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Acknowledgments

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Summary of Major Research Project

Section A presents a meta-synthesis of qualitative studies on women's experiences with intellectual disabilities (WID) around sex and intimate relationships. The review used a standardised appraisal tool to assess study quality and analysed their findings using thematic synthesis. Twenty-two studies met the review's eligibility criteria, with 232 WID participating. The analysis yielded six master themes: *valuing intimacy, autonomy vs safety, abuse and its sequelae, sexual knowledge, "Sex is not for me!"* and *facilitating sex and relationships.* Based on those themes, the review discussed potential clinical implications of how to support WID around their intimate lives. Equally, after considering methodological limitations, the review discussed future research areas.

Section B presents a study on UK-based clinical psychologists' (CPs) experiences supporting adults with ID and their networks around their psychosexual needs. The study employed a purposive-sampling strategy to recruit ten CPs who worked in a combination of NHS-funded community and inpatient settings. Participants engaged in individual semi-structured interviews, and their data were analysed using interpretative phenomenological analysis. The analysis identified three superordinate themes: *"being given the responsibility", "working with the shades of grey", and the "thwarted duty to protect and empower".* In addition, the study discussed potential clinical implications surrounding the support CPs might need when working with individuals, teams and organisations around PWID’s psychosexual needs. Finally, the study examined methodological limitations and future research recommendations.

Section A: Literature review

The experiences of women with intellectual disabilities around sex and intimacy: a thematic synthesis

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Abstract

Background: Previous literature reviews on the experiences of people with intellectual disabilities (PWID) report that they continue to experience social and environmental barriers that hinder their access to sex and intimate relationships. Although invaluable, these reviews only included studies with participants with mild-to-moderate ID and summarised their findings across genders. Focusing solely on intellectual disability may overshadow other intersectional identities' unique challenges and opportunities, e.g., women with ID (WID). McCarthy (2014) attempted to bridge this gap by exploring the sexual lives of women with mild-to-moderate ID across five peer-reviewed studies. Since this review's publication, more studies have emerged.

Aim: This meta-synthesis sought to review the literature on WID's experiences of sex and intimate relationships and update the findings of McCarthy's (2014) review.

Design: The present review searched systematically five databases from inception until September 2021 and hand-searched previous reviews' reference lists. It also used a quality assessment tool to consider the study's methodological quality and analysed the study findings thematically.

Findings: Twenty-two qualitative studies met the review's eligibility criteria. Overall, 232 WID participated in the included studies, aged 17 to 89 years. Of the studies reporting these characteristics, 89% of WID came from a White background, 87% had mild-to-moderate IDs, and 56% were in intimate relationships. The synthesis yielded six master themes*: Valuing intimacy; autonomy vs safety*; *abuse and its sequelae; sexual knowledge; "Sex is not for me!"; and facilitating sex and relationships.*

Clinical and research implications: The data indicated multiple contexts influencing WID's psychosexual experiences. A multiprong approach at the individual (e.g., access to comprehensive sex education) and relational and institutional levels (e.g., addressing their networks' risk-averse attitudes) might further support WID's intimate lives. However, methodological limitations may limit the review findings' transferability, and future research recommendations are drawn.

Key words: women, intellectual disabilities, sex, intimate relationships

Introduction

Definitions

Intellectual disabilities

The terms *intellectual disabilit*ies (ID) or *learning disabilit*ies (LD) describe an aetiologically diverse group of conditions that start before adulthood and are associated with "substantial and lifelong limitations in intellectual functioning and coping with everyday activities" (Department of Health [DoH], 2001, p.14). The diagnostic nomenclature typically classifies ID into mild, moderate, and severe-to-profound levels based on a person's estimated intelligence quotient score (British Psychological Society [BPS], 2015), attempting to gauge the level of support people with intellectual disabilities (PWID) might need daily (World Health Organisation [WHO], 2018).

It is important to note that there is growing recognition of the socially constructed nature of the term ID, whose definition has changed across cultural and historical contexts (Finlay & Lyons, 2005). Furthermore, self-advocacy movements contest the concept of ID because it situates the deficit within the individual, ignoring the impact of relationships with family, professionals, and social and economic policies (Disability Rights UK, 2020). Nevertheless, this review used the term ID, and its associated qualitative descriptors for clarity, as it is the internationally preferred descriptor in clinical and academic research (BPS, 2015).

In the past twenty years, researchers have attended more to the disparities PWID continue to face regarding healthcare outcomes (Heslop et al., 2013) and accessing fundamental human rights (NHS Digital, 2021). Government policies have made pledges (e.g., Valuing People Now, 2007) to reduce disparities and promote community inclusion to align with the principles or normalisation introduced fifty years ago (Wolfensberger et al., 1972). One such principle requires enabling PWID to meet their sex and intimate relationship needs (Care Quality Commission, 2019).

Intimate relationships

*Intimate relationship*s describe relationships between people that involve consensual emotional or physical closeness, sexual or romantic and free from exploitation (WHO, 2019). Researchers have highlighted the importance of intimate relationships for emotional well-being, including the need for connection and security (e.g., Bowlby, 1982; Mikulincer & Shaver, 2007). Crittenden's (2013) Dynamic Attachment Adaptation Maturational (DMM) model, building on Bowlby’s (1982) attachment theory, underscored how adult relationships could reinforce or update people’s internal working models (learnt expectations of how others will respond to their needs).

Sex

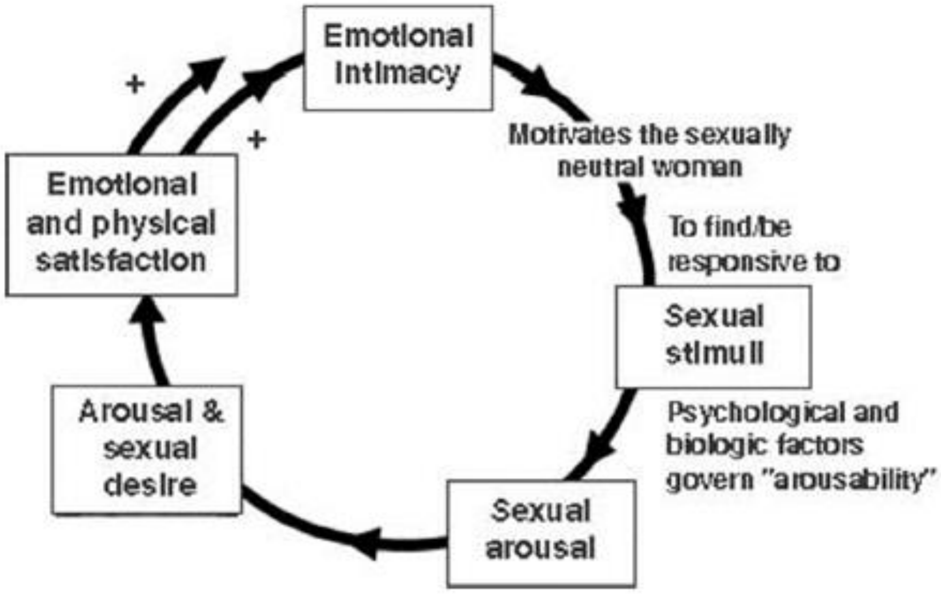
Sexual behaviours encompass actions which can result in sexual gratification. This is associated with a state of psychological well-being and may or may not involve physical stimulation of the genitalia or mental representations of such activity (Reisman et al., 2015). These behaviours cover solitary activities (e.g., masturbation) and interactions with others (e.g., caressing, penetrative sex).

Basson's (2000) circular model of sexual response stipulates that people start from a state of *sexual neutrality*, meaning that arousal (a physiological response to potential sexual stimuli) can be rewarding only when it occurs in a context that helps a person be receptive to interpret those stimuli as pleasurable (see Figure 1). Factors such as attention, stress, and past learning (e.g., previous sexual encounters) can influence this receptivity (Chivers et al., 2010). In the case of physically and emotionally rewarding sexual encounters, women are more likely to report increased emotional intimacy towards their partners and more likely to seek out sexual stimuli in the future (Basson, 2000).

Cultural beliefs and practices affect people's understanding of sex and their experiences of pleasure (WHO, 2019). For example, different meaning-making contexts, e.g., sinning (as documented in some Pre-Reformation teachings [Dabhoiwala, 2012]), medicine, and politics have heavily influenced what is considered ‘normal’ sex; its intended purpose (e.g., procreation) and who has the right to enjoy it (McRuer, 2006; Shildrick, 2009). Therefore, the term *sexual activities* describes both physical and heavily context-mediated psycho-spiritual phenomena (WHO, 2019).

Figure 1

Basson’s model of sexual response cycle



Note. Basson (2000), Figure 1, p. 53

PWID and intimate relationships

Studies have documented the benefits of positive romantic relationships for people with and without ID, citing an increased sense of self-esteem, social communication skills (Fulford & Cobigo, 2016), and emotional well-being (Turner &

Crane, 2016). Equally, Article 23 of the United Nations Convention (2007) and the UK’s Human Rights Act, Article 12 (1998) enshrine the rights of PWID to intimate relationships, both underscoring freedom of sexual self-determination.

PWID tend to have small social networks (Lippold & Burns, 2009) supporting them in developing friendships and romantic relationships. However, despite advances in policies and the broader recognition of PWID’s psychosexual needs, many PWID continue to experience difficulties exercising choice over their intimate lives (Mencap, 2020).

Several systematic reviews on the experiences of paid and unpaid carers supporting PWID with their psychosexual needs cite the following challenges (Brown & McCann, 2019; Chrastina & Večeřová, 2018; Powell et al., 2019; Rushbrooke et al., 2014):

(a) Carers' attitudinal barriers towards PWID's ability or desire to engage in intimate relationships (e.g., a default assumption of asexuality), with PWID's gender and level of disability compounding further these understandings.

(b) Informal and formal carers lacked the training and relevant guidance to support PWID’s psychosexual needs.

(c) Paid and unpaid carers experienced tension trying to balance empowering PWID's sexual self-determination and their duty to protect them from exploitation, with professional carers fearing accountability if things went wrong.

These reviews also underscored the uncertainty regarding who was responsible for supporting PWID’s intimate lives, with support networks needing help understanding PWID's needs and desires. Therefore, it is crucial to understand PWID's perspectives to overcome these barriers in facilitating meaningful intimate relationships.

Previous reviews on PWID’s experiences

Several qualitative reviews have synthesised data on PWID's experiences of sex or intimate relationships: Black & Kammes, 2019; Brown & McCann, 2018; English et al., 2018; Fulford & Cobigo, 2016; Lam et al., 2019; Whittle & Butler, 2018.

The most frequently reported themes included: a desire for relationships and physical intimacy; sociocultural scripts; lack of agency; intimate violence; and comprehensive sex education. Across all reviews, PWID shared a desire for romantic relationships, not always involving sexual intimacy. The most frequently cited reason for wanting a relationship was access to practical support (e.g., Lam et al., 2019; Whittle & Butler, 2018) and companionship (e.g., Black & Kammes, 2019; Brown & McCann, 2018). All reviews reported that irrespective of whether participants desired physical intimacy from their relationships, they often experienced excessive restrictions from paid and unpaid carers, resulting in a lack of privacy and controlling the type of contact, if any, with potential partners. Four reviews highlighted participants resorting to secrecy to avoid being reprimanded and maintain relationships (Black & Kammes, 2019; English et al., 2018; Fulford & Cobigo, 2016; Whittle & Butler, 2018). All reviews documented PWID's frequent experiences of interpersonal violence and sexual abuse. When it came to PWID's experiences of sex education, this was often incomplete and heavily protectionist. Three reviews highlighted the gender stereotypical ideas some PWID held, men with ID typically endorsing a hegemonic view of gender emphasising the role of men as protectors or breadwinners (Lam et al., 2019) and women's roles being homemakers (Brown & McCann, 2018; Whittle & Butler, 2018).

Although invaluable, these reviews only included studies with participants with mild-to-moderate ID and summarised their findings across genders. Given the multitude of contexts that influence psychosexual experiences, focusing solely on intellectual disability may overshadow the unique challenges and opportunities of other intersectional identities, e.g., women with ID (WID), those with severe-to-profound disabilities, perpetuating inequalities further (Frohmader, 2014).

The intimate lives of WID

Historically, compulsory sterilisation and institutionalisation were part of eugenic practices disproportionately affecting WID (Tilley et al., 2012). Similarly, evidence suggests that many WID continue to face disparities regarding their reproductive rights and accessing services (e.g., having involuntary sterilisation [Chou et al., 2015]) and participating less in health check-ups, such as cervical screenings tests (Brown et al., 2016; Xu et al., 2017). Therefore, examining the many WID’s accounts across several studies could helpfully complement the other reviews' findings by providing a more specific account of WID's psychosexual experiences.

McCarthy (2014) explored the sexual lives of women with mild-to-moderate ID across five peer-reviewed studies, one of which included men and women in their sample. As in the reviews above, McCarthy reported that WID had negative experiences with sex, often conceding to pleasureless sex with their partners to please or appease them. Furthermore, McCarthy documented that WID would often abstain from sex because of the above experiences or to guard against unwanted consequences (e.g., pregnancy and sexually transmitted infections [STI]). Finally, in the case of WID wishing to have relationships or sex, they reported lacking opportunities to meet potential partners and faced environmental barriers.

However, McCarthy’s review has limitations; although McCarthy used comprehensive search terms, databases were omitted. These might have identified studies published in allied health professions, such as nursing (Cumulative Index to Nursing and Allied Health Literature, (CINAHL)) and social work (Applied Social Sciences Index and Abstracts, (ASSIA)). Additionally, the review's analysis did not draw themes across studies but summarised them descriptively. In the intervening years, further studies have emerged. Therefore, there is a need for an up-to-date review of WID's experiences of sex and romantic relationships, employing a comprehensive search strategy and an approach that draws themes across studies.

Review aims

This review is a meta-synthesis of qualitative studies exploring the views and experiences of WID around their psychosexual needs. It aligns with the NHS value of everyone counts to improve current knowledge on supporting a population whose sexual needs have been historically marginalised (DoH, 2015). The review will address the following questions:

(a) What are WID's views and experiences around sex and intimate relationships?

(b) What do WID think are the barriers and facilitators to engaging in pleasurable sexual experiences and developing or maintaining affirming intimate relationships?

Methods

Search strategy

The search strategy prioritised sensitivity over specificity to identify as many eligible studies as possible (Siddaway et al., 2019). The following databases were searched from inception until the 24th of September 2021: ASSIA (via ProQuest), CINAHL (via EBSCO), Medline and PsychINFO (via Ovid), and Web of Science. There were two key concepts: ID and sex and intimacy-related terms (e.g., romantic relationships, sexual behaviours). See Table 1 for the search strategy on Web of Science. Reference lists of relevant systematic reviews covered in the introduction section and those of included studies to identify additional records were also reviewed.

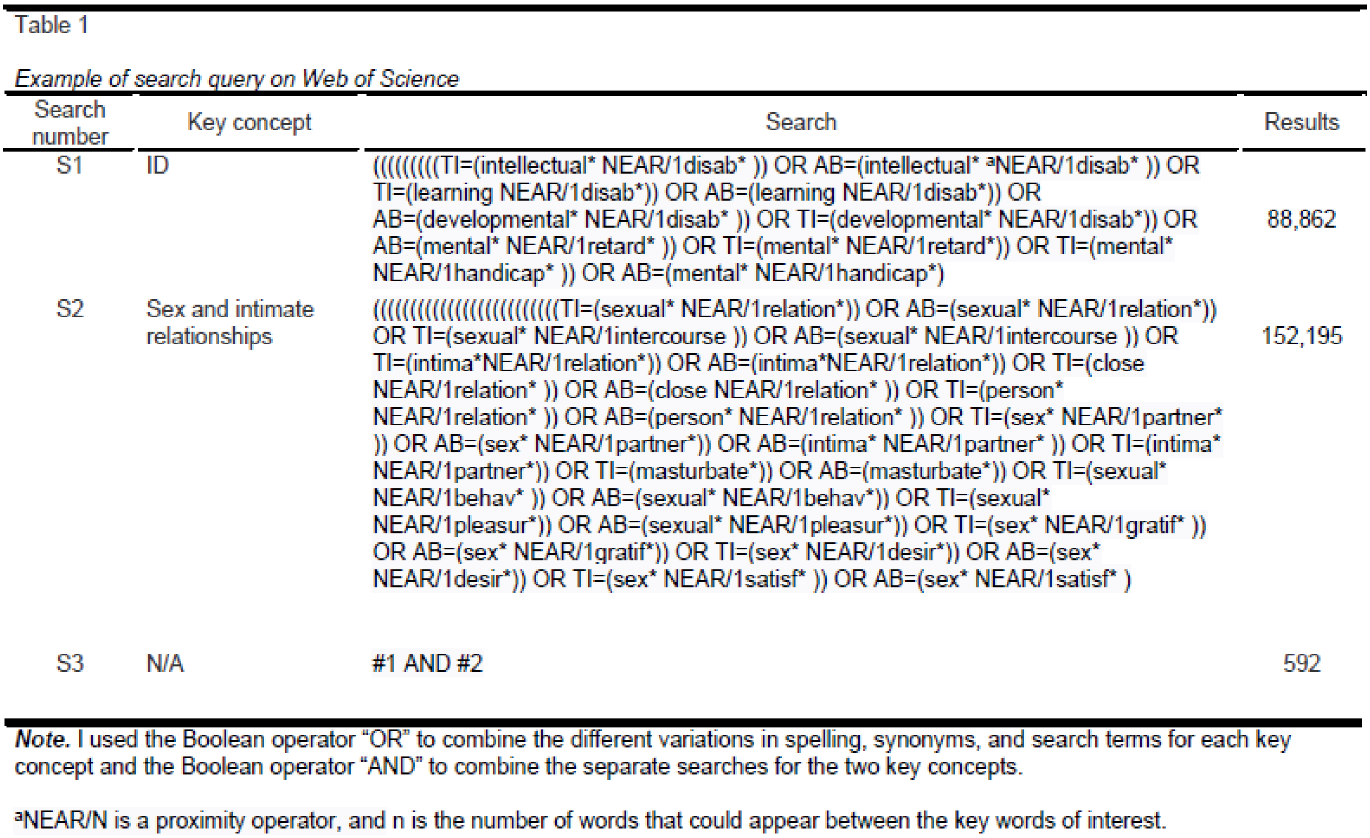


Table 1

Example of search query on Web of Science

Search number	Key concept	Search	Results
S1	ID	(((((((((TI=(intellectual* NEAR/1disab*)) OR AB=(intellectual* [a]NEAR/1disab*)) OR TI=(learning NEAR/1disab*)) OR AB=(learning NEAR/1disab*)) OR AB=(developmental* NEAR/1disab*)) OR TI=(developmental* NEAR/1disab*)) OR AB=(mental* NEAR/1retard*)) OR TI=(mental* NEAR/1retard*)) OR TI=(mental* NEAR/1handicap*)) OR AB=(mental* NEAR/1handicap*)	88,862
S2	Sex and intimate relationships	(((((((((((((((((((((((((TI=(sexual* NEAR/1relation*)) OR AB=(sexual* NEAR/1relation*)) OR TI=(sexual* NEAR/1intercourse)) OR AB=(sexual* NEAR/1intercourse)) OR TI=(intima*NEAR/1relation*)) OR AB=(intima*NEAR/1relation*)) OR TI=(close NEAR/1relation*)) OR AB=(close NEAR/1relation*)) OR TI=(person* NEAR/1relation*)) OR AB=(person* NEAR/1relation*)) OR TI=(sex* NEAR/1partner*)) OR AB=(sex* NEAR/1partner*)) OR AB=(intima* NEAR/1partner*)) OR TI=(intima* NEAR/1partner*)) OR TI=(masturbate*)) OR AB=(masturbate*)) OR TI=(sexual* NEAR/1behav*)) OR AB=(sexual* NEAR/1behav*)) OR TI=(sexual* NEAR/1pleasur*)) OR AB=(sexual* NEAR/1pleasur*)) OR TI=(sex* NEAR/1gratif*)) OR AB=(sex* NEAR/1gratif*)) OR TI=(sex* NEAR/1desir*)) OR AB=(sex* NEAR/1desir*)) OR TI=(sex* NEAR/1satisf*)) OR AB=(sex* NEAR/1satisf*)	152,195
S3	N/A	#1 AND #2	592

Note. I used the Boolean operator "OR" to combine the different variations in spelling, synonyms, and search terms for each key concept and the Boolean operator "AND" to combine the separate searches for the two key concepts.

[a] NEAR/N is a proximity operator, and n is the number of words that could appear between the key words of interest.

Inclusion criteria

The hits obtained from the database and hand search were screened against the criteria in Table 2.

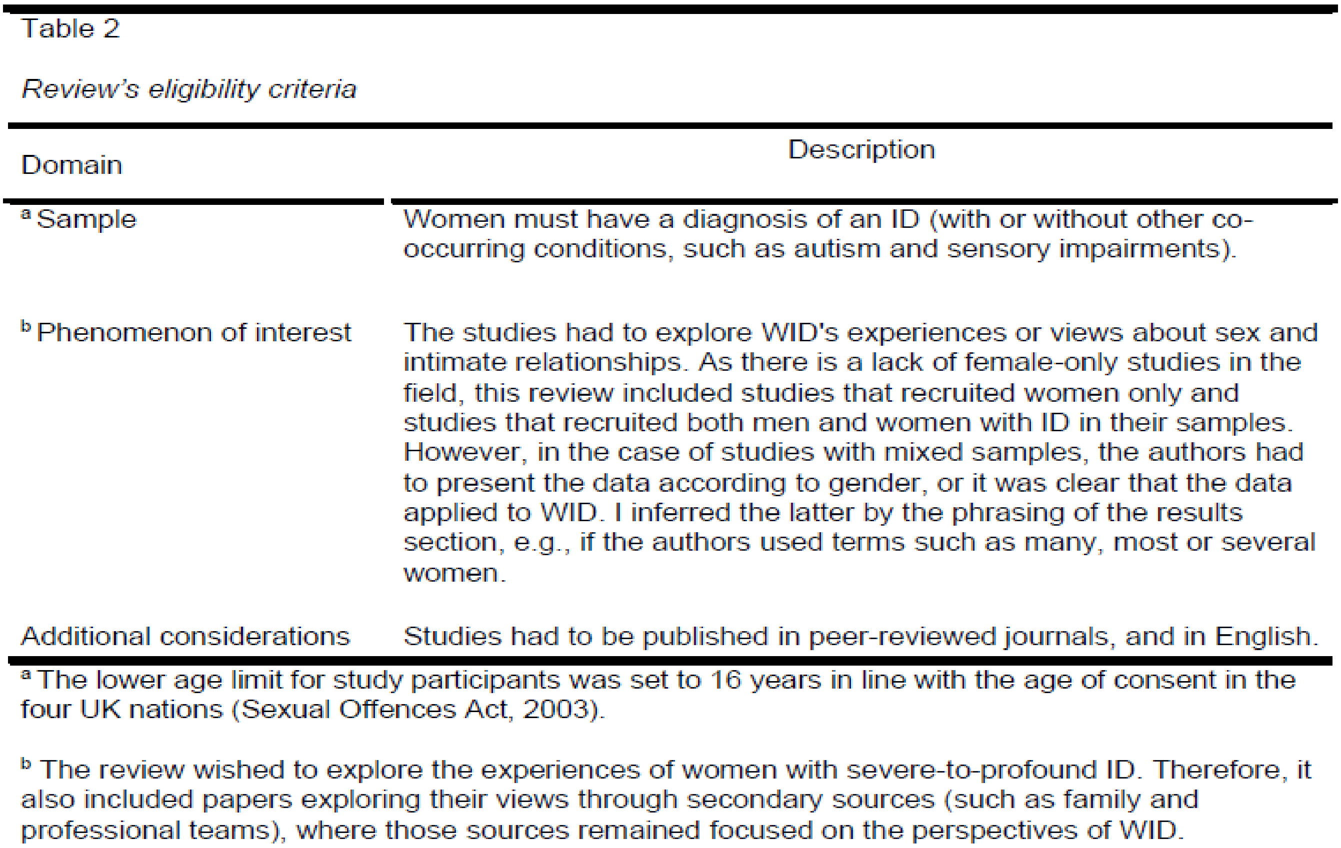


Table 2

Review's eligibility criteria

Domain	Description
[a] Sample	Women must have a diagnosis of an ID (with or without other co-occurring conditions, such as autism and sensory impairments).
[b] Phenomenon of interest	The studies had to explore WID's experiences or views about sex and intimate relationships. As there is a lack of female-only studies in the field, this review included studies that recruited women only and studies that recruited both men and women with ID in their samples. However, in the case of studies with mixed samples, the authors had to present the data according to gender, or it was clear that the data applied to WID. I inferred the latter by the phrasing of the results section, e.g., if the authors used terms such as many, most or several women.
Additional considerations	Studies had to be published in peer-reviewed journals, and in English.

[a] The lower age limit for study participants was set to 16 years in line with the age of consent in the four UK nations (Sexual Offences Act, 2003).

[b] The review wished to explore the experiences of women with severe-to-profound ID. Therefore, it also included papers exploring their views through secondary sources (such as family and professional teams), where those sources remained focused on the perspectives of WID.

Quality appraisal

The author used the Critical Appraisal Skills Programme tool (CASP, 2018) to assess study quality (Appendix A). The CASP is a validated quality appraisal tool frequently used by reviews on PWIDs' experiences of sex and relationships (e.g., Fulford & Cobigo, 2016). Consequently, to compare the quality across the reviewed papers, Harbour and Miller's (2001) criteria, as per Table 3, were consulted to assign each study an overall quality rating of high, moderate, or low. Thomas and Harden (2008) argue that there is limited evidence to exclude studies based on quality ratings from the synthesis. Nonetheless, based on their guidance, study quality is considered in the results and discussion section, e.g., prioritising the themes from high versus low-quality studies or highlighting those that only lower-quality studies endorsed. Equally, when there is no mention of study quality, the reader can assume that a theme was present in both high- and low-quality studies.

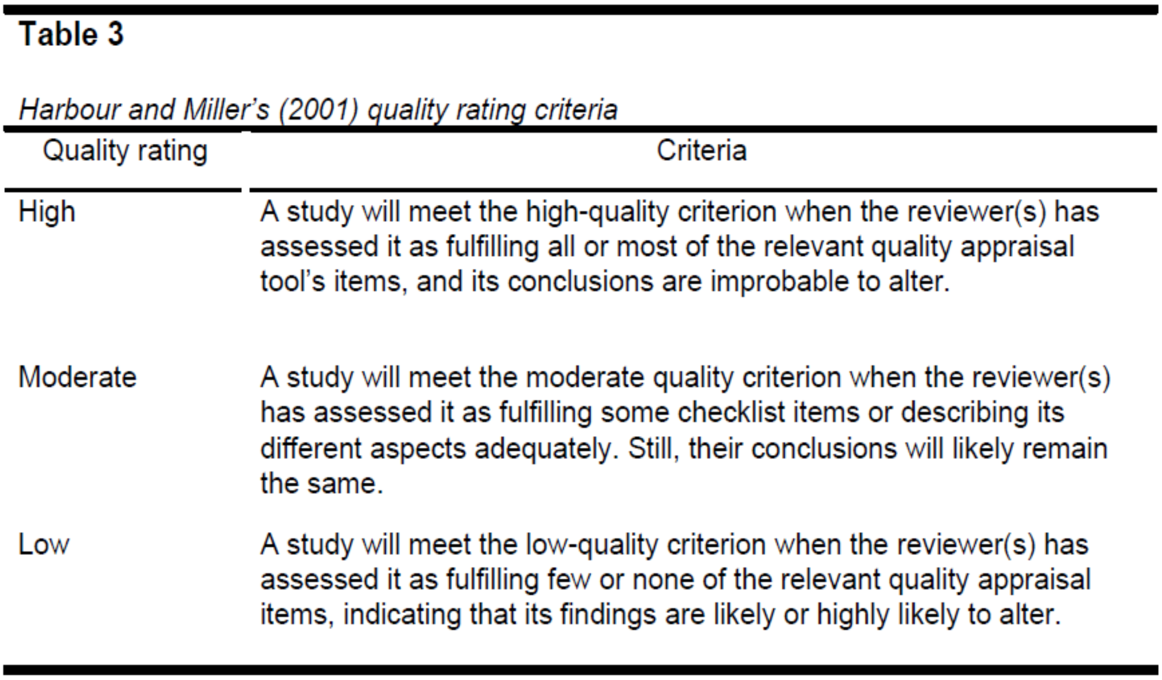


Table 3

Harbour and Miller's (2001) quality rating criteria

Quality rating	Criteria
High	A study will meet the high-quality criterion when the reviewer(s) has assessed it as fulfilling all or most of the relevant quality appraisal tool's items, and its conclusions are improbable to alter.
Moderate	A study will meet the moderate quality criterion when the reviewer(s) has assessed it as fulfilling some checklist items or describing its different aspects adequately. Still, their conclusions will likely remain the same.
Low	A study will meet the low-quality criterion when the reviewer(s) has assessed it as fulfilling few or none of the relevant quality appraisal items, indicating that its findings are likely or highly likely to alter.

Data extraction

The characteristics of studies meeting the inclusion criteria were entered into a word template. In line with Thomas and Harden (2008), all text under the 'findings' section of the study reports formed the review's data set. Therefore, the data included participant quotes (first-order constructs) and their respective interpretations by the study authors (second-order constructs). When studies presented accounts from women and men with ID in their analysis, quotes from or about WID were extracted and imported verbatim into NVivo 1.7 software (QSR International, 2021).

Analysis

The analysis drew on a critical realist position, emphasising that whilst there might be an objective reality, individuals' interpretations and preconceptions will influence how they understand and observe it (Bhaskar & Danermark, 2006). The data analysis proceeded over three, and to some extent, overlapping stages following the principles of thematic synthesis, namely initial coding and developing descriptive and analytic themes (Thomas & Harden, 2008). Table 4 provides further details about each of these stages.

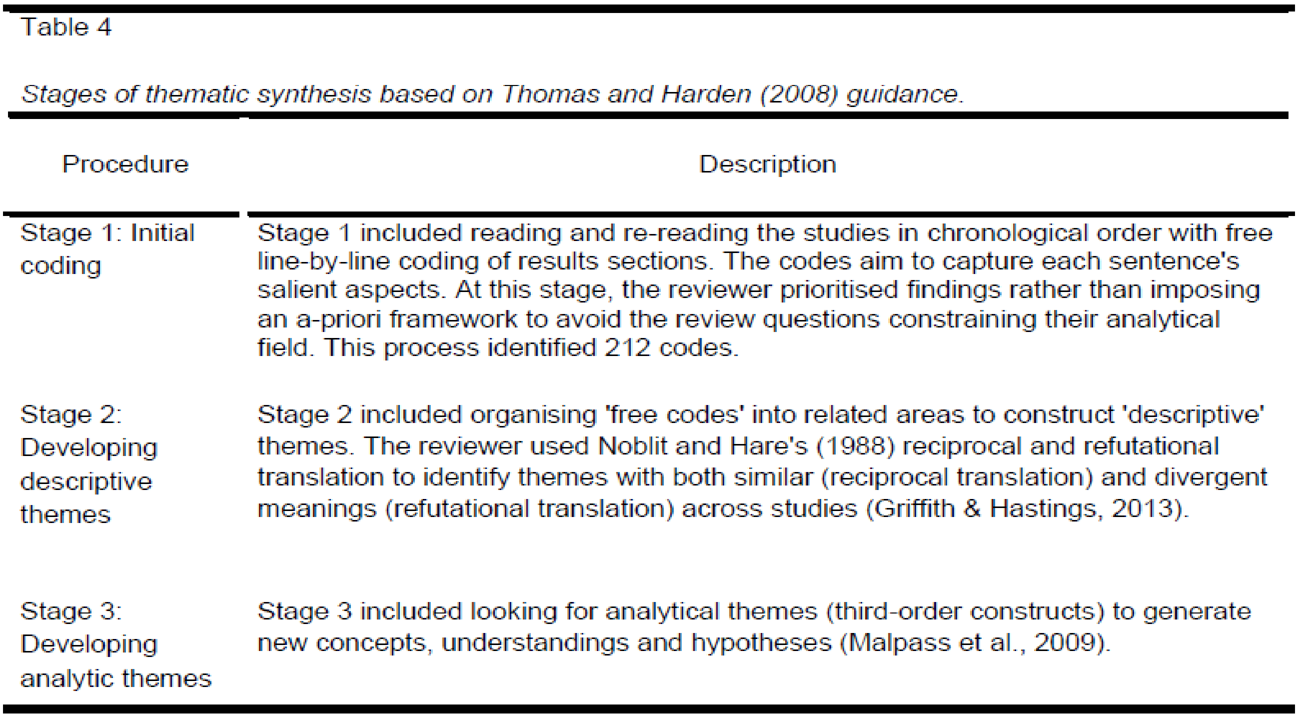


Table 4

Stages of thematic synthesis based on Thomas and Harden (2008) guidance.

Procedure	Description
Stage 1: Initial coding	Stage 1 included reading and re-reading the studies in chronological order with free line-by-line coding of results sections. The codes aim to capture each sentence's salient aspects. At this stage, the reviewer prioritised findings rather than imposing an a-priori framework to avoid the review questions constraining their analytical field. This process identified 212 codes.
Stage 2: Developing descriptive themes	Stage 2 included organising 'free codes' into related areas to construct 'descriptive' themes. The reviewer used Noblit and Hare's (1988) reciprocal and refutational translation to identify themes with both similar (reciprocal translation) and divergent meanings (refutational translation) across studies (Griffith & Hastings, 2013).
Stage 3: Developing analytic themes	Stage 3 included looking for analytical themes (third-order constructs) to generate new concepts, understandings and hypotheses (Malpass et al., 2009).

The reviewer chose thematic synthesis as the primary analysis method because it is suited to synthesising data from epistemologically diverse methodologies (Thomas & Harden, 2008). The reviewer's supervisors audited the coding structure. Where there were areas of disagreement, the supervisors and the reviewer jointly revisited the original data to agree on the final coding based on consensus. Additionally, an external consultant clinical psychologist in ID reviewed the coding. The analysis ended when it stopped yielding further themes that could describe the data

(Charmaz, 2006). Finally, to support his reflexivity, the reviewer attended monthly supervision.

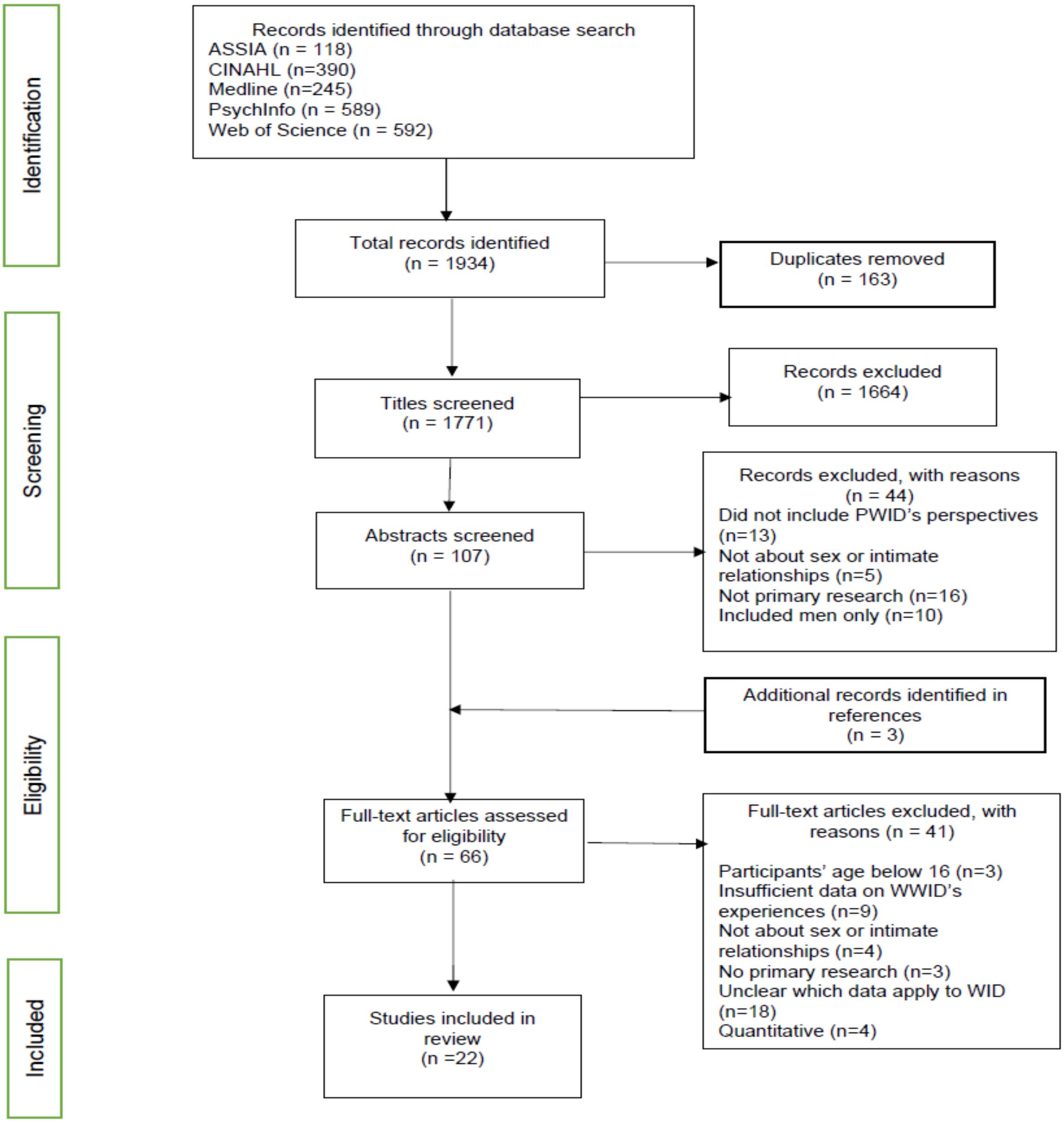
Results

Studies considered

The search and screening process identified 22 eligible articles; see Figure 2 for the PRISMA diagram (Moher et al., 2009).

Figure 2

PRISMA flow diagram of search results and screening process



Note. Adapted from Moher et al., (2009)

Study characteristics

Table 5 contains the included studies' characteristics, and letters *k* and *n* denote the number of studies and participants, respectively. The geographical and cultural contexts differed across the studies. Fifteen studies took place in English-speaking countries: Australia (k= 4), Canada (k=2), Ireland (k=2), the UK (k=5), and the USA (k=2). The remaining seven took place in non-English speaking countries: Belgium (k=1), Finland (k=1), Iceland (k=1), Netherlands (k=1), Poland (k=1), Spain (k=1), and Taiwan (k=1). The study records covered the period from 2002 to 2020.

Data collection methods included focus groups (k=4), individual interviews (k=12), focus groups plus interviews (k=1), ethnographic participant observations (k=1), participant observations plus individual interviews (k=3), individual and dyadic (or couple) interviews (k=1). Analytical frameworks included grounded theory (k= 3), interpretative phenomenological analysis (k=3), hermeneutic phenomenological analysis (k=2), thematic analysis (k=11), thematic and discourse analysis (k=1), content analysis (k=1), performative dialogical analysis (a discourse analysis subtype) (k=1).

The study sample sizes varied from case studies to 44 participants. Furthermore, eight studies recruited only women in their samples, with the remainder having mixed samples (e.g., men with ID). Please note that for the latter papers, the reviewer included only the data from WID. Two studies provided data for the same participant sample but focused on a different research question (Bates et al. 2016; 2017). In total, 232 WID, one identified as non-binary, participated in the studies. The age of participants ranged from 17 to 89 years. No study provided data on religious beliefs, and only three (n=53) described the racial or ethnic composition of their samples, with 89% (n=47) of women identifying as White British or White Other and

11% (n=6) as Black Other. Of the studies that reported participants' ID level (k=8; n =108), 56% (n=60) of women had a mild ID, 31 % (n=46) had a moderate ID, and 11% (n=12) had a severe-to-profound ID. Twelve studies provided data on relationship status (n =82), with 37% (n=30) being currently single, 55% (n=45) presently in a relationship (which includes a relationship longer than six months, and either being engaged or married) and 6% (n=18) reporting that they had never had a relationship. Eleven studies (n=93) reported data on participants' sexuality, with 87% (n=79) of women identifying as heterosexual and 13% as lesbian (n=12) or bisexual (n=2). Of the studies that reported employment (k=6; n=97), 73% (n=55) of women were either in part-time (supported) paid or voluntary work, and 27% (n=42) were unemployed. Finally, 11 studies (n=117) provided data on living arrangements, with 15% (n=12) of women living independently, 28% (n=30) living with their families, and 64% (n=75) in supported accommodation.

Table 5

Included studies characteristics

Year	Study ID, citation (country)	Aims and design	Sample	Data collection method and analysis	Main themes or a summary of the main findings
2002	Lesseliers & Van Hove, 2002 (Belgium)	Aims: To explore what PWID thought were the salient aspects of their intimate lives. Design: Qualitative	34 adults with ID (Aged 20-65 years) (Women, n=23) (Men, n=11) Additional inclusion criteria: Able to communicate verbally.	Data collection: Individual semi-structured interviews Data analysis: Thematic analysis	PWID experienced relationships under organisational and structural constraints. Equally, they reported having insufficient support in making and maintaining relationships. Participants often experienced guilt and disapproval from those around them regarding their intimate lives. Some resorted to having secretive sexual experiences, and there were several references to incidents of sexual violence.
2009	Kelly, Crowley & Hamilton, 2009 (Ireland)	Aims: (a) To explore the views, hopes and experiences of PWID living in Ireland concerning their sexuality and romantic relationships. (b) To understand what help PWID wanted from statutory services concerning their intimate lives. Design: Qualitative	15 adults with ID (Aged 23-41 years [Mean age=32 years]) (Women, n=7) (Men, n=8) Additional information: The researchers recruited from a single ID service.	Data collection: Two focus groups and individual semi-structured interviews with participants Data analysis: Thematic analysis	3 main themes: insufficient sexual knowledge, desiring sex and intimacy, and prohibition.
2011	Eastgate et al., 2011 (Australia)	Aims: To explore the sexual understanding and past relationship experiences of women with ID (WID).	9 women with mild ID (Aged 20-49 years) (Relationship status, in a relationship [n=6]; currently single [n=2]; never had a partner [n=1])	Data collection: Individual semi-structured interviews Data analysis: Thematic analysis	4 main themes: sources and level of WID's sexual knowledge; negotiating sexual relationships, self-protection strategies, and sexual abuse and its effects.
2011	Fitzerald & Withers, 2011 (England, UK)	Aims: To explore how women with IDs understand their sexual identity. Design: Qualitative	10 women with ID • (Aged 19-64 years) Additional sample characteristics: • Able to respond verbally. • Access to participants through professional gatekeepers.	Data collection: Individual semi-structured Data analysis: Thematic analysis	2 main themes: Sex is pleasurable for others and regulated beings.
2012	Bernert & Ogletree, 2012 (Illinois, USA)	Aims: To explore how women with ID constructed 'sex'. Design: Qualitative	14 women with ID • (Aged 18-89 years) • (Women, n=14)	Data collection: Participant observations over 2 years and individual semi-structured interviews	3 themes: sexual experiences, conditions for sex, and negative perceptions

Table 5

Included studies characteristics

Year	Study ID, citation (country)	Aims and design	Sample	Data collection method and analysis	Main themes or a summary of the main findings
			• (Level of ID, Mild ID [n=7], Moderate [n=7]) • (Relationship status, in a relationship [n=1], currently single, [n=4]), never had a partner [n=8]) • (Ethnic background, Black Other [n=4]; White Other [n=10])	Data analysis: Thematic analysis *Additional information:* study employed member checking over 2 focus groups.	
2013	Lafferty et al., 2013 (Ireland)	Aims: To examine the experiences and views of couples with ID about their intimate relationship. Design: Qualitative	8 couples with ID • (Aged, 26-65 years]; Mean age=47]) • (Women, n=8) • (Men, n=8) Additional sample characteristics: (a)Participants had to be in a long-term relationship and able to communicate verbally; (b) recruited through gatekeepers	Data collection: Individual and dyadic semi-structured interviews Data analysis: Grounded theory	3 main themes: valuing companionship, valuing reciprocity, and coping with conflict.
2014	Pestka & Wendt, 2014 (Australia)	Aims: **(a)** To understand the intimate relationship experiences of WID. **(b)** To explore WID's experiences and understandings of belonging in the context of domestically violent relationships.	4 women with mild ID • (Aged 21-69 years) • (Currently in a relationship, n=2) • (Relationship status, in a relationship [n=2], currently single, [n=2])	Data collection: Individual semi-structured interviews Data analysis: Performative dialogical analysis	Three main themes: Not belonging, wanting to belong, and domestic abuse .
2014	Rushbrooke et al., 2014 (England, UK)	Aims: To explore how adults with IDs experienced intimate relationships. Design: Qualitative	9 adults with mild ID • (Aged 21-58 years) • (Women, n=5) ○ (Relationship status, in a relationship [n=1], currently, [n=3]),	Data collection: Individual semi-structured interviews Data analysis: Interpretative phenomenological analysis (IPA)	3 main themes: wanting intimate relationships, the value of intimate relationships, and facing restrictions and control by others.

Table 5

Included studies characteristics

Year	Study ID, citation (country)	Aims and design	Sample	Data collection method and analysis	Main themes or a summary of the main findings
			never had a partner [n=1]) ○ Sexuality, heterosexual [n=4]; bisexual [n=1] • (Men, n=4)		
2015	Chou et al., 2015 (Taiwan)	Aims: (a.) To explore PWID's views and experiences regarding their sexual health. (b.) To explore the differences in attitudes, knowledge, and experiences between male and female adults with ID. Design: Mixed methods	100 adults with ID • (Aged 18-63 years) • (Men, n=56) • (Women, n=44) ○ (Level of ID, Mild ID [n=13]; Moderate ID [n=31]) ○ (Employment status, In part-time or full-time employment [n=28]; Unemployed, [n=15])	Data collection: Focus groups Data analysis: IPA	4 main themes: Controlled by parents, staff and society; views on pornography and masturbation; loving in secrecy; sexual abuse
2016	Bates et al., 2016 (England, UK)	Aims: To understand the meaning of intimate experiences for adults with ID.	11 adults with ID • (Aged 35-60 years) • (Women, n=6) • (Men, n=5) • (Level of ID=C/T) *Additional inclusion criteria:* (a) In a long-term relationship for a minimum of 6 months, (b) Able to communicate verbally. *Additional sample characteristics:* Participants were recruited from two ID charities.	Data collection: (a) Semi-structured interviews (lasting 45-120 minutes) Data analysis: Hermeneutic phenomenology (Van Manen, 1990)	3 themes: The value of intimate relationships, the experience of physical intimacy, and the reparative potential of romantic relationships

Table 5

Included studies characteristics

Year	Study ID, citation (country)	Aims and design	Sample	Data collection method and analysis	Main themes or a summary of the main findings
2016	Frawley & Wilson, 2016 (Australia)	Aims: To explore the experiences and opinions of young people with ID on the effectiveness of sexuality education. Design: Qualitative	25 young people with ID • (Aged 17-19 years) • (Men, n=14) • (Women, n=11) Additional inclusion criteria: Able to communicate verbally.	Data Collection: Four separate focus group interviews with men and women Data Analysis: Grounded theory	The study identified the following challenges: (a) Sex education had a heavily protectionist and functional focus. (b) Participants desired more information on communication skills to navigate relationships
2016	Fish, 2016 (United Kingdom)	Aims: To understand WID's lived experience in a forensic inpatient unit. Design: Qualitative	16 women with ID • (Aged 18-60 years old) • (Ethnicity, White British [n=16]) Additional sample characteristics: Inpatients in a forensic unit 12 ID professionals From the same setting as PWID	Data collection: Ethnographic observations and individual semi-structured interviews Data analysis: Thematic analysis	4 themes: Previous experiences of sexual violence and their effects, excessive monitoring and regulation of WID's lives, resisting restrictions, and same-sex relationships
2016	Rojas et al. (2016) (Spain)	Aims: To explore what PWID see as important in different areas of their lives, including intimate relationships.	16 adults with IDs • (Aged 18-39 years) • (Women, n=6) • (Men, n=9)	Data collection: Individual semi-structured interviews Data analysis: Thematic analysis	2 main themes: sexual relationships, and the role of family and others

2016	Turner et al.,2016
	(USA)
		Aims: To understand how PWID experienced romantic and sexual relationships.
		Design: Qualitative
			5 adults with mild ID
			• (Aged 21-54 years)
			• Women (n=3)
			  ○ (Relationship status, in a relationship [n=2], currently single, [n=1])
			  ○ (Employment status, In part-time or full-time employment
				Data Collection: (a) Semi-structured interviews (b) observations
				Data analysis: Thematic analysis
				Coding involved a combination of deductive and inductive analysis
					3 main themes: sexual pleasure, attitudes towards sex, and sexual self-understanding.

Table 5

Included studies characteristics

Year	Study ID, citation (country)	Aims and design	Sample	Data collection method and analysis	Main themes or a summary of the main findings
			[n=2; Unemployed, [n=1]) - Men (n=2)		
2017	Bates et al., 2017 (England, UK)	Aims: To understand what characteristics PWID desire in a romantic partner.	11 adults with ID - (Aged 35-60 years) - (Women, n=6) - (Men, n=5) *Additional inclusion criteria:* (a) In a long-term relationship for at least 6 months. (b) Able to communicate verbally *Additional sample characteristics:* Participants were recruited from two ID charities.	Data collection: Semi-structured interviews (lasting 45-120 minutes Data analysis: Hermeneutic phenomenology (Van Manen, 1990)	5 main themes: environmental factors affecting partner selection, socio-emotional attributes, valuing companionship, physical attractiveness and expectations.
2017	Matilla et al., 2017 (Finland)	Aims: To explore how PWID understood and described intimate relationships. Design: Qualitative	7 adults with mild ID - (Aged 18-31 years) - (Women, n=5) - (Men, n=2)	Data collection: Semi-structured interviews Data analysis: Deductive thematic content analysis	3 main themes: sharing similar interests, intimacy and socioemotional attributes.
2017	Pariseau & Holmes, 2017 (Canada)	Aims: To explore the experiences of PWID navigating their sex and intimate relationships in the contexts of their lives. Design: Qualitative	5 adults with IDs - (Aged 21-35 years) - (Women, n=4) ○ (Relationship status, in a relationship [n=3], currently single, [n=1]) ○ (Living arrangements, living with family [n=1], supported accommodation, [n=3]) - (Men, n=1)	Data collection: Individual semi-structured interviews Data analysis: IPA	Two main themes: navigating relationships in the face of environmental barriers, attitudes towards sex and intimacy.

Table 5

Included studies characteristics

Year	Study ID, citation (country)	Aims and design	Sample	Data collection method and analysis	Main themes or a summary of the main findings
			6 informal carers 5 paid carers		
2018	Stoffelen et al., 2018 (Netherlands)	Aims: (a) To explore the sex and relationship experiences of lesbian and bisexual WID living in the Netherlands. (b) What do lesbian and bisexual WID think are the barriers and facilitators to their experience of intimate relationships? Design: Qualitative	10 women with mild IDs • (Aged 25-47 years) • (Relationship status, in a relationship [n=10], currently single, [n=6]) Additional inclusion criteria: (a) Participants identifying as lesbian or bisexual. (b) Able to communicate verbally	Data Collection: Individual semi-structured interviews that lasted up to one hour were used to capture participants' experiences. The topic guide was developed by PWID and ID professionals. Data analysis: Thematic analysis	4 main themes: Experiencing loneliness and discrimination, lack of visibility, difficulty finding partners and sex education having a hetero-normative focus.
2019	Martino, 2020 (Canada)	Aims: (a)To explore PWID's intimate lives and the social contexts shaping them. (b) To explore how PWID understand their gender and sexuality. Design: Qualitative	46 adults with IDs • (Aged 18-55 years) • (Women, n=13) ○ (Ethnicity, Black Other [n=2]; White Other [n=11]) ○ (Living arrangements, Live independently [n=3], Living with family, [n=4]; Supported Accommodation [n=6]) ○ (Relationship status, in a relationship [n=7], currently single, [n=6]) • (Men, n=33)	Data collection: Semi-structured interviews Data analysis: Thematic Analysis	3 main themes: lack of visibility, difficulty finding partners, and experiences of abuse and harassment
2020	Bjornsdottir & Stefansdottir, 2020 (Iceland)	Aims: To explore the sexuality-related experiences of adults with severe-to-profound ID. Design: Qualitative	25 adults with severe-to-profound ID • (Women, n=12) • (Men, n=13)	Data collection Observations for over four years Data analysis Thematic analysis	4 main themes: being de-sexualised, lack of privacy, sexual abuse, and suppression of menstruation

Table 5

Included studies characteristics

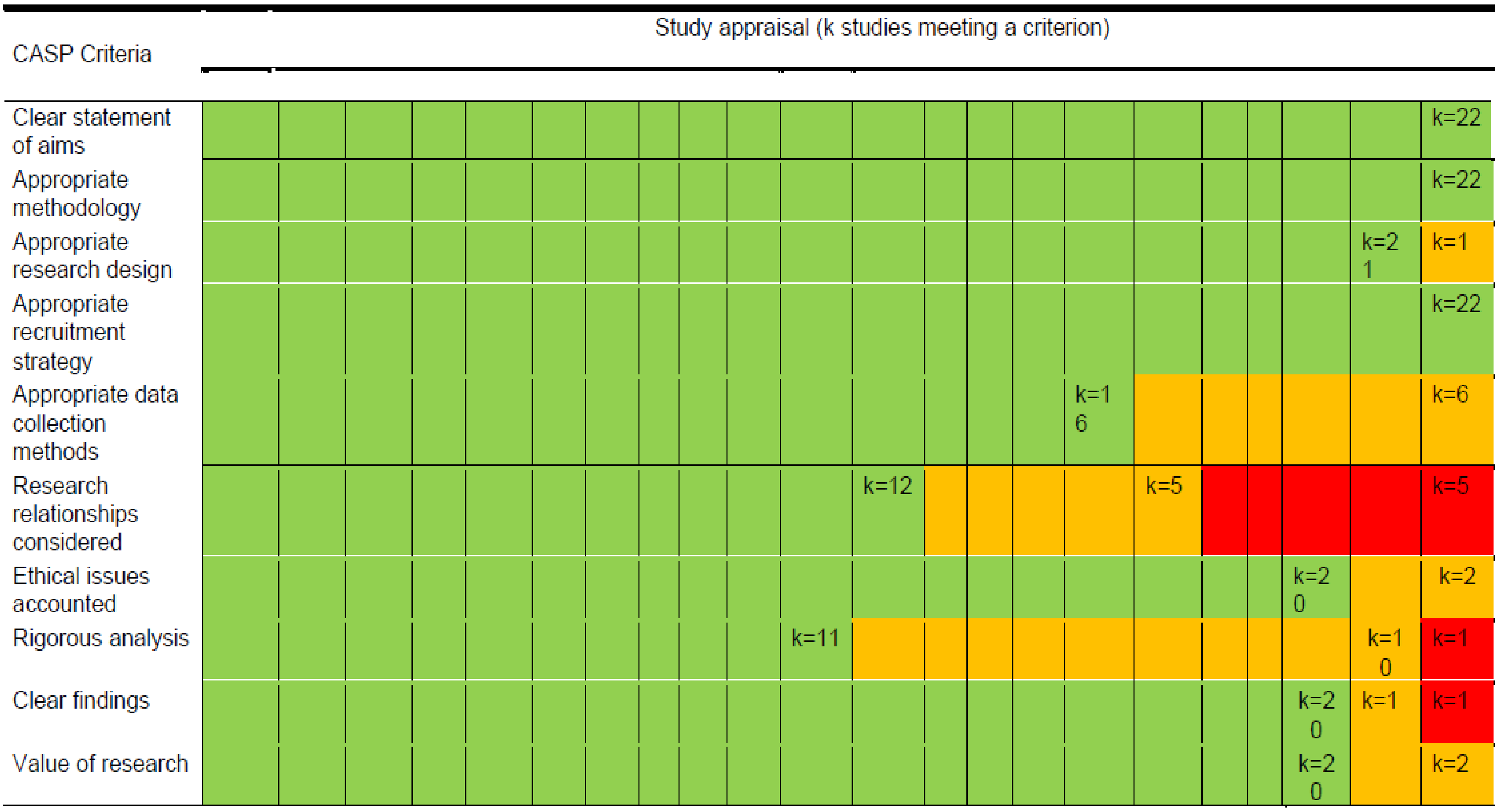
Year	Study ID, citation (country)	Aims and design	Sample	Data collection method and analysis	Main themes or a summary of the main findings
2020	Cytowska & Zierkewich, 2020 (Polland)	Aims: To explore the experiences of WID living in Poland, including intimate relationships. Design: Qualitative	20 women with mild-to-moderate ID • (Aged 19-34 years) • (Employment status, in employment [n=5]; Unemployed [n=15]) • (Lived with family, n=20) Additional inclusion criteria: able to communicate verbally	Data collection: Four focus groups, using a semi-structured interview schedule. Data analysis: Grounded theory	3 main themes: having access to peers, experiencing intimate relationships, and self-determination.
2020	O'Shea & Frawley, 2020 (Australia)	Aims: To explore how young WID viewed and experienced their gender, sexuality and relationships. Design: Qualitative	6 young women with ID • (Aged 18-30 years) • Living arrangements, lived independently, n=2]; lived with family, [n=4]) • (Relationship status, in a relationship [n=3], currently single, [n=3]) • (Worked part-time or job searching, n= 6)	Data Collection: PhotoVoice and semi-structured interviews Data analysis: Thematic analysis was combined with Foucauldian discourse analysis to analyse the data.	3 main themes: living gendered lives, valuing intimacy, and family's reactions to intimate relationships

Study quality

Sixteen studies met Harbour and Miller's (2001) high-quality criterion; three met the moderate and three the low-quality criterion. The latter ratings were assigned when information was limited to judge data collection or analysis rigour. See Table 6 for an overview of study quality and Table 7 for a detailed study appraisal.

Table 6

Study summary appraisal by CASP criterion



CASP Criteria	Study appraisal (k studies meeting a criterion)																					
Clear statement of aims	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩 k=22
Appropriate methodology	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩 k=22
Appropriate research design	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩 k=21	🟧 k=1
Appropriate recruitment strategy	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩 k=22
Appropriate data collection methods	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩 k=16	🟧	🟧	🟧	🟧	🟧	🟧 k=6
Research relationships considered	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩 k=12	🟧	🟧	🟧	🟧	🟧 k=5	🟥	🟥	🟥	🟥	🟥 k=5
Ethical issues accounted	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩 k=20	🟧	🟧 k=2
Rigorous analysis	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩 k=11	🟧	🟧	🟧	🟧	🟧	🟧	🟧	🟧	🟧	🟧 k=10	🟥 k=1
Clear findings	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩 k=20	🟧 k=1	🟥 k=1
Value of research	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩 k=20	🟧	🟧 k=2

Note.

Study meets criterion=	🟩
Study partially meets criterion=	🟧
Study does not meet criterion=	🟥

Table 7

Study appraisal using the CASP tool and Harbour and Miller's (2001) quality rating criteria

CASP Criteria	Study appraised										
	Lesseliers & Van Hove, 2002	Kelly, Crowley & Hamilton, 2009	Eastgate et al., 2011	Fitzerald & Withers, 2011	Bernert & Ogletree, 2012	Lafferty et al., 2013	Pestka & Wendt, 2014	Rushbrooke et al., 2014	Chou et al., 2015	Bates et al., 2016	Frawley & Wilson, 2016
Clear statement of aims	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Appropriate methodology	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Appropriate research design	Y	Y	Y	Y	Y	Y	Y	Y	C/T	Y	Y
Appropriate recruitment strategy	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Appropriate data collection methods	Y	C/T	C/T	Y	Y	Y	Y	Y	Y	Y	Y
Research relationships considered	Y	N	N	C/T	C/T	C/T	Y	C/T	N	Y	Y
Ethical issues accounted	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Rigorous analysis	Y	C/T	C/T	Y	C/T	Y	Y	Y	N	Y	Y
Clear findings	Y	Y	Y	Y	Y	Y	Y	Y	N	Y	Y
Value of research	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Study quality rating	High	Moderate	Moderate	High	High	High	High	High	Low	High	High

Note. Y=Yes; No=N; C/T=Can't tell

Table 7

Study appraisal using the CASP tool and Harbour and Miller's (2001) quality rating criteria-continued

CASP Criteria	Study appraised										
	Fish, 2016	Rojas et al. (2016)	Turner et al.,2016	Bates et al., 2017	Matilla et al., 2017	Pariseau & Holmes, 2017	Stoffelen et al., 2018	Martino, 2019	Bjornsdottir & Stefansdottir, 2020	Cytowska & Zierkewich, 2020	O'Shea & Frawley, 2020
Clear statement of aims	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Appropriate methodology	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Appropriate research design	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Appropriate recruitment strategy	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Appropriate data collection methods	Y	C/T	Y	Y	C/T	C/T	Y	Y	Y	C/T	Y
Research relationships considered	Y	N	Y	Y	N	Y	Y	Y	Y	C/T	Y
Ethical issues accounted	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Rigorous analysis	C/T	C/T	Y	Y	C/T	Y	C/T	C/T	Y	C/T	Y
Clear findings	Y	Y	Y	Y	C/T	Y	Y	Y	Y	Y	Y
Value of research	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Study quality rating	High	Moderate	High	High	Low	High	High	High	High	Low	High

Critical appraisal

The following critical appraisal draws on the CASP tool, going into further detail as appropriate.

Aims and design

The studies' aims were clearly defined, focusing on PWID's views and experiences of sex and intimate relationships. The studies used qualitative methodology appropriately to explore this from WID's perspective.

Participant selection

All studies used purposive sampling strategies, primarily involving gatekeepers nominating potential participants. One study indicated that WID self-selected to participate. This strategy may be necessary when exploring the sensitive topics of sex or romantic relationships (and, in many cases, sexual violence). However, it can be problematic, potentially excluding women in covert relationships or having relationships and characteristics (e.g., LGBTQ+ status) unknown, unrecognised or disapproved by the gatekeepers and further compounded by limited or no contact with established services.

No study recorded reasons for non-participation. Few studies situated their samples in critical contexts affecting the experience of sex and intimacy (e.g., religion). Furthermore, of the studies that reported ID level and ethnic background (k=8 and k=3, respectively), only 11% had a severe-to-profound disability, and 11% identified as Black other. As a consequence, these groups' experiences are likely to be underrepresented, a situation which becomes further complicated as there are no available national estimates for other characteristics (e.g., ethnic or LGBTQ+ status composition) to help gauge the comparability of the study samples to the entire PWID population (Office of National Statistics, 2022; Race Equality Foundation, 2022).

Finally, the studies spanned 20 years, with their sample age varying significantly. Hence, the time at which women navigated sex or intimate relationships might have influenced their experience. The above might limit the review findings' transferability.

Data collection

The CRPD encourages research teams to engage PWID in the research process to move from the research 'done on' to 'done with' paradigm. This goes some way toward addressing the power asymmetry between researchers and participants (UN, 2007). However, only two studies reported consulting PWID when developing interview schedules (Rushbrooke et al., 2014; Stoffelen et al., 2018). Additionally, only one out of four studies employing member checking reframed their analysis following consultations with participants (O'Shea & Frawley, 2020).

Most studies adjusted interview schedules to ensure accessibility to PWID. However, only nine studies described these adjustments. Two studies used illustrations (Turner et al.,2016), and one used PhotoVoice (O'Shea & Frawley, 2020). The remainder gave examples of accessible language prompts. In total, 14 studies referenced interview schedules or sample questions asked; only one provided an example of the interview schedule. The above limited the reviewer's ability to gauge the studies' dependability (Freshwater et al., 2010).

Data analysis and reflexivity

Overall, conclusions grew logically from the interpretations of the data, with all but three studies providing rich accounts and citing participants. In addition, most studies (k=19) used methods such as discrepant case analysis, researcher triangulation (k=10), and multiple data sources (k=9) to enhance the credibility of their findings (Johnson et al., 2020). However, only four studies invited participants to comment on their findings (Bernert & Ogletree, 2012; Frawley & Wilson, 2016; O'Shea & Frawley, 2020; Turner et al., 2016). Six studies used software packages providing a clear audit trail of their analysis.

Ten studies reported their epistemological position, which made assessing the congruity between methodology and philosophical perspective for the remainder problematic. Similarly, only 12 studies situated the researchers' values and characteristics (e.g., occupation, previous experiences), of which 11 reported attempts to mitigate the potential effects at the data collection stage (e.g., participants choosing the interview location, shorter interviews) or the analysis (keeping a diary to aid bracketing interviews, e.g., Rushbrooke et al., 2014). Furthermore, only one study supplied information on the researcher's relationship with the participants (e.g., involvement in WID's care, Fish, 2016) and steps taken to mitigate its impact. The absence of accounting for the risk inherent in the researcher/PWID relationship is striking, not least when considering the challenges in conducting qualitative research in circumstances with an increased likelihood of acquiescence to participation and responses (Nind, 2008).

Summary

The reviewed studies clearly defined their objectives and used appropriate methodologies whilst situating their interpretations in participants' accounts. However, dependability was a concern due to information lacking about data collection and analysis. In addition, the samples' representativeness could limit the transferability of the study findings.

Synthesis

The analysis yielded six master themes and 18 themes related to WID’s experiences and views on sex and intimate relationships. These are outlined in Table 8 and Figures 3 to 8. Furthermore, in addition to an overview of the themes, the reviewer provided supporting excerpts from the primary studies in Tables 9 to 14 at the end of each master theme section.

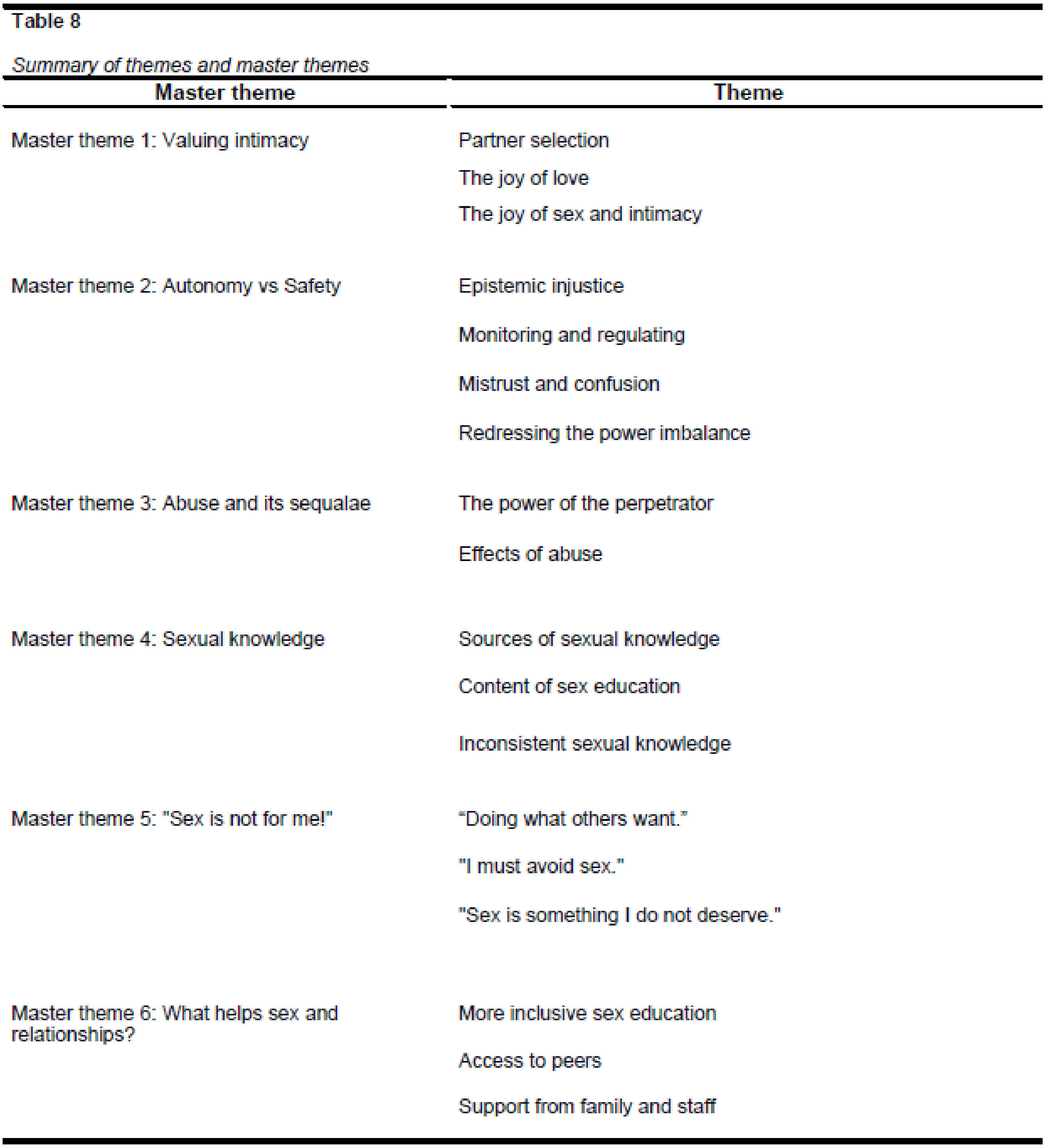


Table 8

Summary of themes and master themes

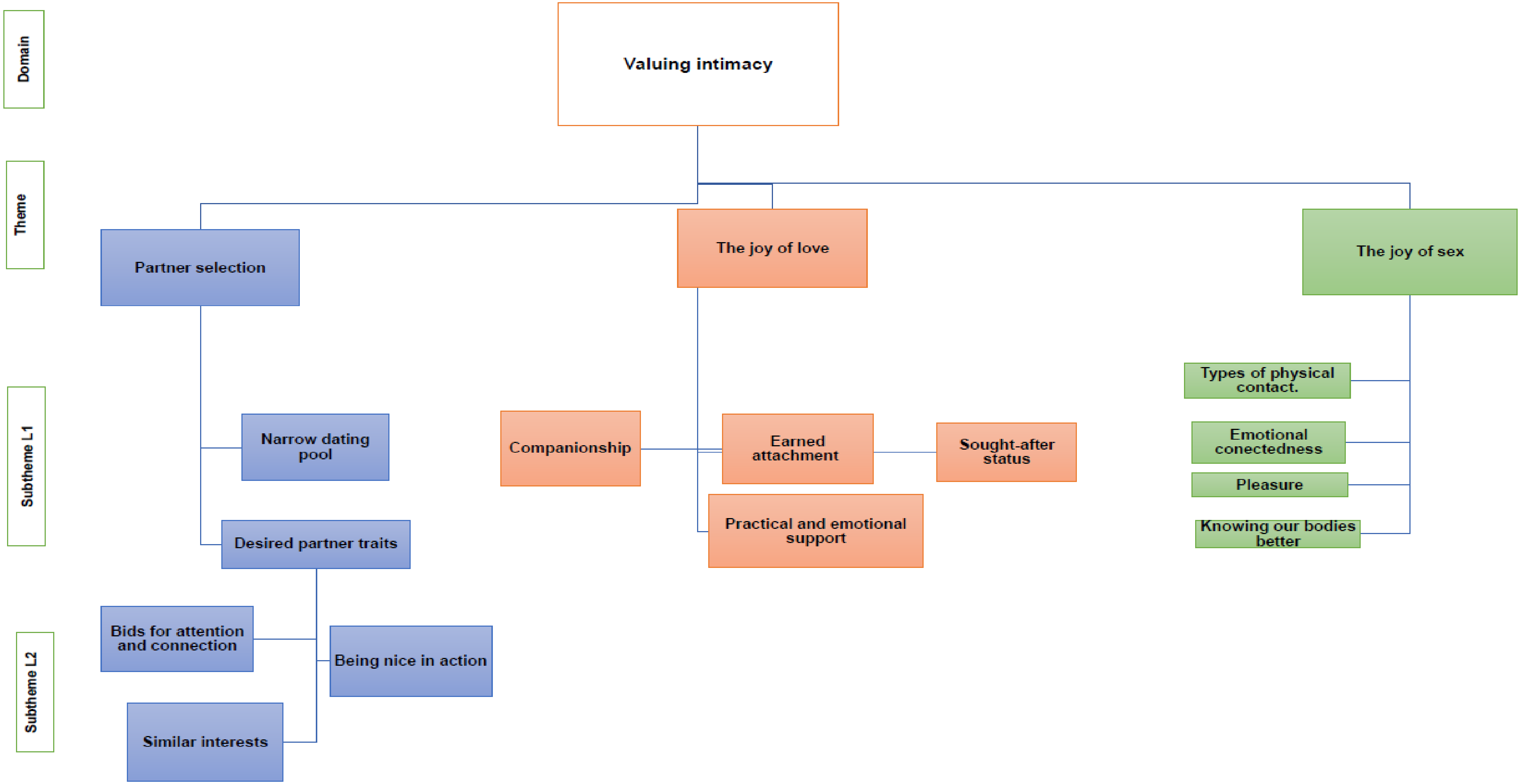
Master theme	Theme
Master theme 1: Valuing intimacy	Partner selection The joy of love The joy of sex and intimacy
Master theme 2: Autonomy vs Safety	Epistemic injustice Monitoring and regulating Mistrust and confusion Redressing the power imbalance
Master theme 3: Abuse and its sequalae	The power of the perpetrator Effects of abuse
Master theme 4: Sexual knowledge	Sources of sexual knowledge Content of sex education Inconsistent sexual knowledge
Master theme 5: "Sex is not for me!"	“Doing what others want.” "I must avoid sex." "Sex is something I do not deserve."
Master theme 6: What helps sex and relationships?	More inclusive sex education Access to peers Support from family and staff

Master theme 1: Valuing intimacy

This master theme appeared in 12 studies, with participants desiring more opportunities to develop close relationships. It comprised three themes and corresponding subthemes: partner selection, the joy of love and the joy of sex (see Figure 3 and Table 9).

Figure 3

Thematic map for the Valuing intimacy master theme



Theme 1.1: Partner selection

Narrow dating pool. In the studies examining this issue, most WID had only experienced relationships with others with an ID and met their partners in PWID-only locations, e.g., group homes or day-care programmes (Bates et al., 2016; Martino, 2020), both creating and constraining opportunities for finding a partner (Martino, 2020). WID identifying as lesbian, bisexual or trans faced additional challenges due to the limited visibility of other LGBTQ+ PWID in the above spaces (Stoffelen et al., 2018; Martino, 2020).

Desired partner traits. WID, in four studies, identified socioemotional attributes they wanted partners to have (Bates et al., 2016, 2017; Matilla et al., 2017; Turner & Crane, 2016), prioritising over financial resources. Furthermore, they referred infrequently to physical appearance (except for the WID in Turner and Crane [2016]).

Being nice in action. WID valued their partner being "*nice*" to them or their loved ones, operationalised as concrete actions and skills partners had to display, e.g., "*giving cuddles*" and "*being good at massage*" (Matilla et al., 2017, p.75).

Sharing similar interests. WID wanted partners to enjoy similar activities (Bates et al., 2016; Matilla et al., 2017).

Bids for attention and connection. In three studies, WID valued partners seeking their attention by flirting or giving presents (Kelly et al., 2009; Bates et al., 2016; Turner & Crane, 2016), gestures they associated with feeling desired and valued**.**

Theme 1.2: The joy of love

Companionship. Seven studies highlighted the effects of loneliness on WID's lives (Bates et al., 2016, 2017; Lafferty et al., 2013; Martino, 2019; Matilla et al., 2017; Stofellen et al., 2018; Turner et al.,2016). The most important function of intimate relationships was providing companionship and affection (Bates et al., 2016, 2017; Rojas et al., 2016; Turner et al.,2016).

Practical and emotional support. WID in three studies spoke about the need for reciprocity in their intimate relationships, with emotional support and practical help with their daily activities being key (Lafferty et al., 2013; Bates et al., 2016, 2017). Some WID associated practical help with increased confidence partly due to improved independence, relying less on paid support staff (Bates et al., 2016). In some cases, an enhanced sense of physical safety increased engagement with community-based activities (Lafferty et al., 2013; Rushbrooke et al., 2014).

Attaining a sought-after status. WID in three studies associated having an intimate partner or being married with progressing on in life and having a more valued or “less disabled” identity (Bates et al., 2016, 2017; O’Shea & Frawley, 2020).

Earned attachment. Some WID said an intimate relationship provided them with a positive experience of an emotional bond and a sense of belonging, often missing in their childhood or later romantic relationships, which were frequently fraught with abuse and rejection (Bates et al., 2016; Pestka & Wendt, 2014; Turner et al.,2016).

Theme 1.3: The joy of sex and intimacy

Types of physical contact*.* WID in 10 studies said they wanted physical intimacy. However, only a minority of participants reported these experiences. Additionally, in descriptions of physical contact, sexual intercourse was not always mentioned, with several WID prioritising other physical expressions of affection (e.g., caressing) to sustain their intimate relationships. In some cases, this contact reflected women's choices but often reflected those of others in support networks.

Emotional connectedness. WID in four studies suggested that physical contact provided a sense of closeness to their partner(s) (Bates et al., 2016; Martino, 2019; Rushbrooke et al., 2014; Turner et al.,2016). They also valued being treated tenderly by partners (Lesseliers & Van Hove, 2002). Equally, discussing sex was instrumental in discovering each other's wants and boundaries (Frawley & Wilson, 2016; Turner et al.,2016).

Pleasure. In four studies, several women shared feelings of aliveness they experienced in their sexual encounters that stemmed from and simultaneously reinforced their connection to their partners (Lafferty et al., 2013; Lesseliers & Van Hove, 2002; Martino, 2019; Turner et al.,2016).

Knowing our bodies better. There were sparse references to masturbation, varying from total lack of knowledge (e.g., Bernert & Ogletree, 2012) to something either desired (Bjornsdottir & Stefansdottir, 2020) or actively avoided (e.g., Chou et al., 2015). However, WID in two studies indicated that masturbation provided a means of self-exploration and “*getting the release out*" without a sexual partner (Pariseau & Holmes, 2017; Turner et al.,2016, p.685).

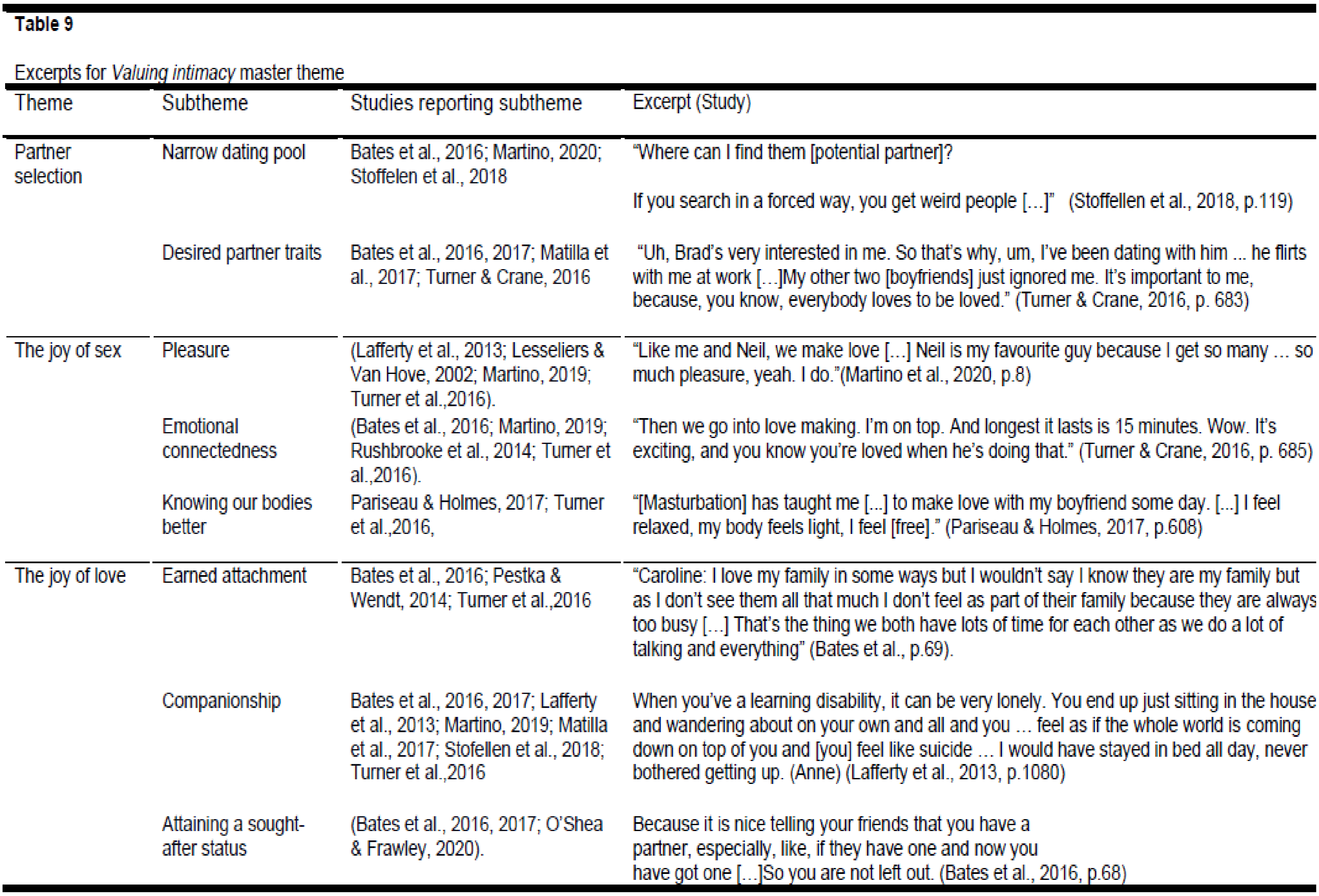


Table 9

Excerpts for *Valuing intimacy* master theme

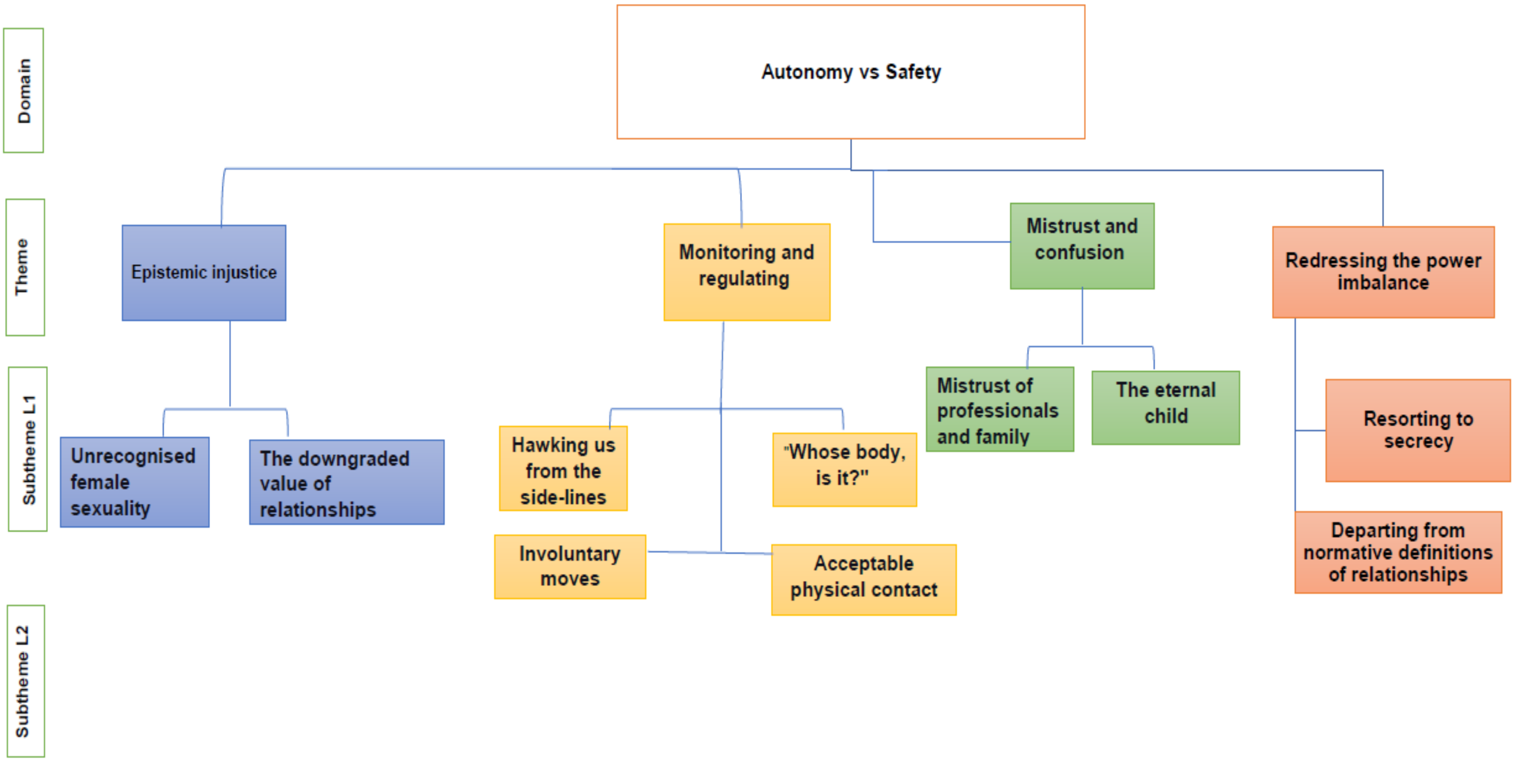
Theme	Subtheme	Studies reporting subtheme	Excerpt (Study)
Partner selection	Narrow dating pool	Bates et al., 2016; Martino, 2020; Stoffelen et al., 2018	"Where can I find them [potential partner]? If you search in a forced way, you get weird people [...]" (Stoffellen et al., 2018, p.119)
	Desired partner traits	Bates et al., 2016, 2017; Matilla et al., 2017; Turner & Crane, 2016	"Uh, Brad's very interested in me. So that's why, um, I've been dating with him ... he flirts with me at work [...]My other two [boyfriends] just ignored me. It's important to me, because, you know, everybody loves to be loved." (Turner & Crane, 2016, p. 683)
The joy of sex	Pleasure	(Lafferty et al., 2013; Lesseliers & Van Hove, 2002; Martino, 2019; Turner et al.,2016).	"Like me and Neil, we make love [...] Neil is my favourite guy because I get so many ... so much pleasure, yeah. I do."(Martino et al., 2020, p.8)
	Emotional connectedness	(Bates et al., 2016; Martino, 2019; Rushbrooke et al., 2014; Turner et al.,2016).	"Then we go into love making. I'm on top. And longest it lasts is 15 minutes. Wow. It's exciting, and you know you're loved when he's doing that." (Turner & Crane, 2016, p. 685)
	Knowing our bodies better	Pariseau & Holmes, 2017; Turner et al.,2016,	"[Masturbation] has taught me [...] to make love with my boyfriend some day. [...] I feel relaxed, my body feels light, I feel [free]." (Pariseau & Holmes, 2017, p.608)
The joy of love	Earned attachment	Bates et al., 2016; Pestka & Wendt, 2014; Turner et al.,2016	"Caroline: I love my family in some ways but I wouldn't say I know they are my family but as I don't see them all that much I don't feel as part of their family because they are always too busy [...] That's the thing we both have lots of time for each other as we do a lot of talking and everything" (Bates et al., p.69).
	Companionship	Bates et al., 2016, 2017; Lafferty et al., 2013; Martino, 2019; Matilla et al., 2017; Stofellen et al., 2018; Turner et al.,2016	When you've a learning disability, it can be very lonely. You end up just sitting in the house and wandering about on your own and all and you ... feel as if the whole world is coming down on top of you and [you] feel like suicide ... I would have stayed in bed all day, never bothered getting up. (Anne) (Lafferty et al., 2013, p.1080)
	Attaining a sought-after status	(Bates et al., 2016, 2017; O'Shea & Frawley, 2020).	Because it is nice telling your friends that you have a partner, especially, like, if they have one and now you have got one [...]So you are not left out. (Bates et al., 2016, p.68)

Master theme 2: Autonomy vs Safety

This master theme appeared in eight studies. It comprised four themes discussed below (Figure 4). This theme concerned the responses of WID's networks when attempting to meet their intimacy needs. It is important to note that multiple meaning-making contexts informed these responses. However, discussing them is outside the remit of this review. Responses largely stemmed from an intention to keep women safe. This domain explored the effects of these responses on different levels of WID's experience, from the realm of meaning to that of action, and how WID understood and responded to them.

Figure 4

Thematic map for the Autonomy vs Safety master theme



Theme 2.1: Epistemic injustice

Fricker (2007) first coined the term *epistemic injustice* to describe the experiences of groups or individuals whose perspectives are not afforded the same level of consideration by other people in positions of power due to them occupying less socially valued identities. The reviewer thought this description captured the experiences of some WID in six included studies, which documented WID's networks sometimes, knowingly, or unknowingly, discounted, disbelieved, and at times, imposed alternative meanings to their attempts to meet their intimacy needs (Bjornsdottir & Stefansdottir, 2020; Chou et al., 2015; Fish, 2016; Fitzerald & Withers, 2011; Kelly et al., 2009; O'Shea & Frawley, 2020).

Unrecognised female sexuality. Two studies suggested that consideration for WID's sexuality was conspicuously missing in the discussions of professional care teams (Bjornsdottir & Stefansdottir, 2020; Fish, 2016). In some cases, professionals did not assess the medication side effects on the WID's sexual function despite having done so for male clients (Fish, 2016). In the case of WID requiring intensive support, professionals failed to afford them the privacy to masturbate (Bjornsdottir & Stefansdottir, 2020).

The downgraded value of relationships. Similarly, in four studies, WID suggested that professionals and their families failed to listen to their relationship needs (Kelly et al., 2009; Fitzerald & Withers, 2011). Moreover, for WID in a relationship, people around them did not accord them equivalent value (O'Shea & Frawley, 2020; Rojas et al., 2016). So, although WID's network did not entirely disallow the relationships, they often negated the potential for deep physical and emotional closeness, e.g., by redefining a WID's engagement as friendship.

Theme 2.2: Monitoring and regulating

"Hawking us from the side-lines." WID in five studies reported that their networks often did not trust them to have a relationship (e.g., Lesseliers & Van Hove, 2002). The reviewer thought the above quote from one of the participants in Kelly et al. (2009, p.313) study succinctly summarised several WID's experiences of feeling under increasing surveillance by others. This was particularly evident for most WID living with family or in supported accommodation. WID's accounts suggested a paradox whereby their living spaces were permeable for everyone to observe but impermeable to their partners. In some cases, this lack of privacy impacted WID's ability to be affectionate and undermined their feeling of being at home (Fish, 2016; Pariseau & Holmes, 2017; Rojas et al., 2016).

Acceptable physical contact. Despite desiring physical contact, participants in three studies shared that their networks prohibited any sexual behaviour that required nudity. Instead, WID resorted to expressing themselves sexually through other behaviours (e.g., hugging, stroking) (Chou et al., 2015; Fish, 2016; Fitzerald & Withers, 2011).

Involuntary moves. There were instances where WID had to relocate after being found breaking restrictions (Fish, 2016; Lesseliers & Van Hove, 2002). In some cases, these involuntary relocations resulted in WID experiencing disrupted attachments, with sadness and an overall hesitation against developing feelings again being participants' common emotional responses (Lesseliers & Van Hove, 2002).

'**Whose body, is it?'** A lack of control or understanding regarding decisions about contraception was evident in the accounts of several WID in four studies (Bernert & Ogletree, 2012; Bjornsdottir & Stefansdottir, 2020; Chou et al., 2015; Frawley & Wilson, 2016). This lack of control extended to WID's appearance, e.g., enforcing hair removal despite signs of discomfort (Bjornsdottir & Stefansdottir, 2020).

Theme 2.3: Mistrust and confusion

Mistrust of professionals and family. In five studies, WID indicated an erosion of trust regarding their sexual and romantic relationships with those around them (Fish, 2016; Fitzerald & Withers, 2011; Kelly et al., 2009; Lesseliers & Van Hove, 2002; Martino, 2019). WID feared the disapproval of family and professionals (Chou et al., 2015; Kelly, Crowley & Hamilton, 2009; Rojas et al., 2016), further prohibition

(Fitzerald & Withers, 2011) or punishment (Fish, 2016). The above resulted in WID navigating important or difficult milestones (e.g., coming out as LGBTQ+ [Fish, 2016; Stoffellen et al., 2018]) and harmful situations in isolation (e.g., experiences of sexual violence [Eastgate et al., 2011]). Additionally, WID described confusion regarding what was permissible, including communicating with partners (e.g., via letters) (Fish, 2016).

The eternal child. Three studies indicated that sometimes this generalised mistrust extended further to how WID perceived themselves. Women described themselves as "*grown teenage girls*" (Fitzerald & Withers, 2011, p.5) or "*mummy's pet*" (Kelly et al., 2009, p.312), unable to make decisions for themselves (Chou et al., 2015).

Theme 2.4: Redressing the power imbalance

The above theme was present in six studies and described the experiences of several WID who tried to meet their psychosexual needs in a climate of excessive monitoring and regulation by people holding power over them (e.g., family, professionals). WID’s responses varied from action-based to epistemic ones.

Departing from normative definitions of relationship. Some WID did not directly challenge their carers' descriptions or views of them; instead, they employed creative ways to re-construct their status as intimate partners and maintain their relationships, sometimes relying on social media (Rojas et al., 2016; O'Shea & Frawley, 2020).

Resorting to secrecy. WID in four studies met partners in secret (Kelly et al., 2009; Martino, 2019). Some had sex in public spaces, endangering their physical safety (Pariseau & Holmes, 2017), and there were accounts of women running away (Fish, 2016).

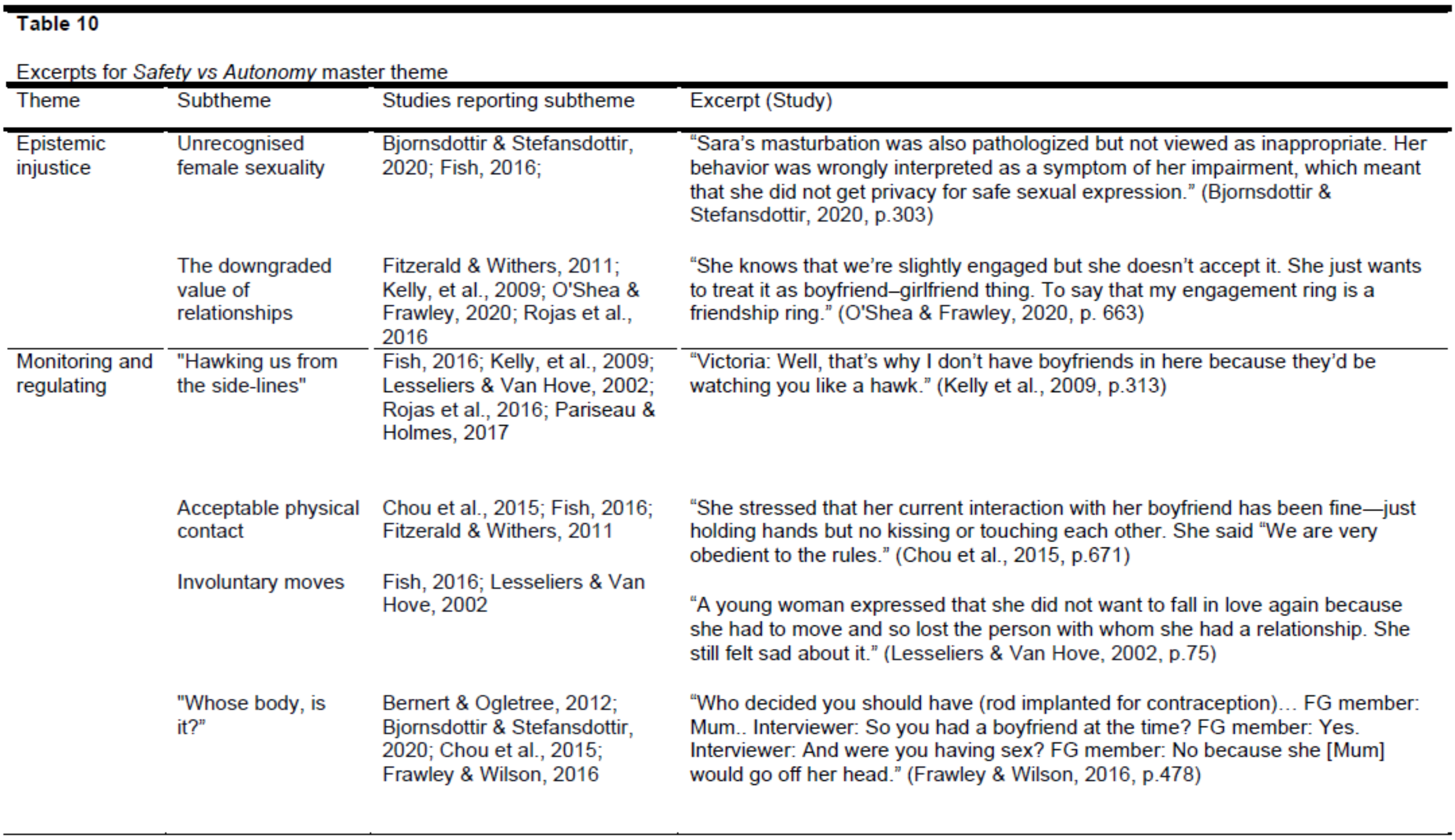


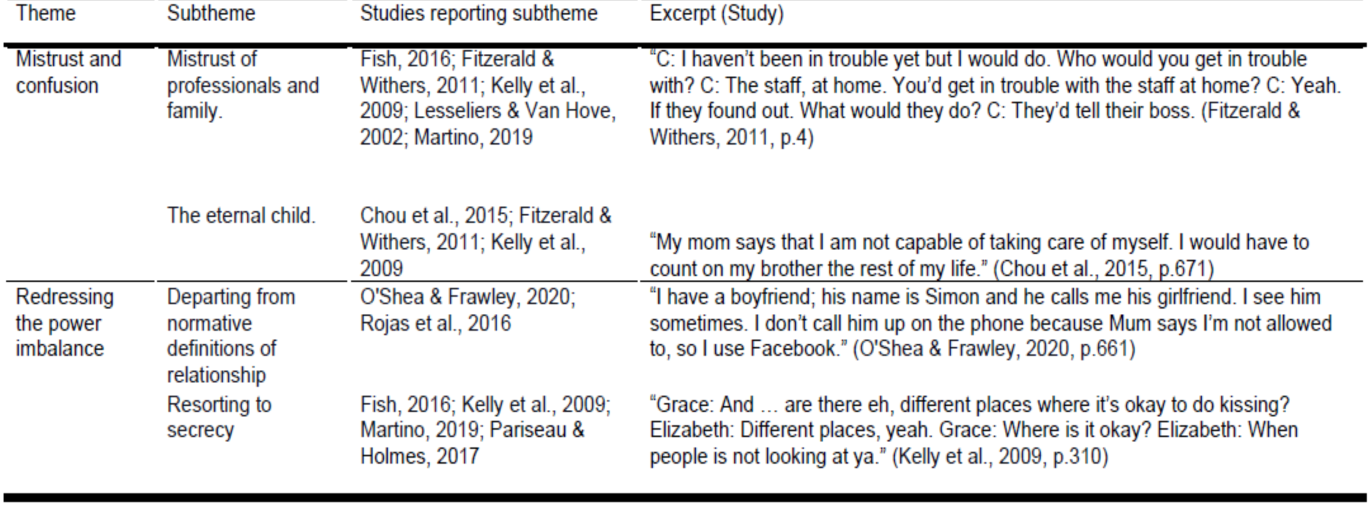
Table 10

Excerpts for *Safety vs Autonomy* master theme

Theme	Subtheme	Studies reporting subtheme	Excerpt (Study)
Epistemic injustice	Unrecognised female sexuality	Bjornsdottir & Stefansdottir, 2020; Fish, 2016;	“Sara’s masturbation was also pathologized but not viewed as inappropriate. Her behavior was wrongly interpreted as a symptom of her impairment, which meant that she did not get privacy for safe sexual expression.” (Bjornsdottir & Stefansdottir, 2020, p.303)
	The downgraded value of relationships	Fitzerald & Withers, 2011; Kelly, et al., 2009; O'Shea & Frawley, 2020; Rojas et al., 2016	“She knows that we’re slightly engaged but she doesn’t accept it. She just wants to treat it as boyfriend–girlfriend thing. To say that my engagement ring is a friendship ring.” (O'Shea & Frawley, 2020, p. 663)
Monitoring and regulating	"Hawking us from the side-lines"	Fish, 2016; Kelly, et al., 2009; Lesseliers & Van Hove, 2002; Rojas et al., 2016; Pariseau & Holmes, 2017	“Victoria: Well, that’s why I don’t have boyfriends in here because they’d be watching you like a hawk.” (Kelly et al., 2009, p.313)
	Acceptable physical contact	Chou et al., 2015; Fish, 2016; Fitzerald & Withers, 2011	“She stressed that her current interaction with her boyfriend has been fine—just holding hands but no kissing or touching each other. She said “We are very obedient to the rules.” (Chou et al., 2015, p.671)
	Involuntary moves	Fish, 2016; Lesseliers & Van Hove, 2002	“A young woman expressed that she did not want to fall in love again because she had to move and so lost the person with whom she had a relationship. She still felt sad about it.” (Lesseliers & Van Hove, 2002, p.75)
	"Whose body, is it?”	Bernert & Ogletree, 2012; Bjornsdottir & Stefansdottir, 2020; Chou et al., 2015; Frawley & Wilson, 2016	“Who decided you should have (rod implanted for contraception)… FG member: Mum.. Interviewer: So you had a boyfriend at the time? FG member: Yes. Interviewer: And were you having sex? FG member: No because she [Mum] would go off her head.” (Frawley & Wilson, 2016, p.478)

Table 10

Excerpts for *Safety vs Autonomy* master theme



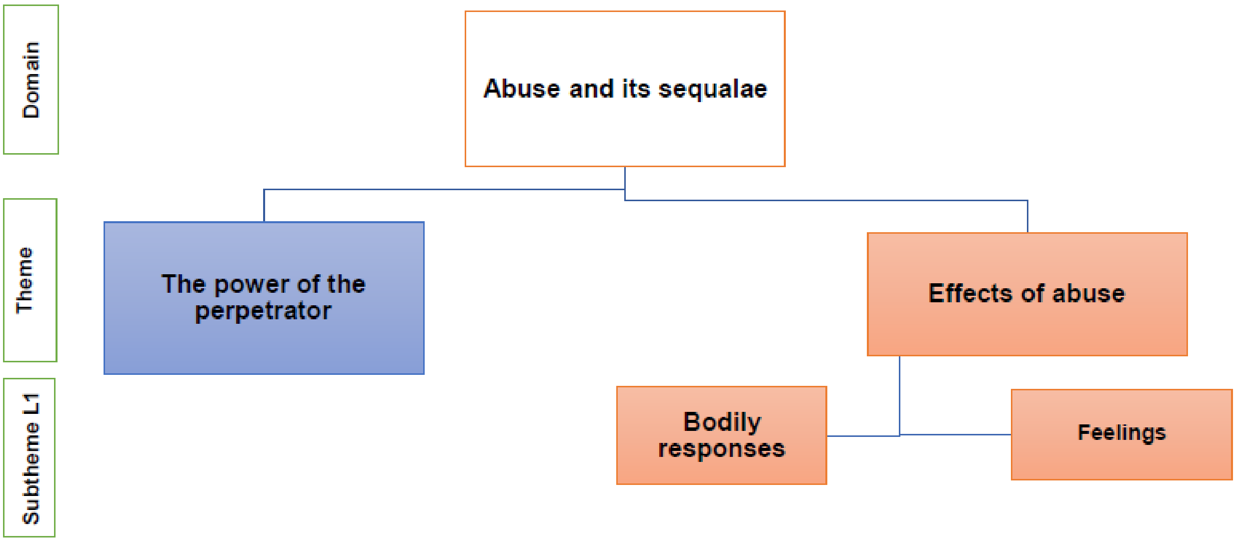
Theme	Subtheme	Studies reporting subtheme	Excerpt (Study)
Mistrust and confusion	Mistrust of professionals and family.	Fish, 2016; Fitzerald & Withers, 2011; Kelly et al., 2009; Lesseliers & Van Hove, 2002; Martino, 2019	"C: I haven't been in trouble yet but I would do. Who would you get in trouble with? C: The staff, at home. You'd get in trouble with the staff at home? C: Yeah. If they found out. What would they do? C: They'd tell their boss. (Fitzerald & Withers, 2011, p.4)
	The eternal child.	Chou et al., 2015; Fitzerald & Withers, 2011; Kelly et al., 2009	"My mom says that I am not capable of taking care of myself. I would have to count on my brother the rest of my life." (Chou et al., 2015, p.671)
Redressing the power imbalance	Departing from normative definitions of relationship	O'Shea & Frawley, 2020; Rojas et al., 2016	"I have a boyfriend; his name is Simon and he calls me his girlfriend. I see him sometimes. I don't call him up on the phone because Mum says I'm not allowed to, so I use Facebook." (O'Shea & Frawley, 2020, p.661)
	Resorting to secrecy	Fish, 2016; Kelly et al., 2009; Martino, 2019; Pariseau & Holmes, 2017	"Grace: And … are there eh, different places where it's okay to do kissing? Elizabeth: Different places, yeah. Grace: Where is it okay? Elizabeth: When people is not looking at ya." (Kelly et al., 2009, p.310)

Master theme 3: Abuse and its sequelae

This master theme was evident in nine studies and comprised two themes (Figure 5 and Table 11). It is important to note that except for Pestka et al.'s (2014) research, the studies did not focus directly on abuse. As such, there could be experiences of abuse that the studies may not have captured.

Figure 5

Thematic map for Abuse and its sequalae master theme



Theme 3.1: The power of the perpetrator

Several WID described abuse in childhood, adolescence, or adulthood. Some had lived through repeated and varied types of abuse (financial, domestic, and sexual) from multiple perpetrators, most frequently men without IDs, within familial, friendship, employment, and residential care environments (Bernert & Ogletree, 2012; Bjornsdottir & Stefansdottir, 2020; Chou et al., 2015; Eastgate et al., 2011; Lesseliers & Van Hove, 2002; Pestka & Wendt, 2014; Stoffelen et al., 2018).

Theme 3.2: Effects of abuse

WID's responses to abuse occurred in a spectrum, from pre-conscious (e.g., physical responses to encounters and dissociative violence [Eastgate et al., 2011; Fish, 2016]), to more conscious ones, e.g., actively avoiding sexual relationships (discussed further under *sex is not for me* domain) (e.g., Bernert & Ogletree, 2012; Eastgate et al., 2011). Feelings of guilt were the most common emotional response, often reinforced by their accounts being discounted by those in their support networks (Fish, 2016; Eastgate et al., 2011). Women shared the reparative effects of people

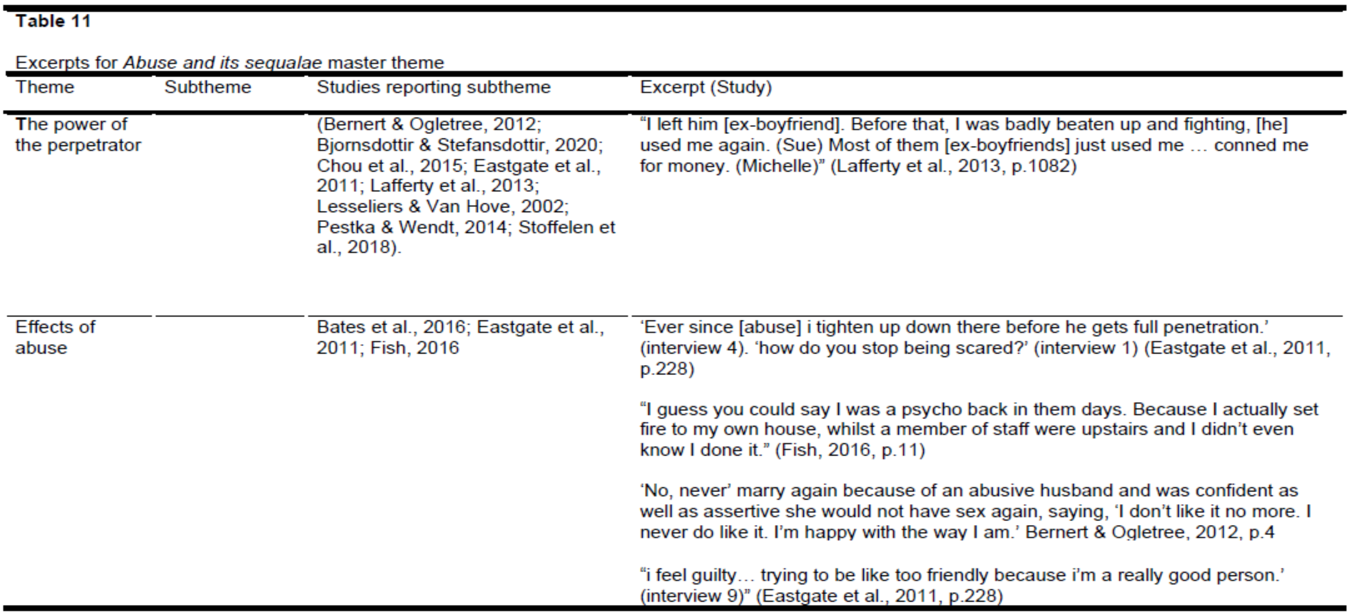


Table 11

Excerpts for *Abuse and its sequalae* master theme

Theme	Subtheme	Studies reporting subtheme	Excerpt (Study)
The power of the perpetrator		(Bernert & Ogletree, 2012; Bjornsdottir & Stefansdottir, 2020; Chou et al., 2015; Eastgate et al., 2011; Lafferty et al., 2013; Lesseliers & Van Hove, 2002; Pestka & Wendt, 2014; Stoffelen et al., 2018).	"I left him [ex-boyfriend]. Before that, I was badly beaten up and fighting, [he] used me again. (Sue) Most of them [ex-boyfriends] just used me … conned me for money. (Michelle)" (Lafferty et al., 2013, p.1082)
Effects of abuse		Bates et al., 2016; Eastgate et al., 2011; Fish, 2016	'Ever since [abuse] i tighten up down there before he gets full penetration.' (interview 4). 'how do you stop being scared?' (interview 1) (Eastgate et al., 2011, p.228) "I guess you could say I was a psycho back in them days. Because I actually set fire to my own house, whilst a member of staff were upstairs and I didn't even know I done it." (Fish, 2016, p.11) 'No, never' marry again because of an abusive husband and was confident as well as assertive she would not have sex again, saying, 'I don't like it no more. I never do like it. I'm happy with the way I am.' Bernert & Ogletree, 2012, p.4 "i feel guilty… trying to be like too friendly because i'm a really good person.' (interview 9)" (Eastgate et al., 2011, p.228)

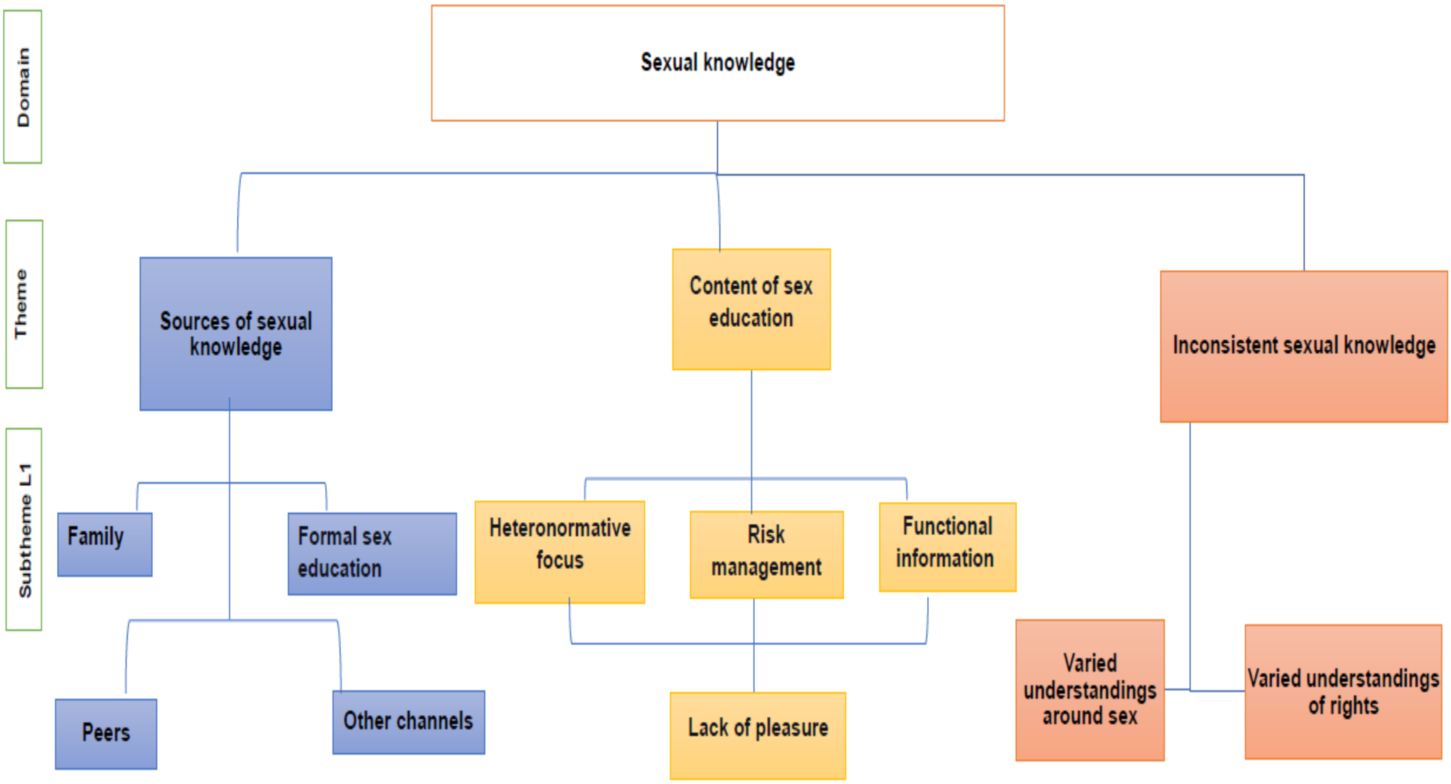
(including intimate partners and professionals) believing and supporting them following the abuse (Bates et al., 2016; Eastgate et al., 2011).

Master theme 4: Sexual knowledge

This master theme appeared in 12 studies and comprised the following three themes (Figure 6; Table 12).

Figure 6

Thematic map for the Sexual knowledge master theme



Theme 4.1: Sources of sexual knowledge

WID cited different sources for sex and intimate relationship information. Access to and usefulness of information varied across cohorts, older WID in one study reported being unable to talk about sex because sex was illegal for them (Lesseliers

& Van Hove, 2002). Opportunistic discussions with family members (k=5) were the most frequently mentioned source of knowledge, their focus tailored at carers' discretion (e.g., if some risk was suspected) (Kelly et al., 2009).

WID also discussed accessing formal sex education in education, social and healthcare settings (Eastgate et al., 2011; Pariseau & Holmes, 2017). WID in two studies reported learning from peers (Cytowska & Zierkewich, 2020; Frawley & Wilson, 2016), whilst others looked for information on television, the internet, or observed others (Frawley & Wilson, 2016; Kelly et al., 2009).

Theme 4.2: Content of sex education

In three studies, WID indicated that conversations with staff and family predominantly focused on protective measures (e.g., saying no to sex), functional information (e.g., hygiene and menstruation) and negative consequences of sex (e.g., pregnancy) (Bernert & Ogletree, 2012; Pariseau & Holmes, 2017; Rojas et al., 2016).

WID in three studies could not name different sexual orientations or gender identities (Eastgate et al., 2011), and those that could generally endorsed negative views (Fitzerald & Withers, 2011). Similarly, WID identifying as LGBTQ+ suggested that they often faced cis-genderism and heterosexism in their interactions and had limited support for exploring and expressing their psychosexual needs (Fish, 2016; Martino, 2019; Stoffelen et al., 2018).

Furthermore, WID's discussions with staff and family rarely covered pleasure as a valid reason for engaging in sexual activities or practical communication skills to navigate relationships (Bernert & Ogletree, 2012; Frawley & Wilson, 2016; Rojas et al., 2016).

Theme 4.3: Inconsistent sexual knowledge

In most studies, WID had a simplistic, often inconsistent, or inaccurate understanding of their bodies and sexual behaviours. Some WID found it easier to name men's genitalia than their own (Lesseliers & Van Hove, 2002) or feared masturbation would harm their health (Chou et al., 2015). A small subset of WID had a developed understanding of sexual intercourse and their bodies (Eastgate et al., 2011).

WID found it easier to talk about the contingencies rather than the mechanics of sex. Some WID thought sex only happened within marriage and for procreation (Chou et al., 2015) or only within a committed relationship (Bernert & Ogletree, 2012; Rushbrooke et al., 2014). WID’s environments sometimes reinforced gender-stereotypical views (Chou et al., 2015; Fitzerald & Withers, 2011). However, it is important to note that some WID rebelled against these ideas, e.g., engaging in pre-marital sex despite being admonished by their local parish (Turner & Crane, 2016).

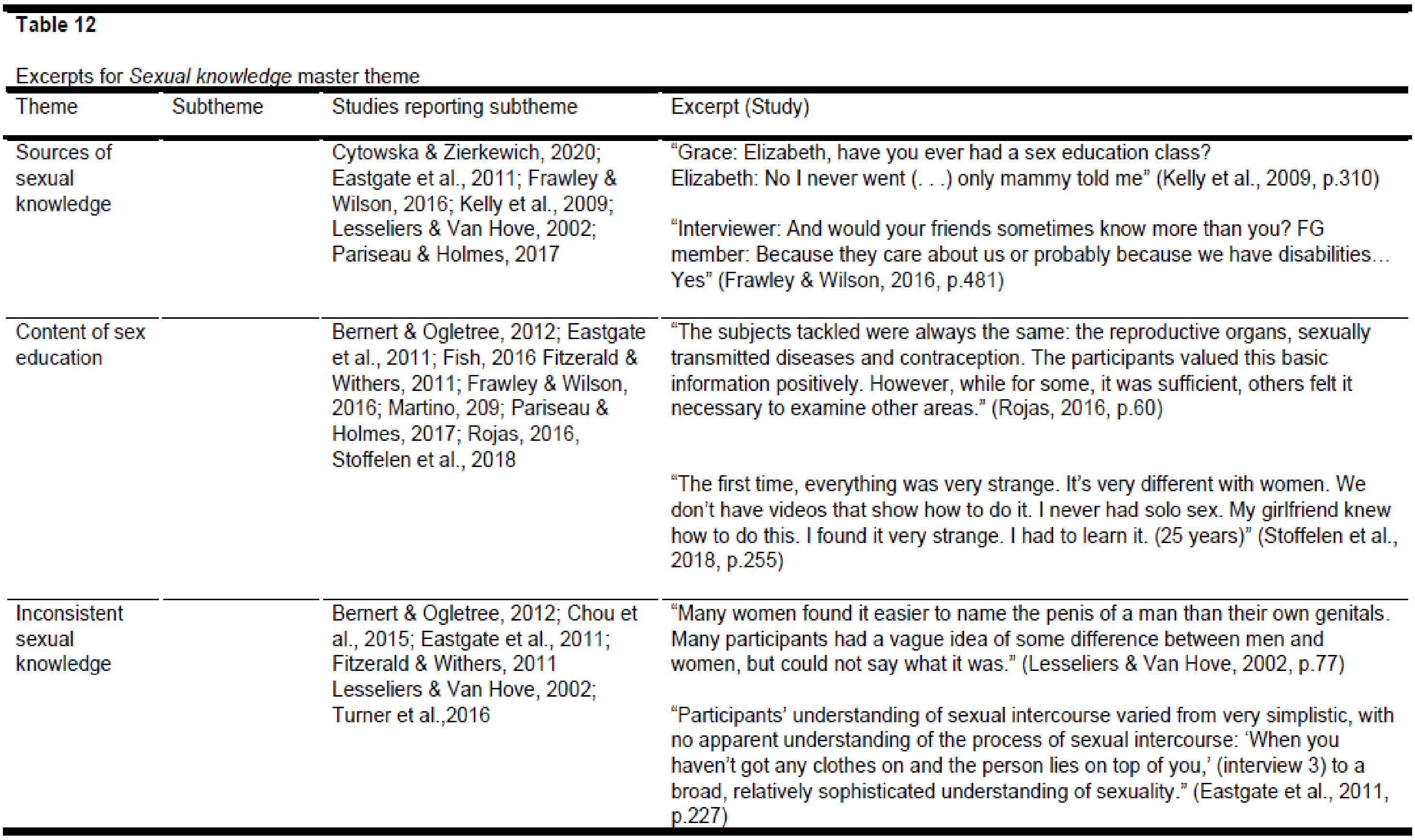


Table 12

Excerpts for *Sexual knowledge* master theme

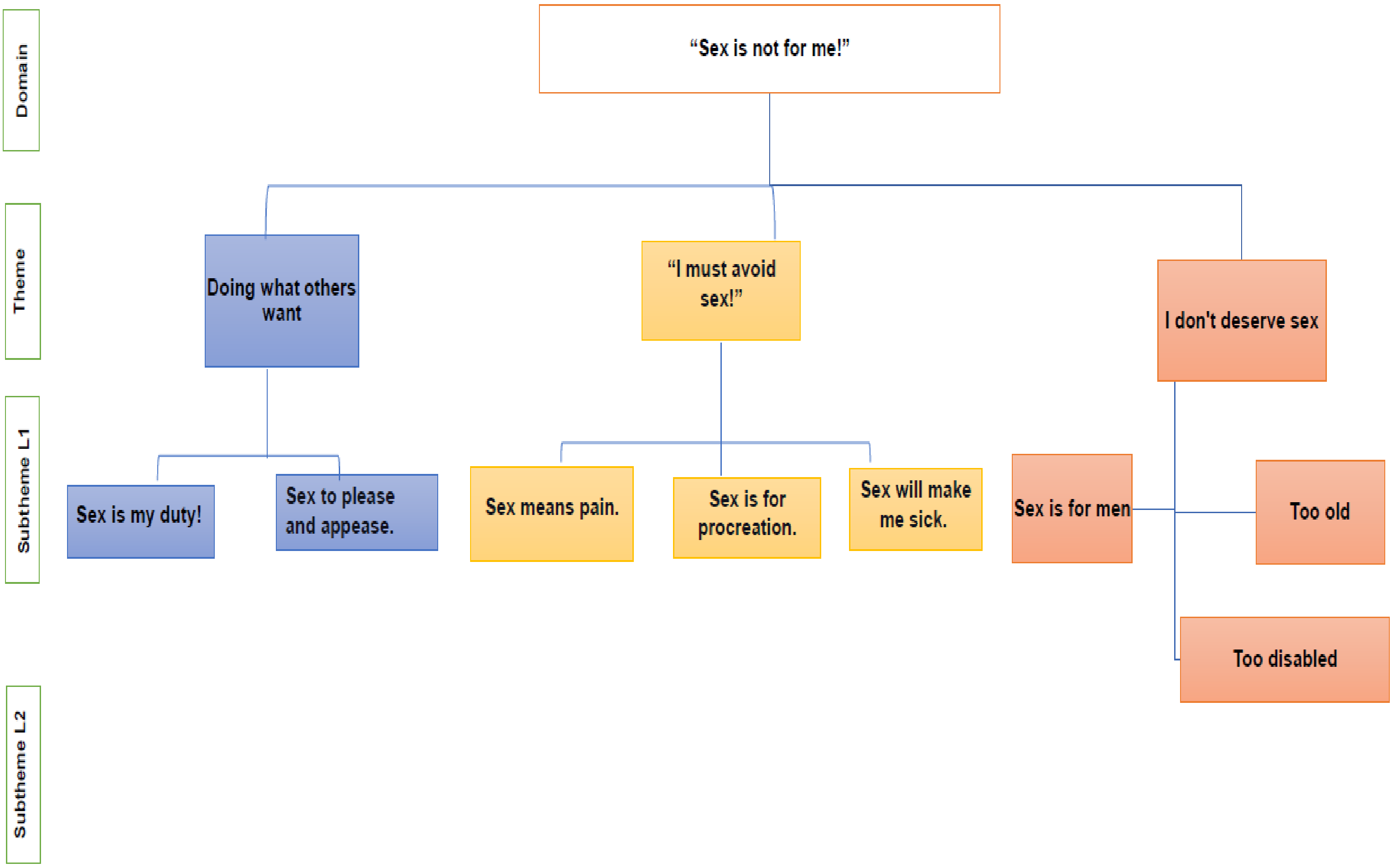
Theme	Subtheme	Studies reporting subtheme	Excerpt (Study)
Sources of sexual knowledge		Cytowska & Zierkewich, 2020; Eastgate et al., 2011; Frawley & Wilson, 2016; Kelly et al., 2009; Lesseliers & Van Hove, 2002; Pariseau & Holmes, 2017	"Grace: Elizabeth, have you ever had a sex education class? Elizabeth: No I never went (. . .) only mammy told me" (Kelly et al., 2009, p.310) "Interviewer: And would your friends sometimes know more than you? FG member: Because they care about us or probably because we have disabilities… Yes" (Frawley & Wilson, 2016, p.481)
Content of sex education		Bernert & Ogletree, 2012; Eastgate et al., 2011; Fish, 2016 Fitzerald & Withers, 2011; Frawley & Wilson, 2016; Martino, 209; Pariseau & Holmes, 2017; Rojas, 2016, Stoffelen et al., 2018	"The subjects tackled were always the same: the reproductive organs, sexually transmitted diseases and contraception. The participants valued this basic information positively. However, while for some, it was sufficient, others felt it necessary to examine other areas." (Rojas, 2016, p.60) "The first time, everything was very strange. It's very different with women. We don't have videos that show how to do it. I never had solo sex. My girlfriend knew how to do this. I found it very strange. I had to learn it. (25 years)" (Stoffelen et al., 2018, p.255)
Inconsistent sexual knowledge		Bernert & Ogletree, 2012; Chou et al., 2015; Eastgate et al., 2011; Fitzerald & Withers, 2011 Lesseliers & Van Hove, 2002; Turner et al.,2016	"Many women found it easier to name the penis of a man than their own genitals. Many participants had a vague idea of some difference between men and women, but could not say what it was." (Lesseliers & Van Hove, 2002, p.77) "Participants' understanding of sexual intercourse varied from very simplistic, with no apparent understanding of the process of sexual intercourse: 'When you haven't got any clothes on and the person lies on top of you,' (interview 3) to a broad, relatively sophisticated understanding of sexuality." (Eastgate et al., 2011, p.227)

Master theme 5: "Sex is not for me!"

This master theme comprised three themes exploring the effects of multiple meaning-making contexts on WID's perceptions of sex (Figure 6). For example, although some women valued intimacy and desired physical contact in the form of sex, as discussed in the *Joy of Sex* theme, many did not see sex as pleasurable or something they deserved, avoiding it altogether.

Figure 7

Thematic map for the "Sex is not for me!" master theme.



Theme 5.1: "Doing what others want."

In three studies, several WID showed limited understanding of legislation about sex; confusion regarding their right to refuse sex within an established relationship was evident. Some feared that refusing sex would end their relationship (Eastgate et al., 2011) and used it to appease their partner (Bernert & Ogletree, 2012). Other women thought sexual intercourse was integral to their role as women (Fitzerald &

Withers, 2011). Interestingly, women indicated they felt more empowered to decline strangers' requests for sex (Eastgate et al., 2011).

Theme 5.2: "I must avoid sex."

The *Monitoring and Regulating theme* discussed abstinence imposed by those in WID's network. However, self-imposed abstinence was also a dominant theme in WID’s accounts in six studies. Some WID avoided sex due to previous abuse (as discussed in the *Sequalae of abuse theme).* Others abstained from sex to avoid pregnancy (Chou et al., 2015), whether on contraceptive medication or not (Eastgate et al., 2011). For others, sex was "*dirty*" and to be avoided because of potential STIs (Bernert & Ogletree, 2012, p.4). Previously experienced pain and violent representations of sex in popular culture were also factors (Fitzerald & Withers, 2011; Lesseliers & Van Hove, 2002).

Theme 5.3: "Sex is something I do not deserve."

WID, in three studies, suggested that sex was pleasurable or permissible for other people, those younger than themselves (Lesseliers & Van Hove, 2002), those who did not have a disability, and men (Chou et al., 2015; Fitzerald & Withers, 2011).

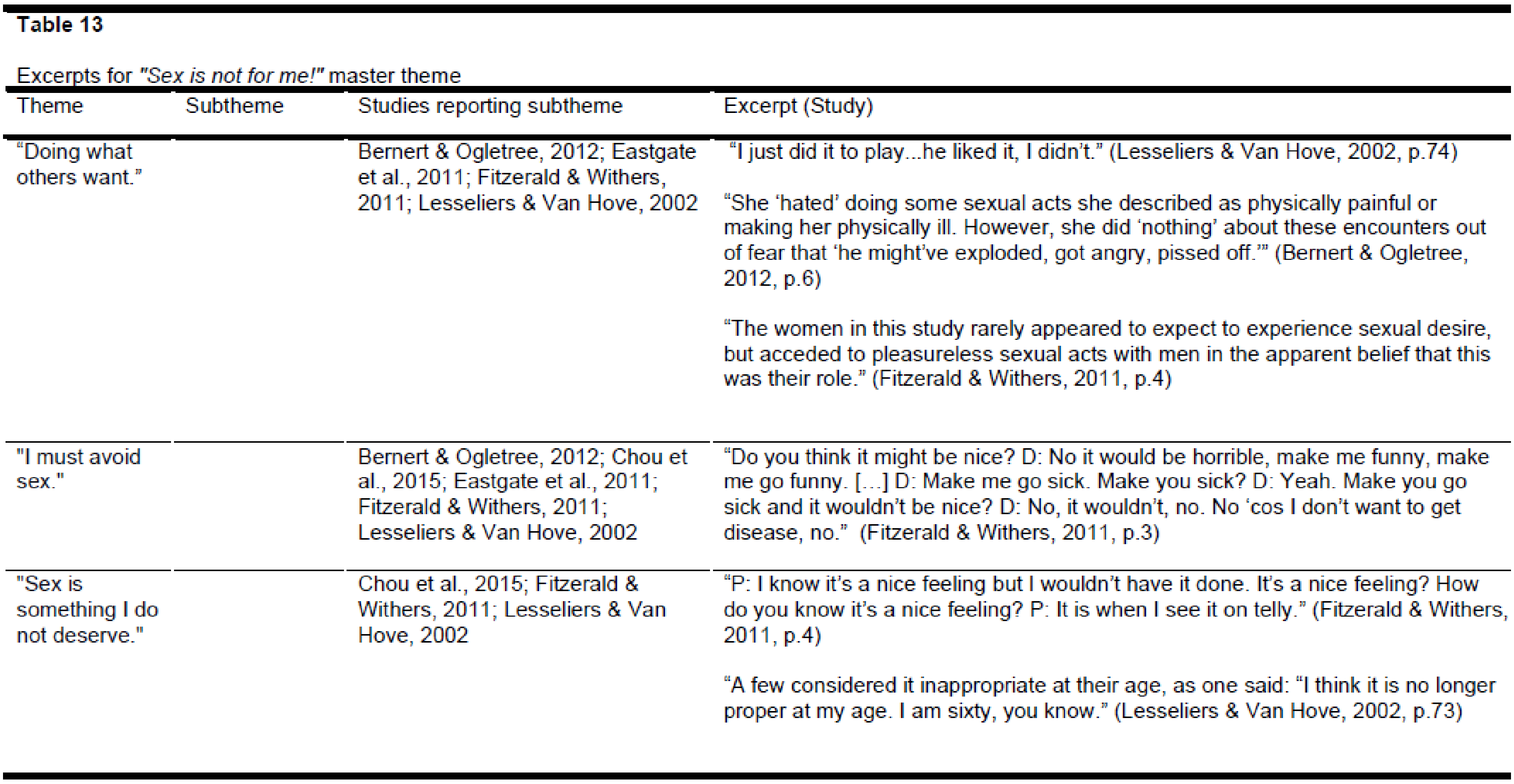


Table 13

Excerpts for *"Sex is not for me!"* master theme

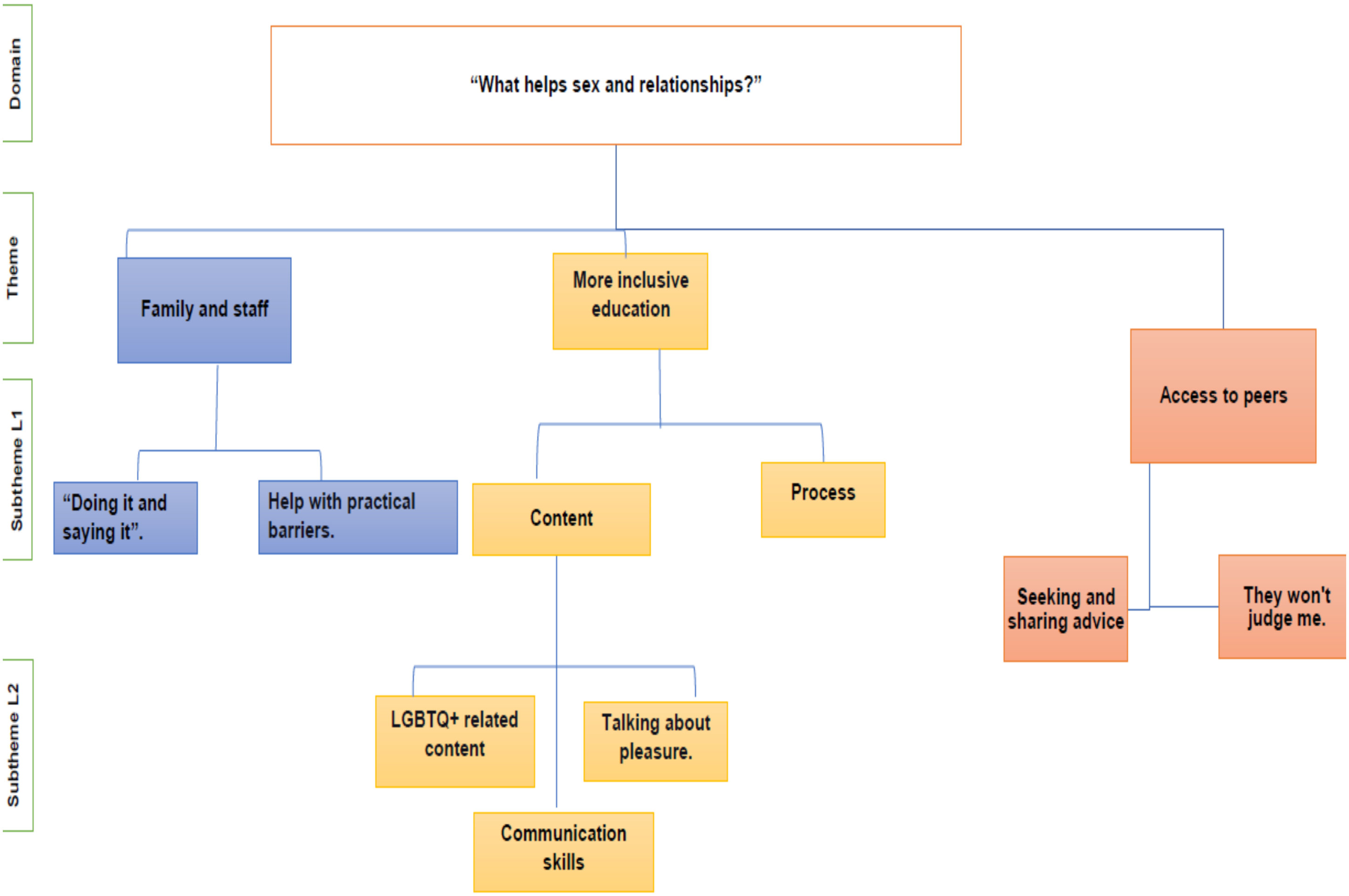
Theme	Subtheme	Studies reporting subtheme	Excerpt (Study)
"Doing what others want."		Bernert & Ogletree, 2012; Eastgate et al., 2011; Fitzerald & Withers, 2011; Lesseliers & Van Hove, 2002	"I just did it to play...he liked it, I didn't." (Lesseliers & Van Hove, 2002, p.74) "She 'hated' doing some sexual acts she described as physically painful or making her physically ill. However, she did 'nothing' about these encounters out of fear that 'he might've exploded, got angry, pissed off.'" (Bernert & Ogletree, 2012, p.6) "The women in this study rarely appeared to expect to experience sexual desire, but acceded to pleasureless sexual acts with men in the apparent belief that this was their role." (Fitzerald & Withers, 2011, p.4)
"I must avoid sex."		Bernert & Ogletree, 2012; Chou et al., 2015; Eastgate et al., 2011; Fitzerald & Withers, 2011; Lesseliers & Van Hove, 2002	"Do you think it might be nice? D: No it would be horrible, make me funny, make me go funny. […] D: Make me go sick. Make you sick? D: Yeah. Make you go sick and it wouldn't be nice? D: No, it wouldn't, no. No 'cos I don't want to get disease, no." (Fitzerald & Withers, 2011, p.3)
"Sex is something I do not deserve."		Chou et al., 2015; Fitzerald & Withers, 2011; Lesseliers & Van Hove, 2002	"P: I know it's a nice feeling but I wouldn't have it done. It's a nice feeling? How do you know it's a nice feeling? P: It is when I see it on telly." (Fitzerald & Withers, 2011, p.4) "A few considered it inappropriate at their age, as one said: "I think it is no longer proper at my age. I am sixty, you know." (Lesseliers & Van Hove, 2002, p.73)

Master theme 6: What helps sex and relationships?

This master theme explored WID's thoughts on the help required to achieve happier intimate lives. It comprised three themes; a common thread was the importance of having ongoing and tailored sex and relationship discussions (Figure 8; Table 14).

Figure 8

Thematic map for the "What helps sex and relationships?" master theme



Theme 6.1: More inclusive sex education

Process of delivering education. WID in two studies discussed valuing accessible information and preferring small group learning to the larger groups experienced in sex education classes at school, as facilitators could slow the pace of discussions (Frawley & Wilson, 2016; Rojas et al., 2016).

Content. In addition to the content of most RSE programmes covered in the studies, several WID indicated they wanted to learn to maximise pleasure and navigate relationship challenges, including handling conflicts (Bernert & Ogletree, 2012; Frawley & Wilson, 2016; Rojas et al., 2016). Two studies highlighted the significance of having LGBTQ+ inclusive materials (Martino, 2019; Stoffelen et al., 2018).

Theme 6.2: Access to peers

WID's accounts in three studies suggested that having access to peers might assist them in gaining knowledge on forming and maintaining relationships, sharing advice, rehearsing skills, and forming alliances with other WID (Cytowska & Zierkewich, 2020; Frawley & Wilson, 2016; Rojas et al., 2016). Some participants valued opportunities for meeting and learning with other WID who would not judge and were more likely to understand them (Frawley & Wilson, 2016).

Theme 6.3: Family and staff

Help with practical barriers. WID, in three studies, valued support from their networks with the practical matters of sex and relationships (Martino, 2019; Stoffelen et al., 2018). Some WID wished to live with or be closer to their partners (Lafferty et al., 2013).

"Doing and saying it". WID in three studies valued staff who verbally communicated their support while protecting or champing their rights (Bates et al., 2016; Eastgate et al., 2011; Kelly et al., 2009).

Table 14

Excerpts for *What helps sex and relationships?* master theme

Theme	Subtheme	Studies reporting subtheme	Excerpt (Study)
More inclusive sex education		Bernert & Ogletree, 2012; Frawley & Wilson, 2016; Martino, 2019; Rojas et al., 2016; Stoffelen et al., 2018	"Susana: Were there things you missed out on? Tesa: Yes.Susana: What exactly do you miss? What would you like to talk about with people? Tesa; Well, when you know you truly like someone, I don't know, for example, how to carry out, I mean as I have never tried it I don't know how to go about it." (Rojas et al., 2016, p.60) "Joan believed women should learn about 'the pleasure' of sex to 'make it more pleasurable for women'." (Bernert & Ogletree, 2012, p.6)
Access to peers		Cytowska & Zierkewich, 2020; Frawley & Wilson, 2016; Rojas et al., 2016	"I need some sort of help, advice… Because I just broke up with my boyfriend, my ex, and a new one caught my eye, and I don't know where I'm standing at the moment (P 1)—one of them said. Talk with him, ask if he truly wants you (P 4)—other women spontaneously replied." (Cytowska & Zierkewich, 2020, p.628)
Family and staff support		Bates et al., 2016; Eastgate et al., 2011; Kelly et al., 2009; Lafferty et al., 2013; Martino, 2019; Stoffelen et al., 2018	"Informal discussion suggested that this organisation had relatively positive attitudes toward supporting clients' sexual relationships". (Eastgate et al., 2011; p.228) "Two women indicated that some staff could be supportive. of relationships. Catherine: I told the social worker (about my relationship). She was very open about it, says I can do what I like. I wasn't expecting her to be so nice, but then she is very nice. They're very good to me here. All the staff and service workers." (Kelly et al., 2009, p.312) "Living arrangements emerged as an important factor in the facilitation, development and maintenance of relationships. For example, one couple could only afford the bus once a week to visit each other. Relocating nearer or finding suitable accommodation to cohabit were the options that this couple were hoping to explore." (Lafferty et al., 2013, p.1083)

Discussion

This meta-synthesis sought to review the literature on WID's experiences of sex and intimate relationships. The search identified 22 papers employing varied qualitative data collection and analytical methods. Sixteen studies were of high quality; three met the moderate and three the low-quality criterion. The study rating variations reflected differences in conduct and reporting. The synthesis yielded six master themes: *valuing intimacy; autonomy vs safety; abuse and its sequelae; sexual knowledge; "Sex is not for me!";* and *facilitating sex and relationships.*

Valuing intimacy

Consistent with previous reviews (including those with findings for both men and women with IDs) WIDs' accounts emphasised their experiences of loneliness (e.g., Black & Kammes, 2019; Lam et al., 2019). WID anticipated intimate relationships meeting their need for companionship and emotional or practical support, relying less on paid workers. WID associated close relationships with improved self-esteem, partly because they felt others would define them less by their disability or feel safer participating in community activities. Finally, the subthemes of *earned attachment* and *bids for connection* underscore the reparative potential of adult relationships, thus aligning with Crittenden's (2013) DMM model.

Sexual intimacy served many functions, including pleasure, emotional connectedness, and self-exploration. These themes echo Basson's (2000) circular model of sexual response; the initial motivation for sex might not be sexual. These findings highlight the importance of asking what WID want from their partners, including whether they desire sex.

Autonomy vs safety

WID across the studies had limited opportunities to meet their psychosexual needs. Networks' responses included acts of omission to acts of commission. WID's accounts suggested that, in part, this risk-averse approach left them feeling unheard, unable to trust those around them and ultimately not trusting themselves. Mistrusting self and mistrusting others have significant implications for those in the WIDs support network, particularly needing to understand how WID's previous *experiences of help* might affect their decision-making skills (Fredman, 2007). Equally, the themes of "*Whose body is it?"* and *epistemic injustice* described how those around WID might undermine attempts to exercise autonomy, a finding that echoes consent scholars' commentary on how interpersonal and broader cultural contexts of people's lives may inadvertently normalise coercion (e.g., Barker, 2013).

Another consequence of experiencing restrictions was risk-taking; WID engaged in secretive activities, occasionally in public spaces, also documented in previous reviews (e.g., English et al., 2018). These behaviours compromised WID's safety and reinforced their network's monitoring and restrictions (e.g., involuntary separation from their partners).

Abuse and its sequelae

The dual role of supporting WID with their intimate lives whilst minimising their risk of harm is fraught with challenges. *The power of the perpetrator* and *the effects of the abuse* themes highlight this challenge and align with previous review findings (e.g., McCarthy, 2014) and cross-sectional data (e.g., Cambridge et al., 2011). Equally, Shapiro (2018) reported that PWIDs were seven times more likely to experience sexual violence compared to their nondisabled counterparts, with 40% of abuse occurring within the person's family (25%) or staff (15%) and 50% with other men with IDs. However, the latter occurrence was more likely to be reported and believed than when staff had been the perpetrators (e.g., Bjornsdottir & Stefansdottir, 2020). These findings highlight the importance of proactively asking WID about experiences of abuse.

Sexual knowledge

As in other reviews, WID suggested access to sex education was often limited and biased (e.g., Brown & McCann, 2018; Lam et al. 2019). Equally, curricula tended to be overly functional or protectionist or have a mono- and gender-normative focus, with conversations about pleasure often missing. As a result, several WID perceived that sex could only happen in marital relationships and for procreation purposes. In the case of LGBTQ+ women, the hetero- and cis-normative focus of education concurred with previous experiences of lacking visibility, which made them feel further alienated by those around them.

"Sex is not for me!"

The "S*ex is not for me"* master theme reflected McCarthy's (2014) review findings; several women often found sex unrewarding, more for their partner's pleasure than their own. This review also found some WID thinking either sex was a pre-condition for keeping their relationships or something they did not deserve because of their disability or age**.** These findings highlight how multiple contexts can influence WID's experiences and perceptions of intimacy. Heuristic tools, such as Burnham's (2018) social [1] GGRRAAACCEEESSSS, which provide an accessible mnemonic for exploring different aspects of people's intersectional identities (see Footnote 1), might assist WID's networks (e.g., healthcare professionals) in paying systematic attention to significant contexts of WID lives that might affect their meaning-making processes around sex and intimacy, which otherwise could go unnoticed. Furthermore, the above tool might also assist their networks in exploring their attitudes towards the different aspects of WID's lives, minimising the chances of them acting, unwittingly, in discriminatory ways towards WID due to visible or invisible differences (Birdsey & Kustner, 2021).

Facilitating sex and relationships

WID also valued sex educators using accessible methods of communication, concurring with the Mental Capacity Act's (2005) principle of empowerment, which states that professionals need to support individuals' understanding, including tailoring their communication. Several WID wanted to learn about pleasure, other sexualities, gender identities and communication skills. Additionally, they wanted opportunities to meet other WID. McCarthy (2014) suggested that facilitated group interactions may provide both spaces for knowledge exchange and opportunities for reversing the personalisation of power inequality (Kitzinger, 1993), as participants might be able to see that what happened to them was not their fault. Finally, in their interactions with paid and unpaid carers, WID valued assistance in meeting potential partners or maintaining their current relationships and networks championing their psychosexual

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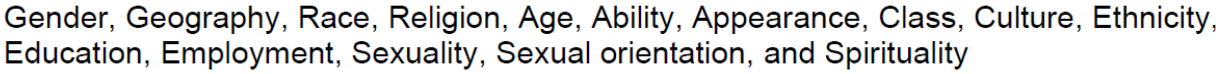
[1]



Gender, Geography, Race, Religion, Age, Ability, Appearance, Class, Culture, Ethnicity, Education, Employment, Sexuality, Sexual orientation, and Spirituality rights. Regarding the latter, documenting and sharing discussions might help WID experience the validity of their psychosexual needs.

Review limitations

Several factors have the potential to limit the transferability of the review findings. For example, studies did not situate their samples regarding critical contexts that could affect WID's psychosexual experiences. Other limitations are recruitment methods dependent on ‘gatekeepers’ and data collection methods dependent on verbal communication resulting in review findings applying more to higher functioning WID. Additionally, an over-representation of WID's negative views of sex and intimacy was evident in the reviews. Although this suggests this to be the dominant emotional valence of WID's experiences, it could also result from the researchers’ focus. Finally, only one reviewer conducted the analysis, which might further limit the review's dependability. Although, he tried to mitigate this by accessing supervision.

Clinical implications

Despite the abovementioned limitations, WID's experiences converged across the reviewed studies. Given the many contexts influencing WID's psychosexual experiences, a multiprong approach might be beneficial at individual, relational and institutional levels. Most importantly, eliciting WIDs' wishes should inform the support given in any of these contexts and elevate their voices in matters of self-determination.

Supporting WID at an individual level

As in other reviews (e.g., Lam et al., 2019), WID might benefit from having access, provided this is their wish, to develop further their sexual knowledge, assertiveness, and self-esteem, whether in 1:1 or group interactions. Relatedly, Loshek and Terrell (2015), in their research with women without IDs, distinguished three dimensions of sexual assertiveness: initiating communication about the desired physical contact (including sex), the ability to discuss risk-mitigating behaviours (e.g., using contraception) and sexual history, as well as to be able to refuse unwanted sex.

WID's accounts suggested that sexual knowledge curricula should emphasise information on sexual rights (including the right to refuse sex in established relationships). Additionally, the curricula should have a more inclusive focus (e.g., different relationship arrangements and LGBTQ+ identities) and cover the pleasurable aspects of intimate relationships and skills development. Equally, education for men with (and without) IDs should focus on healthy sexual expression, including their and their partner's pleasure. Finally, the data highlighted the following as potentially useful for WIDS: adequate time; socio-sexual information being available in different formats; building alliances between WID to reduce isolation and having opportunities to rehearse skills.

Supporting WID at relational and institutional levels

The themes of *unrecognised female sexuality* and *the downgraded value of relationships* highlighted the importance of advancing positive sexuality views within disability-centred environments or PWID's immediate network. Similarly, several reviews have advocated for systems change. For example, facilitated group supervision for caregivers could help draw attention to the different meaning-making contexts that inform their responses and bring people's expertise together to potentially find ways to manage risk positively instead of attempting to eliminate it.

However, to promote a sexually just future for WID, the themes "*Doing it and saying it"* and *Help with practical barrier*s highlight the importance of their networks moving from recognising their right to meaningful intimate lives to explicitly supporting such opportunities. The studies highlighted the following areas for improvement: help with transport and accommodation that ensures privacy; care plans to assess and support WIDs' psychosexual needs (e.g., through access to counselling or advice); and more opportunities to meet friends and new partners. However, without sufficient funding for placements and staffing levels, transportation, and adequate staff training, agencies will likely continue to struggle supporting WID's intimate lives.

Research recommendations

The present review highlighted the need for future studies to describe their samples consistently (e.g., ethnicity and spiritual beliefs) to explore potential differences in experiences within this population reliably. Furthermore, there needed to be a more active involvement of WID in the research process. Future studies may wish to consult ID charities or relevant public research engagement frameworks to increase PWID's part in the study development (e.g., National Institute for Health Research, 2019).

The perspective of women with severe-to-profound IDs and those identifying with the LGBTQ+ community were under-represented in this review. Methods such as participant observations may help future research explore the former group's experiences. Regarding LGBTQ+ WID, other recruitment channels (e.g., postings via social media or posters in public places) might help complement purposive sampling strategies via gatekeepers who may not recognise WID with those characteristics.

The present meta-synthesis also highlighted that some WID sought sex education information from informal channels (e.g., social media and magazines), sometimes being exposed to false representations of intimate relationships. Interestingly, Fowler et al. (2022) performed a content analysis of the 100 most viewed sex-education-related videos on video-sharing platforms (e.g., *TikTok*). One of their findings was that statutory services produced a minimal subset of those videos, which had implications for potential misinformation given the limited content moderation of those platforms. Therefore, future research may need to explore WID's views of what sex-education-related content they want to see on social media or even work towards co-producing that content, which in turn could inform a bank of resources (e.g., videos on *TikTok*) that their networks could share in routine interactions or when initiating communication with them.

Finally, given the role front-line staff and families have in supporting WID to meet their intimacy needs, studies might be helpful to explore the experiences of senior management or clinicians (e.g., clinical psychologists) who help them with daily implementation (e.g., through supervision and line management).

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MAJOR RESEARCH PROJECT

Section B: Empirical paper

Clinical Psychologists' experiences of exploring sex and intimacy with people with intellectual disabilities and their networks: a phenomenological study.

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MAJOR RESEARCH PROJECT

Abstract

Background: People with intellectual disabilities (PWID) continue to experience disparities in accessing fundamental human rights, including developing and maintaining intimate relationships. Several studies on healthcare professionals' experiences often report professionals' reluctance to support PWID's intimate lives or psychosexual needs, which the lack of organisational support and relevant training accentuated further. Another professional group that supports PWID are clinical psychologists (CPs). Yet their experiences of supporting the sexual relationships of PWID have not been investigated. This study attempts to address this gap in the literature by exploring CP's experiences of supporting PWID with their psychosexual needs.

Methods: Ten UK-based CPs who worked in a combination of NHS-funded community and inpatient settings participated in individual semi-structured interviews. Their data were analysed using interpretative phenomenological analysis.

Findings: The analysis identified three superordinate themes: *"being given the responsibility", "working with the shades of grey", and the "thwarted duty to protect and empower".* CPs working with PWID, and their networks face various dilemmas related to intimacy, which are present at individual, relational, and organisational levels. Although this is not the only aspect of their work, it is a prominent feature of their experiences.

Implications: Clinical practice might be useful to address gaps in CPs' sex and relationship training through different avenues. Most importantly, potential collaborations across agencies and special interest groups might help co-create a shared and positive risk-taking approach with and around PWID. Additionally, future research, in the form of rigorously conducted case studies, might be conducive to showcasing good clinical practice.

Key words: intellectual disabilities, sex, intimate relationships, healthcare professionals, clinical psychologists

Introduction

Sexual expression is an important aspect of human experience and well-being, which may entail, whether in or out of long-term relationships, having safe (i.e., free from harm) and pleasurable sexual experiences (World Health Organisation [WHO], 2019). This project adopts this definition whilst recognising that sexual expression can involve abstaining from sexual activity. Furthermore, for this project, the concept of sexual pleasure consists of any of the following: 1) physical pleasure, 2) emotional connectedness, and 3) sexual self-identity (i.e., the extent that someone recognises and accepts themselves as a sexual being with needs, desires, and rights). This definition relies on the key themes from the seminal study of Turner and Crane (2016) on the experiences of people with intellectual disabilities (PWID) of sexual pleasure. The project will also use the term *psychosexual need*s interchangeably with sexual expression.

Historically, PWID’s sexual expression was oppressed by the segregation of sexes (Baum, 2006). With the advent of the normalisation movement (Wolfensberger et al., 1972), however, there has been an increasing recognition of the rights of PWID to determine their sexuality. The United Nations (UN, 2006) asserted that governments should create structures that support PWID's psychosexual needs. Similarly, UK government policies (e.g., Valuing People Now*)* have galvanised local authorities and care services to support PWID in developing intimate relationships (Department of Health [DoH], 2009).

Despite laws, policies, and guidance, literature reviews on PWIDs' experiences of sex or intimate relationships continue to report social and environmental barriers that hinder their access to intimate relationships, such as excessive restrictions and monitoring by their networks (e.g., Black & Kammes, 2019; Lam et al., 2019). Historically, clinical practice with this population has focused mainly on reproduction, sexual health, and abuse prevention, emphasising safety over the possibilities of human connectedness (Rushbrooke et al., 2014; Tepper, 2000). As such, albeit highly valued by PWID, the concepts of pleasure and intimacy are often missing when interacting with their networks. In countries such as the UK, the shift towards deinstitutionalisation policies has meant that PWID now receive support from multiple groups of community workers, e.g., support workers in assisted living arrangements, advocacy groups, and health and social care professionals (Baum, 2006). Therefore, given their critical role in assisting (and potentially hindering) PWID in accessing intimate relationships, it is essential to understand their experiences.

Several qualitative systematic reviews have synthesised data on paid carers' (Charitou et al., 2020) or both paid and unpaid carers' reported difficulties when providing psychosexual support to PWID (e.g., Brown & McCann, 2019; Powell et al., 2019; Rushbrooke et al., 2014). All reviews highlighted that paid and unpaid carers often felt conflicted between balancing their duty to protect PWID from exploitation and enabling them to have fulfilling intimate lives. An associated difficulty was that paid and unpaid carers often felt unsure about who was responsible for supporting PWID in their psychosexual needs, with paid carers fearing professional repercussions if things went wrong. A lack of training and policy guidance exacerbated this worry for the latter group (e.g., Rushbrooke et al., 2014). Other factors included negative attitudes towards PWID's ability or motivation to engage in intimate relationships, which some studies reported to interact with PWID's characteristics, such as gender and the assessed level of intellectual functioning (Charitou et al., 2020). For instance, the terms "Hypersexual" or "Asexual" and "Victims" have frequently permeated discussions around the sexual lives of men and women with ID, respectively (Szollos & McCabe, 1995; Wingez- Yanez, 2014). These challenges often mean that PWID's networks experience ambivalence about their part in supporting them with their psychosexual needs. Equally, they tended to only deal with sexual matters reactively when a problematic situation that required a response arose (Charitou et al., 2020).

The previous reviews indicated that the staff's role in supporting PWID's psychosexual needs is complex, highlighting ethical dilemmas that may arise. Another critical professional group that supports PWID are clinical psychologists (CPs). Yet their experiences of supporting the sexual relationships of PWID have not been investigated. It may be of particular interest to explore the views of CPs partly because they have a different role in PWID's networks than other professionals. Equally, despite their training overlapping with that of other allied health groups, it also has significant differences (e.g., different epistemological underpinnings).

CPs use theoretically informed assessment, formulation, intervention, and leadership skills to nurture change at the individual, group, and organisational levels (British Psychological Society [BPS], 2019a). Their training also entails developing skills at working directly with PWID or indirectly with their professional staff and family networks (BPS, 2019a). Furthermore, the BPS (2019a) encourages continuing education to increase CPs' knowledge in areas their professional education has not covered. Therefore, CPs also have a role in supporting PWID's psychosexual needs.

Evidence suggests that within CP training in the UK that sex and relationship-specific training tends to be inconsistent (Shaw et al., 2008; Southall & Combes, 2022). Survey studies in the USA and Canada have also highlighted that not all CPs (including trainee CPs) were confident in addressing matters of sexuality when working with clients (without IDs) and their networks (Hanzlik & Gaubatz, 2012; Miller & Byers, 2008; Miller & Byers, 2009; Reissing & Giulio, 2011). In these studies, sex and relationship-specific training was the strongest predictor of comfort levels when discussing sexual matters, as assessed by self-reported scales, even after statistically adjusting the outcomes for years of clinical experience (Hanzlik & Gaubatz, 2012; Miller & Byers, 2008; Miller & Byers, 2009). Collectively, these results suggested that comprehensive clinical training (i.e., excluding sex and relationship-specific modules) and clinical experience might not improve therapists' confidence in discussing sexual matters during therapy. Equally, participants endorsing more sex-positive views, as operationalised by higher scores on sexual attitudes scales, reported feeling more comfortable discussing sexual matters with clients (Hanzlik & Gaubatz, 2012; Reissing & Giulio, 2011).

Although, to the author's knowledge, there are no studies on CPs' experiences supporting PWID with their psychosexual needs, some other literature might be relevant. For example, a qualitative study on UK-based CPs' experiences of exploring sexual concerns with clients that met the criteria for psychosis highlighted that despite holding positive views, there were still concerns about the potential negative consequences of these conversations (e.g., client becoming confused about relationship boundaries) (Southall & Combes, 2022). Interestingly, Hanzlik & Gaubtatz (2012) noted no significant differences in self-reported comfort levels discussing sexual concerns between male and female-identifying therapists with female clients. However, female therapists felt less comfortable discussing such matters with male clients than male therapists. Although there are limitations to these studies, most notably their cross-sectional study design, they indicated that, overall, CPs might also feel less competent in addressing sexual matters, a process which might be worth investigating with CPs working with PWID.

Second-order cybernetic systemic theories (Boscolo et al., 1987; Campbell, Draper & Huffington, 1989) suggest that therapists can bring personal and professional experiences to their interactions with clients and their networks. These, in turn, have been hypothesised to impact the process of formulation and intervention. Therefore, inquiring into CP's subjective experiences of supporting PWID (either directly or through their networks) with their psychosexual needs is critical due to the potential impact of these experiences on self-understanding and subsequent professional interactions with clients and their networks.

Given the potential complexity and the nuances of the processes involved, this study lends itself to a qualitative methodology. Due to the inductive focus of this project (i.e., concerned with CPs' lived experience), the discussion section will cover further relevant theories to avoid constraining the researcher's analytic vision before completing the analysis.

Aims

Therefore, this project aimed to address the following:

a. How do CPs experience supporting PWID and their networks around their psychosexual needs?

b. What barriers and facilitators do CPs experience when supporting PWID and their networks around their psychosexual needs (including discussing pleasure)?

NHS values

The research aligns with the NHS values of "improving quality of care" and "everyone counts" as it aims to improve knowledge of how to support a population whose sexual needs have been historically marginalised (DoH, 2015). Developing a deeper understanding of CPs' experiences of barriers and facilitators in supporting PWID and their networks with their sexual needs may inform how CPs can be better prepared to address these issues in research and practice. It may also highlight potential curriculum development needs for pre-qualification and continuing professional training (CPD).

Methods

Design

The study drew on an interpretivist epistemological position, using interpretative phenomenological analysis (IPA) to analyse the data gathered through semi-structured interviews with a small sample of UK-based CPs working in ID services (Smith et al., 2009). IPA's idiographic underpinnings focus on participants' experience and meaning. Additionally, it acknowledges that historical and socio-political contexts will influence that meaning. Given the context-sensitive nature of phenomena such as sex and intimate relationships, IPA has been used extensively in this area, and the researcher considered it as a pertinent analytical approach for the study's purposes (e.g., Flowers et al., 1997; Treisman et al., 2014). IPA also acknowledges that the researcher's pre-understandings influence how they receive another person's world. As such, the researcher engages in a double hermeneutic process in IPA. In this case, the author attempted to make sense of CPs' understanding of their experiences supporting PWID and their networks around their psychosexual needs.

Participants

IPA studies use small and purposefully selected samples (up to ten participants) from relatively homogeneous groups that are very knowledgeable about the topic of interest (Smith et al., 2009). To achieve this aim, the study's field supervisor circulated the approved study advert through the email discussion list of the BPS Division of CP, Faculty for PWID (see Appendix C). However, as not all CPs in ID services choose to join the faculty, the advert requested recipients to forward the information to other CPs meeting the criteria in Table 1.

Table 1

Inclusion criteria

Inclusion criteria	Description
Client group	Adults with a diagnosis of ID, who may or may not have other co-occurring conditions (e.g., autism, or sensory impairments
Setting	Any ID setting within the NHS or private healthcare providers
Job role	HCPC-registered CPs working or until recently (within the past year) have worked in a service for PWID.
Experience	CPs need to have worked either directly with clients or through their networks to help support their psychosexual needs.

In total, 15 CPs expressed interest in the study, and ten NHS-based CPs proceeded to participate, with reasons for non-participation including available interview slots clashing with CPs' clinical commitments. Working with PWID is a relatively small field of clinical practice. Therefore, demographic characteristics are presented in an aggregate form to protect CPs’ anonymity. The participants worked entirely in community-based or both community- and inpatient-based ID services across the UK. Overall, nine women and one man from White-British or White-Other backgrounds participated. Participant ages ranged between 34 and 65 years (Median=45.5), with nine identifying as heterosexual and one as bisexual. Their post-qualification experience varied between 5 and 31 years (Median=13.5), with job roles including senior, principal and consultant CPs.

Procedure and ethics

The Salomons Ethics Committee approved the study and its associated materials, e.g., the participant information sheet (PIS) and consent form (Appendix D). The CPs who contacted the researcher were emailed the PIS and given at least one week to consider whether they wished to participate. On the interview day, participants were reminded that their participation was voluntary and could opt out if they felt distressed or for any other reason. They could also request their pseudonymised transcripts to be deleted within one month after their interview, as their data would be analysed and used for the study beyond that point.

Equally, the researcher informed participants of the confidentiality limits and that he would seek advice from their supervisor, a senior CP in the ID field if any safeguarding concerns emerged during the interview. Finally, having had any questions answered, participants provided written informed consent.

Data collection

The researcher consulted with his two supervisors when developing the study's semi-structured interview schedule. Please see Appendix E for the full interview schedule and Table 2 for a sample of questions. In keeping with IPA, the interview schedule contained open-ended questions to allow the participants to talk about the salient aspects of their experience of a clinical piece(s) of work with PWID or their network concerning their psychosexual needs.

The interviews took place, over MS Teams, between the 17th of December 2020 and the 19th of February 2021, during the third COVID-19 lockdown. They lasted between 56 and 93 minutes. The researcher conducted the interviews from home and assured participants he was alone, whilst the participants were responsible for having access to a private space. The researcher audio-recorded the interviews using the MS Teams recording function and transcribed them onto a Microsoft Word document. He stored the transcripts in a password-protected, with multi-factor authentication, university file space. Finally, he pseudonymised the transcripts and removed any identifying information.

Table 2

Examples of questions from the interview schedule

Topic area	Example of question
Setting up the context of the work	Please could you start by telling me a bit about the setting you currently work?
Agreeing on an example	Can you describe a time when the sexual needs of a person with ID came into the picture regarding your work with the person or their network?
Exploring feelings	Can you talk me through, from referral to finishing the work, focusing on your experiences and including your feelings as part of this? How did these feelings or understandings change during your work with the client or their network?
Pleasure	What place (if any) did the concept of pleasure have in those conversations?
Barriers	What were some barriers to working with this client and their network? Where did they come from?
Facilitators	What were some of the facilitators in the work with this client and their network? What enabled or supported those conversations?
Other salient aspects of participants' experience	Are there other aspects of your experience of working with sexuality that would have been important to cover in our conversation?

Data analysis

The data analysis followed IPA guidance as outlined in Table 3. Over several stages, it attempted to move from a descriptive to an interpretive understanding of participants' experiences and from the particularity of their meaning to their shared experience (Smith et al., 2009).

Table 3

Stages of data analysis based on Smith et al.'s (2009) guidance.

Procedure	Description
Reading and reading of interview transcripts	The first stage involved a close interpretative reading of the first case, allowing the researcher to slow down and immerse himself in the data.
Initial noting	The second stage involved the researcher noting his initial responses to the transcript in one margin. At this stage, he focused on participants' descriptive accounts, language use, and potential implicit meanings.
Developing emergent themes	The third stage involved the researcher turning his initial notes into provisional themes to summarise the salient aspects of participants' accounts.
Connections across themes	The fourth stage entailed the researcher looking at how the emergent themes fit together, as by that point, the analysis had turned the original interview into a set of parts. Partly, at this stage, the researcher returned to the study's initial questions and used processes such as *abstraction* (i.e., gathering similar themes together) to create clusters or superordinate themes. Please consult Appendix F for an annotated transcript.
Repeating the same process for the next case	During this stage, the researcher repeated the above analytic process whilst also trying to bracket ideas from the previous transcripts to maintain an idiographic approach to participants' experiences.
Looking for patterns across cases	At this point in the analysis, the researcher started looking for patterns of meaning across cases and how themes in one case helped to explain or contradict themes in another. He also collated data extracts under the coded themes. This process continued during the write-up of the report as well.

Quality assurance

Yardley's (2000) principles guided the researcher's analytic process. For instance, he kept a reflective journal and used regular supervision to remain mindful of the potential effects of his pre-understandings and epistemological position on the research (Vicary et al., 2016). Additionally, his supervisors audited his coding and interpretation to triangulate perspectives and ensure the themes were credible. Where there were areas of uncertainty, the supervisors and trainee reviewed the relevant raw data and decided on the final coding based on consensus. Finally, the author followed Smith et al.'s (2009) guidance to ensure that at least three participants' accounts evidenced any reported themes.

Researcher reflexivity

The researcher, a white, cisgender gay man with a learning difficulty, has supported PWID around sex and intimate relationships in the past. As such, his embodied self and experiences might have influenced how he conducted the interviews (e.g., what areas he chose to explore further with the interviewees). However, he included prompt questions in the interview schedule to re-orient him to the participants’ experience, asking them for detailed examples.

Equally, as a novice IPA researcher, having completed a meta-synthesis on women’s experiences with intellectual disabilities around sex and intimate relationships might have influenced the way he approached analysis, such as being sensitised to the negative valence of their experiences with healthcare professionals (e.g., often their interactions missing discussions around pleasure). However, he tried to ground the results section in sufficiently rich quotes to enhance transparency and honour the interviewees’ experience.

Results

The analysis yielded three superordinate (or master) themes and ten subthemes regarding CPs' experiences exploring PWID's psychosexual needs in individual sessions with them or their support networks. Please see Table 4 for themes.

Table 4

Summary of master themes and subthemes

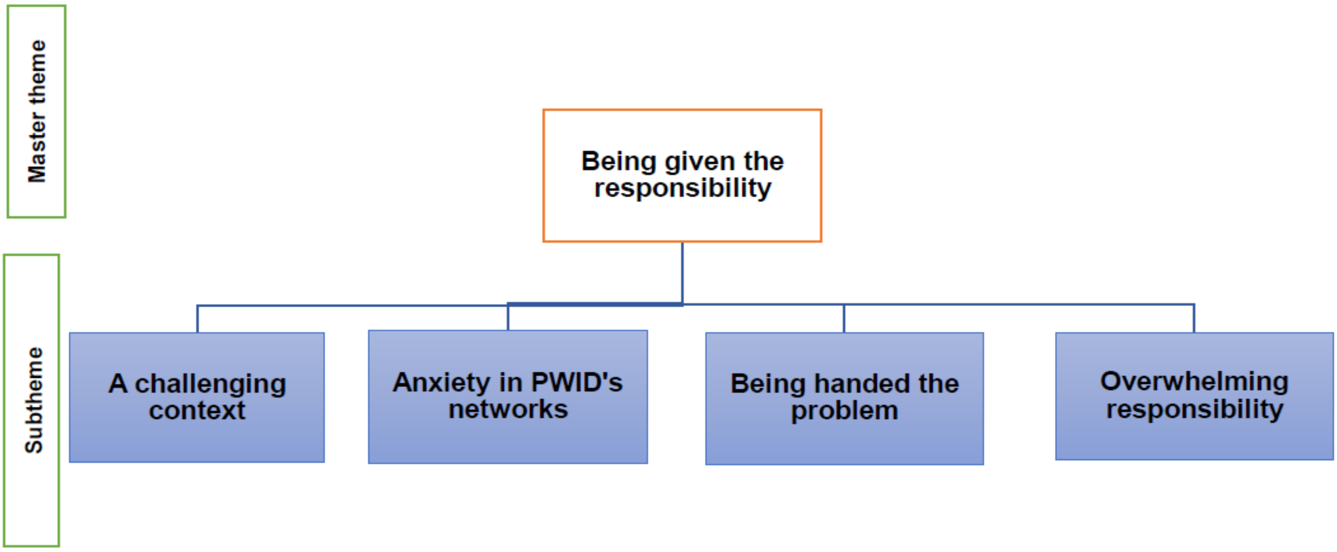
Master theme	Subtheme
Master theme 1: Being given the responsibility.	A challenging context Anxiety in PWID’s networks Being handed the problem Overwhelming responsibility
Master theme 2: Working with the shades of grey.	Motivated to empower and protect Normalising or titillating? The delicate dance of engagement with clients Name it to tame it: working with teams. "What helps me steer a steady wheel in these stormy seas?"
Master theme 3: The thwarted duty to protect and empower.	"It's like knitting with water." The grey area of consent to sex “My heart sinks a bit”.

Master theme 1: Being given the responsibility.

The first master theme encapsulated participants' perceptions of the wider forces influencing their work with PWID. Nearly all participants described that within multiple challenging contexts, they experienced the referrals they received as primarily inviting them to correct PWID's problematic sexual behaviours. In addition, some participants perceived that the referrals communicated PWID's network's implicit desire for a sense of safety. Three themes comprised this master theme (Figure 1).

Figure 1

Thematic map for Being given the responsibility master theme.



A challenging context

This theme focused on CPs' accounts of how broader systemic factors shaped the landscape of the referrals they received. For instance, several participants mentioned how, in a context of dwindling government funding, health and social care teams have reconfigured their service delivery models to manage their limited resources in meeting PWID's complex needs, e.g., by ascribing cut-off points to “the level of disability someone needs to have" to access help (Olivia).

> *“A lot of their support has been taken away from under their feet almost, and they’re not getting anything much.” (Lena)*

However, as some participants, like Charlotte, suggested, an associated difficulty was that PWID would "often fall between the [service] cracks" because the predicted level of disability correlated poorly with the level of the individual's care needs.

> *“How? How do you help somebody when the systems we have, make it difficult to access help. I find that difficult. The phone call earlier was somebody who likely won’t access services for months!” (Sandra)*

In the previous excerpt, Sandra’s emphasis on *how,* might be seen as speaking to her experience of a paradoxical situation, of wanting to help but at the same time feeling unable to because of structural limitations. Equally, several participants felt disheartened and frustrated that "more able clients" often lived isolated lives due to the service vacuum around them, which increased their vulnerability to different forms of exploitation (Rosalind). Many participants also spoke about how the COVID-19 pandemic and the associated lockdown measures had exacerbated the above difficulties. Similarly, some participants spoke about the effects over-relying on diagnosis when working clinically with PWID, including supporting them with their psychosexual lives.

> *"We have a structure dominated by diagnosis that leads to sex being understood as a problem if you like or a diagnosis." (Sandra)*

In the above quote, Sandra described how diagnostic thinking influenced not only service planning but also how healthcare teams thought about sexual behaviours as something that could be fixed.

Anxiety in PWID's networks

This theme focused on CPs' understanding of PWID's immediate systems' emotional reactions to the referred person's psychosexual needs.

> "*Mum went to the GP desperate, saying I don't know what to do, I'm so afraid, and the GP referred to us."* (Lena)

> *"A lot of the work we do around people's sexuality, when there are concerns […] or they are behaving in sexually unsafe ways." (Elizabeth)*

The above quotes provide an example of participants' frequently experiencing paid and unpaid carers feeling worried and, sometimes, demoralised or lacking competency to support the referred person around sexuality issues. Some of the worries were in response to an event, e.g., a client reporting an assault.

> *"He'd physically assaulted her. She had sex with his neighbour […] that was a rape allegation." (Harriet)*

Other times, as Sandra's and Olivia's quotes evidence below, some participants perceived implicit normative beliefs (e.g., gender- or hetero-normative views) or life-cycle issues confounding these feelings of anxiety. There was an overall sense from the interviews that most participants experienced the focus of the referrals for women tended to be how to protect themselves from others, whereas with men was how to protect others from them.

> *"Her mother was ambivalent about her growing up. She was like, 'You look like a baby […] Who would date you […]." (Olivia)*

> *"Mum was very concerned about him; she described herself as quite homophobic." (Sandra)*

Being handed the problem

Several participants perceived that PWID’s carers, in addition to worrying about the potential harm to or from the referred client, also feared ‘who’ in the system would be responsible if "anything went wrong" (Alice).

> *“What I was feeling or mirrored for me […] the staff are the ones picking the pieces […] whenever she goes to the police […] understandably, they want absolute safety […] in a world you can't assure that unless you lock up people 24/7." (Sophie)*

Hence, according to some participants, referrals to the psychology team seemed to be a way of handing "all lock, stock and barrel the responsibility for very complex pieces of work" (Sandra).

Overwhelming responsibility

Several participants commented about how deeply they felt that sense of responsibility to protect PWID from harm and "getting it right for everyone concerned" (Harriet).

> *"You feel the anxiety of what might happen if something goes wrong, and then have 20 people looking at your notes. You can get such tunnel vision, like you only see police prosecution, or mum's view […] There isn't any creativity, and the people would allow me to do because I knew they have my back if things went wrong.* (*Sandra*)

For instance, Sandra's extract above drew attention to her anxiety around risk and how it constrained her thinking. However, it also potentially highlighted her experience working in what felt like persecutory-oriented structures, where a lack of organisational support further compounded her ability to work creatively. Other interviewees, such as Harriet, shared similar experiences, describing guilt and frustration for not exploring topics such as pleasure due to the above barriers.

> *"And I do sort of what I need to do […] but then end up feeling frustrated. There is a lot more that I would like to talk. Probably almost never have spoken to people about female orgasms." (Harriet)*

> *"You are thinking on your feet. That idea of repressing…even with good intentions, it can be easily done." (Lena)*

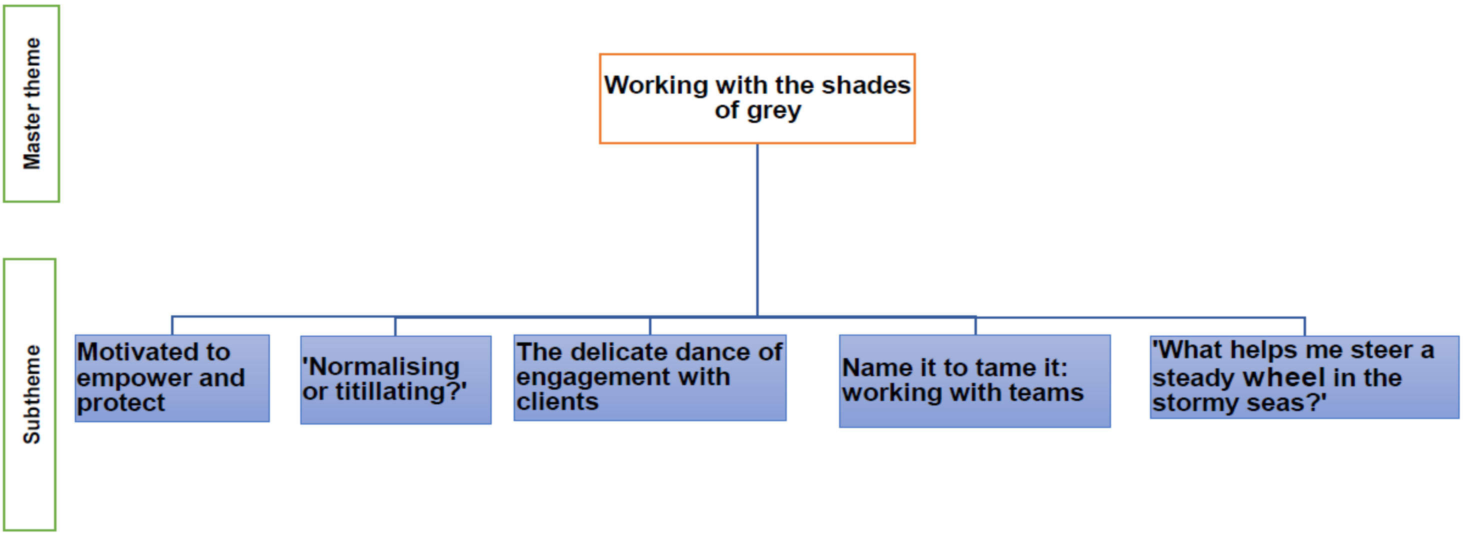
In some cases, as Lena’s account indicated, participants mentioned that especially under time constraints, they ended unwittingly colluding with PWID's networks to stop or delay PWID from engaging in sexual relationships.

Master theme 2: Working with the shades of grey.

This superordinate theme focused on how participants experienced navigating their dual role of empowering and protecting PWID in their work with them and their networks. It entailed five themes (Figure 2), with the first four describing participants’ motivations and perceived tasks with teams and individuals and the last discussing their resources in this complex undertaking.

Figure 2

Thematic map for Working with the shades of grey master theme.



Motivated to empower and protect.

The participants invariably expressed a deep motivation for helping PWID and their networks to live meaningful, intimate lives free from harm. For example, participants discussed how sex and close relationships were universal needs.

> *"There is an important value to help people with learning disabilities to have the same human rights and access to relationships and sex as anybody else." (Jonathan)*

However, most participants reflected on the inherent tensions of protecting and empowering PWID's sexual autonomy.

> *"So, rather than going for one narrative of 'This man is a sexual risk, and he needs to be contained and safeguard other people' or 'He is a man who wants a relationship, and we need to enable him', we are trying to keep an eye on both bits at the same time. That's the difficult bit." (Elizabeth)*

For instance, Elisabeth's quote illustrated her conscious efforts to hold onto a 'both-and' versus an either-or' position, where she did not overlook potential safeguarding risks by focusing on enabling someone's expression of needs and vice versa.

Several participants spoke about feeling motivated by theories and ideologies resonating with their values. For instance, feminism, the social model of disability, and systemic theories were among the most cited frameworks.

> *"I was connected with some third-wave feminist groups who were interested in not treating women as victims within the context of the complex relationships they had." (Sophie)*

Finally, some participants situated their motivation for helping PWID with their intimate lives in their personal experiences, including life-affirming (e.g., inspirational parent figures) and negative, traumatic psychosexual experiences or, in Lena's case below, rejecting early family scripts that sought to subjugate her. These experiences connected participants to their commitments emotionally and intellectually.

> *"I was quite the rebel […] My dad wouldn't let me go out with boyfriends because what would people say, stuff like that…I've always wanted people to be able to do that." (Lena)*

Normalising or titillating?

Invariably, all participants sought to normalise discussions around sex and intimate relationships with PWID. Additionally, a few participants explained how they tried to discuss the emotionally and physically pleasurable aspects of close relationships. However, half of the participants were concerned about the possibility of these conversations becoming "titillating", especially with men who had previously sexually offended (Elizabeth). Relatedly, some participants situated this concern in past experiences of erotic transference from clients.

> *"The dilemma would be around not allowing him a space to get gratification from the intervention […] being able to relive his offences in a way that's making him feel good." (Rosalind)*

> *"The person asked me what underwear I was wearing […] I was kind of 'What do I do with this!'" (Alice)*

It is important to note that several participants also perceived the clients' care teams sharing similar worries, which made discussing their psychosexual needs difficult. To circumnavigate the above dilemma, some participants sought the help of their MDT colleagues or PWID's staff team, e.g., co-attending some meetings to increase feelings of safety.

> *"I think a difficulty about sex and masturbation when talking with staff teams is a fear that they are going to be seen to have encouraged something, to become sexualising." (Sophie)*

The delicate dance of engagement with clients

Several participants spoke about the challenges they faced in their interactions with PWID. For example, some participants shared that they felt "already starting on the back foot with" the referred person, as they had not asked to see a psychologist (Olivia). In addition, some participants worried about being the most recent addition to a pool of healthcare professionals that PWID had seen, often in the context of previous aborted interventions.

> *"I felt trapped, this was somebody people wanted to be in therapy, and she had had kind of three abortive therapeutic relationships." (Alice)*

Similarly, most participants perceived PWID's lives to be subject to excessive control and intrusion in terms of monitoring and coercion by those around them. As such, they frequently wondered how this might impact the therapeutic relationship.

> *“I didn’t want to get positioned as another parent or another person without a disability that is having a go at her.” (Charlotte)*

> *“Every part of his life was scrutinised and reviewed. So, I wonder how that suppresses their expression with me.” (Jonathan)*

Equally, some participants spoke about how they felt conflicted that their privilege might be "like a slap in the [client's] face" as they often had access to things the clients' desired, e.g., having a partner (Olivia). This was a particular concern around female-identifying clients.

> *"The most difficult for me was when I was being pregnant, and women I was working with had their children taken into care when they didn't want it." (Elisabeth)*

With those challenges in mind, several participants' accounts described how they often experienced client engagement as a fluid and dynamic process akin to a dance. They indicated how they sought to work within PWID's window of tolerance, which often they felt as being in flux dependent on the strength of clients' feelings (e.g., due to embarrassment, shame, internalised ableism).

> *“Because it felt like a very delicate dance […] had to tread that ground that felt difficult to tread and was maybe more intimate […]" (Olivia)*

> *“I think she feels ashamed of who she is […] She still cannot look me in the eye." (Alice)*

Most participants spoke about the value of bringing an attitude of respectful playfulness into that dance of engagement with clients.

> *“There was banter in our sessions […] he liked to laugh. And then there was something in terms of the sexuality side of things. I think he was explaining to me the pleasure of wearing this silky flag skirt.” (Jonathan)*

Name it to tame it: working with teams.

The previous two subthemes discussed CPs’ attempts to navigate interactions with clients. Equally, all participants spoke about the importance of engaging with staff teams, which involved equipping them with the language around sex and relationships and enabling them to create a narrative about the often competing and sometimes contradicting contexts that influence their support around PWID's intimate lives.

> *"Giving people the language to ask questions to enable them to have this kind of conversations." (Sophie)*

Relatedly, several participants described an associated and often implicit tension of "trying not to alienate the teams" (Sandra) by balancing the discourse about PWID's rights to intimate relationships while validating their concerns around safeguarding risks.

> *"Because if you lose the staff at that point and they are concerned, they are very unlikely to support someone express their sexuality." (Elizabeth)*

All participants shared that formulation was a vital adjunct to this task, e.g., by helping PWID's team members to voice their concerns and help co-create an understanding of the person's needs and the different network members' interpretations and responses to these. Similarly, some participants spoke about the importance of highlighting good practices and naming how challenging this type of work was.

> *"I used the 5 – P format […] to explain my thoughts about the presentation and give everyone in the room space to say how they felt." (Jonathan)*

> *"Just sitting with…naming and reflecting […] with her support workers and acknowledging what a good job they were doing, and they did have […] permission or legal rights to enquire and to support." (Sophie)*

Finally, several participants suggested that as important as facilitating reflecting spaces with clients and their teams, co-creating actionable plans assisted in their task of not alienating the teams. They suggested that co-creating plans was valued by both PWID and their teams and helped to bridge the teams' desire for more direction in supporting the client without the CP becoming too prescriptive.

> *"We also thought about local places where he could go out with staff. And just suggested to staff that they started supporting him to wear what he wanted, to go shopping..." (Elizabeth)*

"What helps me steer a steady wheel in these stormy seas?"

All participants mentioned that formulation and the different models they drew upon were only part of what influenced their thinking and practice. As such, invariably, they spoke about how much they valued having access to reflective spaces and different perspectives, those of peers, clients, and their advocates, PWID's staff teams, MDT colleagues and supervision.

> *“[...] also connections with people who maybe don't think in exactly the same way as me or for the same reasons as me, but people that see this as an important area.” (Sophie)*

Additionally, participants explained that having access to those spaces not only helped them discuss legal quandaries or share worries but also helped re-orient their thinking in times they had unwittingly acted as a barrier to PWID engaging in intimate relationships.

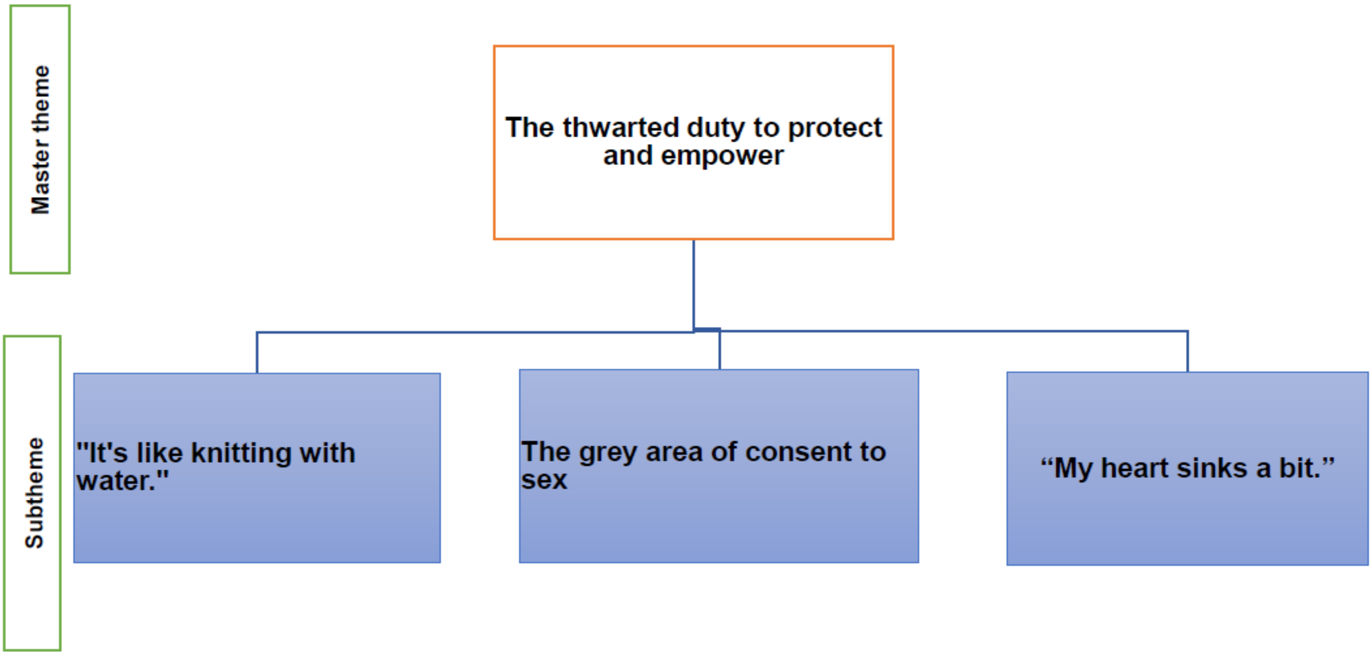
> *"The advocate was saying, 'Why aren't you honest with her and say okay let's have a meeting’ […] I realised I’d been complicit to this delay.” (Lena)*

Master theme 3: The thwarted duty to protect and empower.

This master theme explored some challenges participants faced in supporting PWID or their networks around their psychosexual needs and the emotional consequences of navigating situations that sometimes felt "messy and chaotic circumstances with “'No happily ever after' endings" (Harriet). Three themes comprised this superordinate theme (Figure 3).

Figure 3

Thematic map for the thwarted duty to protect and empower master theme.



The grey area of consent to sex

Many participants spoke about how challenged they felt by the high levels of ambiguity when supporting PWID with their intimate relationships. For instance, several participants mentioned what they regarded as the broader cultures' relationship to consent to sexual relationships, often viewed in binary terms, as adding to the complexity of this type of work. Participants reflected how factors such as power differentials, based on the intersections of clients' and their partners' characteristics (e.g., age, disability), made consenting to sex a more complex decision than processes such as capacity assessments allowed it to be. Nonetheless, they still felt that they were held responsible for "getting it right", especially around capacity decisions.

> *"Something feels uncomfortable…It's about that very grey area between people who legally have capacity to consent when you ask them […] 'What goes in what hole? […] Can they choose to say yes, or no?'. And it would be tick, tick, tick. But what happens in the real world […] feels more complex […] And I am positioned in having this duty of care as a learning disabilities worker […] to make a decision […]" (Sophie)*
>
> *"This is not about capacity […] she's said […] that she is not able to say 'no' to people who she feels are in positions of power." (Elizabeth)*

"Knitting with water."

In the context of the aforementioned complexity and ambiguity, several participants reflected that despite their best intentions, they frequently experienced a thwarted sense of duty to protect PWID from harm and empower them in their sexual lives.

> *"I felt like I was knitting with water with her. We finished not because she disengaged, but because there was limited stuff that could shift now." (Charlotte)*
>
> *"We said, 'Can they not be supported to meet and just have a coffee somewhere?'. And for whatever reason, we're talking almost a year now, and nothing has changed." (Lena)*

The above extracts from Lena and Charlotte seem to be describing moments in their individual sessions or team consultations where they were faced with an increasing realisation that what they were doing, although valuable, in some respects, had minimal impact.

Many participants also felt resentful and sometimes despairing when confronted with what they perceived as the effects of devaluation and loneliness on PWID's lives. For instance, in the excerpt below, Harriet explained that loneliness increased PWID's vulnerability to exploitation and influenced their decision to engage in unwanted sex or stay in unfulfilling relationships.

> *“I feel helpless not knowing how to help her and despairing almost, I suppose, at sort of her sexual risk, trying to achieve that companionship she so wants.” (Harriet)*

Some participants also described the challenges of working in an internet age, which increased the vulnerability of clients they perceived as having an inconsistent understanding of sex and relationships.

> *"These people on the internet send him pictures of someone who clearly wasn't 18, but this girl's profile wrote 18, and… my client approached her […] This wasn't her. Then they asked him for a photograph […] and called the police." (Lena)*

Some CPs juxtaposed how with other therapeutic encounters, they could rely on existing theoretical models or relevant manuals when approaching discussions around sex and relationships. For instance, Charlotte shared that she felt helpless, and her emphasis on "all over the place" in the quote below might indicate her attempt to navigate this complex terrain almost without a map.

> *“I am not doing CBT with her. I am not doing a discreet piece of work with her. It's a bit all over the place! I suppose that's contributing a bit to feeling helpless." (Charlotte)*

Relatedly, half of the participants reported that lacking sex and relationship-specific training for PWID during their doctoral education added to their ambivalence in dealing with sexual matters. As a result, some CPs either ‘taught’ themselves or pursued further CPD opportunities to feel more equipped with sex and relationships conversations.

> *'I've not had any training in this assessment' […] how to ask these questions […] And I'm not a teacher, and this is weird." (Alice)*

> *“I think it’s not something that as psychologists we get any training on talking sex…All that stuff I’ve got [was] outside of clinical psychology.” (Charlotte)*

Finally, participants wondered whether focusing on sex was an appropriate area of enquiry for psychologists, partly because there were not clear clinical pathways in their teams, or there were substantial overlaps with other MDT or other agencies' members' practice remits (e.g., nurses, teachers) due to its biological aspects and others partly because they did not consider sex a disorder that can be "treated".

> *“There is no clear pathway in our service, and it is a muddle. I closed cases when perhaps I shouldn't have done, or there was nowhere to signpost somebody.” (Charlotte)*

> *“There was no mental health element to it. She wasn’t distressed […] you could argue that this is for education to do.” (Rosalind)*

“My heart sinks a bit”.

Several participants shared long-lasting feelings attached to their thwarted sense of duty, varying from "guilt" when they perceived they had not empowered the referred person and "regrets" for being unable to protect them.

> *"I question whether I could have done more to help her choose relationships that I think she deserved rather than what she felt she deserved […] that's quite intrusive of me [...]…But it's still a feeling I have." (Sophie)*

> *"I have been working this for many years, the heart sinks a little bit. I partly don’t want to get involved because I think in my head, I know how it’s going to end. I don’t want to start from that standpoint. I think psychologists have lost a bit their way with that. For me that’s the one thing, immediately it’s all about risk management.” (Lena)*

Lena’s extract draws attention to the time frame of how she developed these feelings, which might resemble moral injury. Under the theme *of motivated to* *empower and protect,* her quote documented her deeply held commitment to supporting PWID with their intimate lives. However, in this passage, she described how her experiences had eroded her hope for the people she helped. She also expressed a sense of loss on behalf of psychology as a profession, supporting PWID with their psychosexual lives.

Discussion

This study sought to understand CPs' experiences supporting PWID around their intimate lives. It employed an IPA methodology to analyse the data from 10 semi-structured interviews. The findings suggested that CPs' task supporting PWID and their networks was often complex and multi-layered. The analysis identified three superordinate themes*: Being given the responsibility, working with the shades of grey, and the thwarted duty to protect and empower.*

In the *being given the responsibility* superordinate theme, several participants shared that, in the context of multiple challenging systemic factors, they felt palpable anxiety in PWID's network surrounding their sexual needs. Participants commented that they experienced the people close to PWID often feeling demoralised and doubtful of their competency to deal with sexual issues. These perceived network reactions echo previous reviews’ findings on carers’ experiences, often reporting reticence to support PWID's sexual expression, which the lack of organisational support and relevant training or policy guidance accentuated further (Brown et al., 2019; Rushbrooke et al., 2014).

Participants reflected that they sometimes experienced referrals as a responsibility handover from PWID's network to provide solutions, e.g., “fix” the referred person's problematic sexual behaviour. Some participants shared that under the weight of that responsibility and in the context of time constraints, they colluded with PWID's professional networks to delay them from engaging in sexual relationships. The above experiences might echo Menzies-Lyth's (1960) construct of institutional defences against anxiety. Menzies-Lyth, drawing from Kleinian theory, suggested that systems (both at team and organisational levels), consciously and unconsciously, used different ways to distance themselves from the fear associated with their primary task. Participants in the present study spoke about their experience of protracted delays of actions, even when the risk was minimal or obscurity at the agency level about who was responsible for what, which often fragmented service provision further exacerbated. These behaviours (e.g., delays, diffusion of responsibility) also featured in Menzies-Lyth's study with nursing teams at a London NHS Trust. Another useful theoretical framework might be Masson's (1993) *positions of safe uncertainty*. In this case, it could be hypothesised that an understandably worry-organised network, which often felt deskilled, invited the CPs to take an expert position to the referred person.

In the *working with the shades of grey superordinate theme,* all participants shared a deep commitment, intellectually and emotionally, to supporting PWID to enjoy safe and meaningful intimate lives. They also spoke about how they try to navigate the challenges of this task. For instance, in *the normalising or titillating subtheme,* participants explained how they strived to normalise discussions around sexual matters with clients and how they aimed to carry out discussions around pleasure with an attitude of respectful playfulness to counteract feelings of shame and embarrassment. This attitude resembles trauma and attachment-informed approaches, which emphasise the importance of bringing playfulness to encourage curiosity and share delight with clients who have experienced attachment ruptures (e.g., Hughes, 2006). However, some participants shared some trepidation about how to keep these conversations from becoming titillating, especially with male clients who do not have other people in their network to discuss sexual matters or clients who had offended. Qualitative reviews on carers' experiences also highlighted similar concerns adding to professionals' reticence supporting PWID with sexual issues, e.g., for fear of coming across as sexualising. Similarly, the CPs, in Southall and Combe's (2022) study raised concerns regarding the potential to confuse relational boundaries by exploring sexual matters with clients with psychosis. Equally, Hanzlik and Gaubatz (2012) noted that female-identifying trainee CPs felt less comfortable discussing sexual matters with male clients. In the present study, participants shared that they regularly asked other staff members to co-attend some of their meetings with male clients.

In *the name it to tame it* subtheme*,* participants conceptualised that one of their primary tasks with teams was to give them permission to see PWID as sexual beings and give them the language to talk about sex, with client-centred formulations playing a vital role in this (e.g., sexual intimacy serving attachment needs). This highlights the crucial role CPs have in supporting networks in thinking in psychologically informed ways (BPS,2010). CPs spoke about the implicit tension inherent to engaging with teams by trying not to alienate them. Andersen's (1995) construct of *appropriately unusual difference* might describe this dialectic tension. CPs, in this case, whilst trying to nurture change in the teams (e.g., by championing PWID's rights) they did not want to introduce a "too big" of a difference and risk coming across as disregarding the network's valid concerns around risk. Participants spoke about acknowledging good practice at a care team level. Equally, they explained that by co-creating actionable plans with PWID's care teams, they attempted to bridge the networks' desire for some level of certainty while not deskilling them and foregrounding their expertise (Papodopoulou & Fredman, 2018).

In the *"What helps me steer a steady wheel"* subtheme, all participants spoke about valuing different perspectives (e.g., those of peers and supervisors) in navigating the challenges of their work. These reflective spaces helped them both discuss legal quandaries or share worries and re-orient their thinking in times they had unwittingly acted in obstructive ways. The value of reflection is central in the BPS (2010) code of practice and systemic theories stipulating that the therapist is influenced by and influences the systems they consult (Boscolo et al., 1987).

In *the thwarted duty to protect and empower* superordinate theme, participants shared that, despite their best intentions, there was an implicit sense that the therapeutic work with clients or consultations with their respective teams around sex and intimacy sometimes felt futile. Specifically, in the *"Like knitting with water"* subtheme, several participants spoke about the different dilemmas they faced when supporting PWID and their networks. For instance, several participants spoke about discomfort when trying to balance promoting PWID's rights whilst working to protect them from harm. This discomfort might mirror Festinger's (1957) construct of *cognitive dissonance*, whereby the CP's dual duty of protecting PWID from harm might sit uncomfortably with rights-orientated discourses around equal access to relationships, as well as the Mental Capacity Act's (MCA, 2005) third principle of people being allowed to make unwise decisions. This challenge echoes the findings of several qualitative reviews about professionals feeling largely conflicted by the ethical dilemma of protection and sexual autonomy, as intimate relationships were predominantly seen as sources of risk (Charitou et al., 2020; Rushbrooke et al., 2014). An associated consequence was that despite CP's commitment towards' having needs-based discussions with PWID, which also featured exploring pleasure, most of them experienced their involvement being more biased towards risk management rather than curious exploration.

Participants shared other critical contextual factors that challenged them, particularly in their duty as decision-makers in MCA assessments around sex and relationships, e.g., consent to sex being a context-dependent and ambiguous decision-making process. This finding overlaps with Ratcliff and Chapman's (2016) study on health and social care workers' experiences facilitating MCA assessments in community ID services, where emotional and relational aspects often confounded PWID's decision-making. Participants explained how they thought loneliness often increased PWID's vulnerability to conceding to unsatisfying, or worse, exploitative intimate relationships, with loneliness interacting and further pronouncing other power differentials, a finding which several qualitative reviews on PWID's experiences also report (Black & Kammes, 2019; Brown & McCann, 2018). These findings further highlight the importance of accounting for a person's relational history and emotional state in MCA assessments as per relevant guidance (BPS, 2019b).

Perhaps, similarly to the networks they support, participants spoke about their experience of a Trust-level pressure to minimise PWID's risk of harm and uncertainty at an MDT level (sex as topic overlapping with other MDT members' remit) or not delivering a model-specific therapeutic intervention or not having encountered clinical sex-related topics in their education. The latter finding mirrors some of the literature on CPs' experiences of exploring sexual concerns with other clinical populations without ID, which in turn suggested that sex-specific professional training was associated with feeling more comfortable exploring sexual concerns (e.g., Hanzlik & Gaubatz, 2012; Southall & Combes, 2022).

Limitations and research implications

In keeping with IPA methodology, the study recruited a small, purposive sample (Smith et al., 2009). However, the study's sampling process will inevitably influence its findings' transferability. For example, the present sample consisted of a White, cis-gender, mostly female-identifying group of very experienced clinicians with high levels of seniority. Therefore, the findings may not apply to samples with different characteristics, e.g., newly qualified CPs. Future research might be helpful to explore this area with a more ethnically or gender-diverse group of CPs from various career points.

Due to Covid-19 restrictions, the author conducted the interviews on MS Teams. While he made every attempt to respect the participants' process (e.g., allowing silences), other non-verbal communication could have been missed and thus influenced the direction of the discussions.

Situating the researcher is important because of their substantial role in the qualitative research process (Tong et al., 2007). For example, the primary author has supported PWID regarding sex and intimate relationships in the past. Equally, he is interested in Narrative Therapy (White & Epston, 1990) and how language, higher levels of context (e.g., culture), and power differentials influence meaning-making processes (Foucault, 1972). These experiences and personal interests might have influenced both the interview conduct and analysis. However, he took different steps to limit their impact, e.g., keeping a reflective journal or discussing themes in supervision. There were several instances in some interviews where the researcher felt that participants approached the discussion in an overly rational or cognitively oriented manner by mainly speaking about what they "thought" versus what they felt. This might be due to different factors, e.g., participants or the primary researcher implicitly attempting to distance themselves from the emotional nature of the topic or the researcher being a trainee CP. It could also reflect the biasing of the researcher's questions, e.g., moving too quickly to higher-level contexts instead of staying with participants' experiences.

Over recent decades, NHS professionals have shown increasing commitment to *evidence-based* practice, typically privileging positivist-informed study paradigms (e.g., randomised trials) (Speedy, 2004). However, such evidence might be less applicable to complex and context-sensitive practice areas, such as supporting PWID's sexual expression. Therefore, future research, in the form of rigorously conducted case studies, might be conducive to showcasing good clinical practice in the field, which eventually reviews would synthesise into more generalisable findings, combining what Margison and colleagues (2000) termed *practise-based* evidence with evidence-based practice.

Clinical implications

The data showed broad commonalities with existing literature. They highlighted several dilemmas that CPs must navigate in their work with PWID and their networks around intimacy, some embedded at individual and relational levels but mostly at service or organisational contexts. Although this was not the sole preserve of CPs' work, it was a strong characteristic of their experiences. The findings suggest two overarching and interacting areas of clinical practice implications: supporting CPs and nurturing organisational change.

The literature mentioned in the introduction underscored that different allied health professionals, including CPs, felt hindered by the lack of sex and relationship-specific training, as it applied to PWID and other client groups during their education and post-qualification. Therefore, this might be a valuable area for CP training courses and CPD opportunities, and specifically, how current legal frameworks might interact with supporting PWID's intimate relationships (e.g., Sexual Offences Act [2003] and MCA). In turn, this might equip CPs in their work guiding PWID care staff, who often express uncertainty about applying legal frameworks to PWID's sexual expression (Charitou et al., 2020). Equally important in this task might be, where appropriate, for CPs to spend time familiarising themselves with individual organisations’ policies around sexual matters, as this will influence staff attitudes (English et al., 2019).

In this study, CPs often experienced being invited to take an expert position by PWIDs’ networks and felt increasing anxiety around the implicit responsibility accompanying this positioning. Assuming some further research suggests that this is an issue more broadly, it may be conducive for individual or peer-facilitated reflective spaces to use tools such as Masson’s (1993) safe uncertainty grid or Peluso’s (2003) ethical genogram to explore the influences on CPs’ experiences and decision making, including a consideration of the complexity of capacity assessments around PWID’s ability to consent to sex. Peer support groups could also be valuable for skill sharing and practising using questions and relevant sex-related tools (e.g., BILD, 2020).

In line with previous literature on PWID networks' ambivalent views towards their sexuality, CPs experienced that they almost needed to give staff permission to PWID's care teams to see them as sexual beings (Rushbrooke et al., 2014). Participants spoke about normalising staff members' emotional reactions, recognising good practice and naming the dilemmas PWID's staff teams faced. Equally, and in line with BPS (2010) and PWID-specific guidance, an essential task for CPs might be assisting staff in reflecting on what influences their views and responses (e.g., cultural scrips around PWID's ability and need for sexual intimacy) (English et al., 2019).

Importantly, helping staff teams feel more confident supporting PWID's sexual expression might require a concerted effort to co-create a shared and positive risk-taking approach, where organisations, staff, and CPs support clients instead of responsibility being passed around to single agents or individuals (English et al., 2019; Menzies-Lyth, 1960). In addition, partnering with specialist groups (e.g., the Supported Loving Network), where resource and experience-sharing can occur, might be valuable adjuncts (Choice Support, 2022).

Conclusion

This study explored the experiences of UK-based CPs when exploring sex and intimacy directly with PWID or through their networks. Similarly to the people they support, participants shared their experiences of working with high levels of uncertainty and the tensions in balancing protecting PWID from harm and empowering their sexual autonomy. Additionally, participants spoke about valuing discussions with MDT colleagues, peers, supervisors, and PWID's networks when navigating the challenges, risks, and emotional consequences of their work. Research and practice might be useful to address gaps in CPs' sex and relationship training through different avenues. Most importantly, potential collaborations across agencies might help co-create a shared and positive risk-taking approach with and around PWID.

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Appendix A: Example of completed CASP checklist

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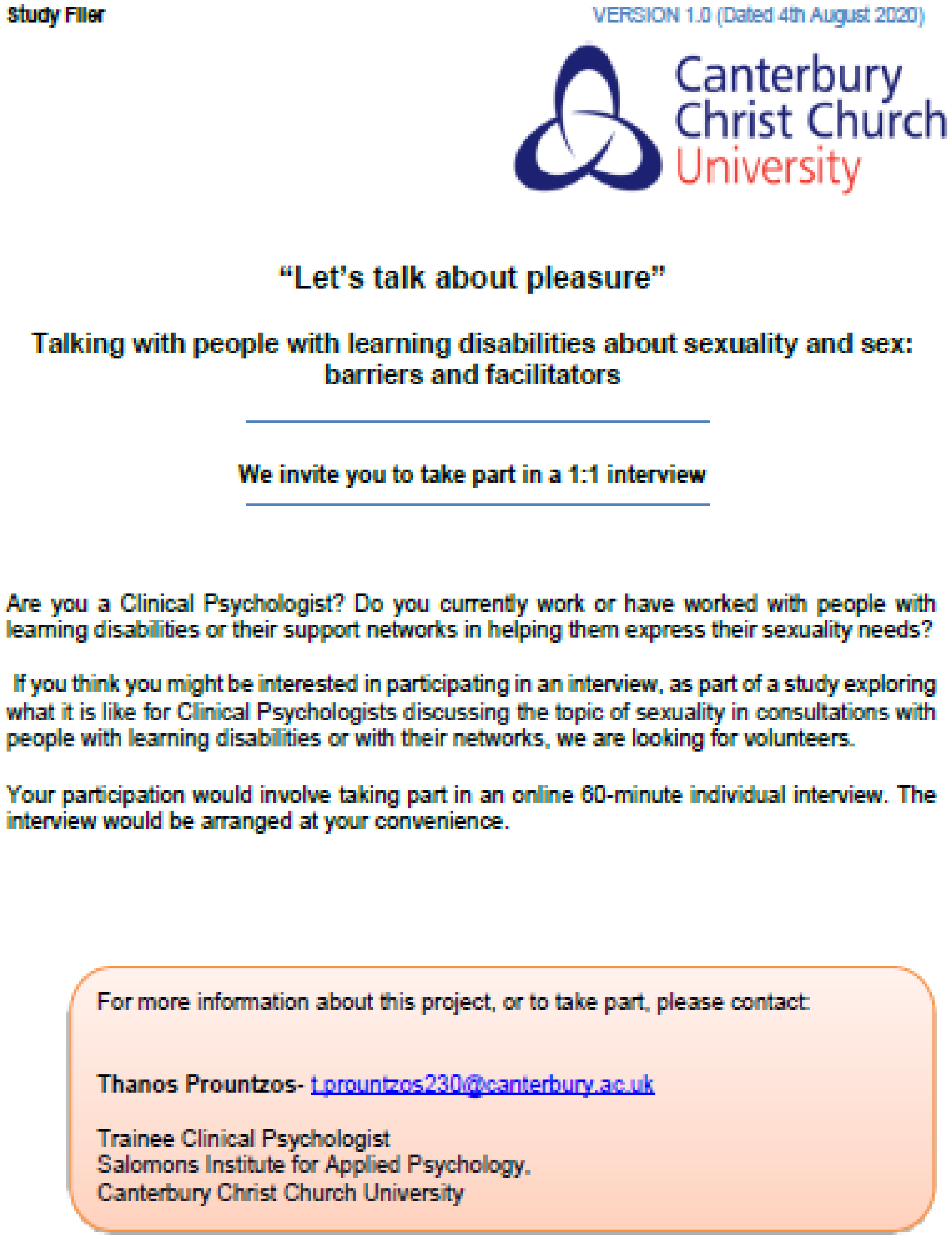
Appendix B: Study flyer and email



Study Filer

VERSION 1.0 (Dated 4th August 2020)

Canterbury
Christ Church
University

"Let's talk about pleasure"

Talking with people with learning disabilities about sexuality and sex: barriers and facilitators

We invite you to take part in a 1:1 interview

Are you a Clinical Psychologist? Do you currently work or have worked with people with learning disabilities or their support networks in helping them express their sexuality needs?

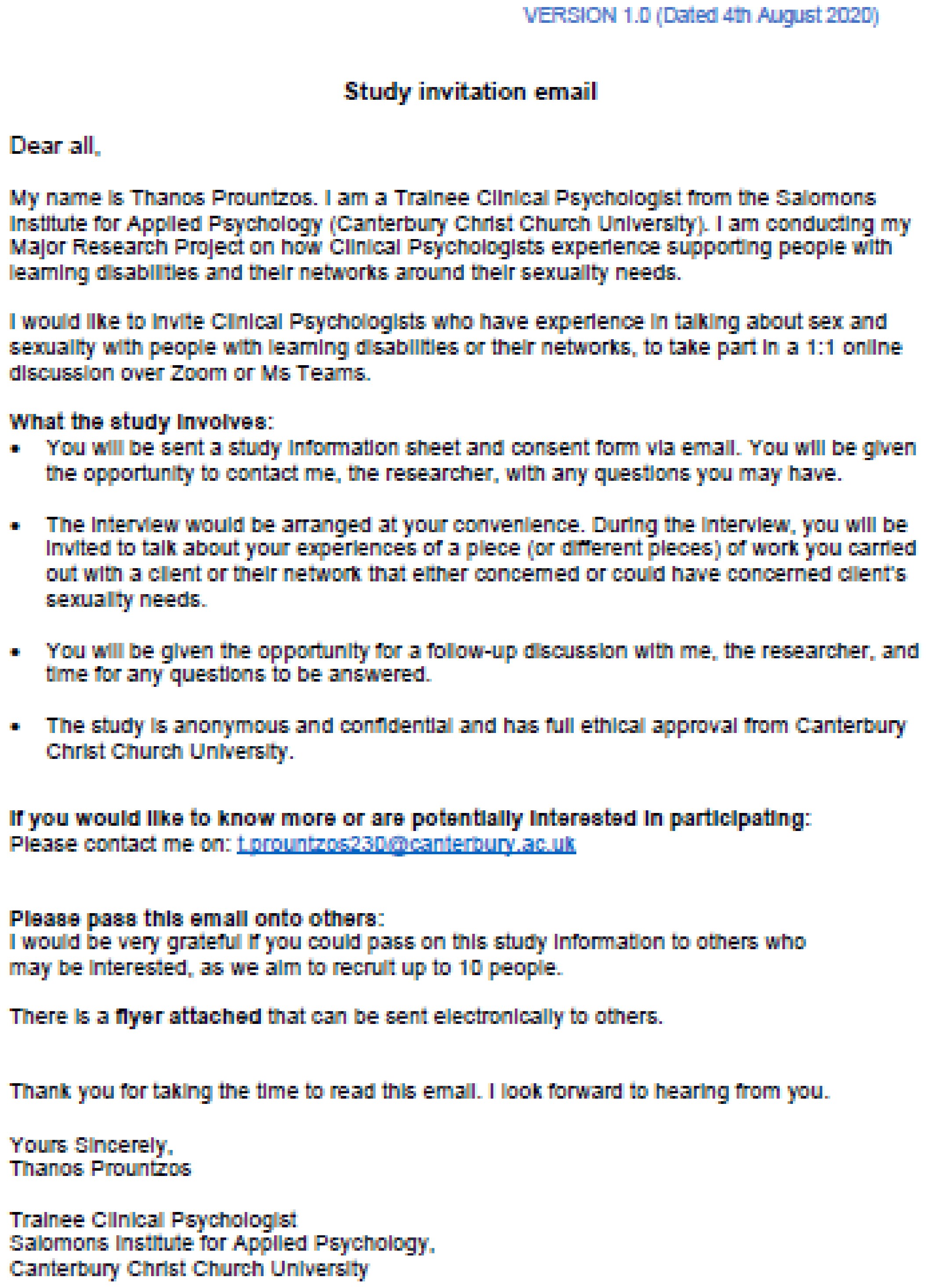
If you think you might be interested in participating in an interview, as part of a study exploring what it is like for Clinical Psychologists discussing the topic of sexuality in consultations with people with learning disabilities or with their networks, we are looking for volunteers.

Your participation would involve taking part in an online 60-minute individual interview. The interview would be arranged at your convenience.

For more information about this project, or to take part, please contact:

Thanos Prountzos- t.prountzos230@canterbury.ac.uk

Trainee Clinical Psychologist
Salomons Institute for Applied Psychology,
Canterbury Christ Church University



VERSION 1.0 (Dated 4th August 2020)

Study invitation email

Dear all,

My name is Thanos Prountzos. I am a Trainee Clinical Psychologist from the Salomons Institute for Applied Psychology (Canterbury Christ Church University). I am conducting my Major Research Project on how Clinical Psychologists experience supporting people with learning disabilities and their networks around their sexuality needs.

I would like to invite Clinical Psychologists who have experience in talking about sex and sexuality with people with learning disabilities or their networks, to take part in a 1:1 online discussion over Zoom or Ms Teams.

What the study involves:

- You will be sent a study information sheet and consent form via email. You will be given the opportunity to contact me, the researcher, with any questions you may have.
- The interview would be arranged at your convenience. During the interview, you will be invited to talk about your experiences of a piece (or different pieces) of work you carried out with a client or their network that either concerned or could have concerned client's sexuality needs.
- You will be given the opportunity for a follow-up discussion with me, the researcher, and time for any questions to be answered.
- The study is anonymous and confidential and has full ethical approval from Canterbury Christ Church University.

If you would like to know more or are potentially interested in participating:
Please contact me on: t.prountzos230@canterbury.ac.uk

Please pass this email onto others:
I would be very grateful if you could pass on this study information to others who may be interested, as we aim to recruit up to 10 people.

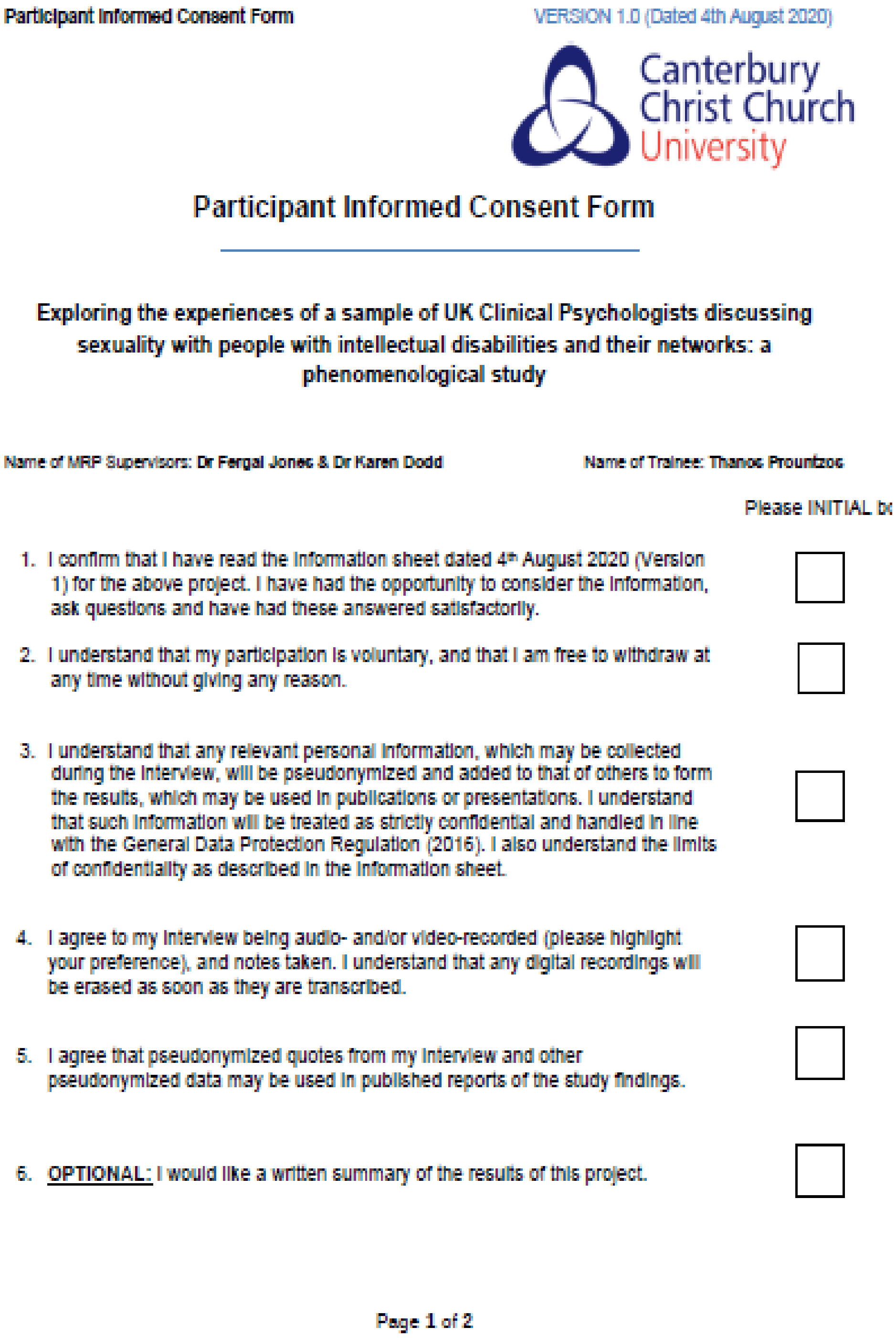
There is a **flyer attached** that can be sent electronically to others.

Thank you for taking the time to read this email. I look forward to hearing from you.

Yours Sincerely,
Thanos Prountzos

Trainee Clinical Psychologist
Salomons Institute for Applied Psychology,
Canterbury Christ Church University

Appendix C: Consent form and PIS



Participant Informed Consent Form

VERSION 1.0 (Dated 4th August 2020)

Canterbury
Christ Church
University

Participant Informed Consent Form

Exploring the experiences of a sample of UK Clinical Psychologists discussing sexuality with people with intellectual disabilities and their networks: a phenomenological study

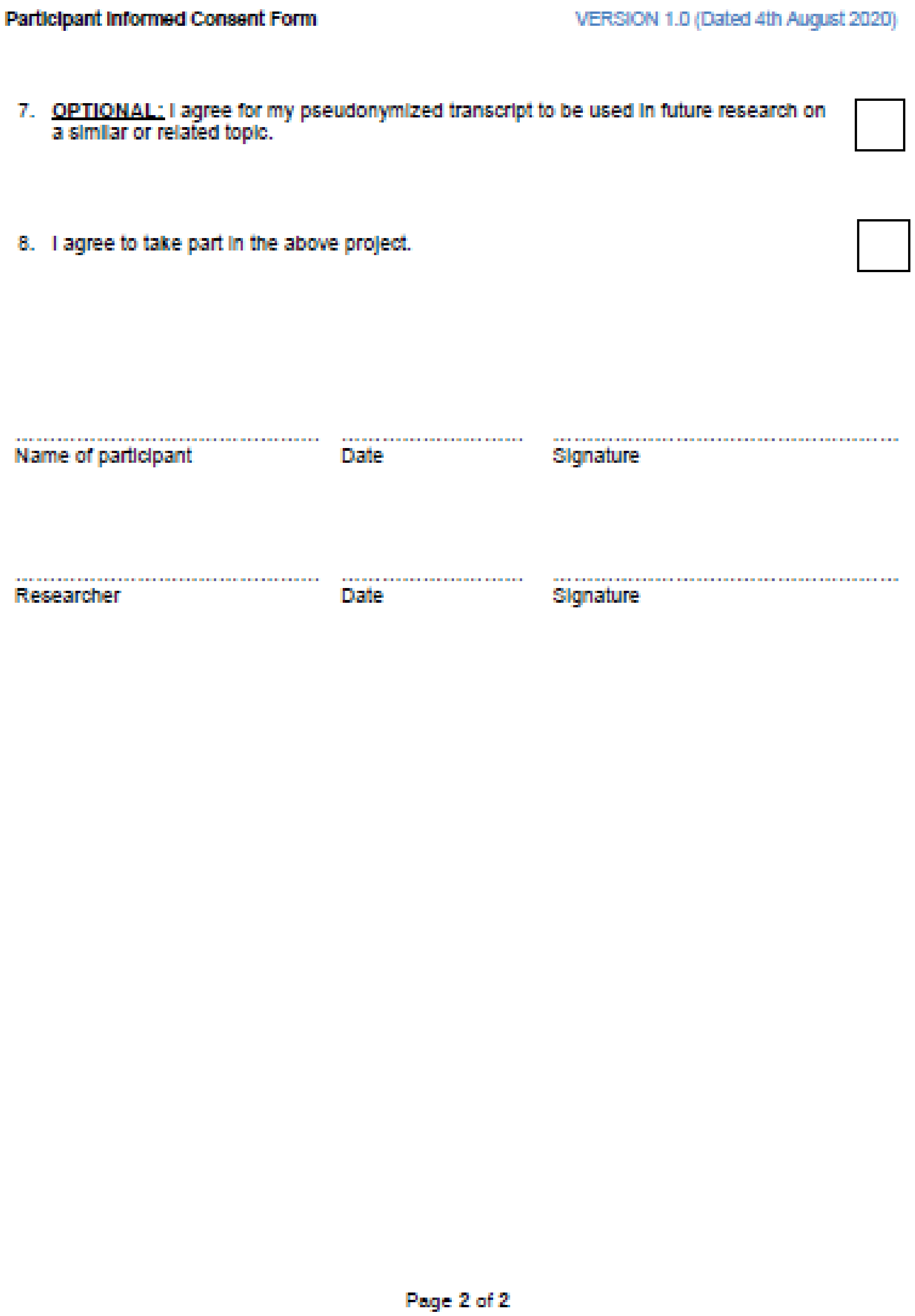
Name of MRP Supervisors: **Dr Fergal Jones & Dr Karen Dodd**

Name of Trainee: **Thanos Prountzos**

Please INITIAL b

1. I confirm that I have read the information sheet dated 4th August 2020 (Version 1) for the above project. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary, and that I am free to withdraw at any time without giving any reason. ☐
3. I understand that any relevant personal information, which may be collected during the interview, will be pseudonymized and added to that of others to form the results, which may be used in publications or presentations. I understand that such information will be treated as strictly confidential and handled in line with the General Data Protection Regulation (2016). I also understand the limits of confidentiality as described in the information sheet. ☐
4. I agree to my interview being audio- and/or video-recorded (please highlight your preference), and notes taken. I understand that any digital recordings will be erased as soon as they are transcribed. ☐
5. I agree that pseudonymized quotes from my interview and other pseudonymized data may be used in published reports of the study findings. ☐
6. OPTIONAL: I would like a written summary of the results of this project. ☐

Page **1** of **2**



Participant Informed Consent Form VERSION 1.0 (Dated 4th August 2020)

7. **OPTIONAL:** I agree for my pseudonymized transcript to be used in future research on a similar or related topic. ☐

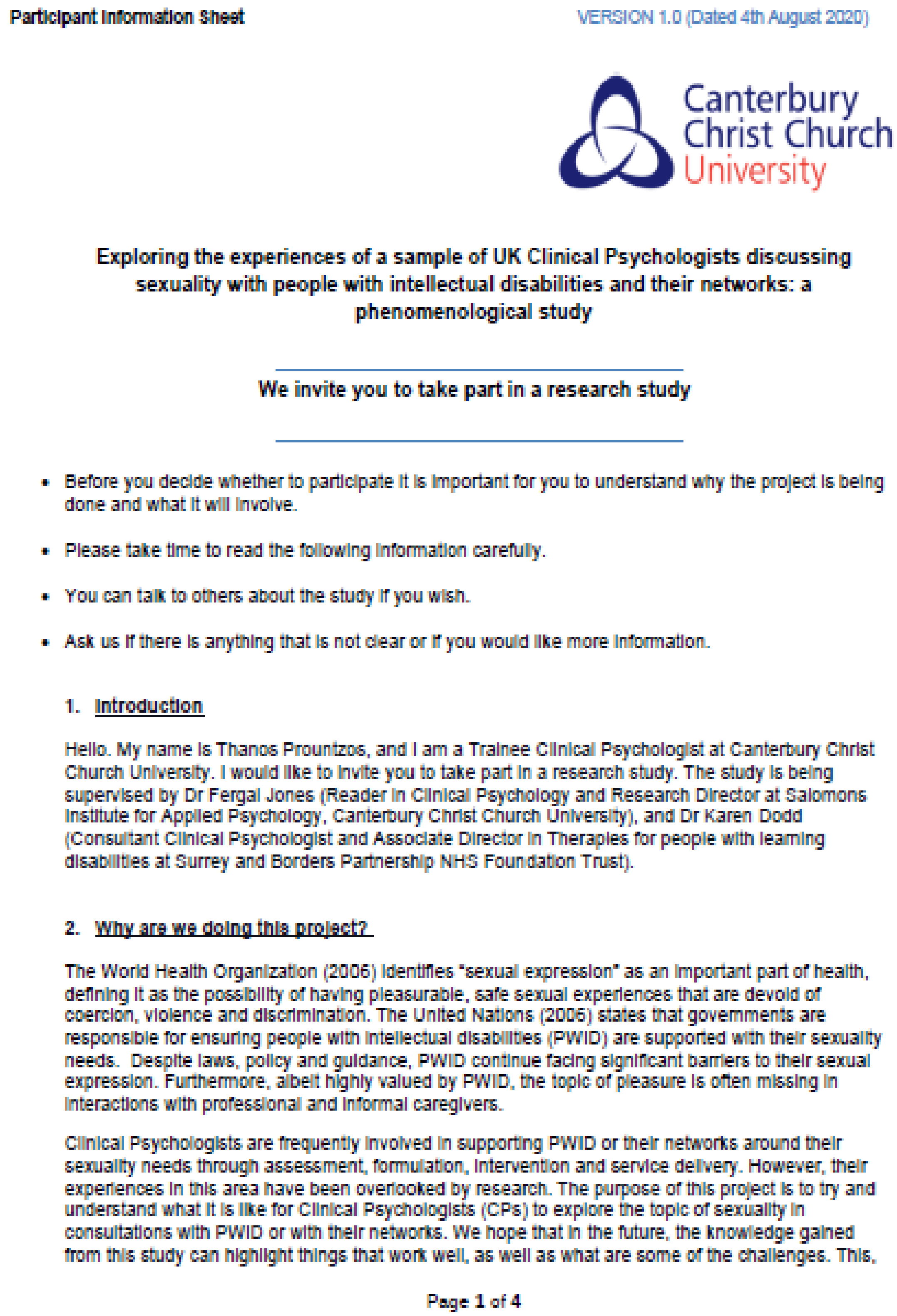
8. I agree to take part in the above project. ☐

……………………………………… ………………………… ……………………………………………

Name of participant Date Signature

……………………………………… ………………………… ……………………………………………

Researcher Date Signature



Participant Information Sheet VERSION 1.0 (Dated 4th August 2020)

Canterbury Christ Church University

Exploring the experiences of a sample of UK Clinical Psychologists discussing sexuality with people with intellectual disabilities and their networks: a phenomenological study

We invite you to take part in a research study

- Before you decide whether to participate it is important for you to understand why the project is being done and what it will involve.
- Please take time to read the following information carefully.
- You can talk to others about the study if you wish.
- Ask us if there is anything that is not clear or if you would like more information.

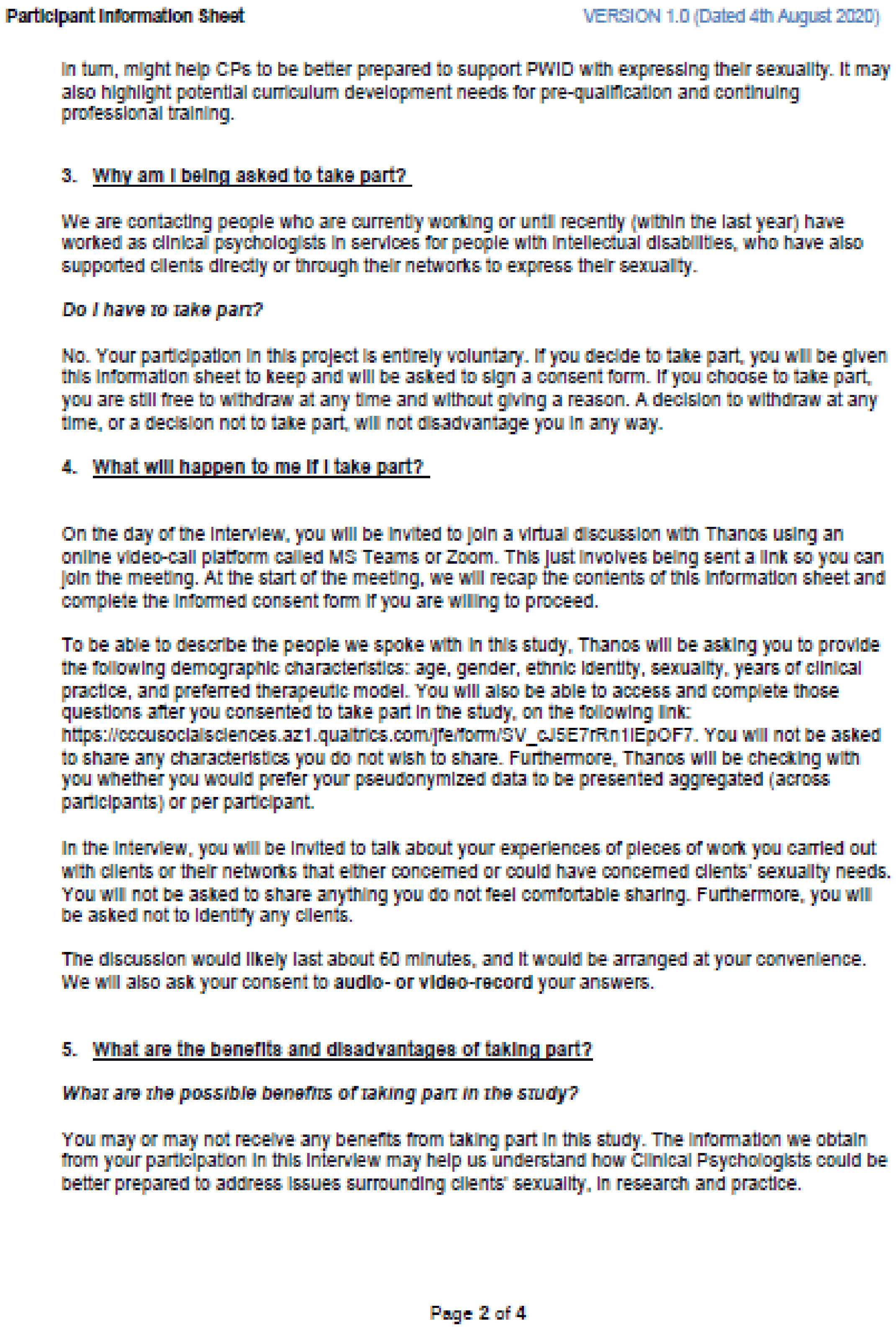
1. Introduction

Hello. My name is Thanos Prountzos, and I am a Trainee Clinical Psychologist at Canterbury Christ Church University. I would like to invite you to take part in a research study. The study is being supervised by Dr Fergal Jones (Reader in Clinical Psychology and Research Director at Salomons Institute for Applied Psychology, Canterbury Christ Church University), and Dr Karen Dodd (Consultant Clinical Psychologist and Associate Director in Therapies for people with learning disabilities at Surrey and Borders Partnership NHS Foundation Trust).

2. Why are we doing this project?

The World Health Organization (2006) identifies "sexual expression" as an important part of health, defining it as the possibility of having pleasurable, safe sexual experiences that are devoid of coercion, violence and discrimination. The United Nations (2006) states that governments are responsible for ensuring people with intellectual disabilities (PWID) are supported with their sexuality needs. Despite laws, policy and guidance, PWID continue facing significant barriers to their sexual expression. Furthermore, albeit highly valued by PWID, the topic of pleasure is often missing in interactions with professional and informal caregivers.

Clinical Psychologists are frequently involved in supporting PWID or their networks around their sexuality needs through assessment, formulation, intervention and service delivery. However, their experiences in this area have been overlooked by research. The purpose of this project is to try and understand what it is like for Clinical Psychologists (CPs) to explore the topic of sexuality in consultations with PWID or with their networks. We hope that in the future, the knowledge gained from this study can highlight things that work well, as well as what are some of the challenges. This,



in turn, might help CPs to be better prepared to support PWID with expressing their sexuality. It may also highlight potential curriculum development needs for pre-qualification and continuing professional training.

3. Why am I being asked to take part?

We are contacting people who are currently working or until recently (within the last year) have worked as clinical psychologists in services for people with intellectual disabilities, who have also supported clients directly or through their networks to express their sexuality.

Do I have to take part?

No. Your participation in this project is entirely voluntary. If you decide to take part, you will be given this information sheet to keep and will be asked to sign a consent form. If you choose to take part, you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not disadvantage you in any way.

4. What will happen to me if I take part?

On the day of the interview, you will be invited to join a virtual discussion with Thanos using an online video-call platform called MS Teams or Zoom. This just involves being sent a link so you can join the meeting. At the start of the meeting, we will recap the contents of this information sheet and complete the informed consent form if you are willing to proceed.

To be able to describe the people we spoke with in this study, Thanos will be asking you to provide the following demographic characteristics: age, gender, ethnic identity, sexuality, years of clinical practice, and preferred therapeutic model. You will also be able to access and complete those questions after you consented to take part in the study, on the following link: https://cccusocialsciences.az1.qualtrics.com/jfe/form/SV_cJ5E7rRn1lEpOF7. You will not be asked to share any characteristics you do not wish to share. Furthermore, Thanos will be checking with you whether you would prefer your pseudonymized data to be presented aggregated (across participants) or per participant.

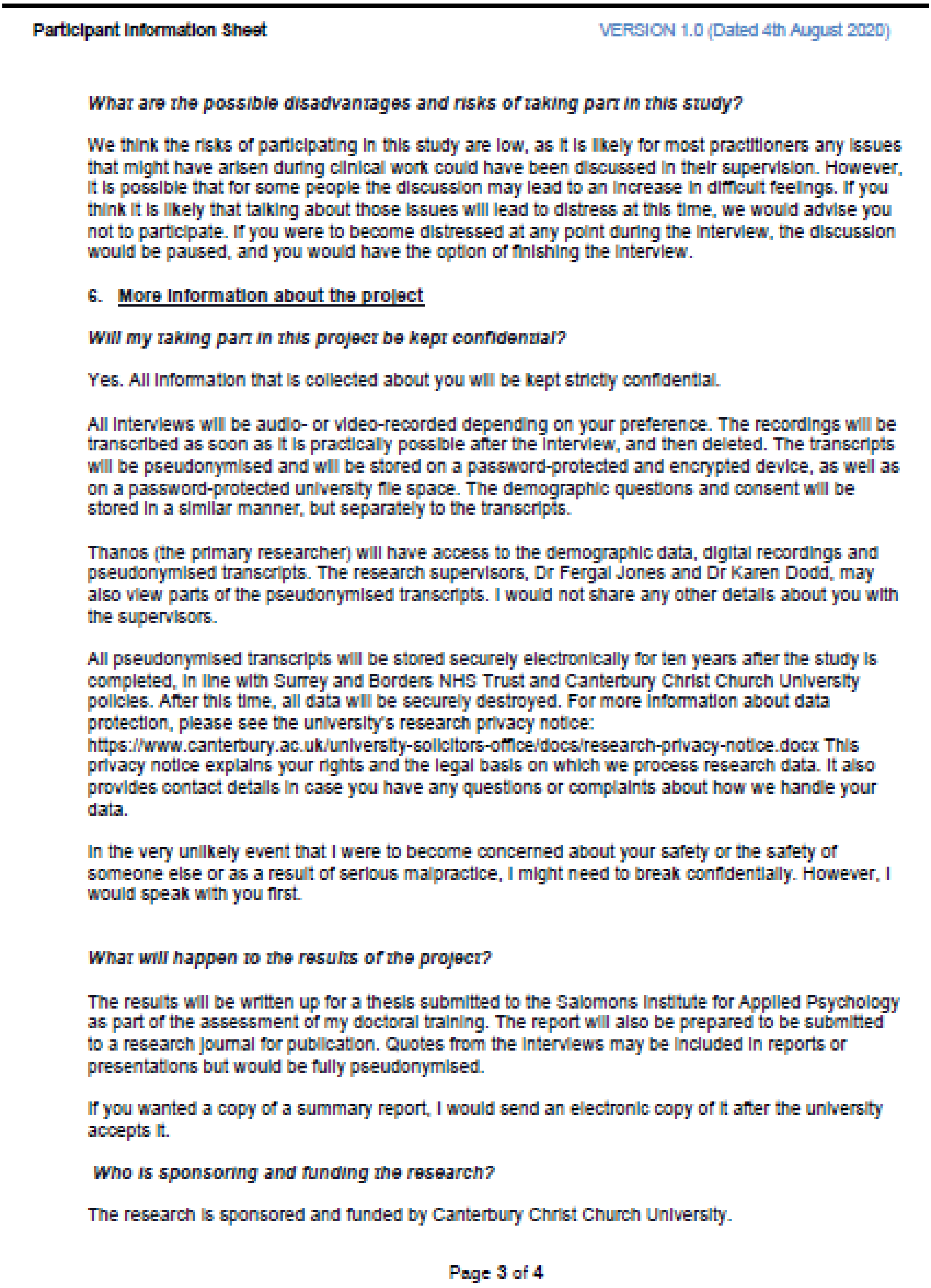
In the interview, you will be invited to talk about your experiences of pieces of work you carried out with clients or their networks that either concerned or could have concerned clients' sexuality needs. You will not be asked to share anything you do not feel comfortable sharing. Furthermore, you will be asked not to identify any clients.

The discussion would likely last about 60 minutes, and it would be arranged at your convenience. We will also ask your consent to **audio- or video-record** your answers.

5. What are the benefits and disadvantages of taking part?

What are the possible benefits of taking part in the study?

You may or may not receive any benefits from taking part in this study. The information we obtain from your participation in this interview may help us understand how Clinical Psychologists could be better prepared to address issues surrounding clients' sexuality, in research and practice.



What are the possible disadvantages and risks of taking part in this study?

We think the risks of participating in this study are low, as it is likely for most practitioners any issues that might have arisen during clinical work could have been discussed in their supervision. However, it is possible that for some people the discussion may lead to an increase in difficult feelings. If you think it is likely that talking about those issues will lead to distress at this time, we would advise you not to participate. If you were to become distressed at any point during the interview, the discussion would be paused, and you would have the option of finishing the interview.

6. More information about the project

Will my taking part in this project be kept confidential?

Yes. All information that is collected about you will be kept strictly confidential.

All interviews will be audio- or video-recorded depending on your preference. The recordings will be transcribed as soon as it is practically possible after the interview, and then deleted. The transcripts will be pseudonymised and will be stored on a password-protected and encrypted device, as well as on a password-protected university file space. The demographic questions and consent will be stored in a similar manner, but separately to the transcripts.

Thanos (the primary researcher) will have access to the demographic data, digital recordings and pseudonymised transcripts. The research supervisors, Dr Fergal Jones and Dr Karen Dodd, may also view parts of the pseudonymised transcripts. I would not share any other details about you with the supervisors.

All pseudonymised transcripts will be stored securely electronically for ten years after the study is completed, in line with Surrey and Borders NHS Trust and Canterbury Christ Church University policies. After this time, all data will be securely destroyed. For more information about data protection, please see the university's research privacy notice: https://www.canterbury.ac.uk/university-solicitors-office/docs/research-privacy-notice.docx This privacy notice explains your rights and the legal basis on which we process research data. It also provides contact details in case you have any questions or complaints about how we handle your data.

In the very unlikely event that I were to become concerned about your safety or the safety of someone else or as a result of serious malpractice, I might need to break confidentially. However, I would speak with you first.

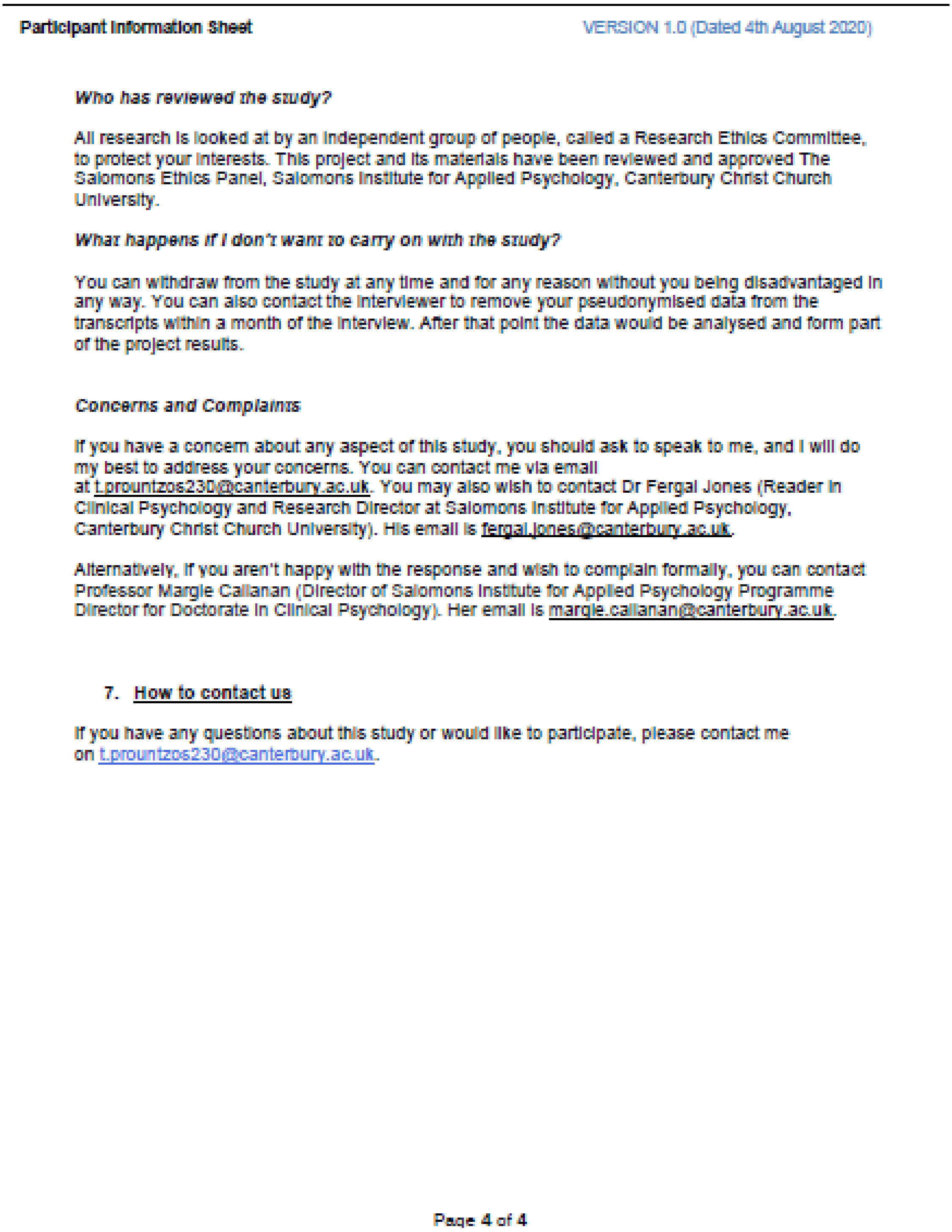
What will happen to the results of the project?

The results will be written up for a thesis submitted to the Salomons Institute for Applied Psychology as part of the assessment of my doctoral training. The report will also be prepared to be submitted to a research journal for publication. Quotes from the interviews may be included in reports or presentations but would be fully pseudonymised.

If you wanted a copy of a summary report, I would send an electronic copy of it after the university accepts it.

Who is sponsoring and funding the research?

The research is sponsored and funded by Canterbury Christ Church University.



Who has reviewed the study?

All research is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This project and its materials have been reviewed and approved The Salomons Ethics Panel, Salomons Institute for Applied Psychology, Canterbury Christ Church University.

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

You can withdraw from the study at any time and for any reason without you being disadvantaged in any way. You can also contact the interviewer to remove your pseudonymised data from the transcripts within a month of the interview. After that point the data would be analysed and form part of the project results.

Concerns and Complaints

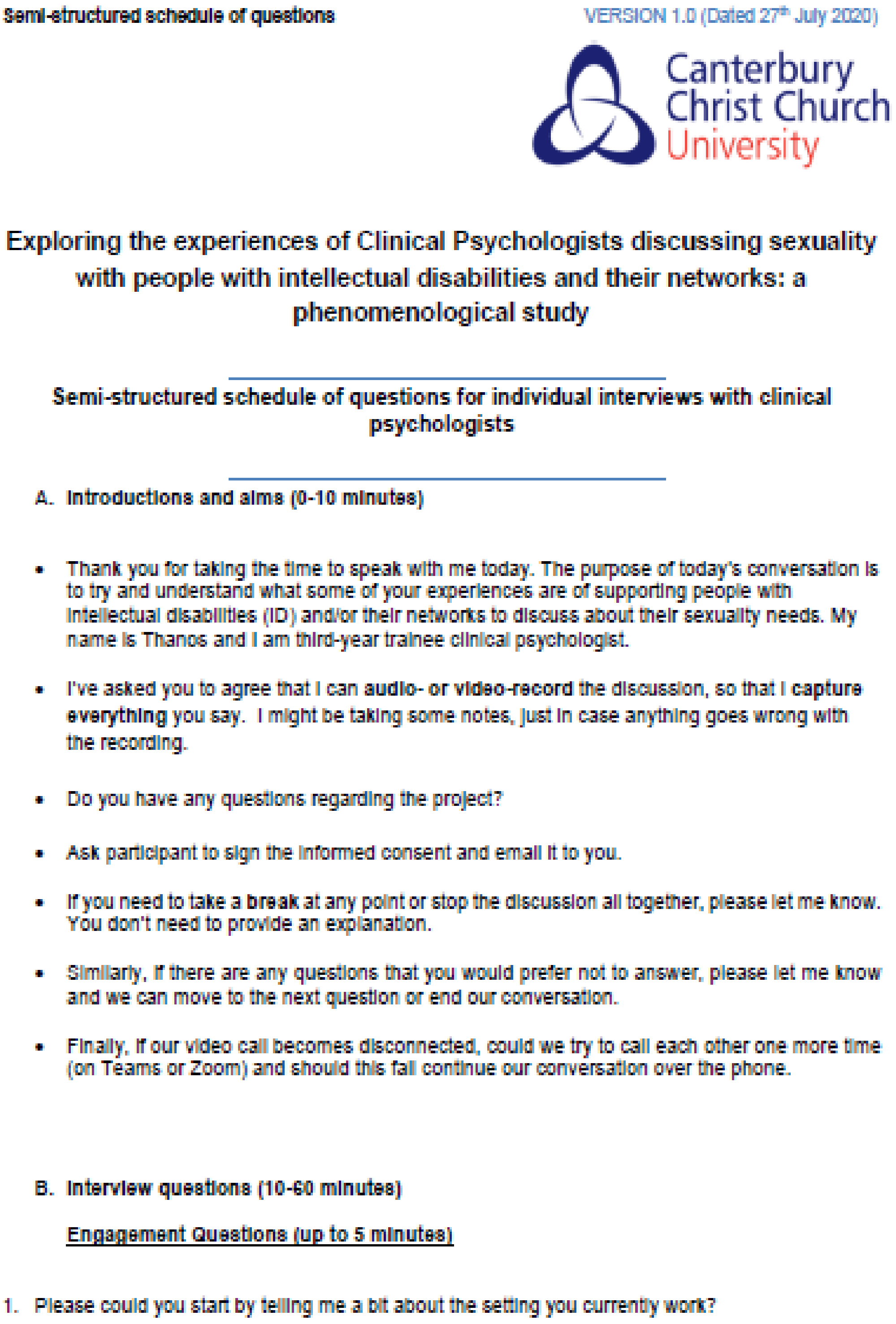
If you have a concern about any aspect of this study, you should ask to speak to me, and I will do my best to address your concerns. You can contact me via email at t.prountzos230@canterbury.ac.uk. You may also wish to contact Dr Fergal Jones (Reader in Clinical Psychology and Research Director at Salomons Institute for Applied Psychology, Canterbury Christ Church University). His email is fergal.jones@canterbury.ac.uk.

Alternatively, if you aren't happy with the response and wish to complain formally, you can contact Professor Margie Callanan (Director of Salomons Institute for Applied Psychology Programme Director for Doctorate in Clinical Psychology). Her email is margie.callanan@canterbury.ac.uk.

7. How to contact us

If you have any questions about this study or would like to participate, please contact me on t.prountzos230@canterbury.ac.uk.

Appendix D: Interview Schedule



Semi-structured schedule of questions

VERSION 1.0 (Dated 27th July 2020)

Canterbury Christ Church University

Exploring the experiences of Clinical Psychologists discussing sexuality with people with intellectual disabilities and their networks: a phenomenological study

Semi-structured schedule of questions for individual interviews with clinical psychologists

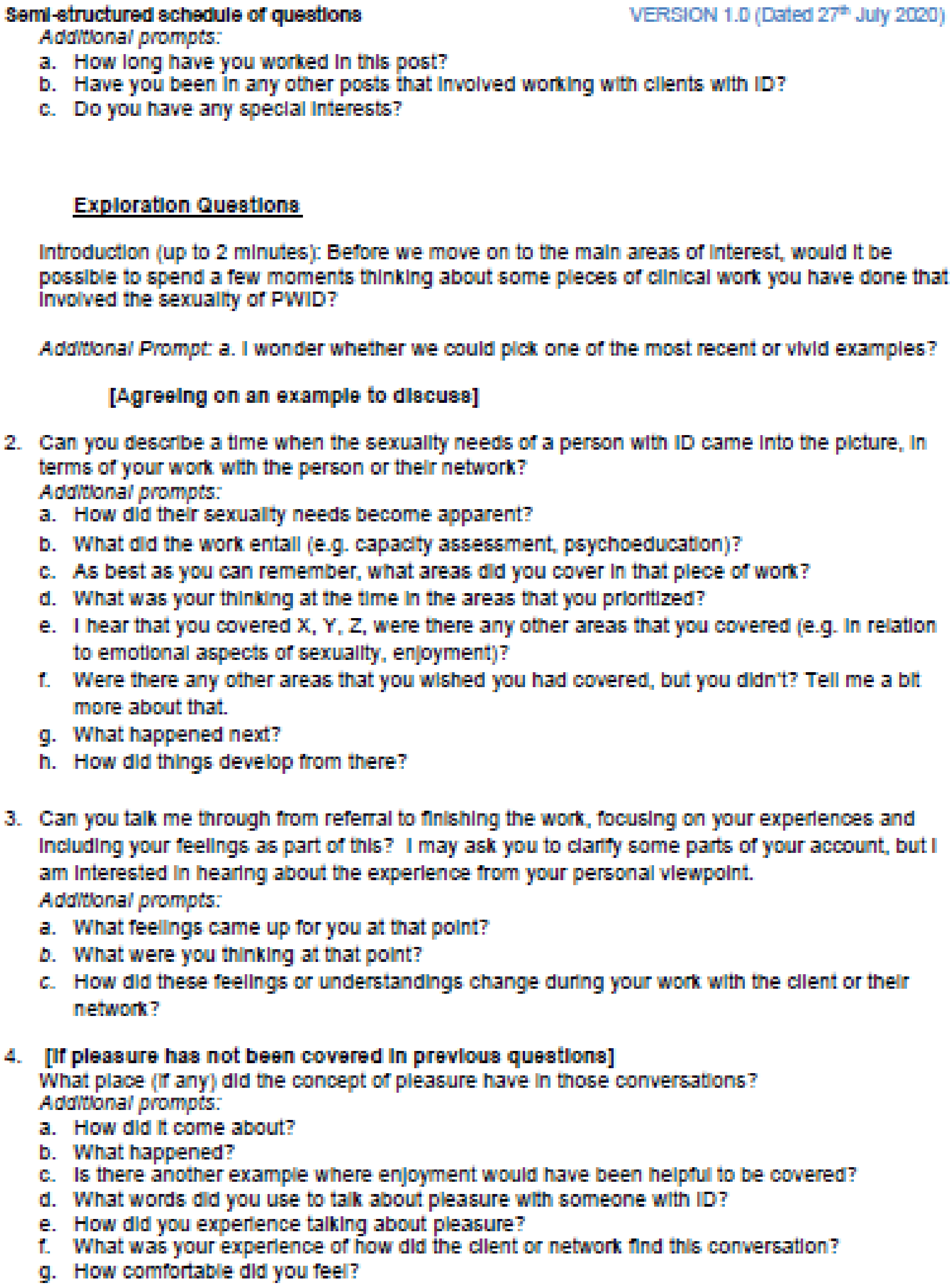
A. **Introductions and aims (0-10 minutes)**

- Thank you for taking the time to speak with me today. The purpose of today's conversation is to try and understand what some of your experiences are of supporting people with intellectual disabilities (ID) and/or their networks to discuss about their sexuality needs. My name is Thanos and I am third-year trainee clinical psychologist.
- I've asked you to agree that I can **audio- or video-record** the discussion, so that I **capture everything** you say. I might be taking some notes, just in case anything goes wrong with the recording.
- Do you have any questions regarding the project?
- Ask participant to sign the informed consent and email it to you.
- If you need to take a **break** at any point or stop the discussion all together, please let me know. You don't need to provide an explanation.
- Similarly, if there are any questions that you would prefer not to answer, please let me know and we can move to the next question or end our conversation.
- Finally, if our video call becomes disconnected, could we try to call each other one more time (on Teams or Zoom) and should this fail continue our conversation over the phone.

B. **Interview questions (10-60 minutes)**

Engagement Questions (up to 5 minutes)

1. Please could you start by telling me a bit about the setting you currently work?



Semi-structured schedule of questions VERSION 1.0 (Dated 27th July 2020)

Additional prompts:

a. How long have you worked in this post?
b. Have you been in any other posts that involved working with clients with ID?
c. Do you have any special interests?

Exploration Questions

Introduction (up to 2 minutes): Before we move on to the main areas of interest, would it be possible to spend a few moments thinking about some pieces of clinical work you have done that involved the sexuality of PWID?

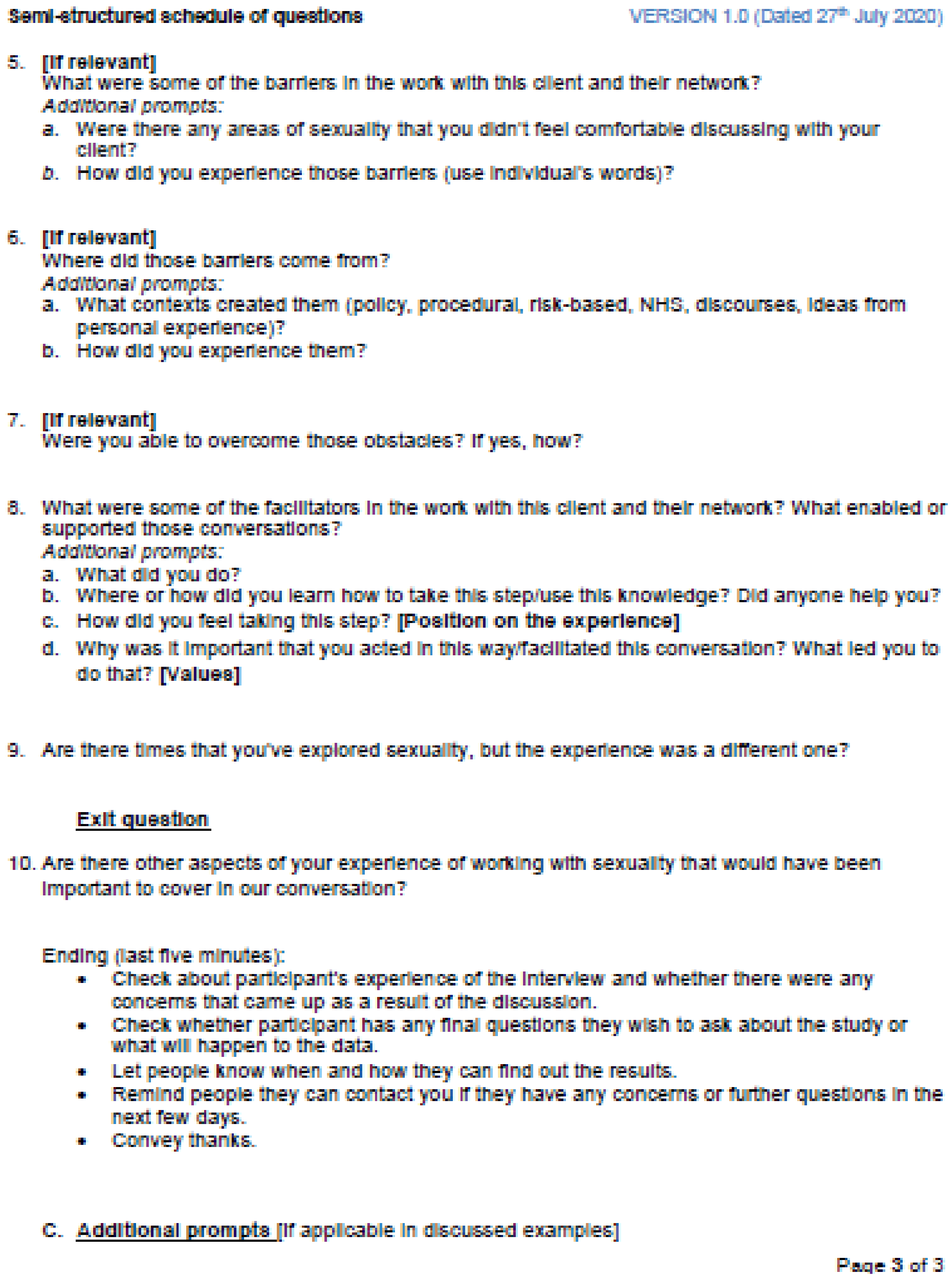
Additional Prompt: a. I wonder whether we could pick one of the most recent or vivid examples?

[Agreeing on an example to discuss]

2. Can you describe a time when the sexuality needs of a person with ID came into the picture, in terms of your work with the person or their network?
Additional prompts:
a. How did their sexuality needs become apparent?
b. What did the work entail (e.g. capacity assessment, psychoeducation)?
c. As best as you can remember, what areas did you cover in that piece of work?
d. What was your thinking at the time in the areas that you prioritized?
e. I hear that you covered X, Y, Z, were there any other areas that you covered (e.g. in relation to emotional aspects of sexuality, enjoyment)?
f. Were there any other areas that you wished you had covered, but you didn't? Tell me a bit more about that.
g. What happened next?
h. How did things develop from there?

3. Can you talk me through from referral to finishing the work, focusing on your experiences and including your feelings as part of this? I may ask you to clarify some parts of your account, but I am interested in hearing about the experience from your personal viewpoint.
Additional prompts:
a. What feelings came up for you at that point?
b. What were you thinking at that point?
c. How did these feelings or understandings change during your work with the client or their network?

4. **[If pleasure has not been covered in previous questions]**
What place (if any) did the concept of pleasure have in those conversations?
Additional prompts:
a. How did it come about?
b. What happened?
c. Is there another example where enjoyment would have been helpful to be covered?
d. What words did you use to talk about pleasure with someone with ID?
e. How did you experience talking about pleasure?
f. What was your experience of how did the client or network find this conversation?
g. How comfortable did you feel?



Semi-structured schedule of questions VERSION 1.0 (Dated 27th July 2020)

5. **[If relevant]**
   What were some of the barriers in the work with this client and their network?
   Additional prompts:
   a. Were there any areas of sexuality that you didn't feel comfortable discussing with your client?
   b. How did you experience those barriers (use individual's words)?

6. **[If relevant]**
   Where did those barriers come from?
   Additional prompts:
   a. What contexts created them (policy, procedural, risk-based, NHS, discourses, ideas from personal experience)?
   b. How did you experience them?

7. **[If relevant]**
   Were you able to overcome those obstacles? If yes, how?

8. What were some of the facilitators in the work with this client and their network? What enabled or supported those conversations?
   Additional prompts:
   a. What did you do?
   b. Where or how did you learn how to take this step/use this knowledge? Did anyone help you?
   c. How did you feel taking this step? **[Position on the experience]**
   d. Why was it important that you acted in this way/facilitated this conversation? What led you to do that? **[Values]**

9. Are there times that you've explored sexuality, but the experience was a different one?

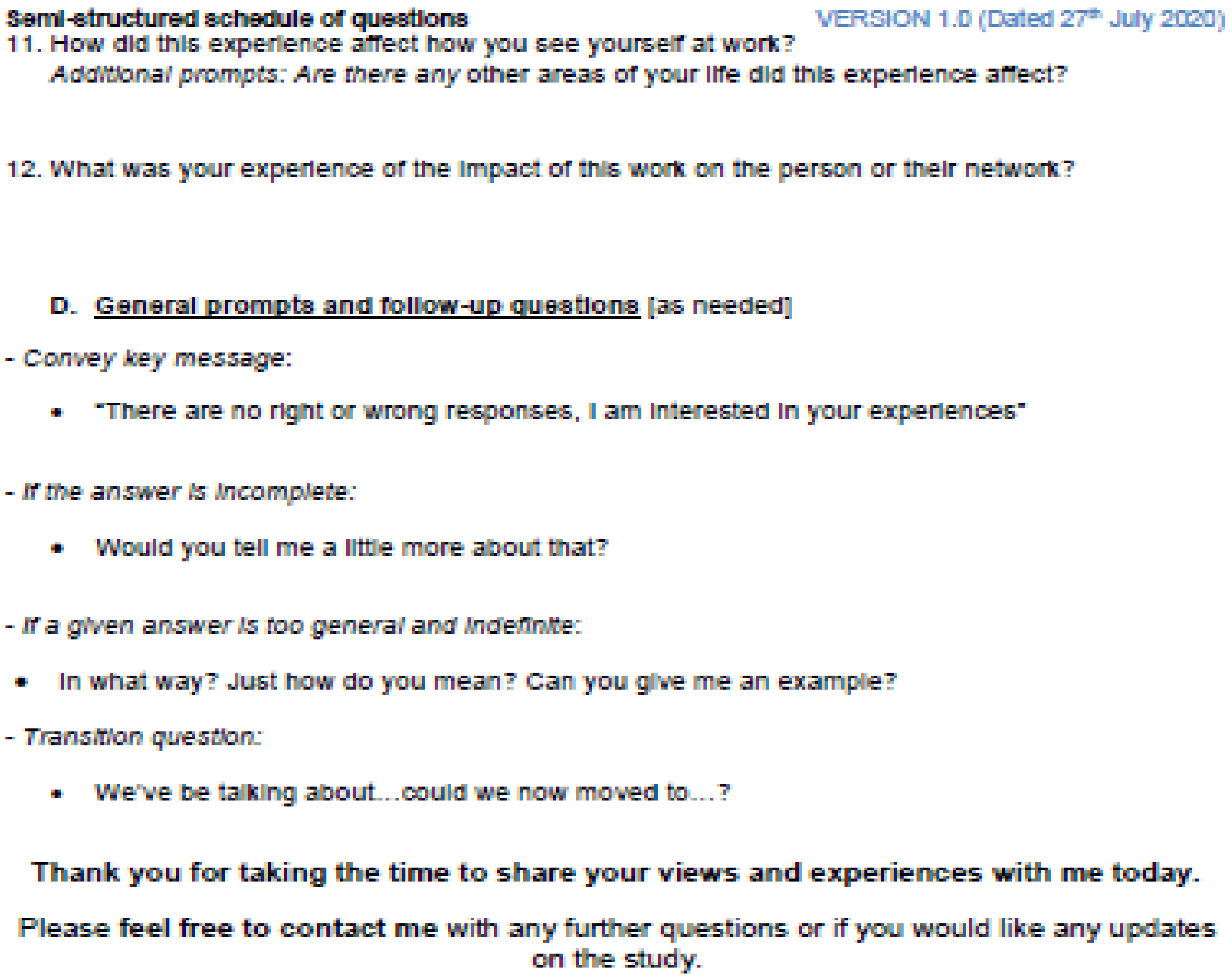
Exit question

10. Are there other aspects of your experience of working with sexuality that would have been important to cover in our conversation?

Ending (last five minutes):

- Check about participant's experience of the interview and whether there were any concerns that came up as a result of the discussion.
- Check whether participant has any final questions they wish to ask about the study or what will happen to the data.
- Let people know when and how they can find out the results.
- Remind people they can contact you if they have any concerns or further questions in the next few days.
- Convey thanks.

C. **Additional prompts** [If applicable in discussed examples]



Semi-structured schedule of questions VERSION 1.0 (Dated 27th July 2020)

11. How did this experience affect how you see yourself at work?
    Additional prompts: Are there any other areas of your life did this experience affect?

12. What was your experience of the impact of this work on the person or their network?

D. <u>General prompts and follow-up questions</u> [as needed]

- *Convey key message:*

  - "There are no right or wrong responses, I am interested in your experiences"

- *If the answer is incomplete:*

  - Would you tell me a little more about that?

- *If a given answer is too general and indefinite:*

  - In what way? Just how do you mean? Can you give me an example?

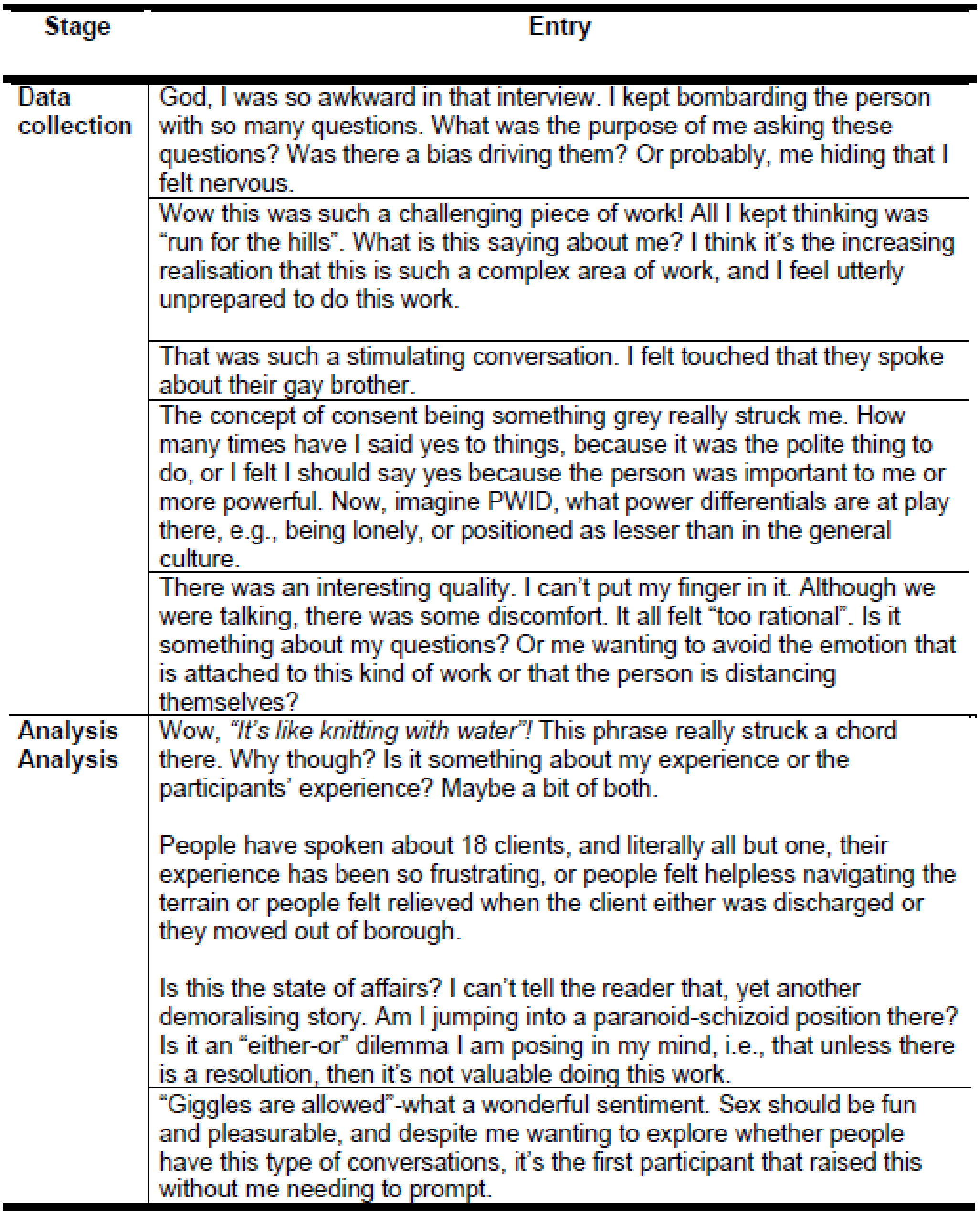
- *Transition question:*

  - We've be talking about…could we now moved to…?

Thank you for taking the time to share your views and experiences with me today.

Please feel free to contact me with any further questions or if you would like any updates on the study.

Appendix E-Reflective journal excerpt



Stage	Entry
Data collection	God, I was so awkward in that interview. I kept bombarding the person with so many questions. What was the purpose of me asking these questions? Was there a bias driving them? Or probably, me hiding that I felt nervous.
	Wow this was such a challenging piece of work! All I kept thinking was "run for the hills". What is this saying about me? I think it's the increasing realisation that this is such a complex area of work, and I feel utterly unprepared to do this work.
	That was such a stimulating conversation. I felt touched that they spoke about their gay brother.
	The concept of consent being something grey really struck me. How many times have I said yes to things, because it was the polite thing to do, or I felt I should say yes because the person was important to me or more powerful. Now, imagine PWID, what power differentials are at play there, e.g., being lonely, or positioned as lesser than in the general culture.
	There was an interesting quality. I can't put my finger in it. Although we were talking, there was some discomfort. It all felt "too rational". Is it something about my questions? Or me wanting to avoid the emotion that is attached to this kind of work or that the person is distancing themselves?
Analysis Analysis	Wow, *"It's like knitting with water"!* This phrase really struck a chord there. Why though? Is it something about my experience or the participants' experience? Maybe a bit of both. People have spoken about 18 clients, and literally all but one, their experience has been so frustrating, or people felt helpless navigating the terrain or people felt relieved when the client either was discharged or they moved out of borough. Is this the state of affairs? I can't tell the reader that, yet another demoralising story. Am I jumping into a paranoid-schizoid position there? Is it an "either-or" dilemma I am posing in my mind, i.e., that unless there is a resolution, then it's not valuable doing this work.
	"Giggles are allowed"-what a wonderful sentiment. Sex should be fun and pleasurable, and despite me wanting to explore whether people have this type of conversations, it's the first participant that raised this without me needing to prompt.

Appendix F-Example of coded interview with Sophie

[This has been removed from the electronic copy due to copyright and confidentiality reasons.]