
**Psychotherapeutic interventions for
sexual problems delivered via the
Internet: Effectiveness, acceptability
and reach**

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Declaration

I, Lorna Jane Hobbs confirm that the work presented in this thesis is my own. Where information has been derived from other sources I confirm this has been indicated in the thesis.

Supervision

This PhD was supervised by Professor Elizabeth Murray (UCL Primary Care and Population Health) and Dr Julia Bailey (UCL Primary Care and Population Health).

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Abstract

Background

There is a high prevalence of people with sexual difficulties and many do not seek help for them. Sexual difficulties can have a negative impact on sexual and psychological wellbeing and interpersonal relationships. Interactive Digital Interventions (IDIs) for sexual difficulties have the potential to provide a convenient, wide-reaching and cost-effective alternative to face-to-face therapy, but research in this area is in its infancy. Currently little is known about their effectiveness, reach and acceptability.

Aim

To investigate the use of the internet to deliver psychotherapeutic interventions for sexual difficulties, and determine their effectiveness, reach and acceptability

Methods

1. A systematic review of the effectiveness of IDIs for adults with sexual difficulties.
2. A secondary data analysis of the data from the third National Survey of Sexual Attitudes and Lifestyles to investigate the potential reach of IDIs and explore the characteristics of people who seek help for their sex lives
3. A qualitative interview study to explore users' views of an IDI for sexual difficulties before and after using one.

Results

IDIs can be effective for sexual difficulties, but the current evidence-base is small, and contains studies that are methodologically flawed, so more research is needed to be sure of these effects. With approximately 427,000-762,000 British people reportedly distressed about their sex lives and looking for information and support online, it appears that IDIs have considerable potential to reach their intended audience. The *sextherapylondon* website appeared to be acceptable to users as it met many of their wants and needs with regards to features, design, usability, user experience and perceived outcomes.

Conclusion

Overall, this thesis suggests that IDIs could have a valuable place in providing an alternative help source for people with sexual difficulties, especially in the light of further cuts to sexual health services.

Conference presentations

Hobbs, L., Bailey, J., & Murray, E. (2014, November). *Users' views on interactive digital interventions for sexual problems: A qualitative study*. Oral presentation at Medicine 2.0 World Congress on Social Media, Mobile Apps, Internet/Web 2.0, Maui, USA.

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Contents

	Page
Declaration	2
Acknowledgements.....	3
Abstract	4
Conference presentations.....	5
List of Tables	11
List of Figures	14
Abbreviations and Glossary	16
Chapter 1 Introduction	19
1.1 Chapter overview	20
1.2 Sexual difficulties	21
1.3 Why are sexual difficulties worth studying?	21
1.4 Prevalence.....	22
1.5 Harms resulting from sexual difficulties	23
1.6 Available treatments and their impact.....	24
1.7 Evidence of effectiveness.....	26
1.8 Evidence of unmet need	26
1.9 IDIs	27
1.10 Advantages of IDIs.....	28
1.11 Disadvantages of IDIs	28
1.12 Evidence of effectiveness (in other areas of physical and mental health)	28
1.13 Evidence of effectiveness (in sexual difficulties).....	29
1.14 Gaps in the evidence	29
1.15 Effectiveness.....	29
1.16 Potential reach and user characteristics.....	30
1.17 Acceptability.....	30
1.18 A health service research perspective.....	30
1.19 Rationale for choice of methods	31
1.20 Overall aim.....	31
Chapter 2 What are sexual difficulties? An introduction and literature review.....	33
2.1 Chapter overview	34
2.2 What do we mean by sex and sexuality?	35

2.3	The importance of sex and sexuality	35
2.4	Sexual motivation and expectations	35
2.5	A brief history of the scientific study of sex and sexual difficulties	36
2.6	What are sexual difficulties? A 'difficulty' of definition	38
2.7	The classification of sexual dysfunctions	38
2.8	Challenges to classification systems	43
2.9	The medicalisation of sexual function and sexual difficulties	43
2.10	Alternative perspectives	44
2.11	Aetiology	46
2.12	Psychotherapeutic intervention in sexual difficulties	48
2.13	My approach to this thesis.....	49
2.14	Implications for the design and development of IDIs for sexual difficulties.....	49
Chapter 3 What are IDIs? And why are they worth studying?		51
3.1	Chapter overview	52
3.2	How and why have IDIs come about?	53
3.3	What are IDIs?	53
3.4	Advantages of IDIs.....	54
3.5	Disadvantages of IDIs	56
3.6	IDIs for physical and mental-health problems.....	59
3.7	IDIs for sexual difficulties.....	60
3.8	Observational studies.....	60
3.9	Randomised Controlled Trials (RCTs).....	60
3.10	Gaps in the literature.....	61
Chapter 4 IDIs for sexual difficulties in adults: A systematic review and meta-analysis		62
4.1	Chapter overview	63
4.2	Background.....	65
4.3	Aims and objectives	66
4.4	Research questions	67
4.5	Definitions	67
4.6	Method.....	67
4.7	Results.....	76
4.8	Discussion	92
4.9	Conclusions	104

Chapter 5 Prevalence of help-seeking/internet help-seeking in people distressed about their sex lives, and how help-seeking varies according to socio-demographic and behavioural characteristics: Findings from the National Survey of Sexual Attitudes and Lifestyles 3 (Natsal-3).....	112
5.1 Chapter overview	113
5.2 Background.....	115
5.3 Aims.....	118
5.4 Research Questions.....	120
5.1 Methods of Natsal-3.....	121
5.2 Methods of current study.....	127
5.3 Results.....	131
5.4 Discussion	183
5.5 Conclusion	197
Chapter 6 Integrating psychological theory into the design of an interactive digital intervention for sexual difficulties: sextherapy.london.nhs.uk (STL).....	198
6.1 Chapter overview	199
6.2 Aims.....	200
6.3 Methods	200
6.4 Circumstances of STL's development	200
6.5 Aims of the intervention.....	201
6.6 Target population	202
6.7 Theoretical rationale.....	203
6.8 Tailoring	205
6.9 Intervention content.....	205
6.10 Development process	211
6.11 Development challenges.....	212
6.12 Post development usage.....	214
6.13 Considerations for the future development and implementation of STL.....	215
Chapter 7 Users' views and experiences of IDIs for sexual difficulties: A qualitative study.....	216
7.1 Chapter overview	217
7.2 Background.....	218
7.3 Aims and objectives	221
7.4 Methods	222
7.5 Reflexivity	229
7.6 Reactivity	230

7.7	Rigour	230
7.8	Transparency	231
7.9	Public and Patient Involvement (PPI)	231
7.10	Results.....	231
7.11	Discussion	268
7.12	Conclusions	284
Chapter 8 General discussion.....		285
8.1	Chapter overview	286
8.2	Background to the thesis.....	287
8.3	Aim and objectives of the thesis	287
8.4	Summary of main findings.....	288
8.5	Overall finding of the thesis	289
8.6	Methodological strengths and limitations of the thesis	290
8.7	Fit with other literature.....	293
8.8	Implications	294
8.9	Implications for practice	294
8.10	Implications for policy.....	296
8.11	Implications for research	296
8.12	Reflections	298
8.13	Conclusions	299
Appendix A Database search strategies		327
Appendix B Data extraction form		322
Appendix C Studies excluded at full text and reasons for exclusion		341
Appendix D Characteristics of included studies tables		343
Appendix E Characteristics of included IDIs table		364
Appendix F Genital health conditions on cards B and C.....		371
Appendix G STL screen shots		372
Appendix H Information letter.....		378
Appendix I Consent form		384
Appendix J Sources of recruitment and reasons for non-participation.....		387
Appendix K Topic guide interview 1		389
Appendix L Topic guide interview 2		394

Appendix M Demographic questionnaire 396

List of Tables

Table	Page
Table 1.1: Descriptions of psychotherapeutic interventions/techniques for sexual difficulties	25
Table 2.1: DSM-5 Labels and diagnostic criteria of sexual dysfunctions.	40
Table 2.2: Predisposing, precipitating and perpetuating factors for sexual difficulties	46
Table 4.1: Additional markers of methodological quality in the individual studies.....	87
Table 4.2: Main outcomes reported in included studies, including direction of change (IDI vs minimally active control conditions).....	105
Table 4.3: Main outcomes reported in included studies tables, including direction of change (IDI vs active interventions).....	109
Table 4.4: Main outcomes reported in included studies tables, including direction of change (IDI vs IDI plus counselling)	111
Table 5.1: Percentage of sexually active women who reported distress about a specific difficulty, seeking help, and source of help by specific type of sexual difficulty	137
Table 5.2: Percentage of sexually active men who reported distress about a specific difficulty, seeking help, and source of help by specific type of sexual difficulty	140
Table 5.3: The prevalence of help-seeking by sociodemographic characteristics in sexually active women with 1+ distressing sexual difficulties (crude & adjusted odds ratios).....	143
Table 5.4: The prevalence of help-seeking by sociodemographic characteristics in sexually active men with 1+ distressing sexual difficulties (crude & adjusted odds ratios).....	145
Table 5.5: The prevalence of help-seeking by health/sexual health characteristics in sexually active women with 1+ distressing sexual difficulties (crude & adjusted odds ratios).....	147

Table 5.6: The prevalence of help-seeking by health/sexual health characteristics in sexually active men with 1+ distressing sexual difficulties (crude & adjusted odds ratios).....	149
Table 5.7: The prevalence of help-seeking by relationship characteristics in sexually active women with 1+ distressing sexual difficulties (crude & adjusted odds ratios).	152
Table 5.8: The prevalence of help-seeking by relationship characteristics in sexually active men with 1+ distressing sexual difficulties (crude & adjusted odds ratios).	154
Table 5.9: The prevalence of help-seeking by sex education and sexual behaviour characteristics in sexually active women with 1+ distressing sexual difficulties (crude & adjusted odds ratios).	157
Table 5.10: The prevalence of help-seeking by sex education and sexual behaviour characteristics in sexually active men with 1+ distressing sexual difficulties (crude & adjusted odds ratios).	159
Table 5.11: The prevalence of help-seeking by sociodemographic characteristics in sexually experienced women who reported being distressed about their sex lives (crude & adjusted odds ratios).....	164
Table 5.12: The prevalence of help-seeking by sociodemographic characteristics in sexually experienced men who reported being distressed about their sex lives (crude & adjusted odds ratios).....	166
Table 5.13: The prevalence of help-seeking by health and sexual health characteristics in sexually experienced women who reported being distressed about their sex lives (crude & adjusted odds ratios).....	169
Table 5.14: The prevalence of help-seeking by health and sexual health characteristics in sexually experienced men who reported being distressed about their sex lives (crude & adjusted odds ratios).....	171
Table 5.15: The prevalence of help-seeking by relationship characteristics in sexually experienced women who reported being distressed about their sex lives (crude & adjusted odds ratios).	173
Table 5.16: The prevalence of help-seeking by relationship characteristics in sexually experienced men who reported being distressed about their sex lives (crude & adjusted odds ratios).....	176

Table 5.17: The prevalence of help-seeking by sex education and sexual behaviour characteristics in sexually experienced women who reported being distressed about their sex lives (crude & adjusted odds ratios).	179
Table 5.18: The prevalence of help-seeking by sex education and sexual behaviour characteristics in sexually experienced men who reported being distressed about their sex lives (crude & adjusted odds ratios).	181
Table 6.1: Examples and aims of STL exercises.....	206
Table 7.1. Interview participant demographic characteristics (N = 30).	233
Table 7.2: Main themes and sub-themes in the dataset.....	236

List of Figures

Figure	Page
Figure 1.1: Summary of the objectives/studies in the thesis.....	32
Figure 4.1: The five areas cognitive-behavioural model of problem activation.....	69
Figure 4.2: Flow chart of literature search.....	77
Figure 4.3: Intervention delivery features	80
Figure 4.4: Intervention support features	81
Figure 4.5: Intervention content features.....	81
Figure 4.6: Risk of bias graph of author's judgements about each risk of bias item presented as percentages across all included studies.	85
Figure 4.7: Risk of bias summary – review author's judgements about each risk of bias item for each included study.	85
Figure 4.8: Comparison of IDI versus minimal intervention for sexual function.....	88
Figure 4.9: Comparison of IDI versus minimal intervention for women's sexual function.....	88
Figure 4.10: Comparison of IDI versus minimal intervention for men's erectile function.....	89
Figure 4.11: Comparison of IDI versus minimal intervention for relationship satisfaction	89
Figure 4.12: Comparison of IDI versus minimal intervention for women's relationship satisfaction	90
Figure 4.13: Comparison of IDI versus minimal intervention for women's negative emotional states.....	90
Figure 5.1: Order of questions in the sexual function section of Natsal-3.....	124
Figure 5.2: Natsal-3 participants, exclusions, and participants included in the final analysis of the current study.....	128
Figure 5.3: The distribution of reporting different types of distress associated with participants' sex lives according to recency of sexual experience (ever had sex vs. in the past year).....	133

Figure 5.4: Prevalence of different types of help-seeking in men and women with 1+ distressing sexual difficulties	135
Figure 5.5: Prevalence of different types of help-seeking in men and women who report being distressed about their sex lives.....	162
Figure 6.1: The home page of STL.	207
Figure 6.2: Intervention development timeline.....	212
Figure 8.1: Objectives and corresponding studies in the thesis.....	287

Abbreviations and Glossary

ANZCTR: Australia New Zealand Clinical Trials Registry

APA: American Psychiatric Association

BT: Behaviour Therapy

CAPI: Computer-assisted personal interview

CASI: Computer assisted self-interview

CBT: Cognitive Behavioural Therapy

cCBT: Computerised Cognitive Behavioural Therapy

CENTRAL: Cochrane Central Register of Controlled Trials

CI: Confidence Interval

CINAHL: Cumulative Index to Nursing and Allied Health Literature

CNWL: Central and North West London Trust

CONSORT: Consolidated Standards of Reporting Trials

CWCTLS: Center Watch Clinical Trials Listing Service

DNA: Did not attend

DSM: Diagnostic and Statistical Manual (of Mental Disorders)

EI: Education Intervention

EM: Elizabeth Murray

EMBASE: Excerpta Medica Database

ERIC: Educational Resources Information Centre

FSD: Female Sexual Dysfunction

GP: General practitioner

GUM: Genitourinary Medicine

HIV: Human Immunodeficiency virus

HMIC: Healthcare Management Information Consortium

IBSS: International Bibliography of the Social Sciences

ICD: International Classification of Diseases

ICRCTN: International Standard Randomised Controlled Trial Number Register

IDI: Interactive Digital Intervention

ITT: Index to Theses

JB: Julia Bailey

JR: Jamie Ross

LGBT: Lesbian, Gay, Bisexual and Transgender

LH: Lorna Hobbs

MI: Motivational Interviewing

N3 network: A highly secure and fast national broadband network for the NHS

Natsal-3: National Survey of Sexual Attitudes and Lifestyles 3

NEL: North East London Trust

NHS: National Health Service

NIHR NRR: National Institute for Health National Research Register

NTIS: National Technical Information Service

ONS: Office of National Statistics

OP: Other Psychotherapy

OR: Odds Ratio

OSIGLE: Open System for Information of Grey Literature in Europe

PDE5: Phosphodiesterase 5

PPI: Patient and Public Involvement

PQDTD: ProQuest Dissertations and Theses Database

PSD: Persuasive Systems Design

PE: Psychoeducation

QOL: Quality of life

RCT: Randomised Controlled Trial

RE-AIM: Reach Effectiveness Adoption Implementation Maintenance

ROB: Risk of Bias

RT: Relationship Therapy

SD: Standard Deviation

SMD: Standard Mean Difference

Sensate focus: A series of touching exercises designed to increase intimacy in a sexual relationship

Sexology: the scientific study of human sexuality

SF: Sexual Function

Squeeze technique: A technique used to control ejaculation

SST: Sexual Skills Training

ST: Systemic Therapy

STI: Sexually Transmitted Infection

STL: Sextherapylondon website

Stop start method: A technique used to control ejaculation

Systematic desensitisation: Gradual increased exposure to sexual activities that cause anxiety

TEC: Technology Enabled Care

UCL: University College London

USNIHS: United States National Institute of Health Service

WHO: World Health Organisation

Chapter 1
Introduction

1.1 Chapter overview

In this chapter I provide the background to the thesis, by providing a brief definition of sexual difficulties, introducing their prevalence and importance to overall health and wellbeing, and the ways in which they can be effectively treated. I describe the current unmet need for treatment of sexual difficulties, and then go on to outline the rationale for considering the potential for Interactive Digital Interventions (IDIs) to meet this unmet need. I highlight the gaps in the evidence and describe the approach I take in the thesis to address these gaps.

1.2 Sexual difficulties

Sexual difficulties are notoriously difficult to define and classify. What is considered sexually 'normal' is culturally, socially and politically relative, and thus heavily context dependent. According to the World Health Organisation (Glasier, Gulmezoglu, Schmid, Moreno, & Van Look, 2006), sexual health is 'a state of physical, emotional, mental and social wellbeing related to sexuality, and not merely the absence of disease, dysfunction or infirmity. Sexual health requires a positive and respectful approach to sexuality and sexual relationships, as well as the possibility of having pleasurable and safe sexual experiences'. For the purpose of this thesis, I define sexual difficulties as any difficulties during any stage of the sexual response cycle (desire, arousal, orgasm and resolution) that prevents an individual and/or their sexual partner(s) from enjoying pleasurable and safe sexual experiences (Masters & Johnson, 1966a). Difficulties can be cognitive, affective, behavioural and/or physiological (Hogan, 1978).

Masters and Johnson proposed a four stage model of sexual response (excitement phase, plateau phase, orgasm phase and resolution phase), and sexual difficulties (referred to by Masters and Johnson as sexual dysfunctions) are often seen as difficulties that arise in one or more of these sexual response phases (Wootten et al., 2015). Sexual Dysfunctions were first classified in the third edition of the Diagnostic and Statistical Manual (DSM-III; American Psychiatric Association, 1987). However, there is ongoing debate about the nature of sexual difficulties; which, in combination with advances in research, has led to changes to the definitions and classifications of sexual difficulties in subsequent revised editions of the DSM. The history of the study and classification of sexual difficulties, and their relationship with cultural and social mores will be explored further in Chapter 2.

1.3 Why are sexual difficulties worth studying?

Historically, identifying and treating sexual difficulties has not been high on policy and practice agendas, and sexual difficulties (and sexual fulfilment) are recognised as a neglected area of sexual-health research and service provision (Medical Foundation for AIDS and Sexual Health, 2008; Mercer et al., 2005). But this appears to be changing. Increasingly, public health institutions are recognising sexual function as a fundamental component of sexual health (WHO, 1992), and more broadly, an integral part of overall health and wellbeing; and this notion is reflected in recent guidelines recommending increased provision of psychosexual services (British Psychological Society, 2006;

Medical Foundation for AIDS and Sexual Health, 2008; World Association for Sexual Health, 2008).

Despite the problems with defining sexual difficulties, there is widespread acknowledgement that they are common and can negatively impact people's lives in multiple ways (see 'harms to the individual' section below). Moreover, the healthcare costs of both treated and untreated sexual difficulties may be considerable (see 'harms to the healthcare system' section below).

1.4 Prevalence

Research indicates that sexual difficulties are fairly common, but prevalence estimates vary widely. Community studies report sexual difficulties in 22-41% of men, and 33-51% in women (Dunn, Croft, & Hackett, 1998; Mercer et al., 2003; Mercer et al., 2013; Nazareth, Boynton, & King, 2003; Nicolosi et al., 2004), and prevalence of sexual difficulties in clinic populations (sexually transmitted infection/STI or genitourinary medicine/GUM clinics) range between 32-37% in men and 20-43% in women (Goldmeier, Judd, & Schroeder, 2000; Shepherd, Heke, & O'Donovan, 2009; Shepherd, Heke, Sarner, & O'Donovan, 2010). The most commonly reported sexual difficulties in women are lack of sexual interest, inability to reach orgasm, and lubrication difficulties, and in men the most common are early ejaculation, lack of sexual interest and erectile difficulties (Mitchell et al., 2013; Nicolosi et al., 2004).

There are a variety of possible reasons for the variability in these estimates. Firstly, estimates very much depend on how sexual difficulties are defined. For example, are the DSM diagnostic criteria for sexual dysfunctions used? If not, are frequency and duration taken into account, and if so what are the cut off points? Is level of distress or any other factors taken into account or just solely the reporting of the difficulty? Estimates also depend on the study population. For example, is the study conducted with a community sample, a clinic sample, or with a particular gender or age group? Estimates also depend on the research methods used to gather the data. For example, the way distress is measured and the response rates of surveys can both affect prevalence estimates. Notwithstanding the difficulties associated with obtaining accurate prevalence estimates, the aforementioned studies demonstrate a global presence of sexual difficulties in both men and women.

1.5 Harms resulting from sexual difficulties

1.5.1 Harms to the individual

Sexual difficulties can have a negative impact on emotional and sexual wellbeing, quality of life and interpersonal relationships (Arrington, Cofrancesco, & Wu, 2004; Laumann, Paik, & Rosen, 1999; Mitchell et al., 2013; World Association for Sexual Health, 2008). Factors associated with sexual difficulties include anxiety (Laurent & Simons, 2009), depression (Laurent & Simons, 2009; Mitchell et al., 2013), poor self-assessed general health (Mitchell et al., 2013), avoidance of sex (Mitchell et al., 2013), sexual distress and dissatisfaction (Mitchell et al., 2013), and negative sexual health outcomes, such as non-volitional sex (Mitchell et al., 2013), sexually transmitted infections (Mitchell et al., 2013) and increased sexual risk behaviour (Cove & Petrak, 2004; de Tubino Scanavino, 2011). While in some cases the direction of causality is unclear, for example with depression and anxiety (Laurent & Simons, 2009), it is widely acknowledged that sexual difficulties can have a substantial negative impact on the lives of those who experience them.

1.5.2 Harms to the healthcare system

When sexual difficulties are *detected*, treatment and support is typically available through mental-health services, genitourinary medicine, and psychosexual clinics. But these services are not universally available, and where they are available, access may be limited by poor awareness/uptake, or long waiting lists, so not everyone who needs help receives it (British Psychological Society, 2006; Medical Foundation for AIDS and Sexual Health, 2008).

When sexual difficulties go *undetected and thus untreated* the costs to healthcare systems are potentially considerable. A significant amount of men are reluctant to seek help for erectile difficulties due embarrassment and social stigma and/or the high cost of medication (Department of Health, 2014; Jackson, Arver, Banks, & Stecher, 2010), and this has contributed to a growth in the counterfeit medicine market as men increasingly seek out counterfeit medication online (Jackson et al., 2010). PDE5 inhibitors are considered the most frequently counterfeited drug in Europe (Jack, 2007), and it is thought that up to 2.5 million European men are exposed to counterfeit PDE5 inhibitors (Jackson et al., 2010). The health impairment risks of these counterfeit medications are commonly underestimated (Sugita & Miyakawa, 2010) and their use can be potentially hazardous (Jackson et al., 2010). Illegal samples have been found to

contain inconsistent levels of active ingredients, contaminants, and unknown pharmaceutically active ingredients; the presence of which can lead to undesirable side effects, interactions with other drugs, accidental overdose, and/or death (Jackson et al., 2010).

A further problem associated with undetected erectile dysfunction (and the growth the counterfeit medicine market) are the potential missed opportunities to assess people for comorbid medical conditions. For example, erectile dysfunction is commonly comorbid with hypertension, dyslipidaemia, and diabetes; and, if left undetected and untreated, these conditions carry a high risk of morbidity or mortality (Jackson et al., 2010).

More generally, sexual difficulties may be the underlying cause of other conditions, such as infertility or depression (Giovanni, 2015; Read, 1999), and failure to address the root cause of these conditions is likely to result in treatment being ineffective. For example, the relationship between infertility and sexual difficulties is considered bi-directional – attempts to conceive can cause sexual difficulties, and (pertinent to this chapter) sexual difficulties can cause problems with conception (Read, 1999). A lack of interest in sex or experiencing pain during sex can lead people to avoid sex, and if a couple are not having sex very often they may miss their window for conception. Failure to achieve or maintain an erection long enough to have intercourse can also lead to fertility problems; as can ejaculatory difficulties, including early ejaculation, where the man has little or no control over the ejaculatory response; retarded ejaculation, where the man is unable or has difficulty ejaculating intravaginally; and retrograde ejaculation, where the sperm enters the bladder instead of going out through the penis (Giovanni, 2015; Read, 1999).

1.6 Available treatments and their impact

A range of interventions have been used to treat sexual difficulties, and they broadly fall into two types: Pharmacological interventions (including mechanical devices) and psychotherapeutic interventions. This thesis is primarily interested in psychotherapeutic interventions.

Psychotherapeutic interventions for sexual difficulties are complex interventions in that they are made up of several components (or active ingredients), which may act independently or interactively to affect outcomes (Medical Research Council, 2000). For example, the components of a cognitive-behavioural intervention for vaginismus

might include sex education, relaxation exercises, gradual exposure, cognitive therapy, and sensate focus exercises (van Lankveld, ter Kuile, de Groot, Melles, & Zandbergen, 2006). See Chapter 2 for full descriptions of these techniques.

The importance of using theory in the design and development of psychotherapeutic interventions is widely accepted (Glanz & Bishop, 2010), and interventions for sexual difficulties are informed by a wide range of theoretical approaches, including systemic, behavioural, cognitive-behavioural, educational, family and psychodynamic approaches (Almas, 2010; Berner & Günzler, 2012; Carr, 2009; Fruhauf, Gerger, Schmidt, Munder, & Barth, 2012; Günzler & Berner, 2012). See Table 1.1 below for descriptions of different types of psychotherapeutic interventions. These interventions can be delivered at the individual, couple or group level—depending on the difficulty, the therapist's judgement, and the particular needs and preferences of the people seeking help (Althof, 2010); and research suggests that targeting and tailoring intervention content to the needs of the individual, couple, or group leads to increased effectiveness and user satisfaction (Krebs, Prochaska, & Rossi, 2010; Ryan & Lauver, 2002).

Table 1.1: Descriptions of psychotherapeutic interventions/techniques for sexual difficulties

Type of intervention	Description
Sexual skills training (SST):	Interventions that focus on exercises aimed to help improve people's sexual function. Exercises can be practiced by individuals or with sexual partners and may involve masturbation exercises, sensate focus, the stop-start technique etc.
Sex therapy (ST):	An approach based on Masters and Johnson's sexual response cycle. It involves psychoeducation, exercises (e.g., sensate focus), and counselling.
Behavioural therapy (BT):	Much of the sex therapy exercises above are behavioural therapy (BT) exercises. Systematic desensitisation is another BT technique, whereby muscle relaxation is used to reduce anxiety associated with particular sexual situations. Vaginal dilator training is included in this category.
Cognitive-behavioural therapy (CBT):	CBT aims to modify dysfunctional beliefs and negative thought patterns (cognitive restructuring). Components of the treatment include between session assignments and activities, psychoeducation, and skills training. Therapists actively influence the process through therapeutic interaction and topics of discussion.

Type of intervention	Description
Relationship therapies (RT):	Focusing on relationship problems, these interventions include communication and social skills training, and cognitive strategies (e.g. perspective taking to improve mutual understanding). Systemic therapy is a common relationship therapy, and holds that difficulties arise in systems, rather than individuals. Difficulties are thought to occur when a system gets 'stuck' in a particular patterns of action and reaction. Thus, understanding the social, cultural and political context in which the difficulties exists is seen as key to understanding the presenting difficulties.
Educational intervention (EI):	Interventions that focus on the provision of information about the psychological and physiological changes that occur during the sexual response, and what might be typical/atypical.
Other psychotherapy (OP):	For example, psychodynamic therapy, hypnotherapy, rational emotive therapy, etc.

(Fruhauf et al., 2012)

1.7 Evidence of effectiveness

The current evidence on the effectiveness of psychotherapeutic interventions for sexual difficulties is positive. In three recent systematic reviews – one of 20 RCTs of psychotherapeutic interventions for male and female sexual difficulties (Fruhauf et al., 2012), one of 15 RCTs of psychotherapeutic interventions for female sexual difficulties (Günzler & Berner, 2012), and one of 19 RCTs of psychotherapeutic interventions for male sexual difficulties (Berner & Günzler, 2012) – the majority of the psychotherapeutic interventions were found to be effective in improving symptom severity and sexual satisfaction. Furthermore, clinicians suggest that many sexual difficulties can be treated successfully with only brief intervention (Gurney, 2015). However, these findings should be treated with caution as the evidence varies across different sexual difficulties (Fruhauf et al., 2012); the methodological quality of the included studies was often low to moderate; the sample sizes were often small; and the drop-out rates were high (Berner & Günzler, 2012).

1.8 Evidence of unmet need

Due to the high prevalence of people with sexual difficulties (Goldmeier et al., 2000; Medical Foundation for AIDS and Sexual Health, 2008; Mitchell et al., 2013; Nazareth et al., 2003), the Medical Foundation for HIV and Sexual Health (MEDFASH; 2008)

states that the NHS should provide access to psychosexual services for all people with sexual difficulties. But in reality very few people with sexual difficulties access services (Abdolrasulnia et al., 2010; Adegunloye & Ezeoke, 2011; Gott & Hinchliff, 2003; Mitchell et al., 2013; Moreira et al., 2004; Shepherd et al., 2010; Shifren et al., 2009). In a recent study on the provision and uptake of psychosexual services in the UK (Shepherd et al., 2010), 36% of patients reported experiencing a sexual difficulty, yet only 7% of those had sought help for it (despite 50% reporting wanting help).

Reasons for low levels of help-seeking for sexual difficulties include a lack of knowledge about the availability of relevant services (Adegunloye & Ezeoke, 2011; Akre, Michaud, & Suris, 2010; Gott & Hinchliff, 2003), geographic inconsistencies in service provision (Adegunloye & Ezeoke, 2011; Medical Foundation for AIDS and Sexual Health, 2008), the belief that problems may be transient (Adegunloye & Ezeoke, 2011), time constraints due to work and childcare responsibilities (Rochlen, Zack, & Speyer, 2004), discomfort and embarrassment discussing sexual difficulties with a health professional (Akre et al., 2010; Gott & Hinchliff, 2003; Harsh, McGarvey, & Clayton, 2008), and health professionals' avoidance (due to discomfort, lack of training, or time) of initiating discussions about sexual difficulties with patients (Abdolrasulnia et al., 2010; Harsh et al., 2008; Moreira et al., 2004; Shepherd et al., 2010).

Notwithstanding the limitations associated with accessing face-to-face interventions for sexual difficulties, there is enough evidence to demonstrate their value in this area. However, the continued cuts within the National Health Service (NHS) mean that current supply cannot meet demand. In order to meet current demand and address the problems associated with accessing services, there is a strong need to develop widely accessible, efficient, and effective alternative interventions for sexual difficulties. The Internet offers a potentially cost-effective platform from which to widely disseminate psychotherapeutic interventions, and IDIs have real potential to be part of the solution.

1.9 IDIs

In this thesis, I define IDIs as programs that provide information and support (emotional, decisional and/or behaviour support) for sexual difficulties via a digital platform. IDIs are interactive, meaning that they require contributions from the user(s), which alter pathways within the program, to produce tailored information and feedback that is personally relevant to the user(s) (Bailey et al., 2010).

1.10 Advantages of IDIs

IDIs have a number of advantages over interventions delivered face-to-face. For the user, IDIs provide private, flexible, 24 hour access to help and support that is anonymous and can meet the individual needs of the user (Lustria, Cortese, Noar, & Glueckauf, 2009). For healthcare providers, policy makers and researchers, IDIs are appealing as they are potentially cost effective, scalable, easily adaptable, and allow for wide, uniform dissemination of evidence-based support programs (Bailey et al., 2010).

1.11 Disadvantages of IDIs

There are, however, some disadvantages of IDIs. The digital divide continues to exclude some people from accessing and benefiting from these types of interventions (Carlbring & Andersson, 2006; National Telecommunications and Information Administration, 2013); online security is a potential concern (Carlbring & Andersson, 2006; Nosek, Banaji, & Greenwald, 2002); IDIs are not appropriate for people with severe mental health problems (Ragusea & VandeCreek, 2003) or those with severe relationship difficulties/intimate partner violence or active substance use problems (Carlbring & Andersson, 2006; Cobia, Robinson, & Edwards, 2008; Ragusea & VandeCreek, 2003); and continued engagement with IDIs is an ongoing problem (Christensen, Griffiths, & Farrer, 2009; Dunn, Casey, Sheffield, Newcombe, & Chang, 2012; Eysenbach, 2005). See Chapter 3 for a more comprehensive discussion of these limitations and how they can be addressed.

1.12 Evidence of effectiveness (in other areas of physical and mental health)

IDIs have been applied in the areas of health-behaviour change, from sexual health promotion (Bailey et al., 2010; Portnoy, Scott-Sheldon, Johnson, & Carey, 2008) and HIV prevention (Noar, Black, & Pierce, 2009) to smoking cessation (Brown et al., 2012) and alcohol consumption (Khadjesari, Murray, Hewitt, Hartley, & Godfrey, 2011); and in mental health, from depression and anxiety (Barak, Hen, Boniel-Nissim, & Shapira, 2008) to panic attacks (Barak et al., 2008; Ritterband et al., 2011) and trauma (Barak et al., 2008; Benight, Ruzek, & Waldrep, 2008). In these areas IDIs have had positive effects, and their increased use in health-related areas holds promise for their use in treating or ameliorating sexual difficulties. See Chapter 3 for a more extensive description of the evidence for IDIs in the areas of health and mental health.

1.13 Evidence of effectiveness (in sexual difficulties)

A small number of studies have been conducted to evaluate online interventions for sexual difficulties. Studies have shown positive effects on problematic pornography use (Hardy, Ruchty, Hull, & Hyde, 2010), erectile difficulties (E. Andersson et al., 2011; McCabe, Piterman, & Lording, 2008; McCabe & Price, 2008; van Lankveld, Leusink, van Diest, Gijs, & Koos Slob, 2009; Wootten et al., 2012), and female sexual dysfunction (Hucker & McCabe, 2014; Hummel et al., 2015; McCabe & Hucker, 2011; Wiljer et al., 2011). However, most of the studies have been conducted on small samples, some with low retention in the trials, and there is a notable lack of RCTs in this area. Notwithstanding these methodological limitations, there is evidence to suggest that IDIs in the area of sexual difficulties are worthwhile exploring further. See chapter 3 for a more extensive description of the evidence for IDIs for sexual difficulties.

1.14 Gaps in the evidence

I used the RE-AIM model (Glasgow, Vogt, & Boles, 1999) to help me determine where the gaps in the evidence were and to plan the appropriate studies to address some of these gaps. The RE-AIM model is a framework that is designed to enhance the quality, speed and impact of research translation. According to the model, the overall impact of an intervention results from the combined effects of the following dimensions: Reach, Efficacy or Effectiveness, Adoption, Implementation and Maintenance. Reach refers to the proportion of the target population that uses the intervention. Efficacy/effectiveness is how successful the intervention is for its users. Adoption refers to the proportion of individuals, settings and institutions that take on the intervention. Implementation is the extent to which the intervention is implemented into practice as intended. Maintenance refers to the extent to which the intervention effects are maintained in individuals and settings over time (Glasgow et al., 1999).

I decided to undertake three studies to explore the areas of Effectiveness, Reach and Adoption (conceptualising acceptability as a first stage of adoption). It was beyond the scope of the thesis to consider Implementation and Maintenance.

1.15 Effectiveness

The use of IDIs in the area of sexual-health and sexual-difficulties is an emerging field. Several systematic reviews of IDIs for sexual health promotion and HIV prevention have been conducted (Bailey et al., 2010; Noar et al., 2009; Noar, Pierce, & Black, 2010), but there are currently no known systematic reviews of IDIs for sexual difficulties.

It is not known whether IDIs for sexual difficulties are effective; how they compare to face-to-face interventions; and if they have the potential to cause harm. Furthermore, IDIs vary on multiple dimensions: their use of feedback and tailoring, level of interactivity, use of human support, use and synchronicity of multi-media channels of communication, audience reach, theoretical base, and target population/sexual difficulty (Portnoy et al., 2008). Therefore, a systematic review is needed to identify the range and type of IDIs available for sexual difficulties, and to determine their effects and relative impact on different sexual difficulties.

1.16 Potential reach and user characteristics

If IDIs are found to be effective in treating or ameliorating sexual difficulties, it then becomes important to determine the potential reach of these interventions—as this (in combination with effectiveness data) enables calculation of impact, cost and cost effectiveness. As far as I am aware, no studies to date have looked at the potential reach of IDIs for sexual difficulties. Therefore, analysis of data from a population-based survey, that provides nationwide prevalence estimates of both sexual difficulties and internet help-seeking for sexual difficulties, is needed. The analysis of this type of data would provide a unique and valuable opportunity to explore the potential reach of IDIs for sexual difficulties, and also enable me to gather information on potential user characteristics that may be applied to future intervention design.

1.17 Acceptability

While it is vital to establish the effectiveness of IDIs for sexual difficulties, it is equally important to determine whether these types of interventions are acceptable to potential users. There is little point in the NHS investing in the design, development and implementation of these interventions if people do not like them and are unwilling to use them. To date, there are no known studies on the acceptability of IDIs for sexual difficulties. A qualitative interview study is therefore needed to explore users' views of these types of interventions and use the information gathered to ensure that IDIs for sexual difficulties are designed with user views and experiences at the fore.

1.18 A health service research perspective

Health services research seeks to examine access, costs and outcomes of healthcare systems, with the aim of informing policy and practice to maximise the effectiveness of organising, managing, financing and delivering high quality care within these systems

(Agency for Healthcare Research and Quality, 2002). The current thesis takes a pragmatic and applied health services research approach to the research, with the aim of providing generalisable evidence that can inform policy making and service delivery locally, nationally and internationally.

1.19 Rationale for choice of methods

A mixed-methods approach involves using both qualitative and quantitative methods to investigate a topic (Schultheiss & Glina, 2010). I chose a mixed-methods approach to the thesis for the following reasons: 1. Sexual difficulties are an under-researched area (Medical Foundation for AIDS and Sexual Health, 2008; Mercer et al., 2005), and mixed methods research facilitates the expansion of the scope of the research to develop a better understanding of this under-researched area (Greene, Caracelli, & Graham, 1989); 2. If designed well, the results of mixed methods research are complementary (with one method informing another), and can also enable triangulation of results (Greene et al., 1989); 3. I had the mixed-methods expertise within my supervisory team from which to draw on; and perhaps most importantly, 4. A mixed methods approach was the most appropriate approach for the chosen research questions: a systematic review to address the question of effectiveness; a secondary analysis of data from a large population-based survey (Natsal-3) to address the question of reach; and a qualitative interview study with users of an IDI for sexual difficulties to address the questions relating to users' views, experiences and acceptability.

1.20 Overall aim

The overall aim of the thesis was to use a mixed-methods approach to investigate the use of the Internet to deliver psychotherapeutic interventions for sexual difficulties.

1.20.1 Objectives

The thesis aimed to address the gaps in the literature through three objectives/studies which can be seen in Figure 1.1.

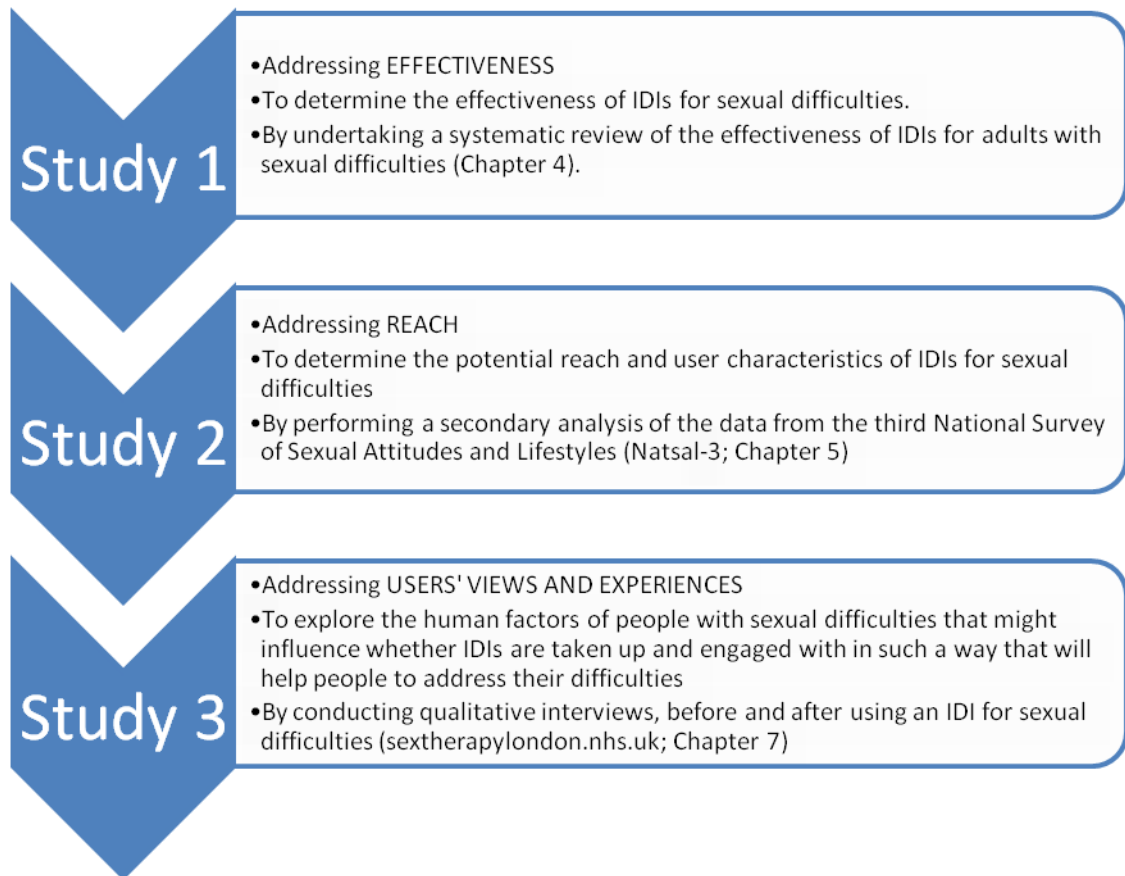


Figure 1.1: Summary of the objectives/studies in the thesis

Chapter 2
What are sexual difficulties?
An introduction and literature review

2.1 Chapter overview

In the introduction chapter we saw that sexual difficulties are prevalent and a source of distress to many; and that this distress can be alleviated through the provision of psychotherapeutic intervention, but that there is a shortage of appropriate services as well as various barriers to accessing services, which has led to an unmet need. In this chapter I will look at some of these factors in more detail, taking a more critical approach. The content within this chapter is not an exhaustive review of the literature but it provides an overview of the broader context of the thesis as it pertains to the conceptualisation and management of sexual difficulties.

I begin the chapter by defining sexuality and using a rights-based approach to discuss the importance of sexuality and sexual difficulties. I then move on to look at the motivations for why we engage in sex, illustrating the complexity of sexual behaviour and how the motivations and expectations of/for sex can determine whether a person perceives their sex life to be problematic or not. Next I provide a brief history of the scientific study of sex and sexual difficulties as this sets the scene for how the contemporary (medical) conceptualisation of sexual difficulties came about. I re-state the thesis definition of sexual difficulties, and describe the ways in which sexual difficulties are influenced by a range of interpersonal, psychological, social and cultural factors—making them difficult to define—and highlight how difficulties with definition directly impacts prevalence estimates and approaches to intervention.

Next I discuss the emergence of (and changes to) contemporary classification systems of sexual difficulties, and outline some of the critiques of these classification systems and medical conceptualisations of sexual difficulties, before discussing some alternate conceptual models of sexual function and sexual difficulties (as these have implications for intervention design and dissemination in the area of sexual difficulties). I then go on to discuss the aetiology and maintenance of sexual difficulties, and approaches to intervention, before ending the chapter with a brief summary of how the information within the chapter applies to the approach of this thesis and to the implementation of IDIs for sexual difficulties.

2.2 What do we mean by sex and sexuality?

According to the World Health Organisation (WHO) 'Sexuality is a central aspect of humanity and encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction. Sexuality is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviours, practices, roles and relationships. Although sexuality can include all of these dimensions, not all are always experienced or expressed. Human sexuality is influenced by the interaction of biological, psychological, social, economic, political, cultural, ethical, legal, historical, religious and spiritual factors' (Glasier et al., 2006).

2.3 The importance of sex and sexuality

Sex and sexuality are recognised as fundamental aspects of being human, and the WHO includes sexual and reproductive rights as essential aspects of human rights; stating that each person has the right to 'pursue a satisfying, safe, and pleasurable sex life' (Glasier et al., 2006). But while human sexuality is seen as universal (Hall & Graham, 2012), its expression is not. Biological, psychological, and socio-cultural factors come together to frame and constrain the expression of human sexuality (Hall & Graham, 2012; Meston & Buss, 2007). The meanings and values attached to sex and sexuality vary between individuals, societies, and cultures, and what is considered normative or accepted in one context (e.g. sex between two men or gay marriage) can be considered abnormal, immoral or even illegal in another (Hall & Graham, 2012).

2.4 Sexual motivation and expectations

Human beings are complex, and, as such, have a wide range of psychologically complex motives and reasons for engaging in sexual activity (Meston & Buss, 2007). The most comprehensive taxonomy of sexual motivation to date cites 237 distinct reasons why people engage in sexual behaviour (Meston & Buss, 2007). The four main categories and 13 sub-categories vary from physical motivations (e.g. pleasure, stress reduction, physical desirability and experience seeking) and goal attainment (e.g. accessing resources, increasing social status, revenge or utilitarian reasons) to emotional motivations (e.g. love and commitment and expression) and insecurity (e.g. boosting self-esteem, duty/pressure, and mate guarding). The taxonomy is by no means exhaustive, but it does illustrate how our sexuality permeates so many areas of our lives, and how people's motivations and expectations for sex can influence whether they perceive their sex life to be problematic or not.

In the following section of the chapter I provide a brief history of the scientific study of sex and sexual difficulties. While one of the main aims of this chapter is to understand the influential factors and causal pathways of sexual difficulties, with a focus on modifiable factors, this historical background also demonstrates the social, cultural and historical relativism of sex and sexual difficulties, and how our current conceptualisations of them came to be.

2.5 A brief history of the scientific study of sex and sexual difficulties

2.5.1 Early pioneers

While the first attempts of western civilisations to study human sexual behaviour date back to the ancient Greeks, it was not until the turn of the 20th century that the scientific study of human sexuality (or sexology) was first established (Schultheiss & Glina, 2010). The contributions of the early pioneers of modern sexology described below are particularly relevant to the current thesis as their work either involved questioning ideas of what was considered 'normal' in sexuality and/or challenging the moral condemnation of particular sexual practices (Mitchell, 2008).

Bloch (1872-1922), sometimes referred to as the father of sexology, was the first to propose the new concept of a science of sexuality. Bloch was among the first to express concerns about the medical focus of sexology being too narrow, and to consider the impact of social and cultural factors on sex and sexuality (Reiss, 1982). von Krafft-Ebing (1840-1902) was known for his interest in female sexual pleasure (albeit from a paternalistic perspective that was the norm at the time) and for bringing many variant sexual acts into the public sphere (Schultheiss & Glina, 2010). Havelock-Ellis (1859-1939) was known for depathologising aspects of sexuality, including homosexuality and masturbation (Bancroft, 2005; Schultheiss & Glina, 2010). Hirschfeld (1868-1935) was an advocate for sexual minorities, and credited for a whole host of achievements including starting the first gay and transgender rights organization, publishing the first journal of sexology, co-founding the Sexological Organisation, opening the first Institute for Sexology, and organising the first international sexological congress (Schultheiss & Glina, 2010). And of course Freud (1856-1939), one of the most influential and controversial psychiatrists of all time, was known most famously for establishing a theory of psychosexual development. Freud proposed that children moved through a series of age-related stages that focus on erogenous zones (oral, anal, phallic, latency, and genital). Successful completion of

these stages was thought to lead to the development of a healthy personality, whereas fixation on any stage was thought to prevent completion of the stage, and the subsequent development of a fixated, unhealthy personality (Freud, 2011). Freud's theories have received much criticism over time, but much of his work remains central to current understandings and practice of psychology and psychotherapy.

Much of this early work in sexology took place in Berlin, but it all came to an abrupt end when Hitler came to power in 1933 and seized the Institute of Sexology's buildings, and destroyed all their documents, photographs and artefacts (Schultheiss & Glina, 2010). Although the work of these early sexologists was in many ways progressive and led to a discourse of sexual diversity, the zeitgeist of Germany at the time was 'a patriarchal culture that prized eternal self-vigilance as the key to manliness, moral worth and material success, and one that projected its sexual anxieties on to its subordinates: women, children, the lower classes and other nations' (Marsh, 2015). It is thought by some that a dominant classification in sexuality grew out of this period (reflecting heterosexual, procreative and male perspectives) that still persists today more than 100 years later (Hart & Wellings, 2002).

2.5.2 Post World War II

After World War II the scientific study of human sexuality was resurrected in the United States with Kinsey's work on codifying and classifying human sexual behaviour (Kinsey, Pomeroy, Martin, & Gebhard, 1953; Kinsey, Pomeroy, & Martin, 1948). By taking over 5000 sexual histories of men, and later more than 6000 sexual histories of women, Kinsey conducted the most comprehensive study of human sexual behaviour of its time, and provided the first ever large scale statistics on sexual behaviour (Brown & Fee, 2003; Bullough, 1998; Granzig, 2006). Although some of his methods were criticised (e.g. his sampling techniques), Kinsey documented a vast spectrum of human sexual behaviours, bringing previously unspoken about sexual practices into the public domain, challenging various long-held (and incorrect) assumptions about sexual behaviour (e.g. that masturbation was harmful, that women were asexual etc.), and paving the way for the decriminalisation of various sexual behaviours between consenting adults such as adultery, unmarried cohabitation, and homosexual relationships (Bancroft, 1999).

More than a decade later, Masters and Johnson (1966a, 1966b) became the first to systematically investigate the anatomy and physiology of the human sexual response by directly observing and measuring physiological response indicators of healthy adult volunteers while they engaged in sexual activity in laboratory settings. Through their

observations, Masters and Johnson theorised that the male and female sexual response cycle was a universal, linear progression through four phases: excitement, plateau, orgasmic and resolution, and that difficulties could arise in any of the phases. Masters and Johnson's work was later extended by Kaplan (1974) and Leif (1977) to include sexual desire, and their collective work formed the basis for the classification systems of sexual dysfunctions (see classification section below).

2.6 What are sexual difficulties? A 'difficulty' of definition

So, what are sexual difficulties? Are all sexual difficulties problematic? And when does a sexual difficulty become a dysfunction?

In Chapter 1 I defined sexual difficulties as difficulties during any stage of the sexual response cycle (desire, arousal, orgasm and resolution) that prevent an individual and/or their sexual partner(s) from enjoying pleasurable and safe sexual experiences (Masters & Johnson, 1966a). Difficulties can be cognitive, affective, behavioural and/or physiological (Hogan, 1978). However, sexual difficulties are subjective, and, much like other areas of our sexuality, the meanings and values given to them are influenced by a wide range of individual, interpersonal, social and cultural factors. Consequently, a sexual difficulty considered distressing and problematic to one person will not necessarily be perceived as distressing and problematic to another (hence the use of the term difficulties throughout this thesis rather than problems or dysfunctions). A person with a lack or loss of sexual desire might be perfectly content not to have sex, and the reasons they might state for not wanting to have sex might even be adaptive (Bancroft, 2002); for example, if they have a new born baby to care for or are experiencing difficulties in their relationship with their partner. Yet for another person, a lack or loss of sexual desire might be experienced as acutely distressing, and have a detrimental impact on their wellbeing and intimate relationship(s). As discussed in Chapter 1, the way sexual difficulties are defined has implications for prevalence estimates and intervention content and dissemination. In medical classification systems sexual difficulties are referred to as sexual dysfunctions.

2.7 The classification of sexual dysfunctions

Sexual difficulties first appeared in the Diagnostic and Statistical Manual of Mental Disorders (DSM-I) in 1952, under the category of 'Psychophysiological autonomic and visceral disorders' (American Psychiatric Association, 1952). They were not referred to as 'Psychosexual Dysfunctions' until the third edition (DSM-III; American Psychiatric

Association, 1987); reflecting the view that psychological factors were key factors in the etiology of sexual difficulties (Graham, 2016). As mentioned above, the DSM sexual dysfunctions were based on Masters and Johnson's four stage model of sexual response (Masters & Johnson, 1966b), and as such, up until the latest version of the DSM (DSM-5), were defined as "Disturbances in sexual desire and/or the psychophysiological changes that characterise the sexual response cycle". However, major changes were made in the DSM-5 classification of sexual dysfunctions, starting with their definition. In the DSM-5 they are now defined as 'a heterogeneous group of disorders that are typically characterized by a clinically significant disturbance in a person's ability to respond sexually or to experience sexual pleasure' (American Psychiatric Association, 2013) – reflecting a move away from the Masters and Johnson's human response cycle framework. The DSM sets out specific criteria that people must meet before being diagnosed with a sexual dysfunction (see Table 2.1); and it is implicit that 'normal' sexual function is the absence of clinically significant disturbance in a person's ability to respond sexually or experience sexual pleasure. .

The DSM criteria for sexual dysfunctions reflects the dominant psychiatric thinking of each period of time. For example, the social, medical and legal approach to homosexuality led to its inclusion in the DSM I and II as a mental disorder, but by the 1970s views on homosexuality were radically changing, and in 1973 homosexuality was removed from the DSM. The DSM has been revised a number of times in response to ongoing debates about the nature of sexual difficulties, and to reflect advances in the research and understanding of sexual difficulties. Until the most recent version (DSM 5; American Psychiatric Association, 2013), each new version has seen a trend of increasing numbers of diagnostic categories (IsHak & Tobia, 2013); from four sexual dysfunctions in 1952 (DSM-I; American Psychiatric Association, 1952) to ten sexual dysfunctions in 2000 (DSM-IV; American Psychiatric Association, 2000); and a convergence of male and female sexual dysfunctions from 1987 onwards (DSM-III-R; American Psychiatric Association, 1987).

The DSM was revised in 2013, and is now in its 5th edition (American Psychiatric Association, 2013). In response to criticism (outlined later in this chapter) and backed up by research (Sand & Fisher, 2007), the latest revisions to the sexual dysfunctions in the DSM-5 (American Psychiatric Association, 2013) mark a trend in the opposite direction to that seen in the past; with the number of diagnostic categories reduced, and a separation of male and female sexual dysfunctions (see table 1 below; IsHak & Tobia, 2013).

In an 'effort to raise the bar for what qualifies as a disorder, given the high rates of female sexual dysfunction reported in some epidemiological studies' (Graham, 2016; Graham, Brotto, & Zucker, 2014; Laumann et al., 1999), and to avoid over-diagnosis (Graham et al., 2014) severity and duration criteria were introduced in the DSM-5. For diagnoses, all sexual dysfunctions must be present for a minimum of 6 months and present 75-100% of the time, and they must cause significant distress, and not be better explained by contextual factors such as partner violence or other significant stressors (Graham, 2016; IsHak & Tobia, 2013).

Further key amendments include the merging of the previous diagnostic categories of female hypoactive desire disorder and female arousal disorder to become female sexual interest/arousal disorder (Graham, 2016; IsHak & Tobia, 2013). Research evidence suggests there is a significant overlap between the concepts of desire and arousal, and to date no empirical evidence exists to suggest that they are distinct phases of a sexual response cycle (Dennerstein & Leherter, 2004; Graham, 2016; Graham, Sanders, Milhausen & McBride, 2004; Laan & Janssen, 2007; Mitchell, Wellings & Graham, 2014). In the new diagnostic category of female sexual interest/arousal disorder, the definition of desire was expanded to include behavioural, subjective, and physical aspects of desire/arousal. Furthermore, a polythetic approach was adopted, with women having to meet three out of six possible criteria (see table 2.1) before being diagnosed, to acknowledge that desire/arousal problems are experienced/expressed differently by different women (Graham, 2016).

While more work still needs to be done (i.e. sexual difficulties remain an under-researched area that is still dominated by the medical model), these revisions reflect the latest scientific and clinical evidence in the area, and represent an important step towards moving away from an outmoded, unidimensional and genital-focused view of the nature of the sexual response (Graham, 2016; Graham et al., 2014).

Table 2.1: DSM-5 Labels and diagnostic criteria of sexual dysfunctions.

DSM-5 Diagnostic Label	DSM-5 Diagnostic Criteria
Female sexual dysfunctions	
Female Orgasmic Disorder	Diagnosis requires one or more of the following: <ol style="list-style-type: none"> 1. Marked delay in, marked infrequency, or absence of orgasm. 2. Markedly reduced intensity of orgasmic sensations.

DSM-5 Diagnostic Label	DSM-5 Diagnostic Criteria
Female sexual dysfunctions	
Female Sexual Interest/Arousal Disorder (FSIAD)	<p>Diagnosis requires three of the following symptoms:</p> <ol style="list-style-type: none"> 1. Absent/reduced interest in sexual activity. 2. Absent/reduced sexual/erotic thoughts or fantasies. 3. No/reduced initiation of sexual activity, and typically unreceptive to partner's attempts to initiate. 4. Absent/reduced sexual excitement/pleasure during sexual activity on almost all or all (approximately 75-100% of) sexual encounters (in identified situational contexts or, if generalized, in all contexts). 5. Absent/reduced sexual interest/arousal in response to any internal or external sexual/erotic cues (e.g. written, verbal, visual). 6. Absent/reduced genital or non-genital sensations during sexual activity on almost all or all (approximately 75-100% of) sexual encounters (in identified situational contexts or, if generalized, in all contexts).
Genito Pelvic Pain/Penetration Disorder	<p>Diagnosis requires difficulty with one or more of the following:</p> <ol style="list-style-type: none"> 1. Vaginal penetration during intercourse. 2. Marked vulvovaginal or pelvic pain during vaginal intercourse or penetration attempts. 3. Marked fear or anxiety either about vulvovaginal or pelvic pain in anticipation of, during, or as a result of vaginal penetration. 4. Marked tensing or tightening of the pelvic floor muscles during attempted vaginal penetration.
Male sexual dysfunctions	
Erectile Disorder	<p>Difficulty with one or more of the following:</p> <ol style="list-style-type: none"> 1. Marked difficulty in obtaining an erection during sexual activity. 2. Marked difficulty maintaining an erection until the completion of sexual activity. 3. Marked decrease in erectile rigidity.
Male Hyposexual Desire Disorder	Persistently or recurrently deficient (or absent) sexual/erotic thoughts or fantasies and desire for sexual activity.
Premature Ejaculation	A persistent or recurrent pattern of ejaculation occurring during partnered sexual activity within approximately 1 minute following vaginal penetration and before the individual wishes it.

DSM-5 Diagnostic Label	DSM-5 Diagnostic Criteria
Female sexual dysfunctions	
Delayed Ejaculation	Difficulty with one or more of the following: <ol style="list-style-type: none"> 1. Marked delay in ejaculation. 2. Marked infrequency or absence of ejaculation.

An alternate classification system of sexual dysfunctions is in the International Classification of Diseases (ICD; World Health Organization, 1992). It is currently in its 10th version (ICD-10), but is in the process of being revised, with the ICD-11 due for release in 2017. The ICD-10 defines sexual dysfunction as 'the ways in which an individual is unable to participate in a sexual relationship as he or she would wish'. Although the ICD-10 definition does not explicitly mention the sexual response cycle, the ICD-10 classification of sexual dysfunctions is also based on the Masters and Johnson's model of sexual response and currently include: lack or loss of sexual desire, sexual aversion and lack of sexual enjoyment, failure of genital response, orgasmic dysfunction, premature ejaculation, nonorganic vaginismus, nonorganic dyspareunia, excessive sexual drive, other sexual dysfunction (not caused by organic disorder or disease), and unspecified sexual dysfunction (not caused by organic disorder or disease).

The DSM is produced by the American Psychiatric Association (APA), which is a national professional association, whereas the ICD is produced by the WHO (a global health agency with a constitutional public health mission). The primary purpose of the DSM classification is to enable psychiatrists to diagnose, discuss, study and treat mental disorders, whereas the main purpose of the ICD is to help countries reduce the disease burden of mental disorders. The DSM is a significant revenue generator for the American Psychiatric Association, whereas the ICD is widely disseminated at low cost, with large discounts for low-income countries (American Psychological Association, 2009). While most researchers and clinicians recognise a need for diagnostic systems within the field of psychiatry, there is much debate about what form they should take, and even what purpose they serve (Bancroft, Graham, & McCord, 2001; Basson et al., 2000).

2.8 Challenges to classification systems

Classification systems of sexual dysfunction (particularly for women) have been criticised for placing too much emphasis on the physical aspects of sexual function, and for failing to acknowledge or adequately address the contextual factors that contribute to sexual difficulties (i.e. the relational context, family of origin, socio-cultural-religious background etc.). Together these factors can lead to the pathologising of normal variation in sexual response (Bancroft et al., 2001; Bancroft, 2002; Bellamy, Gott, & Hinchliff, 2013; Kaschak & Tiefer, 2001; Mitchell & Graham, 2008; Moynihan, 2003), and has led to calls from researchers and clinicians to revise classification systems accordingly (Frank, Mistretta, & Will, 2008; Kaschak & Tiefer, 2001; Leiblum et al., 2003). Using low sexual desire as an example, a lack of desire could be 1. An adaptive response to current relationship difficulties, 2. A maladaptive response resulting from negative learning or problematic personality traits (e.g. holding beliefs that sex is 'wrong' or 'dirty'), or 3. Due to an abnormality in the sexual response system. These three different conceptualisations of the same event have considerably different implications for intervention (Bancroft et al., 2001; Bancroft, 2002), and so without exploration and acknowledgement of the relational and socio-cultural factors that contribute to sexual difficulties, we run the risk of conceptualising them solely in medical terms and treating them as such.

2.9 The medicalisation of sexual function and sexual difficulties

Medicalisation is defined as the 'process through which aspects of life previously outside the jurisdiction of medicine come to be construed as medical problems' (Clarke, Mamo, Fosket, Fishman, & Shim, 2003). Medical discourse views sexual function and behaviour from a health and illness perspective, which largely emphasises the biological aspects of sexual experience, while ignoring or understating the role of the sociocultural contextual factors in the construction of sexual experience (Tiefer, 2012). For example, erectile difficulties can have a whole host of physical causes, including conditions that affect the blood flow to the penis (e.g. cardiovascular disease, high blood pressure and diabetes), the nervous system (e.g. multiple sclerosis, Parkinson's disease, and strokes), hormones (hypogonadism, over/under active thyroid gland and Cushing's syndrome), and the physical structure of the penis (e.g. Peyronie's disease); and certain prescription medications and illegal drug use can cause erectile difficulties (e.g. anti-hypertensives, anti-psychotics, anti-depressants etc.). However, erectile difficulties can also be caused by a whole range of psychological, interpersonal, and

socio-cultural factors, including depression, anxiety, relationship difficulties, a lack of sexual knowledge, past sexual difficulties, a history of sexual abuse, tiredness and stress (Althof et al., 2005; Baldwin, 2001; Heiman, 2002; Lewis et al., 2004; McCabe et al., 2010; Pastuszak, Badhiwala, Lipshultz, & Khera, 2013; Waldinger, 2007). While undoubtedly medical explanations and the availability of safe and effective drug treatments are vital to some people with debilitating sexual difficulties (Moynihan, 2010); the proclivity for immediate (prescribed) solutions such as oestrogen creams, testosterone patches, phosphodiesterase 5 inhibitors, antidepressants, and dilators, without consideration of psychosocial factors gives cause for concern (Goldbeck-Wood, 2010).

The dominance of the western medical perspective has led to the sidelining of competing viewpoints and the consequent biasing of public understanding towards a medicalised view of sexual function (Tiefer, 2012). When normal variation in sexual response becomes pathologised and labelled as 'dysfunctional', this contributes to the development and shaping of social norms around sexual response, and subsequent shame and embarrassment associated with having a sexual 'dysfunction' (Hart & Wellings, 2002). This process has implications for the treatment of sexual difficulties. On the one hand, it can create a 'need' for treatment where one might not exist; and on the other hand, the shame and embarrassment can present as a barrier to treatment for people who might actually want and need it. The medicalisation of sexual difficulties has no doubt increased with the advent and advertising of drugs to improve sexual function (Delamater & Hasday, 2007), but it is important to note that the medicalised view of sexual function is realised through diagnoses-driven psychotherapies as well as pharmaceutical therapies (Tiefer, 2012). IDIs for sexual difficulties have the potential to provide accurate and normalising information, and an anonymous way for people to gain a deeper understanding of their difficulties, explore their complex meaning and significance, and obtain further help and support if needed.

2.10 Alternative perspectives

While the medicalised view of sexual function and difficulties remains the dominant cultural trend, alternate models exist (Kaschak & Tiefer, 2001). Non-medicalised approaches to sexual health and function, such as the World Health Organisation's view of sexual health (Glasier et al., 2006), tend to take a rights-based approach rather than biomedical approach to sexual health – one that privileges potentials over norms and subjective experience over biological universals (Tiefer, 2012).

2.10.1 The New View Classification of Sexual Difficulties

An alternate perspective that has garnered much interest in the literature is the New View of Women's Sexual problems (Kaschak & Tiefer, 2001). The New View's main criticisms of existing classification systems centres on their reductionist view of sexual difficulties as being about physical function. The authors point to three main distortions: 1. The false idea of an equivalency between men and women's sexual function; 2. The neglect of the relational context of sexuality; and 3. The levelling of differences among women (i.e. not all women have the same sexual wants and needs). The New View proposes an alternate classification system of female sexual difficulties based on a biopsychosocial model, in which there are four broad causal areas of sexual difficulties: 1. Socio-cultural, political or economic factors; 2. Partner and relationship factors; 3. Psychological factors; and 4. Medical factors (Kaschak & Tiefer, 2001).

2.10.2 The dual control model

The dual control model (Bancroft, 1999; Janssen & Bancroft, 2006) provides a conceptual framework for how individual differences in sexual response may contribute to sexual difficulties. The model proposes that sexual arousal and response involve an interaction between sexual excitatory and sexual inhibitory processes. These two processes are thought to be independent of one another, and individuals can vary in their propensity for each of these processes. For many people, inhibitory processes are adaptive as they help them avoid sexual situations that might be risky or threatening. However, when the two processes interact, the outcomes can be maladaptive. For example, if a person has high excitation and low inhibition, they might be more prone to sexual risk taking. Conversely, if a person has high inhibition and low excitation they might be more prone to sexual function difficulties (Bancroft, 1999; Janssen & Bancroft, 2006). The model helps us to better understand the variability in human sexuality (Bancroft, Graham, Janssen, & Sanders, 2009); and is welcomed in what has been largely an atheoretical area (Weis, 1998) as it a) provides a framework in which to think about how psychological, physiological, social and cultural factors might interact to cause sexual difficulties; and b) permits the formulation and testing of hypotheses about sexual behaviour (Bancroft et al., 2009). Acknowledging and understanding these differences has implications for prevention and intervention in sexual difficulties (Carpenter, Janssen, Graham, Vorst, & Wicherts, 2008) .

In the final section of this chapter I will focus on the aetiology and maintenance of sexual difficulties, and psychotherapeutic interventions. As mentioned earlier in the

chapter, it is important to think about the historical and medical context of sexual difficulties as this has implications for how we label and define them (i.e. what constitutes a sexual difficulty vs a sexual dysfunction?), and how we define sexual difficulties has implications for whether and how we treat them; what or who gets researched; how services are planned; and who can access them.

2.11 Aetiology

Sexual difficulties can be caused and maintained by a range of psychological, physiological, interpersonal and socio-cultural factors (Hackett et al., 2007; Hogan, 1978). I chose to use the predisposing, precipitating and perpetuating factors from the 5 Ps formulation approach (Johnston & Dallos, 2006) to demonstrate the variety of factors associated with the aetiology and maintenance of sexual difficulties, as together they provide a therapeutically useful tool for assessment and intervention planning (See table 2; British Psychological Society, 2011). Predisposing factors are distal internal and external factors that increase a person's vulnerability to a difficulty; they provide a longitudinal understanding of the difficulty and can include events in childhood and relationships, major life events and transitions, physical and mental health, and core beliefs. Precipitating factors (or triggers) are proximal internal and external factors that trigger the presenting difficulty, and they often provide the focus for an intervention. Perpetuating factors are internal and external factors that maintain the current difficulty, and they also provide the focus for an intervention (Johnston & Dallos, 2006).

Table 2.2: Predisposing, precipitating and perpetuating factors for sexual difficulties

Predisposing factors	Inadequate sexual knowledge or stimulation
	Poor past sexual experience
	Relationship problems
	Religious or cultural beliefs
	Family values/beliefs
	Unresolved issues regarding sexual orientation and gender identity
	Previous trauma or abuse (physical or sexual)
	Physical or mental health problems
	Other sexual difficulties in the person or partner

	<p>Drug or alcohol use (recreational or prescribed)</p> <p>Smoking</p> <p>Impaired body image and/or self-esteem</p> <p>Media influence on beliefs and behaviour</p>
Precipitating factors	<p>New relationships</p> <p>Acute relationship problems</p> <p>Family or social pressures</p> <p>Pregnancy and childbirth</p> <p>Other major life events</p> <p>Acute physical or mental health problems</p> <p>Lack of knowledge about normal changes of ageing</p> <p>Performance anxiety</p> <p>Other sexual difficulties in the person or partner</p> <p>Drug or alcohol use (recreational or prescribed)</p>
Perpetuating factors	<p>Relationship problems</p> <p>Poor communication between partners</p> <p>Continued family or social pressures</p> <p>Physical or mental health problems</p> <p>Lack of knowledge about treatment options</p> <p>Performance anxiety</p> <p>Ongoing physical or mental health problems</p> <p>Other sexual difficulties in the person or partner</p> <p>Drug or alcohol use (recreational or prescribed)</p> <p>Impaired body image and/or self-esteem</p> <p>Inadequate sexual knowledge or stimulation</p> <p>Environmental constraints</p> <p>Feelings of guilt</p>

(Althof et al., 2005; Baldwin, 2001; Lewis et al., 2004; McCabe et al., 2010; Pastuszak et al., 2013)

2.12 Psychotherapeutic intervention in sexual difficulties

Psychotherapeutic interventions can effectively treat sexual difficulties (Berner & Günzler, 2012; Fruhauf et al., 2012; Günzler & Berner, 2012). In a recent systematic review and meta-analysis of psychotherapeutic interventions for sexual difficulties (Fruhauf et al., 2012), 20 randomised controlled trials (RCTs), comparing psychotherapeutic interventions to waitlist control, were combined in a meta-analysis. Post-treatment, the overall effect size was $d = 0.58$ (95% CI: 0.40 to 0.77) for symptom severity, and $d = 0.47$ (95% CI: 0.27 to 0.70) for sexual satisfaction. Although some of the included studies were of low methodological quality, the evidence suggests that psychotherapeutic interventions for sexual difficulties can be effective.

Psychotherapeutic interventions have progressed from the early behavioural approaches, which included sensate focus (a series of touching exercises designed to increase intimacy in a sexual relationship), systematic desensitisation (gradual increased exposure to sexual activities that cause anxiety), and the 'squeeze technique', which is a technique used to control ejaculation (Masters & Johnson, 1966a, 1966b), to those that combine behavioural approaches with cognitive techniques, such as identifying and challenging negative thought patterns (around sex, the self and partners), as well as techniques to manage anxiety and build relationship skills (Binik & Meana, 2009; Bitzer & Brandenburg, 2009). Combining psychoeducation, behavioural techniques and communication skills has been found to be effective, particularly in combination with systemic approaches that view difficulties as arising through patterns of interaction between those in a relationship, rather than in the individual (Gehring, 2003; Heiman & Meston, 1997).

There is still much work to be done to establish a solid evidence base for psychotherapeutic intervention for sexual difficulties, in terms of what approaches works best for particular sexual difficulties (Fruhauf et al., 2012), but existing evidence, in conjunction with the high rate of discontinuation of medical treatments (Jiann, Yu, Su, & Tsai, 2005; Son, Park, Kim, & Paick, 2004), suggests that psychosexual services should be made more widely available to those that might want/need them (Shepherd et al., 2009). Unfortunately, with the recent cuts in the National Health Service, and the imminent further cuts to sexual health services across the UK, the provision of much needed psychosexual services will likely decrease rather than increase. However, IDIs for sexual difficulties have the potential to play a role in increasing psychosexual support to those that want and need it.

2.13 My approach to this thesis

This chapter highlights the complex nature of sexual difficulties, and how they are influenced by a wide range of biological, psychological, interpersonal and socio-cultural factors. Despite this, medical conceptualisations and classifications have largely dominated the field of sexual difficulties. The absence of consistent, well-defined, and broadly accepted definitions and classification systems of sexual difficulties can lead to over-inflation or underestimation of prevalence, and over diagnosis or under-detection of sexual difficulties, and has hampered research progress in this area (Basson et al., 2000). The way we conceptualise and define sexual difficulties is important as it has implications for how sexual difficulties can be treated.

In this thesis I attempt to acknowledge some of these complexities, by conceptualising sexual difficulties using a biopsychosocial approach (Berry & Berry, 2013; McCabe et al., 2010). The biopsychosocial approach is a theoretical framework that suggests that biological, psychological and social factors interact and play a significant role in the cause, manifestation and outcome of psychological and physical health and illness, rather than just biology alone (Engel, 1980).

In line with other researchers I chose to use the term sexual difficulties throughout the thesis (instead of sexual problems or dysfunctions) to avoid making assumptions about what may or may not be problematic to individuals. In Chapter 6, when determining the reach of IDIs for sexual difficulties, I defined the populations of interest to reflect those that might want help for their difficulties (rather than simply those that merely reported sexual difficulties); and in Chapter 7, by not making assumptions about whether people perceived their sexual difficulties as problematic, I aimed to capture each participant's own unique perspective on their difficulties.

2.14 Implications for the design and development of IDIs for sexual difficulties

Effective psychotherapeutic interventions are currently available for sexual difficulties, but multiple barriers prevent many people from accessing services and receiving help. By taking a biopsychosocial approach to sexual difficulties (Engel, 1980), and using language and definitions that do not make assumptions about a person's gender, sexuality, culture or experiences, IDIs are capable of providing anonymous and culturally sensitive information and support to people who want help for their sexual difficulties (Althof et al., 2005; Hall & Graham, 2012). While IDIs are limited in what they can respond to (i.e. they cannot perform the physical investigations that are needed in

men with erectile difficulties and women with sexual pain, and they cannot deal with the unexpected or content not covered by the program), a well-designed and tailored IDI can tackle many different aspects of sexual difficulties: Some of the physical symptoms can be addressed by using behavioural exercises; psychological factors can be addressed by helping users identify and challenge negative thought patterns (around sex, the self and partners) and providing techniques to manage anxiety; and interpersonal and socio-cultural factors can be addressed by using systemic exercises to explore the meaning of a person's sexual difficulties in the context of their own lives, and building or strengthening partner communication skills.

Chapter 3
**What are IDIs? And why are they worth
studying?**

3.1 Chapter overview

In the Introduction (Chapter 1) we saw that IDIs have the potential to meet some of the current unmet need in the area of sexual difficulties. In this chapter I explore the literature on IDIs in more detail to provide the broader context of the thesis as it pertains to IDIs for sexual difficulties. I begin the chapter by outlining why and how IDIs came about. I then move on to discuss the terminology and definitions used in this area, and how these have evolved over time. Building on those mentioned briefly in the Introduction, I provide an in-depth and critical look at the advantages and disadvantages of IDIs, both more broadly in other areas of physical and mental health, and more specifically pertaining to IDIs for sexual difficulties. I then outline what we know about the effectiveness of IDIs in other areas of physical and mental health, before looking more closely at the evidence of effectiveness of IDIs for sexual difficulties. I end the chapter by highlighting some of the gaps in the literature in this area that will be filled by this thesis.

3.2 How and why have IDIs come about?

E-health is an emerging field that involves the use of information and communication technology to improve health and healthcare (Oh, Rizo, Enkin, & Jadad, 2005). Its increasing popularity is, in part, due to the increased burden on the National Health Service (NHS). An ageing population, an increase in long-term health conditions, and an increase in behaviours that are detrimental to health mean that there is growing demand for health care services, and the importance of technology in meeting the challenges placed on the health care system is becoming increasingly more apparent (Liddell, Adshead, & Burgess, 2008). After a period of increased funding within the NHS, we have now entered a period of acute austerity (Murray, 2014); yet widespread dissemination of health promotion and disease prevention information is much needed. IDIs for a variety of different health and mental health problems appear to play a part in the solution and have come to be regarded as a critical evidence-based intervention option (Portnoy et al., 2008; Ritterband & Tate, 2009).

3.3 What are IDIs?

Reflecting the evolving nature of the field, many different terms have been used to describe a wide variety of different health-based treatment and prevention programs typically delivered online; a few examples include e-therapy, online treatment, web-based programs, and internet interventions. Unifying the terminology in this area has been difficult, in part, due to the heterogeneity of web-based programs and online communication capabilities (Barak, Klein, & Proudfoot, 2009; Ritterband & Tate, 2009). Furthermore, rapidly changing technology has led to changes in the way we access and interact with technology, and previous definitions have been unable to account for these changes. If we are to be able to evaluate the effectiveness of different online treatment and prevention programs, then it is important to work towards a consensus on how to define these different types of interventions.

Considering the evolution of the field and its complexities, it is important to clarify the terminology used in this thesis. As outlined in Chapter 1, I use the term IDIs to describe programs that provide information and support for sexual difficulties via a digital platform (i.e. via the internet or software), through a digital device (i.e. desktop computer, tablet, smartphone etc.). IDIs are considered interactive because input from the user(s) alters pathways within the program, to produce tailored and relevant information and feedback to the user(s). IDIs can vary by content (i.e. psychotherapeutic approach, active ingredients, targets for change), extent of

interactivity, tailoring, level of human support provided (e.g. none, engagement, and therapeutic), type of support (professional or peer), mode of delivery of support (e.g. email, phone), multi-media communication type (e.g. synchronous or asynchronous), target users, and recommended frequency/duration of use. IDIs are distinct from counselling and therapy delivered online, Internet-operated therapeutic software (e.g. robotic simulation), web-based education interventions (e.g. non-interactive or static interventions), and other online activities, such as blogs, podcasts, online support-groups, and online assessments (Barak et al., 2009). IDIs are complex interventions, which means they are 'built up from a number of components, which may act both independently and inter-dependently. The components usually include behaviours, parameters of behaviours (e.g. frequency, timing), and methods of organising and delivering those behaviours, such as type(s) of practitioner, setting and location (Medical Research Council, 2000).

3.4 Advantages of IDIs

IDIs have permitted the broadening of the scope and diversity of health interventions (Barak et al., 2009), and have a number of advantages over interventions delivered face-to-face. Two key advantages are their scalability and reach, which are important aspects of public health interventions (Bennett & Glasgow, 2009). In 2014, 22 million UK households (84%) had internet access (ONS, 2014), and although in the past the UK has lagged behind other European countries in extent of adoption of technology-enabled care (TEC), the European Commission is in the process of developing policies to address barriers to adoption of TEC (Taylor, 2014); and in the coming years the speed and scale of adoption of health IT in the UK is set to rise, with 'exploitation of the information revolution' a key part of the NHS Five year forward view (NHS England, 2014).

IDIs allow flexible and convenient usage, as they can be accessed simultaneously, by a large number of users, 24 hours a day (Bennett & Glasgow, 2009). IDIs are also capable of cost-effective (Donker et al., 2015), wide and uniform dissemination of evidence-based support programs (Bailey et al., 2010; Ritterband & Tate, 2009), in a range of different settings (Bennett & Glasgow, 2009); and their content can easily be updated. If designed carefully, and used as intended, IDIs have the potential to increase health literacy and reduce health disparities, particularly among those who are geographically isolated or isolated due to stigma associated with their condition (Ritterband & Tate, 2009). Although there has been limited research into the cost-

effectiveness of IDIs (Griffiths, Lindenmeyer, Powell, Lowe, & Thorogood, 2006; Tate, Finkelstein, Khavjou, & Gustafson, 2009), the costs associated with IDIs are primarily related to their initial development and the ongoing maintenance of the intervention (Tate et al., 2009); and thus, unlike face-to-face intervention, the cost for each additional user is relatively low (Griffiths et al., 2006; Linke, Murray, Butler, & Wallace, 2007; Murray, 2009). If effective and used as intended IDIs have the potential to be more cost-effective than face-to-face interventions (Bailey et al., 2015).

The content of IDIs can be delivered in different formats (e.g. text, video, graphics and audio), and unlike other delivery channels of public health information their interactive nature means that information can be tailored to meet the individual needs of the user (Bennett & Glasgow, 2009; Lustria et al., 2009). In IDI tailoring data-driven decision rules are applied to information that has been inputted by the user to produce automatic and sensitive personalised feedback (Krebs et al., 2010). IDIs also permit the user to define the pace of learning, and revisit in-session content after the end of the session; and automated reminders sent via text or email can likewise be personalised to the user.

When used as an adjunct component of face-to-face therapy, IDIs have the potential to extend the support provided, facilitate skill acquisition and practice, and enhance motivation and engagement, (Andersson & Titov, 2014; Danaher & Seeley, 2009); and when used as part of a stepped care model IDIs can provide initial support and psychoeducation to less severe cases, while freeing up face-to-face therapist time for more complex cases (Ritterband & Tate, 2009; Scogin, Hanson, & Welsh, 2003).

IDIs may be particularly well-suited to the treatment of sexual difficulties for the following reasons:

1. IDIs provide an innovative way of accessing this hard to reach population (Boeltzig & Pilling, 2007).
2. The privacy and anonymity of IDIs are particularly appealing given the stigma and embarrassment often associated with sexual difficulties (Thomas, McLeod, Jones, & Abbott, 2015).
3. IDIs have the potential to address many of the barriers associated with seeking face-to-face therapy that were mentioned in Chapter 1, including a lack of available specialist services, long waiting lists and discomfort and embarrassment raising the issue with health professionals.

4. Research suggests that IDIs facilitate disclosure of sensitive information as people are often less inhibited when using computer-enabled communication, and thus more inclined to disclose sensitive information than when face-to-face with a therapist (Suler, 2004).
5. The provision of 24hr help and support allows couples maximal flexibility in when and how they use the intervention. For example, a person and their sexual partner(s) could watch or read program material separately (or simultaneously but on different computers), perform the prescribed exercises together, and then fill out assessment forms separately on a smart phone and/or computer (Rochlen et al., 2004).

3.5 Disadvantages of IDIs

While there are many advantages of IDIs, there are also some disadvantages. Inequities in the ownership of digital devices (e.g. laptops, tablets and smart phones) and internet access (the 'digital divide') continue to prevent certain groups of people from accessing and benefiting from these types of interventions (Carlbring & Andersson, 2006; National Telecommunications and Information Administration, 2013); these groups include lower income groups, people with no formal educational qualifications, people over 65 years old, and people with disabilities (Dutton, Blank, & Groselj, 2013). While internet access has risen dramatically in the general population (National Telecommunications and Information Administration, 2013; ONS, 2014), from 77% of UK households having access in 2011 (ONS, 2011) to 84% in 2014 (ONS, 2014), and smart-phone access to the internet has more than doubled since 2010, from 24% to 58% (ONS, 2014), internet use levels in these minority groups range between 39-50% (Dutton et al., 2013). No medical interventions or services are equally accessible or effective for all, but equality is not achieved by levelling down; and the provision of IDIs may well free up resources that could target groups that are not well-served by IDIs.

Online security is also a potential concern for IDIs, but there are multiple ways to increase online security, including using SSL certificates, encryption, anonymous login names, automatic timed log-off, and not caching web documents on the local computer (Barak et al., 2009; Carlbring & Andersson, 2006; Midkiff, 2008; Nosek et al., 2002). The stigma associated with sexual difficulties may make the concern of online security particularly salient in IDIs for sexual difficulties, but the methods to increase online security remain the same. The NHS' response to issues of online security has been to

set up the N3 network, which is a highly secure and fast national broadband network created specifically for the NHS (Benn, 2006). Any and all NHS based IDIs would be launched via this network, and benefit from the security it provides.

IDIs are contraindicated for some individuals. For example, IDIs are not considered appropriate for people with more severe mental health problems, such as psychotic disorders, personality disorders, bipolar disorders, people with suicidal ideation or people with active substance use problems (Carlbring & Andersson, 2006; Ragusea & VandeCreek, 2003); and people experiencing severe relationship difficulties or intimate partner violence are advised to address these issues first before addressing their sexual difficulties (Cobia et al., 2008). However, IDIs do have the capability of determining the appropriateness of the IDI for the potential user and can signpost a person to alternative help-sources if necessary. For example, if, based on particular answers to particular questions, a person was deemed at risk of harm to themselves, a screen could pop-up with crisis support numbers on it and signposting information to relevant services (Proudfoot, 2004).

A lack of sustained engagement is an on-going problem for IDIs (Christensen et al., 2009; Dunn et al., 2012; Eysenbach, 2005). It is important to distinguish engagement (use of an intervention over time) with an intervention from poor retention to study follow up, as both have been referred to in the literature as attrition (Geraghty, Wood, & Hyland, 2010). For the purposes of this thesis I define engagement as the extent to which users use an IDI, and this can be measured using the number of site visits, webpages viewed, modules completed, duration of visits, and time spent practicing what has been learned (Danaher & Seeley, 2009). Engagement (also known as website utilisation) is important because it is correlated with effectiveness (Bennett & Glasgow, 2009). While engagement and non-usage attrition can be problematic with IDIs, current evidence suggests that this is modifiable. Factors that have been found to increase adoption and engagement of IDIs are the provision of human support (Andersson, 2009; Bennett & Glasgow, 2009; Brouwer et al., 2011; Christensen et al., 2009; Kelders, Kok, Ossebaard, & Van Gemert-Pijnen, 2012; Schubart, Stuckley, Ganeshamoorthy, & Sciamanna, 2011); tailored advice and feedback (Schubart et al., 2011); increased frequency of website updates (Kelders et al., 2012); telephone reminders (Brouwer et al., 2011; Titov, Andrews, Choi, Schwencke & Johnston, 2009); text message and email reminders (Alkhaldi, Hamilton, Lau, Webster, Michie & Murray, 2016; Brouwer et al., 2011; DeLeon, Fuentes & Cohen, 2014; Woodall, Buller, Saba, Zimmerman, Waters, Hines et al., 2007).

According to the Persuasive Systems Design (PSD) model (Oinas-Kukkonen & Harjumaa, 2009) one of the key mechanisms of action by which people adopt and engage with IDIs is persuasion. According to the model, there are four key areas of persuasive design, which are primary task support, dialogue support, system credibility support and social support (Oinas-Kukkonen & Harjumaa, 2009); an evidence-base for the model is building (Lehto & Oinas-Kukkonen, 2011).

1. Primary task support involves design features that support users in carrying out their primary task, and which include breaking complex behaviours down into smaller and more simple tasks, tunnelling (where the system intentionally guides users through a process that exposes them to persuasive content), tailoring and personalisation, self-monitoring systems (Bennett & Glasgow, 2009), simulation (to demonstrate cause and effect), and opportunities for rehearsal (Lehto & Oinas-Kukkonen, 2011).
2. Dialogue support involves design features that provide user feedback that is intended to help users continue to move towards their goal or target behaviour; these include praise, rewards, reminders, tips/suggestions, similarity (i.e. using language or other content familiar to the user group), liking (i.e. using system features that appeal to users), and social role (i.e. system adopts a social role, such as facilitating communication between users and health professionals) (Bennett & Glasgow, 2009; Kelders et al., 2012; Lehto & Oinas-Kukkonen, 2011).
3. System credibility support involves design features that promote credibility of the system, and include utilising the principles of trustworthiness, expertise, surface credibility, real-world feel (i.e. providing information about the people behind the intervention content and design), authority, third-party endorsements (from respected sources), and verifiability (i.e. users should be able to verify the accuracy of the intervention content; Lehto & Oinas-Kukkonen, 2011).
4. Social support involves design features that motivate users by using social influence, including social learning (i.e. learning by observing others), social comparison, normative influence and social facilitation, cooperation (i.e. achieving change by leveraging humans' innate drive to cooperate), competition, and recognition (for achievements; Lehto & Oinas, Kukkonen, 2011).

While the Persuasive Systems Design model is not a change theory, it does provide a useful framework by which to maximise engagement. However, more research is needed to determine which aspects of IDIs to target to increase engagement in different populations, with different physical or mental-health difficulties.

Other criticisms of IDIs that remain unresolved are the potential risk of negative consequences for users, including aggravating problems they are actually attempting to solve (e.g. isolation), and misdiagnosis and poor treatment selection as a result of self-diagnosis and assessment (Ritterband et al., 2011). The presence of risk does not necessarily preclude the use of an intervention with obvious potential benefits (Childress, 2000), but the trend towards therapist supported IDIs may go some way to minimise misdiagnoses, incorrect treatment decisions and feelings of isolation.

3.6 IDIs for physical and mental-health problems

There is now a substantive body of research to support the feasibility and effectiveness of IDIs across a wide range of behavioural, psychological and somatic problems (Bailey et al., 2010; Ritterband et al., 2011). In the area of health-behaviour change, IDIs have been applied to sexual health promotion (Bailey et al., 2010; Murray, Burns, See, Lai, & Nazareth, 2005; Portnoy et al., 2008) and HIV prevention (Noar et al., 2009); physical activity (van den Berg, Schoones, & Vliet Vlieland, 2007); weight loss (Saperstein, Atkinson, & Gold, 2007; Weinstein, 2006); alcohol consumption (Khadjesari et al., 2011); tobacco use (Brown et al., 2012); and diabetes self-management (Pal. et al., 2013). In the area of mental health, IDIs have been used with people with depression (Barak et al., 2008); anxiety (Barak et al., 2008); panic attacks (Barak et al., 2008; Ritterband et al., 2011); obsessive-compulsive disorder (Andersson et al., 2012; Wootton, Dear, Johnston, Terides, & Titov, 2013), and traumatic stress (Barak et al., 2008; Benight et al., 2008). Finally, in the area of somatic problems, IDIs have been empirically tested on headaches (Barak et al., 2008; Cuijpers, van Straten, & Andersson, 2008; Ritterband et al., 2011); tinnitus (Cuijpers et al., 2008; Ritterband et al., 2011); pain (Cuijpers et al., 2008); insomnia (Cuijpers et al., 2008); and paediatric encopresis (Ritterband et al., 2011). Across all of these areas, IDIs have yielded positive, albeit highly variable and often small effects on outcomes such as symptom reduction, behaviour change, and quality of life; and their increasing use in these health-related areas holds promise for their use in treating or ameliorating sexual difficulties.

3.7 IDIs for sexual difficulties

Over the past decade, a small number of studies have been conducted on IDIs for sexual difficulties.

3.8 Observational studies

Hardy et al. (Hardy et al., 2010) conducted a cross-sectional study of an online psychoeducational program for 138 individuals with problematic pornography use and masturbation. When comparing retrospective ratings to current ratings, all participants showed significant improvements in all measured aspects of recovery. McCabe and Price (McCabe & Price, 2008) conducted a small non-randomised study of 12 men, comparing the effectiveness of an internet-based psychological treatment program for men with erectile dysfunction with the same treatment program plus oral medication. Both treatment groups showed improvements from pre-test to post-test in sexual function, relationships and personal wellbeing.

3.9 Randomised Controlled Trials (RCTs)

Jones and McCabe (Jones & McCabe, 2011) conducted a RCT with 53 women to determine the effectiveness of an Internet-based psychological treatment program for Female Sexual Dysfunction (FSD) compared to no intervention. FSD is a collection of sexual disorders that include sexual interest/arousal disorder, orgasm disorder and sexual pain disorders. Women in the treatment group reported significantly greater improvements in sexual and relationship functioning than women who received no treatment. Schover et al. (Schover et al., 2012) conducted a RCT with 103 couples to compare internet-based counselling with face-to-face counselling for erectile dysfunction relating to prostate cancer treatment. The internet-based treatment was found to be equally as effective as the face-to-face treatment, with improvement in erectile function observed in both groups.

The results of these studies look promising; however, they must be treated with caution due to the small number of studies, and several methodological limitations, including small sample sizes, a lack of randomisation to groups, and high attrition rates. Limitations notwithstanding, these early studies highlight the potential for IDIs to meet some of the demand for accessible treatment for sexual difficulties.

3.10 Gaps in the literature

The field of IDIs is clearly a fertile area for research, as much is still not known about IDIs – particularly IDIs for sexual difficulties. To date, no studies have reviewed the effectiveness, assessed the potential reach, or explored users' views of IDIs for sexual difficulties. As outlined in the Introduction (Chapter 1), this thesis aims to fill these current gaps in the literature, and answer some of the currently unanswered questions about the feasibility of IDIs in the area of sexual difficulties.

Chapter 4
IDIs for sexual difficulties in adults:
A systematic review and meta-analysis

4.1 Chapter overview

Introduction

IDIs have the potential to meet some of the current unmet need for treatment in the area of sexual difficulties, but before healthcare providers invest in the design and development of these interventions it is necessary to review their effectiveness. There are currently no systematic reviews of IDIs for sexual difficulties, and therefore a systematic review of the effectiveness of IDIs for sexual difficulties was a suitable starting point for this thesis.

Objective

The aim of this systematic review was to evaluate the effectiveness of IDIs for sexual difficulties, on sexual outcomes, relational outcomes, negative emotional states, and quality of life in adults aged 18 and over.

Methods

Cochrane Collaboration guidelines informed the review. The search strategy was implemented across 8 databases: Cochrane Central Register of Controlled Trials (CENTRAL), MEDLINE, Cumulative Index to Nursing & Allied Health Literature (CINAHL), Excerpta Medica Database (EMBASE), Web of Science, PsycINFO, International Bibliography of the Social Sciences (IBSS), and Educational Resources Information Centre (ERIC). Databases were searched from inception to January 2013, with no language restrictions, and using three overlapping concepts: randomized controlled trials, sexual difficulties and interactive digital interventions. Grey literature and trials registers were also searched. Titles and abstracts were independently screened by 2 authors, and data from included studies was extracted by one author. Bias was assessed using the Cochrane risk of bias assessment tool. A narrative synthesis was performed on all included studies, and where appropriate, data were pooled using meta-analysis.

Results

A total of 10 studies were included in the review with 858 participants. Of the 10 studies, 4 had sufficient data to be included in the meta-analyses. The meta-analyses suggested that IDIs can have a positive effect on sexual and relationship outcomes in women (there was insufficient evidence to draw conclusions about the effects on men/male sexual difficulties), but due to the small sample sizes, presence of bias within

some trials, and the presence of statistical heterogeneity the findings must be treated with caution.

Conclusion

The conclusions are drawn on a small evidence base, but suggest that IDIs can have a positive effect on sexual and relationship outcomes in women. Despite the methodological limitations of the studies within the review, the findings suggest that IDIs show real promise as a potentially cost-effective method of addressing some of the current unmet need for help and support in the area of sexual difficulties.

4.2 Background

As outlined in the Chapter 1, IDIs present a potentially cost-effective method of providing 24hr access to help for sexual difficulties that is anonymous and tailored to meet individual needs. IDIs have the potential to meet some of the current unmet need for the treatment of sexual difficulties, and in Chapters 1 and 3 I provided an overview of some of the promising research in this area. But research in this area is in its infancy, and, overall, little is currently known about the effectiveness of IDIs for sexual difficulties; how they might compare to face-to-face interventions; and whether they have the potential to cause harm. Furthermore, IDIs vary on multiple dimensions: use of tailoring and feedback, level of interactivity, use of human support, use and synchronicity of multi-media channels of communication, audience reach, theoretical base, target population and sexual difficulty; and the range and types of IDIs for sexual difficulties is currently unknown.

A systematic review is a way of identifying, summarising and synthesising available primary research that answers a specific research question (Cochrane, 1972); they are commonly used to establish the clinical and cost effectiveness of interventions, and strive to bring the same level of rigour to secondary research (i.e. the process of reviewing the primary research evidence) as is expected in the primary research itself (Hemingway & Brereton, 2009). A high quality systematic review seeks to:

1. Identify all published and unpublished evidence relevant to the research question;
2. Select studies for inclusion, according to predefined inclusion and exclusion criteria;
3. Assess the risk of bias of each study, with a view to considering the robustness of the data;
4. Summarise the included studies;
5. Synthesise the data from the included studies;
6. Interpret the findings and present a balanced, unbiased summary that answers the original research question (Cochrane, 1972; Hemingway & Brereton, 2009).

Systematic reviews of interventions contribute to evidence-based practice by informing health care professionals and policy makers about the existing evidence for an

intervention. The findings from systematic reviews also provide directions for future research, as they highlight the methodological rigour of the research that has been conducted in the area and illuminate gaps in the literature. Systematic reviews can be conducted on different study designs, but systematic reviews and meta-analyses of randomised controlled trials are thought to provide the highest level of evidence when investigating the effects of an intervention (Harbour & Miller, 2001).

I decided to conduct a systematic review as the starting point for this thesis as it enabled me to:

1. Identify the evidence of effectiveness in the area of IDIs for sexual difficulties and assess the robustness of the available data;
2. Synthesise the available data with the aim of determining whether IDIs for sexual difficulties show promise as potentially effective interventions;
3. Use the findings from the review to inform the future research of the thesis.

4.3 Aims and objectives

The aim of this systematic review was to evaluate the effectiveness of IDIs on sexual outcomes, relational outcomes, negative emotional states, and quality of life in adults aged 18 and over. The specific objectives were to:

1. Identify, describe and classify the range and types of IDIs for sexual difficulties that have been evaluated for effectiveness;
2. Summarise the available data on effectiveness of such interventions on sexual, relational, emotional and quality of life outcomes, including assessing the robustness of included studies, describing factors likely to influence effectiveness (including differences between study settings, populations, interventions, comparators and outcomes); and coding behaviour change techniques (BCTs) using the BCT taxonomy (Michie et al., 2013);
3. Gather data on any unintended adverse outcomes of IDIs and cost data;
4. Synthesise the available data;
5. Make practice and policy recommendations based on the results of the evidence synthesis.

4.4 Research questions

1. Are IDIs for sexual difficulties more effective than minimally active comparator groups at improving sexual, relational, emotional and quality of life outcomes?
2. Are IDIs as effective as active comparator groups at improving sexual, relational, emotional and quality of life outcomes?
3. Are IDIs combined with face-to-face therapy more effective than either alone?

4.5 Definitions

4.5.1 Sexual difficulties

I defined sexual difficulties as difficulties during any stage of the sexual response cycle (desire, arousal, orgasm and resolution) that prevent an individual and/or their sexual partner(s) from enjoying pleasurable and safe sexual experiences (Masters & Johnson, 1966a). Sexual difficulties can be cognitive, affective, behavioural and/or physiological (Hogan, 1978).

4.5.2 Interactive digital interventions (IDIs)

I defined IDIs as 'programs that provide information and support (emotional, decisional and/or behaviour support) for physical and/or psychological sexual difficulties via a digital platform (i.e. a website or software). IDIs are interactive, meaning that they require contributions from the user(s), which alter pathways within the program, to produce tailored information and feedback that is personally relevant to the user(s). IDIs can vary on multiple dimensions (Bailey et al., 2010; Barak & Grohol, 2011; Barak et al., 2009; Carlbring & Andersson, 2006; Eysenbach, 2011).

4.6 Method

4.6.1 Inclusion criteria

The scope of the review was developed by defining inclusion criteria for participants, interventions, comparators, outcomes, and study design (PICOS; Liberati et al., 2009).

4.6.2 Types of participants

Studies of adult users (aged 18 or over) were included irrespective of gender, sexuality, ethnicity, nationality, health status, and type of sexual difficulty.

4.6.3 Types of interventions

IDIs that aimed to improve sexual difficulties, and which met the study definitions of IDIs and sexual difficulties.

4.6.4 Excluded interventions

I excluded the following types of intervention modules—unless they were included as a structured adjunct component of an IDI—because they did not fit the study definition of IDIs:

- Static information only websites
- Blogs
- Forums/chat rooms
- Mobile phone text support
- E-books
- Computer-based/digital assessment tools
- Telephone helplines
- Digitally-mediated consultations

4.6.5 Types of comparator

I included studies that compared IDIs to any of the following types of comparator, and grouped studies accordingly. Studies with minimally active comparators (e.g. waitlist control, basic written materials, videos or conditions with no sexual difficulty content) were used to determine the effectiveness of the IDI compared to no intervention; studies with active comparators (e.g. face-to-face treatment or online forums) were used to determine the relative effectiveness of IDIs compared to current practice.

4.6.6 Types of outcome measures

4.6.6.1 *Primary outcomes of interest*

I aimed to identify primary outcomes that were relevant to both men and women, and across a broad range of sexual difficulties. The outcomes that best fit these criteria were:

1. Sexual function (physical)
2. Level of distress associated with the sexual difficulty (moods/feelings)
3. Sexual satisfaction (thoughts)

4.6.6.2 **Secondary outcomes of interest**

Secondary outcomes were selected to reflect the proposed pathway of action of IDIs, and outcomes reported in the literature as important to users. See Figure 4.1.

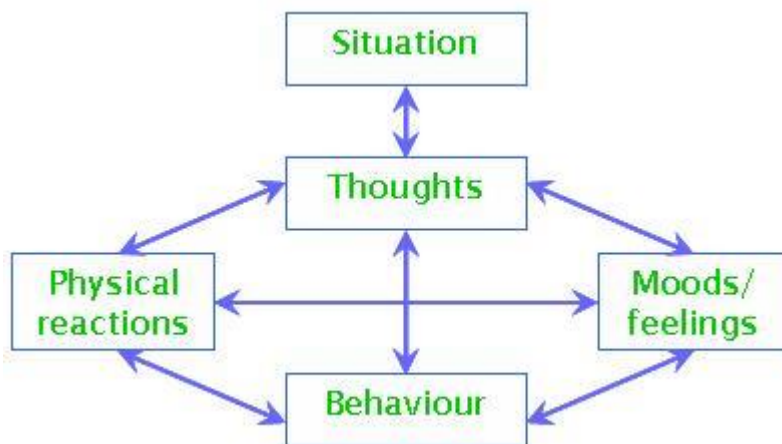


Figure 4.1: The five areas cognitive-behavioural model of problem activation.

(Williams & Garland, 2002)

Secondary outcomes of interest included the following:

- Sexual outcomes
 - o Sexual self-efficacy (thoughts)
 - o Sexual desire (thoughts)
 - o Sexual beliefs (thoughts)
 - o Sexual behaviour (behaviour)
- Relationship outcomes
 - o Communication (behaviour)
 - o Emotional intimacy (behaviour)

- Negative emotional states
 - o Depression (moods/feelings)
 - o Anxiety (moods/feelings; physical)
 - o Distress (moods/feelings)
 - o Stress (moods/feelings)
- Quality of life (thoughts; moods/feelings; behaviour)
- Unintended adverse effects (thoughts; moods/feelings; behaviour; physical)
- Economic outcomes (costs/cost-effectiveness outcomes to permit analysis of cost-effectiveness)

4.6.7 Types of studies

Individual and cluster randomised controlled trials (RCTs). All other study designs were excluded from the review owing to the high potential for bias in these designs.

4.6.8 Search methods for identification of studies

The overall search strategy was performed in four stages. First, I searched for published work in electronic databases. Second, for unpublished work in grey literature databases. Third, for on-going and recently completed trials. And finally, I used hand searching, reference tracking, citation tracking and contacted authors and research groups to identify any further relevant work. All databases were searched from their start date to Jan 2013, with no language restrictions. Alerts remained on all databases of published work up until August, 2015. Consequently two more studies/three more papers (that were considered ongoing trials in the initial search) that were published in 2014 and 2015 were added to the review (Hucker & McCabe, 2014; Hucker & McCabe, 2015; Wootten et al., 2015).

The search strategy consisted of three overlapping concepts:

1) RCT study design filter

AND

2) Sexual difficulties

AND

3) Interactive Digital Interventions

See Appendix A for the database search strategies.

4.6.9 Databases

I searched the following eight databases: Cochrane Central Register of Controlled Trials (CENTRAL), MEDLINE, Cumulative Index to Nursing & Allied Health Literature (CINAHL), Excerpta Medica Database (EMBASE), Web of Science, PsycINFO, International Bibliography of the Social Sciences (IBSS), and Educational Resources Information Centre (ERIC).

4.6.10 Grey (unpublished) literature

I searched the following seven grey literature databases: Open System for Information on Grey Literature in Europe (OSIGLE) <http://www.greynet.org/opensiglerepository.html>; Healthcare Management Information Consortium (HMIC) – accessed online through UCL library website; National Technical Information Service (NTIS) www.ntis.gov; PsycEXTRA – accessed online through UCL library website (unpublished trials); Conference Proceedings Citation Index (formerly ISI proceedings) – this was included in the Web of Science search; Index to Theses (ITT) www.theses.com; ProQuest Dissertations & Theses Database (PQDTD) www.proquest.co.uk – accessed online through UCL library website.

4.6.11 Ongoing and recently completed trials

I searched the following six trials registers: International Standard Randomised Controlled Trial Number Register (ISRCTN) www.controlled-trials.com/isrctn; ClinicalTrials.gov/US National Institute of Health Service (USNIHS) <http://clinicaltrials.gov>; WHO: International Clinical Trials Registry Platform (WHO: ICTRP); NIHR National Research Register (NIHR: NRR) www.nihr.ac.uk/Pages/NRRArchive.aspx formerly the Research Findings Electronic Register - UKDOH: ReFeR); The Australian New Zealand Clinical Trials Registry (ANZCTR) www.anzctr.org.au; and Center Watch Clinical Trials Listing Service (CWCTLS) www.centerwatch.com.

4.6.12 Reference tracking, Citation tracking and Hand searching

To further identify any relevant papers for inclusion I checked the reference lists of all papers that made it through to the full-text extraction phase. I also checked to see if any of the included papers had been cited by more recent papers. After a preliminary scoping review of the literature, I hand-searched the contents pages of the following 12 journals: Archives of Sexual Behavior, Annals of Behavioral Medicine, CyberPsychology and Behavior, Computers in Human Behavior, Journal of Sexual Medicine, Journal of Sex Research, Journal of Sex and Marital Therapy, Journal of Medical Internet Research, Journal of Technology in Human Services, International Journal of Impotence Research, Sexologies, and Sexual and Relationship Therapy.

4.6.13 Expert input

I contacted relevant experts to further identify any relevant studies.

4.6.14 Validation of search strategies

The search was validated by choosing five known papers in the area and seeing if the search strategy picked these known papers up.

4.6.15 Data collection

4.6.15.1 *Study selection*

I downloaded all citations identified by the search and de-duplicated them using EndNote software. I used the inclusion and exclusion criteria to screen all the titles and abstracts for relevance and inclusion in the review. Full texts were obtained for any potentially relevant papers. A second reviewer (JR) independently screened all the titles and abstracts, and any discrepancies were resolved through discussion and the involvement of a third researcher (JB) where necessary.

4.6.15.2 *Data extraction and management*

The data extraction form was developed using the Cochrane Collaboration guidelines (Higgins & Green, 2011), and Consort e-Health reporting guidelines (Eysenbach, 2011). The form included details of the study population (including demographics, sexual difficulty and country), study design, methods, setting, intervention description (including mode of delivery, level of human support, type of support, communication channels used for support, degree of synchronicity of communication, frequency and

duration of support, intervention content [i.e., psychotherapeutic approach], extent of interactivity [i.e., tailoring and feedback], duration of the program, and frequency of program use), fidelity measures, engagement measures, inclusion/exclusion criteria, method of recruitment, success rate of recruitment, incentive/cost to participate, comparator descriptions, informed consent, consumer involvement, intervention costs, methodological risk of bias items, and study outcomes (see Appendix B for data extraction form). Data were extracted for all outcomes of interest, and details on the use of validated measurement scales were noted. Authors were contacted to retrieve any missing outcome data.

The data extraction form was piloted on five eligible full texts and refined as necessary. Using the data extraction form a second reviewer and I independently extracted full-text data (with no blinding to authors or journal), and all data was entered into an excel spread sheet and Revman systematic review software, version 5.2. The use of validated measurement scales was noted. The accuracy of the data transfer was checked by a third researcher (JB). All studies rejected at full text stage were tabulated, and can be found in Appendix C, with reasons for their exclusion.

4.6.16 Assessment of risk of bias (ROB)

I used four domains of the Cochrane Collaboration's tool to evaluate risk of bias (Higgins & Green, 2011). I did not use the fifth domain of blinding as it is essentially impossible to blind participants in an IDI trial unless the comparator is particularly similar to the IDI.

- Sequence generation – was the allocation sequence adequately generated? (Selection bias)
- Allocation concealment – was allocation adequately concealed? (Selection bias)
- Incomplete outcome data – was this adequately addressed for each outcome? (Attrition bias)
- Selective outcome reporting – are reports of the study free of suggestion of selective outcome reporting? (Reporting bias)

Each domain was scored by one reviewer (LH) as either low risk of bias, high risk of bias, or unclear (i.e. there was not enough information to make a judgement). Scoring was then discussed with a second reviewer (EM). The following information was also recorded and used to interpret and discuss the methodological quality and results of

the included studies: Validity and reliability of outcome measures, sample size and power, and length of follow-up. Authors of included studies were contacted to retrieve any missing data required to assess risk of bias.

4.6.17 Data synthesis

4.6.17.1 Selection of outcomes to meta-analyse

Outcome variables were conceptually divided into six groups: Sexual outcomes, relational outcomes, negative emotional states, quality of life, adverse outcomes and costs. To ensure that individual studies contributed equally to the separate meta-analyses, only one outcome was chosen from within each of these groups. When there were multiple outcomes to choose from, the following criteria (adapted from criteria developed by Bailey et. al., (2010)) was used to choose the most appropriate outcome to meta-analyse (criteria are in order of importance):

1. Author's primary outcome (where stated)
2. Outcome reflecting the main aim of the intervention
3. Primary outcome of interest in the current systematic review
4. Superiority in terms of validity/reliability
5. Importance/relevance according to the literature
6. Most frequently reported among the included studies in the review

Where possible, I chose the authors' primary outcomes or outcomes reflecting the main aim of the intervention as this allowed me to determine whether the interventions had an impact on the variables deemed most important by the authors. I chose the longest follow-up period available, as it is important to demonstrate sustained change.

4.6.18 Data analysis

Data from included studies were tabulated to provide a descriptive synthesis of the studies. This allowed assessment of heterogeneity in terms of settings, participants, interventions, comparator groups and outcomes, which in-turn allowed me to determine whether meta-analysis was possible and appropriate.

4.6.18.1 **Criteria for including studies in a meta-analysis**

In line with the research questions, where there was enough data I ran separate meta-analyses for the different *comparator* types: minimal intervention (e.g., waitlist control), active conditions (e.g., face-to-face therapy and online forums), and combined conditions (e.g. IDI with face-to-face therapy). Within these comparator groups, where there was enough information to do so, I performed separate meta-analyses for the different *outcome* types: sexual outcomes, relational outcomes, negative emotional states, quality of life, adverse outcomes and cost. Studies that did not report outcome data that was required for a particular meta-analysis (i.e., means, standard deviations and sample sizes) were excluded from the meta-analysis (Binik, Meana, & Sand, 1994; Ochs & Binik, 1998; Ochs, Meana, Mah, & Binik, 1993; Schover et al., 2012). In the studies that remained, I deemed the *interventions* conceptually similar enough to analyse together.

Where it was deemed appropriate to meta-analyse, the results of the included RCTs were pooled using a random effects model of meta-analysis, with standardised mean differences (SMDs) for continuous outcomes. A random effects model was chosen because it allows for heterogeneity by assuming the underlying effects follow a normal distribution (Higgins & Green, 2011). I assessed the statistical heterogeneity of the studies included in the meta-analysis using the I^2 statistic (Higgins, Thompson, Deeks, & Altman, 2003), which enabled me to determine whether the apriori conceptual judgements I had made about grouping were appropriate.

4.6.19 **Patient and Public Involvement (PPI)**

Potential consumers of IDIs for sexual difficulties are members of the general public who have experience or awareness of sexual difficulties and/or have used the internet to seek advice or information on sexual health and sexual difficulties. In the current study PPI was sought to ensure the outcomes of interest in the review were of interest and relevant to potential users. A user representative subsequently joined the research team and reviewed the study protocol.

4.7 Results

4.7.1 Description of studies

The initial search found 10,364 references. Using the Endnote program and visual identification 1825 duplicates were found and removed, leaving 8539 references. A further two citations were added from grey literature databases, three from trials registers, one from hand-searching, and two from reference tracking, making a total of 8547 references to screen. Of these, 8524 were excluded at the title and abstract level, leaving 23 remaining full text articles (none of which were identified through grey literature databases). Of these 23 articles, 12 papers were excluded due to the following reasons: Two were not RCTs, 6 were not IDIs per the study definition, 2 contained no outcomes of interest (i.e. changes in attitudes towards IDIs and changes in attitudes towards different forms of sex therapy), and 2 were ongoing trials. Ten studies remained in the systematic review (see Figure 4.2 for a flow chart of the literature search).

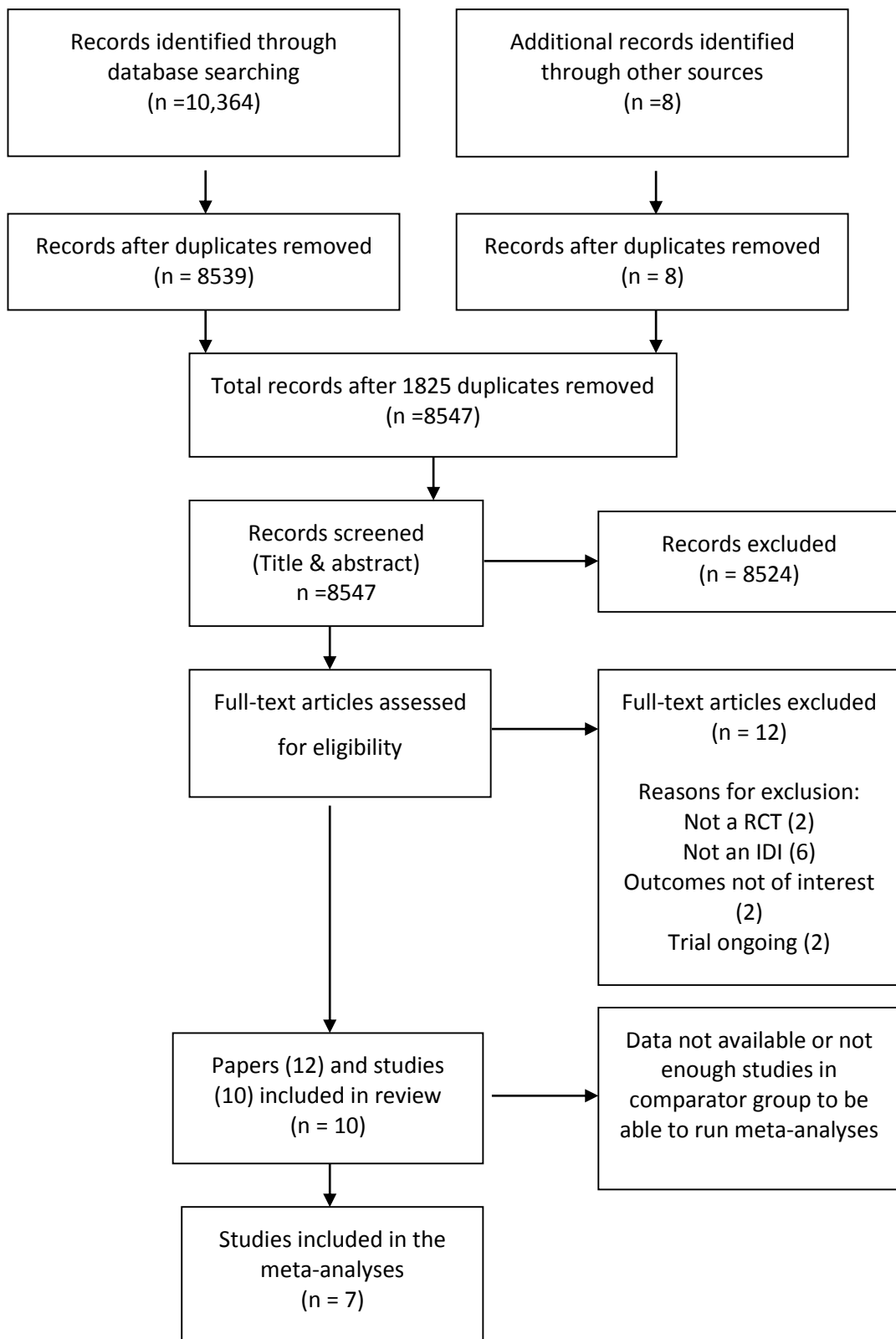


Figure 4.2: Flow chart of literature search.

4.7.2 Results of the search

Within the 10 studies included in the review a total of 858 participants were randomised, and of these, 683 participants had available outcome data. 251 participants received an IDI, and were compared in 2 or 3 arm trials with 246 participants who received minimal intervention (e.g. waitlist control or standard care), 62 who received face-to-face or other active interventions, 71 who received a different type of digital intervention for sexual difficulties, and 53 who received a composite intervention (e.g. IDI combined with face-to-face counselling).

4.7.3 Characteristics of included studies and IDIs

The included studies differed in terms of the following: study population (including demographics, sexual difficulty and country), study design, methods, setting, intervention description (including mode of delivery, level of human support, type of support, communication channels used for support, degree of synchronicity of communication, frequency and duration of support), duration of the program, frequency of program use, engagement measures, inclusion/exclusion criteria, method of recruitment, success rate of recruitment, incentive/cost to participate, comparator descriptions, informed consent, consumer involvement, risk of bias items, and study outcomes. See Appendix D for characteristics of included studies tables and Appendix E for characteristics of included IDIs tables.

The three studies published in the 90s were all trials of a Canadian program known as 'Sexpert' (Binik et al., 1994; Ochs & Binik, 1998; Ochs et al., 1993). The remaining seven studies were published later, between 2008 and 2014. All ten were published in English in peer reviewed journals.

4.7.4 Location and setting

Five of the studies were conducted entirely online (Hucker & McCabe, 2014; Jones & McCabe, 2011; McCabe et al., 2008; Schover et al., 2012; Wootten et al., 2015); one online and via telephone (E. Andersson et al., 2011), one online and face-to-face (Schover et al., 2013), and three were conducted using software in a lab (Binik et al., 1994; Ochs & Binik, 1998; Ochs et al., 1993). Four of the studies were conducted in Australia (Hucker & McCabe, 2014; Jones & McCabe, 2011; McCabe et al., 2008; Wootten et al., 2015); three were conducted in Canada (Binik et al., 1994; Ochs & Binik, 1998; Ochs et al., 1993); one was conducted in Sweden (E. Andersson et al., 2011), and two in the USA (Schover et al., 2012; Schover et al., 2013).

4.7.5 Participants

The study sample sizes varied from 31 couples (McCabe et al., 2008) to 134 couples (Schover et al., 2012). All couples were over the age of 18. Participants were recruited through the following routes: online (Hucker & McCabe, 2014; Jones & McCabe, 2011; Schover et al., 2012; Wootten et al., 2015), television or newspaper advertisements (E. Andersson et al., 2011; Hucker & McCabe, 2014; Jones & McCabe, 2011; Schover et al., 2012; Wootten et al., 2015), universities (Binik et al., 1994; Hucker & McCabe, 2014; Ochs & Binik, 1998; Ochs et al., 1993; Wootten et al., 2015), medical or trials registers (Schover et al., 2013) and medical centres (Schover et al., 2012; Schover et al., 2013). All studies provided information regarding ethical committee permissions, and all but one study (Jones & McCabe, 2011) mentioned obtaining informed consent.

Three studies targeted men with erectile dysfunction (ED; E. Andersson et al., 2011; McCabe et al., 2008; Wootten et al., 2015), three studies targeted women with female sexual dysfunction (FSD; Hucker & McCabe, 2014; Jones & McCabe, 2011; Schover et al., 2013), one study targeted both ED and FSD (Schover et al., 2012), and three studies targeted non-specific sexual difficulties (Binik et al., 1994; Ochs & Binik, 1998; Ochs et al., 1993). Three of the interventions specifically targeted cancer-related sexual difficulties (Schover et al., 2012; Schover et al., 2013; Wootten et al., 2015).

4.7.6 Intervention delivery

All of the interventions were computer-based and were either delivered via the internet (E. Andersson et al., 2011; Hucker & McCabe, 2014; Jones & McCabe, 2011; McCabe et al., 2008; Schover et al., 2012; Schover et al., 2013; Wootten et al., 2015) or via software installed on personal computers (Binik et al., 1994; Ochs & Binik, 1998; Ochs et al., 1993). The majority of the interventions were closed access and were either accessed via a password protected website or via a lab-based computer. Interventions varied in intended frequency and duration of use: three studies involved a single use session of less than 1 hour (Binik et al., 1994; Ochs & Binik, 1998; Ochs et al., 1993), whereas the remaining studies involved regular access and use over a period ranging from 7 to 12 weeks (E. Andersson et al., 2011; Hucker & McCabe, 2014; Jones & McCabe, 2011; McCabe et al., 2008; Schover et al., 2012; Schover et al., 2013; Wootten et al., 2015). See Figure 4.3 for intervention delivery features.

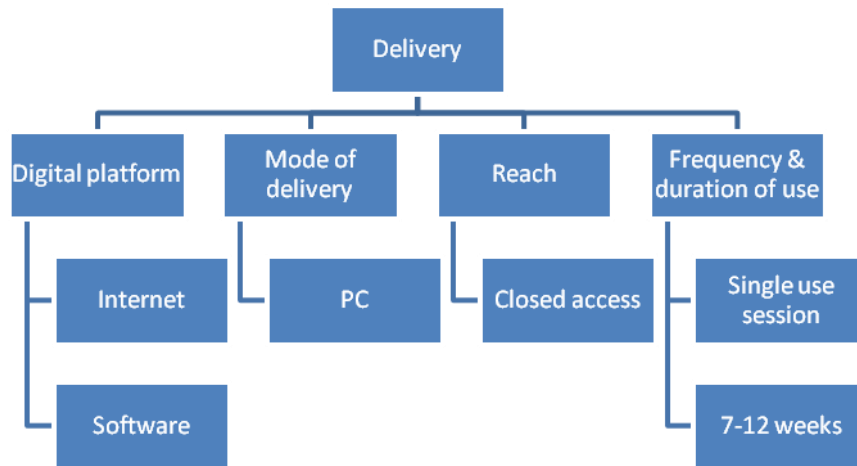


Figure 4.3: Intervention delivery features

4.7.7 Intervention support

Two interventions (4 studies) were classified as involving 'no-support', in that they required no human support from a therapist, health professional or peer (Binik et al., 1994; Ochs & Binik, 1998; Ochs et al., 1993; Schover et al., 2013). Six studies utilised email support from a therapist to facilitate engagement with the intervention (E. Andersson et al., 2011; Hucker & McCabe, 2014; Jones & McCabe, 2011; McCabe et al., 2008; Schover et al., 2012; Wootten et al., 2015). Of these, one was classified as involving 'engagement support' only (Wootten et al., 2015), and the other five involved both engagement support as well as additional therapeutic support (E. Andersson et al., 2011; Hucker & McCabe, 2014; Jones & McCabe, 2011; McCabe et al., 2008; Schover et al., 2012). All but one of the interventions (Wootten et al., 2015) were aimed at couples. The following definitions of the different levels of human support were modified from those used in previous research (Glasgow & Rosen, 1978; Newman, Erickson, Przeworski, & Dzus, 2003). No support: self-guided, with no contact, or contact with a therapist for initial assessment only; Engagement support: primarily self-guided, but a therapist may have contact with the user to promote engagement with the intervention. This may include providing an initial therapeutic rationale, teaching participants how to use the program, and checking in with them via email, phone or infrequent meetings to troubleshoot any problems or difficulties; Therapeutic support: a therapist may have contact with the user to provide additional therapeutic support. See Figure 4.4 for intervention support features.

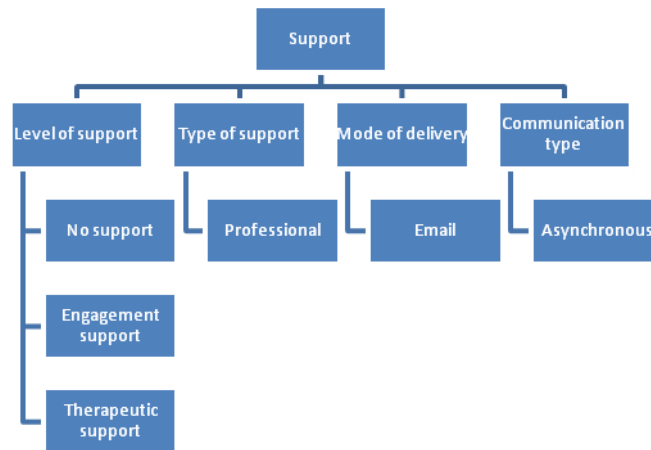


Figure 4.4: Intervention support features

4.7.8 Intervention content

In terms of psychotherapeutic approach, all interventions used a Cognitive Behavioural approach except for one where the approach was not stated (Schover et al., 2013). Five studies also used Masters and Johnson's sex therapy techniques (Hucker & McCabe, 2014; Jones & McCabe, 2011; McCabe et al., 2008; Schover et al., 2012; Schover et al., 2013). No studies provided information on any consultation with consumers in the design, development or implementation of the intervention. I was unable to obtain the study protocols for all but one study, and therefore I could not assess the behaviour change techniques (i.e. active ingredients; Michie et al., 2013) of the interventions. See Figure 4.5 for intervention content features.

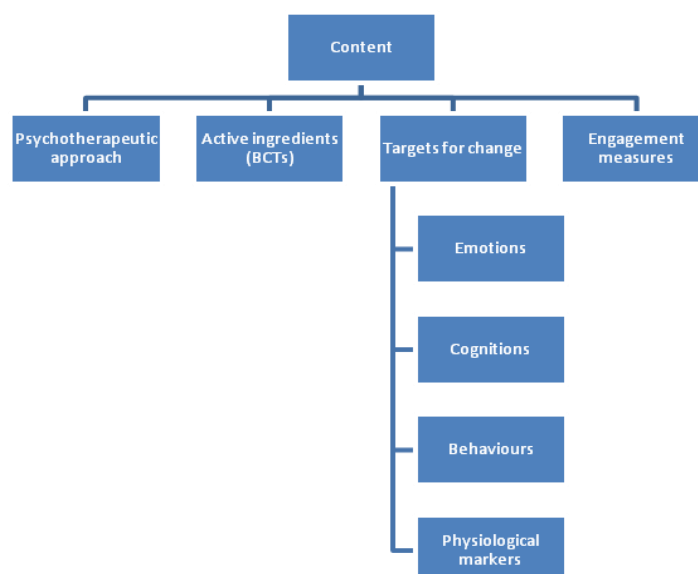


Figure 4.5: Intervention content features

4.7.9 Outcomes

All outcomes were generated subjectively via self-report.

4.7.9.1 *Sexual outcomes*

- Sexual function was measured in five studies (E. Andersson et al., 2011; Jones & McCabe, 2011; McCabe et al., 2008; Schover et al., 2012; Wootten et al., 2015), and included overall measures of female sexual function (Hucker & McCabe, 2014; Jones & McCabe, 2011; Schover et al., 2012; Schover et al., 2013), erectile function (E. Andersson et al., 2011; McCabe et al., 2008; Schover et al., 2012), sexual desire (E. Andersson et al., 2011; Jones & McCabe, 2011; McCabe et al., 2008; Schover et al., 2012; Wootten et al., 2012), arousal (Jones & McCabe, 2011; Schover et al., 2012; Schover et al., 2013), lubrication (Jones & McCabe, 2011; Schover et al., 2012; Schover et al., 2013), orgasmic function (E. Andersson et al., 2011; Jones & McCabe, 2011; McCabe et al., 2008; Schover et al., 2012; Schover et al., 2013), pain (Jones & McCabe, 2011; Schover et al., 2012; Schover et al., 2013), frequency of sexual dysfunction (Jones & McCabe, 2011; McCabe et al., 2008), and erectile strength (McCabe et al., 2008) – physiological and cognitive targets.
- Sexual satisfaction was measured in seven studies (E. Andersson et al., 2011; Binik et al., 1994; Hucker & McCabe, 2014; Jones & McCabe, 2011; McCabe et al., 2008; Schover et al., 2012; Schover et al., 2013), and included overall measures of sexual satisfaction, intercourse satisfaction, and sexual relationship quality – cognitive targets.
- Sexual behaviour was measured in three studies, and included daily self-monitoring of sexual behaviour, and measures of foreplay activity (Binik et al., 1994; Ochs & Binik, 1998; Ochs et al., 1993) – behavioural targets.
- Sexual comfort (a measure of participants' level of comfort of 68 different sexual activities) was measured in one study (Ochs & Binik, 1998) – cognitive target.

4.7.9.2 *Relational outcomes*

- Relationship satisfaction/adjustment was measured in five studies (E. Andersson et al., 2011; Jones & McCabe, 2011; McCabe et al., 2008; Ochs & Binik, 1998; Schover et al., 2012) – cognitive target.

- Communication was measured in three studies, including overall communication and/or sexual communication (Binik et al., 1994; Jones & McCabe, 2011; Ochs & Binik, 1998) – behavioural target.
- Emotional intimacy was measured in two studies (Hucker & McCabe, 2014; Jones & McCabe, 2011) - cognitive target.

4.7.9.3 **Negative emotional states**

- Distress was measured in three studies (Hucker & McCabe, 2014; Schover et al., 2012; Schover et al., 2013).
- Anxiety (general and/or performance anxiety) was measured in four studies (E. Andersson et al., 2011; Jones & McCabe, 2011; Schover et al., 2013; Wootten et al., 2015).
- Depression was measured in two studies (E. Andersson et al., 2011; Jones & McCabe, 2011; Schover et al., 2013; Wootten et al., 2015).
- Stress was measured in three studies (Jones & McCabe, 2011; Schover et al., 2013; Wootten et al., 2015).
- Somatization (reflecting distress arising from perceptions of bodily dysfunction) was measured in one study (Schover et al., 2013).
- Confidence was measured in one study (Wootten et al., 2015).

4.7.9.4 **Quality of life**

- Quality of life was measured in three studies (E. Andersson et al., 2011; Schover et al., 2013; Wootten et al., 2015) – emotional, cognitive and behavioural targets.

4.7.9.5 **Other outcomes**

- Economic outcomes. No studies reported any economic outcomes.
- Adverse effects. No studies reported any unintended adverse effects of the intervention.

4.7.10 Engagement measures

Four studies measured engagement with the intervention: Two measured the number of completed modules (E. Andersson et al., 2011; Wootten et al., 2015); one measured number, duration and content of visits, plus percentage of intervention completed (Schover et al., 2012); and one measured duration of visits only (Schover et al., 2013). One study implemented safeguard checks against the diffusion of treatments to ensure that the participants in each group received only the planned intervention (Wootten et al., 2015).

4.7.11 Timing of follow-up

Intervention group follow-up times ranged from one week to 12 months, but overall there was insufficient long-term follow-up data. In six studies there was no control/comparison group at longer-term follow-up, and so outcome data was taken immediately post-intervention when control/comparison groups were still available (E. Andersson et al., 2011; Hucker & McCabe, 2014; Jones & McCabe, 2011; McCabe et al., 2008; Schover et al., 2012; Wootten et al., 2015). In the remaining studies, timing of follow-up was one week (Ochs & Binik, 1998); two weeks post-intervention (Binik et al., 1994; Ochs et al., 1993); and 6 months (Schover et al., 2013).

4.7.12 Comparators

4.7.12.1 *Group 1: IDI compared to minimal intervention*

In this group I compared IDI with minimal intervention, which I defined as non-interactive comparators or comparators with no sexual difficulties content (e.g., waitlist control, written materials, videos, crossword puzzles and computer games). Five studies used waitlist control (Hucker & McCabe, 2014; Jones & McCabe, 2011; McCabe et al., 2008; Schover et al., 2012); one study used a computer game with no sexual content (Binik et al., 1994); two studies used a crossword puzzle (Ochs & Binik, 1998; Ochs et al., 1993); two studies used written materials (paper questionnaire and book) (Binik et al., 1994; Ochs et al., 1993); and two studies used a video (Ochs & Binik, 1998; Ochs et al., 1993).

4.7.12.2 *Group 2: IDI compared to active intervention*

In this group I compared IDI with active intervention (i.e., face-to-face therapy or online forums). In the review, two studies compared IDI to face-to-face intervention (Ochs & Binik, 1998; Schover et al., 2012), one of which included three face-to-face sessions

from a therapist over 12 weeks (Schover et al., 2012); the other included one session with a psychologist (Ochs & Binik, 1998). Two studies compared IDI to an online discussion forum (E. Andersson et al., 2011; Wootten et al., 2015).

4.7.12.3 Group 3: IDI compared to IDI plus face-to-face therapy

There was only one study that compared IDI to IDI plus face-to-face therapy (Schover et al., 2013) so no meta-analyses could be run in this group.

4.7.13 Risk of bias

The risk of bias information is presented as percentages across all included studies in Figure 4.6, and for each study in Figure 4.7. See Appendix D for more information on how the assessment of risk of bias was calculated for each included study.

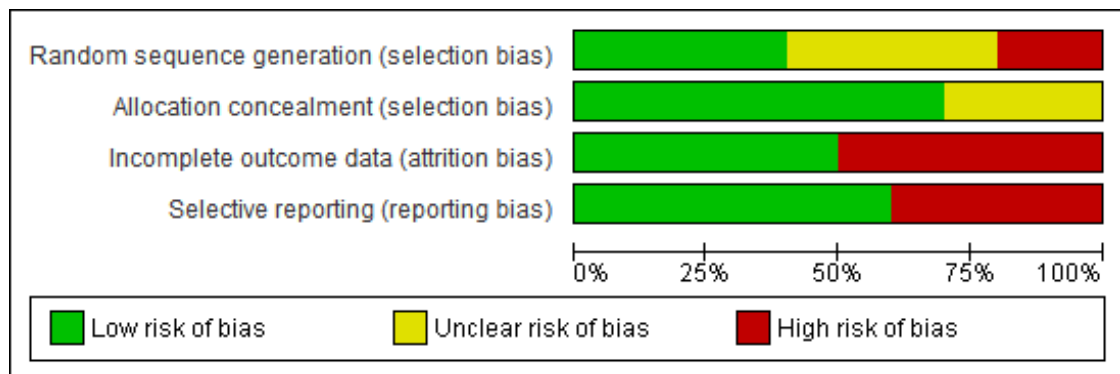


Figure 4.6: Risk of bias graph of author's judgements about each risk of bias item presented as percentages across all included studies.

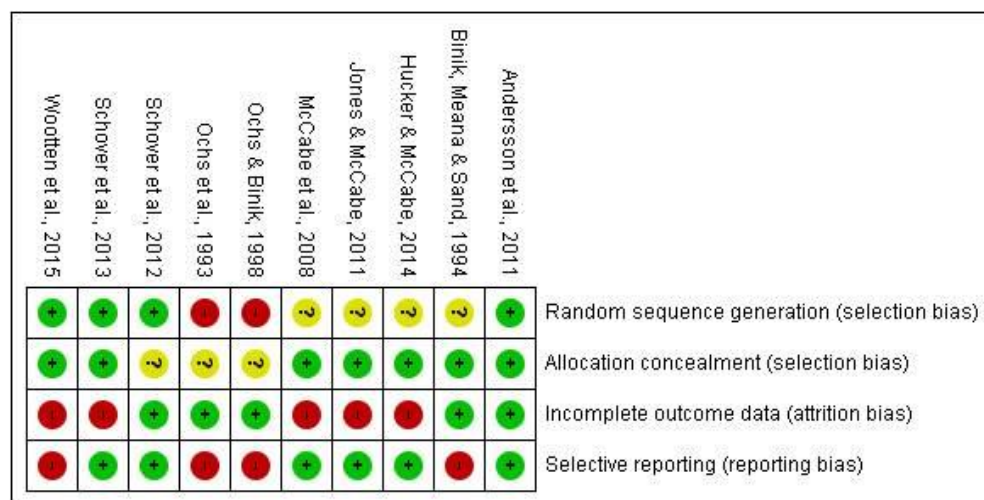


Figure 4.7: Risk of bias summary – review author's judgements about each risk of bias item for each included study.

4.7.13.1 **Sequence generation**

All 10 included studies stated that participants had been randomly allocated to groups, however, only 5 studies provided information about the sequence generation process in the published paper (Ochs & Binik, 1998; Ochs et al., 1993; Schover et al., 2012; Schover et al., 2013; Wootten et al., 2015). This information was supplied at a later date by one author (E. Andersson et al., 2011). Four studies reported adequate sequence generation (E. Andersson et al., 2011; Schover et al., 2012; Schover et al., 2013; Wootten et al., 2015), two reported inadequate sequence generation (i.e., 'couples were assigned on a successive rotating basis...') and were therefore deemed a high risk of selection bias (Ochs & Binik, 1998; Ochs et al., 1993); and the remaining studies did not provide sufficient information in order to judge the adequacy of the sequence generation process (Binik et al., 1994; Hucker & McCabe, 2014; Jones & McCabe, 2011; McCabe et al., 2008).

4.7.13.2 **Allocation concealment**

Seven studies were deemed to have appropriately concealed allocations by assigning participants to groups after they had consented to take part in the study (E. Andersson et al., 2011; Binik et al., 1994; Hucker & McCabe, 2014; Jones & McCabe, 2011; McCabe et al., 2008; Schover et al., 2013; Wootten et al., 2015). In two studies, participants were randomised prior to consenting, but it was not clear if the allocations were concealed (Ochs & Binik, 1998; Ochs et al., 1993), and in one study it was unclear when participants were randomised and unclear whether allocations were concealed (Schover et al., 2012).

4.7.13.3 **Incomplete outcome data**

Five of the ten included studies were deemed at high risk of attrition bias due to large and/or differential losses to follow-up (Hucker & McCabe, 2014; Jones & McCabe, 2011; McCabe et al., 2008; Schover et al., 2013; Wootten et al., 2015).

4.7.13.4 **Selective outcome reporting**

Four studies were deemed at high risk of reporting bias (Binik et al., 1994; Ochs & Binik, 1998; Ochs et al., 1993). In the three studies from the 1990s many of the outcomes were 'lumped together' (i.e. not reported by arm), and often only the results that were statistically significant were reported. (Binik et al., 1994; Ochs & Binik, 1998;

Ochs et al., 1993). In a more recent study, outcomes measured and reported in previous publications were not reported in the results (Wootten et al., 2015).

4.7.14 Additional methodological quality criteria

The following data was gathered to assist in making judgements about the methodological quality and robustness of the study findings (see Table 4.1).

Table 4.1: Additional markers of methodological quality in the individual studies.

First author	Standardised outcome measures used?	Sufficiently powered?	Adequate length of follow-up?
Andersson et al., 2011	Yes	Yes	No*
Binik, Meana & Sand, 1994	No	Unclear	No
Hucker & McCabe, 2014	Yes	Unclear	No*
Jones & McCabe, 2011	Yes	Unclear	No*
McCabe et al., 2008	Yes	Unclear	No*
Ochs & Binik, 1998	No	Unclear	No
Ochs et al., 1993	No	Unclear	No
Schover et al, 2012	Yes	Unclear	No*
Schover et al, 2013	Yes	Unclear	Yes
Wootten et al., 2015	Yes	No	No*

Unclear: Insufficient information provided to make a determination.

*Follow-up measures taken immediately post intervention

4.7.15 Effects of the interventions

See Tables 4.2, 4.3 and 4.4 at the end of the chapter for the main outcomes reported in the included studies.

4.7.16 Comparison 1: Are IDIs effective?

I combined outcomes from studies that compared IDIs to minimal intervention (e.g., waitlist control) to determine whether IDIs for sexual difficulties are effective at improving sexual function and relationship satisfaction.

4.7.16.1 Sexual function

Of the seven studies in the review that compared IDIs to minimal intervention, three were not able to be included in the meta-analysis as the data was reported incompletely such that it could not be entered (i.e. means, standard deviations (SD) and sample sizes were not reported for each study arm ; Binik et al., 1994; Ochs & Binik, 1998; Ochs et al., 1993). I combined data on sexual function from the four remaining studies. Only two of the studies independently showed a statistically significant difference between the IDI and minimal intervention on sexual function, but the Standard Mean Difference (SMD) became statistically significant when the sexual function outcomes were combined in a meta-analysis (SMD 1.05, 95% CI 0.14 to 3.05). This is a large effect size using Cohen's criteria (Cohen, 1988; Higgins & Green, 2011), and demonstrates that IDIs do improve sexual function. However, the I² statistic was 85%, which may indicate substantial statistical heterogeneity between the included studies (Higgins & Green, 2011). See Figure 4.8.

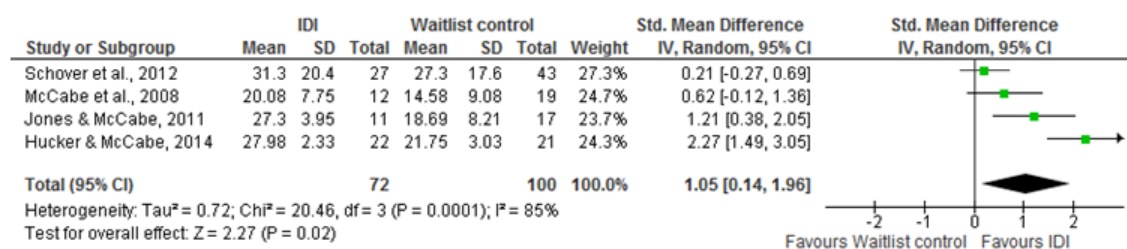


Figure 4.8: Comparison of IDI versus minimal intervention for sexual function

Sub-group analysis: Female sexual function

Due to the statistical heterogeneity in the included studies I performed sub-group analyses by sexual difficulty/gender. When the sexual function outcomes were combined for women the SMD was statistically significant (SMD 1.75, 95% CI 0.72 to 2.79), which is a large effect size. The I² statistic was 70%, and although lower than the previous meta-analysis, still may indicate substantial heterogeneity. See Figure 4.9.

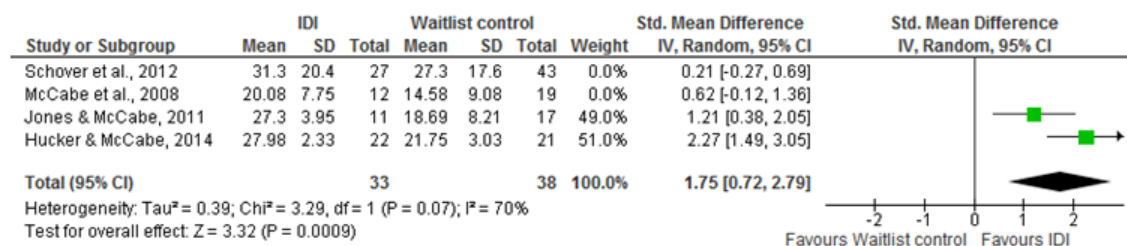


Figure 4.9: Comparison of IDI versus minimal intervention for women’s sexual function

Sub-group analysis: Male erectile function

When the sexual function outcomes were combined for men with erectile dysfunction, the meta-analysis showed a non-significant effect of IDIs on erectile function (SMD 0.33, 95% CI -0.07 to 0.74). See Figure 4.10.

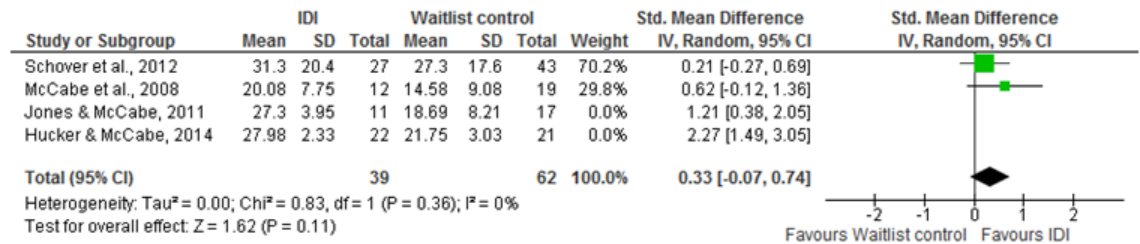


Figure 4.10: Comparison of IDI versus minimal intervention for men’s erectile function

4.7.16.2 **Relationship satisfaction**

Of the seven studies that compared IDIs to minimal intervention on relational outcomes, four studies reported the data incompletely such that they could not be entered into a meta-analysis (Binik et al., 1994; Ochs & Binik, 1998; Ochs et al., 1993; Schover et al., 2012). When relationship satisfaction outcomes from the three remaining studies were combined in a meta-analysis it showed a non-significant effect of IDIs on relationship satisfaction (SMD 0.33, 95% CI -0.07 to 0.74). The I² statistic was 0%, which indicates that statistical heterogeneity was not a concern. See Figure 4.11.

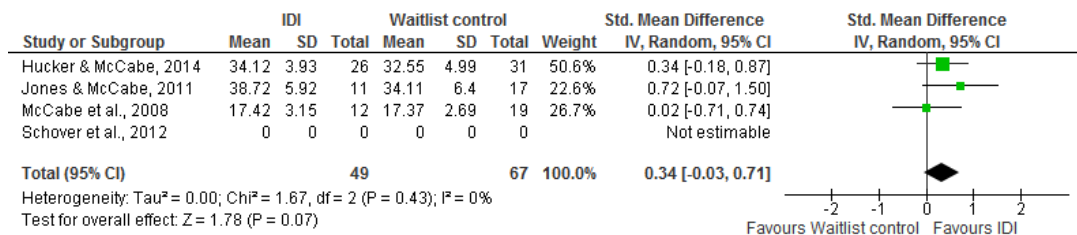


Figure 4.11: Comparison of IDI versus minimal intervention for relationship satisfaction

Sub-group analysis: Relationship satisfaction in women

When the relation satisfaction outcomes were combined for women only, the SMD was statistically significant (SMD 0.46, 95% CI 0.02 to 0.89), which is a moderate effect

size. The I^2 statistic was 0%, which suggests statistical heterogeneity was not an issue. See Figure 4.12.

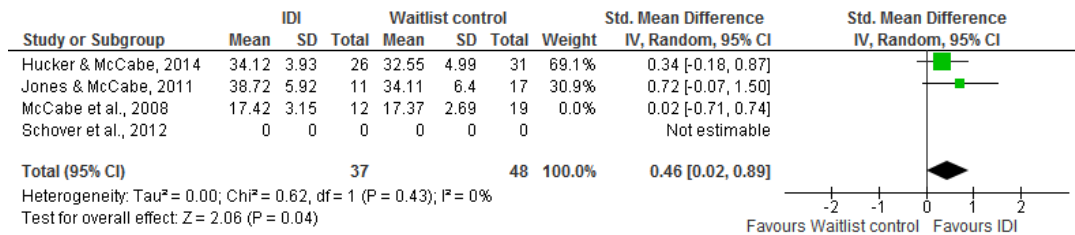


Figure 4.12: Comparison of IDI versus minimal intervention for women’s relationship satisfaction

Sub-group analysis: Relationship satisfaction in men

There were not enough studies to perform a sub-group analysis on relationship satisfaction in men.

4.7.16.3 **Distress levels in women**

Of the three studies that compared IDIs to minimal intervention on the outcome of distress, one study reported the outcome data incompletely such that it could not be entered into a meta-analysis (Schover et al., 2012). The two remaining studies were conducted with women, and when the distress data was combined in a meta-analysis it showed a non-significant effect of IDIs on women’s distress levels (SMD -0.44, 95% CI to 1.67 to 0.79). The I^2 statistic was 84%, which may indicate substantial statistical heterogeneity between the included studies (Higgins & Green, 2011). See Figure 4.13.

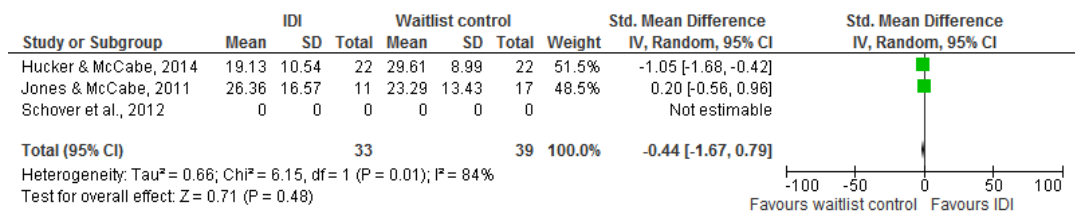


Figure 4.13: Comparison of IDI versus minimal intervention for women’s negative emotional states.

4.7.16.4 **Quality of life, adverse outcomes and costs**

Within the IDI vs minimal intervention comparator group no studies measured quality of life, unintended adverse outcomes of the intervention, or provided any cost data, so no meta-analyses could be run on these outcomes.

4.7.16.5 **Summary (IDI versus minimal intervention)**

In summary, meta-analyses demonstrated that compared to minimal intervention, IDIs had a statistically significant large effect on women's sexual function (but with substantial statistical heterogeneity), a statistically significant moderate effect on women's relationship satisfaction (with no statistical heterogeneity), and a non-significant effect on women's distress levels (with substantial statistical heterogeneity). There was insufficient data to run meta-analyses on quality of life, adverse outcomes and cost data for women. For men, IDIs had a non-significant effect on sexual function (with no statistical heterogeneity), and there was insufficient data to run meta-analyses on relationship satisfaction, negative emotional state, quality of life, adverse outcomes and cost data.

4.7.17 **Comparison 2: Are IDIs as effective as active intervention for sexual difficulties?**

I combined outcomes from studies that compared IDIs to active intervention (e.g. face to face intervention or online discussion forums) to determine the relative effectiveness of IDIs compared to these other intervention types. Of the four studies in this comparator group (E. Andersson et al., 2011; Ochs & Binik, 1998; Schover et al., 2012; Wootten et al., 2015), one study reported outcome data incompletely such that it could not be entered into any of the meta-analyses in this group (Ochs & Binik, 1998), and one study (that had three study arms) had already been included in the meta-analyses for the IDI vs Waitlist comparator group and could therefore not be included in this group.

4.7.17.1 **Sexual function, Relationship satisfaction and Quality of life**

Of the two studies left in this comparator group, one study did not report sexual function or relationship outcomes (Wootten et al., 2015), and the same study did not report outcomes on Quality of life in such a way that it could be entered into a meta-analyses, therefore meta-analyses could not be run on these outcomes in this comparator group.

4.7.17.2 **Negative emotional states**

Two studies in this comparator group reported data on negative emotional states, and when they were combined in a meta-analysis it showed a non-significant difference between IDIs and active intervention on negative emotional states (SMD -0.18, 8=95%

CI -0.52-0.15). The I^2 statistic was 0%, which indicates heterogeneity between the included studies was not an issue.

4.7.17.3 **Summary (IDI versus active intervention)**

In summary, there was no difference between IDIs and active intervention on negative emotional states. There was insufficient data to be able to run meta-analyses, and therefore draw any conclusions, on sexual outcomes, relational outcomes, quality of life, adverse outcomes and cost data.

Unfortunately, there were not enough studies in the review to conduct sensitivity analyses in any of the comparator groups, so I am unable to comment on the robustness of the findings in relation to the decisions made in the process of obtaining them. For example, I was not able to determine whether the observed results would remain the same if I re-ran the analyses after removing the studies that were deemed high risk of attrition bias (due to having <80% retention or >10% difference between retention rates in the IDI and comparator groups). The aforementioned results should therefore be treated with caution.

4.8 Discussion

4.8.1 Summary of main findings

In summary, when compared to waitlist control, the current meta-analyses indicate that IDIs can improve sexual function and relationship satisfaction, but not distress levels in women. In men, there was a non-significant effect of IDIs on sexual function, but insufficient data to be able to draw any conclusions about the effects of IDIs on other outcomes (Research Question 1). There was minimal evidence to suggest that IDIs are as effective as active intervention on improving negative emotional states; but there was insufficient evidence to be able to draw any conclusions about the relative effectiveness of IDIs compared to other forms of active treatments for any other outcomes (Research Question 2) and whether IDIs combined with face-to-face therapy is more effective than either form alone (Research Question 3). However, these data must be considered in light of their limitations – those relating to the included studies (e.g. overall small number of studies, presence of bias, and small sample sizes), as well as those relating to the review methods (e.g. small number of studies in the meta-analyses and the presence of heterogeneity in the included studies). Nevertheless, the results of the individual trials and the meta-analyses both suggest that IDIs show

definite potential as an alternative method of treatment for people with sexual difficulties, and are worthy of further exploration.

4.8.2 Strengths and limitations of the studies included in the review

The studies included in the review have a number of strengths and limitations.

4.8.3 Strengths

4.8.3.1 *Minimal selection bias*

With the exception of the studies from the 1990s, in which the randomisation and concealment procedures were deemed inadequate (and a few studies in which it was unclear), the majority of the studies randomised and concealed allocations adequately. The studies from the 1990s did not publish any of their results in such a way that they could be included in any of the meta-analyses in the review. Consequently, selection bias was not deemed an issue in the studies included in this review.

4.8.3.2 *Minimal reporting bias*

Inadequate reporting of outcomes limits the availability of existing data, and can act in addition to, but in the same direction as publication bias to artificially inflate estimates of treatment effect (Song, Eastwood, Gilbody, Duley, & Sutton, 2000). Although I was only able to source the study protocol for one study (E. Andersson et al., 2011), all the reported results from the studies included in the meta-analyses corresponded with the outcomes described in the methods sections, and included both non-significant and significant findings. Therefore the studies included in any meta-analyses were deemed to be free of reporting bias.

4.8.3.3 *Use of standardised outcome measures*

The validity of an outcome measure refers to the extent to which the measure or instrument measures what it is intended to measure; and the reliability of an outcome measure refers to the stability of the measure, its internal consistency, and the inter-rater reliability of instrument scores. Using outcome measures that are valid and reliable is a key component of conducting quality research (Kimberlin & Winterstein, 2008). With the exception of the studies from the 1990s, the vast majority of measures used in the studies within review were standardised measures with demonstrated validity and reliability.

4.8.3.4 ***Focus on couples***

A further strength of the studies included in the review was that they all targeted their interventions towards people in relationships. Studies show sexual health to be strongly correlated with relationship factors (Epstein, 2002), and there is evidence to suggest that treatment compliance is higher in some cases when partners are involved with the treatment (Riley, 2002). It therefore it makes sense to target and evaluate IDIs in the context of intimate partnerships.

4.8.4 **Limitations**

Systematic and rigorous methods were used to gather and synthesise the current evidence on IDIs for sexual difficulties. However there are a number of limitations of the studies included in the review that warrant discussion, and that might guide future research.

4.8.4.1 ***Attrition bias***

Retention in the trials by those in the IDI groups ranged from 50%-100%. Large or differential losses to follow up can result in an unrepresentative sample being left at follow-up (e.g. more highly motivated), which can impact the validity, reliability and generalisability of the results (Fewtrell et al., 2008; Schulz & Grimes, 2002). Retention rates of less than 80% are considered problematic (Schulz & Grimes, 2002), and while attrition can be dealt with statistically, bias can still remain (Hollis & Campbell, 1999). Three out of four of the studies in the IDI vs Minimal intervention meta-analyses were deemed high risk of attrition bias due to poor and/or differential retention rates. Therefore, the significant findings on women's sexual function and sexual satisfaction should be considered in light of this attrition bias.

4.8.4.2 ***Length of follow-up***

With the exception of the studies from the 1990s, where the follow-up times ranged from 1-2 weeks post-intervention, outcome data was generally taken immediately post-intervention. With such short or non-existent follow-up times I was unable to comment meaningfully on whether any of the observed effects of the interventions remained over time. However, long-term follow up can be difficult to achieve in trials of complex interventions with waitlist control groups, as it is unethical to withhold treatment from the control group for extended periods of time, and research funding is often contingent on ethical study designs.

4.8.4.3 ***Small samples sizes***

The sample sizes of the included studies ranged between 20 and 60 at the point of randomisation, to between 12 and 48 at post-treatment. Confidence intervals communicate the precision (or uncertainty) of the summary estimate (SMD), and small sample sizes can result in large confidence intervals, which means we need to be cautious when interpreting the findings of the meta-analyses, as the true effects could lie anywhere within the confidence intervals. Conversely, small sample sizes could have resulted in some of the studies being underpowered to detect significant effects (if there were effects in the population to detect), and therefore the non-significant findings in the individual studies also need to be considered in light of the small sample sizes. The CONSORT guidelines (Moher, Schulz, & Altman, 2001) highlight sample size calculation as one of the key items to include when reporting a trial, yet only one study in the review reported how the sample size was calculated in terms of being sufficiently powered to detect significant effects (E. Andersson et al., 2011). Recruitment to trials can be challenging, but valid and reliable evidence of effectiveness relies on adequate sample sizes; and transparent reporting of sample size and power calculations enable the accurate assessment of the strengths and limitations of an RCT.

4.8.4.4 ***Generalisability***

With the exception of one study (E. Andersson et al., 2011), the studies within the current review only included heterosexual participants in their research, and therefore the findings can only be generalised to heterosexual individuals. The exclusion of lesbian, gay, bisexual and transgender (LGBT) individuals from research is problematic, beyond issues of generalisability. The LGBT population experience worse physical and psychological health outcomes than their heterosexual counterparts (Fish, 2007; King, Semlyen, Tai, Killaspy, Osborn, Popelyuk et al., 2008), and this is thought to be due to stress associated with rejection, harassment and discrimination, as well as a lack of cultural competency within healthcare systems (Fish, 2007). Unfortunately, due to a consistent lack of data collection on sexual orientation in health settings, the full extent of the inequalities is not known. In order to help close the LGBT health disparities gap, future research should include individuals of all sexual orientations.

Not all sexual difficulties were represented in this review. No studies on early or delayed ejaculation, or problematic sexual behaviour met the inclusion criteria for the review, and therefore, the findings can only be generalised to the sexual difficulties within this review. Furthermore, the studies in the review that looked at women's sexual

difficulties did so by combining women with different sexual difficulties under the broad category of 'Female sexual dysfunctions' (FSD); there were no studies in the review that examined the effects of IDIs on samples of women with specific sexual difficulties (e.g. lack or loss of interest in sex, problems with orgasm, sexual pain etc.). While these sexual function outcomes were measured, different sexual difficulties can have very different presentations, precipitating factors and maintaining factors, and thus respond quite differently to different interventions; and therefore, trials of mixed populations, by looking at averages, can potentially mask the effects of a treatment for a particular population. Future trials of IDIs for the full range of sexual difficulties is needed to determine whether IDIs are effective for all sexual difficulties.

Not all psychotherapeutic approaches were represented in this review. All of the included studies used a cognitive-behavioural approach that often included sex therapy techniques; therefore, the findings can only be generalised to CBT-based IDIs. We still do not know anything about the effectiveness of IDIs that are underpinned by other approaches (e.g. Systemic therapy). This would be a worthwhile area for future study.

All of the studies in the review were from economically developed countries (Australia, USA, Canada and Sweden). However, there is a global presence of sexual difficulties (Adegunloye & Ezeoke, 2011; Nicolosi et al., 2006; Nicolosi et al., 2004), and while large inequalities still exist surrounding access to digital technology and access to the internet in resource-poor countries, IDIs may still be relevant and useful in these countries. Smart-phone ownership in developing countries is growing rapidly, and IDIs for sexual difficulties, delivered via smart-phone apps, could be tailored for use in developing countries where widespread stigma exists, and face-to-face services are limited or non-existent (Adegunloye & Ezeoke, 2011).

4.8.4.5 **Outcomes**

Self-reported outcomes

All of the outcomes in the included studies were generated by self-report. While self-report methods are more susceptible to inaccuracy and bias than objectively measured outcomes, if used appropriately, self-report methods can provide important information about the mechanisms of action of interventions (Bailey et al., 2015). In many cases, and particularly when measuring subjective outcomes such as thoughts and feelings (which are particularly relevant in sexual difficulties), self-report is often the only valid measure to use. Furthermore, due to the anonymous environment of the internet,

participants are often more open and honest when filling in questionnaires online (De Leeuw, Hox, & Kef, 2003; Fear, Seddon, Jones, Greenberg, & Wessley, 2012).

Choice of outcome measures

The choice of outcome measures should reflect the theoretical design of an intervention (i.e. they should reflect the aims of the intervention and capture the outcomes targeted). It is also important to measure the modifiable determinants of the outcomes which are specified in hypothesised pathways of action (e.g. knowledge, self-efficacy etc.). While most IDIs utilised cognitive behavioural and systemic therapy techniques, it was not made explicit (using theory) how the interventions were hypothesised to work, and it was therefore difficult to determine whether the chosen outcomes were appropriate. With what information was available, it appeared that some of the outcome measures chosen were perhaps not the most appropriate for the sexual difficulty being studied. For example, in several studies depression inventories were used to measure emotional states whereas a sexual quality of life measure might have been more appropriate (Arrington et al., 2004).

Missing outcomes of interest

Unfortunately, none of the included studies reported any unintended harms of the interventions or any cost data, so no conclusions could be drawn about these outcomes. Monitoring for, and evaluating, any unintended harms of an IDI during the course of a trial can be difficult (i.e. if the trial is conducted online), but is important in terms of being able to manage adverse events should they arise. Documentation of harms is also important in terms of informing clinical practice and future trials of IDIs (Childress, 2000). IDIs in other areas (e.g. supported IDIs for mental health problems) have been found to be cost-effective (Donker et al., 2015), but due to the paucity of research in the area of IDIs for sexual difficulties, little is currently known about the cost-effectiveness of IDIs in this area. Cost data is much needed in order that the cost-effectiveness of these types of interventions can be evaluated.

4.8.4.6 ***Intervention quality***

The quality of the interventions was not assessed in the current review. While guidelines exist for executing and reporting internet intervention research (Higgins & Green, 2011; Proudfoot et al., 2011), unfortunately there is currently no consensus on what defines a good quality IDI.

4.8.4.7 ***Intervention fidelity***

It is important to know whether an intervention was delivered as intended. Fidelity can be defined as 'the methodological strategies used to monitor and ensure the reliability and validity of behavioural interventions' (Bellg et al., 2004). Content fidelity refers to whether the components of the intervention were delivered as intended, and process fidelity refers to the consistency with which the intervention was delivered (Moncher & Prinz, 1991). Control over the content and aesthetics of an intervention, and the capacity for uniform delivery are particular strengths of IDIs (Murray et al., 2009). However, problems with intervention receipt and enactment can ultimately threaten treatment fidelity (Eaton, Doorenbos, Schmitz, Carpenter, & McGregor, 2011). It is the user that decides on the frequency and duration of their use of the intervention, and the extent to which they follow instructions, and this can make it difficult to evaluate the true effects of internet interventions (Bailey et al., 2010). Only four studies measured engagement with the intervention: Number of completed modules (E. Andersson et al., 2011; Wootten et al., 2015); number, duration and content of visits, plus percentage of intervention completed (Schover et al., 2012); and duration of visits only (Schover et al., 2013). Intervention fidelity can be improved by using robust study designs to avoid contamination between study arms. Fidelity can also be improved by collecting information from process evaluations (i.e., exploring user views and how interventions are used) and feeding it back into the intervention design (Bailey et al., 2010). Furthermore, procedures that ensure the intervention was received and understood (receipt of treatment), and strategies to effectively monitor participant enactment of exercises and skills (enactment of treatment) can also be built into intervention design to maximise the fidelity of internet interventions (Eaton et al., 2011).

4.8.5 **Strengths and limitations of the review methods**

4.8.6 **Strengths**

4.8.6.1 ***Systematic review methods***

Using systematic review methods is what enabled me to identify all published and unpublished evidence related to my specific research questions, which is something that would not have been possible using standard literature review methods. The rigorous search methods used to gather and synthesise the evidence is a key strength of this methodology (I searched 19 databases, including six databases of published studies, seven grey literature databases, and six trials registers; and also performed

reference and citation tracking, and hand searched contents pages of relevant journals), and this enabled me to conclude that there is minimal to no publication bias in the review. Assessment of the risk of bias in each of the included studies enabled me to assess the robustness of the findings, and be cautious of the findings where appropriate. Overall, systematic review methods allowed me to present a high quality, balanced, and unbiased summary of the evidence of effectiveness of IDIs for sexual difficulties, and to use the data to inform the direction of future research and practice, including the direction of the current thesis.

4.8.6.2 ***Selection of studies for inclusion in the review***

Deciding on whether a study was an RCT and/or met the study definition of sexual difficulties was a relatively simple process. However, three studies (all involving the 'Sexpert' intervention) used 'normal populations' without any specific sexual difficulties. The decision to include these studies was made on the basis that one of the main aims of the 'Sexpert' intervention was to assess and treat sexual dysfunction. Furthermore, given the variation in how sexual difficulties are defined in the literature, I sought to cast as wide a net possible (i.e., capturing clinically diagnosable difficulties as well as transient or less severe difficulties), and thus it was deemed important to include the 'Sexpert' studies on this criteria. Ultimately, the Sexpert studies were not included in any meta-analyses because they reported results in such a way that they could not be entered into a meta-analysis. Deciding on whether a study met our definition of an IDI was also, for the most part, easy, and required minimal discussion between the reviewers (LH & JB).

4.8.7 **Limitations**

4.8.7.1 ***Combining diverse outcomes in meta-analyses***

I split the meta-analyses by comparator group, and in these groups by outcome type. But within these groups I combined studies with different aims, populations, settings and outcomes. Where studies reported multiple outcomes of the same type (e.g. sexual, relational, emotional states and/or quality of life) only one outcome was chosen from each category to be entered into a meta-analysis using a selection criteria used in previous research (Bailey et al., 2010). Theoretically, this could have led to diversity in outcomes in each meta-analysis, but in reality all but one of the meta-analyses contained the same outcomes (e.g. sexual function, relationship satisfaction and distress), the majority of which used the same measurement scale. Combining these

studies increased the power to detect statistically significant effects, and enabled me to address the broad question of whether IDIs changed the outcomes they were designed to change; and to draw, albeit tentative, conclusions about the effects of IDIs on sexual and relational outcomes. While these data do not answer specific questions, in terms of exactly what works for whom, and under what circumstances, what they do answer is broad questions about effectiveness, and this is important data for such a new and under-researched area.

4.8.7.2 ***Heterogeneity***

Combining diverse outcomes allowed me to broadly answer one of two questions in the review. However, the combining of diverse studies may have contributed to the considerable statistical heterogeneity that was present in half of the meta-analyses in the review, and the presence of statistical heterogeneity makes it difficult to be certain of the size of the pooled result in the meta-analyses. Statistical heterogeneity is variability in the intervention effects being evaluated (more than would be expected due to random error), and is a consequence of clinical or methodological heterogeneity in the included studies (Higgins & Green, 2011). Some of the statistical heterogeneity was investigated by performing sub-group analyses (by gender/sexual difficulty), but there were not enough studies in the review to perform subgroup analyses by other clinical factors (e.g. other participant or intervention characteristics) or by methodological factors (e.g. risk of bias factors or other aspects of study design, such as internet trials vs non-internet trials) to determine how these factors might influence the effects of IDIs. In sum, although there is uncertainty in the magnitude of the effects in the meta-analyses in the review, all of the effects were in the same direction (in favour of the IDI) and therefore it may be reasonable to conclude that such interventions could have some positive impact, and that further research is warranted.

4.8.7.3 ***Small number of studies***

There was only enough data to compare IDIs to minimally active comparators. Therefore, we still know little or nothing about how IDIs for sexual difficulties compare to existing face to face treatments and other active interventions. We also currently know nothing about how IDIs might work (i.e. what the active components are). In addition to preventing sub-group analysis, the small number of studies in the review meant that I could not perform any sensitivity analyses. For example, I was not able to look at whether using an alternative criteria for minimum retention rate and maximum difference in retention between groups affected the results. The research area of IDIs

for sexual difficulties is in its infancy, and much is still not known about these types of interventions in this area. Many more rigorous and theory driven studies are needed if we are to ultimately determine what works, for whom and under what circumstances.

4.8.8 Results in the context with existing knowledge

As far as I am aware this was the first ever systematic review of IDIs for sexual difficulties, and as such the findings of this review cannot be compared to previous reviews in the area. However, the findings of this review are entirely compatible with previous systematic reviews of IDIs for other health and mental health problems (Barak et al., 2008; Cuijpers et al., 2008; Ritterband et al., 2011), which include, but are not limited to, sexual health promotion (Bailey et al., 2010; Portnoy et al., 2008), HIV prevention (Noar et al., 2009), physical activity (van den Berg et al., 2007), weight loss (Saperstein et al., 2007; Weinstein, 2006), alcohol consumption (Khadjesari et al., 2011), and diabetes self-management (Pal. et al., 2013), depression (Barak et al., 2008), anxiety (Barak et al., 2008), panic attacks (Barak et al., 2008; Ritterband et al., 2011), trauma related stress (Barak et al., 2008; Benight et al., 2008), headaches (Barak et al., 2008; Cuijpers et al., 2008; Ritterband et al., 2011), tinnitus (Cuijpers et al., 2008; Ritterband et al., 2011), pain (Cuijpers et al., 2008) and insomnia (Cuijpers et al., 2008). Like the current review, these systematic reviews concluded that IDIs were effective on outcomes targeted by the interventions when compared to minimal intervention, and were often as effective as face-to-face treatment. These systematic reviews also discussed the same limitations raised in the current review, including concerns about the overall small number of RCTs in the area, small sample sizes, issues regarding methodological quality and quality of reporting, problems with sustained engagement, and a lack of long term follow-up.

4.8.9 Implications

4.8.9.1 *Implications for practice*

Although there was only a small number of studies in the review, the findings demonstrate the use of IDIs with a variety of people of different ages and in different settings, from university students to cancer patients, and with some positive results. IDIs have the potential to reduce some of the barriers to help-seeking for sexual difficulties outlined in Chapter 1, and may be particularly suitable for people with sexual difficulties, due to the discomfort and embarrassment discussing sexual issues directly with a healthcare professional. The review findings suggest that, as a low intensity

treatment method, IDIs could have a place within current health service provision for sexual difficulties in the current climate of austerity; with widespread cuts to NHS sexual health services, as part of a stepped care model (Bower & Gilbody, 2005), IDIs have the potential to reduce long waiting lists, and free up valuable face-to-face resources for people with more complex sexual difficulties.

However, based on the review findings, and the overall paucity of empirical research and lack of funding in the area of sexual difficulties more broadly (Bancroft, 2009), we still do not know which designs of IDIs are most effective for which populations/sexual difficulties. For example, which psychotherapeutic approach (e.g. CBT or Systemic therapy or a mix of both) and/or theoretical model (e.g. the Dual Control Model) might be most useful in IDIs that target women with orgasm difficulties. There is also still much that we do not know about IDIs more broadly, such as how to best target and tailor them to particular populations (Lustria et al., 2009), and what aspects of interactivity and communication technology facilitate change most effectively; and due to its infancy, these areas have not yet been explored in IDIs for sexual difficulties.

Therefore, before IDIs can be implemented into clinical practice more research is needed to address the existing gaps in knowledge regarding their effectiveness, but also to determine the acceptability of these interventions, whether they will reach their intended users and if they can be implemented successfully into routine practice. If and when IDIs are implemented into routine practice, they would require rigorous evaluation to determine whether the effects observed in research settings remain in clinical settings.

4.8.9.2 *Implications for research*

IDIs look promising in terms of their effect on sexual function and relationship satisfaction for women. However, not all trials are well-designed and conducted. More rigorous trials with larger sample sizes across all sexual difficulties are needed to be more certain of the effects on these and other outcomes. Standards could be improved by adherence to CONSORT guidelines (Moher et al., 2001) and CONSORT e-health guidelines (Eysenbach, 2011). Further trials are also needed to determine whether certain IDIs are more or less effective on specific female sexual difficulties (e.g. orgasm difficulties or sexual pain), and to determine whether IDIs are effective across different male sexual difficulties (e.g. early or delayed ejaculation). It is important that researchers clearly describe the application of theory, and the intervention content (e.g. the BCTs used in the intervention), as well as aspects of design and delivery so that

studies are replicable, and so we can start to understand more about the functional relationship between the components of the intervention and the outcomes (Michie et al., 2013). Furthermore, inconsistent reporting and terminology limits the interpretations of meta-analyses.

Further research is also needed to determine whether IDIs are as effective as face to face therapies; and whether a combination of both is more effective than alone. In the current review we are also lacking data on any potential adverse effects and cost-effectiveness of these types of interventions. Without this evidence base, it is difficult to know how to direct funding for service provision in this area.

The majority of the trials included in the review were conducted online. Online trials have certain advantages over trials conducted in person, including access to large numbers of people, access to hard to reach populations, automated randomisation, blind allocation to different online interventions, automated and secure data entry, the ability to send automated reminders, more honest reporting of sensitive information, and potential reduction in research costs. However, while online recruitment is often successful, attrition rates are often high. Therefore, more research is needed to determine the best way to conduct online trials, including the most effective recruitment methods; strategies to use to maximise engagement with the intervention and retention in the trial; verification methods of participant identity online, and ways to make sure data collected is valid and reliable (Murray et al., 2009; Pequegnat et al., 2007) .

With only 10 RCTs of IDIs across all sexual difficulties meeting the inclusion criteria for the review, and given the concerns/lack of clarity regarding the risk of bias in the included studies there is a definite need for more rigorous and well-reported RCTs of IDIs across all sexual difficulties. While it is ethically challenging to obtain long term follow-up in trials comparing IDIs to minimally active comparators, we might ethically learn more about the long term effects of these interventions by conducting more trials comparing the relative effectiveness of these interventions (e.g. by comparing to other intervention forms).

Although RCTs are often considered the gold standard for evaluating the effectiveness of interventions, they are not the only methodologies worthy of consideration when attempting to evaluate (or establish) an evidence-base in a particular research area; and placing too much emphasis on RCT evidence can lead to recommendations that are skewed in terms of both the availability of evidence and the weight given to that evidence (Slade & Priebe, 2001). Different methodologies answer different research

questions, and to address the gaps in the current literature that are not met by systematic review evidence of RCTs, further research, using other methodologies is needed. In addition to more clearly establishing the effectiveness of IDIs for sexual difficulties, user involvement is essential to ensure that IDIs meet their wants and needs, and are appealing to users. For example, knowing what aspects of sexual difficulties are most problematic or distressing, what the barriers to seeking help are, what people hope to achieve from treatment, and what aspects of IDIs are appealing are all factors that can be built into the design of IDIs to maximise engagement and effectiveness. It is also important to use population based survey methods to determine their potential reach, as there is little point in investing in the design and development of these interventions if they do not reach their intended audience.

4.8.9.3 *Implications for policy*

IDIs are an area policy should ultimately support, within a research and evaluation framework. However, IDIs are not yet at a place where they can be commissioned, as much more research is needed. But they have considerable potential for patient benefit and cost saving and are therefore worth pursuing.

4.9 **Conclusions**

In summary, conclusions about the effectiveness of IDIs for people with sexual difficulties have to be drawn on a fairly small evidence base. While there is evidence to suggest that IDIs can have a positive effect on sexual function and relationship satisfaction in women, many questions remain unanswered, and there is great scope for further and more rigorous RCT research into these interventions, across the range of different sexual difficulties. Despite the limitations of this review, IDIs look promising; they appear to have the potential to meet some of the current unmet need in this area, and warrant further exploration.

Table 4.2: Main outcomes reported in included studies, including direction of change (IDI vs minimally active control conditions)

Study	Sexual problem	Arms (number randomized to each condition)	Timing at follow-up	Sexual outcomes				Relationship outcomes			Negative emotional states				
				Sexual function	Sexual satisfaction	Sexual behaviour	Sexual comfort	Relationship satisfaction	Communication	Emotional intimacy	Distress	Anxiety	Depression	Stress	
Binik, Meana & Sand, 1994 (122)	Non-specific	IDI (unclear) Paper questionnaire (unclear)	2 weeks post			Daily self-monitoring of sexual behaviour: no difference Foreplay activities: improved			Communication about sex: improved						
Hucker & McCabe, 2014 2015 (470/486)	FSD	IDI (52) Waitlist (39)	Immediately post	Female sexual function (FSFI): improved Sexual desire: improved Sexual arousal: improved Lubrication: improved Orgasm: improved Sexual pain: no difference Sexual intimacy (PAIR): improved				Relationship satisfaction (PAIR): improved	Communication (PAIR): improved	Emotional intimacy (PAIR): improved	Distress (FSDS): improved				
Jones & McCabe, 2011 (018)	FSD	IDI (26) Waitlist control (27)	Immediately post	Female sexual function (FSFI): improved Sexual desire (FSFI): improved	Sexual satisfaction (FSFI): improved	Sexual Intimacy (PAIR): improved		Relationship satisfaction (SFS): no difference	Communication (SFS): improved	Emotional intimacy (PAIR): improved		Anxiety (DASS21): no difference Performance anxiety (SFS): no difference	Depression (DASS21): no difference	Stress (DASS21): no difference	

Study	Sexual problem	Arms (number randomized to each condition)	Timing at follow-up	Sexual outcomes				Relationship outcomes			Negative emotional states			
				Sexual function	Sexual satisfaction	Sexual behaviour	Sexual comfort	Relationship satisfaction	Communication	Emotional intimacy	Distress	Anxiety	Depression	Stress
				Arousal (FSFI): improved Lubrication (FSFI): improved Orgasmic function (FSFI): improved Pain (FSFI): improved Frequency of sexual dysfunction: improved										
McCabe, Price, Piterman & Lording, 2008 (003)	ED	IDI (24) Waitlist control (20)	Immediately post	Erectile function (IIEF): improved Orgasmic function (IIEF): no difference Sexual Desire (IIEF): no difference Frequency of ED: improved Erectile strength: improved	Sexual satisfaction (ISS): improved Intercourse Satisfaction (IIEF): unclear Overall satisfaction (IIEF): no difference Sexual relationship quality (SEAR): improved			Relationship satisfaction (KMSS): no difference						

Study	Sexual problem	Arms (number randomized to each condition)	Timing at follow-up	Sexual outcomes				Relationship outcomes			Negative emotional states			
				Sexual function	Sexual satisfaction	Sexual behaviour	Sexual comfort	Relationship satisfaction	Communication	Emotional intimacy	Distress	Anxiety	Depression	Stress
Ochs & Binik, 1998 (288)	Non-specific	IDI (unclear) Crossword puzzle (unclear)	1 week			Daily self-monitoring of sexual behaviour: No difference Sexual activity: unclear	Sexual comfort: unclear	Relationship adjustment (DAS): Unclear	Communication about sex: unclear					
Ochs & Binik, 1998 (288)	Non-specific	IDI (unclear) Video (unclear)	1 week			Daily self-monitoring of sexual behaviour: No difference Sexual activity: unclear	Sexual comfort: unclear	Relationship adjustment (DAS): No difference	Communication about sex: unclear					
Ochs, Meana, Mah, Binik, 1993 (226)	Non-specific	IDI (42) Crossword puzzle (40)	2 weeks			Daily self-monitoring of sexual behaviour: no difference Foreplay activity: unclear			Communication: unclear					
Ochs, Meana, Mah, Binik, 1993 (226)	Non-specific	IDI (42) Video (40)	2 weeks			Daily self-monitoring of sexual behaviour: no difference Foreplay activity: no difference			Communication: no difference					
Ochs, Meana, Mah, Binik, 1993 (226)	Non-specific	IDI (42) Book (40)	2 weeks			Daily self-monitoring of sexual behaviour: no difference Foreplay activity: no			Communication: no difference					

Study	Sexual problem	Arms (number randomized to each condition)	Timing at follow-up	Sexual outcomes				Relationship outcomes			Negative emotional states			
				Sexual function	Sexual satisfaction	Sexual behaviour	Sexual comfort	Relationship satisfaction	Communication	Emotional intimacy	Distress	Anxiety	Depression	Stress
						difference								
Schover et al., 2012 (183)	ED & FSD	IDI (55) Waitlist control (48)	Immediately post	Erectile function (IIEF): Improved	Intercourse Satisfaction (IIEF): unclear			Relationship satisfaction (A-DAS): unclear			Distress (BSI-18): no difference			
				Orgasmic function (IIEF): unclear	Overall satisfaction (IIEF): unclear									
				Sexual Desire (IIEF): unclear	Sexual satisfaction (FSFI): unclear									
				Female sexual function (FSFI): no difference										
				Desire (FSFI): unclear										
				Arousal (FSFI): unclear										
				Lubrication (FSFI): unclear										
				Orgasmic function (FSFI): unclear										
				Pain (FSFI): unclear										

BSI-18 – Brief Symptom Inventory; Centre for Epidemiologic Studies Depression Scale; DAS/ A-DAS - Dyadic Adjustment Scale; DASS21 – Depression, Anxiety and Stress Scale; FSFI – Female Sexual Function Index; General Quality of Life (SF-36); IIEF – International Index of Erectile Function; ISS – Index of Sexual Satisfaction; KMSS – Kansas Marital Satisfaction Survey; PAIR – Personal Assessment of Intimacy in Relationships; Prostate Cancer Quality of Life Scale (PCQoL); SEAR – Self-esteem and Relationship Questionnaire; SFS – Sexual Function Scale.

*Unclear: Data not provided in the publication (e.g. data lumped together and not reported by arm).

Outcomes in red ink: Outcomes chosen apriori to be included in meta-analyses (although many were not included due to outcomes being published in such a way that they could not be entered).

Table 4.3: Main outcomes reported in included studies tables, including direction of change (IDI vs active interventions)

Study	Sexual problem	Arms (# randomized to each condition)	Timing at follow-up	Sexual outcomes				Relational outcomes			Negative emotional states				Quality of life
				Sexual function	Sexual satisfaction	Sexual behaviour	Sexual comfort	Relationship satisfaction	Communication	Emotional intimacy	Distress	Anxiety	Depression	Stress	
Ochs & Binik, 1998 (288)	Non-specific	IDI (unclear) Face-to-face (unclear)	1 week			Daily self-monitoring of sexual behaviour: No difference Sexual activity: unclear (data lumped together): unclear**	Sexual comfort: unclear	Relationship adjustment (DAS): higher in face-to-face	Communication about sex: unclear						
Schover et al., 2012 (183)	ED & FSD	IDI (55) Face-to-face (60)	Immediately post	Erectile function (IIEF): no difference Orgasmic function (IIEF): unclear Sexual Desire (IIEF): unclear Female sexual function (FSFI): no difference Desire (FSFI): unclear Arousal (FSFI): unclear Lubrication (FSFI): unclear Orgasmic function (FSFI): unclear Pain (FSFI): unclear	Intercourse Satisfaction (IIEF): unclear Overall satisfaction (IIEF): unclear Sexual satisfaction (FSFI): unclear			Relationship adjustment (DAS): no difference			Distress (BSI-18): no difference				
Andersson et al., 2011 (078)	ED	IDI (39) Online forum (39)	Immediately post	Erectile Dysfunction (IIEF-5): Improved (primary)	Intercourse satisfaction (IIEF): no difference			Relationship satisfaction (RAS): no difference				General anxiety (BAI): no difference	Depression (BDI-II): no difference		Quality of Life (WHOQOL-BREF): no difference

Study	Sexual problem	Arms (# randomized to each condition)	Timing at follow-up	Sexual outcomes				Relational outcomes			Negative emotional states				Quality of life
				Sexual function	Sexual satisfaction	Sexual behaviour	Sexual comfort	Relationship satisfaction	Communication	Emotional intimacy	Distress	Anxiety	Depression	Stress	
				outcome) Erectile function (IIEF): no difference Orgasmic function (IIEF): no difference Sexual desire (IIEF): no difference	Overall satisfaction (IIEF): no difference										
Wooten et al., 2015 (407)	ED	IDI (unclear) Online forum (unclear)	Unclear								Distress (DASS-21): no difference				Prostate cancer quality of life scale (PCa-QoL): unclear

BSI-18 – Brief Symptom Inventory; DAS – Dyadic Adjustment Scale; FSFI – Female Sexual Function Index; IIEF – International Index of Erectile Function.

*Unclear: Data not provided in the publication (e.g. data lumped together and not reported by arm).

Outcomes in red ink: Outcomes chosen a priori to be included in meta-analyses (although many were not included due to outcomes being published in such a way that they could not be entered).

Table 4.4: Main outcomes reported in included studies tables, including direction of change (IDI vs IDI plus counselling)

Study	Sexual problem	Arms (# randomized to each condition)	Timing at follow-up	Sexual outcomes				Relational outcomes			Negative emotional states				Quality of life
				Sexual function	Sexual satisfaction	Sexual behaviour	Sexual comfort	Relationship satisfaction	Communication	Emotional intimacy	Distress	Anxiety	Depression	Stress	
Schover et al., 2013	FSD	IDI (39) IDI w/ counselling (39)	Immediately post	Female sexual function index (FSFI) Primary outcome: Improved in counselled group, marginal in IDI group. Desire (FSFI): Unclear Arousal (FSFI): Unclear Lubrication (FSFI): Unclear Orgasmic function (FSFI): Unclear Pain (FSFI): Unclear Menopausal sexual interest questionnaire (MSIQ): Improved in the counselled group only. Desire (MSIQ): Unclear Responsiveness (MSIQ): Unclear	Sexual satisfaction (FSFI): Unclear Satisfaction (MSIQ): Unclear						Global severity index (BSI-18): Improved in IDI group only. Somatization (BSI-18): Unclear	Anxiety (BSI-18): Unclear	Depression (BSI-18): Unclear		Quality of life in adult cancer survivors (QLACS): Improved in IDI group only.

BSI-18 – Brief Symptom Inventory; DAS – Dyadic Adjustment Scale; FSFI – Female Sexual Function Index; IIEF – International Index of Erectile Function.

* Unclear: Data not provided in the publication

Outcomes in red ink: Outcomes chosen apriori to be included in meta-analyses (although many were not included due to outcomes being published in such a way that they could not be entered).

Chapter 5
Prevalence of help-seeking/internet
help-seeking in people distressed about
their sex lives, and how help-seeking
varies according to socio-demographic
and behavioural characteristics:
Findings from the National Survey of
Sexual Attitudes and Lifestyles 3
(Natsal-3)

5.1 Chapter overview

Introduction

The systematic review in Chapter 4 demonstrated that IDIs can effectively improve outcomes for some people with sexual difficulties. While it is vital to establish the effectiveness of IDIs for sexual difficulties, the overall impact of these types of interventions can only be realised by a combination of both efficacy and reach.

Objective

The aim of the current study was to estimate the potential reach of IDIs for sexual difficulties in the British general population; and to determine the prevalence of help-seeking according to different sociodemographic and behavioural characteristics of people with sexual difficulties.

Method

Complex survey analysis of data from 14,373 sexually experienced persons aged 16-74 years in a 2010-2012 probability survey of Britain's resident population. Prevalence of recent (past year) use of Internet sources for help or advice for sex life was estimated in a) people reporting 1+ specific distressing sexual difficulties and b) people who are more broadly concerned with their sex life. Sociodemographic and behavioural characteristics associated with online help-seeking were identified using logistic regression to calculate age and education-adjusted odds ratios (AORs).

Results

Approximately 16.4% of the sexually experienced British general population reported being distressed about their sex life in some way (either about a specific sexual function difficulty or about their sex life more broadly), and this corresponds to a large number of people that may want help for their difficulties (approximately 6.9 million). Of those people, approximately two thirds are distressed but without any help or support, illustrating a high level of unmet need. Of the men and women who are distressed about their sex lives, between 6.9-10.3% (427,000-762,000) had sought help or advice online.

Conclusion

Although the internet is currently underutilised as a source of help, the findings indicate that it is one of the top three most popular sources of help for British women and men. Despite the various limitations to this study (many of which centre around the fact that the questions were not designed for this study), the findings illustrate a high level of unmet need, as well as the extent and willingness of the British population to look for help online for a range of sexually related issues. IDIs appear to be well-placed to fill some of the current gaps in service provision by providing an alternative help source that matches with current preferences for online help.

5.2 Background

There is a high prevalence of reported sexual difficulties among people in Britain; with the most recent National Survey of Sexual Attitudes and Lifestyles (Natsal-3) indicating that 51.2% of women and 41.6% of men report experiencing one or more sexual difficulties lasting 3 months or longer, in the last year (Mitchell et al., 2013). Sexual difficulties affect a person's sexual health and wellbeing, and according to the World Health Organisation (WHO), sexual health and wellbeing are integral to a person's overall health (Glasier et al., 2006). The WHO defines sexual health as 'a state of physical, emotional, mental and social wellbeing related to sexuality, and not merely the absence of disease, dysfunction or infirmity. Sexual health requires a positive and respectful approach to sexuality and sexual relationships, as well as the possibility of having pleasurable and safe sexual experiences' (Glasier et al., 2006).

Although the recent Natsal-3 figures suggest that many people encounter difficulties in their sex lives, it is important to note that sexual difficulties are not always deemed problematic or distressing by people who experience them (Hayes, Bennett, Fairley, & Dennerstein, 2006; Hendrickx, Gijs, & Enzlin, 2013; Mitchell et al., 2013). The presence (or absence) of distress is often considered a key factor that differentiates people who might perceive their difficulties as problematic and seek help for them from those that do not (Bancroft et al., 2001; Shifren et al., 2009). As discussed in Chapter 2, sex is a psychosocial act that is greatly influenced by culture; therefore if people do not perceive their difficulties to be problematic then it is perhaps right that they are not deemed so by others. However, socio-cultural factors can influence the experience and reporting of distress, and this can lead to the reporting of inappropriate levels of distress (e.g. the media can influence our perceptions about what we think our sex life should and should not be like) and also denial (Mitchell & Graham, 2008). The presence of distress is part of the DSM-5 diagnostic criteria for sexual dysfunctions (American Psychiatric Association, 2013), and while the inclusion of the distress criteria has generated considerable debate (Hendrickx et al., 2013), its inclusion is considered valuable as it helps to prevent pathologising normal variation in sexual response (Meana, 2010).

Sexual difficulties, for those who are distressed by them, can have a negative impact on emotional and sexual wellbeing, quality of life, mental health and interpersonal relationships (Bancroft, Loftus, & Long, 2003; Connor et al., 2011; Jern, Gunst, Sandnabba, & Santtila, 2012; Patrick et al., 2012). Help-seeking behaviour is

considered a highly adaptive method of coping with concerns and difficulties, and fundamental to mental health and wellbeing (Rickwood, Deane, Wilson, & Ciarrochi, 2005). Sexual difficulties are amenable to treatment (Fruhauf et al., 2012; McCabe, 2001; Melnik, Soares, & Nasello, 2007; Melnik, Soares, & Nasello, 2008; Stinson, 2009; Trudel et al., 2001), and some people seek help through general practice and sexual health services. However, as discussed in Chapter 1, there are multiple barriers to accessing face-to-face help, including discomfort and embarrassment associated with discussing sexual difficulties with a health professional, mobility or geographical barriers, a lack of available services, and time constraints due to work or childcare responsibilities. Even when people do seek help for their difficulties, many do not receive any form of treatment (Shifren et al., 2009). A way to overcome some of these barriers might be to offer help and support via the internet (Portnoy et al., 2008; Ritterband et al., 2011; Ritterband & Tate, 2009).

As discussed in Chapters 1 and 3, there are many potential benefits to the use of IDIs, and in Chapters 2 and 4 we saw that they hold promise for the effective treatment of sexual difficulties. However, while it is vital to establish the effectiveness of IDIs for sexual difficulties, the overall impact of these types of interventions can only be realised by a combination of both efficacy and reach (Glasgow et al., 1999).

Determining the reach of an intervention is particularly important when it comes to implementation. If the target users of Internet interventions are actively seeking help and information online for their sexual difficulties then this bolsters support for the development and provision of internet-based interventions. If however the target users are not actively seeking help and information online then this presents a potential barrier to implementation, and strategies will be required to get around this (i.e., by encouraging GP and Sexual Health practitioner referrals and/or using advertising campaigns).

Despite the recent dramatic rise in interest in e-Health (Bennett & Glasgow, 2009), relatively little is known about the actual reach of IDIs. Internet access has risen dramatically over the past decade (National Telecommunications and Information Administration, 2013; ONS, 2014). In 2014, across the UK, 22 million households (84%) had internet access (ONS, 2014), which is up from 77% in 2011 (ONS, 2011); and smart-phone access to the internet has more than doubled since 2010, from 24% to 58% (ONS, 2014). However, the digital divide continues to exist, with one in eight adults (13%) reporting never having used the internet (ONS, 2014), and one in eight

also reporting that they have no home internet access and have no intention of getting it (Ofcom, 2014). The main reasons cited for not using the internet include cost, lack of adequate equipment, and lack of interest (Dutton & Blank, 2011; National Telecommunications and Information Administration, 2013; Ofcom, 2014).

Groups that are more likely to be digitally disconnected and thus vulnerable to inequities surrounding access to IDIs include adults over the age of 65, lower income groups, people with no formal education qualifications, and people with disabilities (Dutton et al., 2013). While almost all 16-54 year olds have accessed the internet (99% of 16-34 year olds and 96% of 35-54 year olds), only 71% of 65-74 year olds and 37% of those over 75 years old have ever used the internet (Ofcom, 2014; ONS, 2014). This suggests that IDIs may not currently reach much of these older age groups. However, since 2012 there has been a nine percentage point increase in the number of people over 65 years old going online: 42% vs. 33% in 2012 (Ofcom, 2014), and this increased uptake suggests that older adults are progressively seeing the value of the internet in terms of meeting some of their needs and circumstances (Milligan & Passey, 2013). Furthermore, as today's (regular) internet users' get older, age is less likely to be a predictor of internet use, and thus IDIs should become more accessible to older adults (with the exception of those that are too physically or psychologically unwell).

While statistics on household internet access and use demonstrate the broad potential reach of IDIs as a whole, they do not provide information about specific online behaviours (i.e. online help-seeking) in specific populations of interest (i.e. people who are distressed about their sex life). The most accurate way to characterise potential reach is to use studies that have used representative population sampling (Bennett & Glasgow, 2009). In representative population sampling, each individual in the population has an equal likelihood of selection, and because the subset is representative of the entire population, the findings can be generalised to that population.

The National Survey of Sexual Attitudes and Lifestyles (Natsal-3) is a national stratified probability sample survey, and one of the largest surveys of sexual behaviour in the world—involving 15,162 men and women, aged between 16 and 74, resident in Britain (Mercer et al., 2013). It is also the first population-based survey in the UK to provide population prevalence estimates of people who report specific distressing sexual function difficulties, as well as those who are distressed more generally about their sex life, and the proportion of these people who have sought help or advice regarding their

sex life, including via information and support sites in the internet (Mercer et al., 2013; Mitchell et al., 2013). Therefore, it is an appropriate data source from which to calculate the potential reach of IDIs for sexual difficulties.

Gaining an understanding of the sociodemographic and behavioural characteristics of help-seekers/online help-seekers who have specific distressing sexual difficulties and/or more general distress about their sex life is important in terms of informing and optimising intervention design and delivery (i.e. targeting and tailoring interventions to user characteristics), with the goal of maximising interest, engagement and effectiveness.

5.3 Aims

The broad aims of the current study are 1. To estimate the potential reach of IDIs for sexual difficulties in the British general population, and 2. To determine the prevalence of help-seeking according to different sociodemographic and behavioural characteristics of people with sexual difficulties.

5.3.1 Defining ‘Potential users of IDIs for sexual difficulties’

The population of interest in the current study were potential users of IDIs for sexual difficulties, which I chose to define/operationalise in two ways:

1. Population of interest A: Sexually-active people reporting 1+ distressing sexual difficulty

I defined group A as sexually active people (i.e. participants reporting at least one sexual partner in the past year) who reported 1+ of eight specific sexual difficulties for 3+ months in the past year (variable ‘SFPrb’ in Natsal-3; see glossary), and who reported that they were distressed by the problem (variable ‘SFPrbDs’ in Natsal-3). I chose to look at this population because as mentioned in the chapter introduction, studies show that having a sexual difficulty in and of itself is not necessarily problematic for a person (Hendrickx et al., 2013); and that it is often the presence or absence of distress or worry about the problem that distinguishes people who might want some help or support from those who might not (Bancroft et al., 2001).

2. Population of interest B: Sexually experienced people who reported being distressed about their sex life.

I defined group B more broadly as sexually experienced individuals (i.e. individuals with at least one sexual experience), who may or may not have been sexually active in the past year, and who reported being distressed or worried about their sex lives more broadly (variable 'SFFDst' in Natsal-3). I wanted to look at this broader population because potential users of IDIs for sexual difficulties are a broad and diverse population; they range from people who fit the more specific Natsal-3 definition of having one of eight specific sexual function difficulties (e.g. erectile difficulties), for 3 months or more, in the past year, to people with problematic sexual behaviours (e.g. excessive masturbation to internet pornography or excessive seeking of sexual partners), and people with intermittent sexual difficulties (e.g. erectile difficulties that last for periods of less than 3 months). I also wanted to look at this population of people because unlike population A (who were all sexually active), this population included both sexually active and non-sexually active people, and it is not only the sexually active that experience sexual difficulties. Using both these definitions I hoped to capture the full range of potential users of IDIs for sexual difficulties.

To determine the extent to which the two populations overlapped, cross-tabulations were run on the two populations of interest/denominator variables (People reporting 1+ distressing sexual difficulties [variable 'probdist'], and people who reported being distressed or worried about their sex life [variable 'sffd2']).

5.4 Research Questions

<p><i>Population of interest A: Sexually-active people reporting 1+ specific distressing sexual difficulty.</i></p> <p><i>Of the sexually active population:</i></p> <ol style="list-style-type: none"> 1. What proportion report 1+ specific sexual function difficulty and were distressed by it? <p><i>Of people with 1+ distressing sexual difficulty:</i></p> <ol style="list-style-type: none"> 2. What proportion report seeking help or advice for their sex life? 3. Where do they seek help? 4. How does the prevalence and source of help-seeking vary by type of sexual difficulty? 5. How does the prevalence of help-seeking vary according to sociodemographic and behavioural characteristics? 	<p><i>Population of interest B: Sexually-experienced people reporting being distressed about their sex life.</i></p> <p><i>Of the sexually experienced population (i.e. those with at least one sexual experience):</i></p> <ol style="list-style-type: none"> 6. What proportion report being distressed about their sex lives? <p><i>Of people who are distressed about their sex life:</i></p> <ol style="list-style-type: none"> 7. What proportion report seeking help or advice for their sex life? 8. Where do they seek help? 9. How does the prevalence of help-seeking vary according to sociodemographic and behavioural characteristics?
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5.1 Methods of Natsal-3

5.1.1 Design

The National Survey of Sexual Attitudes and Lifestyles 3 (Natsal-3) used a multi-stage, clustered and stratified, probability sample design, with postcode sectors from the British Postcode Address File as the primary sampling units (PSUs).

5.1.2 Participants

15,162 male and female residents of Britain (England, Scotland and Wales), aged between 16 and 74 years old, were interviewed between September 2010 and August 2012.

5.1.3 Procedure

Stage 1: In the first stage of sampling, 1727 British postcode sectors (geographical units used to sort mail) were used as the primary sampling units. Stratification: Prior to selection, the postcode sectors were stratified so as to maximise precision of the sample and ensure that different strata in the population were correctly represented. First the post code sectors were sorted into 11 Government Office Regions, with a further distinction between inner and outer London. Within each of the 12 regions, the post code sectors were listed in increasing order of population density to create three approximately equal sized bands. Within each of the 36 region/density bands, the post code sectors were listed in increasing order of the proportion of the population under 60 years of age, and once again divided into three approximately equal sized bands, which gave a total of 108 region/density/age bands. Lastly, within these bands, the postcode sectors were listing in increasing order of the proportion of households with a head of household in a non-manual occupation (Socio-Economic Groups 1-6, 13). The data used to create these strata were taken from the 2001 Census of the Population. The sectors were selected systematically, with each postcode sector being given a probability of selection proportional to its total number of delivery points. Postcode sectors with fewer than 1000 addresses in them were combined with neighbouring sectors so as to avoid any tight clustering of sampled addresses. For practical reasons, addresses north of the Caledonian Canal, the Scottish islands, and the Isles of Scilly were excluded from the sample frame (which led to 0.5% of eligible addresses in Great Britain being excluded).

Stage 2: At the second stage of sampling, 30 or 36 addresses were randomly selected from within each PSU and assigned to interviewers. Participants aged 16-34 were oversampled so as to provide sufficient power to explore sexual behaviours in the age group with the highest risk for poor sexual health outcomes, including teenage pregnancy and STIs. Initially, 30 addresses were selected: 12 addresses were randomly assigned to the core sample (i.e. screened for participants aged 16-74), 10 were boost 1 addresses (i.e. screened for participants aged 16-34), and 8 were boost 2 addresses (i.e. screened for participants aged 16-29).

Due to a higher number of addresses being screened out than originally estimated, 36 addresses were selected in later waves of data collection. Letters and leaflets providing background information about the survey were sent to the selected addresses prior to the interviews.

Stage 3: In the final stage of sampling, interviewers visited the selected addresses, at which point one resident from each household was randomly selected to participate in the survey (Erens et al., 2013). If there was more than one person in the eligible age range one person was selected using Kish grid technique, which is a pre-assigned table of random numbers used to determine which member of a household to interview (Kish, 1949).

The estimated survey response rate was 57.7% (Mercer et al., 2013), and the cooperation rate (of eligible addresses contacted) was 65.8%. Trained interviewers initially conducted a computer-assisted personal interview (CAPI), and then participants self-administered more sensitive questions using a computer-assisted self-interview (CASI). Full details of the survey methods of Natsal-3 are published elsewhere (Erens et al., 2013; Mercer et al., 2013). The Oxfordshire Research Ethics Committee A (10/H0604/27) approved the Natsal-3 study, and participants provided informed consent orally (Mercer et al., 2013).

5.1.4 Placement and wording of questions in the Sexual Function (SF) section of Natsal-3

5.1.5 Population of interest A: Sexually active people reporting 1+ distressing sexual difficulty

The questions used to operationalise the first population of interest (i.e. sexually active people reporting 1+ specific distressing sexual difficulties) were placed in the Component 1 ('Problems with sexual response') of the Natsal-3 Sexual Function (SF)

questionnaire. Participants who reported being sexually active in the past year started the section by reading the following: 'Some people go through times when they are not interested in sex or find it difficult to enjoy sexual activities. The questions that follow are about some common difficulties that people experience'. Participants were then asked 'In the last year, have you experienced any of the following for a period of 3 months or longer? (variable SFPrb). Participants could choose more than one of the following answers: 1. Lacked interest in having sex. 2. Lacked enjoyment in sex. 3. Felt anxious during sex. 4. Felt physical pain as a result of sex. 5. Felt no excitement or arousal during sex. 6. Did not reach a climax (experience an orgasm) or took a long time to reach a climax despite feeling excited/aroused. 7. Reached a climax (experienced an orgasm) more quickly than you would have liked. 8. Had an uncomfortably dry vagina (asked of women only). 9. Had trouble getting or keeping an erection (asked of men only). 10. I did not experience any of these (if a participant chose this answer they could not answer yes to any of the other difficulties). See Figure 5.1 for ordering of questions in the sexual function section of Natsal-3.

If a participant indicated they had experienced 1+ sexual difficulties, for each difficulty they identified they were then asked 'How do you feel about this?' (variable SFPrbDs). Answer options included: 1. Not at all distressed. 2. A little distressed. 3. Fairly distressed. 4. Very distressed. Those responding as fairly distressed or very distressed were classified as distressed, and were combined with the specific sexual difficulties variable (SFPrb) to derive a new variable 'probdist' (i.e. People with 1+ distressing sexual difficulties).

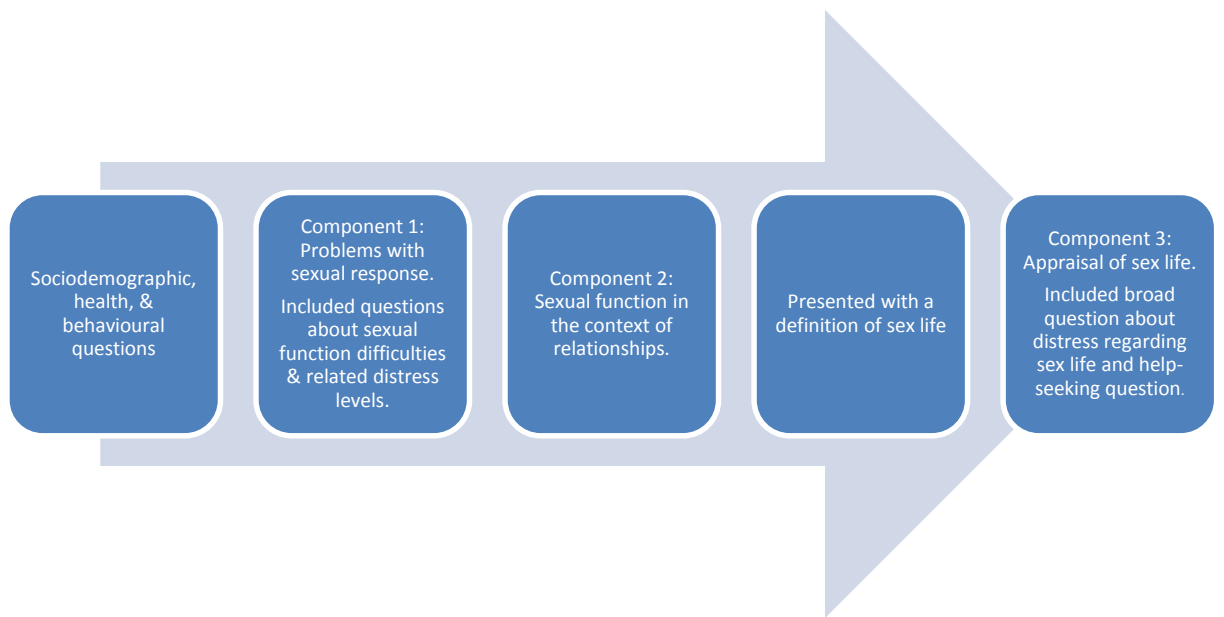


Figure 5.1: Order of questions in the sexual function section of Natsal-3.

Definitions of key terms in the Natsal-3 Sexual Function (SF) section

Sexual function: Sexual function was conceptualised as the extent to which an individual is able to participate in and enjoy a sexual relationship.

Sexual function difficulties: Included lack of interest in sex, lack of enjoyment during sex, feeling anxious during sex, physical pain during sex, no excitement/arousal during sex, delayed or unable to have an orgasm, early ejaculation/orgasm, lubrication problems, and erectile difficulties.

Sex life: Sex life was defined as sexual thoughts, feelings, activity, and relationships.

5.1.6 Population of interest B: Sexually experienced individuals reporting being distressed about their sex life

After the sexual function questions, the questions in Component 2 ('Sexual function in the context of relationships), and being presented with a definition of sex life (see box above), participants moved on to Component 3 ('Appraisal of sex life'). In Component 3 participants who were sexually active (and who thus answered questions in Components 1 and 2), AND participants who reported at least one sexual experience, but who were not sexually active (and who thus did not answer questions in Components 1 and 2) answered the following question used to operationalise the second population of interest (i.e. people who are distressed about their sex life): Participants were asked to think about their sex life in the past year and rate their level of agreement with the following statement: 1. 'I feel distressed or worried about my sex life' (variable SFFDst). Response options included: agree strongly, agree, neither agree nor disagree, disagree, disagree strongly. The SFFDst variable was transformed into a binary variable (yes/no), with agree strongly and agree being recoded as 'yes', and neither agree nor disagree, disagree and disagree strongly being recoded as 'no'.

5.1.7 Outcome variables of interest: Help-seeking and internet help-seeking

The help-seeking variable (which included internet help-seeking) was the outcome variable of interest in the current study and also part of Component 3 of the sexual function section of Natsal-3. Immediately after being asked the question about avoiding

sex, participants who reported at least one sexual experience (but who were not necessarily sexually active) were asked about help-seeking: 'Have you sought help or advice regarding your sex life from any of the following sources in the past year?' (Variable SFHWch). Response options included 1. Family member/friend; 2. Information and support sites on the internet; 3. Self-help books/information leaflets; 4. Self-help groups; 5. Helpline; 6. GP/Family doctor; 7. Sexual health/GUM/STI clinic; 8. Psychiatrist or psychologist; 9. Relationship counsellor; 10. Other type of clinic or doctor; (and 11. Have not sought any help). Participants could choose more than one option from the help-seeking options. A new variable was derived for those who chose at least one response (variable 'anyhelp'), and these people were labelled help-seekers. Those who chose 'Information and support sites on the internet' as a source of help (variable 'spinternet') were labelled as 'internet help-seekers'.

5.2 Methods of current study

5.2.1 Design

The current study was a secondary analysis of the National Survey of Sexual Attitudes and Lifestyles 3 (Natsal-3) data.

5.2.2 Participants

As mentioned previously, the population of interest in the current study were potential users of IDIs for sexual difficulties, which I defined as 'People with 1+ distressing sexual difficulties' and/or 'People who are distressed about their sex life'. The routing of the participants to the variables (SFPrb, SFPrbDs and SFFDst) that were used to define these populations of interest partially depended on participants' reported sexual activity (see Figure 5.2).

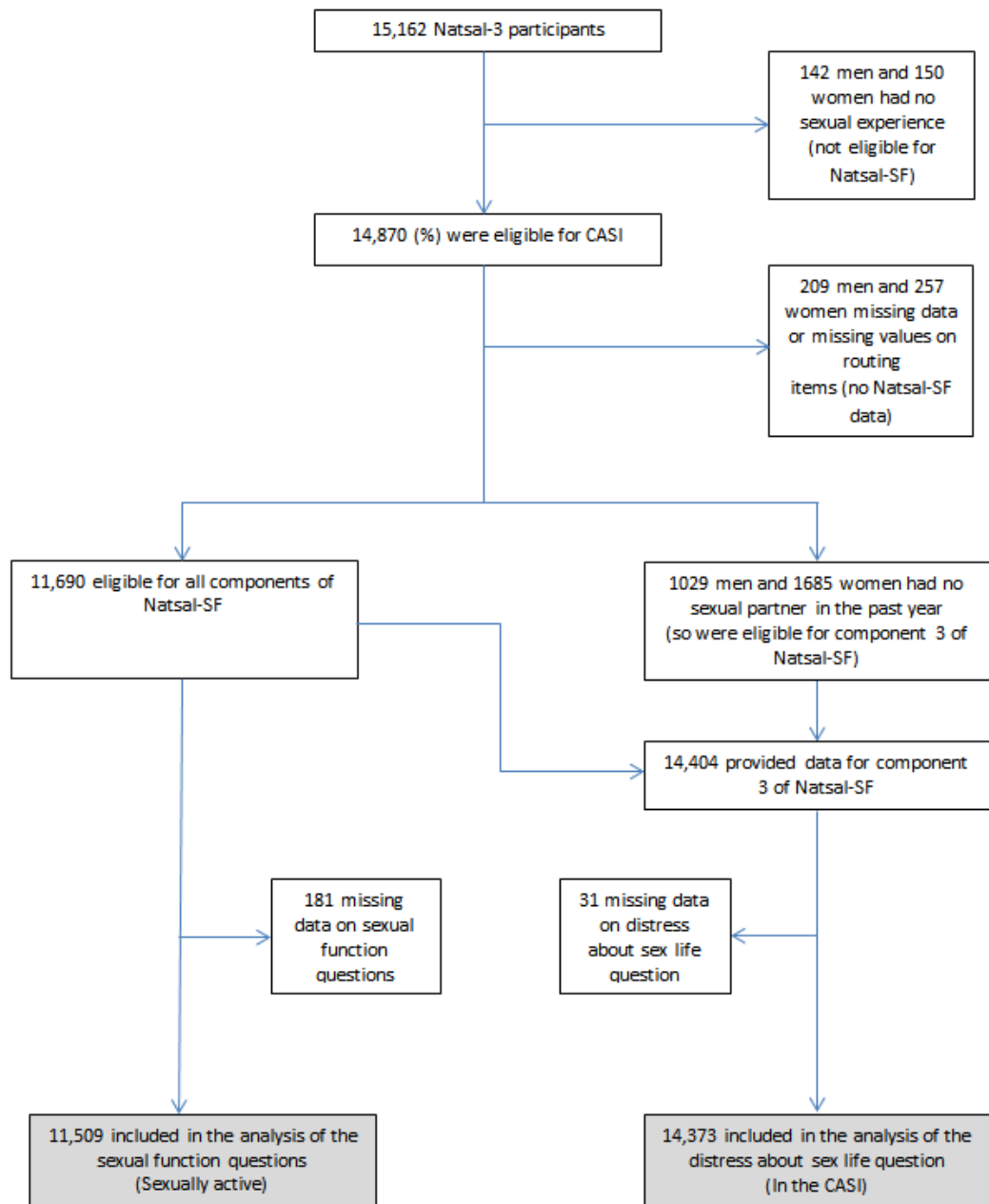


Figure 5.2: Natsal-3 participants, exclusions, and participants included in the final analysis of the current study

Note: the 181 and 31 missing data are participants who actively chose not to answer. The second group contains the participants in the first group plus the participants eligible to complete the Component 3 questions of Natsal-SF.

5.2.3 Variables of interest to the current study

Explanatory variables

The explanatory variables of interest to the current study included the following sociodemographic, health, sexual health, relationship, sex education, sexual behaviour variables. The decision of which variables to include in the analysis was made a priori on the basis of theory or previous research on predictors of help-seeking for sexual difficulties and/or other health and mental health problems (Doherty & Kartalova-O'Doherty, 2010).

Sociodemographic variables

Age (Shifren et al., 2009), gender (Laumann, Glasser, Neves, & Moreira, 2009; Mercer et al., 2003; Mitchell et al., 2013; Moreira et al., 2008), education (Doherty & Kartalova-O'Doherty, 2010), employment (Doherty & Kartalova-O'Doherty, 2010), number of hours worked, relationship status (Doherty & Kartalova-O'Doherty, 2010; Shifren et al., 2009), ethnicity, sexual orientation, religion and area level deprivation (Elofsson, Undén, & Krakau, 1998; Galdas, Cheater, & Marshall, 2005; Lannin, Mathews, Mitchell, & Swanson, 2002) were included in the analysis. Index of Multiple Deprivation (IMD) is a multi-dimensional measure of area (neighbourhood)-level deprivation based on the participant's postcode. IMD scores were adjusted before being combined and assigned to quintiles, using a method by Payne and Abel (Payne & Abel, 2012).

Health/Sexual Health variables

Self-reported health status (Doherty & Kartalova-O'Doherty, 2010; Shifren et al., 2009), health condition in the last year that affected sexual activity, screened positive for current depression, received treatment for depression in the last year, received treatment for another mental health condition in the last year, currently taking medication for depression (Shifren et al., 2009), genital health condition (listed on card B or C – see Appendix F), taken medications that limited sexual activity or enjoyment, and diagnoses of a sexually transmitted infection (STI).

Relationship context variables

Happiness with partner; compatibility with partner(s) in terms of level of interest in sex, sexual likes/dislikes, and emotional closeness during sex; ease of talking about sex with partner(s) (O'Donnell, 2005); satisfaction with sex life; frequency and duration of

any sexual difficulties. Data on these relationship variables were only available for participants who were in a relationship for the whole year prior to being interviewed.

Sex education/learning about sex variables

Given that ease of talking about sex with a partner is positively associated with help-seeking for sexual difficulties, the following variables were included in the analysis (whether participants had discussed sex with 1+ parents at age 14, ease of talking about sex with a parent at age 14, and source of sex education) because if positively associated with help-seeking, they have implications for sex education programs (specifically around facilitating open communication about sex and sexuality).

Sexual behaviour/experiences variables

Sexual competence at first intercourse (a composite measure defined as an absence of duress and regret, autonomy of decision, and use of a reliable method of contraception at first heterosexual sexual intercourse), attempted sex against a person's will, or experienced sex against a person's will were included in the analysis because if associated with help-seeking they have implications for sex education, specifically around the factors that might lead a young person to be 'sexually competent' and in minimising future harm for people recovering from sexual abuse.

5.2.4 Statistical analysis for the current study

Data were analysed using the complex survey data analysis function in STATA version 12.1, which accounts for stratification, clustering, and weighting of the data (as described in the Natsal-3 methods section on p117).

Previous research indicates that men and women have a different prevalence of sexual difficulties (Laumann et al., 2009; Mercer et al., 2003; Moreira et al., 2008), and different patterns of help-seeking for sexual difficulties (Laumann et al., 2009; Mercer et al., 2003; Moreira et al., 2008) and other health/mental health difficulties (Doherty & Kartalova-O'Doherty, 2010; Rickwood et al., 2005; World Health Organization, 2009). Therefore all analyses were conducted separately by gender. Item non-response in Natsal-3 was low: below 0.5% in the CAPI, and 1-3% in the CASI (Erens et al., 2013), and therefore participants with missing data on a particular variable were excluded from that analysis.

The only explanatory variable that was measured continuously was age. To aid interpretation of odds ratios, age was transformed into a categorical variable with the

categories chosen based on previous research (Mercer et al., 2013; Mitchell et al., 2013). Some of the existing categorical variables were transformed into dichotomous variables to increase the cell sizes for less commonly reported items and to ease interpretation of the results (e.g. sexual orientation was dichotomised to heterosexual and non-heterosexual; employment status was dichotomised to employed and not employed; health status was dichotomised to good/very good to fair to very bad etc.).

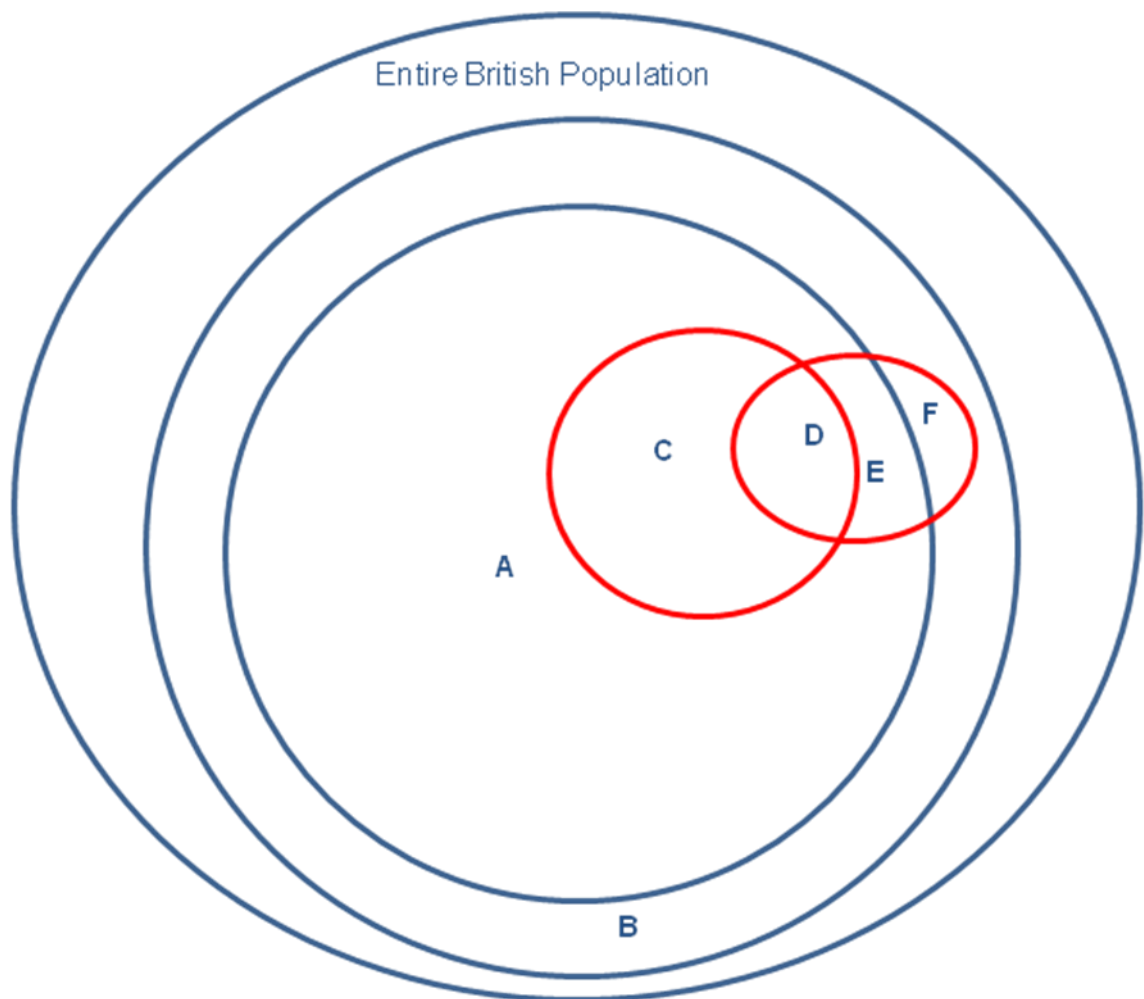
Cross-tabulations were run on all outcome and explanatory variables of interest. The Chi-square test was used to compare differences between groups in bivariate analysis of the association between a hypothesised explanatory variable and the study's outcome of interest (help-seeking). Logistic regression was then used to obtain crude odds ratios (ORs). As age and education were potential confounders of the relationship between the explanatory variables (participant characteristics) and the outcome variable (help-seeking) a multivariable logistic regression was used to observe the association between the explanatory variables and the outcome variable while adjusting for these variables. Logistic regression was chosen because the outcome variable (help-seeking) was a dichotomous variable. All percentages reported are weighted percentages, and weighted and unweighted counts are presented in brackets.

Alpha was set at $p > 0.05$ for all analyses. The p-value is the probability that the observed results are due to normal random variation (i.e. chance). A p value of 0.05 means there is a 5% (or 1/20) chance that the observed statistically significant results are purely due to chance (also referred to as the null hypothesis, in which there is no relationship to be found). When alpha is set to 0.05, p-values less than 0.05 are considered significant, and one would reject the null hypothesis of no association. Conversely, p-values above 0.05 would be considered not significant, and one would accept/retain the null hypothesis.

5.3 Results

Of the sexually experienced population (N = 14,404), 70.0% (CI 69.0 to 70.8) reported being sexually active in the last year, with no distressing sexual difficulties, and no distress about their sex lives (see section A in Figure 5.3). A further 13.6% (CI 13.2 to 14.5) reported they had not been sexually active in the last year and were not distressed about their sex life (see section B in Figure 5.3). This means that 16.4% of the sexually experienced British population report being distressed or worried about their sex life in some way, and therefore may have a need for help via an IDI for sexual

difficulties (see Figure 5.3, sections C, D, E and F). This means that of all sexually experienced people Britain, 1.8% (CI 1.5 to 2.0) reported that they were not sexually active but were distressed about their sex life (section F in Figure 5.3); 5.0% (CI 4.5 to 5.4) reported being sexually active in the last year, and no distressing sexual difficulties, but were distressed about their sex life (section E in Figure 5.3); 5.8% (CI 5.3 to 6.3) reported being sexually active in the last year, 1+ distressing sexual difficulties, but not distressed about their sex life (section C in Figure 5.3); while 3.8% (CI 3.4 to 4.2) reported being sexually active in the last year, 1+ distressing sexual difficulties, and being distressed about their sex life (section D in Figure 5.3).



- A = Sexually active, no distressing sexual difficulties, and not distressed about sex life.
 B = Sexually experienced, not sexually active, and not distressed about sex life.
 C = Sexually active, 1+ distressing sexual difficulties, but not distressed about sex life.
 D = Sexually active, 1+ distressing sexual difficulties, and distressed about sex life.
 E = Sexually active, no distressing sexual difficulties, but distressed about sex life.
 F = Sexually experienced, not sexually active, but distressed about sex life.

Figure 5.3: The distribution of reporting different types of distress associated with participants' sex lives according to recency of sexual experience (ever had sex vs. in the past year).

Note: Groups in red indicate those who may have a need for help via an IDI for sexual difficulties (Circles are not proportionate in size).

The following results apply to population of interest A: Sexually active people reporting 1+ specific distressing sexual difficulties.

5.3.1 Prevalence of reporting 1+ sexual function difficulties and distress, and associated help-seeking among the sexually active population (RQ1&2)

Among the sexually-active British population, 46.4% (95% CI 45.3 to 47.5%) reported at least one of the eight sexual function difficulties asked about in Natsal-3. Of these, 24.7% (95% CI 23.3 to 26.2%) reported being distressed by their sexual difficulty, thus 11.5% (CI 10.8 to 12.2%) of the sexually-active population. And of these, 40.6% (95% CI 37.6 to 43.6%) reported seeking some form of help. The percentage of men who were distressed by their sexual difficulties and sought help 41.0% (CI 36.4 to 45.9%) did not differ statistically from the percentage of women who were distressed by their sexual difficulties and sought help 40.2% (CI 36.4 to 44.1%).

5.3.2 Sources of help among those reporting 1+ distressing sexual difficulty (RQ3)

The prevalence of different types of help-seeking in women and men with 1+ distressing sexual difficulties are summarised in Figure 5.4. The three most common sources of help sought by women were consulting a GP (19.1%, CI 16.1 to 22.5%), talking to a family member or friend (16.8%, CI 14.1 to 20.0%), and seeking information and support on the internet (10.3%, CI 8.3 to 12.7%). The three most common sources of help sought by men were consulting a GP (22.5%, CI 18.5 to 27.1%), seeking information and support on the internet (9.0%, CI 6.8 to 11.9%), and talking to a family member or friend (8.5%, CI 6.3 to 11.4%). The only significant difference between women and men in terms of where they seek help was that women were significantly more likely than men to talk to a family member or friend ($p = 0.0001$).

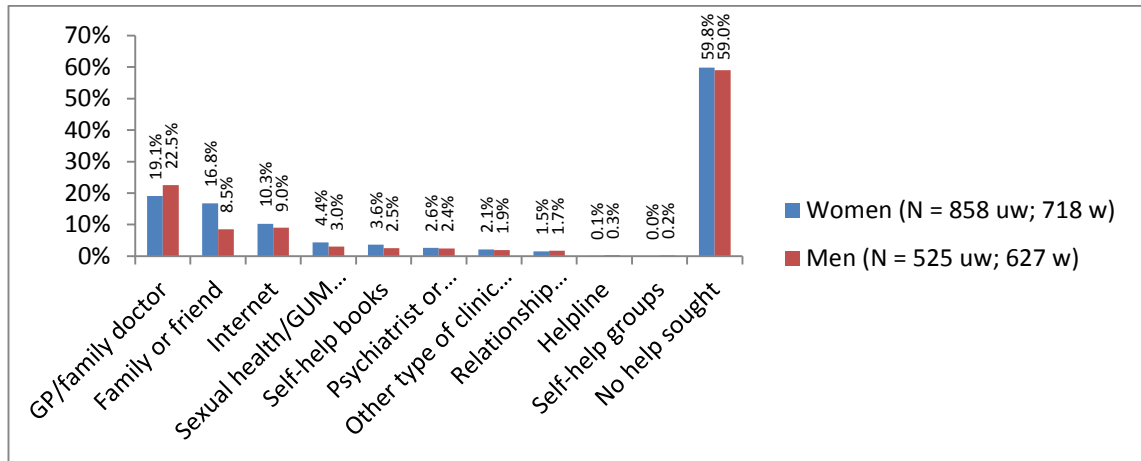


Figure 5.4: Prevalence of different types of help-seeking in men and women with 1+ distressing sexual difficulties

5.3.3 Variations in help-seeking by sexual difficulty (RQ4)

Women:

The prevalence of reported distress associated with each of the eight specific sexual difficulties that Natsal-3 asked about can be seen for sexually-active women in Table 5.1 below. Physical pain during sex was the most common distressing sexual difficulty (45.5%, CI 40.5 to 50.5), followed by anxiety during sex (40%, CI 34.4 to 46.3) and lacking enjoyment during sex (26.9%, CI 23.5 to 30.6) – although the prevalence of women with distressing lubrication problems (26.8%, CI 23.3 to 30.5) and distressing lack of excitement or arousal during sex (26.2%, CI 22.3 to 30.5) were approximately the same as lacking enjoyment. Lacking interest in sex was the least common distressing difficulty (19.1%; CI 17.2 to 21.1).

Variations in help-seeking among sexually active women according to the specific sexual difficulty reported can also be seen in Table 5.1 below. The highest prevalence of help-seeking was observed in women reporting distress due to pain during sex (53.4%; CI 45.5 to 61.1), followed by women reporting distress due to anxiety during sex (50.7%; CI 40.6 to 60.7), and then women reporting distress due to lubrication problems (50.0%; CI 41.5 to 58.5). The lowest prevalence of help-seeking (discounting women who sought help for distressing early orgasm problems where the numbers were too small to analyse meaningfully) was in women who reported distress due to a lack of interest in sex (37.8%; CI 32.6 to 43.3).

For all types of sexual difficulty, formal sources of help-seeking were the most commonly sought, followed by informal sources then self-help methods (see Table 5.1). The highest proportion of formal help-seeking was observed in women reporting distress from pain during sex (76.6%; CI 67.3 to 83.8), followed by women reporting distress from a lack of enjoyment in sex (71.3%; CI 61.2 to 79.6), and then women reporting distress from lubrication problems (69.3%; CI 57.7 to 78.9). The highest proportion of informal help-seekers were women reporting distress from anxiety during sex (52.3%; CI 37.2 to 66.9), followed by women reporting distress from difficulties with orgasms (47.4%; CI 37.3 to 57.7), and then women who reported distress from lacking enjoyment in sex (43.3%; CI 32.4 to 54.8). The highest proportion of self-help seekers were women reporting no excitement or arousal during sex (39.9%; CI 28.0 to 53.1), closely followed by women reporting distress from anxiety during sex (39.3%; CI 28.3 to 51.4), and then women reporting difficulties with orgasms (38.3%; CI 29.2 to 48.2).

Table 5.1: Percentage of sexually active women who reported distress about a specific difficulty, seeking help, and source of help by specific type of sexual difficulty

Specific sexual difficulty	% women reporting distress about a specific difficulty (CI) n	Of women reporting distress about specific difficulty: % who sought help (CI) n	Of those who sought help: Source of help		
			Formal* (CI) n	Informal** (CI) n	Self-help*** (CI) n
Lacked interest in having sex	19.1% (17.2-21.1) n=376w; 430uw	37.8% (32.6-43.3) n=142w; 176uw	66.4% (57.6-74.2) n=94w; 108uw	41.4% (32.8-50.5) n=59w; 84uw	33.4% (26.0-41.7) n=47w; 60uw
Denominator (weighted/unweighted)	1965/2129	376/430	142/176		
Lacked enjoyment in sex	26.9% (23.5-30.6) n=188w; 223uw	45.0% (37.4-52.9) n=85w; 104uw	71.3% (61.2-79.6) n=60w; 66uw	43.3% (32.4-54.8) n=37w; 52uw	35.1% (25.3-46.3) n=30w; 42uw
Denominator (weighted/unweighted)	697/798	188/223	85/104		
Anxiety during sex	40.2% (34.4-46.3) n=121w; 164uw	50.7% (40.6-60.7) n=62w; 83uw	62.6% (50.9-73.0) n=39w; 47uw	52.3% (37.2-66.9) n=32w; 50uw	39.3% (28.3-51.4) n=24w; 33uw
Denominator (weighted/unweighted)	302/405	121/164	62/83		
Physical pain as a result of sex	45.5% (40.5-50.5) n=195w; 226uw	53.4% (45.5-61.1) n=104w; 128uw	76.6% (67.3-83.8) n=80w; 93uw	35.9% (26.7-46.2) n=37w; 54uw	34.0% (24.9-44.4) n=35w; 44uw
Denominator (weighted/unweighted)	429/506	195/226	104/128		
No excitement/arousal during sex	26.2% (22.3-30.5) n=123w; 156uw	45.9% (37.0-55.2) n=57w; 75uw	66.4% (53.9-77.00) n=38w; 46uw	43.0% (30.9-56.1) n=24w; 39uw	39.9% (28.0-53.1) n=23w; 31uw
Denominator (weighted/unweighted)	471/539	123/156	57/75		

Specific sexual difficulty	% women reporting distress about a specific difficulty (CI) n	Of women reporting distress about specific difficulty: % who sought help (CI) n	Of those who sought help: Source of help		
			Formal* (CI) n	Informal** (CI) n	Self-help*** (CI) n
Delayed or no orgasm during sex	22.0% (19.4-24.8) n=206w; 272uw	46.0% (38.9-53.2) n=95w; 128uw	62.3% (52.0-71.5) n=59w; 74uw	47.4% (37.3-57.7) n=45w; 72uw	38.3% (29.2-48.2) n=36w; 53uw
Denominator (weighted/unweighted)	939/1140	206/272	95/128		
Early orgasm problems	3.7%† (1.8-7.3) n=5w; 9uw	30.2%† (7.4-70.0) n=2w; 2uw	30.6%† (2.5-88.2) n=1w; 1uw	30.6%† (2.5-88.2) n=1w; 1uw	100%† - n=2w; 2uw
Denominator (weighted/unweighted)	133/169	5/9	2/2		
Lubrication problems	26.8% (23.3-30.5) n=200w; 197uw	50.0% (41.5-58.5) n=100w; 99uw	69.3% (57.7-78.9) n=69w; 47uw	34.8% (24.47.0) n=35w; 30uw	33.3% (23.6-44.7) n=33w; 28uw
Denominator (weighted/unweighted)	746/749	200/197	100/72		

Note: All women had experienced 1+ sexual difficulties, for 3 months or longer in the last year.

*Formal help included GP, STI/GUM clinic, psychologist or psychiatrist, relationship counsellor or other type of clinic or doctor. **Informal help included family or friends. ***Self-help included internet, self-help books or self-help groups.

† Denominators <20 and thus these results could not be interpreted meaningfully.

w=weighted; uw=unweighted.

Men:

The prevalence of reported distress associated with each of the eight specific sexual difficulties that Natsal-3 asked about can be seen for sexually-active men in Table 5.2 below. Erectile difficulties was the most common distressing sexual difficulty (40.9%, CI 36.5 to 45.5), followed by physical pain as a result of sex (31.6%, CI 21.7 to 43.5) and no arousal or excitement during sex (29.0%, CI 22.1 to 37.1). Lacking interest in having sex was the least common distressing difficulty (14.4%; CI 11.8 to 17.5).

The prevalence of help-seeking, in sexually active men, according to the specific sexual difficulties can also be seen in Table 5.2 below. Discounting distress due to physical pain during sex (where the numbers of help-seekers were too small to analyse meaningfully), the highest prevalence of help-seeking was observed in men reporting distress due to erectile difficulties (50.3%; CI 43.6 to 57.0), followed by men reporting distress due to difficulties with delayed or an absence of orgasms (48.4%; CI 36.1 to 60.9), and then men reporting distress due to anxiety during sex (44.2%; CI 32.3 to 56.9). The lowest prevalence of help-seeking was in men who reported distress due to difficulties with early orgasm (25.3%; CI 18.7 to 33.3).

Overall, formal sources of help were most commonly sought by men. However, it is not possible to comment on which methods (formal, informal or self-help) were most common for each sexual difficulty as the numbers were too small to analyse meaningfully (see Table 5.2).

Table 5.2: Percentage of sexually active men who reported distress about a specific difficulty, seeking help, and source of help by specific type of sexual difficulty

Specific sexual difficulty	% men reporting distress about a specific difficulty (CI) n	Of men reporting distress about specific difficulty: % who sought help (CI) n	Of those who sought help: Source of help		
			Formal* (CI) n	Informal** (CI) n	Self-help*** (CI) n
Lacked interest in having sex	14.4% (11.8-17.5) n=130w; 114uw	43.4% (33.7-53.7) n=56w; 47uw	69.0% (51.0-82.7) n=39w; 30uw	23.1%† (11.9-40.1) n=13w; 14uw	36.4% (20.8-55.5) n=21w; 16uw
Denominator (weighted/unweighted)	898/714	130/114	56/47		
Lacked enjoyment in sex	21.4% (16.4-27.4) n=61w/58uw	43.7% (30.8-57.6) n=26w; 23uw	73.1%† (49.1-88.4) n=19w/16uw	38.7%† (19.5-62.2) n=10w; 9uw	36.6%† (18.1-60.1) n=10w; 8uw
Denominator (weighted/unweighted)	283/250	61/58	26/23		
Anxiety during sex	27.0% (21.4-33.5) n=87w/81uw	44.2% (32.3-56.9) n=39w; 37uw	63.8% (45.4-78.9) n=25w/22uw	31.6%† (16.7-51.5) n=12w; 11uw	39.8%† (23.7-58.4) n=15w; 14uw
Denominator (weighted/unweighted)	323/291	87/81	39/37		
Physical pain as a result of sex	31.6% (21.7-43.5) n=34w/27uw	50.4%† (31.3-69.4) n=17w; 15uw	71.1%† (43.9-88.5) n=12w; 10uw	29.9%† (12.0-57.3) n=5w; 5uw	29.86%† (10.8-60.0) n=5w; 4uw
Denominator (weighted/unweighted)	106/90	34/27	17/15		
No excitement/arousal during sex	29.0% (22.1-37.1) n=55w/48uw	42.5% (29.0-57.2) n=23w; 19uw	79.7%† (57.5-92.0) n=19w; 14uw	35.1%† (15.3-61.8) n=8w; 7uw	39.0%† (19.3-63.0) n=9w; 6uw
Denominator (weighted/unweighted)	188/161	55/48	23/19		

Specific sexual difficulty	% men reporting distress about a specific difficulty (CI) n	Of men reporting distress about specific difficulty: % who sought help (CI) n	Of those who sought help: Source of help		
			Formal* (CI) n	Informal** (CI) n	Self-help*** (CI) n
Delayed or no orgasm during sex	17.3% (13.6-21.7) n=94w/76uw	48.4% (36.1-60.9) n=46w; 35uw	74.1% (55.1-87.0) n=34w; 26uw	28.4%† (14.3-48.4) n=13w; 10uw	26.6%† (13.8-45.0) n=12w; 9uw
Denominator (weighted/unweighted)	546/459	94/76	46/35		
Early orgasm problems	22.2% (18.8-25.9) n=197w/176uw	25.3% (18.7-33.3) n=50w; 51uw	41.9% (27.3-58.0) n=21w; 20uw	29.5%† (16.4-47.1) n=15w; 14uw	44.8% (30.0-60.6) n=22w; 25uw
Denominator (weighted/unweighted)	891/737	197/176	50/51		
Erectile difficulties	40.9% (36.5-45.5) n=314/251	50.3% (43.6-57.0) n=158w; 125uw	77.1% (68.2-84.1) n=122w; 88uw	17.2% (11.2-25.6) n=27w; 29uw	33.3% (23.6-44.7) n=33w; 32uw
Denominator (weighted/unweighted)	767w/587uw	314/251	158/125		

Note: All men had experienced 1+ sexual difficulties, for 3 months or longer in the last year.

*Formal help included GP, STI/GUM clinic, psychologist or psychiatrist, relationship counsellor or other type of clinic or doctor. **Informal help included family or friends. ***Self-help included internet, self-help books or self-help groups.

† Denominators <20 and thus these results could not be interpreted meaningfully

w=weighted; uw=unweighted.

5.3.4 How the prevalence of help-seeking varies by participant characteristics in adults with 1+ distressing sexual difficulties (RQ5)

I explored the prevalence of help-seeking by different sociodemographic, health, relationship, sex education and sexual behaviour variables in sexually active women and men with 1+ distressing sexual difficulties. See Tables 5.3-5.10 for univariate and multivariable analyses adjusted for age and education.

Sociodemographic factors

The mean age of female help-seekers was 37.1 years (SD 16.2), which was significantly younger than the mean age of male help-seekers (43.6 years of age, SD = 13.9, $p < 0.001$). The percentage of women who sought help decreased with age in women (referent age group 16-24 versus age group 35-44 OR = 0.58 (95% CI 0.34 to 0.98) and age group 45-54 OR = 0.45 (95% CI 0.2 to 0.8) but rose again after age 54. No association was observed between age and help-seeking in men (referent age group 16-24 versus age group 55-64 OR = 1.30; 95% CI 0.7 to 2.6). Education was significantly associated with help-seeking in women but not in men, whereby almost half (48.8%) the women with a degree level education (referent group) sought help compared to just under a third (32.5%) of women with a secondary school education (OR = 0.51; 95% CI 0.3 to 0.8; $p = 0.0167$). Employment was not significantly associated with help-seeking in women or men. After adjusting for education, the association between age and help-seeking in women became only borderline statistically significant (age group 35-44 AOR = 0.62; 95% CI 0.4 to 1.1 and age group 45-54 AOR = 0.52; 95% CI 0.3 to 0.9; $p=0.077$). The only statistically significant association that remained in women after adjustment was between education and help-seeking (AOR = 0.53; 95% CI 0.4 to 0.8; $p=0.0484$). No associations were observed, in women or men, between area level deprivation, number of hours worked or religion and help-seeking (see Tables 5.3 and 5.4).

Table 5.3: The prevalence of help-seeking by sociodemographic characteristics in sexually active women with 1+ distressing sexual difficulties (crude & adjusted odds ratios).

	Percentage of women w/1+ distressing sexual difficulty who sought help (95% CI)	OR (95% CI)	p value for OR	AOR* (95% CI)	p value for AOR	Denominator	
						Unweighted	Weighted
All	40.2% (CI 36.4-44.1)	-	-	-	-	858	718
Age							
16-24	49.2% (42.2%-56.2%)	1	0.0100	1	0.0773	256	145
25-34	46.7% (40.3%-53.3%)	0.91 (0.63 - 1.31)		0.95 (0.65 - 1.39)		300	174
35-44	35.8% (26.5%-46.3%)	0.58 (0.34 - 0.98)		0.62 (0.36 - 1.07)		97	117
45-54	30.4% (21.9%-40.4%)	0.45 (0.27 - 0.77)		0.52 (0.30 - 0.89)		111	154
55-64	42.5% (30.9%-55.1%)	0.77 (0.43 - 1.36)		0.89 (0.49 - 1.63)		70	95
65-74	20.8% (8.8%-41.8%)	0.27 (0.10 - 0.77)		0.36 (0.12 - 1.05)		24	33
Quintile of Index of Multiple Deprivation							
1 (least deprived)	44.1% (36.2%-52.2%)	1	0.5249	1	0.4148	140	147
2	40.1% (30.9%-50.0%)	0.85 (0.51 - 1.43)		0.86 (0.50 - 1.46)		138	135
3	43.6% (35.3%-52.3%)	0.98 (0.61 - 1.57)		0.98 (0.60 - 1.60)		175	154
4	36.8% (29.6%-44.7%)	0.74 (0.47 - 1.17)		0.73 (0.45 - 1.18)		192	157
5 (most deprived)	35.6% (28.0%-44.1%)	0.70 (0.43 - 1.14)		0.66 (0.40 - 1.08)		220	125
Education							
Degree	48.8% (41.4%-56.2%)	1	0.0167	1	0.0484	247	229
Higher education	41.7% (34.5%-49.4%)	0.75 (0.49 - 1.16)		0.70 (0.45 - 1.09)		232	173
GCSE- O level or equivalent	32.5% (26.5%-39.2%)	0.51 (0.33 - 0.77)		0.53 (0.35 - 0.80)		299	249
Foreign**	56.8% (19.9%-87.4%)	1.38 (0.25 - 7.56)		1.20 (0.24 - 6.12)		7	5
None	33.8% (22.8%-46.9%)	0.54 (0.29 - 1.00)		0.61 (0.32 - 1.14)		72	62

	Percentage of women w/1+ distressing sexual difficulty who sought help (95% CI)	OR (95% CI)	p value for OR	AOR* (95% CI)	p value for AOR	Denominator	
						Unweighted	Weighted
Employment							
Employed	41% (35.9%-46.4%)	1	0.0413	1	0.7675	475	417
In full-time education	52.9% (40.9%-64.5%)	1.61 (0.95 - 2.74)		1.10 (0.61 - 1.97)		97	58
Unemployed	35.6% (29.5%-42.3%)	0.79 (0.56 - 1.14)		0.90 (0.62 - 1.30)		286	243
Number of hours worked							
35+	39.4% (32.8%-46.5%)	1	0.5091	1	0.2464	270	92
less than 35	42.9% (35.4%-50.7%)	1.15 (0.76 - 1.76)		1.30 (0.85 - 2.00)		219	83
Religion							
None	40.5% (35.2%-46.0%)	1	0.5564	1	0.6196	463	349
Christian	38.8% (33.2%-44.7%)	0.93 (0.67 - 1.29)		1.06 (0.74 - 1.51)		349	328
Other non-Christian religions	48.2% (32.9%-63.8%)	1.37 (0.70 - 2.68)		1.40 (0.71 - 2.78)		46	42

*Variables adjusted for age and education (age variable adjusted for education only; education variable adjusted for age only)

**Denominators in these categories were <20, therefore caution should be taken when interpreting these results as the estimates will not be robust

Table 5.4: The prevalence of help-seeking by sociodemographic characteristics in sexually active men with 1+ distressing sexual difficulties (crude & adjusted odds ratios).

	Percentage of men w/1+ distressing sexual difficulty who sought help (95% CI)	OR (95% CI)	p value for OR	AOR* (95% CI)	p value for AOR	Denominator	
						Unweighted	Weighted
All	41.0% (CI 36.3-45.9)	-	-	-	-	525	627
Age							
16-24	38.7% (28.8%-49.7%)	1	0.9456	1	0.8162	125	93
25-34	39% (30.5%-48.2%)	1.01 (0.56 - 1.84)		1.13 (0.60 - 2.10)		147	125
35-44	39.8% (28.2%-52.7%)	1.05 (0.52 - 2.11)		1.23 (0.60 - 2.54)		73	110
45-54	43.9% (31.4%-57.2%)	1.24 (0.62 - 2.48)		1.54 (0.74 - 3.21)		67	123
55-64	45.2% (33.5%-57.5%)	1.30 (0.66 - 2.57)		1.57 (0.76 - 3.24)		74	119
65-74	36.7% (23.3%-52.5%)	0.92 (0.42 - 1.98)		1.11 (0.49 - 2.50)		39	57
Quintile of Index of Multiple Deprivation							
1 (least deprived)	39.6% (29.8%-50.2%)	1	0.4394	1	0.3093	146	139
2	38.5% (27.1%-51.4%)	0.96 (0.48 - 1.90)		0.96 (0.48 - 1.91)		113	112
3	36.6% (27.9%-46.4%)	0.88 (0.49 - 1.59)		0.93 (0.51 - 1.68)		112	133
4	50.6% (39.4%-61.8%)	1.57 (0.84 - 2.94)		1.76 (0.92 - 3.37)		126	114
5 (most deprived)	40.8% (31.0%-51.5%)	1.05 (0.57 - 1.94)		1.21 (0.65 - 2.27)		164	129
Education							
Degree	50.4% (41.4%-59.3%)	1	0.1000	1	0.0988	147	195
Higher education	37.6% (30.0%-45.8%)	0.59 (0.36 - 0.98)		0.60 (0.36-0.99)		176	197
GCSE- O level or equivalent	33.4% (25.6%-42.3%)	0.50 (0.29 - 0.85)		0.50 (0.29-0.85)		155	167
Foreign**	58.4% (19.4%-89.1%)	1.39 (0.23 - 8.22)		1.48 (0.25-8.88)		6	7
None	41.1% (26.0%-58.2%)	0.69 (0.32 - 1.48)		0.67 (0.31-1.46)		41	62

	Percentage of men w/1+ distressing sexual difficulty who sought help (95% CI)	OR (95% CI)	p value for OR	AOR* (95% CI)	p value for AOR	Denominator	
						Unweighted	Weighted
Employment							
Employed	42.9% (36.9%-49.1%)	1	0.3319	1	0.3785	317	400
In full-time education**	46.1% (29.8%-63.2%)	1.14 (0.54 - 2.41)		1.06 (0.46 - 2.45)		53	42
Unemployed	35.7% (27.8%-44.3%)	0.74 (0.48 - 1.14)		0.70 (0.43 - 1.15)		153	183
Number of hours worked							
35+	41.5% (35.1%-48.2%)	1	0.3613	1	0.4867	108	145
less than 35	49.7% (33.9%-65.5%)	1.39 (0.68 - 2.84)		1.26 (0.60 - 2.66)		24	29
Religion							
None	37.6% (31.4%-44.3%)	1	0.3322	1	0.3304	299	334
Christian	44.4% (36.9%-52.2%)	1.32 (0.87 - 2.03)		1.33 (0.85 - 2.07)		205	260
Other non-Christian religions	49.2% (26.7%-72.0%)	1.61 (0.59 - 4.41)		1.55 (0.58 - 4.14)		21	33

*Variables adjusted for age and education (age variable adjusted for education only; education variable adjusted for age only)

**Denominators in these categories were <20, therefore caution should be taken when interpreting these results as the estimates will not be robust.

Health/Sexual Health factors

After adjusting for age and education, among sexually active people with 1+ distressing sexual difficulties those who reported a health condition/disability in the last year that affected their sexual activity were more likely to seek help or advice for their sex life than those who did not report a health condition/disability in the last year that affected their sexual activity (women: AOR = 2.00, CI 1.42-2.82; men: AOR = 2.42, CI 1.5 to 3.8). An association between help-seeking and receiving treatment for depression reached borderline statistical significance in women only (AOR = 1.37; CI 0.96-1.97). Taking medications that limited sexual activity or enjoyment also reached borderline statistical significance in both women (AOR = 1.48; CI 0.99-2.23) and in men (AOR = 1.62; CI 0.9 to 2.7). After adjusting for age and education, men (but not women)

who had ever been diagnosed with an STI were more likely to seek help or advice for their sex life than those who had not had STIs diagnosed
AOR = 1.99; (CI 1.2 to 3.2) (see Tables 5.5 and 5.6).

Table 5.5: The prevalence of help-seeking by health/sexual health characteristics in sexually active women with 1+ distressing sexual difficulties (crude & adjusted odds ratios).

	Percentage of women w/1+ distressing sexual difficulty who sought help (95% CI)	OR (95% CI)	p value for OR	AOR* (95% CI)	p value for AOR	Denominator	
						Unweighted	Weighted
Self-reported health status							
Very good or good	40.2% (35.9%-44.7%)	1	0.9787	1	0.3373	635	526
Fair- Bad or very bad	40.1% (32.8%-47.8%)	1.00 (0.70 - 1.42)				223	192
Health condition/disability in last year that has affected your sexual activity?							
No	34% (29.2%-39.1%)	1	0.0005	1	0.0001	499	390
Yes	47.8% (41.8%-53.8%)	1.77 (1.28 - 2.45)		2.00 (1.42 - 2.82)		358	326
Screen positive for current depression							
No	41.5% (37.1%-46.1%)	1	0.1751	1	0.1384	628	543
Yes	35.6% (28.7%-43.1%)	0.78 (0.54 - 1.12)		0.75 (0.52 - 1.10)		229	174
Received treatment for depression in the last year?							
Not mentioned	38.2% (33.6%-42.9%)	1	0.0835	1	0.0597	619	530
Mentioned	45.9% (38.6%-53.3%)	1.37 (0.96 - 1.97)		1.37 (0.96 - 1.97)		239	188
Other mental health condition?							
Not mentioned	40.1% (36.1%-44.2%)	1	0.7650	1	0.9170	803	680
Mentioned**	42.2% (29.3%-56.4%)	1.09 (0.61 - 1.98)		1.43 (0.99 - 2.07)		55	38

	Percentage of women w/1+ distressing sexual difficulty who sought help (95% CI)	OR (95% CI)	p value for OR	AOR* (95% CI)	p value for AOR	Denominator	
						Unweighted	Weighted
Currently taking medication for depression?							
No	39.9% (35.6%-44.4%)	1	0.7867	1	0.4878	705	593
Yes	41.3% (32.9%-50.3%)	1.06 (0.70 - 1.60)		1.17 (0.76 - 1.79)		153	125
Genital health condition?							
No	42.2% (37.3%-47.2%)	1	0.2636	1	0.7016	543	393
Yes	37.7% (31.9%-43.9%)	0.83 (0.60 - 1.15)		1.08 (0.74 - 1.57)		315	325
Medications in last year that have limited your sexual activity or enjoyment?							
No	38.4% (34.0%-42.9%)	1	0.0754	1	0.0583	671	561
Yes	47.2% (38.8%-55.8%)	1.44 (0.96 - 2.15)		1.48 (0.99 - 2.23)		186	155
Ever diagnosed with an STI?							
No (only thrush)	39.6% (35.3%-44.0%)	1	0.4484	1	0.7013	644	563
Yes (exc thrush)	42.9% (35.4%-50.8%)	1.15 (0.80 - 1.64)		1.08 (0.74 - 1.56)		213	153

*Variables adjusted for age and education (age variable adjusted for education only; education variable adjusted for age only).

**Denominators in these categories were <20, therefore caution should be taken when interpreting these results as the estimates will not be robust.

Table 5.6: The prevalence of help-seeking by health/sexual health characteristics in sexually active men with 1+ distressing sexual difficulties (crude & adjusted odds ratios).

	Percentage of men w/1+ distressing sexual difficulty who sought help (95% CI)	OR (95% CI)	p value for OR	AOR (95% CI)	p value for AOR	Denominator	
						Unweighted	Weighted
Self-reported health status							
Very good or good	40.9% (35.2%-47.0%)	1	0.9644	1	0.8786	371	419
Fair- Bad or very bad	41.2% (33.0%-49.9%)	1.01 (0.65 - 1.57)		1.04 (0.65 - 1.68)		154	208
Health condition/disability in last year that has affected your sexual activity?							
No	33% (26.9%-39.6%)	1	0.0006	1	0.0002	313	350
Yes	51% (43.6%-58.3%)	2.11 (1.38 - 3.23)		2.42 (1.54 - 3.81)		210	276
Screen positive for current depression							
No	39.8% (34.5%-45.4%)	1	0.3821	1	0.2984	403	484
Yes	45.1% (35.0%-55.7%)	1.24 (0.76 - 2.03)		1.32 (0.80 - 2.17)		122	143
Received treatment for depression in the last year?							
Not mentioned	40.6% (35.5%-45.9%)	1	0.6271	1	0.4704	442	534
Mentioned	44% (31.9%-56.7%)	1.15 (0.66 - 2.01)		1.26 (0.71 - 2.22)		82	92
Other mental health condition?							
Not mentioned	40.5% (35.7%-45.4%)	1	0.1984	1	0.1358	503	602
Mentioned	56.9% (32.8%-78.1%)	1.94 (0.71 - 5.34)		2.14 (0.77 - 5.95)		21	24

	Percentage of men w/1+ distressing sexual difficulty who sought help (95% CI)	OR (95% CI)	p value for OR	AOR (95% CI)	p value for AOR	Denominator	
						Unweighted	Weighted
Currently taking medication for depression?							
No	41.7% (36.7%-46.8%)	1	0.4884	1	0.5802	471	563
Yes	35.9% (22.5%-51.9%)	0.78 (0.39 - 1.56)		0.83 (0.41 - 1.65)		53	63
Genital health condition?							
No	40.2% (34.9%-45.8%)	1	0.5246	1	0.5791	419	495
Yes	43.9% (34.3%-54.0%)	1.16 (0.73 - 1.86)		1.16 (0.72 - 1.90)		106	132
Medications in last year that have limited your sexual activity or enjoyment?							
No	38.5% (33.2%-44.0%)	1	0.0579	1	0.0630	417	492
Yes	49.6% (39.5%-59.8%)	1.58 (0.98 - 2.52)		1.62 (0.99 - 2.65)		105	133
Ever diagnosed with an STI?							
No (only thrush)	37.5% (32.4%-42.9%)	1	0.0075	1	0.0059	417	495
Yes (exc thrush)	53.6% (43.1%-63.8%)	1.92 (1.19 - 3.10)		1.99 (1.22 - 3.23)		106	131

*Variables adjusted for age and education (age variable adjusted for education only; education variable adjusted for age only).

Relationship factors

After adjusting for age and education, sexually active people reporting 1+ distressing sexual difficulties who found it easy to talk to their partners about sex were more likely to seek help or advice for their sex life than those who had not (women: AOR = 1.55, CI 1.0 to 2.4; men: AOR = 1.64, CI 1.0 to 2.7). With regards to additional measures of severity, women (but not men) who avoided sex due to sexual difficulties (AOR = 0.46; CI 0.3 to 0.7), experienced sexual difficulties more frequently (AOR = 1.62; CI 1.1 to 2.5), and for a longer duration (AOR = 1.60;

CI 1.1 to 2.3) were more likely to seek help or advice for their sex life. Relationship status, factors relating to sexual compatibility between partners, and relationship satisfaction/happiness were not associated with help-seeking in women or men (see Tables 5.7 and 5.8).

Table 5.7: The prevalence of help-seeking by relationship characteristics in sexually active women with 1+ distressing sexual difficulties (crude & adjusted odds ratios).

	Percentage of women w/1+ distressing sexual difficulty who sought help (95% CI)	OR (95% CI)	p value for OR	AOR* (95% CI)	p value for AOR	Denominator	
						Unweighted	Weighted
Relationship status at interview							
Living with a partner	37.2% (32.5%-42.1%)	1	0.0652	1	0.5641	497	512
Steady relationship- not cohabitating	47.8% (39.2%-56.6%)	1.55 (1.04 - 2.30)		1.28 (0.85 - 1.94)		194	113
Not in steady relationship- previously cohabitated	44.6% (33.4%-56.3%)	1.36 (0.81 - 2.29)		1.28 (0.74 - 2.23)		89	49
Not in steady relationship- never cohabitated	50.3% (38.4%-62.1%)	1.71 (1.00 - 2.92)		1.29 (0.73 - 2.29)		78	44
Happy in relationship with partner?							
Happy	41.3% (34.3%-48.6%)	1	0.2194	1	0.3204	274	262
Neutral	38.8% (31.8%-46.3%)	0.90 (0.59 - 1.37)		0.91 (0.59 - 1.39)		215	179
Unhappy	29.6% (20.4%-40.9%)	0.60 (0.33 - 1.07)		0.63 (0.35 - 1.14)		89	95
Share same level of interest in having sex as partner							
agree strongly/agree	36.7% (29.1%-44.9%)	1	0.8713	1	0.8704	193	174
neither agree or disagree	39.3% (27.4%-52.6%)	1.12 (0.60 - 2.09)		1.18 (0.62 - 2.22)		83	74
disagree/strongly disagree	39.3% (33.1%-45.9%)	1.12 (0.73 - 1.72)		1.08 (0.70 - 1.68)		303	289
Share same sexual likes and dislikes as partner							
agree strongly/agree	37.2% (31.7%-43.1%)	1	0.6572	1	0.6365	400	375
neither agree or disagree	43.3% (31.8%-55.6%)	1.29 (0.74 - 2.24)		1.31 (0.74 - 2.35)		94	82
disagree/strongly disagree	39.3% (28.5%-51.3%)	1.09 (0.64 - 1.86)		1.11 (0.65 - 1.90)		85	80

	Percentage of women w/1+ distressing sexual difficulty who sought help (95% CI)	OR (95% CI)	p value for OR	AOR* (95% CI)	p value for AOR	Denominator	
						Unweighted	Weighted
Emotionally close to partner when having sex							
always/most of the time	38.7% (33.5%-44.3%)	1	0.6501	1	0.6099	461	430
sometimes	34.6% (24.2%-46.8%)	0.84 (0.48 - 1.46)		0.84 (0.48 - 1.48)		86	78
not very often/hardly ever	44.8% (27.0%-64.0%)	1.28 (0.57 - 2.90)		1.34 (0.59 - 3.03)		32	29
Always find it easy to talk about sex with partners?							
No/other	38.2% (34.1%-42.5%)	1	0.0235	1	0.0493	698	595
Yes	50.4% (40.7%-60.1%)	1.64 (1.07 - 2.52)		1.55 (1.00 - 2.42)		159	122
Feel satisfied with sex life							
agree strongly/agree	38.7% (32.7%-45.1%)	1	0.1247	1	0.1580	348	281
neither agree or disagree	35.2% (28.1%-42.9%)	0.86 (0.57 - 1.30)		0.93 (0.61 - 1.41)		211	177
disagree/strongly disagree	45.2% (38.7%-51.9%)	1.31 (0.89 - 1.92)		1.36 (0.91 - 2.02)		299	260
Avoided sex due to sexual difficulties							
agree strongly/agree	45.2% (39.1%-51.4%)	1	0.0093	1	0.0050	345	315
neither agree or disagree	28.2% (20.6%-37.3%)	0.48 (0.30 - 0.77)		0.46 (0.28 - 0.74)		143	120
disagree/strongly disagree	39.7% (34.1%-45.6%)	0.80 (0.56 - 1.13)		0.71 (0.49 - 1.03)		370	283
Experienced problem(s) frequently past year?							
No	31.2% (23.9%-39.7%)	1	0.0208	1	0.0227	187	154
Yes	42.6% (38.2%-47.1%)	1.63 (1.08 - 2.48)		1.62 (1.07 - 2.46)		671	565

	Percentage of women w/1+ distressing sexual difficulty who sought help (95% CI)	OR (95% CI)	p value for OR	AOR* (95% CI)	p value for AOR	Denominator	
						Unweighted	Weighted
Experienced problem(s) for 6 months or more in past year?							
No	34.3% (27.7%-41.7%)	1	0.0754	1	0.0145	236	180
Yes	42% (37.6%-46.7%)	1.39 (0.97 - 1.99)		1.60 (1.10 - 2.31)		621	537

*Variables adjusted for age and education (age variable adjusted for education only; education variable adjusted for age only).

Table 5.8: The prevalence of help-seeking by relationship characteristics in sexually active men with 1+ distressing sexual difficulties (crude & adjusted odds ratios).

	Percentage of men w/1+ distressing sexual difficulty who sought help (95% CI)	OR (95% CI)	p value for OR	AOR* (95% CI)	p value for AOR	Denominator	
						Unweighted	Weighted
Relationship status at interview							
Living with a partner	39.4% (33.2%-45.9%)	1	0.7791	1	0.5075	265	423
Steady relationship- not cohabitating	44.6% (34.9%-54.7%)	1.24 (0.76 - 2.03)		1.40 (0.82 - 2.39)		123	96
Not in steady relationship- previously cohabitated	45.6% (32.5%-59.4%)	1.29 (0.69 - 2.42)		1.48 (0.78 - 2.77)		58	50
Not in steady relationship- never cohabitated	41.5% (30.3%-53.7%)	1.09 (0.63 - 1.89)		1.29 (0.68 - 2.46)		76	56

	Percentage of men w/1+ distressing sexual difficulty who sought help (95% CI)	OR (95% CI)	p value for OR	AOR* (95% CI)	p value for AOR	Denominator	
						Unweighted	Weighted
Happy in relationship with partner?							
Happy	35.8% (27.8%-44.7%)	1	0.4110	1	0.3814	164	229
Neutral	45.1% (34.9%-55.7%)	1.47 (0.83 - 2.61)		1.50 (0.84 - 2.70)		107	142
Unhappy	41.7% (25.7%-59.6%)	1.28 (0.57 - 2.88)		1.18 (0.52 - 2.68)		35	53
Share same level of interest in having sex as partner							
agree strongly/agree	44% (35.1%-53.3%)	1	0.3044	1	0.3229	147	197
neither agree or disagree	30.1% (17.9%-46.0%)	0.55 (0.25 - 1.19)		0.54 (0.24 - 1.21)		49	75
disagree/strongly disagree	38.8% (29.2%-49.4%)	0.81 (0.45 - 1.44)		0.84 (0.47 - 1.51)		110	153
Share same sexual likes and dislikes as partner							
agree strongly/agree	42.1% (34.5%-50.1%)	1	0.0939	1	0.0878	195	270
neither agree or disagree	24.8% (13.7%-40.7%)	0.45 (0.20 - 1.01)		0.43 (0.18 - 1.00)		53	79
disagree/strongly disagree	46.6% (33.2%-60.5%)	1.20 (0.62 - 2.32)		1.31 (0.68 - 2.52)		58	75
Emotionally close to partner when having sex							
always/most of the time	39.4% (32.9%-46.4%)	1	0.9547	1	0.9396	257	357
sometimes	42.1% (25.5%-60.7%)	1.12 (0.50 - 2.51)		1.16 (0.50 - 2.72)		38	53
not very often/hardly ever**	37.2% (12.8%-70.5%)	0.91 (0.22 - 3.81)		1.05 (0.25 - 4.43)		11	14
Always find it easy to talk about sex with partners?							
No/other	39% (33.7%-44.5%)	1	0.0836	1	0.0451	399	506
Yes	49.1% (39.1%-59.2%)	1.51 (0.95 - 2.42)		1.64 (1.00 - 2.67)		124	120

	Percentage of men w/1+ distressing sexual difficulty who sought help (95% CI)	OR (95% CI)	p value for OR	AOR* (95% CI)	p value for AOR	Denominator	
						Unweighted	Weighted
Feel satisfied with sex life							
agree strongly/agree	39% (31.6%-47.0%)	1	0.6996	1	0.7753	217	250
neither agree or disagree	44.7% (34.3%-55.6%)	1.27 (0.73 - 2.19)		1.24 (0.71 - 2.18)		112	144
disagree/strongly disagree	40.9% (33.2%-49.1%)	1.08 (0.67 - 1.75)		1.07 (0.66 - 1.74)		196	233
Avoided sex due to sexual difficulties							
agree strongly/agree	43.5% (35.7%-51.6%)	1	0.7536	1	0.6442	188	236
neither agree or disagree	39% (27.7%-51.6%)	0.83 (0.45 - 1.54)		0.83 (0.44 - 1.54)		80	95
disagree/strongly disagree	39.7% (32.7%-47.1%)	0.86 (0.54 - 1.35)		0.82 (0.52 - 1.30)		257	296
Experienced problem(s) frequently past year?							
No	36.9% (29.7%-44.8%)	1	0.1741	1	0.2025	213	250
Yes	43.9% (37.8%-50.3%)	1.34 (0.88 - 2.03)		1.32 (0.86 - 2.03)		311	375
Experienced problem(s) for 6 months or more in past year?							
No	35.8% (27.8%-44.7%)	1	0.1761	1	0.1932	167	175
Yes	43% (37.4%-48.9%)	1.36 (0.87 - 2.11)		1.36 (0.86 - 2.15)		358	452

*Variables adjusted for age and education (age variable adjusted for education only; education variable adjusted for age only)

**Denominators in these categories were <20, therefore caution should be taken when interpreting these results as the estimates will not be robust

Sex education and sexual behaviour factors

None of the sex education variables (i.e., talking to parents and ease of talking to parents about sex at age 14, and source of sex education) were associated with help-seeking in sexually active women or men with 1+ distressing sexual difficulty. The only sexual behaviour variable

that was associated with help-seeking was sexual competence at first sexual intercourse in women, such that women who were more competent at first sexual intercourse were more likely to seek help; this association was not observed in men (see Tables 5.9 and 5.10).

Table 5.9: The prevalence of help-seeking by sex education and sexual behaviour characteristics in sexually active women with 1+ distressing sexual difficulties (crude & adjusted odds ratios).

	Percentage of women w/1+ distressing sexual difficulty who sought help (95% CI)	OR (95% CI)	p value for OR	AOR* (95% CI)	p value for AOR	Denominator	
						Unweighted	Weighted
Discussed sex with 1+ parents around age 14?							
Did discuss	42% (36.0%-48.2%)	1	0.4203	1	0.7458	366	294
Did not discuss	38.7% (33.6%-44.0%)	0.87 (0.62 - 1.22)		0.95 (0.67 - 1.34)		469	403
Main source of sex education							
Sex ed lessons	41.3% (33.5%-49.5%)	1	0.7490	1	0.6275	206	176
Friends	39.3% (32.0%-47.2%)	0.92 (0.58 - 1.47)		0.89 (0.56 - 1.43)		220	182
Family	46.6% (36.4%-57.1%)	1.24 (0.72 - 2.13)		1.25 (0.73 - 2.16)		108	83
Media	39.2% (29.1%-50.4%)	0.92 (0.52 - 1.62)		0.85 (0.47 - 1.54)		111	92
Other**	54.3% (24.4%-81.4%)	1.69 (0.45 - 6.39)		1.87 (0.44 - 7.94)		12	9
Ease at which discussed sex with parents around age 14?							
Easy w/one or both	44% (35.9%-52.4%)	1	0.2976	1	0.6285	190	139
Difficult or didn't discuss or varied depending on topic	39.1% (34.8%-43.5%)	0.82 (0.56 - 1.19)		0.91 (0.61 - 1.35)		645	558
Sexual competence at 1st heterosexual sex							

	Percentage of women w/1+ distressing sexual difficulty who sought help (95% CI)	OR (95% CI)	p value for OR	AOR* (95% CI)	p value for AOR	Denominator	
						Unweighted	Weighted
Not competent	37.3% (32.6%-42.2%)	1	0.0331	1	0.0870	515	434
Competent	45.7% (39.5%-51.9%)	1.41 (1.03 - 1.94)		1.33 (0.95 - 1.86)		330	276
Anyone tried to have sex with you against your will?							
Yes	39.5% (32.9%-46.5%)	1	0.9573	1	0.9168	306	253
No	40.6% (35.7%-45.7%)	1.05 (0.73 - 1.50)		1.04 (0.71 - 1.50)		529	451
Don't know**	38.4% (19.4%-61.7%)	0.95 (0.35 - 2.59)		0.85 (0.30 - 2.39)		22	15
Anyone had sex with you against your will?							
Yes	37.3% (29.0%-46.4%)	1	0.5321	1	0.4188	162	131
No	41.1% (36.7%-45.7%)	1.17 (0.77 - 1.78)		1.16 (0.76 - 1.77)		662	565
Don't know	32.7% (18.7%-50.7%)	0.82 (0.35 - 1.89)		0.72 (0.30 - 1.69)		33	21

*Variables adjusted for age and education (age variable adjusted for education only; education variable adjusted for age only)

**Denominators in these categories were <20, therefore caution should be taken when interpreting these results as the estimates will not be robust

Table 5.10: The prevalence of help-seeking by sex education and sexual behaviour characteristics in sexually active men with 1+ distressing sexual difficulties (crude & adjusted odds ratios).

	Percentage of men w/1+ distressing sexual difficulty who sought help (95% CI)	OR (95% CI)	p value for OR	AOR* (95% CI)	p value for AOR	Denominator	
						Unweighted	Weighted
Discussed sex with 1+ parents around age 14?							
Did discuss	44.7% (35.5%-54.3%)	1	0.5591	1	0.4796	147	170
Did not discuss	41.3% (35.5%-47.3%)	0.87 (0.54 - 1.39)		0.86 (0.53 - 1.38)		359	433
Main source of sex education							
Sex ed lessons	40.4% (30.4%-51.1%)	1	0.5378	1	0.5752	97	99
Friends	32.7% (24.6%-42.0%)	0.72 (0.40 - 1.28)		0.71 (0.39 - 1.29)		150	191
Family	37.9% (19.4%-60.7%)	0.90 (0.32 - 2.56)		0.82 (0.27 - 2.52)		22	21
Media	37.9% (26.4%-51.0%)	0.90 (0.45 - 1.79)		0.92 (0.46 - 1.85)		78	90
Other**	14.3% (2.9%-48.6%)	0.25 (0.04 - 1.48)		0.23 (0.04 - 1.50)		7	5
Ease at which discussed sex with parents around 14yrs							
Easy w/one or both	45.2% (32.6%-58.4%)	1	0.6520	1	0.4188	77	73
Difficult or didn't discuss or varied depending on topic	41.8% (36.5%-47.3%)	0.87 (0.48 - 1.57)		0.79 (0.43 - 1.45)		429	531
Sexual competence at 1st heterosexual sex							
Not competent	39.1% (33.0%-45.5%)	1	0.4477	1	0.4325	284	345
Competent	42.9% (35.4%-50.8%)	1.17 (0.78 - 1.77)		1.19 (0.77 - 1.82)		223	261

	Percentage of men w/1+ distressing sexual difficulty who sought help (95% CI)	OR (95% CI)	p value for OR	AOR* (95% CI)	p value for AOR	Denominator	
						Unweighted	Weighted
Anyone tried to have sex with you against your will?							
Yes	54% (38.4%-68.9%)	1	0.2242	1	0.1968	46	57
No	39.6% (34.6%-44.8%)	0.56 (0.28 - 1.09)		0.53 (0.27 - 1.05)		467	559
Don't know**	47.8% (16.6%-80.7%)	0.78 (0.15 - 4.05)		0.70 (0.15 - 3.27)		12	11
Anyone had sex with you against your will?							
Yes	44.6% (22.4%-69.2%)	1	0.9186	1	0.9171	19	23
No	40.8% (35.9%-45.8%)	0.86 (0.30 - 2.45)		0.78 (0.27 - 2.25)		492	592
Don't know**	46.2% (17.4%-77.8%)	1.07 (0.19 - 6.10)		0.90 (0.17 - 4.82)		14	13

*Variables adjusted for age and education (age variable adjusted for education only; education variable adjusted for age only)

**Denominators in these categories were <20, therefore caution should be taken when interpreting these results as the estimates will not be robust

The following results apply to population of interest B: Individuals with at least one sexual experience reporting being distressed or worried about their sex lives.

5.3.5 Prevalence of reporting distress about one's sex life among the sexually-experienced British population, and associated help-seeking (RQ 6&7)

Among the sexually-experienced British population (i.e. those with at least one sexual experience), 10.6% (95% CI 10.1 to 11.3) reported being distressed about their sex life. Around one third of these (34.7%, 95% CI 32.0 to 37.6) reported seeking some form of help. The percentage of men who were distressed about their sex life and sought help 35.2% (95% CI 31.1 to 39.6) did not differ significantly from women who were distressed about their sex life and sought help 34.2% (95% CI 30.2 to 38.0).

5.3.6 Prevalence of different types of help-seeking, among women and men who report being distressed about their sex life (RQ8)

The prevalence of different help-seeking behaviours in women and men who reported being distressed about their sex lives are summarised in Figure 5.6. The three most common sources of help sought by women were talking to a family member or friend (16.4%, CI 13.6 to 19.5), consulting a GP (15.1%, CI 12.5 to 18.2), and seeking information and support on the internet (6.9%, CI 5.3 to 8.9). The three most common sources of help sought by men were consulting a GP (16.9%, CI 13.6 to 20.8), talking to a family member or friend (9.2%, CI 7.1 to 11.8), and seeking information and support on the internet (8.5%, CI 6.6 to 11.0). There were no gender differences in internet help-seeking. The only significant difference between women and men in terms of where they seek help was that women were significantly more likely than men to talk to a family member or friend ($p < 0.001$).

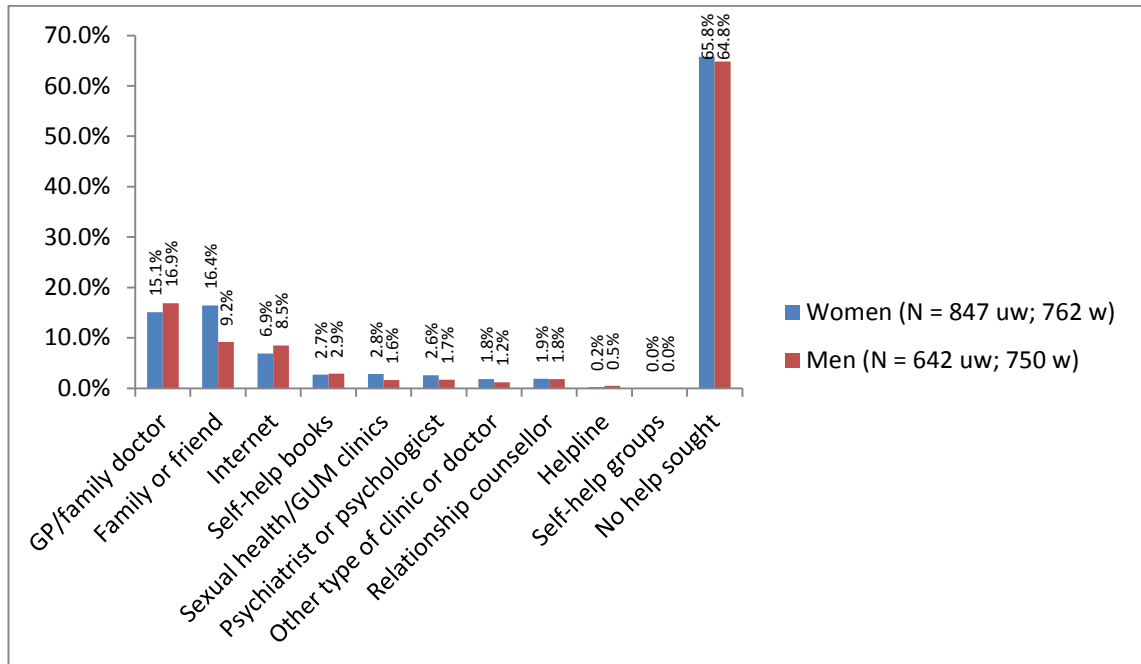


Figure 5.5: Prevalence of different types of help-seeking in men and women who report being distressed about their sex lives.

Note: Help categories not mutually exclusive as participants could choose more than one category.

5.3.7 How the prevalence of help-seeking varies by participant characteristics in adults who report being distressed about their sex life (RQ 9)

I explored the prevalence of help-seeking by different sociodemographic, health, relationship, sex education and sexual behaviour variables in individuals with at least one sexual experience who reported being distressed about their sex life. See Tables 5.11-5.18 for univariate and multivariable analysis adjusted for age and education.

Sociodemographic factors

The mean age of female help-seekers was 38.5 years (SD 15.6), which was significantly younger than the mean age of male help-seekers (43.1 years of age, SD = 15.4, $p = 0.001$). Overall, help-seeking in women decreased with age (referent age group 16-24 versus age group 35-44 OR = 0.51; 95% CI 0.3 to 0.9 and age group 55-64 OR = 0.42; 95% CI 0.2 to 0.8), but not in men (referent age group 16-24 versus age group 55-64 OR = 0.97; 95% CI 0.6 to 1.7). Education was significantly associated with help-seeking in both women and men, whereby 40.2% of women and 48.2% of men with a degree level education (referent group) sought help compared to 30.2% of women (OR = 0.64; 95% CI 0.4 to 1.0; $p < 0.01$) and 26.9% of men (OR = 0.40; 95% CI

0.2 to 0.7; $p < 0.01$) with a secondary school education. Employment and number of hours worked were significantly associated with help-seeking in women only, but not after adjusting for age and education. After adjusting for education, the association between age and help-seeking remained significant in women (referent age group 16-24 versus age group 35-44 AOR = 0.51; 95% CI 0.3 to 0.9 and age group 55-64 AOR = 0.47; 95% CI 0.3 to 0.9). After adjusting for age, the association between education and help-seeking became borderline statistically significant for women (AOR = 0.66; 95% CI 0.4 to 1.1; $p = 0.08$), but remained significant in men (AOR = 0.40; 95% CI 0.2 to 0.7; $p < 0.01$). No associations were observed, in women or men, between area level deprivation or religion and help-seeking (see Tables 5.11 and 5.12).

Table 5.11: The prevalence of help-seeking by sociodemographic characteristics in sexually experienced women who reported being distressed about their sex lives (crude & adjusted odds ratios).

	Percentage of women who were distressed about their sex lives and who sought help (95% CI)	OR (95% CI)	p value for OR	AOR* (95% CI)	p value for AOR	Denominator	
						Unweighted	Weighted
All	34.2% (CI 30.6-38.0)	-	-	-	-	847	762
Age							
16-24	47.2% (38.6%-55.9%)	1	0.0000	1	0.0001	170	103
25-34	46.3% (39.8%-52.9%)	0.96 (0.63 - 1.47)		0.94 (0.61 - 1.45)		272	162
35-44	31.1% (23.4%-40.1%)	0.51 (0.30 - 0.85)		0.51 (0.30 - 0.87)		128	152
45-54	29.6% (21.6%-39.1%)	0.47 (0.27 - 0.81)		0.49 (0.28 - 0.85)		134	170
55-64	27.4% (19.2%-37.4%)	0.42 (0.24 - 0.76)		0.47 (0.25 - 0.87)		89	111
65-74**	14.8% (7.4%-27.4%)	0.19 (0.08 - 0.45)		0.24 (0.10 - 0.57)		54	64
Quintile of Index of Multiple Deprivation							
1 (least deprived)	37.3% (28.3%-47.2%)	1	0.1625	1	0.0960	134	133
2	37.2% (28.5%-46.8%)	1.00 (0.55 - 1.80)		0.99 (0.54 - 1.82)		137	127
3	30.1% (23.3%-37.8%)	0.72 (0.43 - 1.23)		0.70 (0.41 - 1.20)		170	157
4	27.7% (20.9%-35.7%)	0.65 (0.37 - 1.12)		0.59 (0.34 - 1.05)		189	163
5 (most deprived)	39.2% (31.7%-47.1%)	1.08 (0.64 - 1.83)		1.09 (0.63 - 1.89)		217	182

	Percentage of women who were distressed about their sex lives and who sought help (95% CI)	OR (95% CI)	p value for OR	AOR* (95% CI)	p value for AOR	Denominator	
						Unweighted	Weighted
Education							
Degree	40.2% (32.7%-48.3%)	1	0.0048	1	0.0804	239	229
Higher education	38.2% (30.4%-46.8%)	0.92 (0.57 - 1.47)		0.84 (0.52 - 1.36)		179	145
GCSE- O level or equivalent	30.2% (24.6%-36.5%)	0.64 (0.41 - 1.00)		0.66 (0.42 - 1.04)		290	255
Foreign**	67.5% (37.5%-87.7%)	3.08 (0.85 - 1.22)		2.76 (0.70 - 0.88)		13	10
None	23.8% (16.9%-32.5%)	0.46 (0.27 - 0.79)		0.61 (0.35 - 1.08)		124	122
Employment							
Employed	37.3% (32.2%-42.7%)	1	0.0230	1	0.7438	434	395
In full-time education	45% (31.7%-59.0%)	1.38 (0.76 - 2.48)		0.90 (0.48 - 1.70)		72	53
Unemployed	28.5% (23.5%-34.2%)	0.67 (0.47 - 0.95)		0.84 (0.58 - 1.22)		341	313
Number of hours worked							
35+	44.3% (37.1%-51.8%)	1	0.0125	1	0.0684	238	92
Less than 35	30.6% (23.7%-38.5%)	0.55 (0.35 - 0.88)		0.65 (0.41 - 1.03)		210	60
Religion							
None	33.2% (28.0%-38.7%)	1	0.2208	1	0.1954	421	355
Christian	33.6% (28.2%-39.4%)	1.02 (0.72 - 1.45)		1.21 (0.83 - 1.76)		369	356
Other non-Christian religions	45.6% (32.5%-59.4%)	1.69 (0.91 - 3.13)		1.68 (0.88 - 3.21)		57	51

*Variables adjusted for age and education (age variable adjusted for education only; education variable adjusted for age only)

**Denominators in these categories were <20, therefore caution should be taken when interpreting these results as the estimates will not be robust.

Table 5.12: The prevalence of help-seeking by sociodemographic characteristics in sexually experienced men who reported being distressed about their sex lives (crude & adjusted odds ratios).

	Percentage of men who were distressed about their sex lives and who sought help (95% CI)	OR (95% CI)	p value for OR	AOR* (95% CI)	p value for AOR	Denominator	
						Unweighted	Weighted
Age	35.2% (CI 31.1-39.6)	-	-	-	-	642	750
16-24	41.2% [32.7%-50.2%]	1	0.2712	1	0.4120	150	107
25-34	39.7% [32.0%,47.9%]	0.94 (0.57 - 1.56)		1.04 (0.62 - 1.77)		160	129
35-44	29.1% [19.8%,40.5%]	0.59 (0.31 - 1.11)		0.68 (0.35 - 1.30)		87	133
45-54	31.6% [21.4%,43.9%]	0.66 (0.35 - 1.25)		0.87 (0.44 - 1.72)		82	139
55-64	40.3% [30.4%,51.1%]	0.97 (0.55 - 1.71)		1.42 (0.76 - 2.65)		99	159
65-74	27% [17.1%,39.9%]	0.53 (0.27 - 1.04)		0.92 (0.44 - 1.93)		64	83
Quintile of Index of Multiple Deprivation							
1 (least deprived)	33.3% [25.4%,42.2%]	1	0.2593	1	0.0834	140	170
2	27.1% [18.5%,37.8%]	0.74 (0.39 - 1.41)		0.78 (0.41 - 1.46)		109	150
3	33.8% [24.4%,44.6%]	1.02 (0.57 - 1.85)		1.22 (0.66 - 2.22)		110	132
4	41.6% [31.7%,52.2%]	1.43 (0.81 - 2.52)		1.66 (0.93 - 2.95)		123	136
5 (most deprived)	40.8% [31.4%,50.8%]	1.38 (0.79 - 2.40)		1.71 (0.93 - 3.14)		160	162

	Percentage of men who were distressed about their sex lives and who sought help (95% CI)	OR (95% CI)	p value for OR	AOR* (95% CI)	p value for AOR	Denominator	
						Unweighted	Weighted
Education							
Degree	48.2% [39.7%,56.8%]	1	0.0019	1	0.0031	154	193
Higher education	34.7% [27.7%,42.4%]	0.57 (0.36 - 0.91)		0.56 (0.35 - 0.90)		190	203
GCSE- O level or equivalent	26.9% [20.4%,34.5%]	0.40 (0.24 - 0.66)		0.40 (0.24 - 0.66)		188	205
Foreign**	62.8% [30.5%,86.6%]	1.81 (0.45 - 7.23)		1.71 (0.43 - 6.78)		11	14
None	27.8% [18.7%,39.1%]	0.41 (0.22 - 0.76)		0.43 (0.23 - 0.81)		97	132
Employment							
Employed	36.2% [30.8%,41.9%]	1	0.1398	1	0.4260	368	466
In full-time education	46.2% [33.3%,59.6%]	1.52 (0.83 - 2.76)		1.32 (0.68 - 2.57)		60	45
Unemployed	31.3% [24.7%,38.7%]	0.80 (0.54 - 1.20)		0.97 (0.62 - 1.52)		212	239
Number of hours worked							
35+	37.7% [31.8%,43.9%]	1	0.2174	1	0.3558	304	390
less than 35	29% [18.6%,42.2%]	0.68 (0.36 - 1.26)		0.72 (0.39 - 1.34)		73	84
Religion							
None	37.5% [31.6%,43.8%]	1	0.5892	1	0.6837	354	378
Christian	32.8% [26.7%,39.5%]	0.81 (0.55 - 1.21)		0.82 (0.54 - 1.26)		243	316
Other non-Christian religions**	34.5% [20.1%,52.4%]	0.88 (0.41 - 1.89)		0.78 (0.37 - 1.66)		43	55

*Variables adjusted for age and education (age variable adjusted for education only; education variable adjusted for age only)

**Denominators in these categories were <20, therefore caution should be taken when interpreting these results as the estimates will not be robust.

Health/Sexual Health factors

After adjusting for age and education, individuals with at least one sexual experience who reported being distressed or worried about their sex life and who reported a health condition/disability in the last year that affected their sexual activity were more likely to seek help or advice for their sex life (women: AOR = 2.07, CI 1.46-2.94; men: AOR = 3.16; CI 2.1 to 4.8). Women (but not men) receiving treatment for depression were more likely to seek help or advice for their sex life (AOR = 1.49; CI 1.0 to 2.2). Men (but not women) who reported having a genital health condition were more likely to seek help or advice for their sex lives than those without a genital health condition (AOR = 1.94; CI 1.2 to 3.2). Both women and men taking medications that limited their sexual activity or enjoyment were more likely to seek help or advice for their sex life than people not taking those medications (women: AOR = 1.64, CI 1.1 to 2.5; men: AOR = 1.89; CI 1.2 to 3.1). After adjusting for age and education there was no association between self-reported health status, screening positive for current depression, currently taking medication for depression, receiving treatment for other mental health conditions in the past year, ever having been diagnosed with an STI and seeking help about one's sex life in men or women. See Tables 5.13 and 5.14.

Table 5.13: The prevalence of help-seeking by health and sexual health characteristics in sexually experienced women who reported being distressed about their sex lives (crude & adjusted odds ratios).

	Percentage of women distressed about their sex lives who sought help (95% CI)	OR (95% CI)	p value for OR	AOR* (95% CI)	p value for AOR	Denominator	
						Unweighted	Weighted
Self-reported health status							
Very good or good	34.4% (30.0%-39.0%)	1	0.8743	1	0.1712	629	537
Fair- Bad or very bad	33.7% (27.4%-40.7%)	0.97 (0.68 - 1.39)		1.31 (0.89 - 1.94)		236	225
Health condition/disability in last year that has affected your sexual activity?							
No	28% (23.9%-32.5%)	1	0.0001	1	0.0000	536	462
Yes	42.9% (36.5%-49.5%)	1.93 (1.38 - 2.69)		2.07 (1.46 - 2.94)		285	280
Screen positive for current depression							
No	34.8% (30.7%-39.2%)	1	0.4704	1	0.4442	647	579
Yes	31.8% (25.2%-39.2%)	0.87 (0.60 - 1.27)		0.84 (0.57 - 1.25)		217	183
Received treatment for depression in the last year?							
Not mentioned	32.3% (28.2%-36.7%)	1	0.0892	1	0.0319	648	570
Mentioned	39.8% (32.4%-47.7%)	1.38 (0.95 - 2.02)		1.49 (1.01 - 2.20)		217	193
Other mental health condition?							
Not mentioned	34% (30.3%-37.9%)	1	0.6181	1	0.8671	825	731
Mentioned**	38.5% (22.8%-57.0%)	1.22 (0.56 - 2.62)		1.07 (0.49 - 2.31)		40	31

	Percentage of women distressed about their sex lives who sought help (95% CI)	OR (95% CI)	p value for OR	AOR* (95% CI)	p value for AOR	Denominator	
						Unweighted	Weighted
Currently taking medication for depression?							
No	34% (30.0%-38.3%)	1	0.8569	1	0.4953	715	625
Yes	34.9% (26.6%-44.2%)	1.04 (0.68 - 1.60)		1.12 (0.71 - 1.75)		150	138
Genital health condition?							
No	34.6% (30.1%-39.5%)	1	0.7856	1	0.1125	535	417
Yes	33.6% (28.2%-39.5%)	0.96 (0.69 - 1.32)		1.36 (0.94 - 1.96)		330	345
Medications in last year that have limited your sexual activity or enjoyment?							
No	31.7% (27.8%-35.9%)	1	0.0323	1	0.0157	679	190
Yes	42.2% (33.4%-51.5%)	1.57 (1.04 - 2.38)		1.64 (1.08 - 2.50)		141	60
Ever diagnosed with an STI?							
No (only thrush)	33% (29.1%-37.2%)	1	0.0899	1	0.3863	683	204
Yes (exc thrush)	40.9% (32.7%-49.7%)	1.40 (0.95 - 2.08)		1.15 (0.76 - 1.73)		173	56

*Variables adjusted for age and education (age variable adjusted for education only; education variable adjusted for age only)

**Denominators in these categories were <20, therefore caution should be taken when interpreting these results as the estimates will not be robust.

Table 5.14: The prevalence of help-seeking by health and sexual health characteristics in sexually experienced men who reported being distressed about their sex lives (crude & adjusted odds ratios).

	Percentage of men distressed about their sex lives who sought help (95% CI)	OR (95% CI)	p value for OR	AOR* (95% CI)	p value for AOR	Denominator	
						Unweighted	Weighted
Self-reported health status							
Very good or good	35.1% [30.3%,40.3%]	1	0.9463	1	0.4844	481	525
Fair- Bad or very bad	35.5% [27.7%,44.1%]	1.01 (0.66 - 1.55)		1.25 (0.78 - 1.99)		180	225
Health condition/disability in last year that has affected your sexual activity?							
No	26.8% [22.2%,32.0%]	1	0.0000	1	0.0000	410	450
Yes	49.1% [41.7%,56.5%]	2.63 (1.78 - 3.90)		3.16 (2.07 - 4.83)		203	267
Screen positive for current depression							
No	34.5% [29.8%,39.5%]	1	0.4707	1	0.4721	486	561
Yes	38.2% [29.7%,47.4%]	1.17 (0.76 - 1.81)		1.24 (0.80 - 1.94)		172	186
Received treatment for depression in the last year?							
Not mentioned	34.4% [30.0%,39.1%]	1	0.3139	1	0.2753	573	651
Mentioned	40.9% [29.5%,53.4%]	1.32 (0.77 - 2.27)		1.41 (0.80 - 2.48)		88	99
Other mental health condition?							
Not mentioned	34.4% [30.2%,39.0%]	1	0.1344	1	0.0683	616	704
Mentioned	47.9% [31.2%,65.1%]	1.75 (0.84 - 3.64)		2.07 (1.01 - 4.25)		45	46

	Percentage of men distressed about their sex lives who sought help (95% CI)	OR (95% CI)	p value for OR	AOR* (95% CI)	p value for AOR	Denominator	
						Unweighted	Weighted
Currently taking medication for depression?							
No	34.8% [30.5%,39.3%]	1	0.4945	1	0.3710	602	682
Yes	40% [26.4%,55.3%]	1.25 (0.66 - 2.37)		1.42 (0.73 - 2.74)		59	68
Genital health condition?							
No	33% [28.7%,37.7%]	1	0.0329	1	0.0196	562	618
Yes	45.6% [34.9%,56.9%]	1.70 (1.04 - 2.78)		1.94 (1.17 - 3.22)		99	132
Medications in last year that have limited your sexual activity or enjoyment?							
No	32.5% [27.9%,37.4%]	1	0.0281	1	0.0183	491	571
Yes	44.5% [35.1%,54.4%]	1.67 (1.06 - 2.64)		1.89 (1.16 - 3.08)		120	145
Ever diagnosed with an STI?							
No (only thrush)	33.5% [29.0%,38.2%]	1	0.0462	1	0.1018	563	629
Yes (exc thrush)	45.8% [34.7%,57.3%]	1.68 (1.01 - 2.79)		1.60 (0.93 - 2.76)		93	117

*Variables adjusted for age and education (age variable adjusted for education only; education variable adjusted for age only).

Relationship factors

After adjusting for age and education, sexually experienced women who reported being distressed or worried about their sex life, and who found it easy to talk about sex with partners were more likely to seek help or advise for their sex life (AOR = 1.62; CI 1.1 to 2.6) but this association in men was only marginally statistically significant (AOR =1.71; CI 1.1 to 2.8). Women who had avoided sex due to sexual

difficulties were more likely to seek help or advice for their sex life (AOR = 0.46; CI 0.3 to 0.7), but this association was also only marginally statistically significant in men (AOR = 0.61; CI 0.4 to 0.9). Higher frequency and duration of sexual difficulties were positively associated with help-seeking in both women (Frequency: AOR = 1.56; CI 1.1 to 2.3; Duration: AOR = 1.57; CI 1.1 to 2.3) and men (Frequency: AOR = 2.81; CI 1.8 to 4.3; Duration: AOR = 2.35; CI 1.5 to 3.6). In this population, relationship status, factors relating to sexual compatibility between partners, and relationship satisfaction/happiness were not associated with help-seeking in women or men (see Tables 5.15 and 5.16).

Table 5.15: The prevalence of help-seeking by relationship characteristics in sexually experienced women who reported being distressed about their sex lives (crude & adjusted odds ratios).

	Percentage of women distressed about their sex lives who sought help (95% CI)	OR (95% CI)	p value for OR	AOR* (95% CI)	p value for AOR	Denominator	
						Unweighted	Weighted
Relationship status at interview							
Living with a partner	32.7% (28.2%-37.5%)	1	0.0063	1	0.3304	490	531
Steady relationship- not cohabitating	42.8% (31.5%-54.9%)	1.54 (0.90 - 2.64)		1.24 (0.71 - 2.16)		96	58
Not in steady relationship- previously cohabitated	26% (19.3%-34.0%)	0.72 (0.47 - 1.11)		0.72 (0.46 - 1.12)		151	100
Not in steady relationship- never cohabitated	49.9% (37.9%-61.8%)	2.05 (1.22 - 3.44)		1.23 (0.71 - 2.11)		125	72
Happy in relationship with partner?							
Happy	39.6% (31.6%-48.3%)	1	0.5435	1	0.6046	179	175
Neutral	36% (28.5%-44.3%)	0.86 (0.53 - 1.40)		0.80 (0.49 - 1.31)		182	174
Unhappy	31.3% (21.0%-43.9%)	0.69 (0.36 - 1.34)		0.73 (0.37 - 1.44)		79	85

	Percentage of women distressed about their sex lives who sought help (95% CI)	OR (95% CI)	p value for OR	AOR* (95% CI)	p value for AOR	Denominator	
						Unweighted	Weighted
Share same level of interest in having sex as partner							
agree strongly/agree	33.4% (25.3%-42.8%)	1	0.6324	1	0.9425	127	124
neither agree or disagree	33.8% (20.3%-50.7%)	1.02 (0.45 - 2.31)		0.89 (0.40 - 1.98)		51	52
disagree/strongly disagree	38.6% (31.8%-45.8%)	1.25 (0.76 - 2.07)		1.01 (0.60 - 1.69)		262	258
Share same sexual likes and dislikes as partner							
agree strongly/agree	35.5% (29.4%-42.1%)	1	0.6159	1	0.5303	284	279
neither agree or disagree	34.2% (22.4%-48.4%)	0.95 (0.50 - 1.79)		0.84 (0.44 - 1.62)		68	68
disagree/strongly disagree	41.8% (30.4%-54.1%)	1.31 (0.74 - 2.32)		1.25 (0.69 - 2.27)		88	87
Emotionally close to partner when having sex							
always/most of the time	37% (31.2%-43.4%)	1	0.6734	1	0.6425	323	318
sometimes	37.6% (26.5%-50.1%)	1.02 (0.58 - 1.81)		0.93 (0.51 - 1.69)		85	85
not very often/hardly ever	28.7% (14.9%-48.0%)	0.68 (0.28 - 1.66)		0.64 (0.25 - 1.62)		32	31
Always find it easy to talk about sex with partners?							
No/other	31.8% (27.8%-36.0%)	1	0.0321	1	0.0233	681	614
Yes	43.2% (33.7%-53.1%)	1.63 (1.04 - 2.55)		1.62 (1.02 - 2.56)		140	126

	Percentage of women distressed about their sex lives who sought help (95% CI)	OR (95% CI)	p value for OR	AOR* (95% CI)	p value for AOR	Denominator	
						Unweighted	Weighted
Feel satisfied with sex life							
agree strongly/agree	31.8% (25.8%-38.5%)	1	0.3856	1	0.4120	261	230
neither agree or disagree	30.9% (23.3%-39.6%)	0.96 (0.59 - 1.56)		0.82 (0.49 - 1.37)		161	130
disagree/strongly disagree	36.6% (31.3%-42.2%)	1.24 (0.84 - 1.83)		1.13 (0.75 - 1.70)		440	403
Avoided sex due to sexual difficulties							
agree strongly/agree	40.3% (35.1%-45.7%)	1	0.0049	1	0.0001	409	395
neither agree or disagree	26.6% (19.0%-35.9%)	0.54 (0.33 - 0.88)		0.47 (0.28 - 0.78)		129	113
disagree/strongly disagree	28.2% (22.5%-34.7%)	0.58 (0.40 - 0.84)		0.46 (0.31 - 0.67)		308	253
Experienced problem(s) frequently past year?							
No	31.3% (25.6%-37.6%)	1	0.0215	1	0.0335	285	236
Yes	41.2% (35.6%-47.0%)	1.54 (1.07 - 2.21)		1.56 (1.08 - 2.25)		401	377
Experienced problem(s) for 6 months or more in past year?							
No	31.2% (25.4%-37.6%)	1	0.0166	1	0.0245	295	251
Yes	41.7% (36.0%-47.6%)	1.58 (1.09 - 2.28)		1.57 (1.07 - 2.31)		391	362

*Variables adjusted for age and education (age variable adjusted for education only; education variable adjusted for age only)

Table 5.16: The prevalence of help-seeking by relationship characteristics in sexually experienced men who reported being distressed about their sex lives (crude & adjusted odds ratios).

	Percentage of men distressed about their sex lives who sought help (95% CI)	OR (95% CI)	p value for OR	AOR* (95% CI)	p value for AR	Denominator	
						Unweighted	Weighted
Relationship status at interview							
Living with a partner	35.1% [29.5%,41.1%]	1	0.0530	1	0.1151	300	472
Steady relationship- not cohabitating	48.8% [36.4%,61.4%]	1.76 (1.00 - 3.12)		1.69 (0.90 - 3.18)		80	59
Not in steady relationship- previously cohabitated	26.5% [18.5%,36.4%]	0.67 (0.40 - 1.12)		0.67 (0.40 - 1.13)		104	90
Not in steady relationship- never cohabitated	36% [27.8%,45.1%]	1.04 (0.66 - 1.63)		0.95 (0.57 - 1.61)		171	125
Happy in relationship with partner?							
Happy	33.9% [25.4%,43.7%]	1	0.3185	1	0.3676	117	178
Neutral	44.7% [34.9%,54.8%]	1.57 (0.87 - 2.83)		1.39 (0.75 - 2.55)		118	160
Unhappy	39.7% [23.6%,58.3%]	1.28 (0.55 - 3.00)		1.15 (0.48 - 2.76)		31	44
Share same level of interest in having sex as partner							
agree strongly/agree	41.2% [31.6%,51.6%]	1	0.0049	1	0.0060	108	155
neither agree or disagree**	14.8% [6.8%,29.3%]	0.25 (0.10 - 0.64)		0.20 (0.08 - 0.55)		35	58
disagree/strongly disagree	45.5% [36.4%,54.8%]	1.19 (0.68 - 2.08)		1.14 (0.64 - 2.03)		123	169

	Percentage of men distressed about their sex lives who sought help (95% CI)	OR (95% CI)	p value for OR	AOR* (95% CI)	p value for AR	Denominator	
						Unweighted	Weighted
Share same sexual likes and dislikes as partner							
agree strongly/agree	37.9% [29.8%,46.7%]	1	0.6336	1	0.6356	154	232
neither agree or disagree	35.6% [22.8%,50.8%]	0.90 (0.44 - 1.87)		0.76 (0.37 - 1.58)		46	59
disagree/strongly disagree	44.4% [31.8%,57.7%]	1.31 (0.68 - 2.51)		1.22 (0.63 - 2.37)		66	91
Emotionally close to partner when having sex							
always/most of the time	37.6% [30.7%,44.9%]	1	0.4310	1	0.4794	214	313
sometimes	42.1% [26.1%,59.8%]	1.21 (0.55 - 2.65)		1.07 (0.47 - 2.45)		39	51
not very often/hardly ever**	57.5% [28.9%,81.9%]	2.25 (0.64 - 7.89)		2.22 (0.70 - 7.02)		13	17
Always find it easy to talk about sex with partners?							
No/other	33.3% [28.6%,38.4%]	1	0.1405	1	0.0536	470	574
Yes	41.3% [32.2%,51.1%]	1.41 (0.89 - 2.23)		1.71 (1.06 - 2.76)		142	143
Feel satisfied with sex life							
agree strongly/agree	29.6% [22.9%,37.4%]	1	0.1890	1	0.6066	202	241
neither agree or disagree	37.2% [25.7%,50.4%]	1.41 (0.74 - 2.67)		1.18 (0.61 - 2.30)		87	94
disagree/strongly disagree	38.1% [32.7%,43.9%]	1.46 (0.97 - 2.22)		1.25 (0.82 - 1.91)		371	415
Avoided sex due to sexual difficulties							
agree strongly/agree	40% [33.9%,46.3%]	1	0.1186	1	0.0667	288	353
neither agree or disagree	29% [20.2%,39.7%]	0.61 (0.35 - 1.07)		0.56 (0.32 - 0.98)		103	114
disagree/strongly disagree	31.9% [25.2%,39.5%]	0.70 (0.46 - 1.07)		0.61 (0.40 - 0.94)		252	283

	Percentage of men distressed about their sex lives who sought help (95% CI)	OR (95% CI)	p value for OR	AOR* (95% CI)	p value for AR	Denominator	
						Unweighted	Weighted
Experienced problem(s) frequently past year?							
No	26.9% [21.7%,32.8%]	1	0.0000	1	0.0000	287	326
Yes	51.2% [43.5%,58.7%]	2.85 (1.87 - 4.34)		2.81 (1.83 - 4.31)		203	257
Experienced problem(s) for 6 months or more in past year?							
No	28.2% [22.6%,34.7%]	1	0.0002	1	0.0003	259	290
Yes	47.1% [39.8%,54.5%]	2.26 (1.47 - 3.48)		2.35 (1.53 - 3.61)		230	292

*Variables adjusted for age and education (age variable adjusted for education only; education variable adjusted for age only)

**Denominators in these categories were <20, therefore caution should be taken when interpreting these results as the estimates will not be robust

Sex education and sexual behaviour factors

After adjusting for age and education men with at least one sexual experience (but not women) who were distressed about their sex life, and who talked to their parents about sex at age 14 were significantly more likely to seek help or advice for their sex life than men who did not talk to their parents about sex during that time (AOR = 0.60; CI 0.39 - 0.95). Men who had experienced attempted sex against their will were more likely to seek help or advice for their sex life (AOR = 0.31; CI 0.15 - 0.63), but this association was only marginally statistically significant in women (AOR = 0.66; CI 0.44 - 0.98). Ease of talking about sex with parents at age 14, source of sex education, sexual competence and actual sex against a person's will were not associated with help-seeking in women or men (see Tables 5.17 and 5.18).

Table 5.17: The prevalence of help-seeking by sex education and sexual behaviour characteristics in sexually experienced women who reported being distressed about their sex lives (crude & adjusted odds ratios).

	Percentage of women distressed about their sex lives who sought help (95% CI)	OR (95% CI)	p value for OR	AOR* (95% CI)	p value for AOR	Denominator	
						Unweighted	Weighted
Discussed sex with 1+ parents around age 14?							
Did discuss	40.3% (34.2%-46.7%)	1	0.0198	1	0.2076	302	250
Did not discuss	31.4% (27.0%-36.0%)	0.68 (0.49 - 0.94)		0.82 (0.58 - 1.15)		527	478
Main source of sex education							
Sex education lessons	32.6% (25.5%-40.7%)	1	0.1816	1	0.1925	184	158
Friends	33.0% (26.3%-40.6%)	1.02 (0.63 - 1.64)		1.01 (0.62 - 1.63)		220	200
Family	48.8% (37.4%-60.3%)	1.97 (1.08 - 3.59)		1.81 (0.98 - 3.36)		103	83
Media	36.4% (26.4%-47.9%)	1.18 (0.65 - 2.14)		0.98 (0.52 - 1.85)		104	85
Other**	43.6% (18.7%-72.2%)	1.59 (0.47 - 5.43)		2.09 (0.52 - 8.45)		14	11
Ease at which discussed sex with parents around age 14?							
Easy w/one or both	41.5% (32.9%-50.6%)	1	0.0740	1	0.3789	160	124
Difficult or didn't discuss or varied depending on topic	33.0% (29.1%-37.1%)	0.69 (0.46 - 1.04)		0.84 (0.56 - 1.26)		669	604
Sexual competence at 1st heterosexual sex							
Not competent	30.7% (26.3%-35.5%)	1	0.0719	1	0.1201	510	461
Competent	38% (31.8%-44.7%)	1.38 (0.97 - 1.97)		1.34 (0.94 - 1.92)		301	275

	Percentage of women distressed about their sex lives who sought help (95% CI)	OR (95% CI)	p value for OR	AOR* (95% CI)	p value for AOR	Denominator	
						Unweighted	Weighted
Anyone tried to have sex with you against your will?							
Yes	40.8% (33.7%-48.4%)	1	0.0413	1	0.0853	249	226
No	30.0% (25.9%-34.5%)	0.62 (0.43 - 0.90)		0.66 (0.44 - 0.98)		558	507
Don't know**	31.1% (14.6%-54.4%)	0.66 (0.23 - 1.83)		0.56 (0.20 - 1.61)		21	15
Anyone had sex with you against your will?							
Yes	33.8% (25.2%-43.6%)	1	0.6648	1	0.7950	126	115
No	32.9% (28.9%-37.3%)	0.96 (0.61 - 1.53)		1.04 (0.64 - 1.71)		673	613
Don't know	42.1% (24.2%-62.3%)	1.43 (0.56 - 3.60)		1.32 (0.51 - 3.46)		29	20

*Variables adjusted for age and education (age variable adjusted for education only; education variable adjusted for age only)

**Denominators in these categories were <20 and thus the ORs could not be interpreted meaningfully

Table 5.18: The prevalence of help-seeking by sex education and sexual behaviour characteristics in sexually experienced men who reported being distressed about their sex lives (crude & adjusted odds ratios).

	Percentage of men distressed about their sex lives who sought help (95% CI)	OR (95% CI)	p value for OR	AOR* (95% CI)	p value for AOR	Denominator	
						Unweighted	Weighted
Discussed sex with 1+ parents around age 14?							
Did discuss	46.9% (38.2%-55.8%)	1	0.0068	1	0.0241	170	165
Did not discuss	32.8% (28.0%-38.0%)	0.55 (0.36 - 0.85)		0.60 (0.39 - 0.95)		459	552
Main source of sex education							
Sex education lessons	29.6% (21.0%-40.0%)	1	0.1959	1	0.1463	121	122
Friends	31.2% (23.8%-39.8%)	1.08 (0.59 - 1.98)		1.25 (0.67 - 2.33)		159	196
Family	26.1% (14.2%-43.0%)	0.84 (0.34 - 2.07)		0.91 (0.35 - 2.36)		39	33
Media	43.8% (32.8%-55.5%)	1.86 (0.96 - 3.59)		1.89 (0.97 - 3.67)		106	112
Other**	12.0% (1.2%-60.7%)	0.33 (0.03 - 3.84)		0.27 (0.02 - 4.08)		4	3
Ease at which discussed sex with parents around age 14?							
Easy w/one or both	43.9% (30.9%-57.8%)	1	0.2455	1	0.4439	77	61
Difficult or didn't discuss or varied depending on topic	35.3% (30.8%-40.1%)	0.70 (0.38 - 1.28)		0.78 (0.42 - 1.46)		552	657
Sexual competence at 1st heterosexual sex							
Not competent	34.4% (29.0%-40.2%)	1	0.7683	1	0.8451	358	425
Competent	35.7% (29.1%-43.0%)	1.06 (0.72 - 1.56)		0.98 (0.66 - 1.46)		229	268

	Percentage of men distressed about their sex lives who sought help (95% CI)	OR (95% CI)	p value for OR	AOR* (95% CI)	p value for AOR	Denominator	
						Unweighted	Weighted
Anyone tried to have sex with you against your will?							
Yes	61.7% (46.2%-75.2%)	1	0.0017	1	0.0050	49	58
No	32.5% (28.2%-37.2%)	0.30 (0.15 - 0.58)		0.31 (0.15 - 0.63)		547	642
Don't know	36.1% (16.2%-62.2%)	0.35 (0.10 - 1.21)		0.34 (0.09 - 1.24)		23	22
Anyone had sex with you against your will?							
Yes	56.9% (33.6%-77.5%)	1	0.1433	1	0.1608	21	23
No	34.0% (29.7%-38.5%)	0.39 (0.15 - 1.04)		0.37 (0.13 - 1.01)		573	675
Don't know	41.9% (20.9%-66.3%)	0.55 (0.14 - 2.20)		0.47 (0.11 - 1.99)		25	25

*Variables adjusted for age and education (age variable adjusted for education only; education variable adjusted for age only)

**Denominators in these categories were <20, therefore caution should be taken when interpreting these results as the estimates will not be robust.

5.4 Discussion

To my knowledge, this analysis presents the first population prevalence estimates of help-seeking and internet help-seeking in the British general population among those who reported being distressed in some way about their sex lives (i.e. people reporting 1+ distressing sexual difficulties for 3 months or longer in the last year, and people who are distressed about their sex life more broadly). As far as I am aware, it is also the first population-based study to look in this level of detail at how help-seeking varies according to different sociodemographic and behavioural characteristics.

5.4.1 Main findings

5.4.2 Prevalence of distress associated with sex life (RQ1&6)

In this large British population-based study around 16.4% of sexually experienced people reported being distressed in some way about their sex lives (either about a specific sexual difficulty or about their sex life more broadly or both). In line with previous studies, this finding indicates that while a large proportion of people report sexual difficulties (Laumann et al., 2005; Mitchell et al., 2013), a much smaller proportion report feeling distressed or worried about their difficulties (Ferenidou et al., 2007; Mitchell et al., 2013; Shifren et al., 2009; Stephenson & Meston, 2010). Nonetheless, given the British population aged 16-74 years is currently estimated at 42 million (ONS, 2015), then a prevalence of 16.4% corresponds to there being approximately 6.9 million people in Britain currently distressed in some way about their sex lives.

By comparing two different populations of people distressed about an aspect of their sex life, I was able to observe that distress levels were similar in these two contrasting populations; and if the presence of distress is important in terms of helping to differentiate people who might want and benefit from help, from those who might not (Shifren et al., 2009; Shifren, Monz, Russo, Segreti, & Johannes, 2008), then this finding supports the notion and call to focus more on people's own description of what distresses them about their sex life, rather than focus on preconceived ideas and questioning about specific sexual function difficulties per se (Bancroft, Loftus, et al., 2003). Many clinicians refrain from raising the issue of sexual difficulties with their patients (Dyer & das Nair, 2013; Humphery & Nazareth, 2001), and this finding may help to encourage clinicians to ask more broad questions about whether people are

worried or concerned about anything in their sex lives, rather than have to probe about specific sexual function difficulties.

5.4.3 Prevalence of seeking help or advice about sex life (RQ2&7)

In those that were distressed (about a specific sexual difficulty or about their sex life more broadly) 35-40% had sought some form of help or advice for their sex life. These levels of help-seeking are considerably higher than those found in studies that have not measured distress (Laumann et al., 2009; Moreira et al., 2004), but approximately the same as in studies where it was (Shifren et al., 2009) – although this study only included women. These results mean that at least 60% of people who are currently distressed about their sex life are without help and support; demonstrating a large unmet need for help in this area (Mitchell et al., 2015).

By comparing two different populations of sexually distressed individuals, I was able to determine that levels of help-seeking are relatively low, with or without a specific sexual difficulty. Due to their wide-reach and anonymous nature, IDIs have the potential to reduce some of the barriers to help-seeking (see Chapters 1 and 7) and meet some of the current unmet need for help. IDIs are capable of providing full programs of help for people with clinical-level sexual function difficulties, but can also provide help and advice for people with sub-clinical level/intermittent sexual function difficulties or other sexual difficulties such as problematic sexual behaviours (e.g. excessive use of internet pornography or seeking high numbers of sexual partners).

5.4.4 Where people seek help (RQ3&8)

The top three sources of help people reported accessing were a GP, family and friends, and the internet, which was similar to the findings in other national surveys of self-reported sexual difficulties (Laumann et al., 1999; Moreira et al., 2004; Shifren et al., 2009). In the current study, the order of preference varied by population of interest and gender. For women and men with 1+ sexual difficulty the GP was most common source of help (followed by family/friends then the internet for women, and the internet then family and friends for men). This suggests that at least a proportion of people with sexual difficulties might view the nature of their difficulties as medical, and therefore see their GP as the most appropriate source of help.

In women with more overall concerns about their sex life, talking to family or friends was most common source of help (followed by the GP and internet), and in men consulting a GP was most common (followed by the internet and family or friends). This

perhaps suggests that, at least for women, distress about a person's sex life more broadly may not be seen as a medical problem that warrants attention from a GP. These findings also seem to support a more stereotypical gendered pattern of help-seeking in that at least a proportion of men appear less comfortable talking about distressing aspects of their sex life with friends or family.

Although internet help-seeking was the second or third most popular source of help (depending on population and gender), the levels of internet help-seeking were relatively low (ranging between 6.9 and 10.3% depending on population and gender). This finding is somewhat surprising, given the recent rise in online help-seeking for health and mental health problems. However, this finding could be, in part, because people may not think that effective help for sexual difficulties is available online. While several research trials of IDIs for sexual difficulties have been conducted (E. Andersson et al., 2011; Hucker & McCabe, 2014; Jones & McCabe, 2011; McCabe et al., 2008; Schover et al., 2012; Schover et al., 2013; Wootten et al., 2015) as far as I am aware there are currently no IDIs available for public use, and therefore, a person cannot look for something that does not yet exist. Furthermore, while the internet provides a huge amount of information, people often report finding it difficult to know what internet sources to trust (Brodie et al., 2000). Future qualitative research is needed to thoroughly explore the reasons why people may or may not seek help for their sexual difficulties (including online help); explore people's views on what would make it easier for them to seek help; and gather views on IDIs for sexual difficulties, so that this information can be considered and incorporated into the design, development and implementation of these types of interventions.

Regardless of the reasons for it, if people are not looking online for help for their sexual difficulties then this represents a potential implementation problem for IDIs in this area (i.e. how do people access available help if they are not looking for it?). To ensure that people can find the help once it is available, marketing strategies would need to be put in place prior to and during implementation of IDI's (i.e. by using GP and Sexual Health service referrals and widespread advertising campaigns).

Although current levels of online help-seeking for people with distressing sexual difficulties are relatively low (6.9-10.3%), it is important to note that in real terms this means that a large number of British people (between 427,000 and 762,000) are currently looking for help or advice for their sex lives online, and with the introduction of IDIs in this area there exists the potential to reach an even greater number of people,

including those that have not yet sought help but who might want help (Mitchell et al., 2015).

5.4.5 Variations in help-seeking by sexual difficulty (RQ4)

I originally intended to look at source of help-seeking by type of sexual difficulty, as this information would have been useful in determining whether some groups would be more likely to use an IDI or not, and if so, how to encourage uptake by groups less likely to use an IDI. Unfortunately, there were not enough numbers in the sample to be able to do this; however I was able to observe that the highest levels of help-seeking, were in women reporting distressing sexual pain and in men reporting distressing erectile difficulties; and the lowest levels of help-seeking were in women reporting distress associated with lacking interest in sex and in men reporting distressing early ejaculation problems. It could be that people find it easier to seek help when their distressing sexual difficulties have physical symptoms, and that perhaps this in some way legitimises seeking help (Bellamy et al., 2013). However, regardless of whether a person's symptoms are physical, psychological or a combination of both, this finding demonstrates that despite being distressed, large numbers of people are not seeking help across all of the different types of sexual difficulties.

5.4.6 How help-seeking varies according to socio-demographic and behavioural characteristics (RQ5&9)

Sociodemographic characteristics

With regards to sociodemographic characteristics, only age and education had any association with help-seeking. In both populations of interest (people with 1+ distressing sexual difficulty or people distressed about their sex life more broadly), age was associated with help-seeking in women but not in men, such that women were less likely to seek help as they got older. Few population-based studies have analysed factors relating to help-seeking, and in those that have the findings are mixed with regards to age and help-seeking for sexual difficulties. Moreira et al. (2004) found that men were more likely to seek help as they got older, but women less likely to seek help as they got older. Laumann and colleagues (2009) only observed an association between age and help-seeking in men between 60-69 years old compared to a referent group of men aged between 40-49 years old. In a study by Shifren et al. (2009) age was not associated with help-seeking in women.

In both populations of interest, education was associated with help-seeking in women, but the association was less consistent in men. Education was only associated with help-seeking in men who were distressed about their sex life more broadly, and not in men who were distressed about specific sexual difficulties. In previous population-based studies, the findings have also been mixed. Moreira et al. (2004) found an association between education and help-seeking in women but not men, and Laumann and colleagues (2009) found no association in either gender. In a study by Shifren et al. (2009) education was not associated with help-seeking in women.

Two of the previous studies that investigated factors relating to help-seeking for sexual difficulties were part of the Global Study of Sexual Attitudes and Behaviours (GSSAB), which was conducted with men and women between 40 and 80 years old (Laumann et al., 2009; Moreira et al., 2004). The Laumann study focussed on participants from the US, whereas the Moreira study focussed on a more global sample. The GSSAB had a very low response rate (19%), which suggests that the findings may not be externally valid, and the survey did not take distress levels associated with sexual difficulties into account when considering help-seeking. Studies also vary in the way they define help-seeking. Any or all of these factors may contribute to the inconsistencies in associations between help-seeking and age/education. These mixed findings highlight the importance of using consistent, well-defined, and broadly accepted definitions of sexual difficulties when conducting research in this area. However, it could be that education plays less of a role when services are widely available and easy to access with high awareness, or it could be that in some populations, help-seeking for sexual difficulties is more heavily influenced by social-cultural factors and health beliefs (not measured in Natsal-3), than sociodemographic characteristics (Bellamy et al., 2013).

The lack of association between help-seeking and other socio-economic factors (i.e. area level deprivation and employment) could be due to a lack of power in the sample to be able to detect associations that exist in the population as the numbers of participants in some groups were fairly small; but again it could be that socio-cultural factors and health beliefs may have a greater influence on help-seeking behaviour for sexual difficulties than socio-economic factors (Moreira et al., 2004). If this is the case then it has implications for the design and implementation of IDIs for sexual difficulties. In Chapter 2 I discussed how prescriptive social norms can have a powerful influence over people's sexual values, beliefs and behaviours. While IDIs cannot target broad cultural beliefs, their anonymous nature allows help-seekers to circumvent the barriers to help that are associated with cultural beliefs (e.g. shame and stigma). Once people

access an IDI they can obtain psychoeducation and normalising information that can help a person to challenge some of the socio-cultural attitudes and beliefs that might have prevented them from seeking help in the first place.

Health/Sexual Health characteristics

Having a health condition/disability in the last year that affected a person's sex life, having ever been diagnosed with an STI, having a genital health condition, receiving treatment for depression, and taking medications that limit sexual activity or enjoyment were all associated with seeking help or advice. While some of these findings may seem either circular or self-evident, in that the help-seeking may have been related to the health condition indicated, they could also be seen as proxy measures of severity of sexual difficulties.

Due to the broad definition of sex life (see page 120) it is unclear whether people sought help for the genital health condition or a sexual difficulty or something different entirely. If a person believed their sexual difficulty to be related to their genital health condition, then the medical nature of the problem may have provided a legitimate reason for them to seek help. But if the help they sought was for the genital health condition itself, then the finding is circular. It is perhaps more likely to be the former because the genital health condition question was on page 6 of the questionnaire, whereas the sexual function and help-seeking questions did not start until much later on page 90. The association between having an STI and help-seeking may also be circular, but it also could be that having an STI places people in a position where they can seek help for a related sexual difficulty more easily, and if this is the case it suggests that STI and GUM clinics might be useful access points for IDIs in this area.

It is well known that depression is associated with impairments in sexual function, and that many antidepressants can adversely affect sexual function (Baldwin, 2001). It could be that in the context of taking antidepressant medication (or any medication known to have sexual side effects) that it is easier to seek help for a sexual difficulty. This finding suggests that asking about sexual difficulties should be part of routine practice with all people who have been prescribed antidepressant medication or any other medication with known sexual side effects.

The above findings have implications for the role of GPs and sexual health professionals, in that perhaps they need to take a more proactive role in raising issues of sex and sexuality beyond those associated with medical problems. Many health

professionals are uncomfortable about raising issues of sex and sexuality with their patients (Dyer & das Nair, 2013; Humphery & Nazareth, 2001), and therefore policy should support increased training in this area. IDIs can play a part in increasing Health Professional confidence and knowledge by providing a tool that they can use themselves, with a patient, or direct a patient to.

Relationship and sex education characteristics

Ease of talking to a partner about sex was positively associated with help-seeking; this finding has implications for relationship counselling, and the importance of considering the relationship context when working with people with sexual difficulties. Talking about sex in face-to-face therapy may be too difficult for some people, and if this is the case, IDIs could provide a less direct way that couples could communicate about their sex life. Furthermore, IDIs for sexual difficulties often include partner sections in which partners work together on communication exercises, and evidence shows this to be an effective part of treatment for sexual difficulties (Berner & Günzler, 2012; Günzler & Berner, 2012).

Talking to parents about sex at age 14 was also positively associated with help-seeking in men (but not women); this finding has implications for sex education curricula in schools. If young people are to become adults who can openly discuss sexual difficulties and seek help when needed, it is important they be given the opportunity to openly and critically discuss issues relating to sex and sexuality, and explore the shame and embarrassment many people experience when thinking and talking about sex.

Sexual Behaviour characteristics

Men who reported experiencing attempted sex against their will were more likely to seek help or advice for their sex life. It could be that this experience is a proxy for vulnerability in general in relation to one's sex life, as well as a possible cause. It also could be that men who are more aware of their sexual history, and the potential impact this might have on their sex life, might be more willing to seek help. But the stigma and shame surrounding sexual difficulties and sexual assault, and the lack of association between actually having sex against a person's will and help-seeking suggests this is not the case. It is important to point out that the numbers were small and so caution should be taken when drawing any interpretations.

In the current study few personal characteristics were associated with seeking help or advice for a person's sex life. It could be that the samples in the current study were not sufficiently powered to detect associations that exist in the population. But it could also be that socio-cultural factors and health beliefs play a much greater role in influencing help-seeking behaviour in this area. Further research is needed to tease these possibilities apart. While IDIs cannot change the socio-cultural beliefs at the community level, what they can do is provide an anonymous platform in which people can explore and gently challenge their attitudes and beliefs that might have prevented them from seeking face-to-face professional help, and that might also be contributing to the maintenance of their difficulties.

5.4.7 Strengths and limitations

The current study has a number of strengths and limitations.

5.4.8 Strengths and limitations of Natsal-3 methods

The large cross-sectional population survey design and the use of an electronic handheld computer (CASI) to collect data (Mitchell et al., 2013) represent two major strengths of the Natsal-3 methods. In studies with large representative population sampling, each individual in the population has an equal likelihood of selection, and because the subset is representative of the entire population, the study findings can be generalised to that population. Furthermore, the use of the CASI for the majority of the questions applicable to the current study reduced interviewer bias, reduced item non-response/missing data due to routing and skipping errors, minimized data transcription and transfer errors, and offered a high degree of privacy and anonymity, which likely led to increased self-disclosure and less social desirability bias (De Leeuw et al., 2003; Erens et al., 2013).

The 57% response rate for the Natsal-3 survey (Erens et al., 2013; Mercer et al., 2013), while generally acceptable in epidemiological research (Craig & Mindell, 2011; Park, Clery, Curtice, Phillips, & Utting, 2012), raises questions about the external validity of the findings as it may have introduced non-response bias. Non-response bias is the variation between the responses of people sent survey invites and the responses of the actual respondents. This type of bias is usually created by refusals to participate and/or an inability to reach potential respondents, but in the case of Natsal-3, some of the non-response was also due to some addresses not being residential addresses. The sensitive subject matter may have put some people off responding, but

the response rate in Natsal-3 was similar to that of other large population surveys that did not contain sensitive subject matter (Craig & Mindell, 2011; Park et al., 2012) and so it was not likely that this had much influence on the response rate in Natsal-3. Unfortunately one cannot know about that which one does not know, and that is a limitation of epidemiological research (and any research where there are non-responders). However, the Natsal-3 survey used a statistical approach to reduce the effect of non-response bias by weighting the sample (i.e. selection probability weights were applied before comparing the profile of Natsal-3 respondents to 2011 census data for Britain by age, sex and government office region, which helped to support the representativeness of the sample. Furthermore, the item non-response rate was low for the variables in Natsal-3, including the sexual function variables; and the prevalence of sexual difficulties and levels of help-seeking approximated those found in studies using other methods; and therefore, despite the presence of non-responders, the Natsal-3 data do appear to be externally valid.

In Natsal-3 sexual distress was measured using a single item question. After participants indicated they had experienced a particular sexual difficulty they were asked 'How do you feel about this?' and could answer with not at all distressed, a little distressed, fairly distressed or very distressed. This level of detail was appropriate for a population-based survey, but by using a single item question it was not possible to distinguish between distress that was principally a reaction to difficulties in the sexual relationship or with a partner, and distress relating to a person's own capacity for sexual response, or how they feel about themselves as a sexual person (Bancroft, Loftus, et al., 2003). However, while gaining a deeper understanding about the nature of a person's distress would be useful in terms of better tailoring IDIs to their users, the current study sought to obtain prevalence estimates of people who were distressed in some way about their sexual difficulties, and a single item question was deemed appropriate to address this broad research question.

In Natsal-3, participants were asked whether they had sought help or advice regarding their sex life from a number of different sources. Interestingly, there was no option of indicating they had talked to their partner about their difficulties. The closest option was 'family member/friend' (although it is feasible to think that not all participants would consider and label their partner a family member or friend). If participants chose family member/friend, when they actually meant partner, then this could mean the numbers of people seeking help via this source is overestimated in this sample.

The Natsal-3 data relies on self-report data, which can be subject to bias due to systematic misreporting (i.e. under reporting of stigmatized behaviour and over reporting of normative behaviour due to social desirability) or forgetting. However, several techniques have been found to reduce socially desirable responding, including self-administration of the questions and assurances of confidentiality (Tourangeau & Yan, 2007). Natsal-3 participants were assured of confidentiality at the start of the interviews, and self-administered the sensitive questions relative to the current study using the Computer Assisted Self-Interview (CASI) on a handheld computer. Therefore, it is unlikely that misreporting made a substantial contribution to the Natsal-3 results.

As with all cross-sectional survey data, it was not possible to make causal inferences regarding help-seeking for sexual difficulties using the Natsal-3 data set. However, the main aim of the current study was to obtain prevalence estimates of help-seeking behaviour and the Natsal-3 data was ideal for these purposes.

5.4.9 Strengths and limitations of current study methods

The Natsal-3 survey questions were not designed for the current study, and so it is not clear how they were interpreted (or how sensitive they were). The help-seeking question was quite broad (i.e. 'Have you sought help or advice regarding your sex life from any of the following sources in the last year?') and 'sex life' was also defined in broad terms (i.e. an individual's sex life referred to their sexual thoughts, feelings, activity and relationships). But while it is not absolutely clear how people interpreted the help-seeking question, the question was asked within the sexual function section of the questionnaire. For the group that reported 1+ sexual distressing difficulties, the help-seeking question came immediately after the questions about specific sexual function difficulties, sexual satisfaction, sexual distress, and avoidance of sex (due to sexual difficulties), and so it was feasible to assume that many of them would be thinking about sexual function difficulties when answering the help-seeking question. Furthermore, the help-seeking question provided a measure of actual (albeit self-reported) behaviour, rather than intentions to engage in particular behaviour, and therefore avoids the intention-behaviour gap problem found in many other survey studies investigating behaviour.

For the group that reported being distressed about their sex life more broadly, it is more difficult to determine how they might have interpreted the help-seeking question. A proportion of this group were not sexually active in the last year, and so were not asked the questions about sexual function difficulties, but this did not preclude them from

experiencing sexual function difficulties that were not picked up by the Natsal-3 questionnaire; some may have experienced sexual function difficulties when they were last sexually active (i.e. prior to the last year) and some may have experienced intermittent (yet distressing) sexual function difficulties (i.e. for less than 3 months in the last year). It is therefore reasonable to assume that these people might also have been thinking about sexual difficulties when answering the help-seeking question.

For the remaining responders the question may have been interpreted more broadly. For example, when thinking about help-seeking for a person's sex life, some people may have been thinking about the question in the context of relationship difficulties, problematic sexual behaviours (e.g. excessive use of internet pornography or excessive seeking of sexual partners), related health problems (e.g. prostate or breast cancer), or sexually transmitted infections (STIs). These varied potential interpretations are, however, not problematic for the current study, as IDIs for sexual difficulties often include help and support for relational aspects, problematic sexual behaviours, and coping with the sexual side effects of having and being treated for prostate and breast cancers or STIs (Schover et al., 2012; Wootten et al., 2015). So while a more specific line of questioning would have been more informative in terms of knowing exactly what people sought help for, the existing questions adequately captured the extent to which people were willing to look for help online for a range of sexually related issues.

Reach is technically defined as 'the absolute number, proportion, and representativeness of individuals who are willing to participate in a given initiative, intervention or program' (Glasgow, Vogt & Boles, 1999). In the current study I obtained the absolute number, proportion and representativeness of individuals who looked for help or advice regarding their sex life from information and support sites on the internet, which is not quite the same as obtaining estimates of willingness or actual use of an IDI for sexual difficulties. However, these types of interventions are not yet available on the internet, and so it is perhaps not possible or appropriate to ask this more specific question in a large population-based survey. It might be more appropriate to first explore perceptions of, and willingness to use, an IDI in a qualitative study (to ensure people understand what an IDI is and does) before using this information to develop appropriate related survey questions. It is also worth noting, that given that IDIs are not yet available outside of research contexts, it is possible that the current estimates of online help-seeking for sexual difficulties could be underestimates (i.e. once people are aware of the existence of IDIs for sexual difficulties, and understand

how they might be of benefit, it is feasible to think that more people might look online for help with sexual difficulties).

If it had been possible to design the questionnaire specifically for the current study then it could have been more closely tailored to the goals of the study. In Natsal-3 participants could tick as many sexual difficulties and sources of help as they felt applicable, which was useful in terms of knowing the range of difficulties experienced and sources of help accessed. But given the categories were not mutually exclusive I was unable to run statistical analyses to determine which were the most common difficulties and sources of help. I also was unable to determine what specific aspects of people's sex life they felt most distressed about? What sources of help were most useful? What was it specifically that people sought help online for? And would people be willing to use an IDI for sexual difficulties if it was available? Using more specific questions would potentially have generated a more sensitive measure of reach of IDIs, but imperfections notwithstanding, the Natsal-3 questions were fit for purpose in terms of enabling me to calculate the potential reach of IDIs for sexual difficulties.

Another limitation associated with using previously collected survey data was that not all desired information was available to develop a clear picture of the factors associated with help-seeking for sexual difficulties. Common confounders (e.g. age and education level) were controlled for, and the analysis was run separately by gender, but I could not rule out that certain unmeasured confounders explain some of the observations (e.g. trait characteristics or environmental factors that influenced help-seeking behaviour). I also did not know whether people perceived help and support to be available or even whether people felt they could be helped. Furthermore, due to missing predictor variables within the dataset I was unable to generate a predictive model of help-seeking for sexual difficulties. The inclusion of variables known or hypothesised to be associated with help-seeking for sexual difficulties (and other stigmatising health and mental health problems), such as embarrassment discussing sexual difficulties with a medical professional (O'Donnell, 2005; Shifren et al., 2009), perceptions of prognosis (O'Donnell, 2005), perceived availability and accessibility of help (Doherty & Kartalova-O'Doherty, 2010), GP characteristics (Moreira et al., 2008; Nazareth et al., 2003), and self-reported quality of life (Doherty & Kartalova-O'Doherty, 2010) would have helped to explain some of the variance in help-seeking for sexual difficulties, and this information would be useful in determining what to include in an IDI for sexual difficulties.

Unfortunately, I was unable to analyse the help-seeking patterns of people from different ethnic groups and sexual orientations, due to small numbers in the non-white and non-heterosexual groups. If help-seeking behaviours in people with sexual difficulties is, as I suggested earlier in the chapter, related to cultural factors (e.g. taboos around the discussion of sex) then I may have missed out on the opportunity to look at this. Furthermore, research indicates that lesbian, gay, bisexual and transgender (LGBT) individuals encounter significant health inequalities, and without sufficient numbers of these groups I was unable to determine whether sexual difficulties is another area of health inequality for LGBT individuals. In addition to boosting the numbers of young people, future surveys might benefit from boosting the numbers of people from different minority ethnic groups and LGBT groups to allow exploration of help-seeking patterns in these groups, and explore the socio-cultural factors that might drive sexual attitudes and behaviours.

I had intended to explore the associations between internet help-seeking and different sociodemographic, health, relationship, sexual behaviour and sex education variables in the two populations of interest. However, due to the relatively small number of people who sought help via the internet there were not enough numbers in the sociodemographic and other categories to perform a regression analysis.

5.4.10 Implications

5.4.11 Implication for practice

The widespread lack of help-seeking in people with distressing sexual difficulties suggests that NHS service provision in this area does not currently meet the needs of many people with distressing sexual difficulties. Alternative models of service delivery are needed, and IDIs for sexual difficulties are well-placed to offer help that might appeal to people who, for whatever reason, would not present to face-to-face services.

If socio-cultural factors and health-beliefs are key drivers of help-seeking, then healthcare professionals have a responsibility to raise issues of sex and sexuality with their patients, and to be sensitive and reflexive in their approach when discussing people's sexual attitudes and beliefs. Increased medical education and continued professional development in the area of sex and sexuality is needed, and would benefit from including the socio-cultural context of sexual difficulties in their curricula.

5.4.12 Implications for research

More research is needed to explore what aspects of people's sex life they find distressing and what type of help they have sought (or would seek) for different difficulties, to provide a more sensitive measure of reach and usefully inform intervention planning and implementation. A cross-sectional survey which includes potential predictor variables for help-seeking would be useful in terms of generating a predictive model of help-seeking for sexual difficulties; and boosting samples of ethnic and sexual minority groups would facilitate the exploration of cultural factors that might influence help-seeking.

With the quantitative data from the current study it is difficult to determine the reasons why people do not seek help online. It could be due to a dislike of the medium, but equally it could be because people are unaware of what help might be available online. Future qualitative studies are needed to clarify the reasons, and also to explore more broadly why people do not seek help; what people think of IDIs for sexual difficulties; whether people would be prepared to use an IDI for sexual difficulties; and which features of IDIs might maximise interest and engagement.

The findings from the current study can only be generalised to the British public, thus it would be beneficial to replicate the findings in other countries to see if the patterns and associations (and lack of associations) hold. If socio-cultural factors and health-beliefs have a greater effect on help-seeking behaviour than socio-demographic characteristics, it would be worthwhile investigating how these vary from country to country, and what effect they have (if any) on patterns of help-seeking, as this information would be useful in terms of making sure the content of IDIs are relevant and tailored to the social and cultural contexts of their users.

While the current study demonstrates a need for alternative sources of help for sexual difficulties, and highlights the potential of IDIs to fill some of the gaps in service provision, implementation research is needed to uncover any implementation barriers that might prevent IDIs being incorporated into routine clinical practice, and to develop strategies to overcome them.

5.4.13 Implications for policy

As mentioned in the previous chapter, IDIs for sexual difficulties are a relatively new area of research, and consequently are not yet at a stage where they can be commissioned. While evaluation and implementation research continues, and in

anticipation of their implementation into routine clinical practice, it would be helpful if policy could focus on closing the digital divide as much as possible to ensure that health inequalities do not increase as a result of the proliferation of IDIs in this area (Bennett & Glasgow, 2009).

If socio-cultural factors and health-beliefs do have a greater influence on help-seeking behaviour for sexual difficulties (than the variables measured in Natsal-3), then sex and relationship education policy could play a key role in providing young people with accurate information and open discussion about sexual difficulties, and pointing them towards sources of online and offline support. Unfortunately, in the UK, there is currently no statutory requirement to teach sex and relationships education, beyond that of the biological basics of reproduction and STIs.

5.5 Conclusion

Approximately 16.4% of the sexually experienced British general population report being distressed about their sex life in some way (about a specific sexual function difficulty or their sex life more broadly), which corresponds to a large number of people (approximately 10.6 million). Of those people, approximately two thirds are distressed but without any help or support, demonstrating a high level of unmet need for help in this area. Of the men and women who are distressed about their sex lives, between 6.9-10.3% (427,000-762,000) have sought help or advice online. Despite being a relatively small proportion of those distressed, the internet remains in the top three sources of help sought by British women and men; and although the internet is currently underutilised as a source of help for sexual difficulties, with the introduction and increased awareness of IDIs in this area, there exists the potential to reach an even greater number of people.

Chapter 6
**Integrating psychological theory into
the design of an interactive digital
intervention for sexual difficulties:
sextherapy london.nhs.uk (STL)**

6.1 Chapter overview

STL is the IDI that was evaluated as part of the current thesis. While I was not involved in the design and development of STL (which took place between 2007 and 2009), as part of this thesis I designed and undertook a qualitative evaluation of the acceptability of the intervention (see Chapter 7). I obtained detailed information about the design and development process by conducting interviews with the authors of STL, and then performed a post-hoc mapping exercise to enable me to fully describe the content of the intervention and how theory informed its design. In this chapter I describe the aims and methods of the chapter, the context in which STL was developed, the aims of the intervention and the target population, the theoretical rationale for the intervention, the content and features within the website, and the design and development process (including the challenges). I end the chapter with a section on how STL was implemented and used within a psychosexual clinic context, and briefly outline some considerations for the future development and use of STL.

6.2 Aims

The aim of the current chapter was to describe the content and theoretical design of the STL intervention. STL was chosen as an example of an interactive, theory-based digital intervention to show to potential users with the aim of gathering their views on the potential of these types of interventions for (their) sexual difficulties; and also as an example of an IDI to discuss in the context of whether implementation of IDIs is desirable and feasible in the UK.

6.3 Methods

The information for this chapter was gathered via two different methods. 1. Through interviews and iterative discussions with the two psychologists that wrote the content of STL. 2. Using a post-hoc intervention mapping exercise, I worked through each step of the intervention with the authors of the content, considering how theory had been operationalised, and how users' needs had been addressed.

6.4 Circumstances of STL's development

6.4.1 The Margaret Pyke psychosexual clinic

The idea for STL was first conceived in 2007 by two clinical psychologists from Sexual Health Psychology Services in the Margaret Pyke centre: Dr Karen Gurney (Deputy Head of Psychology Services, Psychosexual Lead) and Dr Naomi Adams (Head of Psychology Services). The Margaret Pyke Centre is a large sexual and reproductive health clinic based in Central London. Research and internal clinic audits for the psychosexual clinic at the Margaret Pyke Centre supported the view that sexual difficulties were widespread within the population, but that psychosexual services were not available in all areas, and the services that were available could not adequately meet demand. It is an open access clinic with most attendees coming from the London area. So it was within this context and climate that Camden Provider Services (the NHS trust) advertised an initiative grant whereby staff could bid for funding for the design and development of innovative clinical tools. This was the grant that funded the design and development of STL.

6.4.2 Technological context

Over the decade prior to developing STL, there had been a rapid rise in internet use, which had been accompanied by a dramatic increase in online help-seeking for different health issues, and a proliferation of online sources of health-related

information and support (Bailey et al., 2015). At the time of STLs development major funding cuts within the NHS had not yet started, but innovation in healthcare was widely supported and encouraged.

6.5 Aims of the intervention

The main aim of the STL intervention was to make sex therapy available to a wide audience, and address some of the mismatch between the prevalence of sexual difficulties and the availability of face-to-face treatment.

Another central aim was to widely disseminate accurate and normalising information about sexual difficulties with the intended outcomes being change in the user's understanding or meaning they ascribe to their sexual difficulties. Based on clinical experience, and in-line with Systemic Theory, it is thought that many non-clinical level sexual difficulties are not really problems per se, but are problems of perception influenced by social discourse (Anderson, 1992; Anderson & Goolishian, 1986). Clinicians report that while most people who are referred to the Margaret Pyke psychosexual clinic are distressed about a sexual difficulty, the majority do not have a clinical level DSM-5 sexual dysfunction. According to clinicians, many people are distressed because they believe their sex life is somehow different from how it 'should' be. Using early ejaculation as an example, the aim of the STL intervention would be to provide normalising information about ejaculation (i.e. the average length of time to ejaculation), and to deconstruct assumptions (e.g. Who is length of time to ejaculation a problem for and why). Providing accurate information about sexual difficulties, sharing real life case studies, and gently questioning a person's beliefs and perceived meaning of their sexual difficulties can have a beneficial effect.

For those that might require more than psychoeducation and normalising, a further aim of the intervention was to provide some simple sex therapy techniques. Many people who seek face-to-face therapy can be helped by using these simple techniques, and it was thought that these people should not have to wait 6 months to see a face-to-face therapist when these simple techniques could easily be delivered online. However, in face-to-face practice, clients often require some encouragement to try these exercises, and they also need a certain level of motivation to continue with them; for these reasons, the authors were unsure whether people would engage with the online sex-therapy exercises.

As sex is often a relational activity involving one or more partners, in addition to including modules targeting individuals, the authors included modules targeting couples. The partners section is available for people who are in a relationship and wish to work through exercise with their partner. The partners sections are exclusively grounded in Systemic Theory, and encourage couples to engage in 'problem free talk' (de Shazer, 1982), demonstrate how talking can be most useful, and encourage the sharing of multiple perspectives. Together these exercises bring about change by introducing the 'difference that makes a difference' (Bateson, 1972) amongst other things. In this way, the 'problem' is seen in part to exist in the lack of shared meaning or understanding of the problem.

A final aim of the intervention was to educate GPs and other health professionals about the treatment of psychosexual difficulties. In this respect, one use of the intervention was to encourage GP and health professional learning and education by providing information about best clinical practice guidelines around sexual difficulties. This function is operationalised within the website whenever a user completes the initial assessment section of the website and is referred to their GP. For example, users who report erectile difficulties are referred to their GP to rule out cardiovascular disease before starting the online program. At this point there is an option for the user to print a version of their assessment for their GP, and when it is sent to the GP it provides them with a link to best practice guidelines. The issue of sexual difficulties are often raised with GPs and STI/GUM clinic staff, but staff often lack the time and/or the confidence to address these concerns (Abdolrasulnia et al., 2010; Harsh et al., 2008; Moreira et al., 2004; Shepherd et al., 2010). Not all of the issues raised warrant a referral to a psychosexual clinic, and in these cases it was hoped that staff could either direct their patients to the website, or if required, explore the website themselves to help them gain the confidence to help patients directly.

6.6 Target population

The intervention is targeted at people who would like some help for a sexual difficulty, but for various reasons, are not comfortable or able to seek face-to-face support (see barriers to help-seeking outlined in Chapter 1). Clinically, the intervention is designed to be used as part of a stepped-care approach (Bower & Gilbody, 2005), where the least intrusive/intensive intervention is tried first. Initially the website was intended to be made available to all ages, but due to legal requirements relating to the age of sexual consent in the UK, the website had to be aimed at people aged 16 or over.

In order to appeal to as wide an audience as possible, the intervention was designed to avoid assumptions about a person's gender, sexuality or culture (i.e. users are encouraged to answer questions in accordance with their own sexuality, religion and culture etc.). And while the intervention does not explore specific socio-cultural beliefs about sex (as would happen in face-to-face therapy), within each program there is a 'coordinated management of meaning' section (Cronen, 1994; Pearce, 1994) in which the program attempts to draw out differences in attitudes and opinions between users, relating to their socio-cultural contexts; and encourages users to take a position on these perspectives, or critically appraise the influence of these on their sexual difficulties.

6.6.1 Problems and populations for whom the intervention is not suitable

Research shows that sex therapy is not effective, and also unethical, in the context of domestic abuse (Hof, 2013), so in the triage section of the website, people who might be in abusive relationships are advised to seek help for that before starting a web-based program of sex therapy. Sex therapy is also not undertaken in the context of significant recreational drug use given the effect that many recreational drugs (and prescribed drugs to manage drug dependency) have on sexual function (Regev & Schmidt, 2009), and therefore people who currently use/abuse drugs are also directed to seek help for this before starting the web-program. As erectile difficulties can be an early sign of cardiovascular disease, all users of the erectile difficulties program are requested to see their GP before starting the program.

6.7 Theoretical rationale

Cognitive Behavioural therapy (Beck, 1995), Systemic therapy (Cronen, 1994; Hertlein, Weeks, & Gambescia, 2009), and Motivational Interviewing (Rollnick, Miller, & Butler, 2008) are the evidence-based treatments for sexual difficulties that underpin the intervention content of STL.

6.7.1 Psychoeducation (PE)

Psychoeducation is an important component of many different therapies (including Cognitive Behavioural therapy), and in the context of sexual difficulties psychoeducation involves providing information about the anatomy and physiology of sex, addressing unrealistic expectations of the self and the sexual encounter, and addressing myths about sexuality (e.g. about the frequency of sexual desire). Many

therapies begin with psychoeducation, but psychoeducation often continues throughout the course of the therapy.

6.7.2 Cognitive Behavioural Therapy (CBT)

CBT is based on the idea that our thoughts influence how we feel, behave, and react to our environment. Therefore, one goal of CBT, as applied to sexual difficulties, is to identify and challenge any negative beliefs, thoughts and attitudes about sex, that prevent a person from pursuing a satisfying, safe, and pleasurable sex life (i.e. cognitive restructuring). For example, the belief that pain means damage in women with chronic vulva pain is one that might be gently challenged. Behavioural techniques might include sex therapy techniques, such as systematic desensitisation, to gradually increase exposure to sexual activities that cause anxiety; the stop-and-start method or squeeze technique to help with early ejaculation; sensate focus to lessen or remove performance anxiety; or self-stimulation exercises to help with difficulties with erections and orgasms (Masters & Johnson, 1966a, 1966b).

6.7.3 Systemic sex therapy (ST)

According to Systemic theory, sexual difficulties are thought to arise within systems, rather than individuals; with a system referring to the individual, their partner(s), family, friends, and their broader socio-cultural context (i.e. class, religion, ethnicity, sexual orientation etc.). In Systemic sex therapy, the focus is on patterns of interaction/reaction and the meaning of problem saturated stories. From a Systemic perspective, a female client presenting with low sexual desire may be distressed by it as she is influenced by the meaning her partner is making of her lack of initiation of sex, and broader socio-cultural norms or perceptions about frequency of desire. Both partners may be influenced by societal discourses such as 'sexual difficulties mean relationship problems' leading them to seek help. The therapy may be structured to help the couple reflect on where their ideas about 'normal' desire come from, what is behind their concern about desire levels (the meaning) and helping them understand the patterns that maintain the 'problem' (e.g. the more one partner highlights the lack of sex, the more they might argue and both feel distant, the less physical contact they have, the less change of initiation of sex. In systemic sex therapy, a person's beliefs and behaviours are not conceptualised as right, wrong or dysfunctional; rather they are seen as helpful or unhelpful, in terms of maintaining the current patterns of interaction in the system (Cronen, 1994; Hertlein, Weeks, & Gambescia, 2009). Systemic sex

therapy is useful to address the interpersonal and socio-cultural factors that influence sexual difficulties discussed in Chapter 2 (Hertlein et al., 2009).

6.7.4 Motivational interviewing (MI)

MI is an evidence-based, goal oriented, and client-centred form of counselling designed to elicit behaviour change. MI is often used in conjunction with other approaches, and is thought to work by addressing ambivalence, increasing motivation, and consolidating commitment to change (Rollnick et al., 2008). MI draws on Self-perception theory (Bem, 1972), with the idea that people are more likely to commit to behaviour change when they are able to articulate and stand by the reasons for change. Verbalising intentions and action planning also increases the probability of change. Evidence suggests that MI is useful to strengthen a client's commitment to change in conjunction with other approaches (Hettinga, Steele, & Miller, 2005).

6.8 Tailoring

In Chapter 3 I defined tailoring as 'a process for creating individualized communications by gathering and assessing personal data related to a given health outcome in order to determine the most appropriate information or strategies to meet that person's unique needs'. Research indicates that tailoring can be effective for supporting health-related change, and dynamic tailoring, using iterative assessment and feedback, has been deemed an important intervention strategy (Krebs et al., 2010). When providing feedback, STL uses names and terminology chosen by the user themselves. All typed entries are saved and quoted in later sections of the programs. A tailored summary of self-assessed progress is also presented at the end of each programme, with suggestions for future help.

6.9 Intervention content

At the time of STL's development, interactive interventions for sexual difficulties were virtually non-existent, so the content for STL was based on research evidence, best practice guidelines (Hackett et al., 2007; Richardson, Goldmeier, Green, Lamba, & Harris, 2006), and clinical practice for face-to-face sex therapy. Examples of the types of exercises in the programs can be seen in Table 6.1.

Table 6.1: Examples and aims of STL exercises

Program	Type of exercise	Topic Heading	Aim of the exercise	Theory
Erectile difficulties	Information	Negative thoughts and sex	Psychoeducation	CBT
	Thinking	Your brain and better sex	Psychoeducation	CBT
	Practical	Losing and gaining erections	Systematic desensitisation and cognitive restructuring	CBT
Early ejaculation	Information	How does ejaculation happen	Psychoeducation	CBT (not exclusively)
	Thinking	Getting started	Setting an appropriate context	Sex Therapy
	Practical	The Stop-Start technique	Behavioural skills training	Sex Therapy
Vaginal pain	Information	Staying motivated	Troubleshooting ambivalence	CBT
	Thinking	My ladder of success	Systematic desensitisation	CBT
	Practical	Practising penetration	Systematic desensitisation	CBT
Anal pain	Information	Ground rules	Co-constructing boundaries	Systemic Therapy
	Thinking	My pain threshold	Developing graded hierarchy	CBT
	Practical	Kegel exercises	Physical technique	None
Difficulties with orgasms	Information	What does not having orgasms mean to your relationship?	Naming alternative perspectives from the dominant view	Systemic Therapy
	Thinking	Understanding your attitudes towards sex	Co-ordinated Management of Meaning	Systemic Therapy
	Practical	Learning to give your body pleasure	Systematic desensitisation/sensate focus/Skills training	CBT/Sex Therapy
Lack or loss of desire	Information	What is sexual desire?	Deconstructing/ Psychoeducation	Systemic Therapy/Sex Therapy
	Thinking	Who says your sex drive is too low?	Deconstructing the 'problem'	Systemic Therapy
	Practical	Getting re-acquainted	Sensate focus	Sex therapy
Problematic sexual behaviour	Information	Understanding my behaviour	Identifying antecedents	CBT
	Thinking	How do you feel afterward	Identifying consequences	CBT

Program	Type of exercise	Topic Heading	Aim of the exercise	Theory
	Practical	Masturbation with fantasy sex	Sexual skills training/Cognitive focus	Sex Therapy/CBT

As can be seen on the homepage (see Figure 6.1), there are seven different interactive programs: 1. Confidence in getting and keeping erections; 2. Controlling when you ejaculate (for men); 3. Overcoming pain during vaginal sex; 4. Overcoming pain during anal sex; 5. Having orgasms (for women); 6. Improving sex drive; and 7. Changing sexual behaviour. In the following pages I show a selection of screenshots from the different programs to illustrate the intervention content at each stage.

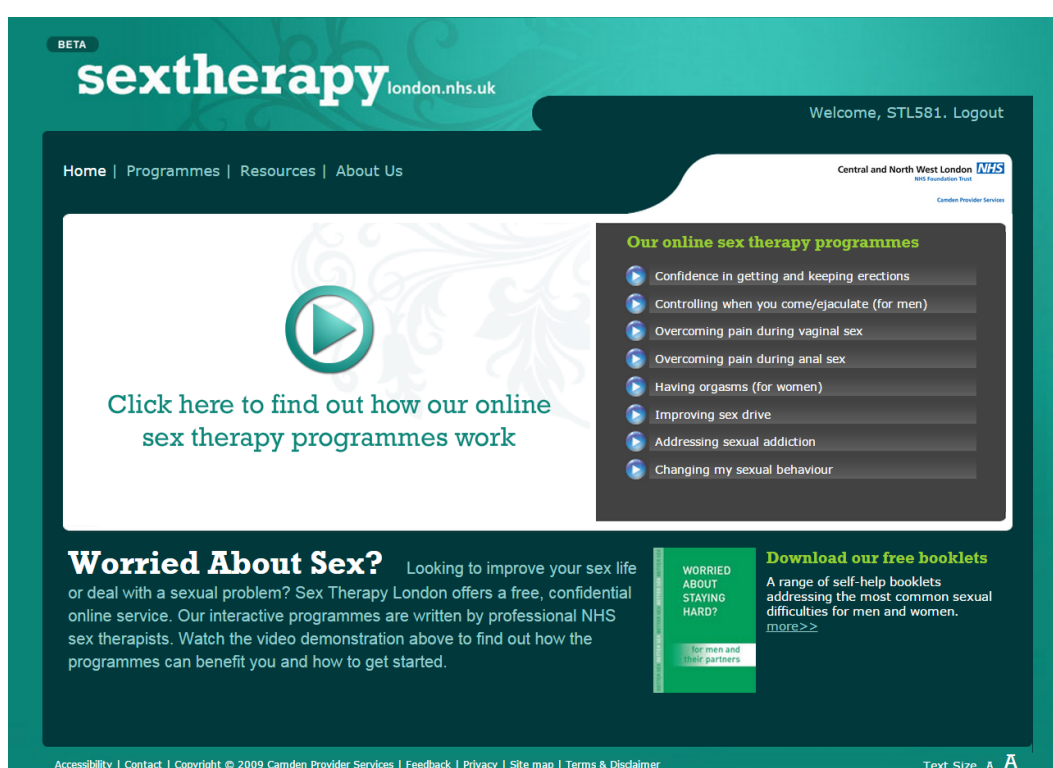


Figure 6.1: The home page of STL.

Note: the 'Changing my sexual behaviour' program is exactly the same program as 'Addressing sexual addiction'. The concept of sex addiction resonates with some people yet repels others, which is why the program was presented in two ways.

Each program consists of 6-8 stages. In the contents page of each program the contents are broken down into information exercises, thinking exercises, and practical exercises.

6.9.1 Stage 1: Initial consultation – is this the right way forward for me?

Each program starts off with an assessment and triage section (see Figure 1 in Appendix G), which is based on clinical safety and best practice guidelines. According to the British Society of Sexual Medicine (BSSM), erectile dysfunction should be treated as a symptom of cardiovascular disease until proven otherwise; so at the start of the program, erring on the side of caution, any users with erectile difficulties are encouraged to consult their GP before starting the web-program. As mentioned above, questions about possible abusive relationships and drug use were also in the triage section. The overall purpose of the assessment and triage section is to direct the user to the best way forward and give them the confidence that they are on the right track in terms of treatment (this is similar to what happens at the start of face-to-face therapy).

6.9.2 Stage 2: Evaluation of the problem

In stage 2 the program takes the user through a series of questions to evaluate the extent to which the sexual difficulty interferes with the person's life and relationships (see Figure 2 in Appendix G).

6.9.3 Stage 3: Lifestyle factors and change

In stage 3 the program explores factors that might be contributing to the problem (e.g. negative thoughts or worries during sex or difficulty using condoms; see Figure 3 in Appendix G). Information about the physiology of ejaculation is provided in the program 'Controlling when you ejaculate' (PE); and in the 'Changing sexual behaviour' users explore their attitudes towards sex, assess their readiness for change, and weigh up the pros and cons of change (MI).

6.9.4 Stages 4-7: Information, thinking and practical exercises (length and content varies by program)

'Confidence in getting and keeping erections' – In stage 4 the user works through the program alone. Information is provided on the physiology of erections and how negative thoughts can impact on sexual performance (PE/CBT; see Figure 4 in Appendix G). Practical exercises include strengthening pelvic floor muscles, self-stimulation exercises, such as learning to pleasure the penis when it is soft, focused masturbation, working with losing and gaining erections, and using fantasy while masturbating (BT). The chapter ends with a troubleshooting section for real sexual encounters. In stage 5 the user works through exercises with a partner (if they have

one). Information is given on how to work together effectively (PE), and thinking exercises include how to get started and setting goals for their sex life (ST). Practical systematic desensitisation exercises include getting reacquainted, exercises with the penis when it is soft and hard, losing and gaining erections with a partner, gradual penetration and penetration with movement (BT).

‘Controlling when you ejaculate’ – In stage 4 the user works through the program alone. Information is provided on how negative thoughts can affect sexual performance (CBT), factors that can exacerbate the problem (e.g. a new partner), and the trap of reducing foreplay (as this limits sensation to the penis making sensation more stimulating when it happens). Practical exercises include strengthening pelvic floor muscles (see Figure 5 in Appendix G), and using the stop-start and squeeze techniques (BT). In stage 5 the user works through exercises with a partner (if they have one). Information is given on how to work together effectively, and thinking exercises include how to get started and setting goals for their sex life (ST). Practical exercises are the same as in stage 4 but practiced alongside a partner and then during sex (BT).

‘Overcoming pain during vaginal or anal sex’ – In stage 4 users learn more about their body, sexual arousal and pain (PE). Information is provided on the anatomy and physiology of the genitals (i.e. what they look like and what happens when they are aroused; PE). Information is also given on the cycle of pain and how negative thoughts can influence sexual performance (PE/CBT). In stage 5 users explore the meaning of the difficulty and develop an action plan involving pain threshold and using a ladder of success tool (i.e. graded exposure to penetration). Graded exposure involves developing a hierarchy with the aim of moving through it step by step to reduce anxiety (ST & CBT; see Figure 6 in Appendix G). In stage 6 exercises include strengthening pelvic floor muscles and practicing penetration (vaginal or anal; BT). Users are also given information to help stay motivated and problem solve for future sexual encounters (MI or CBT). In stage 7 users work with partners (if applicable). Information is provided on setting ground rules (PE/ST). Thinking exercises include working on how to get started and setting goals for the couple’s sex life (ST). Practical exercises involve working through the ladder of success together (CBT/BT).

‘Having orgasms’ for women– In stage 4 users learn more about their body, sexual arousal and pain (PE). Information is given on the anatomy and physiology of the vulva, including what happens when a woman is aroused, what an orgasm is and what it feels

like (PE). Normalising information is provided (PE). Exercises include strengthening pelvic floor muscles, exploring attitudes toward a person's own genitals (CBT; see Figure 7 in Appendix G), and the link between our thoughts and sexual performance (CBT). In stage 5 users work on practical exercises alone, including learning to give their own body pleasure and experimenting with sexual touch (BT). Information and tips are provided as to other things that might help (PE). Thinking exercises enable the user to explore their attitudes to masturbation (CBT). Stage 6 explores the idea of having orgasms with a partner. It includes information about communicating with a partner about what turns them on and about the impact of negative thoughts or worries on sex and the body (PE/CBT/ST). Users also explore why it is or is not important to have orgasms with a partner and the user's attitudes towards sex (CBT/ST). Stage 7 involves exercises with a partner (if applicable); these include thinking about the meaning of not having orgasms in a relationship (ST), making and agreement together and setting goals for their sex life (ST). Practical exercises include getting (re)acquainted, taking things further and learning from each other, the aim of which is to improve sexual communication about what works for each other (BT or ST).

'Increasing sex drive' – In stage 4 users learn more about their body and desire (PE). Information is provided about sexual desire, the barriers to sexual desire, and choosing the right way forward (PE). Exercises include exploring the nature and meaning of sexual desire (SI) and who determines when someone's sex drive is too low (SI). Stage 5 contains exercises to work on alone. Information is provided about the physiology of arousal (PE), how negative thoughts can affect desire (PE/CBT), understanding what shapes a person's attitudes towards sex (CBT/SI; see Figures 8 and 9 in Appendix G), tips on things that might help increase sex drive (PE), and communicating with a partner (CBT/ST). Stage 6 contains exercises to work on with a partner (if applicable), which include thinking exercises exploring the link between thoughts and sex (CBT), and practical exercises such as learning to give your own body pleasure (BT).

'Changing sexual behaviour' – In stage 4 users learn more about the problematic behaviour by exploring the situational and emotional triggers of their behaviour, learning how to tackle difficult emotions, and gain a deeper understanding of their behaviour (PE/CBT). Exercises include keeping an online trigger diary (CBT; see Figure 10 in Appendix G) and using fantasy with masturbation (BT). In stage 5 users focus on how the problem leaves them feeling. Questions are designed to evaluate whether the person sees themselves as 'addicted' and the effect this label might have on them in terms of maintaining the difficulties (ST). Thinking exercises involve

assessing how the person feels after engaging in the behaviour, and perceptions of self in relation to the behaviour (CBT).

6.9.5 Final stage: Evaluation of the problem now and feedback on progress

In the final stage of all the programs there is a (re)evaluation of the problem. The users are asked the same questions they were asked at the beginning of the program – regarding how the sexual difficulty interferes with their life and relationships. The user is then given feedback on their progress throughout the program, and in the final section of the program there is a tailored summary of what might happen next (see Figure 11 in Appendix G). This section is designed to encourage the person to reflect on the work they have done and help them determine what to do next (e.g. continue working with the program or seek further help).

6.10 Development process

The STL intervention was built on a pre-existing set of booklets called the Better Sex books. The booklets contained psychoeducation and well known sex therapy techniques. Drs Gurney and Adams wanted to provide a source of accurate and helpful information to as wide an audience as possible, and they believed that a NHS branded website would give people confidence in the information provided. The trust supported the use of NHS branding as this was profile-raising for the trust.

The STL website was developed using an iterative process over a 13 month period (from October 2008 to November 2009; see Figure 6.13). This included a review of relevant literature on the most appropriate theoretical base for the intervention, regular consultation with the web-developers while writing the content, and user involvement on content and site navigation. In consultation with the web-developers, the authors started writing the content using a visual map of how people might proceed through the programs; this and the website changed iteratively as the content was developed.



Figure 6.2: Intervention development timeline

6.11 Development challenges

The authors encountered various challenges during the development process. One of the biggest challenges was translating what happens in face to face therapy onto 7 web programs in a very short period of time (8-13 months). At the time there was little to no empirical work from which to draw on (in reference to IDIs for sexual difficulties). The process involved writing a huge amount of content with minimal time for reflection, testing and redevelopment due to the short time frame set by the funders, and ongoing work commitments.

It also became apparent that developing seven programs simultaneously was overly ambitious. During the process of writing the programs, the authors thought of different ways to do things (e.g. when writing a coordinated management of meaning exercise in the sex drive program, it occurred to the authors to add a similar exercise to some of the other programs), and given the overlap on many of the programs, the authors would then have to edit all the other programs each time a change was made, which was time consuming. If time had allowed, the authors would have written one program at a time, worked out any problems and glitches, before proceeding with another program.

Due to the time limits, there was no apriori thinking about which programs would be more or less difficult to write/translate online. However, as the programs were being written it became apparent that some programs were more formulaic and descriptive, and contained more straightforward and well-established sex therapy techniques (e.g. the erectile difficulties program), and were therefore easier to write. The lack or loss of sex-drive program was much more systemic in its approach and therefore more difficult to translate online (e.g. the questions required the person or couple to challenge their understanding, develop their communication and/or change the meaning of their sexual difficulties, which is much harder to achieve online than prescribing techniques or providing information).

Due to tight time frames, user involvement was not conducted with people with sexual difficulties. However, different sections of the website were user-tested on 20-30 people who were not psychologists, and who knew nothing about sex therapy (from administrators and colleagues, to friends and family). Testing involved asking people about the ease/difficulty of site navigation and whether they understood the content and language of the website. The authors also included a question at the end of each program, asking users for feedback about any aspect of the website, and also whether they would be interested in giving more extensive feedback at a later date. The intention was to build up a group of users with sexual difficulties that might provide feedback on any future changes made to the website.

The authors had initially wanted to include more interactive functions on the website, in the form of moderated noticeboards or forums and blogs. However, this was not possible as there was no funding for the maintenance of these functions.

The authors had also wanted to allow people to use the website as they wished (i.e. 'dip in and out' of any section they chose). However, they felt it was not clinically sound to allow people to skip important sections of the programs (e.g. the deconstructing meaning section in the changing sexual behaviour program) because in order to change behaviour it was seen to be crucial to first consider whether the difficulties were experienced as problematic, or just being labelled as such and it may also be that a person needs to consider their readiness to change (Prochaska & DiClemente, 1983). A further reason, was that the authors wanted to measure change for each user (which necessitated each user completing the same program in the same way). Therefore they made each program a step by step sequential program that only allowed users to proceed in one direction. In line with recent usability studies on IDIs (Andersson,

Estling, Jakobsson, Cuijpers, & Carlbring, 2011) it might be better to highlight the most important sections of the program, but allow users to self-navigate around the site, and implement robust measures of engagement with the site (e.g. the pages that were visited, length of time spent on page, and the extent to which the program was completed).

Initially, the website was to be open-access. The trust's legal team were concerned that the NHS would be liable for any harm done by the website and so they developed a terms and conditions section requiring the website only be used by individuals 16 or over. However, after consultation with the web-developers, who said that it was very difficult to restrict the use of an open access website to a particular age group, the trust's legal team decided to make the website a closed access site.

6.12 Post development usage

The original intention was for the intervention to be open-access, but due to a combination of legal concerns about the site being accessed by under 16 year olds, and the changing political and financial climate, the website was kept for use by patients of the Trust only. One way it was used in the assessment clinic was as a triage and opt-in tool. At the time, the wait time from referral to first appointment was approx. 6 months, and the 'Did not Attend' (DNA) rate for first appointments was high at 43%. The DNA rates could be high due to the long wait times or because it was the referrer's idea (rather than the client's idea) to be referred. Wasted appointments are expensive, and so in an attempt to reduce wait times and DNA rates, people who got to the top of the waiting list were sent a link to the website, and a username and password. After logging on to the website and filling out the assessment section of the program (which only take a few minutes), they were given their clinic appointment date/time. People who did not speak English were not asked to use the intervention (although the intervention could easily be converted into other languages), and people without internet access were given a paper version of the assessment questions. People were invited to complete more of the website if they chose to. An unintended outcome was that a proportion of people found it helped sufficiently that they cancelled their clinic appointment stating they felt they no longer needed professional help – reducing some of the burden on the face to face service. Importantly, the use of the intervention as an opt-in tool dramatically reduced DNA rates from 43% to 5% over the course of a year. This had a significant impact on waiting times, which in-turn enabled more people to access the clinic.

Using the intervention as a triage tool prior to a clinic visit also enabled the psychologists to gather basic client information, which was helpful in terms of getting clients booked into the most appropriate appointment times (e.g. clients with erectile difficulties need to be seen in the mornings as this is the best time to measure testosterone levels); and also made it easier to start the first sessions (by being able to ask more tailored questions).

The intervention is currently available to patients of the local STI/GUM clinics within the Camden and Islington Trust in North London, and due to the long wait list for the face-to-face service, and the limitations of helping patients during short appointment times in sexual health clinics, staff are reportedly happy to be able to offer STL to their patients.

6.13 Considerations for the future development and implementation of STL

If designing the website now, the authors would consult the literature on engagement with IDIs, which has grown substantially in the seven years since STL was first developed, and build in features to maximise engagement (e.g. regular text reminders to do the sex therapy exercises). As a result of the findings from the qualitative evaluation of STL (see Chapter 7) a funding application is in process (Health Technology Assessment Programme). If successful, STL will be redeveloped, incorporating users' experiences, views and feedback gathered in the qualitative study (Chapter 7) in its re-design; and then evaluated in a randomised pilot trial.

Chapter 7
**Users' views and experiences of IDIs for
sexual difficulties: A qualitative study**

7.1 Chapter overview

Introduction

The systematic review in Chapter 4 demonstrated that IDIs can effectively improve outcomes for some people with sexual difficulties; and the secondary analysis of the Nasal 3 data in Chapter 5 demonstrated a high level of unmet need for help and support for sexual difficulties, and a willingness in the British-population to look for help online for a range of sexually related issues. The next step, and the focus of this chapter, is to explore users' views of IDIs for sexual difficulties.

Objective

To explore the thoughts, beliefs, experiences and emotions of people with sexual difficulties that might influence whether IDIs are taken up and engaged with, in such a way that people will find them beneficial.

Method

The study was a prospective qualitative study using semi-structured interviews conducted before ($n = 30$) and after ($n = 22$) participants used the STL intervention. The target population was adults aged 18 or older, who had one or more of the following sexual difficulties: erectile difficulties, a lack or loss of interest in sex, or problematic sexual behaviour (e.g. excessive use of internet pornography or seeking an excessive number of sexual partners). Participants were recruited in sexual health/sexual problems clinics and online. The data was coded and analysed using thematic analysis.

Results

STL was acceptable to most participants as it met many of the users' want and needs with regards to features, design, usability, and perceived outcomes. The findings also indicate that an IDI has real potential to reduce some of the many barriers to accessing help. Users identified various barriers to use and areas for improvement.

Conclusion

Although further work is needed to address barriers to use, if shown to be safe and cost-effective, IDIs could have a valuable place in providing access to help for sexual difficulties, especially in the light of contractions to face-to-face psychosexual services.

7.2 Background

The previous studies in this thesis have demonstrated the effectiveness of IDIs for sexual difficulties across a wide range of difficulties and outcomes (Chapter 3); as well as their potential to reach a large number of people who are distressed about their sexual difficulties but currently not accessing any help (Chapter 5). The next step, and the purpose of the current chapter, is to explore the thoughts, beliefs, experiences, and emotions, of people with sexual difficulties that might influence whether IDIs will be taken up and engaged with in a way that will help people to address their difficulties.

Acceptability is an important factor to consider when implementing new healthcare technologies into routine clinical practice; treatment acceptability impacts uptake, engagement and adherence to the treatment, and will therefore influence the clinical effectiveness of the treatment (Kaltenthaler et al., 2008). For example, if users of an IDI do not feel favourably towards the intervention they are unlikely to sign up to use it; but even if they do sign up to use it, if it seems too difficult, too long, or uninteresting then users are unlikely to engage with it and may even drop out of the treatment program altogether (Kaltenthaler et al., 2008; Kazdin, 1980).

While treatment acceptability is important, if we are to invest in the design and development of IDIs, and implement them as part of sexual health services, we must also develop an understanding of the views and experiences of potential users beyond just acceptability. Users will no doubt conceptualise their difficulties in different ways, and have diverse prior experiences of help-seeking for their difficulties. Consequently, users may have quite different expectations and requirements of an IDI. In order to maximise uptake and engagement, we must be sensitive to the different views and experiences of people with sexual difficulties when designing these interventions.

Overall, not much is known about how users experience IDIs for sexual difficulties. The only study to date in this area was a survey study assessing the acceptability of an online intervention to help men cope with prostate cancer treatment and its side effects, which include sexual function difficulties (Wootten et al., 2014). Interest in participation was high, and men liked the anonymity, convenience and self-help aspects of web-based support. At 69%, the retention rate for the men who completed baseline measures and started the online intervention was comparable or better than in other internet-based interventions for non-cancer populations (Geraghty et al., 2010; Klein, Meyer, Austin, & Kyrios, 2011; Lintvedt et al., 2013). Unfortunately, no data was collected on actual engagement with the intervention (i.e. click-through rates from the

home page or individual page view data). However, user suggestions to maximise engagement included allowing users to choose the topics they wished to focus on, sending weekly emails, and encouraging men to make a commitment to use the intervention for 10 weeks prior to consenting to participate (Wootten et al., 2014).

In other areas of health/mental health, a systematic review of computerized Cognitive Behaviour Therapy (cCBT) for depression measured acceptability using patient recruitment and drop-out rates, reasons for drop outs, and survey items on acceptability and satisfaction (E. Kaltenthaler et al., 2008). No conclusions could be drawn about engagement as very little information about engagement with the interventions was reported in the review. There was considerable variability in the acceptability and satisfaction of cCBT across studies, but the majority of participants found the programs acceptable and/or were satisfied with them. However, these findings should be treated with caution as most studies only provided data for those who completed the study.

Although quantitative studies can tell us about the acceptability of an intervention in terms of uptake of the intervention and drop-out rates, they are limited in how much they can tell us about why people sign up, why they do or do not engage, why they stop using an intervention, and what contextual factors might influence these outcomes (i.e. people's thoughts, beliefs, experiences, and emotions). Qualitative research is 'concerned with the meanings people attach to their experiences of the social world and how they make sense of that world', and as such, is well placed to explore the 'what', 'how' and 'why' questions of health and mental healthcare research (Britten, 2000). Consequently, qualitative assessment of the acceptability of complex interventions is highly recommended (Campbell et al., 2007; Kaltenthaler et al., 2008).

To date no qualitative studies have explored user views of IDIs for people with sexual difficulties. However, these types of studies have been conducted in other areas of health/mental health, including depression, multiple sclerosis, bipolar disorder, and substance use. Across multiple studies, a majority of IDI users reported feeling positively about the presentation, content and usability of the IDIs they used (Gerhards et al., 2011), and were attracted by the accessibility, anonymity and privacy afforded by the IDIs (Darvell, Kavanagh, & Connolly, 2015; Gerhards et al., 2011; Poole, Simpson, & Smith, 2012); although some users valued the privacy, they also felt it contributed to feelings of social isolation (Hind et al., 2010). In most studies, participants made constructive suggestions for improvements.

Across multiple studies, the limitations and barriers to use of IDIs included lack of identification with and/or relevance of the intervention (Darvell et al., 2015; Gerhards et al., 2011); a lack of support to adhere to or help with the program (Darvell et al., 2015; Gerhards et al., 2011; Hind et al., 2010); experiencing symptoms of illness such as low mood (Poole et al., 2012) or fatigue and concentration difficulties (Hind et al., 2010); inadequate computer skills, equipment or access (Gerhards et al., 2011; Montero-Marín et al., 2015); and competing demands on time (Hind et al., 2010). Facilitators for using IDIs included the freedom and anonymity (Gerhards et al., 2011), experiencing improvement through use of the intervention (Gerhards et al., 2011), email reminders (Gerhards et al., 2011), and participating in a scientific study (Gerhards et al., 2011). In terms of perceived outcomes after using an IDI, users reported increased knowledge about their illness or problem (Poole et al., 2012); improved self-awareness (Darvell et al., 2015; Poole et al., 2012); changes in health behaviours (Darvell et al., 2015; Poole et al., 2012); improved mood (Darvell et al., 2015); changes in attitudes towards their illness or problem (Darvell et al., 2015; Poole et al., 2012); improvement in social and intimate relationships (Darvell et al., 2015); and greater understanding and support from others (Poole et al., 2012).

The findings from the aforementioned qualitative studies demonstrate that users generally hold positive views of IDIs that cover a range of health and mental health problems. However, poor engagement remains a key area of concern for digital interventions (Christensen et al., 2009; Darvell et al., 2015; Dunn et al., 2012; Eysenbach, 2005). There are concerns that people are not using interventions as intended (Eysenbach, 2005) or that the interventions do not meet users' needs. Recent qualitative studies show that different aspects of technology and interaction with technology predict greater acceptability and engagement (Kelders et al., 2012), and therefore this area of study warrants further exploration. As far as I am aware, the current study is the first in-depth qualitative interview study to look at user views and experiences of using an IDI for sexual difficulties.

7.2.1 The Intervention: sextherapy.london.nhs.uk

The IDI used in this study was sextherapy.london.nhs.uk (STL), which is described in detail in Chapter 6. STL is a structured, step by step, self-guided software program that provides tailored advice and support for adults with sexual difficulties. The program covers six types of sexual difficulties including erectile difficulties, early ejaculation, sexual pain (i.e., vaginal and anal pain), difficulties with orgasm, lack or loss of interest

in sex, and problematic sexual behaviour (e.g., excessive masturbation to pornography or excessive seeking of sexual partners). The program contains a preliminary assessment tool to determine suitability and potential benefit from the intervention. STL is theory-based (Craig et al., 2008; Medical Research Council, 2000), and uses evidence-based sex therapy and cognitive-behavioural techniques within a systemic framework; these include psycho-education around anatomy and sexual response, cognitive and behavioural techniques, systemic exercises with individuals and their sexual partner(s), and motivational interviewing for people who want to change any sexual behaviour they deem problematic. Cultural and religious sensitivity is kept in mind throughout the website (e.g., participants are always asked to answer questions in accordance with their own sexuality, religion and culture), and no assumptions are made about a person's sexual orientation or the gender of their partner(s).

7.3 Aims and objectives

The aim of the current study was to explore the thoughts, beliefs, experiences and emotions of people with sexual difficulties that might influence whether IDIs are taken up and engaged with, in such a way that will help people to address their difficulties. The specific objectives were as follows:

1. Explore how people conceptualise their sexual difficulties: The way people conceptualise and frame their experiences of having a sexual difficulty has implications for whether people will seek help and whether they will see an IDI as a potentially useful form of help. This information will inform the content and design of IDIs and ensure they fit with the way people view and experience their difficulties.
2. Identify facilitators, barriers and patterns of help-seeking: This information is also key in determining whether people will see IDIs for sexual difficulties as potentially beneficial. Addressing barriers to help-seeking in the design of IDIs for sexual difficulties will help to maximise uptake and continued engagement.
3. Identify what people want and need from sex therapy: Utilising this information in the design of IDIs will help to ensure that users' wants and needs are at the centre of IDI design.
4. Explore people's views and experiences of using an example IDI for sexual difficulties (sextherapylondon): Information about the likes, dislikes, and barriers

to use of an IDI for sexual difficulties are key factors that will influence the uptake and engagement with IDIs in this area.

5. Make practice and policy recommendations based on the findings.

7.4 Methods

7.4.1 Design

The study was a prospective qualitative study using semi-structured interviews conducted before and after participants used the STL intervention.

7.4.2 Why qualitative interviews?

By their nature sexual difficulties are a sensitive topic and therefore I chose to use individual interviews as they enabled detailed investigation of each participant's perspective, and facilitated in-depth understanding of the personal context of the phenomenon under study, in a safe and private environment (Gillman, 2000; Ritchie & Lewis, 2003).

Semi-structured interviews are loosely structured, and contain open-ended questions that define the areas to be explored (Britten, 2000). I used a semi-structured approach in the current study because it allowed me to ask quite specific questions (e.g. What are the barriers to help-seeking?) alongside more open-ended questions (e.g. Can you tell me about your thoughts and experiences of having a sexual difficulty?); and also provided me with the flexibility to pursue related topics that participants found important.

7.4.3 Ethical and Research Governance approval

Ethical approval was obtained from the Camden and Islington National Health Service ethics committee (REC reference number 12/LO/1785) and Research Governance approval was granted by Central and North West London (CNWL) NHS Foundation Trust for the clinics located in Camden and Islington NHS, and the North East London (NEL) NHS Foundation Trust for the clinic in Hackney.

7.4.4 Participants, Setting and Eligibility criteria

The research was carried out with patients attending Psychosexual Clinics and Sexual Health/GUM/HIV clinics in North and East London, and with Facebook users in and outside of London. The target population was adults aged 18 or older (with no upper

age limit), who had one or more of the following sexual difficulties: erectile difficulties (i.e. difficulty gaining and or maintaining an erection), a lack or loss of interest in sex, or problematic sexual behaviour (e.g. excessive use of internet pornography or seeking an excessive number of sexual partners – 'excessive' was defined by the participant not by any external criteria). There were no requirements for eligibility regarding severity or duration of symptoms, or associated distress. The age of sexual consent in the UK is 16 years old, but I decided to exclude under 18 year olds from participating in the study. The rationale for this was twofold: Gaining ethical approval to conduct research with minors, and recruitment via Facebook, is notoriously difficult; and given their potential lack of sexual experience, I did not feel that excluding 16-17 year olds would be detrimental to the study.

As this prospective study was interested in the views of participants both before and after using the STL intervention, participants were all first-time users of an IDI for sexual difficulties. People who were unable to provide informed consent (e.g. due to mental health problems), and people who did not adequately understand verbal or written information in English, or who had special communication needs were excluded from participating in the study.

7.4.5 Sampling strategy

7.4.5.1 Age, gender, ethnicity and sexual identity

I aimed to recruit a diverse sample. To help ensure the sample was varied in these areas I kept a record of the demographic information of each participant. Research participants were diverse in terms of age and ethnicity (see Table 7.1), but as the recruitment process proceeded it became apparent that women were underrepresented in the interviews and gay men were overrepresented. At this point I stopped interviewing gay men, and undertook theoretical sampling to specifically target women because by this point in the data collection/analysis gender identity had become a salient theme.

To achieve diversity in sexual difficulties, help-seeking for sexual difficulties, internet proficiency, and geographical location, I undertook purposive sampling (i.e. I selected groups or categories to study on the basis of their relevance to the research questions):

7.4.5.2 ***Sexual difficulties***

STL includes programs for six different types of sexual difficulties, but due to constraints on time and resources I chose to narrow the focus of this study to three sexual difficulties to allow me to reach data saturation. I decided to focus on erectile difficulties as this is one of the most common sexual difficulties in men (Mitchell et al., 2013); lack or loss of interest in sex as this is common to both men and women (Mitchell et al., 2013); and problematic sexual behaviour, as there is a dearth of research in this area (Bancroft & Vukadinovic, 2004; Fong, 2006; Kaplan & Krueger, 2010; Levine, 2012; Skegg, Nada-Raja, Dickson, & Paul, 2010).

7.4.5.3 ***Help-seeking experience***

I aimed to interview people with different levels of help-seeking experience as I thought this might influence people's perceptions of IDIs for sexual difficulties. I hoped to capture people who reported having a sexual difficulty and: 1. Had received professional help, 2. Had actively sought help, but had not yet received help (e.g. those on waiting lists), 3. Had not sought professional help, and 4. Had not sought help of any sort. I was particularly interested in sampling people who had not received any help (the latter three categories) because, as much as possible, I hoped to capture people's unique views, experiences and conceptualisations of their difficulties. I hoped to achieve this diversity of experience by recruiting from three different sources (for more details see recruitment section below).

7.4.5.4 ***Internet proficiency***

I thought it was important to interview people with varying levels of internet experience and interest as I felt this would influence people's perceptions of IDIs for sexual difficulties. I hoped to achieve this by recruiting from three different sources (for more details see recruitment section below).

7.4.5.5 ***Geographic location***

Service provision for sexual difficulties varies by geographic location, so I aimed to interview people from different parts of the UK as I felt this might influence people's experiences of help-seeking and therefore perceptions of IDIs for sexual difficulties (due to the differences in availability of services). To achieve this I recruited online via Facebook (for more details see recruitment section below).

7.4.6 Recruitment

I recruited participants from three different sources: 1. Psychosexual Clinics: A proportion of the participants were recruited through the North London Sexual Problems Assessment and Treatment Service (SPATS; n = 3). Patients are either referred to SPATS from Sexual and Reproductive Health Clinics or GP services within the Boroughs of Camden and Islington, or self-referred from any Borough. 2. Sexual and Reproductive Health Clinics: A proportion of participants were recruited through Sexual and Reproductive Health Clinics in the London Boroughs of Camden, Islington and Hackney (n = 21). 3. Online via Facebook: A proportion of participants were recruited via online advertisements on Facebook (n = 4).

Posters and leaflets were placed on the wall or on television screens in clinic waiting rooms and leaflets were also handed out to patients during routine clinic appointments by clinic staff. An online version of the leaflet was created and posted on the Facebook pages of users over the age of 18 and within the UK. An information leaflet and consent form (see Appendix G and H) was provided to all potential participants who contacted me about the study; potential participants were then given at least 24 hours to think about the study before I contacted them to discuss participation. All participants were offered £15 per interview as a gesture of thanks for their participation and input. Interviews were conducted in the clinics, in the Research Department of Primary Care and Population Health, University College London (UCL), or by telephone.

Recruitment continued until data saturation had been reached (i.e. until no new themes emerged regarding participants' views/experiences of using IDIs for sexual problems) (Saumure & Given, 2008). Seventy four people initially enquired about the study (via phone or email), of which 30 agreed to participate (see Appendix I for sources of recruitment & reasons for non-participation). All 30 people completed the first interview, and 22 of those returned for the second interview.

7.4.7 Data collection/procedure

Participants were given the option of being interviewed in person, via webcam or by telephone. The majority of interviews were conducted face-to-face (25/30 first interviews and 18/22 second interviews); and the remaining interviews took place by telephone as per participant request. The interviews were all held in a safe location at a safe time (i.e., in a clinic or university office when other staff were present in the department). A named person (usually the e-Health unit or clinic administrator) was

responsible for monitoring my safety during each interview. I contacted the administrator (or a member of the clinic staff) at the beginning and end of each interview.

To ensure each participant knew what they were consenting to, at the start of the first interview I went over the information sheet and consent form again verbally and gave the participant the opportunity to ask any questions. I informed participants that they could choose not to answer a particular question if it made them uncomfortable, and that they could pause or terminate the interview at any time without this decision impacting on their care in any way. I then collected the signed consent form. All participants provided written consent to record the interviews and publish anonymised quotations.

I hoped that the discussion of sexual difficulties would be an informative and empowering experience for participants, but recognised that some participants may have found discussing sexual difficulties embarrassing, uncomfortable or distressing. If a participant became distressed during the course of an interview, which happened with one participant, the interview was paused and the participant given time to recover. After a short period of time, at the participant's request, I re-started the interview.

Given the nature of the interview topic, I foresaw the potential for disclosure of serious mental health difficulties, or possible sexual or physical abuse. In the participant information sheet, and at the start of each interview, I explained that I had a duty of care to contact a member of the participant's care team (or GP in the case of participants recruited online) should they disclose that they intended to harm themselves or others. This did not happen with any participants, but if it had this would have been discussed with the participant first. A list of sexual and physical abuse services and other potentially useful resources was provided to every participant on the information sheets. At the end of the second interviews all participants were given details of how to contact and register with the Sexual Problems Assessment and Treatment Service should they feel they needed further assistance.

The first interviews lasted between 45 and 90 minutes, but most commonly around 60 minutes. The first interviews enabled me to explore participants' experiences of seeking help for a sexual difficulty (prior to seeing the STL website), the perceived barriers and facilitators to seeking help, what they wanted in (content) and from (outcomes) a program of help, and what their initial perceptions were of IDIs for sexual

difficulties. During the first (in-person) interviews I showed the participants the STL website on a tablet computer. The participants interviewed via telephone were given the STL website address and a password, and I verbally directed them to different parts of the website while on the phone. After the first interviews, participants used the STL program alone (or with a partner) for between 6 and 10 weeks, and then were invited to return for a second interview. The second interviews lasted 30-60 minutes, and enabled me to look at and compare views regarding the acceptability, perceived outcomes, barriers to use, and suggested changes to the STL intervention.

The interviews consisted of open questions to allow exploration of users' views. I used a semi-structured topic guide that was developed in consultation with experts in sexual health, sexual difficulties and qualitative research (see Appendices J and K). To test the flow of the topic guide (i.e. regarding the wording and placement of questions/prompts), before starting the data collection, I piloted Interview 1 topic guide on two participants, which led to only minor changes. At the end of the interview, participants filled out a short demographic questionnaire, which included questions about date of birth, post code, gender, ethnicity, religion, sexual orientation, relationship status, level of educational attainment, employment, internet access and previous experience looking for help online. This provided descriptive information about the sample, and allowed me to keep a track of the diversity of the sample as the study progressed (see Appendix L).

The interviews were recorded, and all data were kept confidential and stored in accordance with the data protection act (1998). Electronic copies of personal details were stored in a password protected computer file and paper copies in a locked file cabinet within a locked office. Non-anonymised recordings were held in a secure Data Safe Haven provided by UCL, which is certified to the ISO27001 information security standard, and conforms to the NHS Information Governance Toolkit.

7.4.8 Data analysis

All interviews were transcribed verbatim by a professional transcriber, and then uploaded onto ATLAS.ti software (Version 7) for data management. All transcripts were checked for errors while listening to the original recordings. I coded and analysed the data using a thematic analysis technique (see below). Transcripts were initially coded according to the topic guide categories, and subsequently free-coded thematically. Thematic coding occurred iteratively, whereby I moved back and forth between transcripts, the coded data extracts, the research literature, and the analysis I was

producing. Emergent themes were discussed with other researchers at intervals throughout the coding process, and explored in subsequent interviews. To ensure thoroughness and rigour, one of the transcripts was discussed collectively by a group of researchers in a data clinic. Once all transcripts had been coded, codes were grouped into parent and sub-themes, and both common and divergent themes identified.

7.4.9 Why thematic analysis?

Thematic analysis (TA) involves searching across a dataset to find repeated patterns of meaning (Braun & Clarke, 2006); TA can be used by researchers coming from different theoretical or epistemological positions, and has the capacity to be flexibly applied across a range of theoretical frameworks to produce a rich and detailed account of data (Braun & Clarke, 2006). Using thematic analysis allowed me to use a mixture of inductive and deductive reasoning to generate the analysis. For example, using deductive reasoning I was able to explore whether the barriers to using other types of IDIs (identified in the literature) also applied to IDIs for sexual difficulties. Using inductive reasoning I was able to observe that in an area that is often considered taboo and where many myths abound, providing psychoeducation and a means to explore a person's beliefs and experiences can have differential effects; for some it highlighted that their difficulty was indeed problematic for them, whereas for others it made them realise their 'difficulty' was not actually problematic for them.

7.4.10 Theoretical position

Overall I took a pragmatic mixed-methods approach to the thesis, recognising that all research methods have their limitations, but can complement each other. However, in this qualitative study I took a critical realist perspective (Clark, MacIntyre, & Cruickshank, 2007) because I was interested in analysing the meanings of people's experiences, and the impact the broader social context had on those meanings, while acknowledging the material and other limits of reality (Braun & Clarke, 2006).

This study was designed within a Health Service Research context. In order to produce findings that would be accessible to policy makers and of direct benefit to people with sexual difficulties I made sure the goals and objectives of the research were specific and pragmatic. The main goal was to explore the thoughts, beliefs, experiences and emotions) of people with sexual difficulties that might influence whether IDIs are taken up and engaged with, in such a way that will help people to address their difficulties.

This main goal was achieved through several specific objectives (see aims and objectives section above). I initially took a more descriptive approach to the data, whereby I started identifying themes by coding data content. Later I took a more interpretive approach by exploring latent themes (i.e. theorising about the underlying ideas, assumptions and conceptualisations that are thought to inform the descriptive content of the data (Braun & Clarke, 2006). I thought about the significance of the patterns in the data and their broader meanings and implications within the socio-cultural contexts of the participants (Braun & Clarke, 2006)—all the while trying not to deviate from the original goal and objectives of the research.

Reflective account of the research process

The following methods were used to ensure the rigour of the research:

7.5 Reflexivity

I was reflexive in my approach to the research by critically examining my different roles and identities (i.e., as a PhD student, researcher, psychologist, and gay woman), as well as my own thoughts and experiences of sexual difficulties; and considering how these factors may have influenced the different areas of the research process, including the formulation of research questions, sample choice, recruitment, choice of location, my behaviour during the interview, the participants' impressions and reactions to me, and analytic decisions (Britten, 2000). At each step of the research process I used a diary to reflect on my thoughts, decisions and actions, and considered any implications they might have had on the research.

I believe my psychology training, and experience working in a counselling and support capacity in domestic violence enabled me to quickly develop a rapport with participants and to communicate warmth and empathy in the interview setting. Furthermore, I was raised to be open and comfortable discussing issues of sex and sexuality, and thus I am not easily shocked or surprised by much in this regard, which I also think was helpful in terms of putting participants at ease and facilitating discussion of sensitive topics.

However, these factors appeared to have an unintended impact on some participants. The interview process appeared to facilitate consciousness-raising around their sexual difficulties for many of the participants, and some also reported finding the interview a

therapeutic experience in itself. Participants also reported that contact with me helped to stimulate initial engagement with the intervention, and continued engagement through email contact, which served as a reminder about the intervention (Gerhards et al., 2011). So with this in mind, my role and behaviour can be considered both a strength (as it points to what engagement support might be needed) and a limitation of the study, as it makes it more difficult to know whether the participants would have engaged with the intervention without my presence. I was fully aware that I was conducting research interviews, rather than therapeutic interviews, but many of the skills used are the same (e.g. active listening and demonstrating warmth, empathy etc.), and it is known that participating in qualitative research can be therapeutic (Murray, 2003).

7.6 Reactivity

As a researcher, I tried to remain neutral by avoiding leading questions and refraining from sharing my opinions with the interviewees, while still trying to remain approachable and open. My psychology training in communication skills helped in terms of providing me with strategies that I used to preserve neutrality as much as possible; these included staying focussed on the participants 'story', paying attention to their whole context, trying not to filter or evaluate what they were saying, or get distracted with my own interpretations. If I felt I had information that was potentially useful for the participant (e.g. information about resources and/or services) I would wait until the interview had finished before sharing this information and discussing it with the participant.

7.7 Rigour

To achieve rigour in the research I took a systematic and self-conscious approach to the design, data collection, data analysis, interpretation and writing of the research. At regular stages in the research I consulted with my supervisors, the wider research team, the intervention designers, a user representative and fellow PhD students to ensure a variety of perspectives were taken on the data analysis. Early on in the data collection I held a data clinic with the wider research team and PhD students to discuss one of the anonymised interview transcripts to harness the expertise of the wider team to ensure the rigour of the interview process and analytic decision-making.

7.8 Transparency

Transparency was achieved by maintaining meticulous records of the research process, including outlining theoretical frameworks used, describing the context of the interviews, making a full (anonymised) transcript of the data available for inspection by others, clearly detailing and theoretically justifying the procedures for sampling and data analysis, describing how themes were derived from the transcripts, and providing participant numbers and sources of quotes. Divergent views were actively sought (through prompting if necessary). For example, among the many negative aspects of having a sexual difficulty some participants described positive aspects of their sexual difficulties (e.g. for one woman, vaginismus protected her from undesired sexual encounters and for one man, seeking a large number of sexual partners had enabled him to meet a diverse range of people he would otherwise never have met). Furthermore, some participants expressed views that contradicted those of the other participants (e.g. one participant did not perceive seeking sex with a large number of partners as problematic and some participants did not perceive a lack of interest in sex as problematic).

7.9 Public and Patient Involvement (PPI)

In collaboration with other sexual health colleagues we planned to recruit a panel of user representatives. Initially we contacted Involve (the NIHR PPI advisory group) but none of their members had experience of sexual difficulties. Next we placed recruitment posters in two sexual health clinics and passed leaflets out to potential user representatives via sexual health outreach workers. However, recruiting a panel proved to be more challenging than anticipated. Eventually we were able to recruit one female user representative with experience of sexual difficulties, from one of the sexual health clinics, who looked over all the research materials for this study and made some small suggestions for changes in wording.

7.10 Results

Results are presented thematically. Participants are identified by participant number, gender, age, sexual orientation, and sexual difficulty.

7.10.1 Participant characteristics

Interviews were conducted with 30 participants aged between 22-70 years old.

Demographic characteristics of the sample are outlined in Table 7.1. The median age

of participants at the time of interview was 35.5 years (mean age 37 years), and over two-thirds of the sample (70%; 21/30) were male. The sample were highly educated and most were regular and proficient users of the internet.

Table 7.1. Interview participant demographic characteristics (N = 30).

Characteristics		n (%)
Age	18-24	3 (10%)
	25-34	11 (36.5%)
	35-44	10 (33%)
	45-54	3 (10%)
	55-64	2 (7%)
	65-74	1 (3.5%)
	75+	0
Gender (choice of 3 categories)	Female	9 (30%)
	Male	21 (70%)
	Transgender	0
Relationship status (choice of 3 categories)	Single	15 (50%)
	Married/living with partner	8 (27%)
	In relationship but not living with partner	7 (23%)
Sexual orientation (choice of 4 categories)	Heterosexual	13 (43%)
	Lesbian/Gay	12 (40%)
	Bisexual	3 (10%)
	Other	2 (7%)
Ethnicity (self-defined)	White-British	14 (47%)
	White-Other	7 (23%)
	Black-British	3 (10%)
	Asian	3 (10%)
	Mixed race	3 (10%)
Highest level of educational attainment (choice of 7 categories)	Postgraduate	10 (33%)
	Undergraduate	10 (33%)
	College/6 th form	3 (10%)
	Diploma/vocational qualification	5 (17%)
	Secondary school qualification	1 (3.5%)
	Left school before 16	1 (3.5%)
	Other	0

Characteristics		n (%)	
Employment status (choice of 7 categories)	Working (full or part time)	20 (66.5%)	
	At college or university	7 (23%)	
	In training	0	
	Unemployed	2 (7%)	
	On long term sick	0	
	Retired	1 (3.5%)	
	Other	0	
Recruitment route	STI/HIV clinic	21 (70%)	
	Sexual problems clinic	3 (10%)	
	Online	4 (13%)	
	Passed leaflet by partner/friend	2 (7%)	
Sexual difficulty (1 st four were part of the selection criteria)	Lack or loss of interest in sex	18 (60%)	Men (8); Women (9)
	Erectile difficulties	16 (53%)	Men (16); Women (0)
	Problematic sexual behaviour: frequent masturbation to online pornography (what was considered problematic was defined by the participant)	8 (27%)	Men (8); Women (0)
	Problematic sexual behaviour: seeking a high number of sexual partners (what was considered problematic was defined by the participant)	5 (17%)	Men (5); Women (0)
	Sexual pain (vaginal or ejaculatory)	4 (13%)	Men (1); Women (3)
	Orgasm difficulties	2 (7%)	Men (0); Women (2)
	Delayed ejaculation	2 (7%)	Men (2); Women (0)
	Early ejaculation	1 (3%)	Men (1); Women (0)
	Number of participants reporting >1 sexual difficulty	18 (60%)	
Internet access at home	Yes	30 (100%)	
	No	0 (0%)	
Internet access on mobile phone	Yes	25 (83%)	
	No	5 (17%)	

Characteristics		n (%)
Looked for help for sexual difficulties online	Yes	24 (80%)
	No	6 (20%)

The main themes, subthemes etc. in the dataset can be seen in Table 7.2.

Table 7.2: Main themes and sub-themes in the dataset

Level 1	Level 2	Level 3
Participants' conceptualisation of their sexual difficulties	Perceived causality/ maintaining factors	Relationship difficulties
		Fatigue
		Physical Illness
		Mental health (e.g. depression and anxiety)
		Medication
		Aging
		Shame about sexual identity
		Childhood sexual abuse
		Strict religious upbringing
		Internet 'addiction'
		Other sexual difficulties (e.g. pain causing lack or loss of interest in sex)
	Importance of context	Relationship
		Family
		Social
		Cultural
	Difficulty not always perceived as problematic	Problematic
		Problematic in the context of a relationship
		Not problematic
		Unsure
	Psychological vs physical understanding	Psychological
Physical		
Both		
Legitimacy (difficulty 'worthy' of seeking professional help or not)	n/a	
Impact of sexual difficulties	On emotional wellbeing	Shame/embarrassment
		Feeling 'abnormal'
		Lonely/isolated
		Feelings of inadequacy
		Frustration/disappointment
		Worry/distress
		Anxiety/depression
		Performance anxiety
		Fear

Level 1	Level 2	Level 3
		Loss
	On cognitions	Sexual objectification (of others/sexual partners)
		Sexual expectations (of sexual partners)
		Loss of motivation (in other areas of life)
		Identity (masculinity, femininity, gay male identity etc.)
		Low self-esteem
		Low sexual self-confidence
		Confusion (difficulty determining whether sexual difficulties were problematic or not)
	On behaviour	Lack of honesty
		Avoidance of sex
		Reluctantly engaging in sex
		Managing partner anxiety
		Escalation patterns (in frequency & intensity of problematic sexual behaviour)
		Avoidance of new relationships
		Inability to discuss difficulty with friends
	Perceived link to other sexual difficulties	Excessive masturbation to online pornography → erectile difficulties/delayed ejaculation
		Erectile difficulties → loss of interest in sex
		Lack of interest in sex → erectile difficulties
		Sexual pain → loss of interest in sex
	Barriers to help-seeking	Emotions
Embarrassment		
Fear		
Cognitions		Perceptions of whether the difficulty is a 'medical problem' or not <ul style="list-style-type: none"> • Not seen as a medical problem • Difficulty not seen as problematic • Thought it would pass • Thought it was a natural part of ageing • Unsure if it was problematic and warranted seeking help • Incapable of being helped • GPs not appropriate place to seek help
		Resignation
		Not ready
		Denial
		Stigma

Level 1	Level 2	Level 3
	Behaviours	Avoidance of professional help (by purchasing medication online)
	Perceived problems accessing help via general practice	Lack of relationship with GP
		No fixed GP
		GP opposite gender to self
		Dislike GP
		Concerns about anonymity
		Fear of not being understood by GP (due to nature of difficulty or sexual identity)
		Appointment times too short
		Dissatisfied with previous help from GP
		GPs not seen as an appropriate source of help for a sexual difficulty
	Perceived problems accessing help via existing specialist services	Lack (or perceived lack) of local services
		Lack of knowledge about what is available and where
		Belief that current help is inadequate
		Potential costs involved
		Lack of clear, consistent and trustworthy information and support online
Facilitators of help-seeking	Online help sources	Web-based self-help
		Online decision-making programs
	Anonymous help sources	n/a
	Trustworthy help sources	n/a
	Advertising of available help sources	n/a
Healthcare professionals to be more proactive about discussing sex and sexual difficulties	n/a	

Level 1	Level 2	Level 3
Wants in a program of help (content)	Content	Case studies (normalising their experiences)
		Reassurance (of being within 'normal' range)
		Normalising/de-stigmatising information
		Advice, tips and strategies
		Indicator of credibility and trustworthiness
		Human support (professional or peer)
		Signposting (to external resources and services)
	Design and features	Private and confidential
		Structured program
		Interactive features (e.g. online diary, exploration of the difficulty, goal setting/monitoring, partner exercises)
		Use of different types of multi-media
		Tailoring (i.e. adapted to be personally relevant to the user)
	Usability	Simple layout
Easy to use		
Wants from a program of help (desired outcomes)	Physical outcomes	Ability to gain and/or maintain an erection
		Ability to ejaculate within an 'acceptable' time frame (not early or delayed)
		Ability to engage in intercourse (without pain or vagina 'closing up')
		Ability to reach orgasm
	Cognitive outcomes	Greater acceptance of the difficulty
		Change in attitudes/thought relating to the difficulty
		Increased knowledge and understanding of the difficulty
		Clarification as to whether the difficulty is problematic or not (and warrants seeking help)
		Knowledge of where to seek further help
		Increased sexual self-confidence and enjoyment of sex
		Gain or regain interest in sex
	Emotional outcomes	Reduced feelings of embarrassment and shame
		Reduced feelings of worry and anxiety
	Behavioural outcomes	Increased control over the behaviour (regarding frequency of masturbating to online pornography or number/frequency of sexual partners sought)
		Greater ability to relax during sex
		Greater ability to talk about the difficulty

Level 1	Level 2	Level 3
		Gain practical skills to deal with the difficulty effectively
First impressions (before using STL)	Positive feedback	Program perceived as reputable
		Visually appealing
		Simple and organised layout
		Liked that program was broken into stages
		Interesting and relevant content
		Comprehensive and practical
		Accessible and gender neutral language
		Self-paced and tailored to the individual
		Privacy/anonymity particularly appealing
	Negative feedback	URL not very discreet
		Lacked imagery
		Too much content
		Too much text
		Language too medicalised
		Lack of human contact
		Concerns about the program maintaining the interest of users

The following themes arose in the second interviews, after participants had used the STL intervention for 6-10 weeks.

Positive feedback (after using the STL intervention)	Content & design	Informative & comprehensive
		Liked the practical exercises
		Identified with the case study examples (found them normalising)
		Found the website relevant
		Liked the privacy/confidentiality of the program
	Usability	Easy and intuitive to use
		Easy to navigate around the website
		Liked the clear and simple layout of the website
		Like tone of language (not too medical or technical)
	User experience	Website exceeded expectations (after initial scepticism of perceived benefit)
		Found it enjoyable
		Felt more hopeful and empowered

		Liked the convenience and accessibility of the website
		Programs were helpful and thought provoking
		Liked that program encouraged/facilitated communication with partners
Negative feedback (after using the STL intervention)	Content & design	Lacked information on the inter-relationship between the emotional and physical aspects of sexual difficulties
		Information on the biology and physiology of sexual difficulties was too basic
		Slider tool to evaluate change was not sensitive enough
		url not discreet enough (sextherapylondon.nhs.uk)
		Program too long
		Program not interactive or tailored enough
	Usability	Disliked the fixed, linear direction of the program
		Disliked being unable go back and edit responses
		Language too clinical
		Too much text
		Text too small
	User experience	Program seemed like a lot of hard work
		Program practical but not much fun
		Program was factual, but a bit 'cold and disconnected'
		Too much focus on cause and not enough on solutions
		Disliked the lack of human support
		Anonymity increased the hidden nature and shame surrounding the difficulty
	Perceived changes/outcomes (after using the STL intervention)	Cognitive changes
Greater understanding of partner's perspective		
Greater acceptance of self and the difficulty		
Increased confidence (sexual confidence, confidence to manage the difficulty, and confidence to seek further help)		
Increased motivation (to work on change or seek further help)		
Difficulty perceived as less of a problem than before (increased clarity & reassurance)		
Difficulty now recognised as a definite problem (increased clarity & confirmation)		
Increased knowledge of available help and where		

		to find it
		More relaxed having sex
		Enjoying sex more/more satisfied with sex life
	Emotional changes	More optimistic and hopeful about the difficulty
		Less embarrassed and ashamed
		Less alone with the difficulty
	Behavioural changes	Gained practical skills to deal with difficulty more effectively
		Increased communication with partner
		Changes in partner's behaviour (e.g. partner more supportive or more physically affectionate)
	Physical changes	Fewer or no erectile difficulties
		Stronger erections
Barriers to use	Intrinsic or person-related factors	Feeling tired
		Low in mood
		Lack of motivation
		Forgetting about the intervention
		Having a preference for face to face therapy
		Feeling stressed
	Extrinsic or contextual factors	Lack of time
		External stressors
		Partner resistance or unable to discuss program with partner
		Lack of accountability (relating to no human support for engagement)
		Lost login details
	Program factors	Program not a good fit (e.g. no program for painful ejaculation)
		Program not discreet enough to use in public places
		Mode of delivery unacceptable (e.g. some people did not want to spend time on the computer after working at a computer all day)
	Suggested modifications (to the website)	Content & design
Include more solution focussed tips and suggestions		
Include more comprehensive definitions and descriptions		
Expand website to become a 'one stop shop' sexual health portal		
Include facility to purchase safe medication (i.e. Viagra, Cialis etc.)		

		Add links to further help/resources
		Add videos (of real people talking about their difficulties)
		Add quick exit button
		Change url to something more discreet
		Add percentage progress bar to each page
		Add facility to chat with other people with sexual difficulties
	Usability	Add tool to help users choose the most appropriate program
		Include guidance (on how to use, time to allow, why certain sections are important etc.)
		Increase interactivity (e.g. include more reflective questions)
		At log in allow people to start from the beginning or resume where they finished last
		Ensure website is set up for multiple devices
		Make the language less formal
		Enable users to navigate anywhere in the program
		Enable one password for all programs
Add function to change or retrieve password if lost		

7.10.2 Conceptualising sexual difficulties

7.10.2.1 *Perceived causality/maintaining factors*

How people conceptualise their difficulties, in terms of the factors they think may have caused and/or maintained them has implications for the uptake of an IDI, users' views of the appropriateness of program content, and treatment aims within a program.

Perceived causality/maintaining factors appeared to differ according to sexual difficulty.

Lack or loss of interest in sex (n=18)

All but one participant made a causal attribution about their lack of interest in sex. For some, the lack or loss of interest in sex was thought to stem from relationship difficulties (i.e. discord or feeling like they had become 'more friends than lovers' with their partner. For others, a lack of interest was thought to be due to stress, fatigue, illness (liver cancer, HIV and hepatitis C) or medication (for depression, hepatitis C and chemotherapy). One woman linked her lack of interest to childhood sexual abuse, and

one woman to her strict religious upbringing in which she was taught that sex was 'wrong' and 'dirty'.

Erectile Difficulties (n=16)

Many of the men reporting erectile difficulties pointed to physical factors that may have caused or contributed to their difficulties (including age, illness, fatigue, medication and other sexual difficulties). However, upon probing further, it appeared that in all but one case, the erectile difficulties only occurred in the presence of a sexual partner (and not when masturbating alone), which suggests that in the majority of the sample the difficulties were psychogenic rather than physical. Some men did associate their difficulties with relationship problems and one man linked his difficulties to shame about his sexual identity.

Problematic sexual behaviour (n=13)

Two participants reporting problematic sexual behaviour were gay and in open relationships, and they both linked their problematic sexual behaviour (seeking a large number of sexual partners) to relationship difficulties. For both men, prior to the relationship difficulties their behaviour had not felt problematic, but with a loss of intimacy in the primary relationship it was now perceived as problematic. Other participants linked their problematic behaviour (excessive masturbation to pornography and seeking a large number of sexual partners) to feeling lonely and wanting a relationship, but being unable to find one. And one participant felt his excessive use of internet pornography was linked to an 'addiction' to the internet more broadly. Many (but not all) participants said that they no longer enjoyed the behaviours they were engaging in but felt that their behaviour was out of their control (as evidenced by the frequent use of words such as 'addiction' and/or 'compulsion' when describing the behaviour).

7.10.2.2 **Comorbidity**

Research suggests that sexual difficulties are frequently comorbid with other sexual difficulties and also mental health problems such as depression and anxiety, and this was evident in this sample. Participants linked erectile difficulties and sexual pain with a corresponding loss of interest in sex; a lack of interest in sex to erectile difficulties or sexual pain (e.g. pain during vaginal penetration, pain due to psoriasis, or painful ejaculation); and excessive masturbation using internet pornography to subsequent erectile difficulties or delayed ejaculation. When probed further about the link between

excessive masturbation to internet pornography and erectile difficulties, participants spoke about not being able to get turned on by 'real people' and needing to generate pornographic images in their minds in order to gain an erection and/or ejaculate with a sexual partner. A large number of the participants reporting problematic behaviours also mentioned depression in their personal histories, but only a few men connected depression directly to their behaviour.

7.10.2.3 *Importance of context*

The role of contextual factors in people's conceptualisations of their difficulties was quite apparent as most of the causal and maintaining factors people spoke of lay outside the individual – supporting the idea that sexual difficulties do not occur in a vacuum as the DSM has long suggested (American Psychiatric Association, 2013). Sexual difficulties were most often discussed in the context of intimate relationships, with partners' attitudes and behaviours often influencing their own perceptions, and the extent to which the difficulties were perceived as problematic. The influence of family was raised by several participants, with parenting styles seemingly influencing people's level of comfort discussing and expressing their sexuality (e.g. strict parenting or religious views). More broadly, participants spoke about societal expectations surrounding sex and sexuality, and how this impacted on the way they viewed themselves and their difficulties (i.e. expectations about the frequency and nature of sex). Religion was mentioned by one woman, in the context of feeling shame around sex and holding beliefs that sex was dirty and wrong, which led to a lack of interest in sex. Cultural expectations were also implicated in the cause and maintenance of sexual difficulties. As an example of the complex interweaving of interpersonal, social and cultural factors, one Asian Muslim woman spoke about the factors that precipitated and maintained her lack of interest in sex. The woman was newly married, with a young baby, currently living with her husband's parents (limiting privacy), and her husband had recently become unemployed. The woman spoke of cultural expectations of her as a wife, and the sexual expectations of her from her husband (influenced by his pornography viewing habits), and being exhausted from looking after their baby, and how all these factors combined to make her feel quite stressed and low, and not interested in sex. This example illustrates the complexities of sexual difficulties, and highlights the intersectionality of concepts such as gender and culture in this area.

7.10.2.4 *Difficulties are not always perceived as problematic and distressing*

Lack or loss of interest in sex (n=18)

For some participants, their lack or loss of interest in sex was either not problematic at all, or only problematic in the context of an intimate relationship. For those that were distressed by their lack or loss of sexual interest, it was often due to the impact it had on their intimate relationship or because it prevented them from pursuing intimate relationships.

Erectile difficulties (n=16)

Erectile difficulties presented a clearer picture, in that erectile difficulties were perceived as problematic for all but one man who was in his 70s and recovering from chemotherapy for liver cancer. Erectile difficulties were often perceived as a threat to masculine identity, and which appeared to exacerbate the magnitude of the difficulties by heightening feelings of shame.

'Problematic' sexual behaviours (n=13)

When considering behaviours such as frequent masturbation to internet pornography and seeking a high number of sexual partners, the extent to which people found their behaviour problematic depended partly on contextual factors. One participant said that he only felt his behaviour was problematic in the context of the value system he was raised with and in the face of opinions of friends, and that it was for these reasons that it caused him distress (rather than the nature of the behaviour itself). He then went on to discuss positive aspects his behaviour, and how the pursuit of many sexual partners had allowed him to meet men from all walks of life, and who were not part of his 'prescriptive class-based world'.

Another participant said that the extent to which he saw his behaviour as problematic depended on his mood. If he was feeling happy about his life then he did not see it as problematic, but if he was feeling low then he did. Again, this illustrates the complexities of human sexual behaviour and the importance of considering context and people's own perceptions of their difficulties, when thinking about 'treatment' of sexual difficulties. For both types of 'problematic' behaviours (seeking a high number of sexual partners and frequent masturbating to internet pornography), it was often the frequency of the behaviour and/or the 'compulsive' nature of the behaviour, rather than the behaviour itself, that most men found problematic.

Sexual pain (n=4)

Although the study did not specifically recruit participants with sexual pain, four participants (3 women and 1 man) spoke about experiencing pain during sex (in addition to other sexual difficulties), and all found this experience problematic and distressing. All had previously sought professional help with no success. However, one of these women also spoke positively about her difficulties in that she felt the 'closing up' of her vagina protected her from having intercourse when she did not really want it or was not ready for it.

While most people could describe their sexual difficulties, some people were confused or unclear as to whether what they were experiencing was problematic or not. When probed further, this appeared to be because they were unable to determine whether their experiences (i.e. their emotions, cognitions, behaviours etc.) were 'normal' or 'abnormal' in reference to the experiences of others. The stigma associated with openly acknowledging and discussing sexual difficulties means that it is difficult for people to accurately gauge how they feel about what is happening to them and what to do about it.

7.10.2.5 ***Psychological and physical understanding – a search for legitimacy***

People often described (or desired to find) physical reasons for their difficulties, as there was a sense that this somehow legitimised them. The influence of the medical model, and its view of the body as 'a machine that can be fixed' (Bellamy et al., 2013; Tiefer, 1995) could be seen in the way many participants described their difficulties.

I don't think it's a sexual problem, I think it's more, erm...Ok, I don't think I have a biological problem, I think I would call it a psychological problem that happens to affect my sex life. I know if I had a medical problem I would talk to him [partner] about it. We would discuss it and I would be open with him and say, "I need this".

P001, Bisexual Male, 29 years, Erectile Difficulties.

Difficulties that were seen to stem from emotional/psychological factors were often seen as less legitimate than those that had physical roots.

So basically we still need surgeons, we need heart doctors, we need nurses, we need midwives, but the idea of having, let's say, dedicated centres where people could ring up anonymously and talk about their

sexual problems, we don't have that. And there's no way the government would fund that because it's not surgical. It's more emotional and wellbeing.

P019, Heterosexual Female, 41 years, Loss of interest in sex.

The extent to which a person can hypothesise about the psychological vs physical nature of their difficulties depends somewhat on the type of sexual difficulty (i.e. those with an obvious physical manifestation, such as erectile difficulties or pain, versus those with an absence of a physiological element, such as a lack of interest in sex or problematic sexual behaviour). Consequently, most people (though not all) who reported a lack or loss of interest in sex OR a problematic sexual behaviour conceptualised this as an emotional or psychological difficulty.

I think it's very, very psychological for me. It's a lot about my upbringing, my family values, which have always been that one shouldn't have sex before getting married.

P027, Heterosexual Female, 26 years, Lack of interest in sex.

Many of the men with erectile difficulties initially talked about possible pathological causes of their difficulties. But during discussion in interviews, most men acknowledged their difficulties generally occurred when they were with a sexual partner (and not while masturbating alone), and so most conceptualised their erectile difficulties as being emotional/psychological difficulties that manifested as a physical difficulty.

I just thought there's something wrong here, this is not physical. I know it's not physical because I wake up in the morning with an erection.

P012, Gay Male, 46 years, Problematic seeking of sexual partners and Erectile Difficulties.

Of the participants who reported sexual pain, two (a man and a woman) were in long term relationships and reported no difficulties in the relationships other than the sexual difficulties. For these two participants the pain had started in adulthood, sometime during their current relationships. These participants conceptualised their difficulties as physical difficulties. Conversely, the other two participants were not in long term relationships, and reported experiencing sexual pain or discomfort since their early teenage years. One of these women conceptualised her difficulties as primarily psychological but with a physical manifestation (i.e. pain). The other woman, who had

sought help repeatedly over many years struggled to conceptualise her difficulties as psychological, and still felt there was physically something wrong with her (despite being told otherwise by medical professionals).

It appears that the partner's conceptualisation of the difficulties (i.e. problematic or not), has implications for whether help will be sought, and if so, what help might be useful.

7.10.3 The impact of sexual difficulties

Participants discussed a wide range of ways in which their sexual difficulties impacted upon their lives, and these fell into four areas: emotional wellbeing, cognitions, behaviours and further sexual difficulties (see Table 7.2). Gaining an understanding of the ways in which sexual difficulties can impact people's lives is important because many of these areas represent targets for change in IDIs. While the primary outcome of interest in most studies of IDIs for sexual difficulties is improvement in sexual function, other changes, such as changes in a person's perceptions about their difficulties or their emotional reactions to them are important aims of sex therapy.

7.10.3.1 *Emotional wellbeing*

Participants spoke of a whole spectrum of negative emotions associated with having a sexual difficulty. Some of the most prevalent emotions were feelings of **embarrassment** and **shame**; and concerns about feeling '**abnormal**', **lonely** and **isolated**.

Yeah, because I'm aware that it's not normal [to have a lack of interest in sex], like stereotypically normal. I worry that I'm doing something wrong or there's something wrong with me, or something isn't working.

P013, Bisexual Female, 22 years, Lack of Interest in Sex.

Participants also spoke of feeling **inadequate**, **frustrated**, **disappointed**, **worried**, **distressed**, **anxious** and **depressed** in relation to their difficulties.

Well when it happens, you feel really small, you feel insufficient, you feel, I don't know, not very manly. I suppose that's the word...I can't really put it into words...there's got to be a more articulate way of putting it, but you don't feel very masculine. You feel quite insufficient.

P017, Heterosexual Male, 29 years, Erectile Difficulties and Loss of Interest in Sex.

However, not all participants felt distressed about their difficulties, which supports the notion that it is the meaning people ascribe to their sexual difficulties, not the difficulties themselves, that lead people to view their difficulties as problematic and/or distressing (Adams, 2006).

So I come to you really in a rather false way because it's not a big problem for me...I'm quite a happy person and I've got lots of interests. So where sex used to be an exciting and valuable part of my life, it no longer is...But as I said, if I hadn't seen the leaflet [about the study] I may not ever have done anything about it. I may just have let it go on the way it is because I can't emphasise enough, it's not that big a deal in my life.

P007, Gay Male, 70, Loss of Interest in Sex and Erectile Difficulties

Performance anxiety was another prevalent emotion. Several women described feeling anxious about whether sex was going to be painful or in anticipation that they would not be able to orgasm during sex.

Various men with erectile difficulties described a vicious cycle of anxiety whereby the anticipated fear of not being able to get or maintain an erection (or ejaculate) exacerbated the existing erectile difficulties (or difficulties with ejaculation).

I suppose it kind of puts me off meeting new people, starting new relationships because it's just quite a stressful period of time; like I always say to myself, it's fine, I can do it. But then when it comes down to it I kind of freak out about it and it's just always on my mind and thinking about it, and then problems arise.

P008, Heterosexual Male, 31 years, Erectile difficulties and Loss of Interest in Sex.

And then it's kind of developed quite quickly into a pattern where now I feel quite apprehensive about putting myself into certain situations because I don't want the risk of not being able to perform.

P015, Gay Male, 43 years, Erectile difficulties and Loss of Interest in Sex.

Performance anxiety occurs when a person becomes overly focussed on their need to perform rather than on their own pleasure and satisfaction, and is considered a major contributor to the maintenance of sexual difficulties (McCabe, 2005). Performance anxiety is thought to be associated with 'willing' an erection (or ejaculation, orgasm etc.) to happen, rather than allowing it to occur 'naturally' in response to sexual enjoyment and pleasure (McCabe, 2005). This 'willing' was clearly experienced by one participant:

It's just this real desire to climax...It's almost you want to force the issue but you know it doesn't work like that. My mind is racing thinking of 101 ways to make myself climax and it just doesn't work. It just gets me into a bit of a state of anxiety really.

P026, Heterosexual Male, 39 years, Problematic use of Internet Pornography and Delayed ejaculation.

Other emotions participants spoke of were **fear** and **loss**. Fear of disappointing or not satisfying a partner, fear of rejection or relationship breakdown if a couple broke their silence and talked about their sex life and fear of getting into a new relationship because of their difficulties (Sutherland, 2012); and **loss** of passion and/or a previously satisfying sex life.

7.10.3.2 **Impact on cognitions**

Sexual difficulties also had an impact on people's thoughts and perceptions. In connection to problematic use of online pornography, some men (both gay and straight) spoke of how they felt they **objectified** or **sexualised other people** in ways they were not entirely comfortable with.

I don't like the way it makes me look at and think about women that I meet...I feel like it makes it much more easy to objectify women in a kind of like, she's very pretty or sexy or attractive, and she's not...and so there's both the aspect of not really having any curiosity of who they are as people; real people become almost as flat as the pictures on the screen in some way, if that makes sense.

P004: Heterosexual Male, 37, Problematic use of Internet Pornography.

Does it make me kind of sexualise people, and when I get into an intimate situation, do I revert to a porn-type behaviour? Is the kind of

interactions I have with people classically more porn-like rather than loving and intimate?

P010: Gay Male, 46 years, Erectile Difficulties and Problematic use of Internet Pornography.

Some of the men that were concerned about their internet pornography use spoke of how the type of pornography they watched informed the **sexual expectations** they had of their sexual partners in ways they were not necessarily comfortable with.

And I'm a little concerned about having used a lot of porn now, and then needing things to kind of be or look or happen in a particular way within a sexual scenario to kind of then be able to be excited about it. So I've been aware that at times, especially when I'm with someone I'm wanting to get into a relationship with, I want the sex to be about that person, not about me imposing some fantasy that I've seen in a video onto the situation. So I don't like that kind of disconnect that it brings to sex.

P016: Gay Male, 26 years, Problematic use of Internet Pornography and Erectile Difficulties.

I mean, you sort of get an image of porn stars and how they behave, and it's almost like I sort of want my partner to be a bit like a porn star I suppose.

P026: Heterosexual Male, 39 years, Problematic use of Internet Pornography.

When speaking about problematic sexual behaviours (i.e. problematic use of pornography or seeking a high number of sexual partners) some men felt that this had led to a **loss of motivation** in other areas of their lives (e.g. at work, pursuing relationships, friendships and other interests).

It affects my life because I get the lack of desire to do things.

P006: Gay Male, 40 years, Problematic seeking of sexual partners.

One of the things that I recognise that I did was I spent time on the internet, and particularly I would spend time looking at pictures and/or masturbating, rather than getting out of the house and going to work.

P004: Heterosexual Male, 37, Problematic use of Internet Pornography.

Sexual difficulties impacted on people's sense of **identity** in different ways. A common response from men with erectile difficulties was that they felt emasculated; that being unable to get and/or maintain an erection, and 'perform' sexually, was central to their identity as a man. This was true for both gay and straight men, and present even for men who felt they did not fit or subscribe to the 'masculine ideal'.

I noticed in myself that it's kind of some sort of loss of self-esteem when I think, and some ideas of...I don't have those ideas very strong, but there are those ideas, especially in my country of origin, of being a man...So I kind of can intellectually fight those ideas, but somehow they're very deeply embodied and I realise that they sometimes manifest as just [me] being upset.

P018, Heterosexual Male, 24 years, Erectile Difficulties, Early Ejaculation, Loss of Interest in Sex, and Problematic use of Internet Pornography

I guess you feel as a man that that's an essential part of what a man is. I've never felt particularly masculine or whatever anyway, but I've kind of always had this strong sexual desire and I've kind of, in a way, I think made up for it by being quite virile. So it's kind of like the last straw for me a bit, and that's now been taken away.

P015, Gay Male, 43 years, Erectile difficulties and Loss of Interest in Sex.

For some gay men, experiencing sexual difficulties made them feel that they could not live up to the image of the 'highly sexual gay man', or that their erectile difficulties had shaped their gay sexual identity as a receptive partner. **Low self-esteem** and a **lack of sexual self-confidence** were also frequently reported by participants.

7.10.3.3 **Behavioural impact**

Sexual difficulties had an impact on people's behaviour (both within and external to their relationships). There was a notable **lack of honesty** in some relationships whereby some participants kept information relating to their sexual difficulties from their partners (i.e. about taking Viagra, their struggles with internet pornography, or that they were not really interested in having sex with their partner).

When asked about the impact of having a sexual difficulty, participants spoke about how they either **avoided sex** (more men than women) or **reluctantly engaged in sex** despite not wanting to (more women than men). In some instances, avoidance of sex

was connected to sex being painful in some way (e.g. vaginal pain, pain on ejaculation, or genital psoriasis), and in others it was related to experiencing a lack or loss of interest in sex.

So I think what's happened is, because it's painful, I avoid it...Basically we've not had sex for the last 2½ years.

P025, Heterosexual Male, 57 years, Loss of Interest in Sex.

Continuing to have sex with a partner, despite having a lack of interest in sex tended to be acceptable to the person with the lack of interest if there were no problems with the relationship, but if there were problems with the relationship or a lack of attraction towards the partner then the choice to continue to have sex was not a willing or positive one.

I get it over and done with! (slight laugh)...I do what all women do, I fake it...It's like we're still stuck in the seventies, still faking it. God, nothing's changed!

P019: Heterosexual Female, 41 years, Loss of Interest in Sex.

I think because it got to the point where it nearly kind of tore us apart, so I think I just got it fixed in my head, look, I'm just going to have to pretend to enjoy it and just do it...So I'm just sort of forcing myself to like it, and it's more that I've just got to do it; not so much that I want to.

P023, Heterosexual Female, 26 years, Lack of Interest in Sex.

Intercourse is often taken for granted to be part of an intimate relationship (Hinchliff, Gott, & Wylie, 2009), and most women (but not men) with a lack or loss of interest in sex felt obligated have sexual intercourse with their partner even though they did not want to (Sutherland, 2012).

Another theme that emerged was the concept of **managing partner anxiety**. Some women and gay men seemed to actively attempt to manage their partner's anxiety surrounding their sexual difficulty (287). For example, one woman was not particularly concerned about her lack of orgasms, but felt she has to boost her partner's confidence so that he did not feel sexually inadequate (p023, p027).

Several men who had felt their use of internet pornography was problematic described being caught in a **pattern of escalation**, such that they needed to look at pornography that was increasingly more explicit in order to get an erection and/or ejaculate.

There's a lot of hard-core pornography which is really awful, and I don't like it, but I recognise that there is this kind of cycle which is very easy to fall into of always looking for something that's just a bit more edgy.

P004: Heterosexual Male, 37, Problematic use of Internet Pornography.

Mmn, it's interesting because I've been looking at quite a bit of this research that's been coming out recently about pornography addiction and kind of the escalation that that can have. And being aware that I'm somewhat down that road and just wanting to go down a different road!

P016: Gay Male, 26 years, Problematic use of Internet Pornography and Erectile Difficulties

And having a sexual difficulty not only impacted on people's behaviours in existing relationships, but in some cases it led to **avoidance of pursuing new relationships**.

I suppose it kind of puts me off meeting new people, starting new relationships because it's just quite a stressful period of time, like I always say to myself, it's fine, I can do it. But then when it comes down to it, I kind of freak out about it and it's just always on my mind and thinking about it, and then problems arise.

P008: Heterosexual Male, 31 years, Erectile Difficulties and Loss of Interest in Sex.

For some participants, having a sexual difficulty also impacted negatively on their **friendships**, through stigma, teasing, and feeling unable to share certain information with their friends. However, it appears that being in a **happy and stable relationship**, where partners are able to discuss their difficulties, can act as a buffer against some of the negative impact of sexual difficulties.

7.10.4 Help-seeking for sexual difficulties

The extent to which people seek help, and the reasons why people do not seek help has implications for the uptake of IDIs. Approximately half of the participants in the

study had sought some sort of professional help for their difficulties (usually from their GP), but almost all participants reported wanting some sort of help. Overall, the attempts at to seek help were largely unsuccessful. The majority of people who had sought professional help were men with erectile difficulties (most of whom were not satisfied with the help they received) and people experiencing some sort of sexual pain (none of whom had found anything particularly helpful). A few participants had recently sought help for seeking sex with an excessive number of partners, but it was too early to tell whether they found it helpful or not. Interestingly, the one person who did try to seek help for his problematic use of internet pornography in a sexual health clinic was turned away and told that they only deal with problematic sexual behaviour that is in some way risky (i.e. frequently engaging in unsafe sex). All but one of the participants with a lack or loss of interest in sex or problematic use of internet pornography had not sought any professional help for their difficulties, despite wanting help. Approximately two thirds of the sample had looked for help online, but only a minority had found it helpful to look online. Taken together, these findings highlight a need for alternative help-sources, and suggest that people are interested in obtaining help online.

7.10.4.1 *Barriers to help-seeking*

Emotions

One of the most common barriers to help-seeking (and a theme that was prevalent throughout the interviews), was the **stigma** and **embarrassment** associated with having a sexual difficulty. Participants talked about how **shame** prevented them from talking about sexual difficulties to friends, family, health-care professionals and partners. Several participants referenced the contradiction between an increasingly sexualised media and the continued repressive attitudes within many cultures when it comes to talking about sex. Another barrier was feeling **fearful** of seeking help, due to uncertainties of the implications (e.g. discovering that there is something wrong with them or their relationship, and what the long term implications of this might be).

Perceptions of whether the difficulty constituted a legitimate 'medical problem' or not

While some participants explicitly stated that they did not seek help because they did not see their difficulty as a medical issue, other people expressed this sentiment in different ways. People reported not seeking help earlier because they **did not perceive the difficulty as problematic**, felt their **difficulties might pass**, were just a **natural part of aging**, or that **GPs were not the appropriate place to seek help**.

Furthermore, some participants were **unsure** about whether their difficulties were problematic and warranted seeking help, and some felt **incapable of being helped**. Several participants seemed to have a sense of **resignation** towards the difficulty, in that they felt it was something they just had to 'put up with', and some recalled **not feeling ready** to seek help or previously being in **denial** about the problem. Some participants **avoided seeking professional help** for the underlying issues by purchasing medication (for erectile difficulties) online.

Perceived problems accessing help via General Practice

Significant barriers existed to seeking help in primary care settings. For instance, some participants did not feel comfortable approaching their GP for help because they felt they had **no relationship with their GP**, often because they **saw a different GP each time**. When participants did have a dedicated GP, some were uncomfortable because their **GP was the opposite gender** to them or they simply **disliked their GP**. Some participants had concerns about the **lack of anonymity** if they talked to their GP (i.e. not wishing the information to go on their permanent medical record), some spoke of a fear of **not being understood by their GP** (due to their sexual difficulty or their sexual identity). Some felt their **GP lacked the time** to help them, and some were **dissatisfied with help** they had previously received from their GP in relation to their sexual difficulties. And finally, as mentioned above, some participants felt that the **GP was not the appropriate place to seek help for sexual difficulties**.

'You don't want to be wasting their time and you realise the number of people they have to see, you know? So then I think it's not really their place to give you advice on...! I don't know, that's my personal opinion that it's not a GP's place to give you advice on sexual problems'.

P017, Heterosexual Male, 29 years, Erectile Difficulties and Loss of Interest in Sex.

Perceived problems accessing help via specialist services for sexual difficulties

Another cluster of barriers to seeking help were associated with existing specialist services for sexual difficulties; these included a **lack (or perceived lack) of available services in the area** or a **lack of knowledge about what types of services are available**. Other barriers included perceptions that the **current help available is inadequate**, in that services are not available outside of office hours, treatment is not long enough in duration, and/or does not adequately address the psychological side of

having a sexual difficulty. Participants also spoke about concerns regarding the **potential costs** involved. With regards to online help/support, a good proportion of people felt there was a general **lack of clear, consistent and trustworthy information about sexual difficulties online, with much of the existing information contradictory**.

7.10.4.2 *Facilitators of help-seeking*

When asked about what would make it easier for people to seek help for sexual difficulties, participants identified the need for **alternative sources of help**, such as web-based help and online decision-making programs (so that people could anonymously determine whether they had a problem or not, and where to seek help for it if they concluded that they did). Participants felt that **anonymity** and **trustworthiness** (i.e. NHS or University branded websites or GPs who they trusted) were important factors in terms of encouraging people to seek help. Participants also said that seeking help would be easier if they knew **what help was available and how to access it**. Participants felt this could be achieved by their GPs being more pro-active and competent about discussing sexual issues and difficulties with their patients or by available services being more widely advertised.

7.10.5 **What people want in a program (content, design, usability)**

In the first interview (prior to looking at or using the STL intervention) participants were asked what they wanted in a program of help (i.e. the content and features of the intervention). The responses fell into three areas: Content, design, and usability.

Participants said they wanted to see **case studies** and/or information that was **reassuring, normalising and de-stigmatising**. Participants wanted **advice, tips and strategies** to deal with the difficulty; and some way of knowing that the program was **credible** (i.e. that the information was from a **trustworthy** source).

A desire for **human support** (professional or peer) was raised by several participants. A small number expressed a preference for face-to-face therapy (versus an online program), whereas others were positive about the idea of an online program but discussed the idea of having some type of **therapist support** available alongside the program (e.g. an initial consultation to help people explore what was going on for them and to determine the best course of action; a person to contact when they had questions about the program; or someone to provide feedback along the way). Other participants wanted access to **peer support** through the provision of an online

discussion forum. At the end of the program, if needed, participants wanted to be signposted to **external resources and services**.

In terms of design, participants wanted a program that was **private, structured, and tailored/personally relevant**. In Chapter 3 I defined interactivity as 'requiring contributions from the user(s), which alter pathways within the program, to produce tailored information and feedback that is personally relevant to the user(s)'. Interactive elements participants expressed an interest in included an **online diary** to track their sexual difficulty (i.e. when it occurs, the precipitating factors, what happens afterwards etc.). Participants also spoke of wanting the facility to **explore the difficulty** in-depth (e.g. exploring possible causal factors and the link between the body and the mind), and **exercises** to do with partners (e.g. helping improve communication about sex). Participants wanted the ability to **set goals**, and a **monitoring function** so they could track their progress and flag any problems that might arise. Participants also wanted to see different types of multi-media in the program (e.g. videos).

In Chapter 3 I defined tailoring as 'a process for creating individualized communications by gathering and assessing personal data related to a given health outcome in order to determine the most appropriate information or strategies to meet that person's unique needs' (Lustria et al., 2009; Rimer & Kreuter, 2006). Participants spoke of the importance of information being tailored to them personally:

'If I went on a program and it just went "Here's your problem, here's your tick list to sort it out" I wouldn't even look at it...But [tailoring] gives you a bit more of a thing that actually this understands me, and it isn't just giving me a generalised answer that I could probably go on any website and get.'

P002, Lesbian Female, 36 years, Loss of Interest in Sex.

With regards to usability, participants wanted the program to be **simple and easy to use**.

7.10.6 What people want from a program (desired outcomes)

Participants were also asked about what they wanted from a program of help (i.e. desired outcomes). Not surprisingly, the most common answer was **improvement in sexual function** (i.e. improvement with erections, ejaculation time, decreased pain and

ability to orgasm). However, participants also noted a range of other desirable outcomes.

7.10.6.1 **Cognitive outcomes**

Desired cognitive outcomes included greater acceptance of the difficulty, and changes in attitudes and thoughts relating to the difficulty (e.g. increased sexual confidence and/or less worry); increased knowledge and understanding of the difficulty; clarification as to whether it is a problem or not; and knowledge of how and where to seek help for it if it is. Participants also wanted to increase their sexual self-confidence and enjoy sex more.

7.10.6.2 **Emotional outcomes**

Explicitly, the desired emotional outcomes included reduced feelings of embarrassment, shame, worry and/or anxiety, but implicitly, the reversal of any of the distressing emotional factors discussed under the impact theme above would feasibly also be desirable to users.

7.10.6.3 **Behavioural outcomes**

Desired behavioural outcomes included increased control over the difficulty, greater ability to relax during sex and/or talk about the difficulty, and gaining practical skills to deal with it effectively (e.g. how to discuss difficulties with a partner).

7.10.7 **Participant first impressions of sextherapylondon (STL)**

7.10.7.1 **Initial scepticism**

While most participants were interested and curious about the concept of IDIs for sexual difficulties, a few people (prior to being shown STL for the first time) expressed some initial scepticism about the idea of IDIs for sexual difficulties. One participant did not see how *'a load of text on a screen'* could make a difference and felt that *'it's important to verbalise and speak about the problem'* (Lesbian Female, 36 years, Loss of Interest in Sex). Two participants recalled their previous negative experiences with online programs for depression. One had previously used the Beating the Blues online program (for depression) and had felt that it was too generic in content and not tailored or specific enough to him. He also felt that due to the more nuanced nature of sex there would be *'a million more little things [for the web-program] just to get right and personal about me'* (P010, Gay Male, 46 years, Erectile Difficulties and Problematic use of

Internet Pornography). One participant had previously used the Mood Gym online program (for depression) and reported that he had '*...found it was like work, and just felt, oh god...I'm really tired; I feel depressed and tired as it is, do I really want to have more stuff thrown at me?*' (P012, Gay Male, 46 years, Erectile Difficulties and Problematic Seeking of Sexual Partners).

Participants were shown around the homepage of STL to give them a clear idea of what an IDI was, and were then asked about their first impressions of the website. First impressions were largely very positive, although there was some negative feedback.

7.10.7.2 **Positive first impressions**

Participants perceived the website as reputable, and found it visually appealing; they also liked the straightforward and organised layout of the homepage and contents page. Participants liked the level of detail provided, the fact that the program was broken down into stages, and the comprehensive and practical nature of the program. The content was perceived as interesting and relevant, and participants could see that it would be tailored to the individual. The program was seen as user-friendly, gender neutral, and the language accessible. Participants liked that users could go through the program at their own pace, and found the privacy/anonymity of the program particularly appealing.

I think because it doesn't involve other people; that would be my primary reason [for using an IDI]...getting information from the internet is probably more useful because you're more likely to say what you actually want, and you're looking for what you actually want, whereas if you saw a doctor, you're likely to censor yourself and not mention certain things, because it's embarrassing...It's like I saw one of the things [programs] was [about] pain during anal sex; a lot of people would not bring that up with their doctor. They might bring up pain during sex, but not that specifically.

P013: Bisexual Female, 22 years, Lack of Interest in Sex.

7.10.7.3 **Negative first impressions**

Several participants felt that the www.sextherapy london.nhs.uk URL was not sufficiently discreet, and several did not like the lack of imagery. Generally, this was a highly educated sample, but one participant who was not highly educated and had

dyslexia was concerned about amount of content and text, and was put off by what she perceived to be formal medical language (e.g. sexual desire vs interest in sex). Several participants disliked not being able to actually speak about their difficulties with a person, and several were concerned about maintaining interest in the program.

7.10.7.4 ***Willingness to use the program***

The vast majority of participants said they were prepared to use the program. Two participants felt they would be unlikely to use the program if they had come across it online (i.e. outside of a research context). One participant said this was because she felt the program was too wordy and there was too much content (this was the participant with dyslexia), and one participant was hesitant to use the program, as he preferred face-to-face support, but said that he would be willing to try it if it felt relevant to him and was structured with clear goals.

After using one of the seven STL programs for between 6 and 10 weeks, participants returned for a second interview.

7.10.8 **Participant views of the program: Positive feedback (after using intervention)**

Participants expressed a wide range of positive views about STL, and much of the positive feedback matched with what participants had said they had wanted (in and from a program) in the first interviews (relating to content, usability, design, outcomes etc.).

7.10.8.1 ***Content and design***

Participants found the STL website informative and comprehensive, and liked the practical exercises and tools provided by the program. People identified with the case study examples and found sections of the content reassuring/normalising.

There was this bit that said a lot of people actually have different expectations about their sexual desires and that's normal, and there are ways to work around it, so that felt quite reassuring'.

P027, Heterosexual Female, 26, Lack of Interest in Sex.

Users perceived the website as relevant and personal, and they liked the accessibility, anonymity and privacy of the intervention; appreciating that they could work through

the program at their own pace, knowing everything they entered was confidential – these are all qualities unique to IDIs.

7.10.8.2 **Usability**

Participants found the programs easy and intuitive to use, and reported being able to navigate around the website without any problems. Users liked the clear and simple layout of the website, and most liked that the language style was not too technical or medical.

7.10.8.3 **User experience**

The website exceeded the expectations of some of the participants.

'I had kind of low expectations of it [the program] presenting any concrete solutions or even probably really changing my thinking about it, because I felt like I had already thought through a lot of the aspects of the problem pretty thoroughly. But actually, I think that was the thing which was more remarkable about the experience of using it. I felt that actually, at least in a few areas, it really did clarify my thinking about the problem'.

P004: Heterosexual Male, 37 years old, Problematic use of Internet Pornography.

Overall participants found the STL website enjoyable, and several people felt more hopeful and empowered as a result of using one of the programs. Users liked the convenience and accessibility of the website. Participants found the programs thought provoking and helpful in terms of gaining clarification and insight into their difficulties, and in correcting misinformation; and many felt reassured by this. Several of the participants who had partners liked that the program encouraged communication with partners; and some of the participants who used the intervention alongside face-to-face therapy found that the website complemented the face-to-face therapy. For example, one women who was recruited via a sexual problems clinic, felt it was useful to use the program while waiting for face-to-face therapy to start, and another participant, also recruited via a sexual problems clinic, thought it was useful to look at and practise the exercises in between sessions either because they either reinforced or complemented what was said in face-to-face therapy.

7.10.9 Participant views of the program: Negative feedback (after using intervention)

7.10.9.1 *Content and design*

One participant felt that the program was lacking in information on the relationship between the emotional and physical aspects of sexual difficulties, and another participant felt the information on the biology and physiology of sexual difficulties was too basic, but acknowledged that some people may need basic information. One participant felt that the slider tool that evaluated change at the end of the problematic sexual behaviour program was not sensitive enough. For example, he wanted to reduce the time he spent masturbating to internet pornography from approx. 12% of the time to approx. 2% but the measurement tool was not sensitive enough to do this. As mentioned earlier in the chapter, several participants found the 'sextherapylondon.nhs.uk' url off-putting (mostly in terms of privacy but one participant found the words sex therapy quite confronting), and several participants felt the program was quite long, and not interactive and/or tailored enough, or that the tailoring did not always work as intended. For example, in one section users entered their religion, and later, they are asked to think about their religion's perspective on masturbation. However, when one participant checked 'would rather not state' to the initial religion question, the program later produced the following sentence: '*As a would rather not state* female masturbating is...'. Glitches and technical problems like this are easily remedied, but the findings do demonstrate the need to undertake formal usability testing prior to further evaluation of the intervention.

7.10.9.2 *Usability*

Several participants wanted to be able to choose where they went in the program (rather than following a step-by-step program) and some wanted the ability to move back to previous screens and change responses (G. Andersson et al., 2011). Several thought the language was too clinical, that there was too much text and that the text was too small.

7.10.9.3 *User experience*

Several participants felt the program seemed like a lot of hard work; practical, but not much fun. Other participants felt that the program was very factual, but a bit cold and disconnected (Darvell et al., 2015). One participant felt the Pain Program spent too much time trying to find the cause of the difficulty and not enough time on solutions.

Several participants' did not like the lack of human support within the program either because they did not want to go through the process alone, that they felt at a loss when not feeling motivated (Darvell et al., 2015), or they felt unable to address deep emotional issues (Andersson et al., 2008; Barak & Grohol, 2011).

While the vast majority of participants were drawn to the anonymity of the program, one participant who had reportedly tried many times to get help for her lack of interest in sex and difficulties with orgasms, felt the website reinforced an already hidden aspect of her life and left her feeling quite lonely. The same participant felt that all the things the program suggested were things she had already tried before with self-help books and previous therapy, and nothing had 'worked'. The participant assumed the program had 'worked' for all the other people in the study, and consequently felt participating (and 'failing') had made her feel worse about herself.

7.10.10 Perceived changes as a result of using the program

When asked if there had anything changed as a result of using the program, almost all participants had at least one change to report. Changes included cognitive, emotional, physical or behavioural outcomes.

7.10.11 Cognitive changes

Participants reported increased awareness and understanding of their sexual difficulties (i.e. about the nature of their difficulty, their attitudes surrounding sex, causal factors, triggers etc.); this also included greater clarity on whether or not the difficulty was problematic for them. In some instances the difficulty was no longer perceived as problematic or perceived as less of a problem than it was initially, and in other cases, the difficulty was confirmed as problematic. Several people also reported greater understanding of their partner's perspective or position:

Oh, there was one section where both of us had to fill out, I think, how do you feel when your significant other doesn't show interest, or something along those lines... So what he said was that if I don't show any interest in have any sex with him, he would be thinking that maybe I'm contemplating breaking up with him sometime in the future and that's why I'm not engaging in sexual activity... And, well, it was surprising for me to find out what my boyfriend thought because I didn't think he was thinking that! Which is not true, and so it was helpful to clarify that I don't think that.

P027, Heterosexual Female, 26, Lack of Interest in Sex.

Participants reported greater acceptance of themselves and the difficulty; increased sexual confidence and increased confidence in ability to manage the difficulty or speak to a health professional about it; increased motivation to work on making changes or to seek further help if needed; and increased knowledge about what help is available and where to find it. People reported being more relaxed during sex, enjoying sex more, and feeling more satisfied with their sex life.

7.10.11.1 ***Emotional changes***

Participants reported feeling more optimistic and hopeful about the difficulty; less embarrassed and ashamed; and less alone with the difficulty.

7.10.11.2 ***Behavioural changes***

Behaviour changes reported included increased or improved communication with partners, and changes in partner behaviour. For example, the partner of a woman who was working on the orgasm program was reluctant to work on the program with her, but despite his reluctance, he started making oral sex a priority in their sex life, when previously he had focussed mostly on intercourse. For another participant, after working on the erectile difficulties program with his wife, his wife stopped teasing him about his difficulties and became more physically affectionate towards him, and they started going to bed at the same time, rather than at separate times.

7.10.11.3 ***Physical changes***

Some men reported fewer or no erectile difficulties, and/or stronger erections.

7.10.12 Barriers to use

The main reasons participants gave for not accessing the intervention fell into three areas:

Intrinsic or person related factors: Including feeling tired (Wiljer et al., 2011), low in mood, unmotivated, forgetting about the intervention, having a preference for face-to-face therapy and feeling stressed.

Extrinsic or contextual factors: Including lack of time, external stressors, partner resistance or feeling unable to discuss program with partner, lack of accountability (i.e.

it was easy to put off using the program because it did not involve meeting with a therapist), and losing login details.

Program factors: Including program not a good fit for some participants (i.e. one woman did not identify with any of the reasons why women might experience vaginal pain during sex, and one man with painful ejaculations felt there was no program to fit his difficulty), program was not discreet enough to use in public places, and mode of delivery was not acceptable to some participants. For example, some people reported that the last thing they wanted to do after working in front of a computer all day was to spend more time on a computer. One man said that after spending time on the computer masturbating he would feel guilty and would then try and stay away from the computer. And some people wanted to be able to use it on a phone because a computer was not always convenient or there was concern about leaving a trail on a shared computer (the programs are not yet formatted for use on smart phones).

7.10.13 Suggested modifications to the website

After using the intervention for 6-8 weeks participants had a wide range of useful suggestions for ways to modify and improve the website.

Content and Design

- Add information about the intervention developers (to convey credibility and trust)
- Include more solution-focussed tips and suggestions
- Include more comprehensive definitions and descriptions
- Expand intervention to become a 'one stop shop' sexual health portal
- Include facility to purchase safe medication (i.e. Viagra, Cialis etc.)
- Add links to further help/resources
- Add videos (e.g. of real people talking about their sexual difficulties)
- Add a quick exit button
- Change URL to something more discreet
- Add percentage progress bar to each page

- Add facility to chat with other people with sexual difficulties

Usability

- Add tool to help users choose the most appropriate program (as many people have more than one sexual difficulty and which one to focus on first is not always obvious)
- Include guidance (on how to use programs, time to allow, rationale for certain sections)
- Increase interactivity (e.g. include more reflective sections)
- At login allow people to start from the beginning or resume from where they left off last time
- Ensure website is set up for multiple devices
- Make language less formal
- Enable users to navigate anywhere in the program
- Enable one password for multiple programs
- Add function to change or retrieve password if lost

7.11 Discussion

7.11.1 Principal findings

As far as I am aware, this is the first ever in-depth qualitative interview study to explore the thoughts, beliefs, experiences and emotions that might influence uptake and engagement with IDIs for sexual difficulties. The study demonstrates that this form of intervention was acceptable to participants as it met many of the users' wants and needs with regards to features, design, usability, user experience, and perceived outcomes. The findings also indicate that the provision of web-based help has real potential to reduce some of the many barriers to accessing help in this population (e.g. discomfort seeking face-to-face help, a lack/perceived lack of local specialist services, and confusion over whether the difficulty warrants professional help). Users were largely positive about their experiences with the program, but also identified barriers to use and areas for improvement.

Conceptualisation of sexual difficulties

The way people conceptualise their difficulties has implications for whether a person will seek help at all, the extent to which they might perceive an IDI as relevant and potentially useful, what their expectations and requirements of an IDI might be, and implications for program aims and content. Sub-themes that are particularly relevant to IDI design are the perceived causality of sexual difficulties, and factors that maintain the difficulties (Sutherland, 2012), the importance of the immediate and wider context (Bellamy et al., 2013), and the fact that sexual difficulties are not always perceived as problematic.

Factors that cause and/or maintain a person's sexual difficulties represent key intervention targets. As these factors vary according to type of sexual difficulty, it is important that program content of IDIs is tailored to address specific sexual difficulties. The conceptual model of sexual difficulties influences the source and type of help that is seen as appropriate (e.g. for some people GPs are seen as appropriate sources of help for physical and medical sexual difficulties, but not necessarily for psychosexual difficulties). IDIs can help address a variety of psychosocial factors that cause and maintain sexual difficulties (e.g. relationship factors, beliefs, attitudes etc.), and may also be able to help people cope with physical or medical difficulties through normalising and reframing.

Using a combination of systemic, cognitive and behavioural, and sex therapy techniques, STL takes a holistic biopsychosocial approach to sexual difficulties. Programs like those in STL can tackle the physical elements of sexual difficulties using behavioural exercises; address psychological aspects of sexual difficulties by helping users identify and challenge negative thought patterns (around sex, the self and partners) and providing techniques to manage anxiety; and explore the interpersonal and socio-cultural factors by using systemic exercises to explore the meaning of their difficulties in the context of their own lives, and build partner communication skills. IDIs can only respond to what is covered by the program, and cannot deal with the unexpected, the inclusion of human support could make this less of an issue (see later in the discussion for more information about human support).

As discussed in Chapter 2, the immediate and wider contextual factors and distress levels have historically been neglected when diagnosing sexual difficulties or reporting prevalence, and this has contributed to over-diagnoses, inflated prevalence estimates, and pathologising of normal sexual experience (Bancroft et al., 2001; Bancroft, 2002;

Moynihan, 2003). The findings from the current study provide further support for the New View classification of sexual difficulties (Kaschak & Tiefer, 2001) and the call to clinicians and researchers to consider contextual and relationship factors when working with people with sexual difficulties. The most recent National Survey of Sexual Attitudes and Lifestyles (Natsal 3) used a newly developed measure of sexual function that included questions about the relationship context, satisfaction and distress levels (Mitchell et al., 2013). But while accurate diagnoses and avoiding pathologising those who are not distressed is important, an IDI could meet the needs of those that are distressed and who would like help. The STL program tackles the wider contextual factors that users judge to be important, such as family, religion, culture etc. (albeit in a more limited way than in face to face sex therapy).

7.11.1.2 *Impact of sexual difficulties*

The findings demonstrate that sexual difficulties impact people's lives in many different ways. The areas of impact identified were similar to those found in previous studies, and included detrimental effects on emotional wellbeing (Hinchliff et al., 2009; Sutherland, 2012; Tomlinson & Wright, 2004); cognitions, such as self-esteem, self-confidence, sexual attitudes and expectations, identity, and motivation (Sutherland, 2012; Tomlinson & Wright, 2004); sexual behaviours (Sutherland, 2012; Tomlinson & Wright, 2004); and interpersonal relationships (Hinchliff et al., 2009; Sutherland, 2012).

In the context of IDIs, the ways in which sexual difficulties impact on people are important as they represent potential targets for change. One of the aims of STL is to achieve improvement in one or more of the above areas with the overarching goal of reducing the impact of a person's difficulties. It goes beyond the scope of the current study to discuss in detail every possible emotion/cognition/behaviour that could be targeted by an IDI for sexual difficulties, so I will now outline and discuss a selection that I considered unique or particularly relevant to sexual difficulties, and illustrate how they might be incorporated into and addressed by IDIs for sexual difficulties.

Embarrassment, shame and feeling 'abnormal' and alone were emotions commonly felt across the sample and in previous research (Hinchliff et al., 2009; Sutherland, 2012), and appear to relate to the social stigma surrounding sexual difficulties (Goffman, 1990). Stigma refers people who are labelled as different from the social norm, in this instance people with sexual difficulties, and who are devalued as a result. Stigma consists of 3 elements: Ignorance (a problem of knowledge), prejudice (a problem of attitudes), and discrimination (a problem of behaviour), and can occur at different levels

(Ben-Zeev, Young, & Corrigan, 2010; Young Minds, 2010). Public stigma refers to large group endorsement of stereotypical beliefs about people with sexual difficulties (e.g. men with erectile difficulties are not 'real men' and women who have difficulty having orgasms are 'frigid' or 'prudish'). Self-stigma refers to the internalisation of these publicly held stigmatizing beliefs, and is thought to lower self-esteem and self-efficacy (Ben-Zeev et al., 2010; Young Minds, 2010). Media messages are also thought to contribute to the feelings of abnormality and inadequacy in people with sexual difficulties (Hinchliff et al., 2009; Markovic, 2012). Label avoidance is where people do not seek help for their sexual difficulties so as to avoid the consequences of having a stigmatizing label (Ben-Zeev et al., 2010). The impact of stigma has been well documented, although most notably in reference to mental health (Ben-Zeev et al., 2010; Herek, Chopp, & Strohl, 2007; Minds, 2010; Tomlinson & Wright, 2004; Young Minds, 2010). While education, protest and contact are considered the most effective way to tackle public stigma (Corrigan & Watson, 2002), IDIs have real potential to tackle self-stigma and address label avoidance. They achieve this by providing anonymous access to normalising information, myth busting exercises, cognitive reframing exercises, facilitating contact with other people with sexual difficulties, and promoting disclosure (Thomas et al., 2015). STL tackles the stigma surrounding sexual difficulties by providing accurate statistics about who experiences sexual difficulties and normalising people's experiences.

Performance anxiety occurs when a person becomes overly focussed on their need to perform rather than on their own pleasure and satisfaction, and is considered a major contributor to the maintenance of sexual difficulties (McCabe, 2005). Performance anxiety is thought to be associated with 'willing' an erection (or ejaculation, orgasm etc.) to happen, rather than allowing it to occur 'naturally' in response to sexual enjoyment and pleasure (McCabe, 2005). Studies indicate that performance anxiety contributes to the variance in levels of sexual dysfunction over and above attitudes to sex, lifestyle factors, relationship factors and sexual satisfaction (McCabe, 2005), and therefore (in addition to addressing the other contributing factors) it is important that intervention strategies specifically target performance anxiety by isolating the source of the performance concerns and using psychoeducation and cognitive restructuring techniques to address these concerns (McCabe, 2005). STL does just this. For example, users with erectile difficulties are provided with information on the physiology of erections and introduced to a CBT formulation about how negative thoughts can impact sexual performance. Using cognitive restructuring the program enables the user to explore and challenge their automatic negative thoughts around their erectile

difficulties and sexual performance, and aims to help the user replace these thoughts with more adaptive thoughts (see Chapter 5 for a more detailed description of how STL uses cognitive restructuring).

Fear - of disappointing a partner, relationship breakdown, getting into a new relationship etc. can be addressed and overcome by exploring the rationality of the fear beliefs, deconstructing the meaning of the fears, and increasing communication skills to enable open discussion of fears with partners, if applicable (Binik & Meana, 2009; Bitzer & Brandenburg, 2009). STL addresses fear by using systemic therapy based exercises that explore and deconstruct the meaning of the fear for the individual (and their partner's perceptions of the fear if applicable) and by using cognitive restructuring techniques.

Depression and anxiety are often comorbid with sexual difficulties. Bancroft and colleagues (2003) observed that 42% of men with depression reported decreased interest and enjoyment in sex. Similarly, Mao and colleagues (2009) found that men with sexual difficulties were more likely to suffer from depression. However, depression is not always associated with a reduction in sexual interest, and low mood can be associated with increased sexual interest and arousal (Bancroft, Janssen, et al., 2003; Lykins, Janssen, & Graham, 2006). While the direction of causality between depression and anxiety and sexual difficulties remains unclear, it is important that IDIs address depression and anxiety, either by screening for symptoms of depression and anxiety and referring or signposting people to appropriate services, or by addressing them directly as part of the IDI (Kaltenthaler, Parry, Beverley, & Ferriter, 2008). STL does not currently address symptoms of depression and anxiety within the programs.

A variety of intervention functions can address other areas of impact raised by the participants, including CBT and partner communication exercises around sexual expectations; motivational interviewing techniques and reminders to address problems with motivation; CBT and systemic exercises to explore and deconstruct the meanings and beliefs held about gender norms and identity; CBT and exposure techniques to deal with avoidance of sex; and CBT, systemic and partner communication exercises to explore reluctant engagement in sexual activity. This is by no means an exhaustive description, but it does highlight the ways in which IDIs can target factors for change that are deemed important by users.

Barriers to seeking help

In the current study, only half of the participants had sought any professional help for their sexual difficulties, despite most people wanting help, which matches low help-seeking levels found in previous research (Gott & Hinchliff, 2003; Moreira et al., 2004; Murray, 2009; Shepherd et al., 2009; Shepherd et al., 2010; Shifren et al., 2009). Unique to the current study, was the finding that those that had sought help had generally not been happy with the help (or perceived lack of help) they had received. Approximately two thirds of the sample had looked for help online, which supports previous findings that people are interested in online help (Akre et al., 2010).

It goes beyond the scope of this study to discuss in detail every possible barrier to help-seeking for sexual difficulties, so I have chosen to focus on the barriers that can be addressed by IDIs for sexual difficulties. Shame and embarrassment was a major barrier to help-seeking and has already been discussed earlier in terms of how this can be addressed by IDIs. For people who report problems accessing professional help (either via the GP or specialist services) IDIs provide a convenient, self-paced, private, and confidential alternative help-source that addresses many of the barriers associated with accessing professional help. Furthermore, people who are unsure whether their difficulties are 'medical problems' or problems that warrant seeking professional help, can use IDIs to gain clarity on their difficulties by exploring associated thoughts and beliefs, and continue with the programs if appropriate.

Initial acceptance of the idea of an IDI for sexual difficulties

Prior to using STL, the idea or concept of an IDI for sexual difficulties was well received, and views and expectations were generally very positive, although that was somewhat to be expected in this self-selecting sample. Most participants (though not all) felt that an IDI could help them and were enthusiastic about using one. As this study is the first in-depth qualitative study on user views of IDIs for sexual difficulties, the findings cannot be contrasted with previous studies in this area. However, previous qualitative findings on participants' expectations of IDIs for depression were similarly positive (Hoa Ly et al., 2015; Montero-Marín et al., 2015).

Acceptability and views of a specific IDI for sexual difficulties (STL)

After using STL participants expressed a wide range of positive views about the programs that matched well with what they had said they wanted in and from a program of help prior to using STL (i.e. desired content and outcomes). Much of the

positive and negative feedback will be useful in terms of informing the content and design of future IDIs for sexual difficulties, as well as the re-development of STL. Much of the negative feedback related to usability and user experience, and given that engagement is already an issue with IDIs, it is important that designers collaborate with human computer interaction (HCI)/user interface design specialists to ensure that IDIs meet users' needs and fulfil their full potential (Pagliari, 2007).

One participant who had dyslexia was put off by the amount of text and what was perceived as formal medical language. With the digital divide already creating inequities in access to IDIs, it is important that further inequities are not created by their use of language, content and design. User interface design would again be important in this regard.

In the current study, and similar to previous studies on IDIs for depression (Hoa Ly et al., 2015; Montero-Marín et al., 2015), reluctance or reservation towards using an IDI for sexual difficulties was associated with a disinclination to use the internet, a preference for face-to-face therapy and concerns about maintaining motivation and interest with the intervention. Recent eHealth research indicates that human support can help to boost engagement with IDIs, and that this helps to increase their effectiveness (Andersson & Titov, 2014; Khaylis, Yiaslas, Bergstrom, & Gore-Felton, 2010; Mohr, Cuijpers, & Lehman, 2011; Palmqvist, Carlbring, & Andersson, 2007; Schubart et al., 2011). While it may be more costly to provide human support, the potential positive impact on engagement and effectiveness is likely a worthwhile trade-off. The level of support can vary. Engagement support might involve an introductory session with a therapist or healthcare professional to explain the therapeutic rationale of the intervention, teach users how to use the program, discuss potential barriers to use, address any client concerns or misunderstandings, and check in with users via email or phone to troubleshoot any problems or difficulties. Therapeutic support might involve contact with users to provide additional therapeutic support (Andersson & Titov, 2014; Glasgow & Rosen, 1978; Newman et al., 2003).

Desired and perceived outcomes

Asking participants about desired outcomes (prior to using STL) and perceived outcomes (after using STL) enabled me to observe the range of outcomes that are important to users, and how these can be of use when evaluating IDIs for sexual difficulties (or any psychotherapeutic intervention for sexual difficulties for that matter). Given that this is the first in-depth qualitative study of IDIs in this area, the findings

represent a unique contribution to the literature in this area. Many of the perceived outcomes reported after using STL matched the desired outcomes participants spoke about before using STL, which suggests that STL met many of the users' needs:

- Increased awareness/understanding of the difficulty
- Greater acceptance of self/the difficulty
- Increased clarity about the problem and whether it warrants seeking professional help
- Increased knowledge on what help/services are available
- More relaxed during sex
- Enjoying sex more
- Less embarrassed/ashamed
- Gained practical skills to deal with the difficulty more effectively
- Improved communication with partner
- Fewer erectile difficulties
- Stronger erections

There were also a range of unanticipated outcomes reported by users, which suggests that in some ways the intervention surpassed expectations:

- Feel less alone
- Greater understanding of the partner's perspective
- Increased confidence (sexual self-confidence, confidence to manage the difficulty and confidence to seek further help if needed)
- Increased motivation (to work on change or seek further help if needed)
- Difficulty perceived to be less of a problem than before
- More hopeful/optimistic about the difficulty
- Changes in partner (e.g. partner more supportive or partner more affectionate)

There were also outcomes that were desired, but not achieved, namely relating to sexual function. While it is not possible/appropriate to make causal claims from the results of qualitative studies, it is worth exploring why some people might not observe changes in sexual function when using IDIs for sexual difficulties. It could be that they did not engage with the intervention enough to see benefit, but equally it could be that people with long standing and complex sexual difficulties (i.e. many of the study participants) are less suitable for IDIs, and that IDIs are less capable of facilitating sexual function improvement under these circumstances. These are questions to be answered by future research.

It is also important to consider potential harms of IDIs for sexual difficulties. With regards to safety, IDIs are limited in their ability to assess risk (i.e. self-harm, suicidal ideation and safeguarding issues), and less likely to be able to pick up more complex mental health issues. IDIs rely on self-report, and cannot pick up on non-verbal or subtle cues, such as body language or a demotivated client. One participant in the study who had multiple longstanding and complex sexual difficulties felt her use of the program, and perceived 'failure' to achieve change, had resulted in reinforcing negative beliefs she held about herself. This is a valuable finding, and one that could only be picked up through qualitative research. Currently, little is known about the characteristics of people who are more or less likely to benefit from IDIs (Andersson & Titov, 2014). It could be that IDIs are not appropriate for people with longstanding and complex sexual difficulties. Providing clear and comprehensive information (about who the program is best suited to, what the program entails in terms of content covered and time commitment required, and tips and suggestions on how to get the best out of the program) to users before they start an IDI may help to manage expectations and minimise some risk of harm. The provision of human support for an initial assessment, and to check in regularly with the user would also help to prevent or minimise risk of harm (Andersson & Titov, 2014).

Patterns of use

The majority of participants accessed it at home when they were alone (or with partners where applicable); and often in the evening (although those that worked from home reported using the website in the afternoons when they were alone. Several people accessed the website either on their phone or laptop when out of the home or workplace. Some liked the fact that they could read the website and think about the content, but then wait until they felt ready to do the exercises. No data was collected on

actual website usage, but some participants reported that their use of the website was more frequent at the start of the program (but tapered off over time), whereas others completed the entire program fairly consistently. Several participants felt that they had rushed through the program too quickly, and felt they would benefit from doing the program again more slowly. Most participants felt they had ample time to complete the program.

Barriers to use/reasons for disengagement

One of the main reported barriers to engagement with the STL program was that some participants felt unmotivated to engage with/continue using the program. Motivation is a well-documented determinant of behaviour change, and is considered one of the more difficult determinants to manipulate/change (Deci & Ryan, 1985; Michie, van Stralen, & West, 2011). However, this is an area of research that is receiving much attention in the literature (Michie et al., 2013; Rubak, Sandbæk, Lauritzen, & Christensen, 2005). As mentioned earlier in the chapter, human-support has been found to increase engagement with IDIs in other areas of health/mental health (Palmqvist et al., 2007; Schubart et al., 2011; Wilhelmsen et al., 2013), as has prompts and reminders (Fry & Neff, 2009; Gerhards et al., 2011; Webb, Joseph, Yardley, & Michie, 2010). Further research is needed to determine whether these engagement strategies apply to IDIs for sexual difficulties.

7.11.2 Methodological strengths and limitations

7.11.2.1 Study design

Using qualitative research methods, and developing a rapport with participants in an interview setting enabled me to explore and understand complex, subjectively defined phenomena that were situated and embedded in each participant's socio-cultural context – something that would be impossible to do using quantitative methods. More specifically, through using qualitative interviews I was able to gather rich and detailed data on how people conceptualise their sexual difficulties, the impact of having a sexual difficulty, the intrapersonal and external factors that prevent people from seeking help, what people want and need from online sex therapy, the aspects of the intervention that were appealing and unappealing to users (i.e. features, design and usability etc.), and gain insight into the factors that led people to disengage with the intervention. Sexual difficulties are an under-researched area (Medical Foundation for AIDS and Sexual Health, 2008; Mercer et al., 2005), and therefore it was important to

explore the phenomena in-depth as the data gathered will help shape the direction of future research. The data gathered will also enable STL (and other IDIs for sexual difficulties) to be (re)developed with users wants and needs at the very centre of their design, with the aim of maximising engagement and effectiveness.

A further strength was the rigorous approach taken in the study, including taking a reflexive approach and ensuring transparency (see methods section of this chapter). A limitation of the study design was that I had to rely on self-reported engagement with the intervention as actual engagement was not measured. It would have been useful to have data on actual engagement to reduce the impact of social desirability and so that reasons for disengagement could be explored more deeply with the relevant participants.

7.11.2.2 ***Representation of different groups***

Women were underrepresented in the current study. Other research shows that women are more likely to seek help than men (Akre et al., 2010; World Health Organization, 2009). However, the underrepresentation was more likely to do with the type of sexual difficulties that were the focus of the study, which by their nature were somewhat biased towards men (erectile difficulties, lack or loss of interest in sex and problematic sexual behaviours) and that gay men are over-represented in some of the clinics where participants were recruited. In a recent UK study (Mitchell et al., 2013) a lack of interest in having sex was the most common sexual difficulty in both men and women (14.9% and 34.2% respectively). There are no reliable and rigorously derived prevalence data for the problematic sexual behaviours reported in the current sample (i.e. excessive levels of masturbation to online pornography and seeking a high number of sexual partners), but the literature estimates compulsive sexual behaviour to have a prevalence of between 3% and 6% in the US (Kaplan & Krueger, 2010), and that these difficulties are experienced by more men than women, with estimates around 80% of reported cases being men and 20% being women (Kaplan & Krueger, 2010; Levine, 2012). Erectile difficulties need no explanation in this regard. An additional factor that may have compounded the imbalance was the fact that many women who experience a lack or loss of interest in sex are not distressed by this, and therefore may not identify as having a sexual difficulty nor seek help (Bancroft, Loftus, et al., 2003).

When it became apparent that women were underrepresented, I stopped recruiting men in the hope that the sample would balance out. In hindsight, it would have been a good idea to have obtained ethical approval at the start of the study for a greater

number of research sites so that if recruitment was slow, or in this case lacked female participants, then I could have attempted to recruit elsewhere. Nevertheless, the current study was an exploratory qualitative study. I did not seek to generalise these findings to the wider population of people who experience sexual difficulties, which is why I did not use methods that would have produced a statistically representative sample. Rather, I aimed to recruit a diverse sample of participants, with varying perspectives on having a sexual difficulty and help-seeking, so that I could fully explore the commonalities and differences in the meanings and experiences of having a sexual difficulty (with a particular population of people, with a particular set of sexual difficulties). I do believe I achieved this goal, and that the findings are conceptually transferable to similar individuals in similar contexts. Future research should extend the current research to explore the meanings and experiences of people with sexual difficulties that were not fully covered in this study (i.e. vaginal pain, anal pain, problems with orgasm, and early/delayed ejaculation).

There was an overrepresentation of gay men in the current study, which may have been an artefact of the choice of recruitment centres. The majority of the sample were recruited from sexual health clinics, one of which is particularly popular with gay men. Compounding this, studies show that men who have sex with men (MSM) are more likely to attend sexual health clinics for HIV testing than heterosexual men (Yin et al., 2014). So these factors combined may explain why a relatively large number of gay men signed up to the study. Nevertheless, similar to the comments I made above about the underrepresentation of women in the study, I feel I achieved the aim of diversity in sampling and obtained a wide-range of experiences and views on having and seeking help for a sexual difficulty. Even themes that might seem specific to a particular group (e.g. the impact of sexual difficulties on the gay male identity), were often closely related to themes of other groups (e.g. male or masculine identity) and are therefore theoretically transferrable. However, if I were to recruit over again it would be good practice to recruit from a wider range of community contexts where gay men are not overrepresented, such as in GP clinics, community centres, and education centres.

7.11.2.3 **Response rates**

The response rate from sexual difficulty clinic attendees was much lower than the sexual health clinic attendees, so there was a danger that I did not interview enough people who had received face-to-face help for sexual difficulties. However, within the participants recruited from sexual health clinics and Facebook there were people who

had previously sought professional help for their difficulties. So ultimately I was able to achieve the balance I was looking for in a sample in terms of varying levels of help-seeking experience. If however people who have received face-to-face help for their difficulties are perhaps (initially) less interested in IDIs for sexual difficulties, and thus more difficult to recruit, then future recruitment strategies might benefit from including more sexual difficulty clinics in the recruitment process.

7.11.2.4 **Data saturation**

Data saturation was judged from the first interviews and not the second, but this is not likely to have been problematic as the first interview contained a greater diversity of questions than the second interview, which primarily explored users views of STL.

7.11.2.5 **Transferability of findings**

Those who took part in the study were self-selecting and therefore may have been atypical in their comfort level of talking about sexual issues. While many of the participants had talked about their difficulties before (with partners or health professionals), for some participants taking part in this research study was the first time they had ever spoken openly to anyone about their difficulties. I was therefore satisfied that the sample included a range people with varying comfort levels discussing sexual issues.

The choice to limit the focus of the study to three types of sexual difficulties (erectile difficulties, lack or loss of interest in sex, and problematic sexual behaviour) made it easier to reach data saturation given the time and resources available. Initially one might conclude that the current findings are only transferable to the three sexual difficulties covered, but while certain themes were specific to certain difficulties (e.g. the impact of problematic pornography use on sexual expectations), many of the themes were common across all the sexual difficulties (e.g. shame and embarrassment). Furthermore, it is common to have more than one sexual difficulty (Mitchell et al., 2013) and this was evident in the current sample. In addition to reporting one of the three main sexual difficulties, participants reported other difficulties including sexual pain (vaginal and ejaculatory), difficulties with orgasm, and both early and delayed ejaculation. So despite limiting the inclusion criteria to one of three sexual difficulties, the data ultimately reflected the views of people with a much broader range of sexual difficulties and therefore the findings are theoretically transferable.

7.11.2.6 *Influence of interview/interviewer*

Some participants reported finding the interview beneficial or therapeutic. It was therefore important to consider how much of the perceived benefit of the intervention might have been to do with the human contact in the interviews as opposed to the intervention itself. The interview itself may have helped to put participants at ease, lessened feelings of shame and embarrassment, and helped with motivation. But it appeared that the vast majority of the perceived outcomes corresponded with the aims and content of the intervention (see Chapter 5). For example, the provision of accurate and normalising information corresponds with reports of increased awareness and understanding of the difficulty and decreased feelings of shame and embarrassment.

While it is important to think about external factors that may have influenced the perceived outcomes, it is also important to remember that this was not an impact study, and that determining causality requires controlled conditions and randomisation to groups. This was an exploratory study, to determine participants' views of the intervention. In this context, the fact that some participants found the interview beneficial was informative. It supports a 'desire for human support theme' that ran throughout the interviews, and is supported by evidence that shows the inclusion of human support to be beneficial as it increases satisfaction, promotes engagement, and increases efficacy (MacGregor, Hayward, Peck, & Wilkes, 2009; Murray et al., 2003; Waller & Gilbody, 2009).

7.11.2.7 *Retention*

Eight participants did not return for the second interview. Although 73% retention is considered acceptable/high for an interview study, I know nothing about the views and experiences of those that did not return for a second interview (i.e. did they not return for reasons relating to the IDI, such as disliking or not using it, or for reasons unrelated to the IDI). However, in the remaining sample I was able to gather a wide range of views and experiences of using STL, both positive and negative. If I were to do the study again, I would try to communicate the importance of gathering feedback from all participants, users and non-users alike. Restructuring the timing of financial incentives may also help with this (i.e. providing them after the second interview).

7.11.3 Implications

7.11.4 Implications for practice

While further research in this area is needed, IDIs have real potential to change the way services are delivered and/or provide additional support to existing services. Existing psychosexual services are currently provided in a diverse range of settings, such as in general practice, genitourinary medicine, and dedicated sexual problems clinics (Medical Foundation for AIDS and Sexual Health, 2008), but there is a lack of clarity in referral pathways to specialist services, and service provision is inconsistent (Medical Foundation for AIDS and Sexual Health, 2008). Competing demands and limited budgets within sexual health settings present further challenges to the provision of specialised psychosexual services (Shepherd et al., 2010). The introduction of open-access IDIs for sexual difficulties on a national level could reduce the need for duplication of resources on a local level, and free up valuable resources; they could also provide an alternative care pathway for people with sexual difficulties, one that could address the many barriers to accessing services raised in this study.

A stepped care model is a model of healthcare delivery whereby the recommended treatment is the least restrictive of those available in terms of the amount of specialist therapist time needed (i.e. treatment intensity), but still likely to provide significant health gain to the patient (Bower & Gilbody, 2005). If delivered as a low-intensity treatment within a stepped care model (Bower & Gilbody, 2005; NCCMH, 2011; Scogin et al., 2003), IDIs have the potential to reduce waiting lists, relieve the burden on existing services that are already underfunded and stretched to capacity, and free up valuable face-to-face resources for people with a higher level of need. If used in between sessions, IDIs could augment the small number of sessions provided by current services, and could also be used after face-to-face therapy as a maintenance tool to prevent relapse. However, delivering IDIs in this way necessitates entry criteria and requires face-to-face contact with health professionals.

While not specifically related to IDIs, the findings in the current study highlight the importance of increasing awareness of the psychosexual services currently available, perhaps by providing leaflets in GP surgeries, and links on related websites.

7.11.5 Implications for teaching

The use of IDIs in clinical practice will necessitate raising the awareness of clinicians to help them understand these interventions and identify and refer eligible patients who

could benefit. The study findings highlight the need to decrease the stigma associated with sexual difficulties, by making sex and sexual difficulties a greater focus of education in schools, with medical students in universities, and in continued professional development with qualified health professionals. The findings also highlight the many ways GPs can be a barrier to help-seeking in people with sexual difficulties. Increasing GP awareness of this, and the ways they can facilitate help-seeking for their patients would help to reduce some of these barriers.

7.11.6 Implications for research

While the findings of the current study demonstrate the broad acceptability of IDIs for sexual difficulties, qualitative process evaluations are needed to evaluate how these complex interventions work, and to assess engagement and implementation in practice (Bailey et al., 2015). Qualitative observation in practice can help to assess patterns of engagement and implementation, and to discover unanticipated adverse effects of interventions (Weaver, Horyniak, Jenkinson, Dietze, & Lim, 2013). Formal usability testing, in consultation with IDI designers/developers is also needed, as usability can influence the accuracy and completeness of tasks, and the overall effectiveness of the intervention (Bevan & Macleod, 1994).

STL (and other IDIs for sexual difficulties) need to be empirically validated through a well-designed and conducted RCT, and further quantitative studies of all components are needed to understand the mechanisms by which these interventions might work. Ongoing investigation of possible risks/adverse effects is also important. Implementation studies are also needed to determine the best methods of delivery, to identify any implementation barriers that might prevent IDIs being incorporated into routine clinical practice, and to develop strategies to overcome them. Stakeholders should be involved at every stage of intervention development and implementation, particularly users.

The findings of the current study have informed recommendations for revising the design of STL, in preparation for a feasibility RCT to test the website effectiveness.

7.11.7 Implications for policy

While IDIs are not yet at the stage where they can be commissioned, as further research is needed, it would be useful to begin formulating a vision for the future of IDIs for sexual difficulties, and to start thinking about ethical and professional guidelines for the safe use of these interventions.

There is currently no statutory requirement to teach sex and relationships education in UK schools, beyond the biological basics of reproduction and sexually transmitted infections (STI). The widespread feelings of embarrassment and shame surrounding sexual difficulties (Adegunloye & Ezeoke, 2011; Dyer & das Nair, 2013; Humphery & Nazareth, 2001) suggests that the current sex education provision in schools is inadequate, and is doing little to help the stigma surrounding sexual difficulties. If young people are to become adults who can openly discuss sexual difficulties and seek help when needed, it is important they be given the opportunity to discuss issues relating to sex and sexuality, and explore the shame and embarrassment many people experience when thinking and talking about sex. Education policy should address this.

7.12 Conclusions

Sexual difficulties are complex. They are influenced by a wide range of biopsychosocial and cultural factors, and can have a detrimental impact on people's lives in many different ways – negatively affecting emotions, beliefs, thoughts, attitudes, behaviours and interpersonal relationships. Many barriers exist that prevent those who want help from accessing it, but the provision of IDIs in this area have the potential to overcome many of these barriers. This study demonstrates that an IDI for sexual difficulties (i.e. STL) was acceptable to participants as it met many of the users' wants and needs with regards to features, design, usability, user experience and perceived outcomes. The findings also indicate that a web-based intervention has real potential to address some of the many barriers to accessing help. If shown to be effective, safe and cost-effective, IDIs could have a valuable place in providing access to help for sexual difficulties, especially in the light of further cuts to sexual health services.

Chapter 8
General discussion

8.1 Chapter overview

In this final chapter of the thesis I provide a brief summary of the main findings of the thesis and highlight the original contributions to research. Next I present the methodological strengths and limitations of the thesis as a whole. I then go on to discuss how the findings fit with the existing literature in the area of sexual difficulties, and the overall implications of the findings for practice, policy and research. After this I briefly reflect on the process and experience of undertaking this PhD, before ending the chapter with the conclusions of the thesis.

8.2 Background to the thesis

There is a high prevalence of reporting of sexual difficulties within general practice and sexual health services, and many more people experience sexual difficulties but do not seek help for them. Sexual difficulties can have a negative impact on emotional and sexual wellbeing, quality of life and interpersonal relationships, and the costs of untreated sexual difficulties are considerable. IDIs for sexual difficulties have the potential to provide a convenient, wide-reaching and cost-effective alternative to face-to-face therapy, but research in this area is in its infancy. There is little point in the NHS investing in the design, development and implementation of these interventions until more is known about their effectiveness, reach and acceptability.

8.3 Aim and objectives of the thesis

The overall aim of the thesis was to use a mixed-methods approach to investigate the use of the Internet to deliver psychotherapeutic interventions for sexual difficulties. In order to address some of the existing gaps in the literature, and produce findings that were relevant to policy and practice in the area of sexual difficulties, there were three specific objectives (that corresponded to three empirical studies):

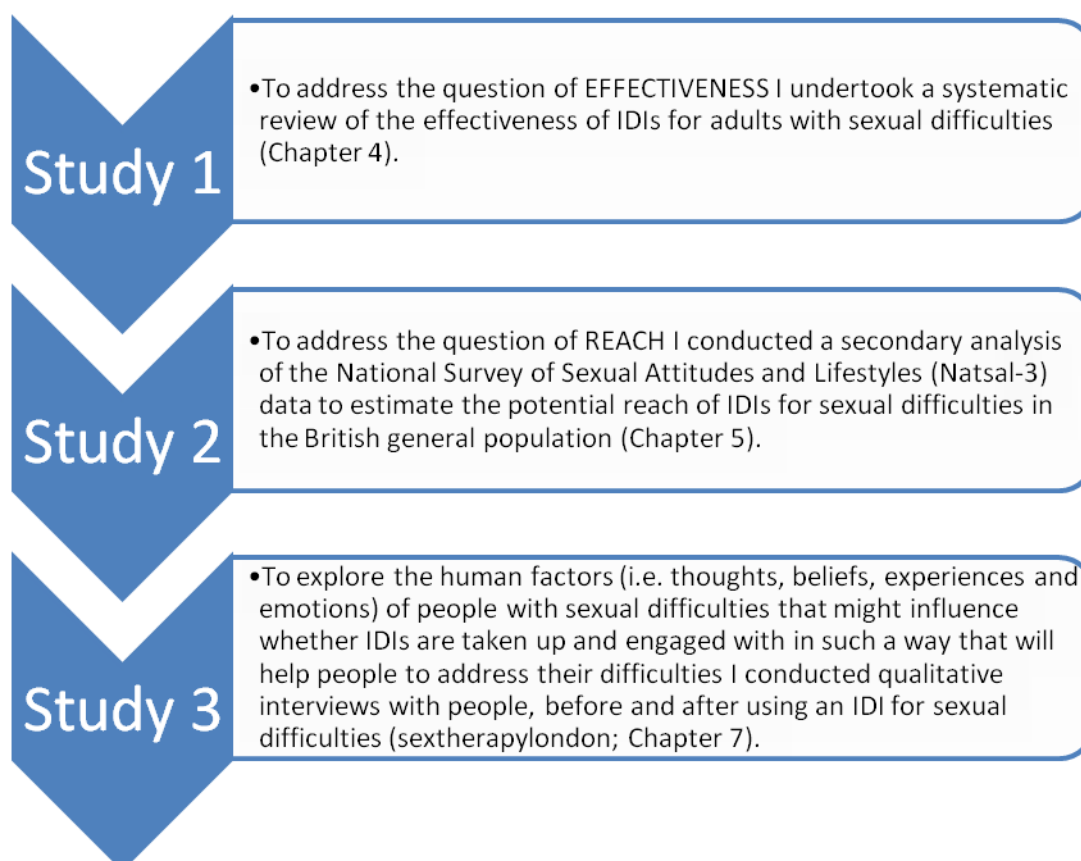


Figure 8.1: Objectives and corresponding studies in the thesis.

8.4 Summary of main findings

8.4.1 Study 1: Systematic review (Chapter 4)

This was the first ever systematic review of the effectiveness of IDIs for sexual difficulties. As mentioned in Chapter 1, effectiveness is the second dimension in the RE-AIM framework, which is a model designed to enhance the speed, quality and impact of research translation (Glasgow, et al., 1999). The conclusions are drawn on a small evidence base, but suggest that IDIs can have a positive effect on sexual and relationship outcomes in women (there was insufficient evidence to draw conclusions about the effects on men/male sexual difficulties). However, the findings must be considered in light of their limitations including the overall small number of studies in the area, the presence of bias within trials, small sample sizes, and the presence of statistical heterogeneity in the meta-analyses. Despite these limitations, the findings suggest that IDIs show real promise as a potentially cost-effective method of addressing some of the current unmet need for help and support in the area of sexual difficulties.

8.4.2 Study 2: Secondary analysis of the Natsal 3 data (Chapter 5)

This analysis presents the first population prevalence estimates of help-seeking and internet help-seeking in people who are distressed in some way about their sex life. As mentioned in Chapter 1, reach is the first dimension in the RE-AIM framework (Glasgow, et al., 1999). Approximately 16.4% of the sexually experienced British general population report being distressed about their sex life in some way (either about a specific sexual function difficulty or about their sex life more broadly), and this corresponds to a large number of people that may want help for their difficulties (approximately 6.9 million). Of those people, approximately two thirds are distressed but without any help or support, illustrating a high level of unmet need. Of the men and women who are distressed about their sex lives, between 6.9-10.3% (427,000-762,000) had sought help or advice online. Although the internet is currently underutilised as a source of help, the findings indicate that it is one of the top three most popular sources of help for British women and men. Despite the various limitations to this study (many of which centre around the fact that the questions were not designed for this study), the findings illustrate a high level of unmet need, as well as the extent and willingness of the British population to look for help online for a range of sexually related issues. IDIs

appear to be well-placed to fill some of the current gaps in service provision by providing an alternative help source that matches with current preferences for online help.

8.4.3 Study 3: Qualitative interviews (Chapter 7)

This study was the first in-depth qualitative interview study to look at user views and experiences of using an IDI for sexual difficulties (sextherapy.london). As mentioned in Chapter 1, adoption is the third dimension in the RE-AIM framework (Glasgow, et al., 1999), and I conceptualised acceptability as the first stage of adoption. The study demonstrates that an IDI for sexual difficulties was acceptable to participants as it met many of the users' wants and needs with regards to features, design, usability, user experience and perceived outcomes. The findings also indicate that a web-based intervention has real potential to reduce some of the many barriers to accessing help. If shown to be effective, safe and cost-effective, IDIs could have a valuable place in providing access to help for sexual difficulties, especially in the light of contractions to face-to-face psychosexual services.

8.5 Overall finding of the thesis

The concept of what is sexually 'normal' is culturally, socially and politically relative, and thus heavily context dependent. Consequently, sexual difficulties are notoriously difficult to define and classify. In spite of these complexities, and whether you define sexual difficulties narrowly or more broadly (Chapter 5), this thesis provides both quantitative and qualitative evidence of the high level of unmet need for help with sexual difficulties (Chapters 5 and 7). IDIs can be effective for sexual difficulties (Chapter 4), but the current evidence-base is small, and contains studies that are methodologically flawed, so more research is needed to be sure of these effects and to determine the effectiveness of different types of IDIs on different populations and sexual difficulties. With approximately 427,000-762,000 British people reportedly distressed about their sex lives and looking for information and support online, it appears that IDIs have considerable potential to reach their intended audience (Chapter 5). There is also the potential to reach a much larger audience—those who are not currently seeking help and support online, but who might do if IDIs were made widely available (Chapter 5). Lastly, the STL IDI appeared to be acceptable to users as it met many of their wants and needs with regards to features, design, usability, user experience and perceived outcomes. While more research is needed to determine the most effective strategies to promote sustained engagement with these interventions,

they appear to have real potential to reduce many of the existing barriers to accessing help. Taken together, the evidence in the current thesis suggests that IDIs have real potential to meet some of the current unmet need for help in the area of sexual difficulties, and are well worth exploring further.

8.6 Methodological strengths and limitations of the thesis

The methodological strengths and limitations of the individual studies can be found in the corresponding chapter discussions (Chapters 4, 5 and 7). The following strengths and limitations pertain to the thesis as a whole.

8.6.1 Mixed-methods approach

The research questions of the thesis (relating to effectiveness, reach and users' views and experiences) were all previously unanswered questions in this relatively new area of research. The questions constituted an appropriate focus for a health service research approach to evaluating a new treatment method for sexual difficulties. Using a mixed-methods approach allowed for a comprehensive exploration of the use of the Internet to deliver psychotherapeutic interventions for sexual difficulties, and was deemed the most appropriate set of methods to address the chosen research questions: a systematic review to address the question of effectiveness; a secondary analysis of data from a large population-based survey (Natsal-3) to address the question of reach; and a qualitative interview study with users of an IDI for sexual difficulties to address the questions relating to users' views, experiences and acceptability.

The thesis benefitted from combining newly gathered empirical data (from the qualitative interview study), with published data (from the studies in the systematic review) and previously collected survey data (from Natsal-3). Due to time and resource constraints, it would not have been possible to have collected this amount of data in a PhD, but following a mixed-methods approach made it possible to combine these types of data, and enabled the thesis to make a real contribution to new knowledge in this field.

A mixed-methods approach allowed some triangulation of the results. For example, the evidence of unmet need in this area was demonstrated quantitatively in Chapter 5 and qualitatively in Chapter 7. The results of the different studies also complemented each other well, for example, Chapter 5 demonstrated the proportions of people affected by

sexual difficulties, whereas Chapter 7 provided insight into the impact sexual difficulties can have.

8.6.2 Systematic review methods

The decision to perform a systematic review of RCTs was made because according to the hierarchy of evidence, systematic reviews constitute the highest level of evidence when it comes to assessing the effectiveness of health care interventions. RCTs were chosen as the focus of the systematic review as they are often considered the 'gold standard' method with which to establish an evidence-base for the effectiveness of a particular intervention. However, other methodologies may be worth looking at. Due to constraints on time, resources and/or expertise it is not always possible to conduct a RCT to evaluate the effectiveness of an IDI. Furthermore, the rate at which technological innovations are being developed, and the corresponding redundancy of old technology, means that faster methods of evaluating IDIs are much needed. Exploratory non-randomised methods, such as pre-post designs are a cost-effective way of determining whether interventions are worthy of further investigation, and can be useful when it may not be acceptable to randomise users (this may be particularly salient in cases where people are notably distressed about their difficulties such that withholding treatment would be unethical). Although the findings of these studies are subject to numerous threats to their validity (i.e. observed changes can be the result of historical changes, maturation in subjects and/or artefacts of testing), they are still valuable, and particularly in new areas of research. It therefore may have been illuminating to have included other designs within the review, as long as their findings were discussed within the context of their limitations.

In systematic reviews, the quality of the results, and the conclusions drawn, are closely tied to the quality of the methods used in the primary studies, and so in using these methods, one is constrained by what previous researchers have done. The methodological strengths and limitations of the studies included in the systematic review have been outlined in detail in Chapter 4. As a method, systematic reviews and meta-analyses have both strengths and limitations, and these have also been discussed in Chapter 4. Overall, through the use of explicit and robust methods, doing a systematic review allowed me to draw, albeit tentative, broad conclusions about the effects of IDIs for people with sexual difficulties, and offer suggestions for healthcare providers, researchers and policy makers. However, while systematic reviews and meta-analyses are often considered the best evidence for obtaining a definitive answer

to a research question, and were appropriate for the research questions in this thesis, alternative review methods are worthy of consideration.

As we have seen in this thesis, it can be challenging to systematically review complex interventions and synthesise data from separate heterogeneous studies; and while systematic reviews help us to understand whether a particular type of intervention has a positive effect on the problem(s) they target, they do not tell us about what works, for whom, and under what circumstances, which is the type of information needed for service and implementation planning. Realist reviews are a relatively new model of research synthesis designed to evaluate complex social interventions (Pawson, Greenhalgh, Harvey, & Walshe, 2005). By explaining the relationship between the theory (i.e. the underlying assumptions about the mechanisms by which the intervention works), the context in which the intervention is applied, and the outcomes produced by the intervention, the goal of a realist review is to determine what works for whom, and under what circumstances, in what respect, and how. While a systematic review was the appropriate method to answer the research question on effectiveness, a realist review would complement a systematic review by providing rich and detailed information about the specific interventions and how they might work most effectively (Pawson et al., 2005).

8.6.3 Survey methods and secondary data analysis

Natsal-3 used rigorous sampling procedures (i.e. by using a multistage, clustered, and stratified probability sample design); an electronic handheld computer to gather data (thereby reducing interviewer bias, item non-response/missing data due to routing and skipping errors, data transcription and transfer errors, and offering a high degree of privacy and anonymity); and reduced the effect of non-response bias by using weighting. The relatively low response rate of 57%, although generally acceptable in epidemiological studies, raises questions about the external validity of the survey findings. Furthermore, the questions in Natsal-3 were not designed for the current study and were quite broad in their wording, and therefore I could not be sure exactly how they were interpreted and whether they were sensitive enough. However, I was satisfied that they adequately captured the extent to which people were willing to look for help online for a range of sexually related issues.

8.6.4 Qualitative methods

By using qualitative research methods and developing a rapport with participants was I able to gather rich and detailed data on people's experiences of having and seeking help for sexual difficulties. Gathering this type of data at this level of detail is particularly useful in new areas of research and/or areas that are under-researched, as it helps researchers to gain an in-depth understanding of the phenomena of interest, and is useful to inform future research. In the context of sexual difficulties using these methods enabled me to gain insight and understanding regarding people's experiences of using an IDI for sexual difficulties, and uncover patterns and trends in the data. As a method, qualitative interviews have strengths and limitations that have been outlined in Chapter 7. While qualitative methods were deemed the most appropriate method to explore users' views and experiences, it is worth noting that they can be limited in their ability to sample diversely. For example, in the qualitative study, women were underrepresented and, due to limited time and resources, not all of the sexual difficulty programs in STL were evaluated.

8.6.5 Limited Patient and Public Involvement (PPI)

I used PPI when formulating the Systematic Review questions and outcomes, and to get feedback on the tone and content of the interview recruitment materials. On reflection I wish I had been able to incorporate more PPI into the current thesis. If time and resources would have allowed, it would have been beneficial to have had people who had experienced sexual difficulties involved in actually generating the research (rather than providing feedback on what had already been done), by assisting with the interviews, the analysis of the data and the dissemination of the results to participants and the public.

8.7 Fit with other literature

The area of sexual difficulties is an underfunded and understudied area (Medical Foundation for AIDS and Sexual Health, 2008), and there is currently only a sparse amount of literature on IDIs for sexual difficulties. But the findings from this thesis largely fit with the existing literature on IDIs more broadly. As with IDIs for other health and mental health issues, users are generally quite positive about the idea of IDIs, and are attracted to the privacy and convenience they afford (Darvell et al., 2015; Gerhards et al., 2011; Poole et al., 2012). The obstacles to the implementation of IDIs for sexual difficulties are also similar to those for IDIs targeting other health and mental health

issues (Christensen et al., 2009; Darvell et al., 2015; Dunn et al., 2012; Eysenbach, 2005). Low engagement is common, and much of the current research in the area of IDIs focusses on content, techniques and design features that will maximise engagement (Brouwer et al., 2011; Kelders et al., 2012; Schubart et al., 2011). IDIs, across all areas, are not widely implemented or used. Across IDIs as a whole, there is a general lack of clarity about what works for whom, and under what circumstances. Therefore, much more research is needed, using different methodologies, to answer these currently unanswered questions.

8.8 Implications

8.9 Implications for practice

The cuts in the National Health Service are beginning to take hold in the sexual health sector. Due to the NHS restructuring, commissioning of services is now the responsibility of local authorities, and without government mandated sexual health promotion, further cuts to sexual health services are likely, and will affect patient access to sexual health services and restrictions in treatment. As a low intensity method of treatment, IDIs would fit well within the current service provision for sexual difficulties as part of a stepped care model (Bower & Gilbody, 2005). IDIs have the potential to reduce some of the burden on resource-stretched face-to-face services, by reducing long waitlists and DNA rates, and freeing up face-to-face resources for those with more complex difficulties. Furthermore, if IDIs were used to provide psychoeducation to clients on waiting lists for face-to-face services or used to facilitate tasks in between sessions, they also have the potential to reduce the number of face-to-face sessions required by each client, maximise the existing sessions, and help support maintenance and relapse prevention. If delivered in sexual health and psychosexual clinic settings, IDIs would have a captive audience, which would enable the interventions to be delivered with high fidelity and over a specified period of time; and if IDIs were provided through referrals from GPs and sexual health services, although some of the existing barriers to access would remain, they could be commissioned and funded by individual trusts.

The findings of this thesis support previous research that states that therapist-supported IDIs are more effective and often rated more highly by users, than those that are not (Andersson & Titov, 2014; Khaylis et al., 2010; Mohr et al., 2011; Palmqvist et al., 2007; Schubart et al., 2011); and therefore these models may be the most appropriate to implement. However, the lack of anonymity would remain a barrier to

some, and the need for entry criteria would also exclude certain people from using this model of service.

Utilising local knowledge is vital to the success of intervention development and implementation. When implementing IDIs into routine practice, adaptations to the interventions are often required in order to fit to local contexts, however, in order to maintain effectiveness, care should be taken to identify and preserve the core components of the intervention (Bailey et al., 2015). Technical support, ongoing monitoring, and updating are further challenges for implementing sustainable IDIs for sexual difficulties into routine practice (Bailey et al., 2015).

In contrast, if delivered via open access, IDIs for sexual difficulties could address many of the barriers to face-to-face help and provide a private and convenient alternate care pathway to this hard to reach population (who are often not linked to mainstream services). IDIs have numerous advantages over face-to-face therapy (see Chapter 3), some of which include privacy, anonymity, convenience and self-pacing. However, this method of delivery would require that users first find the intervention, and second, have the motivation required to stay with it (Bailey et al., 2015). Furthermore, with the current reorganisation of the NHS, and local councils acquiring commissioning responsibilities for sexual health, and without a centrally mandated sexual health promotion commitment, it remains unclear whether IDIs for sexual difficulties could be implemented nationally, and if so who would fund them (e.g. the user, primary care or nationally).

If IDIs were delivered via open access, it would be vital to minimise any risks associated with the self-help aspects of IDIs. For example, men with erectile difficulties that are related to cardiovascular disease might not get the medical attention they need if they were to use an IDI instead of seeking face-to-face help. In *sextherapylondon* the program directs all men with erectile difficulties to contact their GP prior to starting the program, however, as this thesis has demonstrated, there are multiple barriers to accessing GPs. To prioritise the safety of users, all IDIs for sexual difficulties should endeavour to make the contacting of face-to-face services as simple as possible (e.g. by providing links to GP websites, drug and alcohol services for people with substance misuse problems, and relationship counselling and domestic violence services for people in violent/abusive relationships).

The reach of IDIs for sexual difficulties could be enhanced by linking them with existing digital systems (e.g. STI testing) or with trusted websites (e.g. NHS direct, sexual

health/psychosexual health clinic websites) or popular social networking sites (Bailey et al., 2015).

To maximise the proportion of the target population that could gain access to IDIs for sexual difficulties, it appears that mixed delivery through complementary routes (i.e. in static clinic settings and online) might be the most appropriate way to deliver IDIs in this area (Andersson & Titov, 2014; Bailey et al., 2015).

8.10 Implications for policy

Over the past decade or so there have been some important policy commitments regarding the integration of digital communications into healthcare systems to reduce unnecessary face-to-face contact between patients and healthcare professionals, provide healthcare that is flexible and convenient for patients, and at a lower cost (Bailey et al., 2015). This thesis has demonstrated that IDIs have considerable potential for patient benefit and cost saving and therefore appear to be an area that policy should aim to support, within a research and evaluation framework. However, the current unanswered questions regarding their effectiveness and how to best implement these interventions into routine practice means that IDIs are not yet at a place where they can be commissioned, and more research is needed.

8.11 Implications for research

This thesis demonstrated a high level of unmet need among people with sexual difficulties; that a relatively large number of people have sought information or support for their sex lives online; and that the levels are similar whether you use strict or broad criteria to define people with sexual difficulties. The questions used to operationalise the populations and outcome of interest (i.e. seeking help online) were deemed fit for purpose for the study in this thesis as they captured the extent to which people were willing to look for help online for a range of sexually related issues. However, due to the fact they were not designed for the study there are some concerns about the sensitivity and specificity of these questions, and therefore it would be useful to conduct a survey, using a more specific line of questioning to determine the extent to which those findings would match the current findings. For example, it would be useful to know whether people with specific sexual difficulties (and people with concerns about their sex life more broadly) would be interested in using an IDI for sexual difficulties if it was available open access and/or via primary care referral.

With regards to their positive effects on sexual and relational outcomes for women, IDIs look promising and show considerable potential as a new method of service delivery in this area. However, the number of trials in this area are small, and not all trials are well-designed, conducted and/or reported; thus many more rigorous trials are needed, with larger sample sizes, in different settings, with different populations, across the spectrum of sexual difficulties, and using the most appropriate outcomes measures for particular populations if we are to be certain of their effects for different populations and difficulties. I had originally intended to code the interventions in the systematic review using the BCT taxonomy (Michie et al., 2013), as this is a useful method of specifying the 'active ingredients' and evaluating behaviour change interventions. However, it was not possible to obtain detailed descriptions of intervention design content?? Further research is also needed to explore the mechanisms of action in IDIs for sexual difficulties, and determine which component features of IDIs are most likely to be associated with beneficial outcomes in the target populations (i.e. what constitute the active ingredients of these interventions; Michie et al., 2013).

Other suggestions for future research might be to identify individual differences that predict the acceptability of IDIs, such as a preference for human contact. Lastly, research is needed to determine the optimum exposure, 'dosage', and timing of IDIs for sexual difficulties.

This thesis demonstrated that an IDI for sexual difficulties (STL) was deemed acceptable to many users as it met many of their wants and needs. However, similar to IDIs in other areas of physical and mental-health, achieving sustained engagement with these interventions can be problematic. Qualitative observation in practice is needed to help to assess patterns of engagement and to discover any unanticipated adverse effects of interventions. Further research is also needed to determine the optimum strategies to maximise interest and engagement, including the most effective levels/types of human support.

Other remaining gaps in the literature include the following:

- The long term effects of IDIs for sexual difficulties are still unknown
- The effectiveness of alternative models of intervention delivery are currently unknown (e.g. direct online access vs facilitated access)
- Any unintended adverse effects of interventions should be actively monitored during evaluation, and after implementation

- Barriers and facilitators to implementing IDIs in clinics should be explored
- The costs of different models of implementation, and the costs of disseminating and maintaining IDIs for sexual difficulties is currently unknown, and therefore the best way to proportion the cost of an IDI (development, implementation and maintenance) over the longer term, in order to calculate the mean cost per person, is also unknown
- The best ways of measuring sexual wellbeing and capturing the complexities of sexual behaviour should be explored
- While the thesis provided some support for three of the RE-AIM evaluation dimensions (reach, effectiveness, and adoption), and highlighted questions remaining for future research in these areas, it was beyond the scope of the current thesis to explore the dimension of implementation and maintenance.

8.12 Reflections

As mentioned previously, the decision to conduct a mixed-methods thesis was made on the basis that it was the most appropriate set of methods to address the research questions. An added benefit of this decision was that it provided me with some solid and varied methodological training. I now feel knowledgeable and confident enough to be able to conduct a rigorous systematic review in any area of health or mental health. The experience of dealing with a large amount of population based survey data gave me an understanding of the complexities of dealing with large amounts of complex survey data (i.e. the purpose of clustering, stratification and weighting and how to account for these in the analysis).

In addition to receiving a high standard of methodological training, through conducting a large number of one-to-one interviews I honed my interviewing skills and gained a new appreciation and understanding of the sensitivity required when interviewing people who have experienced an incredibly personal and often stigmatising sexual difficulty. Within most societies, sexual difficulties are little spoken about. Prior to undertaking this thesis I do not think I fully grasped the extent to which some people suffer and struggle with sexual difficulties, and I certainly did not realise how connected these negative experiences are to the silence and shame surrounding sexual difficulties. The understanding and skills I have gained in this area will stand me in good stead for my upcoming training as a Clinical Psychologist, and as I continue research in this field.

8.13 Conclusions

In the current thesis I used a mixed-methods approach to evaluate the effectiveness, reach, and user views and experiences of IDIs for sexual difficulties. The three empirical studies each provide a unique contribution to the emerging field of IDIs for sexual difficulties, and have succeeded in filling some of the gaps in the literature in this area. The thesis demonstrates a high level of unmet need for help and support for people with sexual difficulties. IDIs can be effective for sexual difficulties, and they appear to have considerable potential to reach the large number of people in Britain who are currently distressed about their sex life and who might want help. IDIs appear to be acceptable to users as they meet many of their wants and needs from an intervention. Despite the various limitations of the studies within this thesis, overall, the thesis suggests that IDIs could have a valuable place in providing an alternative help source for people with sexual difficulties, especially in the light of further cuts to sexual health services.

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Appendix A Data extraction form

Initial inclusion/exclusion questions:

- 1. Is this study an RCT? Yes/No/Unclear**

- 2. Does it meet our study definition of an interactive computer based intervention? Yes/No/Unclear**

Interactive computer-based interventions:

'We define interactive computer-based interventions (ICBIs) as programmes that provide information and support (emotional, decisional and/or behaviour support) for physical and/or mental health problems via a digital platform (i.e., via a website or software). ICBIs are interactive, meaning that they require contributions from the user(s), which alter pathways within the program, to produce tailored information and feedback that is personally relevant to the user(s)'.

Exclude the following (unless they are included as a structured adjunct component of an ICBI) as they do not fit our definition of ICBIs:

- Static information only websites
- Blogs
- Forums/chat rooms
- Mobile phone text support
- E-books
- Computer-based/digital assessment tools
- Telephone helplines
- Digitally-mediated consultations

- 3. Does it meet our study definition of sexual problems? Yes/No/Unclear**

Sexual problems

'Difficulty during any stage (desire, arousal, orgasm, and resolution) of the sexual response cycle, which prevents an individual and/or their sexual partner/s from enjoying sexual activity'.

If the answer to all 3 questions is Yes, please continue on to the full text data extraction items. → → →

If the answer to any question is No, please indicate reason for exclusion and stop here.

If the answer to any question is Unclear, please seek clarification at supervision before proceeding.

Full text data extraction items

1. Study ID:
2. Study title:
3. Sexual problem(s):

Author details

4. Names of authors:
5. Affiliations (institution):
6. Email address (of first author):
7. Country (of first author):
8. Year of publication:

Study characteristics

9. Target population (E.g., Adult women, adolescent males, MSM, menopausal women etc.):
10. Gender:
11. Age (groups):
12. Setting or context (E.g., all online or some face-to-face contact with researchers):
13. Country of sample:
14. Method of recruitment:
15. Method of assessment of sexual difficulties:
16. Other inclusion/exclusion criteria for participation:
17. Incentive or cost to participate:
18. Total study duration:
19. Year of study:

Risk of bias (use additional question sheet if required)

20. Adequate sequence generation? Yes/No/Unclear
 - a. Description:
21. Allocation concealment? Yes/No/Unclear
 - a. Description:
22. Blinding? Yes/No/Unclear
 - a. Description:
23. Incomplete outcome data address (for all outcomes)? Yes/No/Unclear
 - a. Description
24. Free of selective outcome reporting? Yes/No/Unclear
 - a. Description
25. Other concerns about bias? Yes/No/Unclear
 - a. Description

Intervention characteristics

26. Description of intervention (Include the degree of user interactivity offered by the program and the ways in which the program was tailored and produced feedback. Give examples of component interactive features and their purpose – feedback on knowledge tests, scenarios tailored to participants' previous answers, feedback on goal achievement etc.):
27. Was theory mentioned in the relationship to the intervention design?:
28. Recommended frequency and duration of use of intervention:
29. Web address or link to view intervention:
30. Mode of delivery (PC or smartphone etc.):
31. Digital platform (CD-rom or internet):
32. Access (open or closed):
33. Describe how participants gained access to intervention:
34. Target user (individual, couple, group):
35. Level of human support (Entirely self-guided; Primarily self-guided [human involved in assessment, initial role and instructions on how to use the ICBI]; Partial human support [human in regular contact with user, but no clinical

content in the contact); Full support (human in regular contact with user; contact includes clinical contact); Adjunct component of face-to-face therapy

36. Type of support (professional, peer, technical):
37. Frequency of support:
38. Duration of support:
39. Mode of delivery of support (email, telephone, skype etc.):
40. Communication type of support (synchronous or asynchronous):

Comparator

41. Total number of study arms (inc. intervention and comparators):
42. Comparator type(s) (i.e., Minimally active conditions [Waitlist control; Information only written materials]; Active conditions [Usual treatment; Pharmacological interventions; Face to face treatment; Different type of ICBI]):
43. Description of comparator(s):

Analysis

44. Did they use intention to treat analysis? **yes/no/unclear**
45. Was there any sub-group analysis? **yes/no/unclear**
 - a. If yes, was the sub-group analysis pre-specified? **yes/no/unclear**

Outcomes

46. Include the following information for each outcome:
 - Timing of measurements & follow-up
 - Primary or secondary outcomes (if stated by authors)
 - Meaning of a high or low score
 - Details of whether scales used were published or validated
 - Total study duration

Results

47. Number of participants initially allocated to each intervention group

For each outcome of interest:

48. Time-point

49. Sample size in each intervention group at follow-up

50. Summary data: Means & SDs for each intervention group

51. Key conclusion of the authors

Miscellaneous

52. Funding source:

53. Ethical permissions (Yes/No/Unclear)

54. Described procedures for obtaining informed consent (Yes/No/Unclear)

55. Consumer involvement?

a. (Yes/No/Unclear)

b. If yes, please describe

56. Pre-trial testing?

a. (Yes/No/Unclear)

b. If yes, please describe:

57. Correspondence with the author required? Yes/No/Unclear

This data extraction form was developed using the Cochrane Collaboration Guidelines (Higgins & Green, 2011), Guidelines for Executing and Reporting Internet Intervention Research (Proudfoot et al., 2011), and the CONSORT-EHEALTH Checklist (Eysenbach, 2011).

Appendix B Database search strategies

CINAHL (with SIGN filter)

- 1) (MH "Clinical Trials+")
- 2) PT Clinical trial
- 3) TX clinic* n1 trial*
- 4) TX ((singl* n1 blind) or (singl* n1 mask*)) or TX ((doubl* n1 blind) or (doubl* n1 mask*)) or TX ((tripl* n1 blind*) or (tripl* n1 mask*)) or TX ((trebl* n1 mask*))
- 5) TX randomi* control* trial*
- 6) (MH "Random Assignment")
- 7) TX random * allocat*
- 8) TX placebo*
- 9) (MH "Placebos")
- 10) (MH "Quantitative Studies")
- 11) TX allocat* random*
- 12) S1 or S2 or S3 or S4 or S5 or S6 or S7 or S8 or S9 or S10 or S1
- 13) (MH "Sexual Dysfunction, Female+") OR (MH "Sexual Dysfunction, Male+") OR (MH "Sexual Dysfunction (Saba CCC)") OR (MH "Sexual Dysfunction (NANDA)") OR (MH "Psychosexual Disorders+")
- 14) (MH "Sexual Addiction") OR (MH "Internet Pornography Addiction")
- 15) (MH "Sexual Counseling") OR (MH "Sexual Counseling (Iowa NIC)")
- 16) TX ((sex* N2 aversion) or ((lack or loss) N2 (sex*N2 enjoy*)) or (sexual N1 anhedonia))
- 17) TX ((early or premature or rapid or retrograde or inhibited or disorder*) N3 ejaculat*)
- 18) TX ((sex* N1 (addict* or compuls* or impuls*)) or (problematic N1 sex* N1 behavio*) or hypersexual* or (excessive N1 sex* N1 drive) or nymphomania or satyriasis)
- 19) TX ((desire N1 disorder) or (lack or loss) N2 desire or frigid* or libido)
- 20) TX ((orgasm* N1 (disorder or dysfunction or inhibit*)) or anorgasm*)
- 21) TX (((sexual or genital) N1 (arousal or response)) or (erectile N1 (dysfunction* or disorder* or failure)) or impoten* or (persistent N1 genital N1 arousal))
- 22) TX ((sexual N1 pain) or (genito-pelvic pain) or dyspareunia or vaginism* or vestibulod* or vulvodynia or unconsummat*)
- 23) (MH "Computer Communication Networks+") OR (MH "Telehealth+") OR (MH "Telecommunications+") OR (MH "Electronic Bulletin Boards+") OR (MH "Electronic Mail") OR (MH "Instant Messaging") OR (MH "Interactive Voice Response Systems") OR (MH "Internet+") OR (MH "Television") OR (MH "Videoconferencing") OR (MH "Voice Mail") OR (MH "Wireless Communications")
- 24) (MH "Health Informatics") OR (MH "Medical Informatics")
- 25) (MH "Decision Support Systems, Clinical")

- 26) (MH "Educational Technology")
- 27) (MH "Multimedia")
- 28) (MH "Health Education")
- 29) (MH "Computers, Hand-Held") OR (MH "Therapy, Computer Assisted") OR (MH "Decision Making, Computer Assisted+") OR (MH "Computer Assisted Instruction")
- 30) (MH "User-Computer Interface+")
- 31) (MH "Hypermedia")
- 32) (MH "Video Games") OR (MH "Virtual Reality") OR (MH "Artificial Intelligence")
- 33) (MH "Computer Graphics") OR (MH "Computers, Hand-Held")
- 34) TX (Computer* or microcomputer*)
- 35) TX (Internet or (local N1 area N1 network*) or LAN)
- 36) TX (Decision tree* or decision aid*)
- 37) TX Software
- 38) TX ((Compact N1 (disk* or disc*)) or cd-rom* or CDROM*)
- 39) TX ((Mobile or cell*) N1 (phone or telephone)) or iphone or smartphone or apps
- 40) TX ((Electronic N1 mail) or e-mail or email)
- 41) TX (Video or DVD)
- 42) ((World N1 wide N1 web) or world-wide-web or www or (world-wide N1 web) or (worldwide N1 web) or website*)
- 43) TX (Online or on-line)
- 44) TX (Chat room* or chatroom*)
- 45) TX (blog* or web-log* or weblog*)
- 46) TX ((bulletin N1 board*) or bulletinboard* or messageboard* or message board*)
- 47) TX (Interactive N1 health N1 communicat*)
- 48) TX (interactive N1 televis*)
- 49) TX (cyberpsychology or cybertherapy or etherapy or ecounsel* or telehealth)
- 50) TX social network*
- 51) TX (sexual N1 ((wellbeing or wellbeing) or enjoyment or pleasure or self-esteem or medicine or response or satisfaction or communication))
- 52) TX sexology
- 53) TX ((sex* or psychosexual) N2 (counsel* or therap* of intervention* or treatment*))
- 54) S13 or S14 or S15 or S16 or S17 or S18 or S19 or S20 or S21 or S22 or S51 or S52 or S5
- 55) S23 or S24 or S25 or S26 or S27 or S28 or S29 or S30 or S31 or S32 or S33 or S34 or S35 or S36 or S37 or S38 or S39 or S40 or S41 or S42 or S31 or S31 or S44 or S45 or S46 or S47 or S48 or S49 or S50
- 56) S54 and S55
- 57) S12 and S56

CENTRAL (Cochrane)

- 1) ((sex* NEAR/2 aversion) or ((lack or loss) NEAR/2 (sex* NEAR/2 enjoy*)) or (sexual NEXT adhedonia)) OR (ejaculat* NEAR/3 (early or premature or rapid or retrograde or inhibited or disorder*)) OR ((sex* NEXT (addict* or compuls* or impuls*)) or (problematic NEXT sex* NEXT behavio*) or hypersexual* or (excessive NEXT sex* NEXT drive) or nymphomania or satyriasis) OR ((desire NEXT disorder) or ((lack or loss) NEAR/2 desire) or frigid* or libido) OR ((orgasm* NEXT (disorder or dysfunction or inhibit*)) or anorgasm*) OR (((sexual or genital) NEXT (arousal or response)) or (erectile NEXT (dysfunction* or disorder* or failure)) or impoten* or (persistent NEXT genital NEXT arousal)) OR ((sexual NEXT pain) or dyspareunia or vaginism* or vestibulodynia or vulvodynia or unconsummat*) OR (sexual NEAR/1 (wellbeing or well being or enjoyment or pleasure or self-esteem or medicine or response or satisfaction or communication)) OR sexology OR ((sex* or psychosex*) NEAR/2 (counsel* or therap* or intervention* or treatment*)):ti,ab,kw in Trials
- 2) MeSH descriptor Sexual Dysfunctions, Psychological explode all trees
- 3) MeSH descriptor Sexual Dysfunction, Physiological explode all trees
- 4) MeSH descriptor Internet explode all trees
- 5) MeSH descriptor Decision Making, Computer-Assisted explode all trees
- 6) MeSH descriptor Artificial Intelligence explode all trees
- 7) MeSH descriptor Computers explode all trees
- 8) MeSH descriptor Computer-Assisted Instruction explode all trees
- 9) (Computer* or microcomputer*) OR (Internet or (local NEXT area NEXT network*) or LAN) OR (Decision tree* or decision aid*) OR (software) OR ((Compact NEXT (disk* or disc*)) or cd-rom* or CDROM*) OR (Mobile or cell*) NEXT (phone or telephone) or iphone or smartphone or apps OR ((Electronic NEXT mail) or e-mail or email) OR (Video or DVD) OR ((World NEXT wide NEXT web) or world-wide-web or www or (world-wide NEXT web) or (worldwide NEXT web) or website*) OR (Online or on-line) OR (Chat room* or chatroom*) OR (blog* or web-log* or weblog*) OR ((bulletin NEXT board*) or bulletinboard* or messageboard* or message board*) OR (Interactive NEXT health NEXT communicat*) OR (interactive NEXT televis*) OR (cyberpsychology or cybertherapy or etherapy or ecounsel* or telehealth) OR social network*:ti,ab,kw in Trials
- 10) MeSH descriptor Ejaculation explode all trees
- 11) MeSH descriptor Libido explode all trees
- 12) MeSH descriptor Orgasm explode all trees
- 13) MeSH descriptor Sexual behavior explode all trees
- 14) MeSH descriptor Sex counseling explode all trees
- 15) MeSH descriptor Sex education explode all trees
- 16) MeSH descriptor Sexology explode all trees
- 17) MeSH descriptor Erectile dysfunction explode all trees
- 18) MeSH descriptor Vaginismus explode all trees
- 19) MeSH descriptor Dyspareunia explode all trees
- 20) MeSH descriptor Vulvodynia explode all trees

- 21) #1 OR #2 OR #3 OR #10 OR #11 OR #12 OR #13 OR #14 OR #15 OR #16 OR #17 OR #18 OR #19 OR #20
- 22) #4 OR #5 OR #6 OR #7 OR #8 OR #9
- 23) #21 AND #2

EMBASE (with SIGN filter)

- 1) Clinical trial/
- 2) Randomized controlled trial/
- 3) Randomization/
- 4) Single blind procedure/
- 5) Double blind procedure/
- 6) Crossover procedure/
- 7) Placebo/
- 8) Randomi?ed controlled trial\$.tw.
- 9) Rct.tw.
- 10) Random allocation.tw.
- 11) Randomly allocated.tw.
- 12) Allocated randomly.tw.
- 13) (allocated adj2 random).tw.
- 14) Single blind\$.tw.
- 15) Double blind\$.tw.
- 16) ((treble or triple) adj blind\$.tw.
- 17) Placebo\$.tw.
- 18) Prospective study/
- 19) 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18
- 20) exp sexual dysfunction/
- 21) exp sexual function/
- 22) exp psychosexual disorder/
- 23) exp male sexual dysfunction/
- 24) exp female sexual dysfunction/
- 25) exp sexual satisfaction/
- 26) exp sexology/
- 27) exp sex therapy/ or exp sexual counseling/
- 28) exp sexual education/
- 29) ((sex* adj2 aversion) or ((lack or loss) adj2 (sex\$ adj2 enjoy\$)) or (sexual adj anhedonia)).mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]
- 30) (ejaculat\$ adj3 (early or premature or rapid or retrograde or inhibited or disorder\$)).mp. [mp=title, abstract, subject headings, heading word, drug trade

- name, original title, device manufacturer, drug manufacturer, device trade name, keyword]
- 31) ((sex\$ adj (addict\$ or compuls\$ or impuls\$)) or (problematic adj sex\$ adj behavio\$) or hypersexual\$ or (excessive adj sex\$ adj drive) or nymphomania or satyriasis).mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]
 - 32) ((desire adj disorder) or ((lack or loss) adj2 desire) or frigid\$ or libido).mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]
 - 33) ((orgasm\$ adj (disorder or dysfunction or inhibit\$)) or anorgasm\$).mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]
 - 34) (((sexual or genital) adj (arousal or response)) or (erectile adj (dysfunction\$ or disorder\$ or failure)) or impoten\$ or (persistent adj genital adj arousal)).mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]
 - 35) ((sexual adj pain) or genito-pelvic pain or dyspareunia or vaginism\$ or vestibulod\$ or vulvodynia or unconsummat\$).mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]
 - 36) (sexual adj1 (wellbeing or well being or enjoyment or pleasure or self-esteem or medicine or response or satisfaction or communication)).mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]
 - 37) sexology.mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]
 - 38) ((sex\$ or psychosexual) adj2 (counsel* or therap* or intervention* or treatment*)).mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]
 - 39) Exp human computer interaction/ or exp computer/ or exp computer assisted therapy/
 - 40) exp decision support system/
 - 41) exp educational technology/
 - 42) exp Internet/
 - 43) exp multimedia/
 - 44) exp telecommunication/
 - 45) (Computer\$ or microcomputer\$).mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]
 - 46) (Internet or (local adj area adj network\$) or LAN).mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]

- 47) (Decision tree\$ or decision aid\$).mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]
- 48) software.mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]
- 49) (Compact disk\$ or compact disc\$ or cd-rom\$ or CDROM\$).mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]
- 50) (((Mobile or cell\$) adj (phone or telephone)) or iphone or smartphone or apps).mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]
- 51) ((Electronic adj mail) or e-mail or email).mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]
- 52) (Video or DVD).mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]
- 53) ((World adj wide adj web) or world-wide-web or www or (world-wide adj web) or (worldwide adj web) or website\$).mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]
- 54) (Online or on-line).mp. [mp=title, original title, abstract, name of substance word, subject heading word]
- 55) (Chat room\$ or chatroom\$).mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]
- 56) (blog\$ or web-log\$ or weblog\$).mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]
- 57) ((bulletin adj board\$) or bulletinboard\$ or messageboard\$ or message board\$).mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]
- 58) (Interactive adj health adj communicat\$).mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]
- 59) (interactive adj televis\$).mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]
- 60) (cyberpsychology or cybertherapy or etherapy or ecounsel\$ or telehealth).mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]
- 61) social network\$.mp. [mp=title, abstract, original title, name of substance word, subject heading word, protocol supplementary concept, rare disease supplementary concept, unique identifier]

- 62) 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34 or 35 or 36 or 37 or 38
- 63) 39 or 40 or 41 or 42 or 43 or 44 or 45 or 46 or 47 or 48 or 49 or 50 or 51 or 52 or 53 or 54 or 55 or 56 or 57 or 58 or 59 or 60 or 6
- 64) 62 and 6
- 65) 19 and 6

ERIC (no filter)

(all(((sex* NEAR/2 aversion) OR ((lack OR loss) NEAR/2 (sex* NEAR/2 enjoy*)) OR (sexual NEAR/4 anhedonia))) OR all((ejaculat* NEAR/3 (early OR premature OR rapid OR retrograde OR inhibited OR disorder*))) OR all(((sex* NEAR/1 (addict* OR compuls* OR impuls*)) OR (problematic NEAR/1 sex* NEAR/1 behavio*) OR hypersexual* OR (excessive NEAR/1 sex* NEAR/1 drive) OR nymphomania OR satyriasis)) OR all((((desire NEAR/1 disorder) OR frigid* OR libido OR ((lack OR loss) NEAR/2 desire)))) OR all((orgasm* NEAR/1 (disorder OR dysfunction OR inhibit*)) OR anorgasm*) OR all(((sexual OR genital) NEAR/1 (arousal OR response)) OR (erectile NEAR/1 (dysfunction* OR disorder* OR failure)) OR impoten* OR (persistent NEAR/1 genital NEAR/1 arousal)) OR all(((sexual NEAR/1 pain) OR "genito-pelvic pain" OR dyspareunia OR vaginism* OR vestibulod* OR vulvodynia OR unconsummat*)) OR all((sexology) OR all(((sex* OR psychosexual) NEAR/2 (counsel* OR therap* OR intervention* OR treatment*))) OR all((sexual NEAR/1 (wellbeing OR "well being" OR enjoyment OR pleasure OR self-esteem OR medicine OR response OR satisfaction OR communication)))) AND

((su.Exact("intervention" OR "interventions") AND ("internet (37500)" OR "internet")) OR all((Computer* OR microcomputer*)) OR all((Internet OR (local NEAR/1 area NEAR/1 network*) OR LAN)) OR all(("Decision tree*" OR "decision aid*")) OR all((software) OR all("cd-rom*" OR CDROM* OR (Compact NEAR/1 (disk* OR disc*))) OR all(((Mobile OR cell*) NEAR/1 (phone OR telephone)) OR iphone OR smartphone OR apps) OR all((Electronic NEAR/1 mail) OR "e-mail" OR email) OR all((video OR dvd) OR all(((World NEAR/1 wide NEAR/1 web) OR "world-wide-web" OR www OR ("world-wide" NEAR/1 web) OR (worldwide NEAR/1 web) OR website*)) OR all((online OR "on line") OR all(("Chat room*" OR chatroom*) OR all((blog* OR "web-log*" OR weblog*) OR all((bulletin NEAR/1 board*) OR bulletinboard* OR messageboard* OR "message board*")) OR all(Interactive NEAR/1 health NEAR/1 communicat*) OR all((Interactive NEAR/1 health) NEAR/1 communicat*) OR all((cyberpsychology OR cybertherapy OR etherapy OR ecounsel* OR telehealth) OR all("social network*"))

IBSS (no filter)

(all(((sex* NEAR/2 aversion) OR ((lack OR loss) NEAR/2 (sex* NEAR/2 enjoy*)) OR (sexual NEAR/4 anhedonia))) OR all((ejaculat* NEAR/3 (early OR premature OR rapid OR retrograde OR inhibited OR disorder*))) OR all(((sex* NEAR/1 (addict* OR compuls* OR impuls*)) OR (problematic NEAR/1 sex* NEAR/1 behavio*) OR hypersexual* OR (excessive NEAR/1 sex* NEAR/1 drive) OR nymphomania OR satyriasis)) OR all((((desire NEAR/1 disorder) OR frigid* OR libido OR ((lack OR loss) NEAR/2 desire)))) OR all((orgasm* NEAR/1 (disorder OR dysfunction OR inhibit*)) OR anorgasm*) OR all(((sexual OR genital) NEAR/1 (arousal OR response)) OR (erectile NEAR/1 (dysfunction* OR disorder* OR failure)) OR impoten* OR (persistent NEAR/1 genital NEAR/1 arousal)) OR all(((sexual NEAR/1 pain) OR "genito-pelvic pain" OR dyspareunia OR vaginism* OR vestibulod* OR vulvodynia OR unconsummat*)) OR all((sexology) OR all(((sex* OR psychosexual) NEAR/2 (counsel* OR therap* OR intervention* OR treatment*))) OR all((sexual NEAR/1 (wellbeing OR "well being" OR

enjoyment OR pleasure OR self-esteem OR medicine OR response OR satisfaction OR communication)))) AND

((su.Exact("intervention" OR "interventions") AND ("internet (37500)" OR "internet")) OR all((Computer* OR microcomputer*)) OR all((Internet OR (local NEAR/1 area NEAR/1 network*) OR LAN)) OR all(("Decision tree*" OR "decision aid*")) OR all(software) OR all("cd-rom*" OR CDROM* OR (Compact NEAR/1 (disk* OR disc*))) OR all(((Mobile OR cell*) NEAR/1 (phone OR telephone)) OR iphone OR smartphone OR apps) OR all((Electronic NEAR/1 mail) OR "e-mail" OR email) OR all(video OR dvd) OR all(((World NEAR/1 wide NEAR/1 web) OR "world-wide-web" OR www OR ("world-wide" NEAR/1 web) OR (worldwide NEAR/1 web) OR website*)) OR all(online OR "on line") OR all("Chat room*" OR chatroom*) OR all(blog* OR "web-log*" OR weblog*) OR all((bulletin NEAR/1 board*) OR bulletinboard* OR messageboard* OR "message board*") OR all(Interactive NEAR/1 health NEAR/1 communicat*) OR all((Interactive NEAR/1 health) NEAR/1 communicat*) OR all(cyberpsychology OR cybertherapy OR etherapy OR ecounsel* OR telehealth) OR all("social network*"))

MEDLINE (with SIGN filter)

1. Randomized Controlled Trials as Topic/
2. Randomized controlled trial/
3. Random Allocation/
4. Double blind method/
5. Single blind method/
6. Clinical trial/
7. Clinical trial, phase i.pt.
8. Clinical trial, phase ii.pt.
9. Clinical trial, phase iii.pt.
10. Clinical trial, phase iv.pt.
11. controlled clinical trial.pt.
12. Randomized controlled trial.pt.
13. multicenter study.pt.
14. clinical trial.pt.
15. exp Controlled Clinical Trials as Topic/
16. (clinical adj trial\$.tw.
17. ((single\$ or doubl\$ or treb\$ or tripl\$) adj (blind\$3 or mask\$3)).tw.
18. PLACEBOS/
19. placebo\$.tw.
20. randomly allocated.tw.
21. (allocated adj2 random\$).tw.
22. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or
23. exp Sexual Dysfunction, Physiological/
24. exp Sexual Dysfunction, Psychological/
25. exp Ejaculation/

26. exp Libido/
27. exp Sex counseling/
28. exp Couples therapy/
29. exp Sexual Behavior/px (Psychology)
30. exp Compulsive Behavior/px (Psychology)
31. 29 and 30
32. ((sex* adj2 aversion) or ((lack or loss) adj2 (sex\$ adj2 enjoy\$)) or (sexual adj anhedonia)).mp. [mp=title, abstract, original title, name of substance word, subject heading word, protocol supplementary concept, rare disease supplementary concept, unique identifier]
33. (ejaculat\$ adj3 (early or premature or rapid or retrograde or inhibited or disorder\$)).mp. [mp=title, abstract, original title, name of substance word, subject heading word, protocol supplementary concept, rare disease supplementary concept, unique identifier]
34. ((sex\$ adj (addict\$ or compuls\$ or impuls\$)) or (problematic adj sex\$ adj behavio\$) or hypersexual\$ or (excessive adj sex\$ adj drive) or nymphomania or satyriasis).mp. [mp=title, abstract, original title, name of substance word, subject heading word, protocol supplementary concept, rare disease supplementary concept, unique identifier]
35. ((desire adj disorder) or (lack or loss) adj2 desire) or frigid\$ or libido).mp. [mp=title, abstract, original title, name of substance word, subject heading word, protocol supplementary concept, rare disease supplementary concept, unique identifier]
36. ((orgasm\$ adj (disorder or dysfunction or inhibit\$)) or anorgasm\$).mp. [mp=title, abstract, original title, name of substance word, subject heading word, protocol supplementary concept, rare disease supplementary concept, unique identifier]
37. (((sexual or genital) adj (arousal or response)) or (erectile adj (dysfunction\$ or disorder\$ or failure)) or impoten\$ or (persistent adj genital adj arousal)).mp. [mp=title, abstract, original title, name of substance word, subject heading word, protocol supplementary concept, rare disease supplementary concept, unique identifier]
38. ((sexual adj pain) or (genito-pelvic pain) or dyspareunia or vaginism\$ or vestibulod\$ or vulvodynia or unconsummatus).mp. [mp=title, abstract, original title, name of substance word, subject heading word, protocol supplementary concept, rare disease supplementary concept, unique identifier]
39. (sexual adj1 (wellbeing or well being or enjoyment or pleasure or self-esteem or medicine or response or satisfaction or communication)).mp. [mp=title, abstract, original title, name of substance word, subject heading word, protocol supplementary concept, rare disease supplementary concept, unique identifier]
40. sexology.mp. [mp=title, abstract, original title, name of substance word, subject heading word, protocol supplementary concept, rare disease supplementary concept, unique identifier]
41. ((sex\$ or psychosexual) adj2 (counsel* or therap* or intervention* or treatment*)).mp. [mp=title, abstract, original title, name of substance word, subject heading word, protocol supplementary concept, rare disease supplementary concept, unique identifier]
42. exp Computer Communication Networks/

43. exp Medical Informatics/
44. exp Medical Informatics Applications/
45. exp Decision Support Techniques/
46. exp Educational Technology/
47. exp Audiovisual Aids/
48. exp Telecommunications/
49. exp Multimedia
50. exp Health Education/
51. exp Computer-Assisted Instruction/
52. exp Public Health Informatics/
53. exp User-Computer Interface/
54. exp Hypermedia/
55. exp Video Games/
56. exp Computer Graphics/
57. exp Internet/
58. (Computer\$ or microcomputer\$).mp. [mp=title, original title, abstract, name of substance word, subject heading word]
59. (Internet or (local adj area adj network\$) or LAN).mp. [mp=title, original title, abstract, name of substance word, subject heading word]
60. (Decision tree\$ or decision aid\$).mp. [mp=title, original title, abstract, name of substance word, subject heading word]
61. software.mp. [mp=title, original title, abstract, name of substance word, subject heading word]
62. (Compact adj (disk\$ or disc\$) or cd-rom\$ or CDROM\$).mp. [mp=title, original title, abstract, name of substance word, subject heading word]
63. (((Mobile or cell\$) adj (phone or telephone)) or iphone or smartphone or apps).mp. [mp= title, original title, abstract, name of substance word, subject heading word]
64. ((Electronic adj mail) or e-mail or email).mp. [mp=title, original title, abstract, name of substance word, subject heading word]
65. (Video or DVD).mp. [mp=title, original title, abstract, name of substance word, subject heading word]
66. ((World adj wide adj web) or world-wide-web or www or (world-wide adj web) or(worldwide adj web) or website\$).mp. [mp=title, original title, abstract, name of substance word, subject heading word]
67. (Online or on-line).mp. [mp=title, original title, abstract, name of substance word, subject heading word]
68. (Chat room\$ or chatroom\$).mp. [mp=title, original title, abstract, name of substance word, subject heading word]
69. (blog\$ or web-log\$ or weblog\$).mp. [mp=title, original title, abstract, name of substance word, subject heading word]

70. ((bulletin adj board\$) or bulletinboard\$ or messageboard\$ or message board\$).mp. [mp=title, original title, abstract, name of substance word, subject heading word]
71. (Interactive adj health adj communicat\$).mp. [mp=title, original title, abstract, name of substance word, subject heading word]
72. (interactive adj televis\$).mp. [mp=title, original title, abstract, name of substance word, subject heading word]
73. (cyberpsychology or cybertherapy or etherapy or ecounsel\$ or telehealth).mp. [mp=title, abstract, original title, name of substance word, subject heading word, protocol supplementary concept, rare disease supplementary concept, unique identifier]
74. social network\$.mp. [mp=title, abstract, original title, name of substance word, subject heading word, protocol supplementary concept, rare disease supplementary concept, unique identifier]
75. 23 or 24 or 25 or 26 or 27 or 28 or 31 or 32 or 33 or 34 or 35 or 36 or 37 or 38 or 39 or 40 or
76. 42 or 43 or 44 or 45 or 46 or 47 or 48 or 49 or 50 or 51 or 52 or 53 or 54 or 55 or 56 or 57 or 58 or 59 or 60 or 61 or 62 or 63 or 64 or 65 or 66 or 67 or 68 or 69 or 70 or 71 or 72 or 73 or 7
77. 75 and 76
78. 22 and 77

PSYCINFO (with JB filter)

- 1) clinical trials.de.
- 2) ((Randomised adj1 controlled adj1 trial) or (randomized adj1 controlled adj1 trial)).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
- 3) (clinic\$ adj1 trial\$).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
- 4) ((singl\$ or doubl\$ or trebl\$ or tripl\$) adj1 (blind\$ or mask\$)).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
- 5) placebo\$.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
- 6) placebo.de.
- 7) random\$.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
- 8) experiment\$ control\$.de.
- 9) (random\$ adj1 allocat\$).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
- 10) ((pre adj1 (test or pretest)) or (post adj1 (test or posttest))).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
- 11) trial.ti,ab.
- 12) RCT.ti,ab.

- 13) (experimental design\$ or experiment method\$).de.
- 14) 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 1
- 15) exp sexual function disturbances/ or exp psychosexual behavior/ or exp dyspareunia/ or exp erectile dysfunction/ or exp female sexual dysfunction/ or exp inhibited sexual desire/ or exp premature ejaculation/ or exp priapism/ or exp vaginismus/
- 16) exp Sex Therapy/
- 17) exp Sex Education/
- 18) exp sexual addiction/ or exp hypersexuality/ or exp promiscuity/
- 19) exp Libido/ or exp Sex drive/
- 20) ((sex* adj2 aversion) or ((lack or loss) adj2 (sex\$ adj2 enjoy\$)) or (sexual adj anhedonia)).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
- 21) (ejaculat\$ adj3 (early or premature or rapid or retrograde or inhibited or disorder\$)).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
- 22) ((sex\$ adj (addict\$ or compuls\$ or impuls\$)) or (problematic adj sex\$ adj behavio\$) or hypersexual\$ or (excessive adj sex\$ adj drive) or nymphomania or satyriasis).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
- 23) ((desire adj disorder) or ((lack or loss) adj2 (desire or libido)) or frigidity).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
- 24) ((orgasm\$ adj (disorder or dysfunction or inhibit\$)) or anorgasm\$).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
- 25) (((sexual or genital) adj (arousal or response)) or (erectile adj (dysfunction\$ or disorder\$ or failure)) or impoten\$ or (persistent adj genital adj arousal)).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
- 26) ((sexual adj pain) or (genito-pelvic pain) or dyspareunia or vaginism\$ or vestibulod* or vulvodynia or unconsummat\$).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
- 27) (sexual adj1 (wellbeing or well being or enjoyment or pleasure or self-esteem or medicine or response or satisfaction or communication)).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
- 28) sexology.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
- 29) ((sex\$ or psychosexual) adj2 (counsel* or therap* or intervention* or treatment*)).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
- 30) exp Computer Applications/
- 31) exp Computer Assisted Therapy/
- 32) exp Computer Assisted Instruction/
- 33) exp Computer Games/
- 34) exp Computer Mediated Communication/

- 35) exp Computer Software/
- 36) exp Decision Support Systems/
- 37) exp Educational Audiovisual Aids/
- 38) exp Electronic Communication/
- 39) exp Expert Systems/
- 40) exp Health Education/
- 41) exp Human Computer Interaction/
- 42) exp Hypermedia/
- 43) exp Intelligent Agents/
- 44) exp Internet/
- 45) exp Multimedia/
- 46) exp Online Social Networks/
- 47) exp Online Therapy/
- 48) exp Telemedicine/
- 49) (computer\$ or microcomputer\$).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
- 50) (Internet or (local adj area adj network\$) or LAN).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
- 51) (Decision tree\$ or decision aid\$).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
- 52) software.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
- 53) ((Compact adj (disk\$ or disc\$)) or cd-rom\$ or CDROM\$).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
- 54) ((Mobile or cell\$) adj (phone or telephone) or iphone or smartphone or apps).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
- 55) ((Electronic adj mail) or e-mail or email).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
- 56) (Video or DVD).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
- 57) ((World adj wide adj web) or world-wide-web or www or (world-wide adj web) or (worldwide adj web) or website\$).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
- 58) (Online or on-line).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
- 59) (Chat room\$ or chatroom\$).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
- 60) (blog\$ or web-log\$ or weblog\$).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
- 61) ((bulletin adj board\$) or bulletinboard\$ or messageboard\$ or message board\$).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]

- 62) (Interactive adj health adj communicat\$).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
- 63) (interactive adj televis\$).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
- 64) (cyberpsychology or cybertherapy or etherapy or ecounsel\$ or telehealth).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
- 65) social network\$.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
- 66) 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29
- 67) 30 or 31 or 32 or 33 or 34 or 35 or 36 or 37 or 38 or 39 or 40 or 41 or 42 or 43 or 44 or 45 or 46 or 47 or 48 or 49 or 50 or 51 or 52 or 53 or 54 or 55 or 56 or 57 or 58 or 59 or 60 or 61 or 62 or 63 or 64 or 65
- 68) 66 and 67
- 69) 14 and 68

Web of Science

TS=(((sex* near/1 aversion) or ((lack or loss) near/2 (sex* near/2 enjoy*)) or (sexual near/1 anhedonia)) OR (ejaculat* near/3 (early or premature or rapid or retrograde or inhibited or disorder*)) OR ((sex* near/1 (addict* or compuls* or impuls*)) or (problematic near/1 sex* near/1 behavio*) or hypersexual* or (excessive near/1 sex* near drive) or nymphomania or satyriasis) OR ((desire near/1 disorder) or ((lack or loss) near/2 desire) or frigid* or libido) OR ((orgasm* near/1 (disorder or dysfunction or inhibit*)) or anorgasm*) OR (((sexual or genital) near/1 (arousal or response)) or (erectile near/1 (dysfunction* or disorder* or failure)) or impoten* or (persistent near/1 genital near/1 arousal)) OR (sexology) OR ("sexual wellbeing" or "sexual well being" or "sexual enjoyment" or "sexual pleasure" or "sexual self-esteem" or "sexual medicine" or "sexual response" or "sexual satisfaction" or "sexual communication") OR ((sex* or psychosexual) near/2 (counsel* or therap* or intervention* or treatment*)) OR ((sexual near/1 pain) or ("genito-pelvic pain disorder") dyspareunia or vaginism* or vestibulod* or vulvodynia or unconsummat*))

AND TS=(((Computer* or microcomputer*) OR (LAN or Internet or (local near/1 area near/1 network*)) OR (Decision tree* or decision aid*) Software ((Compact near/1 (disk* or disc*)) or cd-rom* or CDROM*) OR ((Mobile or cell*) near/1(phone or telephone) or iphone or smartphone or apps) OR ((Electronic near/1 mail) or e-mail or email) OR (Video or DVD) OR ((World near/1 wide near/1 web) or world-wide-web or www or (world-wide near/1 web) or (worldwide near/1 web) or website*) OR (Online or on-line) OR ("Chat room*" or chatroom*) OR (blog* or web-log* or weblog*) OR ((bulletin near/1 board*) or bulletinboard* or messageboard* or "message board*") OR (Interactive near/1 health near/1 communicat*) OR (interactive near/1 televis*) OR ("social network*" or socialnetwork) OR (cyberpsychology or cybertherapy or etherapy or ecounsel* or telehealth)))

Appendix C
Studies excluded at full text and reasons for exclusion

Authors, date	Reason for exclusion
Binik, Y. M., Westbury, C. F., & Servan-Schreiber, D. (1989). Interaction with a 'sex-expert' system enhances attitudes towards computerized sex therapy. <i>Behaviour Research & Therapy</i> , 27(3), 303-306.	Outcomes not of interest (i.e. attitudes towards different forms of sex therapy)
Classen, C. C., Chivers, M. L., Urowitz, S., Barbera, L., Wiljer, D., O'Rinn, S., & Ferguson, S. E. (2013). Psychosexual distress in women with gynecologic cancer: a feasibility study of an online support group. <i>Psycho-Oncology</i> , 22(4), 930-935.	Not an IDI (online discussion group linked to a static psychoeducational website)
Coren, C. M. (2008). <i>Computer-assisted sex therapy: revisiting sensate focus</i> . (Doctor of Psychology), Widener University.	Not a RCT
Chisholm, K., McCabe, M., Wootten, A., Abbott, J., Austin, D., Klein, B. & Murphy, D. (2012). Predictors of engagement in an online psychological support program for men treated for prostate cancer. <i>Asia-Pacific Journal of Clinical Oncology</i> , 8, 225.	Ongoing trial
Giesler, R. B., Given, B., Given, C. W., Rawl, S., Monahan, P., Burns, D., & Champion, V. (2005). Improving the quality of life of patients with prostate carcinoma. <i>Cancer</i> , 104(4), 752-762.	Not an IDI (computer-based/digital assessment tool and decision aid for nurses)
Lee, J. Y. (2011). <i>Effects on cyberporn consumption of an adapted online motivational interviewing intervention with personalized feedback with or without an accountability partner</i> . (Doctor of Philosophy), Fuller Theological Seminary, ProQuest Dissertations and Theses.	Not an IDI (computer-based/digital assessment tool)
McCabe, M. P., & Price, E. (2008). Internet-based psychological and oral medical treatment compared to psychological treatment alone for ed. <i>Journal of Sexual Medicine</i> , 5, 2338-2346.	Not a RCT
Ochs, E. P., Meana, M., Pare, L., Mah, K., & Binik, Y. M. (1994). Learning About sex outside the gutter: Attitudes toward a computer sex- expert system. <i>Journal of Sex and Marital Therapy</i> , 20(2), 86-102.	Outcomes not of interest (i.e. attitudes towards IDIs)
Optale, G., Munari, A., Nasta, A., Pianon, C., Baldaro Verde, J., & Viggiano, G. (1997). Multimedia and virtual reality techniques in the treatment of male erectile disorders. <i>International Journal of Impotence Research</i> , 9, 7.	Not an IDI (i.e. does not provide information and support)

Authors, date	Reason for exclusion
Optale, G., Pastore, M., Marin, S., Bordin, D., Nasta, A., & Pianon, C. (2004). Male sexual dysfunctions: immersive virtual reality and multimedia therapy. <i>Studies in health technology and informatics</i> , 99,165-178.	Not an IDI (i.e. does not provide information and support)
van Lankveld, J. J., Leusink, P., van Diest, S., Gijs, L., & Koos Slob, A. (2009). Internet-based brief sex therapy for heterosexual men with sexual dysfunctions: A randomized controlled pilot trial. <i>Journal of Sexual Medicine</i> , 6, 2224-2236.	Not an IDI (i.e. digitally mediated consultation)
Erskine Online Psychoeducation for Sexual Dysfunction in Cancer Survivors (OPES). ClinicalTrials.gov identifier: NCT01159678	Ongoing trial

Appendix D

Characteristics of included studies tables

Andersson et al., 2011 (078) – Journal article

Participants	<p>68 heterosexual and homosexual men, 18 or over, and their partners completed the study</p> <p>Mean age: 57.6 years (SD 10.1)</p> <p>Sexual difficulty: Erectile Dysfunction (ED)</p> <p>Country: Sweden</p>
Interventions	<p>IDI:</p> <ul style="list-style-type: none"> • Module 1:ED was presented from a biological, psychological, and social perspective and information was given as to how various factors could be contributing to the maintenance of the difficulty • Module 2: Participants learned about the CBT perspective (operant and respondent conditioning) and its relation to ED symptoms • Module 3 consisted of relationship exercises where the participant was instructed to discuss the implications of the disorder with his partner and invited the couple to attempt to conceptualise the disorder from a CBT perspective together • Modules 4-6 consisted of exposure tasks that engaged the participant in various structured exercises <p>Psychotherapeutic approach: Cognitive behavioural therapy, classical & operant conditioning</p> <p>PPI: No</p> <p>Duration: 7 weeks</p>
Comparator(s)	<p>Online discussion forum: Participants had access to a closed internet chat forum, in which they could send messages anonymously to each other for the duration of the treatment (7 weeks). They were also encouraged to be active and discussion topics were posted on the forum on a weekly basis by the therapists to encourage activity. One of the therapists in the study monitored the forum on a daily basis and participants were encouraged to discuss their erectile difficulties and helpful ways of coping with it.</p>
Outcomes	<p>All measures taken pre- and immediately post-intervention (at 7 weeks)</p> <p>Erectile Dysfunction (IIEF-5) PRIMARY</p> <p>Erectile function (IIEF)</p> <p>Orgasmic functioning (IIEF)</p> <p>Sexual desire (IIEF)</p> <p>Intercourse satisfaction (IIEF)</p> <p>Overall satisfaction (IIEF)</p> <p>Relationship satisfaction (RAS)</p> <p>General anxiety (BAI)</p> <p>Depressive symptoms (BDI-II)</p> <p>Quality of life (WHOQOL-BREF)</p>
Study design	<p>Randomised controlled trial</p>
Other information	<p>Inclusion/exclusion criteria: 1. Computer and internet access, 2. 18 or over, 3. Score <21 on the IIEF-5, 4. In stable partner relationship for 3 months or longer, 5. No medical conditions that could jeopardize the subject's health, 6. No severe depression or anxiety disorders, 7. No alcohol or drug related problems in need of medical treatment, 8. No prior medical history that could be a primary cause of ED, or 9. No medication use that</p>

Andersson et al., 2011 (078) – Journal article

could produce ED as a side effect.

Method of recruitment: Participants were recruited through articles and interviews on TV and in newspapers.

Success rates of recruitment: Two hundred and forty four applied for the study, 196 completed screening, 115 submitted written consent, 108 were interviewed, 30 of which were excluded for the following reasons: medical reasons, too far from partner, multiple partners, severe marital distress, inability to verify diagnosis, and chose not to participate. Leaving 78 participants randomised to the intervention (39) and online discussion (39) groups.

Incentive to participate: None

Engagement measured: Yes

Risk of Bias

Item	Author's assessment of risk	Description
Adequate sequence generation?	Low risk	All participants were randomized simultaneously after the recruitment phase had ended. After all patients had been included, www.random.org was used to shuffle a list of anonymous patient IDs and allocate the ID numbers to the experimental arms.
Allocation concealment?	Low risk	After consenting to take part in the study, participants were randomly allocated simultaneously using www.random.org .
Incomplete outcome data addressed?	Low risk	<ul style="list-style-type: none"> Attrition and exclusions reported Reasons for exclusions reported 39 randomised to each group # of participants in each arm at each time point <p>Baseline assessment:</p> <ul style="list-style-type: none"> IDI (37) – Two excluded after randomisation due to lack of partner Internet discussion forum (39) <p>Post assessment:</p> <ul style="list-style-type: none"> IDI (33) – 85% retention (33/39) Internet discussion forum (35) – 95% retention (35/39) <ul style="list-style-type: none"> Missing outcome data balanced in numbers across groups No information provided about imputing missing data <p>Authors used an intention to treat analysis Absence of large or differential losses to follow-up? Yes</p>
Free of selective reporting?	Low risk	All outcomes listed in the methods were reported in the results. Trimbos questionnaire (measuring costs associated with psychiatric illness) and the Working Alliance Inventory (measuring therapeutic alliance) were also measured, but the results will be published elsewhere.

Binik, Meana & Sand, 1994 (122) – Journal article

Participants	<p>50 heterosexual couples, 18 or over completed the study Mean age: 22.9 years (SD 4.7) Sexual difficulty: Non-specific Country: Canada</p>
Interventions	<p>IDI:</p> <ul style="list-style-type: none">• Sexpert is a rule-based production system designed for direct use by couples who want information or advice about their sexual behaviour and relationship• Sexpert gathers background information about the couple, and determines whether or not a sexual dysfunction exists. If it does, Sexpert investigates the underlying historical antecedents and cognitive misconceptions• Whether or not there is a dysfunction, Sexpert investigates the couple's regular sexual repertoire (e.g., initiation, foreplay, intercourse positions, afterplay, etc.) and of the nonsexual aspects of the relationship• Sexpert offers feedback and provides the couple with opportunities to learn about different aspects of sexual behaviour. It may propose a treatment plan and guide couples on a step-by-step implementation of this plan <p>Psychotherapeutic approach: CBT (not explicit in this paper, but indicated in other related papers) PPI: unclear Duration: 4 weeks</p>
Comparator(s)	<p>Paper questionnaire: All possible questions asked by Sexpert were reproduced for a standard paper-and-pencil questionnaire) Computer game: A computer adventure game where the goal is to find a lost object. It engages both members of the couple in a non-competitive way, and has no sexual content</p>
Outcomes	<p>Daily self-monitoring of sexual behaviour: who initiated, length of foreplay, occurrence of orgasm, length of afterplay, and satisfaction of initiation, foreplay, intercourse positions, and afterplay. Retrospective sexual behaviour questionnaire: individual activities, nonsexual affection, intercourse, foreplay, sex not leading to intercourse, afterplay, communication about sex, communication about non-sexual matters, and feelings about their relationship</p>
Study design	Randomised controlled trial
Other information	<p>Inclusion/exclusion criteria: Couples living together and/or married for a minimum of 6 months, 2. Not taking any medication for chronic conditions, 3. Not suffering from any physical or psychological condition that might affect their sexual functioning Method of recruitment: Through advertisements on university campus bulletin boards and student newspapers. Success rates of recruitment: Sixty-six couples were initially recruited. Twelve of the 66 couples did not show up for the initial session and were not re-contacted. Four couples dropped out during the study (after randomisation), leaving 50 couples remaining in the study. Incentive to participate: Participants were paid for participation (amount unclear) Engagement measured: unclear</p>

Risk of Bias

Item	Author's assessment of risk	Description
Adequate sequence generation?	Unclear	'Couples were randomly assigned to one of three experimental conditions...' (No information provided about the sequence generation process in the paper).
Allocation concealment?	Low risk	Randomisation occurred after consent and baseline measures were taken.
Incomplete outcome data addressed?	Low risk	<p>Not clear where attrition was. Not many stats reported</p> <ul style="list-style-type: none"> • There were no exclusions, and attrition was reported but it was not clear where the attrition was (i.e., the authors just wrote 'four couples, spread over the three experimental groups, dropped out of the study in the course of the experiment') • # of participants in each arm at each time point <p>Baseline: unclear Post: unclear 2 weeks:</p> <ul style="list-style-type: none"> • IDI (18) • Paper questionnaire (16) • Computer game (16) <p>No information provided about imputing missing data Absence of large or differential losses to follow-up? Yes</p>
Free of selective reporting?	High risk	<ul style="list-style-type: none"> • Not all comparisons were made/reported. Authors did not report the computer game results when asking retrospectively if the experimental manipulation had affected any aspects of their sexual behaviour (i.e., 'Only Sexpert and the questionnaire groups were compared, since it made little sense to ask the [crossword] couples whether playing a computer game affected their sex life'). • One or more of the outcomes of interest in the review are reported incompletely so that they cannot be entered into a meta-analysis. • Do not have protocol.

Hucker & McCabe, 2014 (470 & 486)

Participants	57 heterosexual women, 18 or over, and their partners completed the study Sexual difficulty: Female Sexual Dysfunction (FSD) Mean age: 33.3 years (SD 7.4) Country: Australia
Interventions	IDI: 'Pursuing pleasure' (PP) is an online, mindfulness-based, cognitive-behavioural therapy treatment for women with missed female sexual difficulties. The aim of PP is to decrease symptoms of sexual dysfunction through both sexual activity-based and relationship-based interventions, and to decrease levels of distress associated with sexual functioning. To achieve these aims, the program consists of both change-based interventions (e.g. challenging negative automatic thoughts and behavioural exercises) and acceptance-based interventions (e.g. mindfulness and normalising through psychoeducation). The program consists of six online modules which incorporate psychoeducation, communication exercises, sensate focus exercises, partner engagement, CBT exercises, mindfulness exercises, email contact with a therapist and fortnightly online chat groups Psychotherapeutic approach: CBT/Sex therapy technique and mindfulness PPI: Unclear Duration: 12 weeks (approx.)
Comparator(s)	Waitlist control
Outcomes	Sexual function scale (SFS) – communication and relationship satisfaction subscales Personal assessment of intimacy in relationship scale (PAIR) – sexual intimacy and emotional intimacy subscales were used Female sexual function index (FSFI) Female sexual distress scale (FSDS) International index of erectile function (IIEF) Premature ejaculation diagnostic tool (PEDT) Frequency of sexual difficulties
Study design	Randomised controlled trial
Other information	Inclusion/exclusion criteria: Participants were included if they were 18 or older, currently experiencing self-reported sexual difficulties (related to desire, arousal, orgasm, and/or pain), in a stable heterosexual relationship, reported no significant mental illness and no significant relationship problems (e.g. violence, abuse), were English speaking, and had regular access to the Internet. It was also necessary for partners to participate in treatment because some components of the program require partner involvement. Method of recruitment: Women were recruited via worldwide health websites, a press release in two Australian newspapers, noticeboards in an Australia university and through a database of previous participants in a project completed by the second author. Success of recruitment: 300 women responded to study advertisements; 102 couples consented to the study after receiving the plain language statement about the study. Incentive or cost to participate: Unclear Engagement measured: No

Risk of Bias

Item	Author's assessment of risk	Description
Adequate sequence generation?	Unclear	'Women were then randomly assigned to either the treatment group or waitlist control'. (No information provided about the sequence generation process)
Allocation concealment?	Low risk	Randomisation occurred, after consent was taken but before baseline measures were taken
Incomplete outcome data addressed? All outcomes.	High risk	<p>Attrition reported:</p> <ul style="list-style-type: none"> o 11 women dropped out of the study after consenting, but before randomisation o 5 women dropped out of the intervention group after randomisation & completing baseline measures, but before starting treatment (46 started the treatment) o Number of drop outs during the intervention period reported from each group <ul style="list-style-type: none"> • 20 women dropped out of the intervention group during the treatment period • 7 women dropped out of the waitlist control group between completing the pre- and post-waitlist questionnaires o Missing outcome data was not balanced in numbers across groups (7 IDI; 9 Waitlist) <p>• Reasons for attrition: time commitment, partner unsupportive, expectations of treatment not met, natural disaster, ambivalence about treatment, and no reason given.</p> <p>Exclusions reported:</p> <ul style="list-style-type: none"> o After randomisation 2 women were excluded due to mental illness (one from each group). <p>• # of participants, in each arm, at each outcome point:</p> <p>Baseline:</p> <ul style="list-style-type: none"> • IDI (52) • Waitlist (39) <p>Post:</p> <ul style="list-style-type: none"> • IDI (26) – 50% retention (26/52) • Waitlist (31) – 80% retention (31/39) <p>No information provided about imputing missing data Absence of large or differential losses to follow-up? No</p>
Free of selective reporting?	Low risk	<ul style="list-style-type: none"> • All outcomes, except listed in the methods were reported in the results • Do not have protocol

Jones & McCabe, 2011 (018) – Journal article

Participants	<p>39 heterosexual women, 18 or over, and their partners completed the study Mean age: 34.9 years (SD 10.3)</p> <p>Sexual difficulty: Female Sexual Dysfunction (FSD): Hypoactive sexual desire disorder, sexual arousal disorder, anorgasmia or genital pain</p> <p>Country: Australia</p>
Interventions	<p>IDI:</p> <ul style="list-style-type: none">• An Internet-based CBT program that aims to resolve the individual and relationship factors related to FSD• Consists of three well-established and validated treatment components: communication skills training, sensate focus exercises, and regular e-mail contact with a therapist• Contains five treatment modules, with earlier modules providing the foundation for later models. <p>Psychotherapeutic approach: CBT</p> <p>PPI: Unclear</p> <p>Duration: 10 weeks</p>
Comparator(s)	<p>Waitlist control: Women were told they would be on the waitlist for 10 weeks. A therapist emailed each waitlist participant halfway through the waitlist phase to facilitate engagement and commitment to the study. Following the post-wait-list questionnaire, women in the control group were given the option of enrolling in treatment</p>
Outcomes	<p>Female sexual function (FSFI)</p> <p>Desire (FSFI)</p> <p>Arousal (FSFI)</p> <p>Lubrication (FSFI)</p> <p>Orgasmic function (FSFI)</p> <p>Pain (FSFI)</p> <p>Frequency of FSD</p> <p>Sexual satisfaction (FSFI)</p> <p>Sexual intimacy (PAIR)</p> <p>Relationship satisfaction (SFS)</p> <p>Communication (SFS)</p> <p>Emotional intimacy (PAIR)</p> <p>Anxiety (DASS21)</p> <p>Performance anxiety (SFS)</p> <p>Depression (DASS21)</p> <p>Stress (DASS21)</p> <p>Body image (SFS)</p>
Study design	<p>Randomised controlled trial</p>
Other information	<p>Inclusion/exclusion criteria: 1. Currently experiencing FSD (hypoactive sexual desire disorder, sexual arousal disorder, anorgasmia, or genital pain), 2. In a stable relationship, 3. Heterosexual, 4. Regular internet access, 5. Willingness and motivation of partners to participate in treatments, 6. Commitment to at least 3hrs per week for a minimum of 10 weeks to complete the program, 7. Participants were asked to refrain from taking part in any additional psychological or medical treatment FSD while participating in the study (but permitted to continue any medical treatment if already receiving treatment).</p>

Jones & McCabe, 2011 (018) – Journal article

Method of recruitment: Via an online advertisement posted on a number of sex- and health-related websites, through an advertisement in a local newspapers, and from an online university-based newsletter.

Success rates of recruitment: Sixty-five women completed the pre-treatment questionnaire and agreed to participate. Eight women did not respond to emails after this point, and an additional four women did not meet eligibility criteria. The remaining 53 women were randomly assigned to the treatment (26) or waitlist control (27) groups.

Incentive to participate: Participants were offered a \$50 gift voucher for participation (of the 39 who completed treatment, 17 accepted voucher)

Engagement measured: No

Risk of Bias

Item	Author's assessment of risk	Description
Adequate sequence generation?	Unclear	'The remaining women...were randomly assigned to either the treatment group of the wait-list control group' (No information provided about the sequence generation process)
Allocation concealment?	Low risk	Randomisation occurred after consent and baseline measures were taken.
Incomplete outcome data addressed? All outcomes.	High risk	<p>Attrition and exclusions reported</p> <ul style="list-style-type: none"> • Reasons for attrition and exclusions reported • # of participants, in each arm, at each outcome point: <p>Baseline:</p> <ul style="list-style-type: none"> • IDI (26) • Waitlist control (27) <p>Post:</p> <ul style="list-style-type: none"> • Retention <ul style="list-style-type: none"> • IDI (17) - 65% retention (17/26) • Waitlist control (22) – 82% retention (22/27) • Retention after exclusions <ul style="list-style-type: none"> • IDI (11) – 42% retention (11/26) • Waitlist control (17) – 63% (17/27) • Total women randomised = 53; 17/26 women in the intervention group completed the program and the post-test measures; 6 were excluded from the analysis due to reporting no sexual activity in the previous month at pre-test, leaving 11/26 women in the analysis (26->17->11); 22/27 women in the control group completed the post-test measures; 5 were excluded from the analysis due to reporting no sexual activity in the previous month at pre-test; leaving 17 women in the analysis (27->22->17); • Reasons for attrition: partner no longer willing to participate, marriage dissolution/breakdown, unable to commit sufficient time to the program, and program no longer suitable • Missing outcome data not balanced across groups (9 missing from IDI; 5 missing from WL)

Jones & McCabe, 2011 (018) – Journal article

		No information provided about imputing missing data Absence of large or differential losses to follow-up? No
Free of selective reporting?	Low risk	<ul style="list-style-type: none"> All outcomes listed in the methods (except the total DASS-21 score) were reported in the results Do not have protocol

McCabe, Price, Piterman & Lording, 2008 (003) – Journal article

Participants	31 heterosexual men, over 18, and their partners completed the study Mean age: unclear Sexual difficulty: Erectile Dysfunction (ED) Country: Australia
Interventions	IDI: <ul style="list-style-type: none"> Internet CBT program (Rekindle) that focusses on the resolution of psychological and relationship factors related to ED Consists of three main treatment components, including sensate focus, communication exercises, and email contact with a therapist The program is completed over five modules, with goal setting, communication exercises, sensate focus activities, and a reminder that further support from a therapist, via email, is available. The therapist maintained contact with participants at least once a fortnight. If two weeks had passed without contact, the therapist would send an email to the participant to facilitate engagement and ensure that the participant was not experiencing any difficulties. Psychotherapeutic approach: Sex therapy, CBT PPI: Unclear Duration: 10 weeks
Comparator(s)	Waitlist control: Men who were randomly allocated to the control group were placed on a waitlist for the program. After post-test completion of the questionnaire, men in the control group enrolled in the treatment program.
Outcomes	Erectile function (IIEF) Orgasmic function (IIEF) Sexual Desire (IIEF) Frequency of ED Erectile strength Sexual satisfaction (ISS) Intercourse satisfaction (IIEF) Overall satisfaction (IIEF) Sexual relationship subscale (SEAR) Relationship satisfaction (KMSS)
Study design	Randomised controlled trial
Other information	Inclusion/exclusion criteria: 1. Persistent or recurrent difficulties attaining or maintaining an erection during sexual activity, 2. Aged 18 or over, 3. Absence of major medical or psychiatric problems, 4. Involvement in a stable heterosexual relationship, 5. Willingness and motivation from partners to participate in treatment, 6. Regular internet access Method of recruitment: Unclear

McCabe, Price, Piterman & Lording, 2008 (003) – Journal article

Success of recruitment: Ninety one men initially contacted the researchers, 66 of which returned consent forms. After completing medical screening, 12 men were referred back to their GP for medical treatment and deemed ineligible to participate. A further 10 men did not continue with the study due to the following reasons: decided not to continue (2), not involved in a stable relationship (1), could not meet the time commitment (3), no regular internet access (4). The remaining 44 men were randomly allocated to the treatment (24) or waitlist control (20) groups.

Incentive or cost to participate: Unclear

Engagement measured: No

Risk of Bias

Item	Author's assessment of risk	Description
Adequate sequence generation?	Unclear	'Men were randomly allocated to the treatment or control condition' (No information provided about the sequence generation process)
Allocation concealment?	Low risk	Randomisation occurred after consent has been taken.
Incomplete outcome data addressed? All outcomes.	High risk	<p>Attrition and exclusions reported</p> <ul style="list-style-type: none"> Reasons for attrition and exclusions reported # of participants, in each arm, at each outcome point: <p>Baseline:</p> <ul style="list-style-type: none"> IDI (24) Waitlist control (20) <p>Post:</p> <ul style="list-style-type: none"> IDI (12) – 50% retention (12/24) Waitlist control (19) – 95% retention (19/20) Total men randomised = 44; 12/24 men from intervention arm completed the program & post-test measures; 19/20 men from control arm completed post-test measures; Reasons for attrition included: separation from partner, unable to commit sufficient time to the program, and partner was unwilling to participate in the program There were no significant differences in any of the pre-test scores on any of the variables between treatment completers and dropouts Missing outcome data was not balanced across groups (12 IDI; 1 WL) High attrition rate in the IDI may have biased the results in favour of the IDI <p>No information provided about imputing missing data Absence of large or differential losses to follow-up? No</p>
Free of selective reporting?	Low risk	<ul style="list-style-type: none"> Most outcomes listed in the methods were reported in the results (except frequency of ED and erectile strength, which were reported but not mentioned in methods)

McCabe, Price, Piterman & Lording, 2008 (003) – Journal article

- Do not have protocol

Ochs & Binik, 1998 (288) – Journal article

Participants	77 heterosexual couples, 18 or over completed the study Mean age: 27.0 years (SD 6.2) Sexual difficulty: Non-specific Country: Canada
Interventions	IDI: <ul style="list-style-type: none">• Sexpert is a rule-based production system comprising approximately 4000 rules, and several hundred pages of texts• Program is designed to interact dynamically with couples in order to assess their sexual functioning, to provide appropriate feedback, and if necessary, to instruct the couple in a cognitive-behaviourally oriented therapy program to deal with identified difficulties• Communication with the program is managed through structured questions that the couple responds to via keyboard inputs• Sexpert combines its knowledge base with the responses given by the couple to dynamically generate relevant information for the couple• Sexpert can deal flexibly with sensitive information it obtains during the course of an interview. Psychotherapeutic approach: Cognitive behavioural therapy PPI: Unclear Duration: 1 week
Comparator(s)	Therapist: Couples met with the supervisor of the study (a psychologist and Director of Sex and Couple Therapy at Royal Victoria Hospital) to discuss their relationship and sex life Video condition: Couples watched a segment of a self-help video called 'Better sex' Crossword: Couples were asked to work together on a crossword puzzle with no sexual content
Outcomes	Daily self-monitoring of sexual behaviour Sexual activity Sexual comfort Relationship adjustment (DAS) Communication about sex
Study design	Randomised Controlled Trial
Other information	Inclusion/exclusion criteria: 1. English language fluency, 2. In a sexually active, heterosexual relationship, and living together or married for at least 9 months. Reasons for exclusion included a current, planned, or recent pregnancy, medication with potential sexual side effects, previous personal contact with investigators in the study, or any planned major lifestyle disruptions. Method of recruitment: Through advertisements in campus and community newspapers. Success of recruitment: One hundred and forty four couples responded to the advertisements, 119 of whom met the criteria for study participation.

Ochs & Binik, 1998 (288) – Journal article

Eighty were successfully scheduled for an initial session, and 77 completed the entire study protocol.

Incentive or cost to participate: Participants were paid \$15 each (\$30 per couple) for their participation in the study

Engagement measured: No

Risk of Bias

Item	Author's assessment of risk	Description
Adequate sequence generation?	High risk	Concerns about the randomisation procedure: 'Couples were assigned on a successive rotating basis to one of the four conditions in the study'.
Allocation concealment?	Unclear	Couples were assigned to condition before consent and baseline measures were taken, but it is not clear whether their allocation was concealed or not.
Incomplete outcome data addressed? All outcomes.	Low risk	<ul style="list-style-type: none"> Attrition and exclusions were reported, but it was not clear where the attrition was (i.e., which groups the 3 couples dropped out of). Exclusion criteria specified, but the specific reasons for why 25 couples were excluded were not provided # of participants, in each arm, at each outcome point: Baseline: <ul style="list-style-type: none"> IDI (unclear) Crossword (unclear) 1 week: <ul style="list-style-type: none"> IDI (unclear) Crossword (unclear) <p>However, overall 80 couples were scheduled, and 77 completed, so there could have been no large or differential losses to follow up</p> <p>No information provided about imputing missing data</p>
Free of selective reporting?	High risk	<ul style="list-style-type: none"> Much of the data was lumped together (and not reported by arm), and often only statistically significant results were reported Do not have protocol

Ochs, Meana, Mah, Binik, 1993 (226) – Journal article

Participants	81 heterosexual couples, 18 or over, completed the study. Mean age: 25.9 years (SD 6.3) Sexual difficulty: Non-specific Country: Canada
Interventions	IDI: <ul style="list-style-type: none">• Sexpert is an expert system designed for direct use by individuals or couples who want information or advice about their sexual behaviour and relationship• The system directs multiple choice, yes/no, or quantitative questions to either or both individuals throughout a session• Sexpert gathers background information about the couple. If a sexual dysfunction exists, Sexpert investigates the underlying historical antecedents and potential cognitive misconceptions about sexuality• Sexpert does an extensive investigation of the couple's regular sexual repertoire (e.g., initiation, foreplay, intercourse positions, "afterplay", etc.) and of the nonsexual aspects of the relationship• Sexpert presents feedback and gives the couple opportunities to learn about different aspects of the relationship. In the case of dysfunction, Sexpert proposes a treatment plan and guides couples on a step-by-step implementation of this plan• Characteristics built into Sexpert include: Simulation of the process of dialogue, presentation of accurate feedback in natural language, provision of both immediate and continuous feedback, ability to shift focus on the basis of users' answers, ability to monitor when the system may lack adequate knowledge and to inform the user accordingly, ability of the user to change previous answers and expect the system will react appropriately, ability of the user to ask the system why is had conclude something and to receive an answer• In the current study, the introductory and repertoire sections were used, the main topics included initiation, foreplay activities, intercourse frequency, and 'afterplay'. Psychotherapeutic approach: CBT (not explicit in this paper, but indicated in other related papers) PPI: Unclear Duration: 4 weeks
Comparator(s)	Video: Same as the Sexpert condition except participants spent the 50 min watching a self-help video, which was designed to help couples discuss some typical kinds of relationship, communication, and sexual behaviour issues Book: Same as the Sexpert condition except participants spent the 50 min reading 4 chapters of the book 'Building Sexual Happiness' (1. Non-demanding pleasure, 2. Sexual variations: When does experimentation become kinky?, 3. Equality between the sexes, 4. Guidelines for your marital and sexual relationship Crossword control: Same as the Sexpert condition except participants spent the 50 min doing crossword puzzles
Outcomes	Daily self-monitoring of sexual behaviour
Study design	Randomised controlled trial
Other information	Inclusion/exclusion criteria : 1. English language fluency, 2. In a sexual

Ochs, Meana, Mah, Binik, 1993 (226) – Journal article

active, heterosexual relationship, and cohabitating for at least 12 months, 3. No current, planned, or recent pregnancies, 4. No medication with potential sexual side effects, 5. No previous personal contact with an investigator or prior participation in a previous study, 6. No planned lifestyle disruptions.

Method of recruitment: Via on-campus notices and advertisements in university and local newspapers

Success of recruitment: One hundred and fifty-one individuals responded to advertisements, 118 of whom met the eligibility criteria. Eighty five couples turned up to the first session and 81 completed the study.

Incentive or cost to participate: Participants were paid for their participation in the study (amount unclear)

Engagement measured: No

Risk of Bias

Item	Author's assessment of risk	Description
Adequate sequence generation?	High risk	Concerns about the randomisation procedure: 'The couples were assigned on a successive rotating basis to one of three experimental conditions or to the control condition'.
Allocation concealment?	Unclear	Couples were assigned to condition before consent and baseline measures were taken, but it is not clear whether their allocation was concealed or not.
Incomplete outcome data addressed? All outcomes.	Low risk	<ul style="list-style-type: none"> Couples were randomised after 4 couples dropped out so no incomplete outcome data # of participants, in each arm, at each outcome point: Baseline: <ul style="list-style-type: none"> IDI (21) Video (20) Book (20) Crossword (20) 2 weeks: <ul style="list-style-type: none"> IDI (21) – 100% retention (but one off use of intervention and short follow-up) Video (20) Book (20) Crossword (20) <p>Absence of large or differential losses to follow-up? Yes</p>
Free of selective reporting?	High risk	<ul style="list-style-type: none"> Much of the data was lumped together (and not reported by arm) Not all comparisons were made/reported. Authors did not report the computer game results when asking retrospectively if the experimental manipulation had affected any aspects of their sexual behaviour (i.e., 'Only expert and the questionnaire group were compared, since it made little sense to ask the [crossword] couples

Ochs, Meana, Mah, Binik, 1993 (226) – Journal article

whether playing a computer game affected their sex life')

- One or more of the outcomes of interest in the review are reported incompletely so that they cannot be entered into a meta-analysis.
- Do not have protocol

Schover et al., 2012 (183) – Journal article

Participants 134 heterosexual men who had been treated for localized prostate cancer, over 18, and their partners completed the study.
Mean age: 64.0 years (SD 8.0)

Sexual difficulties: Erectile Dysfunction (ED) & Female Sexual Dysfunction (FSD)

Country: USA

Interventions

IDI:

- On first visit to CAREss, participants complete an online questionnaire about their sex history, current practices, and beliefs about sexual function and cancer
- Program includes exercises to increase expression of affection, improve sexual communication, increase comfort in initiating sexual activity, and facilitate resuming sex without performance anxiety (using a sensate focus framework)
- Suggestions are provided to treat postmenopausal vaginal atrophy or cope with male urinary incontinence
- Gender specific exercises help participants identify negative beliefs about sexuality and use cognitive reframing
- Treatments for ED after prostate cancer are described, with suggestions on their efficacy and using them optimally
- The program includes a decision aid for choosing an ED treatment
- Relapse prevention exercises were included near the end of the intervention
- Booster telephone calls of 15-30 min were made to both groups at 1 month and 3 months to discuss progress with end of treatment goals and ways to overcome remaining barriers
- The homework exercises have standardized report forms completed online and submitted by each partner. Therapists email feedback and reminders. Participants can email their therapist any time

Psychotherapeutic approach: CBT

PPI: Unclear

Duration: 12 weeks

Comparator(s)

Face-to-face: The face-to-face (FF) group received 3 face-to-face sessions over 12 weeks (90mins for session 1 and 50-60 minutes for session 2). FF included the same content and cognitive-behavioural homework. FF participants received printed handouts of material from the website (except for animations and videos). Homework exercises were completed on paper, and homework was discussed in session. Information on sex history, current practices, and beliefs about sexual function and cancer was elicited by interview.

Waitlist control: After 3 months in the waitlist condition participants completed a post-WL assessment. WL participants were randomised a

Schover et al., 2012 (183) – Journal article

	second time to one of the intervention groups.
Outcomes	Erectile function (IIEF) Orgasmic function (IIEF) Sexual desire (IIEF) Female sexual function (FSFI) Desire (FSFI) Arousal (FSFI) Lubrication (FSFI) Orgasmic function (FSFI) Pain (FSFI) Intercourse satisfaction (IIEF) Overall satisfaction (IIEF) Sexual satisfaction (FSFI) Relationship satisfaction (A-DAS) Distress (BSI-18)
Study design	Randomised controlled trial
Other information	<p>Inclusion/exclusion criteria: 1. Male partner heterosexual, 2. 18 or over, 3. Either definitive surgery or radiotherapy between 3 mon & 7 years previously, 4. Couples married or living together for 1 year or longer, 5. Men unable to achieve and maintain an erection sufficient for sexual intercourse on 50% (or more) attempts in the past 3 months, or had not attempted intercourse for 3 months and also had not noted firm erections on waking from sleep.6. Men not using a satisfactory medical treatment for ED (couples were also excluded if man was on hormone therapy for prostate cancer because of the profound impact of such therapy on the desire for sex , 7. Couples willing to visit the University 3 times during the 12 week treatment period.</p> <p>Method of recruitment: Invitation letters mailed to men in the University of Texas MD Anderson tumour registry who met eligibility criteria; physician referrals; fliers placed in outpatient clinics; and public service announcements in local media or on web sites of prostate advocacy groups; presentations at local churches, and community health fairs.</p> <p>Success of recruitment: Unclear</p> <p>Incentive or cost to participate: Unclear</p> <p>Engagement measured: Yes. The duration, number, and content of visits were recorded electronically. A graphic on each participant's home page displayed the percentage of the intervention completed (pages visited or homework reports submitted).</p>

Risk of Bias

Item	Author's assessment of risk	Description
Adequate sequence generation?	Low risk	'Couples were adaptively randomized to 1 of 3 groups using minimization'
Allocation concealment?	Unclear	It is unclear whether participants were randomised before or after consent was taken. Method of concealment, if any, was not described.
Incomplete	Low risk	Attrition reported:

Schover et al., 2012 (183) – Journal article

outcome data addressed?	• 163 randomised to groups (IDI 55, FtoF 60, WL 48)
All outcomes.	• Number of drop outs reported from each group, and missing outcome data balanced in numbers across groups (7 from IDI; 7 from face-to-face; 5 from waitlist control)
	Exclusions not reported:
	• Exclusion criteria specified but no specific information provided about actual exclusions
	• # of participants, in each arm, at each outcome point:
	Baseline:
	• IDI (55)
	• Face to face (60)
	• Wait list (48)
	Post:
	• IDI (48) – 87% retention (48/55)
	• Face to face (43) – 72% retention (43/60)
	• Wait list (43) – 90% retention (43/48)
	No information provided about imputing missing data
	Absence of large or differential losses to follow-up? Yes
Free of selective reporting?	Low risk
	• All outcomes listed in the methods were reported in the results. One or more of the outcomes of interest were reported incompletely and could not be entered into a meta-analysis
	• Do not have protocol

Schover et al., 2013 (326) – Journal article

Participants	42 women who had been treated for localized breast or gynaecological cancer, over 18, and their partners completed the program. Mean age: 53.0 years (SD 9.0) Sexual difficulties: Female Sexual Dysfunction (FSD) Country: USA
Interventions	IDI: The intervention included text, graphics, animations, and multicultural photos and clip art. Education was provided on genital anatomy, including an interactive, vulvar self-portrait with pain and pleasure mapping. The site covered: sex after menopause; managing vaginal dryness and pain; causes and treatment options for loss of desire or orgasm problems; ways to improve body image; resuming sex comfortably using a sensate focus framework; sexual issues for women with ostomies or incontinence; training on communication with sexual partners and health professionals; dating; lesbian relationships; and sex after childhood and adolescent cancer. Videos included 11 interviews with women cancer survivors and vignettes played by actors illustrated common difficulties and coping strategies. Psychotherapeutic approach: Sex therapy techniques PPI: Unclear Duration: 12 weeks

Schover et al., 2013 (326) – Journal article

Comparator(s)	IDI with face-to-face counselling: In addition to accessing the intervention, the group had access to 3x face-to-face counselling sessions (1x90mins, and 2x60mins), which were provided by masters' level mental health professionals. The counsellors guided women through the website and discussed behavioural homework.
Outcomes	Female sexual function index (FSFI) Primary outcome Desire (FSFI) Arousal (FSFI) Lubrication (FSFI) Orgasmic function (FSFI) Sexual satisfaction (FSFI) Pain (FSFI) Menopausal sexual interest questionnaire (MSIQ) Emotional distress (BSI-18) Somatization (BSI-18) Depression (BSI-18) Anxiety (BSI-18) Global severity index (overall psychological stress) (BSI-18) Quality of life in adult cancer survivors (QLACS)
Study design	Randomised controlled trial
Other information	Inclusion/exclusion criteria: 1. 1-7 years post-diagnosis of localized breast cancer or gynaecological cancer and off active treatment, other than hormonal therapy, 2. Scored as sexually dysfunctional (under 26.5) on the Female Sexual Function Index (FSFI), 3. In a sexual relationship for at least 6 months and had a partner willing to participate in behavioural homework, 4. Lived close enough to attend 3 in-person counselling sessions. Method of recruitment: Introductory letters and flyers were sent to 1123 women from a tumor registry who met eligibility criteria for cancer type, stage, and date of diagnosis. Flyers were distributed at breast and gynecological outpatient clinics. The study was also listed on ClinicalTrials.gov. Success of recruitment: 117 women were screened in-person or by phone: 22 declined to participate or did not response to follow-up calls, and 23 were ineligible. The remaining 72 were randomized to the intervention group or the intervention plus counselling. Incentive or cost to participate: Participants received a US\$20 gift card upon completing questionnaires at each follow-up. Engagement measured: Yes. Time spent using website was recorded.

Risk of Bias

Item	Author's assessment of risk	Description
Adequate sequence generation?	Low risk	'Couples were adaptively randomized, using minimization...'
Allocation concealment?	Low risk	Women were randomised to treatment group after consenting to take part in the study
Incomplete outcome data	High risk	Attrition reported: <ul style="list-style-type: none"> • 72 women were randomised to treatment group

Schover et al., 2013 (326) – Journal article

addressed?

(36 in each)

All outcomes.

- 14 women (5 from IDI and 9 from IDI w/counselling) dropped out after randomisation, but prior to filling out baseline measures
- Number of drop outs during the intervention period reported from each group; missing outcome data was balanced in numbers across groups (7 from IDI; 9 from IDI + counselling)

Exclusions reported:

- 23 women were deemed ineligible and excluded prior to randomization
- # of participants, in each arm, at each outcome point:

Baseline:

- IDI (31)
- IDI plus counselling (27)

Post:

- IDI (24) – 66% retention (24/36)
- IDI plus counselling (18) – 50% retention (18/36)

No information provided about imputing missing data

Absence of large or differential losses to follow-up? No

Free of selective reporting?

Low risk

- All outcomes listed in the methods were reported in the results
- Do not have protocol

Wooten et al., 2015 (407) – Journal article

Participants	104 men treated for prostate cancer completed the study. Mean age: 61.0 years (SD 7.0) Sexual difficulty: Erectile dysfunction (ED) Country: Australia
Interventions	IDI: 'My road ahead' is a self-guided cognitive behavioural therapy (CBT)-based intervention that provides psycho-education (through text, video, audio and graphics), a series of interactive exercises, and regular automated feedback as participants' progress through the program. The intervention is a six-module online program that offers a range of topics to work through at an individual pace for 10 weeks. The six modules focus on (1) The emotional impact of prostate cancer, (2) cognitive strategies and effective communication, (3) coping with the physical challenges related to prostate cancer, (4) sexuality and masculinity, (5) sexuality and intimacy, and (6) planning for the future. Psychotherapeutic approach: CBT PPI: Unclear Duration: 10 weeks
Comparator(s)	Moderated online forum only: The forums used a simple topic-based discussion system in which participants could post comments and start discussions. IDI plus access to a moderated online forum: Participants in this condition used a separate forum to the forum only condition to avoid contamination across groups.
Outcomes	Depression, anxiety, stress and total distress scales (DASS-21). Prostate Cancer-related quality of life (PCa-QoL) Confidence (single item measure)
Study design	Randomised controlled trial
Other information	Inclusion/exclusion criteria: Participants were included if they had a diagnosis of localised prostate cancer and had received or were currently receiving treatment with curative intent within the past 5years. Participants were excluded if they had a diagnosis of advanced or metastatic disease. Method of recruitment: Via invitation from urologists, advertisements in newspapers and website, and via postcards. Success of recruitment: Unclear Incentive or cost to participate: Unclear Engagement measured: Yes. Completion of intervention content and time spent on the forum was monitored

Risk of Bias

Item	Author's assessment of risk	Description
Adequate sequence generation?	Low risk	Participants were randomised to one of three intervention conditions using a computer-generated sequential one-to-one allocation across three conditions.
Allocation concealment?	Low risk	Randomisation occurred after consent and baseline measures were taken.
Incomplete outcome data addressed? All outcomes.	High risk	<p>Attrition reported:</p> <ul style="list-style-type: none"> • 142 men were randomised to treatment group • 19 men dropped out during the first half of the intervention period (between being enrolled in their allocated group and the mid-point assessment point at week 5) and a further 19 men dropped out during the second half of the intervention period (between week 5 and the assessment at completion of the intervention at week 10). The number of drop outs were reported from each group. Missing outcome data was approximately balanced in numbers across groups (14 from IDI; 13 from IDI + forum; 11 from forum only). <p>Exclusions reported:</p> <ul style="list-style-type: none"> • 10 men were excluded prior to randomisation due to advanced disease • # of participants, in each arm, at each outcome point: <p>Baseline:</p> <ul style="list-style-type: none"> • IDI (47) • IDI plus forum (48) • Forum only (47) <p>Midpoint assessment:</p> <ul style="list-style-type: none"> • IDI (39) • IDI plus forum (43) • Forum only (41) <p>Post:</p> <ul style="list-style-type: none"> • IDI (33) – 70% retention (33/47) • IDI plus forum (35) – 73% retention (35/48) • Forum only (36) – 77% retention (36/47) <p>Intention to treat analysis used.</p> <p>Absence of large or differential losses to follow-up? No</p>
Free of selective reporting?	High risk	<ul style="list-style-type: none"> • Outcomes listed in previous publications were not reported in the results: International Index of Erectile Function (IIEF), the Dyadic Sexual Communication Scale short form (DSCS-SF), the Communication Pattern Questionnaire short form (CPQ-SF), and the Kansas Marital Satisfaction Survey (KMSS) • Do not have protocol

Appendix E
Characteristics of included IDIs table

Andersson et al., 2011 (078)	
Intervention	
Digital platform	Internet
Mode of delivery	Personal computer
Access	Closed (accessed using password)
Target user	Couples
Duration of use (of the program)	7 weeks
Frequency of use	Once a week
Content	CBT
Human Support	
Level of human support	Therapeutic support
Type	Professional (therapist)
Description	The therapists were all clinical psychology students in their final year of training. Their main function was to provide therapeutic support through clarifying information, reviewing progress, and giving the participants feedback on homework assignments
Mode of delivery	Email
Communication type	Asynchronous
Frequency	Unlimited (could expect a response within 24hrs)
Duration	n/a

Bink, Meana & Sand, 1994 (122)	
Intervention	
Digital platform	Software
Mode of delivery	Personal computer
Access	Closed (accessed in lab)
Target user	Couples
Duration of use (of the program)	40 minutes
Frequency of use	One time
Content	CBT
Human Support	
Level of human support	No support
Type	n/a
Description	n/a
Mode of delivery	n/a
Communication type	n/a
Frequency	n/a
Duration	n/a

Hucker & McCabe, 2014 (470 & 486)	
Intervention	
Digital platform	Internet
Mode of delivery	Personal computer
Access	Closed (accessed using a password)
Target user	Couples
Duration of use (of the program)	12 weeks
Frequency of use	unclear
Content	CBT, Mindfulness & Sex therapy techniques
Human Support	
Level of human support	Engagement & therapeutic support
Type	Professional (therapist)
Description	All therapists specialised in the treatment of sexual difficulties and dysfunctions. Therapists facilitated online chat groups every 2 weeks to review module exercises, discuss challenges, make suggestions, facilitate reflection and discuss relapse prevention. Participants were also offered unlimited email contact with the therapist.
Mode of delivery	Chat group and email
Communication type	Synchronous and asynchronous

Hucker & McCabe, 2014 (470 & 486)	
Frequency	Chat group every 2 weeks; email unlimited
Duration	Chat group 1 hr; email unlimited

Jones & McCabe, 2011 (018)	
Intervention	
Digital platform	Internet
Mode of delivery	Personal computer
Access	Closed (accessed using a password)
Target user	Couples
Duration of use (of the program)	10 weeks
Frequency of use	Min 3hrs per week
Content	CBT & sex therapy techniques
Human Support	
Level of human support	Engagement & therapeutic support
Type	Professional (therapist)
Description	Therapists were all female, and in the process of completing doctoral degrees in clinical psychology. Email contact with a therapist was available at any time for those seeking extra support. The therapist maintained regular contact with each participant by sending an individual email once a week. This was to facilitate engagement, to prevent the likelihood to participant dropout
Mode of delivery	Email
Communication type	Asynchronous
Frequency	Unlimited
Duration	n/a

McCabe, Price, Piterman & Lording, 2008 (003)	
Intervention	
Digital platform	Internet
Mode of delivery	Personal computer
Access	Closed (accessed using a password)
Target user	Couples
Duration of use (of the program)	10 weeks
Frequency of use	unclear
Content	CBT & sex therapy techniques
Human Support	
Level of human support	Engagement & therapeutic support
Type	Professional (therapist)
Description	Unlimited email contact with a therapist was provided to participants. The therapist maintained contact with participants at least once a fortnight. If two weeks had passed without contact, the therapist would send an email to the participant to facilitate engagement and ensure that the participant was not experiencing any difficulties. The main purpose of the contact was to resolve any individual or relationship difficulties that the men experienced as a result of the sensate focus or communication exercises.
Mode of delivery	Email
Communication type	Asynchronous
Frequency	Unlimited
Duration	n/a

Ochs & Binik, 1998 (288)	
Intervention	
Digital platform	Software
Mode of delivery	Personal computer
Access	Closed (accessed in lab)
Target user	Couples
Duration of use (of the program)	44-50 minutes
Frequency of use	One time
Content	CBT
Human Support	
Level of human support	No support
Type	n/a
Description	n/a
Mode of delivery	n/a
Communication type	n/a
Frequency	n/a
Duration	n/a

Ochs, Meana, Mah, Binik, 1993 (226)	
Intervention	
Digital platform	Software
Mode of delivery	Personal computer
Access	Closed (accessed in lab)
Target user	Couples
Duration of use (of the program)	50 minutes
Frequency of use	One time
Content	CBT
Human Support	
Level of human support	No support
Type	n/a
Description	n/a
Mode of delivery	n/a
Communication type	n/a
Frequency	n/a
Duration	n/a

Schover et al., 2012 (183)	
Intervention	
Digital platform	Internet
Mode of delivery	Personal computer/laptop
Access	Closed (accessed using password)
Target user	Couples
Duration of use (of the program)	12 weeks
Frequency of use	unclear
Content	CBT & sex therapy techniques
Human Support	
Level of human support	Engagement & therapeutic support
Type	Professional (therapist)
Description	Unlimited email contact with a therapist was available to participants. Therapists also emailed feedback to participants on homework. If no homework reports were returned within 2 weeks of entering the study therapists sent email and telephone reminders.
Mode of delivery	Email
Communication type	Asynchronous
Frequency	Unlimited
Duration	n/a

Schover et al., 2013 (326)	
Intervention	
Digital platform	Internet
Mode of delivery	Personal computer/laptop
Access	Closed (accessed using password)
Target user	Couples
Duration of use (of the program)	12 weeks
Frequency of use	unclear
Content	Sex therapy techniques
Human Support	
Level of human support	No support
Type	n/a
Description	n/a
Mode of delivery	n/a
Communication type	n/a
Frequency	n/a
Duration	n/a

Wooten et al., 2015 (407)	
Intervention	
Digital platform	Internet
Mode of delivery	Personal computer/laptop
Access	Closed (accessed using password)
Target user	Men with prostate cancer who had been or were being treated
Duration of use (of the program)	10 weeks
Frequency of use	unclear
Content	CBT
Human Support	
Level of human support	No support
Type	n/a
Description	n/a
Mode of delivery	n/a
Communication type	n/a
Frequency	n/a
Duration	n/a

Appendix F
Genital health conditions on cards B and C

B (Men)

- Prostate enlargement
- Prostate cancer
- Prostate surgery
- Bladder surgery
- Genital surgery
- Abdominal surgery
- Broken hip or pelvis bone
- Hip replacement

C (Women)

- Hysterectomy
- Bladder surgery
- Genital or gynaecological surgery
- Abdominal surgery
- Caesarean section/C section
- Broken hip or pelvis bone
- Hip replacement

Appendix G STL screen shots

Stage 1 Stage 2 Stage 3 Stage 4 Stage 5 Stage 6

Confidence in getting and keeping erections

About the Problem

How long have you had a problem with your erections? For a few years *

Does the problem happen alone or with a partner? Just with a partner *

Do you get morning erections? Yes *

What have you tried already to resolve your sexual problem?
(Pick more than one if you like)

Talking to my partner

Talking to my GP

Back Next

Figure 1: Assessment questions

Stage 1 Stage 2 Stage 3 Stage 4 Stage 5 Stage 6

Step one | Evaluation of the problem

Programme Contents

Think about how much the problem is affecting your life at the moment

At the moment, how often do you have difficulty with erections?

None of the time Half of the time All of the time

How much does it bother you?

Not at all A little A fair amount A lot Significantly

How much do you think this bothers your sexual partner(s)?

Save and Exit < Back Save and Continue >

Figure 2: Evaluation of the problem

Stage 1 Stage 2 Stage 3 Stage 4 Stage 5 Stage 6

Step two | Lifestyle factors Programme Contents

Feedback

At the moment, you are having difficulty with your erections 70% of the time. It bothers you significantly and you think it bothers your sexual partners a lot.

From what you have told us there seem to be other factors such as: negative thoughts or worries during sex, which may also be partly responsible.

Continue to find out more about how these factors may be contributing to problems with erections.

[Negative thoughts or worries during sex](#)

Negative thoughts and worries during sex

Worrying during sex or having thoughts such as "What if I contract or transmit a sexually transmitted infection?" "What if they think I'm no good in bed?" can make it difficult to focus on the situation you are in and enjoy the sexual contact or touch for what it is. This can reduce how turned on you are, leading to difficulties with erections. If this happens on one or more occasion, it can create a vicious cycle whereby next time you have sex you worry about it happening again, and are therefore more likely to lose your erection again. This is a really common problem and over time can produce a real difficulty getting and maintaining erections. This programme will teach you more about how negative thoughts or worries get in the way, as well as how to address them and feel more confident about penetration.

Men who have had sexual experiences which were unwanted or forced can find that these experiences intrude on their sex life, encouraging them to associate sex with something unpleasant or wrong. Others find that they 'clam up' or 'feel panicky' when someone touches them sexually, or avoid sexual contact as much as possible to avoid being reminded of what happened.

If this is the case for you, before you continue with the programme consider whether what happened to you is intruding in other parts of your life as well as your sex life in a way that you are unhappy with. Have you had a

Save and Exit < Back Save and Continue >

Figure 3: Feedback on factors that might be contributing to the problem.

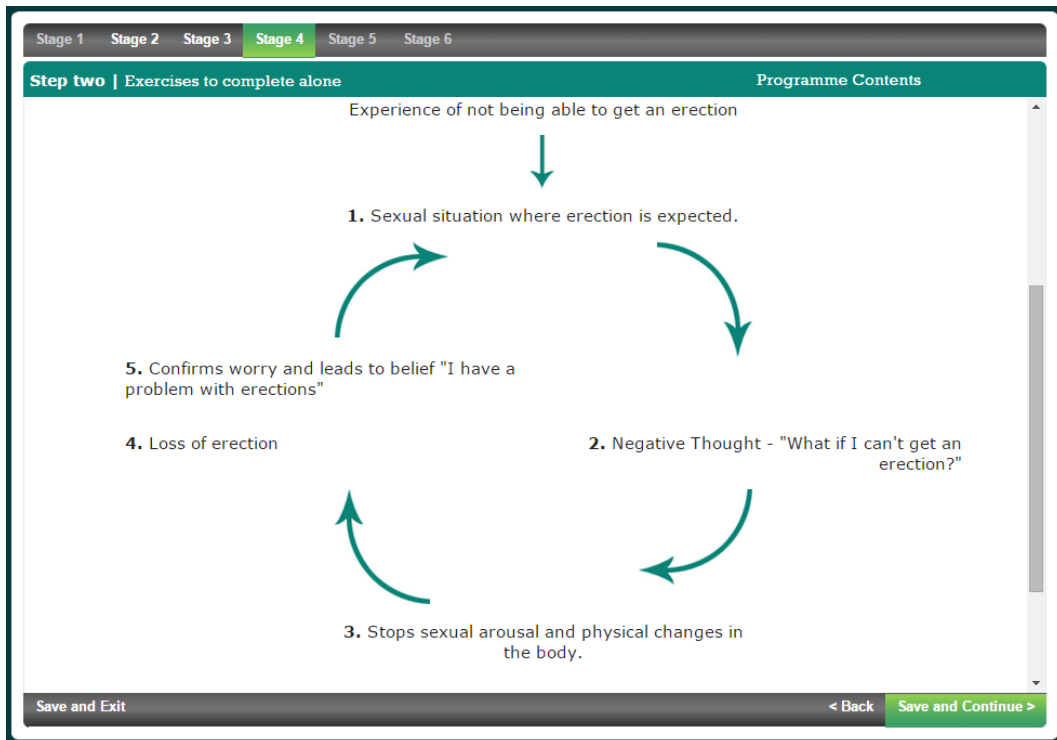



Figure 4: CBT formulation of how negative thoughts can affect sexual performance.

Stage 1 Stage 2 **Stage 3** Stage 4 Stage 5

Step two | Exercises to complete alone Programme Contents

 Exercise: strengthening your pelvic muscles

These are some simple exercises you can start with to increase the blood flow to your penis and help to strengthen your erections. These exercises are called Kegel exercises, and are designed to strengthen the muscles that run from your pubic bone to your spine. Men who do these exercises regularly also report better orgasms and more control over when they ejaculate.

You can feel these muscles if you contract your anus as if you are holding back a bowel movement, or by stopping and starting the flow of urine as you are peeing. Start off by doing this fifteen times, a couple of times per day. Increase until you can do 30-50, twice per day. You can do these exercises while watching TV or sitting on the train. They need to be done regularly to show results but you should notice some improvement within a month to six weeks of doing them regularly.

Practise this exercise now, as you are looking at the screen. Once you have mastered Kegel exercises, continue to practise them as you work through the rest of the programme whenever you can remember to.

We will shortly take you through a series of practical exercises to complete alone. For the remaining exercises you will need to read to the end of the exercise, then log off and take some time to practise them when instructed.


Log off now. Only return to the programme when you feel confident to move on, as each of these exercises build on the previous one.

Save and Exit < Back Save and Continue >

Figure 5: Practical exercises to strengthen pelvic floor muscles.

Stage 1 Stage 2 Stage 3 Stage 4 **Stage 5** Stage 6 Stage 7 Stage 8

Step one | Developing a personalised action plan Programme Contents

 Why is it important to you to be having penetrative sex?

The first question we'd like you to consider is who wants you to be having penetrative sex? Perhaps you feel like it's the 'normal' thing to do? Perhaps your partner is very keen to have penetrative sex in your relationship, or perhaps you just feel as though you should? How often would you like to be having penetrative sex? Are there other things you would like to be doing instead?

We are interested in what would be different if you were able to overcome this pain.

Consider and answer the following questions;

What difference would it make to the way you see yourself? Would it affect your relationship?


Why is this important to you?

Save and Exit < Back Save and Continue >

Figure 6: Systemic therapy exercise to explore the meaning of the difficulty for the person and develop a personalised action plan

Stage 1 Stage 2 Stage 3 **Stage 4** Stage 5 Stage 6 Stage 7 Stage 8

Step three | Your body and sexual arousal Programme Contents

 **Exercise: What do my genitals look like?**

Getting familiar with your body and your genitals is one of the key parts of any programme designed to help you enjoy your sex life more.

For this exercise, find some time when you won't be disturbed, get undressed, hold a mirror between your legs and look at your own genitals. See if you can spot all the features on the diagram that you saw earlier. You may need to move your labia to see the vaginal and urethral openings, or retract your clitoral hood to see the tip of the clitoris beneath. Don't worry if you can't see any of these things, every woman is different, and sometimes parts of your anatomy can be hard to spot. [Log off](#) now. Return to this page of the programme when you have had a chance to do this exercise.

What did you think?
Could you identify all the different parts?
Were you surprised by what you saw?
Did you like the way your genitals looked? If not, why?

If it's the first time you've looked at yourself this closely, it might be interesting to ask yourself why you have not done this before. There can be negative messages around this part of women's bodies, and many women grow up believing that looking at or touching themselves is something they shouldn't be doing. One of the important parts of knowing how to give yourself sexual pleasure, or experiencing sexual pleasure with a partner is knowing your way around your own body. After all, you wouldn't drive to a new place or give someone directions without looking at a map!


If you have negative feelings about touching yourself or looking closely at your own genitals, we will address these in an exercise on how your feelings about this have developed later.

Save and Exit < Back Save and Continue >

Figure 7: Exercise to explore attitudes towards a person's own genitals

Stage 1 Stage 2 Stage 3 Stage 4 **Stage 5** Stage 6 Stage 7

Step five | Increasing your sex drive alone Programme Contents

 **Understanding your attitudes towards sex**

Sometimes how we feel about sex in general can get in the way of sexual desire. Who we are (our identity) is made up of lots of different components. The ideas that we have about the world and ourselves come from our gender, our ethnicity, our age, our religion, the views of the family we grew up in, our sexuality and many other influences. Each of these give us messages or rules about how we should behave in all kinds of different ways, some we may agree with and act upon and some we may not.

For example, men often get different messages about the acceptability of showing emotion. "Real men don't cry" "Being sensitive and in touch with emotions is a good thing." How do men know which to listen to?

Sometimes these ideas are so much part of you that it's hard to recognise them (for example, ideas from the family you grew up in). Even if we don't agree with all of these ideas, we might absorb them into what we expect for ourselves and judge ourselves by them. Ideas we have from the different influences in our lives often contradict each other, as with the example above.

Understanding where these different ideas come from can be useful in understanding how you feel about aspects of your sex life, and which may be affecting your desire to be sexual.

Look at this example for a woman who was confused about whether it was OK to enjoy sex, looking at the different messages from the different influences (contexts) in her life.

<p>Gender</p> <p><i>Enjoying sex is ... sometimes seen as a good thing for women, but sometimes is dangerous in that if it's with more than one person is seen to mark you out as 'easy' or 'promiscuous'</i></p>	<p>Ethnicity</p> <p><i>"Enjoying sex is ...something that as a Dutch woman I feel more laid back about than friends of mine from the UK- it was around more and talked about"</i></p>
--	--

Save and Exit < Back Save and Continue >

Figure 8: Psychoeducation about the socio-cultural factors that influence attitudes towards sex

Stage 1 Stage 2 Stage 3 Stage 4 **Stage 5** Stage 6 Stage 7

Step five | Increasing your sex drive alone Programme Contents

Understanding where these different ideas come from can be useful in understanding how you feel about aspects of your sex life, and which may be affecting your desire to be sexual.

Look at this example for a woman who was confused about whether it was OK to enjoy sex, looking at the different messages from the different influences (contexts) in her life.

<p>Gender</p> <p><i>Enjoying sex is ... sometimes seen as a good thing for women, but sometimes is dangerous in that if it's with more than one person is seen to mark you out as 'easy' or 'promiscuous'</i></p> <p>Age</p> <p><i>"Enjoying sex is ... something that women in their 30's are expected to be doing."</i></p> <p>Sexuality</p> <p><i>"Enjoying sex is ... something that within a straight relationship you are supposed to work at (like all the articles I read in women's magazines)"</i></p> <p>Religion</p> <p><i>"Enjoying sex is ... something that my religion would say is not necessary"</i></p>	<p>Ethnicity</p> <p><i>"Enjoying sex is ...something that as a Dutch woman I feel more laid back about than friends of mine from the UK- it was around more and talked about"</i></p> <p>Family</p> <p><i>"Enjoying sex is ...something that I don't think my parents would have advocated. My family were not relaxed about sex and I certainly grew up with negative messages around sex, even though it wasn't talked about openly- or perhaps because it wasn't talked about openly"</i></p> <p>Culture</p> <p><i>"Enjoying sex issometimes frowned upon in British culture and the media and seen as degrading and the cause of many problems, but also there is an expectation in this culture of what a person's sex life should be like."</i></p>
--	---

Save and Exit < Back Save and Continue >

Figure 9: Psychoeducation about the socio-cultural factors that influence attitudes towards sex (continued).

Stage 1 Stage 2 Stage 3 Stage 4 Stage 5 **Stage 6**

Trigger Diary My Diary Programme Contents

? Trigger Diary

<p>Date <i>(Click Below)</i></p> <input type="text"/>	<p>Situation What triggered your behaviour?</p> <input type="text"/>	<p>Emotion How did you feel?</p> <input type="text"/>	<p>Behaviour What did you do?</p> <input type="text" value="use of porn"/>
---	--	---	--

[Add another trigger](#)

Save and Exit Save and Continue >

Figure 10: Online trigger diary.

Stage 1 Stage 2 Stage 3 Stage 4 Stage 5 Stage 6

Step six | Evaluation of the problem now and feedback on my progress My Diary Programme Contents

What next?

You told us that things haven't changed too much since you first logged on to tackle this problem. If you feel this may be as you missed out some of the key steps, or didn't have enough time to commit to them, why not go back and try them again? Use my programme to revisit any sections of the programme that you weren't able to devote enough time to the first time round.

However over the course of the program you may have drawn the conclusion that this problem is more about what other people think of your sex life than what you think. As we said earlier, people express their sexual identity in many different ways, and just because what you like to do or the frequency you like to do it is different from other people does not mean you need to change it.

Or perhaps there is something else maintaining the problem that we haven't been able to address here (such as alcohol/ recreational drug use), or difficulties in your relationship that have got in the way. If this is the case it's unlikely that you will be able to make changes in your sex life until these are resolved. You may have more success seeing a therapist face to face - online programmes don't suit everybody and you may prefer a more individual approach. You can find out more about this or accessing private relationship counselling via the [resources](#) page.

Remember that you can come back to the programme any time in the future should your circumstances change and you feel like you'd like to revisit the exercises, the information or work through the programme again.

Log off to logout and close this window. This will return you to the [sextherapylondon](#) website where we give you the opportunity to give us some feedback on this programme.

Save and Exit < Back Logout >

Figure 11: Tailored summary at the end of the program in terms of 'what happens next'.

Appendix H Information letter



Central and North West London 
NHS Foundation Trust

Camden Provider Services

Participant Information Sheet

People's Views on Using Web-based Programs for Sexual Problems

This study has been approved by the NHS Research Ethics Committee.

Project ID Number: 12/LO/1785

Protocol reference number: Version 1.0; Date 24.8.12

-
- We would like to invite you to take part in our research study. Before you decide whether to take part we would like you to understand why the research is being done and what it would involve for you
 - Part 1: Tells you about the study and what will happen if you choose to take part
 - Part 2: Gives you more detail about the conduct of the study
 - Please ask if there is anything that is not clear

Part 1

Why are we doing the study?

Many people experience sexual problems (e.g., erectile problems or lack or loss of sexual desire), all of which can have a negative impact on emotional and sexual well-being, quality of life and interpersonal relationships. Some people seek face-to-face help through their GP or Sexual Health Services, but for a variety of reasons many

people do not. One alternative way of helping people with sexual problems could be to offer information and support through a web-based program. Before the NHS adopts this approach it is important to know what people think of the idea and whether they would be willing to use a programme like this.

Why have I been chosen?

We have written to everyone on the Sexual Problems Assessment and Treatment Service waiting list and to patients attending Sexual and Reproductive Health Clinics in North and East London, inviting them to take part in the study. However, we are specifically looking for people aged 18 or over who have experienced one of the following sexual problems: problems with erections, lack or loss of sexual desire, or sexual behaviours that cause distress.

Do I have to take part?

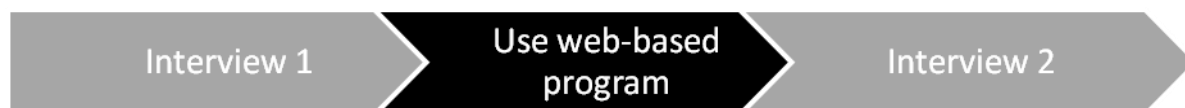
No. It's up to you to decide whether or not to participate in the research. Your usual health care will not be affected by whether you choose to take part or not. Take as long as you need to reach a decision, and please do talk to others about the study if you wish. If you do decide to take part, you will be asked to sign a consent form. Even after signing this form you do not have to discuss anything you feel uncomfortable discussing, and you may pause or leave the interview at any time without having to give a reason

What will happen to me if I take part?

If you decide to take part you will meet with a researcher (in person or via telephone or webcam as chosen by the participant) to discuss your views and experiences of having a sexual problem. Topics covered include the following: How do people describe and define their sexual problem? What are people's experiences of seeking help (or not)? What do people want from sex therapy? What are people's views of web-based programs for sexual problems? The first interview will take 45-60 minutes, and will usually take place face-to-face in a clinic or university room (but you may request an interview via webcam or telephone if you feel more comfortable with this).

After this first meeting you will be invited to use a web-based program for sexual problems which was developed by clinical psychologists and sex therapists at sextherapy london.nhs.uk. You will be given a user ID and password that will enable you to log on at a time and place that is convenient to you.

After using the program, you will be invited to a second interview to discuss your views and experiences of using this web-based program. The second interview will take 30-45 minutes.



Your views are very valuable, and will feed into improving the design of the [sextherapy london](http://sextherapy london.nhs.uk) program.

Will I benefit from taking part?

Talking about sexual problems can be helpful. You will also have the opportunity to use a new web-based sex therapy program designed to help people with a sexual problem (sextherapy london.nhs.uk). Your contribution may improve future services for people with sexual problems. Each participant will also receive £30 as a thank you for their input in the study (£15 after each interview).

Are there any risks involved?

We hope that you will find discussing your views and experiences an informative and enjoyable experience. However, you may find discussing sexual problems difficult, embarrassing or upsetting, and if this happens, we will pause the interview and only carry on if you wish to continue. The interviewer will provide a list of support services.

What happens when the study ends?

The information from the interviews will be used to improve the web-based program and improve future services.

Will I be contacted after the study has ended?

The researcher may contact you in the future, to invite you to participate in a follow-up study, but only if you agree to this on the consent form. You are not under any obligation to participate in any follow-up studies.

Will my GP and health care team know I am in the study?

No.

Will the information I give in the study be kept confidential?

Yes. We will follow all ethical and legal guidelines, and all information about you will be handled in confidence. Detailed information on this is given in Part 2.

Can I withdraw from the study once I'm in it?

Yes. You can withdraw from the study at any time without giving a reason.

Part 2: Detailed information about the conduct of the study

What will happen to the information I provide?

All information about you will be treated confidentially and in accordance with the Data Protection Act 1998. We will keep your personal identification data (your name and address) separate from the rest of the study information about you, which will only be identifiable by a unique participant identification number. All anonymised data will be kept on a password protected computer, which will be kept in a locked office. Only authorised persons (the research team and the regulatory bodies that monitor researchers in the UK) will have access to your personal data. The information you provide will not be shared with your care team or GP.

Confidentiality is only broken under exceptional circumstances (i.e., if a participant discloses that they intend to harm themselves or others). If this should happen we have a duty of care to inform a member of the participant's care team. In the event that this should happen, we will always discuss this course of action with you first.

What if there is a problem or what if something goes wrong?

If you wish to complain, or have any concerns about any aspect of the way you have been approached or treated by members of staff due to your participation in the research, National Health Service or UCL complaints mechanisms are available to you. Please ask your research doctor if you would like more information on this. In the unlikely event that you are harmed by taking part in this study, compensation may be available. If you suspect that the harm is the result of the Sponsor's (University College London) or the hospital's negligence then you may be able to claim compensation. After discussing with your research doctor, please make the claim in writing to Dr Elizabeth Murray who is the Chief Investigator for the research and who is based at the UCL e-Health Unit, Research Department of Primary Care and Population Health, Royal Free Hospital, Rowland Hill St, London, NW3 2PF. The Chief Investigator will

then pass the claim to the Sponsor's Insurers, via the Sponsor's office. You may have to bear the costs of the legal action initially, and you should consult a lawyer about this.

What will happen to the results of this study?

The results of this study will be submitted for publication in academic journals and presented at conferences. We hope the findings will lead to improved web-based health services for patients. We would be happy to send you a summary of the results – if you would like us to do so please sign the appropriate box on the consent form.

Loss of capacity

In the very unlikely and unfortunate event that someone taking part in the study lost the ability to make informed decisions for him/herself, that person would not continue to take part in the study.

Who is organising and funding the study?

The study is being run by University College London. It is funded by the National Institute for Health Research as part of a PhD thesis. It is sponsored by University College London. The research team are: Ms Lorna Hobbs (PhD researcher); Dr Elizabeth Murray (General Practitioner and Researcher); and Dr Julia Bailey (Community Sexual Health Doctor and Researcher).

Who has reviewed the study?

To protect the interests of participants, all research in the NHS is looked at by an independent group of people, called a Research Ethics Committee. This study has been reviewed and given a favourable opinion by Camden & Islington Research Ethics Committee.

Is there an independent contact point where I can get general advice about taking part in research?

Yes. INVOLVE is a national advisory group that supports greater public involvement in NHS, public health and social care research. They provide advice and information on public involvement in research. You can find more information on their website: www.invo.org.uk or you can contact them at: INVOLVE, Wessex House, Upper Market Street, Eastleigh, Hampshire, SO50 9FD or Telephone: 023 8065 1088.

Is there a contact point where I can find out further details about the study?

Yes. If you have any questions or would like more information please contact Lorna Hobbs (contact details below).

Who do I contact if I wish to take part?

If you are interested in taking part please contact Lorna Hobbs (contact details below). She will contact you to arrange an appointment to discuss the study further.

CONTACT DETAILS

Name		
Role		
Tel		
Email		
Address		
Fax		
Web		

**Appendix I
Consent form**



Homerton University Hospital 
NHS Foundation Trust

Site address: The Ivy Centre
St Leonard's Hospital
Nuttall Street
London N1 5LZ

Participant Consent Form

Title of Project: *People's Views on Using Web-based Programs for Sexual Problems*

Name of researcher [person taking consent]:.....

Please initial
inside boxes

1. I confirm that I have read and understand the information sheet dated 6.12.12 (Version 3.0b) for the above study.

2. I have received satisfactory answers to all my questions and been told whom to contact in the event of any concerns or problems relating to the research (contact Lorna Hobbs, telephone 020 7794 0500 ext 31025 or email l.hobbs@ucl.ac.uk).

3. I understand that my participation will be audiotaped and saved on a computer, and I consent to the use of this information for the research project only. I also understand that once the information has been transcribed, names and all other personal data will be destroyed in accordance with the Data Protection Act 1998.

4. I understand that data collected during the study may be looked at by individuals from authorities which regulate research. I give permission for these individuals to have access to my records.

Participant Consent form date of issue: 6.12.12
Participant Consent form version number: V3.0b (clinic samples in HOMERTON)

REC ref: 12/LO/1785
Submission code: 117978/374592/1/685

People's views on using computer-based interventions for sexual problems

5. I understand that the research will be published in a report but that it will not be possible to identify participants in any publications.
6. I agree that I may be contacted in the future, by the researcher, to invite me to participate in a follow-up study. However, I am not under any obligation to participate in any follow-up studies.
7. I understand that what is discussed between the researchers and myself will not be disclosed to anyone else, unless I disclose an intention to harm myself or others. If this should happen, I understand that the researcher will contact a member of my care team.
8. I understand that I am free to withdraw from the study at any time if I wish, without having to give a reason.
9. I agree to take part in the above study.

Name of Participant

Date

Signature

Name of Person taking consent.

Date

Signature

If you would like us to send you a summary of the results once the study is finished, please initial the box and provide your email address below.

Email address.....

This piece of paper will be stored separately from your consent form, and will not be linked to the data you provide in any way.

Appendix J
Sources of recruitment and reasons for non-participation

Recruitment site	Reason (if any) for non-participation
Sexual health clinic	Participant felt too vulnerable
Sexual health clinic	No contact after info sheet
Sexual health clinic	No contact after info sheet
Sexual health clinic	No contact after info sheet
Sexual health clinic	Did not speak fluent English
Sexual health clinic	No contact after info sheet
Sexual health clinic	No contact after info sheet
Sexual health clinic	No show at Interview 1
Sexual health clinic	Cancelled twice – too busy
Sexual health clinic	Family crisis
Sexual health clinic	No show at Interview 1
Sexual health clinic	Under 18
Sexual health clinic	Under 18
Sexual health clinic	No contact after info sheet
Sexual health clinic	No contact after info sheet
Sexual health clinic	No contact after info sheet
Sexual health clinic	No contact after info sheet
Sexual health clinic	No contact after info sheet
Sexual health clinic	No contact after info sheet
Sexual health clinic	No contact after info sheet
Sexual health clinic	No contact after info sheet
Sexual health clinic	No contact after info sheet
Sexual health clinic	Stopped recruiting gay men
Sexual health clinic	No contact after info sheet
Unclear	No contact after info sheet
Unclear	No contact after info sheet
Unclear	No contact after info sheet
Unclear	No contact after info sheet
Sexual health clinic	Partner did not want person to participate
Sexual health clinic	No show at Interview 1
Unclear	Participant said she would find the interview too difficult (embarrassing/distressing)
Unclear	Person not currently experiencing difficulties
Friend	No contact after info sheet
Facebook	No contact after sending initial expression of interest
Unclear	No contact after info sheet

Recruitment site	Reason (if any) for non-participation
Facebook	No contact after info sheet
Sexual health clinic	Dropped out of contact while trying to schedule interview
Unclear	Dropped out of contact while trying to schedule interview
Sexual health clinic	Recruitment closed
Unclear	Dropped out of contact while trying to schedule interview
Unclear	Said it was too much of a time commitment
Unclear	Recruitment closed
Unclear	Recruitment closed
Unclear	Recruitment closed
Unclear	Recruitment closed

Appendix K
Topic guide interview 1

Interview 1 – Topic Guide

[Before turning on the recorder]

- Introduce myself
- Go through the participant info sheet (inc. what happens to data)
- Go through consent form & sign
- Go over areas to cover
- Explain that I'm going to note down anything I want to come back to
- Reiterate there's no right or wrong answer etc.

[Turn on the recorder]

Exploring users' perceptions and definitions of sexual problems

1. Ok _____, so you're here today because when we spoke before you said you _____, is that right?

2. Ok, so perhaps you could start off by telling me a bit about when you first _____?

(Allow person to 'tell their story'; trying to get some coherence in time – what happened and when; duration; frequency; the person's understanding of the problem; the impact it has on their life; their thoughts & feelings surrounding the problem)

3. Would you say you have a sexual problem or difficulty?

4. If yes to 3, how would you define or describe your sexual problem?

(Is it Physical/biological? Psychological/emotional? Both? Related to another problem or situation?)

5. If no to 3, how would you define the problem?

6. Does the problem happen in all situations or are there times it's not a problem (e.g. erectile problems during masturbation and desire to masturbate vs having sex with another person, and situations where problematic sexual behaviour occurs more or less frequently)

7. SPATS Clinic patients only – Who referred you to the service?

8. Does anyone else see this problem as a problem? (Partner(s), doctor etc.)
9. Refer back to what the person told me at the start – You've told me a bit about how this problem affects your life, can you tell me anything else about how having _____ affects your life? Are there any other ways _____ affects your life?

(Thoughts, feelings, experiences)
10. Do you currently have a partner (if no, move on to Q15; if yes, move onto Q11)
11. Can you tell me a bit about your relationship with your partner(s)?
12. Are you satisfied with your relationship with your partner(s)?
 - a. If yes - Ask what makes it satisfying
 - b. If no – Ask why
13. Are you satisfied with your sexual relationship(s)?
 - a. If yes - Ask what makes it satisfying
 - b. If no – Ask why
14. Does your partner(s) have any sexual problems or difficulties?
15. How would you describe an ideal sexual relationship?
16. How would you describe a satisfactory (or good enough) sexual relationship?
17. How would you describe an unsatisfactory sexual relationship?

So, we've been talking about your thoughts of the problem, are there any final points you'd like to add before we move on?

Identifying facilitators, barriers and patterns of help-seeking behaviour for sexual problems

1. Have you sought any help before now?
 - a. If yes, where was that? (GP, online, psychologist, friend etc.)
 - b. If no then skip to Q6.

2. Can you tell me a bit about what you found helpful or unhelpful, and why?
3. Did you seek help anywhere else? (Helpful/unhelpful?)
4. How long after the problem started did you seek help?
5. What enabled you to get some help?
6. What prevented you from getting help (or getting help earlier)?
7. Can you think of anything that makes it difficult for people to seek help?(barriers to help-seeking)
8. Can you think of anything that would make it easier for people to seek help? (facilitators of help-seeking)
9. Have you ever looked for help online?
 - * If no, move onto next section
 - *If yes, can you tell me a little bit about that (was it helpful/unhelpful, and why)?

So, we've been talking about help-seeking for sexual problems, are there any final points you'd like to add before we move on?

Identifying what people want and need from sex therapy

1. What things would you want a program of help to include?
(info, knowing what's 'typical', peer or professional support, behavioural exercises, convenient location etc.)
2. If you took part in a program of help, what changes would you most hope to see?
(sexual function, sexual satisfaction, improved relationship OR changes in thoughts, feelings, behaviours etc.)

So, we've been talking about what you might want from sex therapy, and the changes you'd hope to see if you participated a sex therapy, are there any final points you'd like to add before we move on?

Exploring people's perceptions of computer-based interventions for sexual problems and sextherapylondon.nhs.uk

So now we're going to have a quick look at sextherapylondon.nhs.uk (or screen shots), which is a web-based sex-therapy program.

1. Now that you've seen the website, what are your initial thoughts and feelings about it?
2. Is there anything you liked or disliked about the program?
3. If it were up to you, is there anything you'd change about the program to make it more appealing to users? (Interface, design, wording, content etc.)
4. Would you be prepared to use a program like this?
*Yes – move onto Q
*No – could you tell me why this is?
5. Do you think a program like this could help you?
*Yes – in what ways?
*No – could you tell me why this is?
6. If a GP or psychologist recommended using a program like this would this influence your decision to use it or not?
*Yes – in what way?
*No – could you tell me why this is?
7. Do you think a program like this could help other people?
*Yes – in what ways?
*No – could you tell me why this is?
8. How did you hear about the study?
(Recruitment pathway)
9. What made you decide to take part in the study?

So, we've been talking about your views of web-based programs for sexual problems and difficulties, are there any final points you'd like to add before we close the interview?

Is there anything you feel we haven't covered here?

[Turn off the recorder]

Debrief

- Discuss using the website at home
- Give the participant user name and password
- Get email or phone number for follow-up reminder
- Give email and phone number to contact for any problems
- Book time for 2nd interview

Make field notes

- Any notable themes?
- Social/organisational characteristics of the setting
- Participant characteristics (physical appearance, tired, embarrassed, talkative, shy etc.)
- My perceptions of the person, my thoughts, my emotions
- Any notable events during the interview (my behaviour or theirs)
- Context (Historical, political, policy etc.)
- Any changes I want to make to the topic guide

Appendix L
Topic guide interview 2

Interview 2 – Topic Guide

1. Were you about to access the website (sextherapylondon) after we looked at it during the last interview?
 - * Yes – Can you tell me what you were hoping to get out of using the website?
 - * No
 - Can you tell me why you didn't access the website?
 - What would you change about the website that would then encourage you to use it more?
2. What did you think of the website?
 - a. Were there parts of the website that were helpful/worked well? Which parts and why?
 - b. Were there parts of the website that were unhelpful/didn't work so well? Which parts and why?
3. Did you feel anything changed as a result of using the website?
4. Did the website make you think or feel differently about your sexual problem in any way? In what way?
5. Did you find the website easy or difficult to use?
Which parts?
6. Can you remember, approximately, how many times you logged on to the website?
7. How much of the website did you complete?
All, majority, a little, none? Reason?
8. Did you do the exercises?
 - *Yes – what did you think of them?
 - *No – was there a reason why you didn't complete them?
9. Was there anything that made it difficult for you to use the website?
(Components of the actual intervention OR external factors: fatigue, time, privacy etc.)

10. What, if anything, would you change about the website that would then make you more likely to use the website more?
11. When and Where did you tend to use the website?
12. Overall, were you satisfied with the website?
Why/why not?
13. Would you recommend the website to others?
Why/why not?
14. If applicable, how does this website compare with other forms of treatment for sexual problems and difficulties?
15. If it were up to you, would you change anything about the website?
16. If there was an opportunity, within the program, to talk to a counsellor or psychologist (via email, skype or phone) would that be something you'd use? If so, would you prefer email, skype or phone?
17. Thinking back to when we first met, before you'd used the program, and then to now. Do you think you are more likely, less likely, or about the same, to seek out some face to face help for...?
18. Did you use the website alone, with a partner(s) or both?
*Alone – End of interview
*With partner(s) or both, go onto Q17
19. What did your partner(s) think and feel about the website?
20. Did it make them think differently about the problem?
21. Did it change their behaviour in any way?

Appendix M
Demographic questionnaire



People's Views on Using Web-based Programs for Sexual Problems

Answers to these questions will help us to know more about the people we have interviewed and make sure that we have talked to people from different backgrounds and with different experiences.

This information will be kept confidential and individual answers will not be disclosed to anyone else. Your answers will not be linked to your name.

1. What is your date of birth? _____
2. What is your postcode? _____
3. What gender are you?
 Male Female Transgender
4. What is your ethnicity? _____
5. What (if any) religion were you brought up with? _____
6. Where were you born? _____
7. What is your sexual orientation:
 Heterosexual Gay Lesbian Bisexual
Other (please state _____)

Please turn over to the next page →

8. What is your current relationship status
- Single
 - In relationship but not living with partner(s)
 - Living with partner(s)
 - Married/Civil Partnership
9. What is the highest level of education you have achieved
- Left school before 16
 - Secondary school qualification
 - College/sixth form qualification
 - Diploma/vocational qualification
 - Undergraduate degree
 - Postgraduate degree
 - Other (please state _____)
10. Are you
- Working (full or part-time)
 - At college or university
 - In training
 - Unemployed
 - On long-term sick
 - Retired
 - Other (please state _____)
11. Do you have access to the internet at home?
- Yes
 - No

12. Do you have a mobile phone with Internet access?

Yes No

13. Have you ever looked for information about sexual problems online?

Yes No

14. Is there anything else you would like to tell the researchers?