being human/good enough. A small number of trainees identified positive changes that allowed them to consider themselves as learning. This process involved being *"more comfortable with being imperfect"* (Sasha) and *"good enough"* (Andy). Two participants underscored the value of being reminded to utilise self-care.

Learning about CAT. Seven trainees cited their goals from CAT PRs as to learn about CAT concepts and tools, including "*reformulation 'in action' after our second year teaching sparked an interest in this model for me"* (Yoshi). Two wanted to understand CAT maps, and one in particular was working a CAT case and "*thought it would be interesting to see how my map compares and might interact"* (Ziggy).

Discussion

Whilst structured reflective opportunities are included in many forms in DClinPsy training, there is a lack of mixed methods research into components of effectiveness of reflective practices, particularly in relation to specific therapeutic models.

Aim 1: To evaluate the effectiveness of CAT personal reformulations as a tool to improve reflective capacity of trainees.

Quantitative RPQ results did not indicate any significant (aggregate) change in reflective capacity, or associated psychological constructs following CAT PRs in this sample of trainees. Evidence exists for the utility of the RPQ in detecting practitioner differences in reflective capacity across sub-scales (Priddis & Rogers, 2017; Rogers et al. 2019), although sample sizes have been somewhat higher in previous published research. Individual-level analyses indicated most participants reported no reliable change following CAT PRs. CAT is an integrative and relational model affecting changes through the therapeutic relationship (Darongkamas, John, & Walker, 2014). One disadvantage of the PR tool is its brevity, and CAT PRs may not provide a comprehensive opportunity for meaningful changes in reflective capacity. In fact, no reliable changes were detected in core components of reflection (Reflective-in-action, Reflective-on-action, Reflective with others), indicating that CAT PRs were not effective as a tool to improve the reflective capacity of trainees in this sample.

Individual level improvements were observed for ‘Confidence – general’ and ‘Confidence – communication’ for some participants. This is in line with data from a mental health practitioner sample described by Rogers and Priddis (2017), who reported high levels of confidence as measured by the RPQ. It is not possible to conclude by what methods an increase in confidence may have occurred. CAT utilises a specific process of mapping through modelling and communication, and CAT PRs may have led to an increase in self-rated confidence through this process. However, there is research evidence that confidence may be subject to over-estimation (Ames & Kammrath, 2004), and a reliable shift in confidence in this sample is not linked to evidence of changes in clinical practice, such as increased competence.

For some participants, CAT PRs were associated with reductions on the sub-scales ‘Uncertainty’ and ‘Stress interacting with clients’. Further, qualitative data indicated that CAT PRs provided opportunities for trainees to see patterns previously unseen, and to allow themselves to be imperfect in their practice. This may indicate why improvements in ‘Uncertainty’ and ‘Stress interacting with clients’ were found for some, although quantitative and qualitative results were not matched in this evaluation. In the absence of improvements in reflective capacity and data on how respondents reflect on and in practice, results do not reflect meaningful post CAT PR improvements in reflective capacity. Furthermore, improvements in psychological constructs associated with reflective capacity such as uncertainty, confidence and stress interacting with clients may also be influenced by clinical experiences on placement and other components of DClinPsy training not captured in this evaluation, such as teaching and reflective practice groups.

Quantitative online survey data indicated improvements in self-awareness, but there was a mixed picture for increased knowledge of emotions affecting others, and on ability to interact with clients, with some participants rating ‘not at all’ to these questions. This may indicate the ability of CAT PRs to improve personal awareness, in the absence of ability to affect these changes in client work. In fact, qualitative data provides supportive evidence that CAT PRs improved components of reflective capacity for some trainees, however this is not supported by quantitative data, and limited information was given regarding how changes were used or applied to clinical practice. Due to the non-visible nature of reflection, it can be a challenge to explore the relationship between changes in reflection and changes in clinical practice (Mann, Gordon, & MacLeod, 2009), calling into question the clinical utility of reflection amongst healthcare professionals in the absence of supportive evidence.

Aim 2: To gain an understanding of how CAT reformulation sessions were experienced by a group of trainees, including how they have impacted on clinical practice.

It is difficult to disentangle the effects of CAT PRs from other CPD and training activities such as placement and teaching, which may impact on reflective capacity. Qualitative data provides some evidence of partial changes in awareness of self and others. CAT is a relational approach which requires attunement to the roles of self and others, including unconscious processes (Ryle, Poynton, & Brockman, 1990). This includes identification of ‘exits’ from unhelpful ways of relating (Ryle & Kerr, 2003). Therefore, it is in line with expectations that CAT PRs supported the identification of relational patterns for some trainees, including previously hidden ones. However, quantitative data did not support the effectiveness of CAT PRs to improve reflective capacity, calling into question the specific skills or metacompetencies that CAT PRs may target. In fact, many trainees reported that the more general therapeutic process, rather than CAT-specific elements, were most helpful for personal and professional development. Considering research evidence that therapeutic outcomes are heavily influenced by general rather than specific components (Wampold & Imel, 2015), the most important mechanisms of change in these sessions may have been the therapeutic relationship and safe space provided.

CAT PRs were identified by some trainees as supporting their understanding of themselves in relation to clients, as well as providing opportunities to experience a client's perspective. Research suggests that greater self-awareness can increase empathy and understanding of client's needs (Strozier & Stacey, 2001). A small number of trainees also identified intent to apply their discoveries on placement with supervisors and colleagues, which may indicate the positive impact of CAT PRs on trainees' clinical work. However, most trainees spoke of greater self-awareness in the absence of any information on how this would impact on their behaviour. Without data on changes in practice for trainees, it is difficult to determine how, if at all, CAT PRs impacted on trainee's clinical work and client outcomes, over and above self-reported increased awareness.

A theme regarding the process of CAT PRs as uncomfortable yet helpful for some may indicate the experience as one of self-discovery. Chaddock (2007) found that new insight and self-awareness can result in a questioning of confidence and competence. However, RCI criterion suggest that confidence increased reliably in a small proportion of trainees, which would contradict an expectation that confidence may decrease as trainees become more aware of their skill level (Bennett-Levy & Beedie, 2007). Therefore, the evaluation would have benefitted from attempts to match qualitative and quantitative data in order to contextualise this data further.

Strengths, Limitations and Future Directions

This evaluation is the first to use the RPQ as a measure of change in a pre-post intervention design, and to attempt to evaluate CAT PRs on their ability to improve reflective capacity. However, aggregate differences were not detected with the RPQ in this study. More longitudinal research with larger participant samples may be required to determine the utility of the RPQ for examining within-group differences more generally. In order to disentangle the effects of CAT PRs relative to other reflective opportunities, the RPQ may not be applicable to future evaluation of CAT PRs. Use of a reflective measure oriented to CAT theory could support the identification of CAT PR-specific changes, although at present no quantitative CAT measures exist. The Helper's Dance Checklist (Potter, 2014) provides scaffolding for building reflective discussion, however this measure is not appropriate for determining within-group change. Therefore, other methods of evaluating reflection may need to be utilised, such as ratings of aspects of reflective capacity in reflective writing (Rogers et al., 2019).

This evaluation was strengthened by a mixed methods design in order to detect change through objective measurement, and capture participant experiences. However, the small sample size utilised in a specific training context over a short time span limits the generalisability and utility of the current study. Further, the evaluation would have been improved by asking participants specific questions regarding behavioural change, considering the purpose of using two CAT PR sessions is for trainees to have opportunities to apply the 'mapping' process to a real world context.

Implications for the Trent Programme and DClinPsy Training

Overall findings from online survey data indicate that CAT PRs were experienced by some trainees as a helpful addition to training and CPD already offered. There is partial qualitative evidence for the use of CAT PRs to increase some aspects of reflective capacity, such as awareness. However, this is not supported by data from the validated measurement used in this study, which did not find any improvements in reflective capacity sub-scales. The addition of triangulated measurement methods such as CAT-specific qualitative measures, and appropriately timed placement supervisor ratings of reflective capacity, may be required in future evaluations on CAT PRs to provide multi-source data. However, future studies may want to first consider the utility of using reflection as a focused training technique, in the absence of empirical grounds for these practices (Mann et al., 2009). Further, components of CAT PRs identified as supporting personal and professional development were not identified to be CAT-specific. This supports the addition of CPD opportunities in which reflective processes are used, but does not provide specific evidence or rationale for CAT PRs.

A small number of trainees identified limitations of CAT PRs, relative to timing in their clinical training, and an unclear distinction as to whether sessions should focus on professional or personal situations. It is a challenge to separate one's 'personhood' from reflective processes, and there is debate as to how understanding the self from a personal perspective in a professional role should be incorporated into professional psychology training (Norcross, 2005). From this evaluation, consideration should be given to how this distinction may be achieved in a containing way, as the difference between personal development and individual therapy may lie in the depth of examining oneself in the work (Izzard & Wheeler, 1995). One recommendation may be for clear written or oral information on CAT PRs, and contracting regarding the nature of sessions, to be provided to trainees in preparation of the process.

Timing issues for some trainees may have also impacted on how much benefit they were able to derive from CAT PRs, reflected here in RPQ scores and qualitative comments. It would be justified to offer CAT PRs and other CPD opportunities more flexibly for trainees to derive the most benefit from them as a resource.

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The data that support the findings of this study are available from the corresponding author, [author initials], upon reasonable request.

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