

**Adapting, testing and evaluating an eLearning resource for  
healthcare professionals to enhance the provision of sexual support  
with patients and their partners in cancer care.**

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## **DEDICATION**

I consider it an honour to have worked alongside the late Professor Eilís McCaughan, to whom this thesis is dedicated, who worked tirelessly to improve patient reported sexual outcomes in cancer care. Her expertise, dedication, attention to detail, enthusiasm, and belief in me will continue to influence my thinking and practice for years to come.

## **ABSTRACT**

### **Introduction**

Cancer and treatment can cause devastating and enduring changes to the experience of sexuality. While healthcare professionals (HPs) should initiate sexual support for patients and partners, this does not happen routinely. Key barriers for HPs, are a lack of knowledge and training opportunities. To address the gap, a prostate-specific eLearning resource for HPs was adapted, creating the Maximising Sexual Wellbeing: Cancer Care eLearning resource (MSW: CC). This thesis reports on adaption, optimisation and evaluation of MSW: CC.

### **Methods**

Intervention development was guided by the Person Based Approach (PBA), using mixed methods, across three phases. Phase 1 - intervention planning, included an extensive literature review and guiding principles to inform the adaptation of the prostate-specific eLearning resource to one for use across cancer care (MSW: CC). During Phase 2- intervention optimisation, MSW: CC prototype was reviewed by an expert group, iteratively tested and refined using 18 think-aloud (TA) interviews with HPs. Phase 3- intervention evaluation involved pre-test and post-test surveys (n=87) to determine the impact of MSW: CC on HPs' sexual attitudes and beliefs related to providing sexual support in cancer care. This evaluation phase also determined HP's views on acceptability and usability.

### **Results**

TA interviews highlighted necessary modifications, which centred around navigation issues. Thematic analysis identified two themes, "sexual support, it is the HP role but there is room for improvement" and "MSW: CC eLearning resource meets our needs."

The evaluation demonstrated HPs acceptability and usability of the resource. Statistically significant changes in pre-test to post-test survey scores demonstrated capability of the MSW: CC to reduce HPs' attitudinal barriers related to the provision of sexual support in cancer care.

### **Conclusions**

The MSW: CC has been successfully adapted, displaying potential to reduce HPs' attitudinal barriers to the provision of sexual support. This resource has potential to assist in implementation of global healthcare guidelines advocating for HP-led sexual support across cancer care.

**Keywords:** sexual support, healthcare professionals, cancer care, Person Based Approach, mixed methods, eLearning, intervention adaptation

## ABBREVIATIONS

BPS	Biopsychosocial
CARD	Cancer, Assessment, Referral, Document
CF	Carrie Flannagan
CNS	Clinical Nurse Specialist
CPD	Continuing Professional Development
CRUK	Cancer Research, United Kingdom
CS	Cherith Semple
DfE	Department for the Economy
DHSSPS	Department of Health, Social Care and Public Safety
DoH	Department of Health
EASSi	Engagement, Assessment, Support & Signposting
EM	Eilís McCaughan
EONS	European Oncology Nursing Society
EORTC QLQ-BR23	European Organisation for the Research and Treatment of Cancer Quality of Life Questionnaire – Breast Cancer
Ext PLISSIT	Extended Permission, Limited Information, Specific Support, Intensive Therapy
GDPR	General Data Protection Regulation
GP	General Practitioner
GRISS	Golombok-Rust Inventory of Sexual Satisfaction
HIV	Human Immunodeficiency Virus
HNC	Head and Neck Cancer
HP	Healthcare professional
HPV	Human Papilloma Virus
HSC	Health and Social Care
HSCT	Health and Social Care Trust
ICO	Information Commissioner’s Office
IPOS	International Psycho-Oncology Society
IRAS ID	Integrated Research Application System IDentification
LC	Local Collaborator
LD	Lynn Dunwoody
LGB & T	Lesbian, Gay, Bisexual & Transgender
LMS	Learning Management System
MRC	Medical Research Council
MSW: CC	Maximising sexual wellbeing: Cancer Care
MSW: PC	Maximising sexual wellbeing: Prostate Cancer
NHSCT	Northern Health and Social Care Trust
NI	Northern Ireland
NICE	National Institute for Health and Care Excellence
NPT	Normalising Process Theory
OREC NI	Office for Research Ethics Committee, Northern Ireland
PBA	Person Based Approach
PIS	Participant Information Sheet
PLISSIT	Permission, Limited Information, Specific Support, Intensive Therapy
PPI	Public and Personal Involvement
QoL	Quality of Life
SABS	Sexual Attitudes and Beliefs Survey
SCT	Social Cognitive Theory

SHC-A Scale	Sexual Health Care – Attitude Scale
SKAT	Sexual Knowledge and Attitude Test
TA Interviews	Think aloud interviews
TDF	Theoretical Domains Framework
TPB	Theory of Planned Behaviour
UK	United Kingdom
UKONS	United Kingdom Oncology Nursing Society
UU	Ulster University
WHO	World Health Organisation

**DECLARATION**

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## CHAPTER ONE: INTRODUCTION

### 1.1 Introduction

The aim of this PhD study was to adapt, test and evaluate an eLearning resource for healthcare professionals (HPs) to enhance the provision of sexual support in cancer care. This chapter has set the research context and provided a rationale for the study, after which it has presented the study aim and objectives. Following an examination of key definitions used throughout the study, the chapter concludes with a presentation of the thesis overview and structure. A traditional approach was taken in the production of this thesis, however there are papers prepared for journal submission based on content within Chapters 4 and 5.

### 1.2 Background and study context

Cancer incidence is rapidly growing worldwide with approximately 17 million people receiving a diagnosis annually and many of these individuals becoming long-term survivors (Bray *et al.* 2018). Globally, lung, breast, prostate and colorectal cancers account for over 40% of cancers diagnosed (Bray *et al.* 2018). Although cancer incidence rates generally increase with advancing years, there is a marked epidemiological change for some tumour groups in respect to younger age at diagnosis. This is evident in cancers such as colorectal and head and neck (HNC), with increases within the young adult population due to factors such as diet and the Human Papilloma Virus (HPV) respectively (Meyer *et al.* 2010; Chaturvedi *et al.* 2011).

Worldwide, cancer survival rates (five-year) have increased significantly in the last ten years; rising from 28.8 million people to 43.8 million (Bray *et al.* 2013; Bray *et al.* 2018). In the UK, it is estimated that 50% of people are surviving cancer for 10

or more years; with survival rates doubling in the last 40 years (Quaresma *et al.* 2014). This equates to around 2.5 million people in the UK living with or recovering from cancer and it is estimated that by 2030 there will be over 4 million cancer survivors in the UK (Macmillan Cancer Support 2015). Parallel to this growth in people surviving their cancer, there is mounting recognition that people with cancer need to be supported to improve their quality of life (QoL) after active treatment (Manganiello *et al.* 2011; Macmillan Cancer Support 2016; Arndt *et al.* 2017). Cancer care should be built around what matters to individuals (Downing *et al.* 2015) and people should feel prepared for the life consequences of their cancer and its treatment, equipped to manage their care (Lawn *et al.* 2017) and supported to take control over their life to promote long-term QoL (Arndt *et al.* 2017).

Sexuality is one aspect of QoL which is significantly impacted by a cancer diagnosis and treatment. Experiencing a cancer diagnosis may dramatically alter the way a person feels about themselves, their body and their intimate relationships (Bitzer and Hahn 2017). Approximately 60% of patients can experience difficult and enduring sexual challenges after cancer, regardless of tumour group (Charif *et al.* 2016b; Maiorino *et al.* 2016; Bober *et al.* 2019; Downing *et al.* 2019; Di Mattei *et al.* 2020), although there are varied experiences of the level of sexual challenges across the tumour groups. The physical impact of treatments including surgery, chemotherapy, radiotherapy, hormone therapy, alongside the social, emotional and body image difficulties, can all disrupt sexuality. For some, this is due to specific anatomical changes such as the shortening of the vagina, or nerve damage causing bowel problems and erectile difficulties (Aerts *et al.* 2009; Panjari *et al.* 2011; Traa *et al.* 2012) which may result in painful sexual intercourse or the avoidance of sexual activity. For others, treatment-related physical changes such as lymphoedema, pain, fatigue, infertility and early menopause can affect a

patient's sense of sexuality and their intimate relationships (Mercadante *et al.* 2010; Bober and Varela 2012; Schover 2019). Such challenges can affect body image, sexual attractiveness, sexual identity and additional emotional changes, including depression and anxiety, which may exacerbate the physical challenges encountered (Vermeer *et al.* 2016; White *et al.* 2013; Boquiren *et al.* 2016; de Vocht 2017; Begovic-Juhant *et al.* 2012; Bae and Park 2015). Unlike some other cancer treatment-related effects, challenges to sexuality will typically affect partners too. For partners, this can potentially result in reduced intimacy, loss of a sexual relationship, coping with partner's frustrations and increased tension within the relationship (Grondhuis Palacios *et al.* 2018). This is at a time when an intimate relationship can be an anchor point; providing a source of strength to navigate the disease experience. Therefore, importance rests on supporting both patient's and partner's sexual health and wellbeing (Flynn *et al.* 2012).

The highly individualised nature of a cancer diagnosis and treatment, alongside the uniqueness of the experience of sexuality means that patients can have different priorities for addressing sexual concerns along the treatment trajectory (Hay *et al.* 2018). Furthermore, patients may have differing levels of willingness and motivation to address sexual concerns (Hoole *et al.* 2015) and varied preferences related to the provision of sexual support (Hubbs *et al.* 2019; Albers *et al.* 2020b). It is clear, however, from the literature that many patients and partners have a desire for the provision of HP-led sexual support in cancer care (Flynn *et al.* 2012; Sporn *et al.* 2015; Den Ouden *et al.* 2018). HPs across cancer care are well-placed to address sexuality concerns, having frequent contact with patients during the provision of physical care and emotional support throughout the treatment trajectory and recovery (Krouwel *et al.* 2015b; Nisbet *et al.* 2021). Globally, healthcare guidelines recognise patients' and partners' need for sexual support,

detailing that biopsychosocial sexual support should be provided across the treatment trajectory (Carter *et al.* 2018, NHS 2016, Cancer Australia 2019). The provision of sexual support has been identified as helpful to normalise sexual challenges, engender a sense of hope and provide helpful strategies to improve patient-reported sexual outcomes (Brotto *et al.* 2010; Nisbet *et al.* 2021).

### **1.3 Rationale for the study**

Despite healthcare guidelines detailing the need for sexual support to be provided routinely to patients with cancer and their partners (Carter *et al.* 2018; NHS 2016; Cancer Australia 2019) and patients' desire for HP-led sexual support; globally, this is not commonplace in healthcare settings (Flynn *et al.* 2012; Charif *et al.* 2016a, Sporn *et al.* 2015, Reese *et al.* 2017b; Frederick *et al.* 2019b). Furthermore, research indicates that when HP-led sexual support is provided to patients and partners in cancer care it is largely dependent on type of tumour, gender, or age of patient (Flynn *et al.* 2012; Ussher *et al.* 2013). A recent systematic review examined the principal barriers to HP provision of sexual support (O'Connor *et al.* 2019). The consensus was that HP related attitudinal barriers prevent the provision of sexual support, alongside patient and professional and organisational factors. Research indicates that HPs have a need for education to improve their knowledge of the sexual challenges faced by patients and partners and a framework to guide sexual support conversations (Moore *et al.* 2013; Gleeson and Hazell 2017; Canzona *et al.* 2018; Almont *et al.* 2019b; Krouwel *et al.* 2020). In addition, HPs required effective support strategies to promote patient coping, along with access to supportive resources and referral pathways, all of which could contribute to addressing this gap in practice (Fitch *et al.* 2013; Vermeer *et al.* 2015; Gleeson and Hazell 2017; Canzona *et al.* 2018; Frederick *et al.* 2019a; O'Connor *et al.* 2019). To date, several educational interventions have been designed to address these barriers, but these

have been limited in scope with a reliance on a face-to-face delivery modality (Wang *et al.* 2015; Afiyanti *et al.* 2016; Jonsdottir *et al.* 2016; Reese *et al.* 2019a; 2019b) and confined to individual tumour group, such as prostate, a specific gender, or theme such as fertility (Wang *et al.* 2015; McCaughan *et al.* 2021a; Quinn *et al.* 2019; Reese *et al.* 2019a; 2019b). These interventions have shown success at increasing HPs awareness, frequency and comfort of discussing sexual concerns, thus reducing HP perceived barriers related to the provision of sexual support. However, intervention research in this area is still in its infancy with a small number of heterogenous studies. Moreover, there is a lack of clarity on which components of interventions can maximise effectiveness of sexual support, with Albers *et al.* (2020a) stating a need for more evidence-based research.

The Maximising Sexual Wellbeing: Prostate Cancer (MSW: PC) eLearning resource (McCaughan *et al.* 2021a) was a recently developed educational resource with the aim to enhance the provision of HP-led sexual support in prostate cancer care. This eLearning resource was designed and developed to offer foundational level education and training, under the guidance of an international collaboration of experts in the field of cancer care, using a three-step approach. This resource was developed to challenge HPs' attitudinal barriers to providing sexual support in prostate cancer care, equip HPs with tools and a language to discuss sexual concerns, furnish HPs with supportive resources and establish referral pathways for patients and partners who faced more complex challenges. The MSW: PC eLearning resource included a conceptual framework which provided a structure for the provision of sexual support to patients, namely, Engagement, Assessment, Support and Signposting (EASSi) (McCaughan *et al.* 2020). The evaluation indicated that the MSW: PC eLearning resource demonstrated a positive shift in HPs' attitudes relating to their role to provide sexual support, together with significant improvements in

awareness of the impact of prostate cancer on sexual wellbeing (McCaughan *et al.* 2021a). The resource employed an eLearning approach to maximise on resource accessibility. This was an important step, given that eLearning has been regarded as an 'integral and ubiquitous component of health professional education' (Sinclair *et al.* 2017, p.127). The contribution of an eLearning approach has been magnified during the recent global pandemic when most face-to-face training ceased (Alvin *et al.* 2020). The online learning environment has been considered by numerous researchers, to be comparable to traditional face-to-face methods and in many cases, users report high levels of satisfaction (Du *et al.* 2013; McCutcheon *et al.* 2015; Sinclair *et al.* 2016; Martin *et al.* 2018; Souza *et al.* 2018; Kirana *et al.* 2020). Furthermore, online learning approaches have been reported to be superior to no intervention at all (Sinclair *et al.* 2016). It is recognised that online approaches may not be suitable for all HPs or organisations due to initial cost, access to technology and internet connectivity (Ramsey *et al.* 2016). Online approaches, however, can provide the opportunity to create person-centred, self-paced, flexible opportunities to learn; with reduced travel and less impact on work schedules (Atreja *et al.* 2008; Du *et al.* 2013; Kirana *et al.* 2020).

The evidence base highlighted the need for an accessible educational resource to enhance HP-led sexual support across cancer care. The MSW: PC eLearning resource offered scope to adapt a tumour specific eLearning resource to address this gap. Building on this previous work by McCaughan *et al.* (2021a), this PhD study chose to conduct a planned adaptation of the MSW: PC eLearning resource, that is, translating the MSW: PC eLearning resource, an evidence informed intervention for a new context (Moore *et al.* 2021b). The resultant intervention would be the Maximising Sexual Wellbeing: Cancer Care (MSW: CC) eLearning resource for use by HPs working with mixed cancer populations. There is a strong rationale to adapt

an intervention for a new context rather than 'reinvent the wheel' when there are credible interventions which already exist (Copeland *et al.* 2021). Doing so, can be considered both more efficient and less resource intensive, albeit some researchers would contest this position and argue that adapting an intervention can be time-consuming, depending on the level of complexity involved (Copeland *et al.* 2021). Moreover, adapted interventions tend to be more effective than those used without any adaptation (Sundell *et al.* 2016).

Although there can be pros and cons to involving original intervention developers in the adaptation of an intervention (Moore *et al.* 2021b), this study involved members of the research team who conceptualised, developed, tested and evaluated the MSW: PC eLearning resource. The involvement of the original developers circumvented some of the challenges related to the adaptation of the intervention. They provided key insights into the logic model for the intervention (Appendix 1) (Moore *et al.* 2021b) and the study capitalised on established working relationships and communication methods with the Learning Management System (LMS) developers. The MSW: CC eLearning resource aimed, similarly to the MSW: PC eLearning resource, to enhance the provision of sexual support at foundation level, a gap identified within the literature (Papadopoulou *et al.* 2019). Therefore, the MSW: CC eLearning resource would be suitable for HPs with limited or no experience of working with patients and partners experiencing sexual concerns after a cancer diagnosis and treatment. The key area for adaptation was to broaden the intervention context to address the educational needs relating to the provision of sexual support across the cancer care workforce and not limited to those caring for patients and partners with prostate cancer alone. This was achieved by using the Person Based Approach (PBA)(Yardley *et al.* 2015b), which prioritised key stakeholder involvement throughout all phases and was led by an in-depth

understanding of the needs of end-users and their context as recommended by Moore *et al.* (2021b) in their recent ADAPT guidance for intervention adaptation.

The choice of focus for this study had involved consideration of a patient orientated resource. It could be argued that a self-management intervention for patients was warranted, given the difficulties patients have raising sexual concerns with HPs (McCallum *et al.* 2012; Dai *et al.* 2020) and the lack of HP-led sexual support patients and partners currently receive from HPs (Reese *et al.* 2017b). However, there was a consistent message throughout the literature that patients and partners wished for sexual support to be initiated and provided by an HP (Flynn *et al.* 2012; Sporn *et al.* 2015; Albers *et al.* 2020b; 2020c). Moreover, the evidence highlighted that HPs recognised their role to provide sexual support and identified a need for education and training opportunities to address an information and skills deficit (O'Connor *et al.* 2019). As such, the researcher prioritised the adaptation of an HP-focused eLearning resource.

### 1.3.1 Study aim

The aim of this study was to:

Adapt, test and evaluate an eLearning resource to enable HPs working across cancer care to provide routine sexual support to patients and partners.



### 1.3.2 Study objectives

Underpinned by the PBA this study achieved its aim by addressing the following objectives:

1. Adapt the content of the MSW: PC eLearning resource to a resource suitable for HPs working across cancer care (MSW: CC eLearning resource), providing core information for general use with some additional information for specific issues related to breast, colorectal, head and neck, gynaecological and prostate cancers.
2. To iteratively test and refine the MSW: CC eLearning resource.
3. To determine the impact of the MSW: CC eLearning resource on HPs sexual attitudes and beliefs related to the provision of sexual support for patients and partners in cancer care.
4. To ascertain the acceptability and usability of the MSW: CC eLearning resource for HPs in the cancer care setting.

## **1.4 Definitions**

Throughout this PhD study, the term sexuality and sexual support have been used extensively. Before moving into the body of this PhD study it is important to provide clear definitions as these terms have several accepted meanings.

### 1.4.1 Defining sexuality

Sexuality is a complex concept which many have grappled with over time (Wilmoth 2006). The term 'sexuality' is understood in different ways and in some cases the term is synonymous with sexual orientation (Ziegler 2016). With others, sexuality can be limited to 'what we do' with a focus on sexual activity, as opposed to embracing 'who we are'. This stance fails therefore to recognise the importance of psychological and social dimensions to a person's expression and experience of sexuality (Brotto *et al.* 2010; Cleary and Hegarty 2011). For example, earlier

definitions, like that of Shell *et al.* (2007) defined sexuality as the process of giving and receiving sexual pleasure, explaining it to be associated with a sense of belonging or acceptance by another. This definition is limited in focus to the physical aspect of sex and pleasure; ignoring people who may not be in a current relationship, or an intimate relationship. Realising the scope of sexuality is important to be able to comprehend the full impact of cancer and treatment-related effects on sexuality and therefore to inform adequate provision of sexual support to patients and their partners in the healthcare context (Sears *et al.* 2018).

The World Health Organisation (WHO 2006) have provided a more comprehensive definition of sexuality which recognises the interaction between the biological, psychological, social, economic, political, cultural, ethical, legal, historical, religious and spiritual factors in society. They acknowledge that although sexuality includes many dimensions, they may not all be experienced. Sexuality is defined by the WHO (2006, p.10) as:

“a central aspect of being human throughout life and encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction. It is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviours, practices, roles and relationships.”

This definition is evident in the many accounts provided by patients with cancer and partners within the literature (Perz *et al.* 2014; Rose *et al.* 2017; Bamidele *et al.* 2018). First, sexuality is considered as an essential aspect of human life; this viewpoint is echoed in studies where patients have identified sexuality as essential to maintain and promote QoL (Ratner *et al.* 2010; Abbott-Anderson and Kwekkeboom 2012; Ferreira *et al.* 2015). Studies of sexuality and cancer, with participants such as children and young adults, older people and those at end of life, also have identified sexuality's enduring nature. Sexuality predates puberty,

extends beyond fertility, or a time when sexual activity ceases (de Vocht 2017). Third, the biological, psychological and social influences on sexuality have been acknowledged mirroring the recent literature, which has given more prominence to the psychosocial aspects of sexuality after cancer (Varela *et al.* 2013; Perz *et al.* 2014; Ussher *et al.* 2015; Sears *et al.* 2018). Finally, this definition has recognised that sexuality is highly individualised, evident in patients' varied accounts of sexual challenges, some of which relate to partner status and cultural differences (Bamidele *et al.* 2018; Dorfman *et al.* 2019). Based on the encompassing nature of this definition, this study will adopt the WHO definition of sexuality.

#### 1.4.2 Defining sexual care and support

Sexual care and sexual support, unlike other terms such as sexuality or sexual health, are not clearly defined within the literature. These concepts are difficult to operationally define, due to not only the great diversity of sexual challenges experienced by individuals and couples after cancer (de Vocht 2011, Girodet *et al.* 2019), and cultural and ethical understandings (Dune *et al.* 2017; Rahman 2018). In addition, terms like care and support are used somewhat interchangeably in the literature, for example, one principle of person-centred care is to offer personalised care or support (Collins 2014).

The concept of sexual support within this thesis has been considered as an element of sexual care. Sexual care includes the delivery of more specialised treatments to address specific issues including sexual dysfunction, management of pain and emotional distress. Sexual support, therefore, for the purpose of this thesis, will be defined as (1) Information and advice including a pre-treatment discussion of treatment-related effects, normalising sexual concerns, providing advice for rehabilitation including strategies which promote intimacy beyond penetrative

intercourse and coping with the emotional impact. (2) Encouragement for sexual communication within couples. (3) Attentive to partners' needs and that which (4) Provides access to onward referral as appropriate which could include, erectile dysfunction clinic, physiotherapy, counselling, or peer support (Ussher *et al.* 2012b; Canzona *et al.* 2016; Frederick *et al.* 2019b; Mehta *et al.* 2019). As sexual challenges may be experienced by patients and partners at many points on the treatment trajectory, it is pertinent that the provision of sexual support is a matter for multidisciplinary HPs (Carter *et al.* 2018), including roles such as oncologists, surgeons, general practitioners (GPs), nurses, physiotherapists, social workers, counsellors and psychologists, who have interactions with patients and partners at various timepoints in treatment and survivorship.

### **1.5 Overview of study**

Using mixed methods guided by the PBA (Yardley *et al.* 2015b), this thesis has outlined how it adapted, tested and evaluated the MSW: CC eLearning resource over three phases; namely, intervention planning, intervention optimisation and intervention evaluation. The MSW: PC eLearning resource was adapted to create a novel prototype for use across cancer care. This process was guided by the literature and supported through iterative review by an expert group and the research team. A qualitative design was employed to test and refine the intervention with HPs working in cancer care across five Health and Social Care Trusts (HSCT) in Northern Ireland. Finally, with a quantitative pre-test post-test survey, the MSW: CC eLearning resource was evaluated using a modified version of the sexual attitudes and beliefs survey (SABs) with HPs working with mixed cancer populations.

To guide the reporting of the adaptation, the researcher used the updated FRAME guidance (Stirman *et al.* 2019) alongside ADAPT guidance v1.0, additional guidance provided by Moore *et al.* (2021a). This has provided the reader with the detail necessary to inform judgements on the impact of the adaptation on intervention effectiveness (Leijten *et al.* 2016) and to enable methodological lessons to be learned and incorporated into future intervention development procedures (Duncan *et al.* 2020).

## **1.6 Organisation and structure of the thesis**

This study is presented in six chapters which are outlined in Table 1.

**Table 1: Organisation of thesis by chapter**

CHAPTER	TITLE	CHAPTER CONTENT
1	Introduction	Provides an introduction and context to the thesis, defines key constructs, provides an overview of study.
2	Methodology	Outlines the pragmatist philosophy which underpinned the mixed methods study which was guided by the PBA. It also provides an overview of the methodology for each phase of study. While the literature review informed the design of the study, it has been presented after the methodology. This action was taken to enhance the readability of the thesis by presenting the three PBA phases within three distinct chapters.
3	Phase 1 - Intervention Planning: MSW: CC eLearning resource	Presents the four elements which supported the planning of the study: (1) a critical overview of the existing literature in relation to the impact of cancer and treatment on sexuality of both patients and partner, current provision of sexual support in cancer care, the barriers and facilitators to HPs providing sexual support and critically reviews current interventions which seek to change HP practice; (2) a background information for the MSW: PC eLearning resource and reviews the theoretical basis of the MSW: PC eLearning resource and its relationship to the MSW: CC eLearning resource; (3) establishment of an expert group to co-produce the MSW: CC eLearning resource; and (4) the formation of the guiding principles.
4	Phase 2 - Intervention Optimisation: MSW: CC eLearning resource	Reports on the iterative process of the adaptation of the MSW: PC eLearning resource to the MSW: CC eLearning resource. Next, this chapter has described the optimisation process which involved the expert group and research team and later multidisciplinary HPs using Think Aloud (TA) interviews. This process produced the final version of the MSW: CC eLearning resource for evaluation.
5	Phase 3 - Intervention Evaluation: MSW: CC eLearning resource	Details the evaluation process which used a modified version of the SABS with multidisciplinary HPs, as the primary outcome measure. Using descriptive and inferential statistical analysis, the impact on the sexual attitudes and beliefs of HPs related to the provision of sexual support in cancer care are reported. Furthermore, the chapter provides

CHAPTER	TITLE	CHAPTER CONTENT
		insight into HPs views of the MSW: CC eLearning resource acceptability and usability as an educative resource for HPs in cancer care.
6	Discussion & Conclusion	Provides an overview of the key findings from the study, highlighting contribution to knowledge, study limitations and recommendations for future research.

## 1.7 Conclusion

This chapter has presented a brief introduction and overview of this study and provided a rationale for adapting, testing and the evaluation of an eLearning resource, which has aimed to enhance HPs' provision of sexual support in cancer care. Furthermore, an outline of the organisation and structure of the thesis has been provided.

## CHAPTER TWO: METHODOLOGY

### 2.1 Introduction

This chapter presents the methodology for the study which, guided by the PBA, was used to adapt the MSW: PC eLearning resource for use with a mixed cancer population, creating the MSW: CC eLearning resource. The MSW: CC eLearning resource was then tested and evaluated with HPs from across cancer care. This chapter will present the following sections:

- philosophical assumptions that informed the study
- an outline of the research design
- an overview of ethical considerations.

### 2.2 Philosophical assumptions and their application to study

Before conducting research, a researcher should consider their philosophical assumptions (Wright *et al.* 2016). Evidence also highlights that the rigour and credibility of research findings can be strengthened by connections between the researcher's philosophical assumptions, aim and objectives of study and chosen research design (Bryman 2016). According to Creswell *et al.* (2007), a researcher's choice of a particular research approach is broadly influenced by their ontological (definition of reality), epistemological (how reality is known) and methodological (research procedure) assumptions.

The researcher's ontological belief resonated in the principle of pragmatism, which asserts that the claim by post-positivists, namely, the world exists independent of our understanding of it, is equally as important as that of constructivists, who purport that the world is created by our conceptions of it (Dewey 2008b). On one hand, our experience in the world is constrained by the nature of our world and on the other hand our understanding of the world is limited to our interpretations of our experiences (Morgan 2014). For the pragmatist, truth is not absolute (Dewey 1938); the consequences



of any act are dependent on the situation in which it occurs (Dewey 1938). Pragmatism calls for researchers to be open-minded, tentative and willing to change (Morgan 2014). This ontological belief stems from the researcher's personal and work experiences as a Specialist Health Improvement Manager at the Northern Health & Social Care Trust (NHSCT) for two key areas, sexual health and learning disability. The activities within the role were guided by, despite being out-of-date, the Sexual Health Promotion Strategy 2008-2013 (DHSSPS 2008) and the Teenage Pregnancy Strategy 2002-2007 (DHSSPS 2002). Underpinning this work was the strategic vision "to improve, protect and promote the sexual health and wellbeing of the population in Northern Ireland" (DHSSPS 2008). The main aim of these strategies was to reduce sexual transmitted infections and unplanned teenage pregnancy. As such, the broader sexual health needs of those with chronic conditions including cancer were not addressed. Despite raising the profile of the need to address wider sexual concerns, in the absence of an updated strategy there was a lack of resource and reluctance to commit to actions without the development of new implementation plans. At this time, her close friend at 35 years old received an unexpected, devastating diagnosis of metastatic cancer. As a family, they journeyed this closely with her friend, her husband and child, maximising the time left to ensure many lasting memories. Reflecting on her friend's last few days in the hospital with her husband, the researcher wondered what could be done to ensure that the intimacy needs of a patient with cancer and partner could be maximised? How could HPs ensure space and privacy for couples to meaningfully hold and comfort each other at a time when it is needed the most? Beyond this, the situation caused the researcher to consider how patients and partners navigate such devastating diagnosis and the presenting physical and psychological treatment-related effects. With a pragmatist ontology, it is possible to realise that treatment impacts upon sexuality, but the experience, expression and interpretation of these effects are socially constructed (Gilbert *et al.* 2011).

Epistemologically, the researcher identified with a pragmatist's focus, which is on action, as the basis for knowledge (Morgan 2014). Therefore, the research paradigm selected for this study was pragmatism. Pragmatist philosophy does not consider one methodology to be 'superior' to another, instead it supports the methodology which will be most appropriate to achieve the research goals (Morgan 2014). Although often perceived as a narrow approach which merely asks 'what works' (Dewey 2008a); the pragmatist approach was deemed to be suitable for this study due to its recognition of the many ways of interpreting the world and that multiple realities exist (Kelly and Cordeiro 2020). This approach pays attention to the importance of the research context and its evolving components which include sexuality and society, cancer treatments, technology and the healthcare environment. Specifically, for this study, the pragmatist approach supported the adaptation of the existing theory and evidence-based eLearning resource purposed for a prostate cancer population, to one suitable for a mixed cancer population. Furthermore, the pragmatism's recognition of the evolving context, supported the opportunity to maximise the acceptability and usability of the MSW: CC eLearning resource as the researcher assessed and responded to feedback throughout the intervention development.

### **2.3 Mixed methods research design for study**

A pragmatist approach to research permits the integration of positivist (deductive) and constructivist (inductive) research data collection, which typifies the most appropriate research design for this study, being 'mixed methods.' The research design was guided by the PBA (Fig. 1), as it addressed the specific goals of the study, namely, intervention planning, optimisation and evaluation. Mixed methods research designs involve combining or integrating qualitative and quantitative research and data in a research study (Creswell and Creswell 2018). This approach can be viewed as addressing bias and weaknesses in other research methods by triangulating data sources. There are several

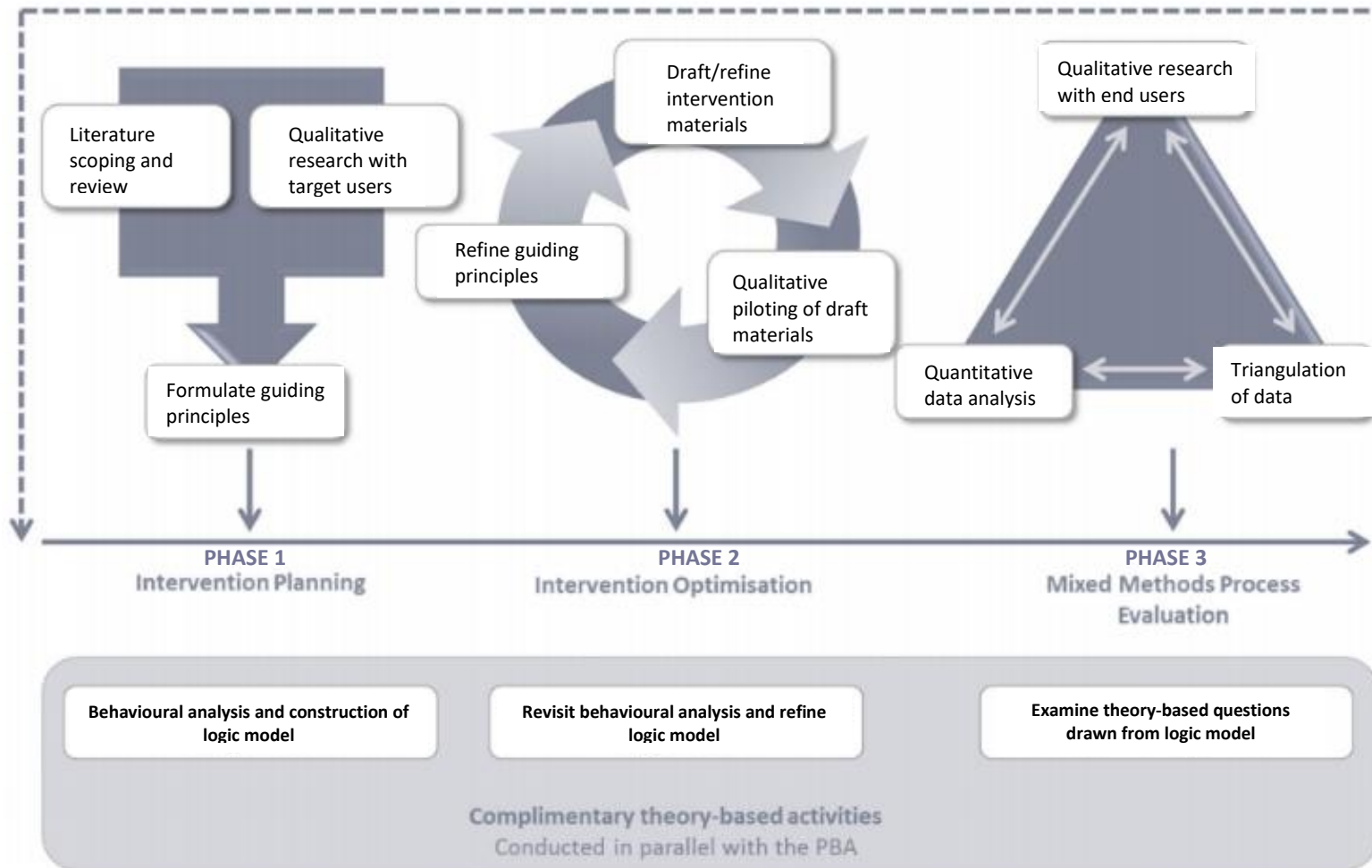
mixed methods designs available to researchers however, the choice of design is dependent on the focus of the research. This study used an exploratory sequential mixed methods approach as outlined by Creswell and Creswell (2018). Inherent within the study was sequential triangulation, that is, that the qualitative phase of the study explored HPs views of the eLearning resource leading to the creation of a final eLearning prototype which was then evaluated using quantitative methods. The qualitative component to the research design carried more weight (QUAL → quan) (Morse 1991) as this element was instrumental to the prototype which was evaluated. This two-phased research design was supported by the PBA through its multi-phased approach to intervention development.

The Medical Research Council (MRC) guidelines for developing and evaluating complex interventions (Craig *et al.* 2008) was an approach also considered, as it identifies that interventions should be systematically based on the latest evidence and be guided by theory (Craig *et al.* 2008). Researchers have acknowledged that intervention development should be both evidence-based and theory-driven, to promote efficacy of the intervention in a real-life context (Semple and McCaughan 2019). Theory and evidence-base for interventions while critical, can be enhanced through the PBA (Yardley *et al.* 2015b). Using the PBA framework for intervention development, enabled the combination of theory and the evidence-base, with user-centred approaches to yield vital insights into the potential barriers that end-users may encounter with the intervention, while also assessing for and maximising acceptability and usability (Yardley *et al.* 2015b). Furthermore, PBA has advocated for the use of key stakeholder involvement throughout the intervention development phases to gain a greater diversity of feedback, which would not be possible by qualitative research or patient and public involvement (PPI) methods alone (Muller *et al.* 2019). The PBA also advocates for complementary theory-based logic model activities to be conducted alongside the PBA in the development of interventions (see Fig. 1). This study was seeking to adapt, not develop a new resource, and a detailed

review of the existing logic model for the MSW: PC eLearning resource indicated that there was no need for amendments. Appendix 1 provides an overview of the MSW: PC eLearning resource structure and logic model.

Recently published ADAPT guidance has provided a useful model for the adaptation of interventions (see Fig. 2) (Moore *et al.* 2021a). The ADAPT guidelines, similar to PBA recommend the involvement of diverse stakeholders across all four steps of intervention adaptation and implementation, but unlike PBA do not identify the use of qualitative research with end users. This is a fundamental component within PBA to elucidate key issues or insights during the intervention optimisation phase, to enhance not only the effectiveness of the intervention but its acceptability and usability with intended users, being clearly embedded within this study.

Figure 1: Person Based Approach (Muller et al. 2019)



The PBA has two core elements. First, PBA prioritises fostering an in-depth understanding of the views of intervention users as noted above, to include the contexts within which they are engaging with the intervention and their experiences of it (Yardley *et al.* 2015b; Morrison *et al.* 2018). As illustrated in Figure 1, this in-depth understanding is generated from the evidence base and is often complemented with additional qualitative research throughout each of the PBA phases. The PBA framework supports this further with feedback from expert stakeholders and end-users (Morrison *et al.* 2018). As the PBA has evolved, there has been greater value placed on the involvement of expert stakeholders. Expert stakeholders can include those who may be expected to use the intervention, those who are expert in the topic and those with a lived experience of the problem to be addressed (O’Cathain *et al.* 2019). Inclusion of expert input provides intervention designers with a better understanding of user’s experiences of similar initiatives and potential barriers to implementation (Santillo *et al.* 2019). Secondly and uniquely to PBA, intervention designers are encouraged to produce ‘guiding principles’ from an in-depth understanding of the psychosocial characteristics of end users of the intervention. Guiding principles identify [i] the main intervention design objectives in terms of behaviour change and outcomes and [ii] the key features of the intervention required to achieve each objective. Acting as a blueprint for the study, the guiding principles provide the means to embed the evidence base and theory, along with the views of end-users to develop effective and engaging interventions. There is a growing body of evidence highlighting the efficacy of a range of complex interventions which have been developed using the PBA, within the healthcare context, that have been robustly evaluated using randomised control studies (Little *et al.* 2013; Anthierens *et al.* 2014; Little *et al.* 2015; Little *et al.* 2016).

Inherent within PBA is a mixed methods research design. Figure 3 presents an overview of the research design used for this PhD study, clearly depicting how the researcher used

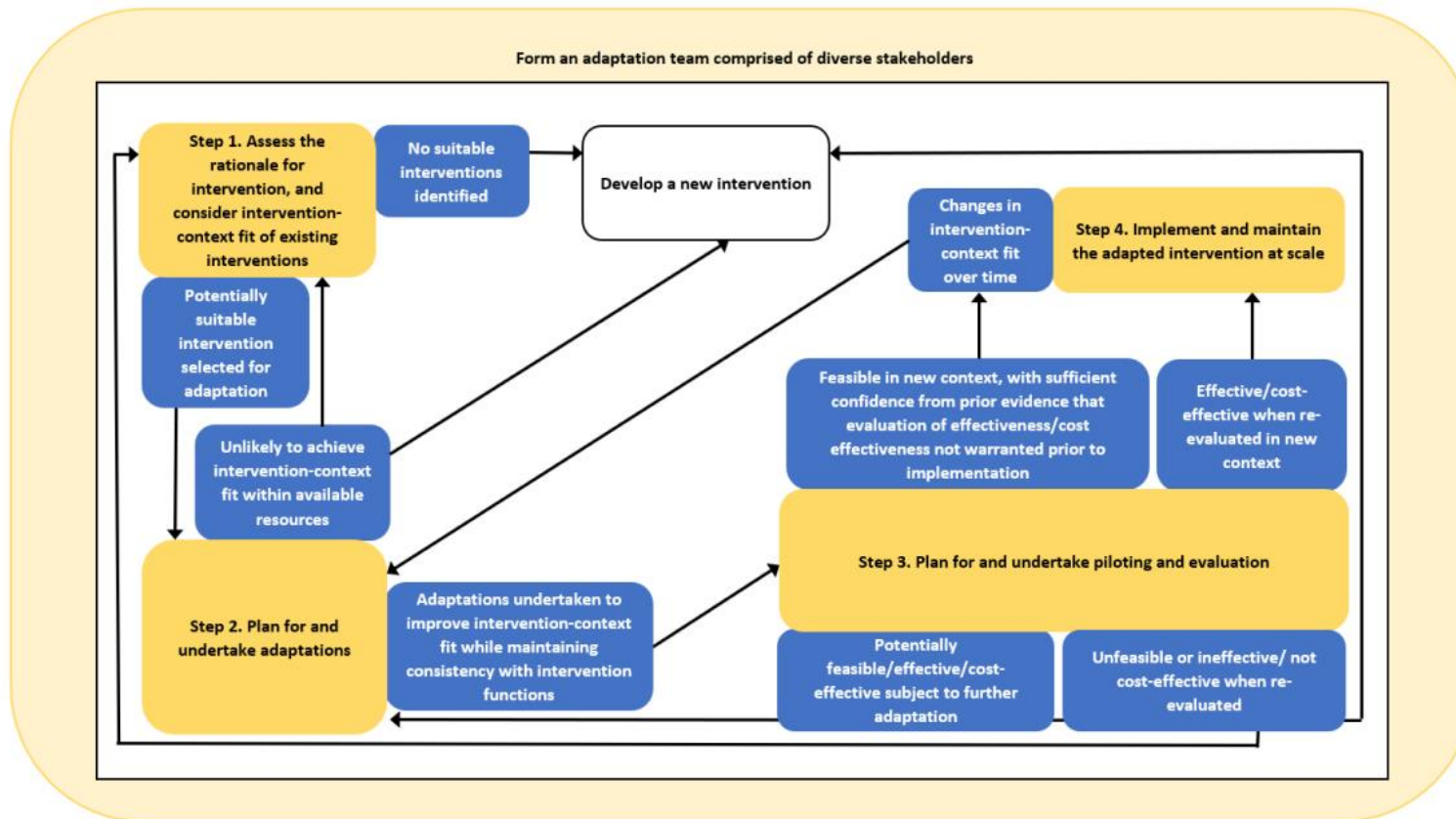
a mixed methods approach across the three phases of intervention development, as guided by PBA. A brief overview accompanies this, explaining the researcher's use of the PBA within the current study, across the three clearly identified phases:

Phase 1 – Intervention planning

Phase 2 – Intervention optimisation

Phase 3 – Intervention evaluation.

Figure 2: ADAPT process model for adapting interventions for a new context (Moore et al. 2021a)



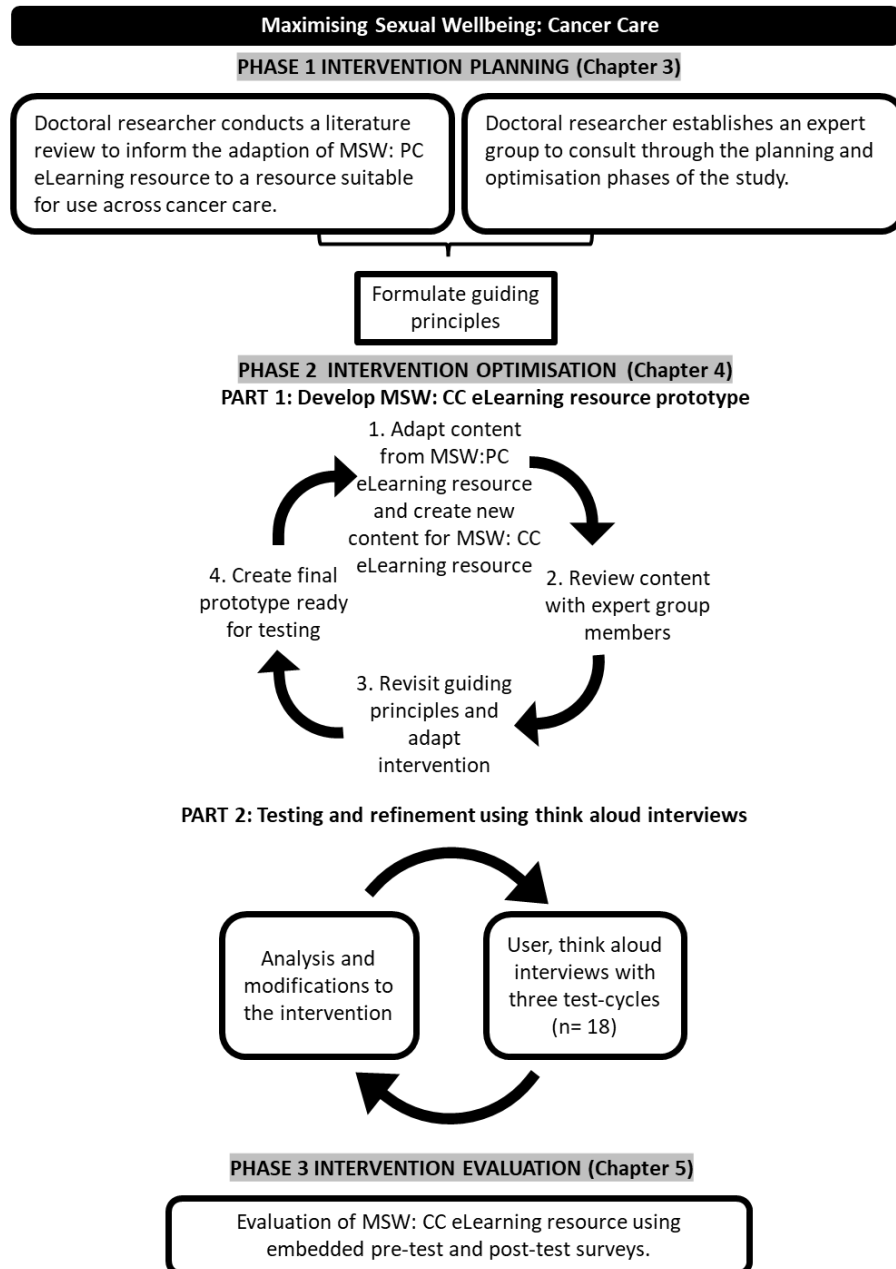
Yellow boxes=stages of ADAPT step-by-step guidance.

Blue boxes=categories of potential conclusion from each stage.

Directional arrows=recommendations for moving, forward or backward through ADAPT stages (or exiting), based on stage conclusions.



**Figure 3: Overview of the study design**



### 2.3.1 Phase 1: Intervention planning – (Chapter 3)

The intervention planning phase for this study included four elements, namely, (1) a review of the literature, (2) background information on the MSW: PC eLearning resource and an exploration of the theoretical underpinnings of the MSW: PC eLearning resource and their relationship to the MSW: CC eLearning resource, (3) the establishment of an expert group to co-produce the MSW: CC eLearning resource and (4) the formation of the guiding principles to facilitate the development of the MSW: CC eLearning resource. The

review of the existing literature identified the sexual challenges faced by patients and partners across cancer populations, the current provision of sexual support within healthcare settings along with the barriers and facilitators influencing the provision of sexual support. Furthermore, the review explored existing educational interventions designed to enhance HP-led sexual support in cancer care.

During the planning phase, PBA suggests that following a review of the evidence base, if there are existing gaps, further empirical qualitative research should be conducted. However, the PBA authors recognise that if extensive literature exists, it is prudent to use this (Yardley *et al.* 2015b). An in-depth review of the literature (Chapter 3), identified recent extensive empirical research which had been complemented with systematic reviews in the field, investigating HPs barriers to the provision of sexual support and the sexual challenges faced by patients. Therefore, no further empirical qualitative research was required. Instead, it was opportune to move the research field forward, by adapting the MSW: PC eLearning resource to create a novel eLearning resource to enhance sexual support across cancer care. An expert group was established who would co-produce the MSW: CC eLearning resource. Initial feedback from the expert group, ongoing input from the research team and the evidence base, supported the development of the guiding principles which would guide decision making in each PBA phase (see Chapter 3, Section 3.6, Table 8, pp.108-109).

### 2.3.2 Phase 2: Intervention optimisation (Chapter 4)

Phase 2, the intervention optimisation<sup>1</sup>, was achieved in two distinct parts corresponding with study objectives 1 and 2 (previously noted in Chapter 1.3.2).

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<sup>1</sup> Refers to the testing and refining process to improve an intervention's acceptability, persuasiveness, ease of use and feasibility (Yardley *et al.* 2015b)

1. Adapt the content of the MSW: PC eLearning resource to a resource suitable for HPs working across cancer care (MSW: CC eLearning resource), providing core information for general use with some additional information for specific issues related to breast, colorectal, head and neck, gynaecological and prostate cancers.
2. To iteratively test and refine the MSW: CC eLearning resource.

Adapting the content for the MSW: CC eLearning resource was an iterative process with members of an expert group, which included: (i) identifying content from MSW: PC eLearning resource to be used in MSW: CC eLearning resource and (ii) developing new content which included advice on key treatment effects for many patients and specific advice on treatment effects for five tumour groups. This culminated in the production of the MSW: CC eLearning resource prototype. This eLearning prototype was subsequently iteratively tested using think aloud (TA) interviews with HPs working with mixed cancer populations. Analysis of the data from TA interviews with HPs enabled the identification of modifications and timely refinement of the intervention prior to further testing. The qualitative data not only shaped the optimisation of the intervention prior to evaluation but provided key insights into HP views of the eLearning resource for use in routine cancer care.

### 2.3.3 Phase 3: Intervention evaluation (Chapter 5)

The third phase, intervention evaluation, used a quantitative approach with a modified validated survey (full details in Chapter 5) to achieve study objectives 3-4, (previously noted in Chapter 1.3.2) hence the mixed methods research design.

3. To determine the impact of the MSW: CC eLearning resource on HPs sexual attitudes and beliefs related to the provision of sexual support for patients and partners in cancer care.

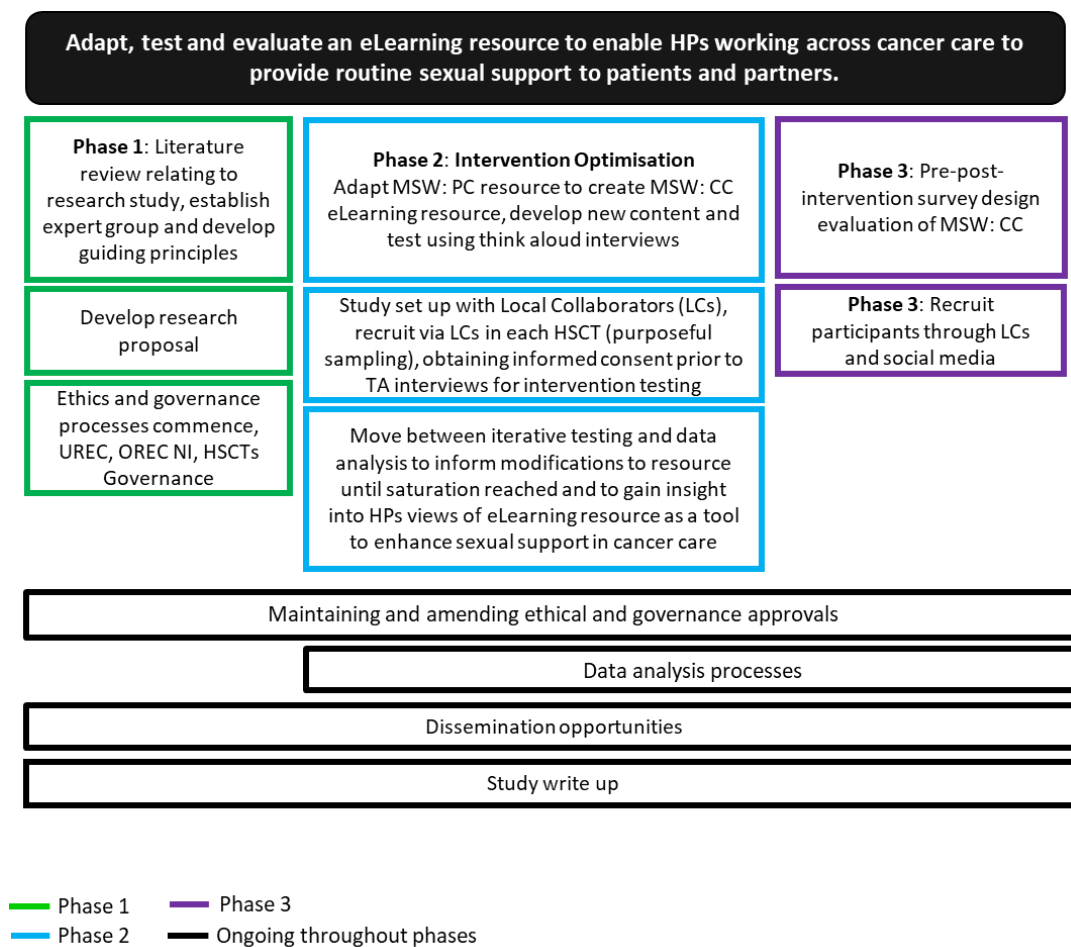
4. To ascertain the acceptability and usability of the MSW: CC eLearning resource for HPs in the cancer care setting.

The quantitative element to the study provided evidence of the impact of the eLearning resource on HPs sexual attitudes and beliefs relating to the provision of sexual support in cancer care. Furthermore, this phase of the study provided evidence on acceptability and usability of the MSW: CC eLearning resource for future use in cancer care.

#### **2.4 Research processes used for PhD study**

The research processes employed to conduct this study from preliminary discussions through to write up and dissemination of study are illustrated in Figure 4. While there were three distinct phases, managing ethical and governance approvals were ongoing throughout the project, as was communicating the findings from the study. The colour codes are provided to help the reader depict activities aligned with each phase of the study.

**Figure 4: Overview of research process for study**



## 2.5 Ethical considerations

Enhancing the provision of sexual support in cancer care can have a positive influence on the quality of human life through elevating sexual healthcare provision and therefore reducing the burden of sexual challenges (Shirmohammadi *et al.* 2018); although this is not without risk. For many people, particularly in conservative societies, sexuality is a sensitive and often taboo subject. Sexuality is often viewed as socially unacceptable to discuss openly and within some cultures, associated with strong feelings of shame and modesty (Traumer *et al.* 2019). Each person's knowledge and confidence relating to the provision of sexual support will be influenced by the culture of communication related to sexuality both within the individual's family home and education curriculum (Mansour and Mohammed 2015). Therefore, participating in a sexuality related study, such as this,

may cause a sense of embarrassment and create internal conflicts with personal views on sexuality, or may cause tensions and dilemmas within professions because of challenges to cultural or societal norms (Gune and Manuel 2007; Fouka and Mantzorou 2011). Due to the possibility of this research evoking sensitive feelings, this study made important ethical considerations to reduce harm to the research participants and researcher.

That said, this study was somewhat lower risk to participating HPs than other studies in the field, which directly enquired into HPs previous sexual support practice or personal views on providing sexual support. This study's focus was resource adaptation, testing and subsequent evaluation. The optimisation study (Phase 2) using TA interviews focused on gaining participant feedback on the content, navigation, layout and appearance of the eLearning resource, while the intervention evaluation (Phase 3), sought to ascertain the impact of the MSW: CC eLearning resource on attitudes and beliefs of HPs surrounding the provision of sexual care after. Yet, it would be ethically dismissive to overlook the emotional risk to participants that reviewing the eLearning resource could elicit. For example, HPs could be reminded of previous challenging encounters when providing sexual support or indeed, feelings of guilt at failing to provide adequate routine sexual support. Therefore, important ethical issues related to protecting anonymity and confidentiality, participant autonomy and informed consent and beneficence and non-maleficence of the research, were addressed. These considerations are presented in detail in Chapters 4 and 5, aligned to the phase of study to which they relate.

### 2.5.1 Obtaining ethical approval

The study was guided by the Ulster University's (UU) Policy for the Governance of Research Involving Human Participants (Ulster University 2018) and the Declaration of Helsinki (Williams 2008). Early in the process the researcher obtained an Enhanced Disclosure Certificate through the lead HSCT, which was shared with each participating

Trust. The study's application for ethical approval was peer reviewed within UU's Institute of Nursing and Health Research (INHR) and with minor amendments was submitted to UU Centre for Higher Education Research & Practice Ethic Filter Committee. Upon approval of the application in August 2019, an application was made to the Office for Research Ethics Committee, Northern Ireland (OREC NI) (IRAS ID: 259926). Following a minor amendment relating to the start date, the application was approved in October 2019 (Appendix 2). In parallel, the application was submitted to the NHSCT, who acted as the lead Trust for the study. Governance approval was subsequently received from each of the five HSCTs in Northern Ireland (NI) between Nov 19 and Feb 20. In August 2020, with the COVID-19 restrictions in place, the researcher applied to OREC NI for an amendment to the ethical approval to allow data collection to utilise video conferencing technologies (19.0076 Amend 1 (S)) (Appendix 3). Furthermore, to increase participant numbers given the clinical pressures during a pandemic and the potential reach of the evaluation survey to a more diverse population, a second amendment detailing an adjunct method of recruitment for Phase 3 of the study, using social media, was submitted and approved (19.0076 Amend 2 (S)) (Appendix 4).

## **2.6 Conclusion**

The purpose of this chapter was to present the methodological underpinnings of the research processes to be employed in the current study. It describes the researcher's choice of and rationale for a mixed methods study, guided by the PBA which was aligned with the researcher's pragmatic philosophical assumptions and the study's aims and objectives. The study processes are outlined in three phases which provide the basis for following chapters within this study thesis. Finally, initial considerations relating to ethics are outlined with details of ethical and governance approval processes employed.

### CHAPTER THREE: PHASE 1 - INTERVENTION PLANNING

This chapter details the intervention planning processes used for this study which includes four elements (1) a review of the literature (Section 3.1), explaining how the literature has informed the way forward (Section 3.2), (2) background information and an exploration of the theoretical underpinnings of the MSW: PC eLearning resource and their relationship to the MSW: CC eLearning resource (Section 3.3-3.4), (3) the establishment of an expert group to co-produce the MSW: CC eLearning resource (Section 3.5) and (4) the formation of the guiding principles to facilitate the development of the MSW: CC eLearning resource (Section 3.6). The guiding principles are informed by the integration of information from the literature, underpinned by an appropriate theoretical framework for this study and guided by an expert group. These guiding principles formed the basis for the development of the MSW: CC eLearning resource. Each of these four elements will be presented below, commencing with an extensive review of the literature.

#### 3.1 Review of the literature

A narrative review of pertinent literature for the study was conducted. A narrative review enables the researcher to gain a broad and comprehensive background for understanding the current state of knowledge in this area (Greenhalgh *et al.* 2018; Gilleece *et al.* 2019). The narrative review differs from other literature review types, such as integrative and systematic reviews, where the purpose is to appraise and aggregate the data between studies or that of a scoping review which aims to map key concepts, types of evidence and gaps in research related to a defined area (Gilleece *et al.* 2019). This typology of literature review was selected as the aim was to summarise the existing body of literature and provide a comprehensive overview (Ferrari 2015) on the provision of sexual support within cancer care. Reviewing a large body of extant literature was fundamental for this study, as the key premise was to inform the content for the eLearning resource, which



would be applicable for a range of tumour groups, throughout the cancer trajectory and across a gamut of treatment modalities.

When deciding which type of review to conduct, a systematic review was a considered approach; a method which is often placed higher in an assumed hierarchy of secondary research evidence (Greenhalgh *et al.* 2018). This method was discounted as its narrow focus could risk missing intriguing diversity and variations within the literature (Greenhalgh *et al.* 2018), which could be important to consider in the development of the eLearning resource. Furthermore, Greenhalgh *et al.* (2018) have warned that the under-acknowledged limitations of systematic reviews, along with missed opportunities for undertaking and using narrative reviews to extend understanding within a field risks legitimising and perpetuating a narrow research agenda and contributing to research waste. In addition to considering a systematic review, the researcher explored the utility of a scoping review, however, as Munn *et al.* (2018) highlight, scoping reviews can be a useful alternative to a systematic review when there is a need to clarify a concept or theory but reports that the narrative review serves a use by providing a useful overview of a topic or issue.

### 3.1.1 Literature search

In preparation for this study, a preliminary review of the literature and consideration of the task to develop an eLearning resource to enhance the provision of HP-led sexual support across cancer care identified several key themes that should be addressed by a narrative review to inform the development the eLearning resource. These themes included identifying the impact of a cancer diagnosis and cancer treatment on sexuality, healthcare guideline recommendations, sexual support needs of patients and partners, current levels of provision of sexual support in cancer care and the factors mediating the provision of sexual support in cancer care. This preliminary review of the literature

identified key experts worldwide who have added extensively to this field of study, including, E. McCaughan, Q. Quinn, J. Reece, L. Schover, J. Ussher and D. Wittmann. Their works influenced the development of literature themes, for example ensuring the biopsychosocial perspectives relating to cancer treatment (Wittmann *et al.* 2011; Ussher *et al.* 2015).

To identify the relevant literature, searches were conducted using electronic databases including MEDLINE, EMBASE, PsycINFO, Cumulative Index to Nursing and Allied Health (CINAHL) and Scopus. The preliminary review of the literature informed key words to use as search criteria. The key words used in the search were reviewed and critiqued by a member of the Librarian Subject Team at Ulster University, leading to a combination of these key words and subject terms being used: sexuality, sexual dysfunction, intimacy, neoplasms, cancer, healthcare professional, education and communication. Truncation (\*) and speech marks were used as appropriate and terms were combined with Boolean operators 'AND' or 'OR' to focus and broaden the scope of the search. The literature included original articles and review (narrative, scoping, systematic, integrative) papers. A comprehensive overview of the inclusion/exclusion criteria for the search strategy is outlined in Table 2. When extensive articles were available, for example, on the impact of surgical interventions on treatment, findings from papers were reviewed to ascertain that the topic under question was central to the primary focus of the article, and the author considered the representativeness of population, the sample size, and validity and reliability of the data collection tools used. Debate within the literature was sought, for example, relating to patients and partners desire for the provision of HP-led sexual support, in order to facilitate wide consideration of issues within the field and to inform the development of an evidenced-based, relevant and acceptable eLearning resource for HP's use across cancer care.

When reviewing the literature on the current provision of HP-led sexual support in cancer care, the literature research was restricted by date (January 2010 - August 2021). This was essential to support the development of evidence-based content which had relevance and applicability to the current cancer care workforce. All other specific searches performed as part of the narrative review were not restricted by date, however it was clear from this process that most of the studies identified were conducted in the past two decade, and even more so in the last 10 years. Only literature available in English language was included, as translational resources were unavailable. Reference lists were manually searched from key papers and included in this review. Grey literature was identified through Google Scholar and the British Library E-THOS. Furthermore, cancer care guidelines were examined to identify the emphasis placed on the provision of HP-led sexual support. An initial literature search was conducted in 2018-2019 and subsequently updated in 2021.

**Table 2: Inclusion/exclusion criteria for narrative review**

<b>Literature review section</b>	<b>Inclusion criteria</b> Qualitative, quantitative and mixed method empirical studies including narrative, systematic, scoping and integrative reviews  <b>Exclusion criteria</b> Not in English	<b>Example of search criteria</b>
3.1.2 – 3.1.2.4	<b>Impact of cancer and treatment on sexuality after cancer</b>  <b>Inclusion criteria</b> <ul style="list-style-type: none"> <li>- Flexible date range to encompass range of treatments, tumour groups, population groups</li> <li>- Evidence that reflected the biopsychosocial impacts of cancer and treatment on sexuality</li> </ul> <b>Exclusion criteria</b> <ul style="list-style-type: none"> <li>- Impact of treatment for other chronic conditions on sexuality</li> </ul>	Oncology OR neoplasm* OR cancer AND sexuality OR sexual* OR fertility OR “sexual wellbeing” OR sex* OR “sexual side*effect* OR sexual function OR sexual dysfunction* OR psychosexual disorder* AND surgery or radiotherapy OR hormone therapy or chemotherapy OR systemic therapy OR cancer treatment
3.1.3	<b>Sexual healthcare guidelines recommendations for cancer care</b>  <b>Inclusion</b> <ul style="list-style-type: none"> <li>- Open range of dates as healthcare guidelines for tumour groups are not always updated</li> <li>- Worldwide search for sexual healthcare guidelines within cancer care</li> </ul>	Oncology OR neoplasm* OR cancer AND sexuality OR sexual* OR fertility OR “sexual wellbeing” OR sex* OR “sexual side*effect* OR sexual function OR sexual dysfunction* OR psychosexual disorder* OR intimacy OR body image OR “sexual satisfaction” OR “interpersonal relationships AND “healthcare guidelines” or “healthcare recommendations”
3.1.4	<b>Sexual support needs of patients and partners after cancer</b>  <b>Inclusion criteria</b> <ul style="list-style-type: none"> <li>- Search criteria including dates from 2010 – current</li> <li>- Identifying sexual support needs either as the primary aim of the paper or as an issue identified in a wider assessment of support needs after cancer</li> </ul>	Oncology OR neoplasm* OR cancer AND sexuality OR sexual* OR fertility OR “sexual wellbeing” OR sex* OR “sexual side*effect* OR sexual function OR sexual dysfunction* OR psychosexual disorder* OR intimacy OR body image OR “sexual satisfaction” OR “interpersonal relationships” AND patient OR partner AND “support needs” OR “unmet needs” OR “information needs”

	<p><b>Exclusion criteria</b></p> <ul style="list-style-type: none"> <li>- Prior to 2010</li> <li>- Articles which did not highlight sexual support needs</li> </ul>	
3.1.5	<p><b>Current provision of sexual support</b></p> <p><b>Inclusion criteria</b></p> <ul style="list-style-type: none"> <li>- Restricted search for articles from 2010 – current.</li> <li>- All types of HP-led sexual support including assessment, support, signposting, referrals, provision of resources</li> <li>- Articles which identified HP views and patient and partner views on the provision of HP-led sexual support</li> </ul> <p><b>Exclusion criteria</b></p> <ul style="list-style-type: none"> <li>- Articles prior to 2010</li> <li>- Patients’ self-management of sexual issues</li> </ul>	<p>Oncology OR neoplasm* OR cancer <b>AND</b> sexuality OR sexual* OR fertility OR “sexual wellbeing” OR sex* OR “sexual side*effect* OR sexual function OR sexual dysfunction* OR psychosexual disorder* OR intimacy OR body image OR “sexual satisfaction” OR “interpersonal relationships” <b>AND</b> healthcare professional OR nurse* OR doctor* OR physician* OR oncologist* OR radio* OR physio* OR psycho* OR counsel* OR “health* personnel” OR “allied health professional” OR “professional role” <b>AND</b> “sexual support” “emotional support” OR “coping” OR “psychosocial support” OR “nursing intervention” OR “patient education” OR “psychosocial care” OR “client education” OR “patient-provider communication”</p>
3.1.6 – 3.1.7.1	<p><b>Perceived mitigating factors to the provision of sexual support in cancer care</b></p> <p><b>Inclusion criteria</b></p> <ul style="list-style-type: none"> <li>- Search restricted to articles from 2010 – current</li> <li>- Articles that investigated the barriers and facilitators to the provision of HP-led sexual support in cancer care</li> </ul> <p><b>Exclusion criteria</b></p> <ul style="list-style-type: none"> <li>- Articles prior to 2010</li> <li>- Patient barriers to raising the topic of sexual support in cancer care</li> </ul>	<p>Oncology OR neoplasm* OR cancer <b>AND</b> sexuality OR sexual* OR fertility OR “sexual wellbeing” OR sex* OR “sexual side*effect* OR sexual function OR sexual dysfunction* OR psychosexual disorder* OR intimacy OR body image OR “sexual satisfaction” OR “interpersonal relationships” <b>AND</b> communication OR “health communication” OR “communication barrier*” OR “communication facilitator*” <b>AND</b> healthcare professional OR nurse* OR doctor* OR physician* OR oncologist* OR radio* OR physio* OR psycho* OR counsel* OR “health* personnel” OR “allied health professional” OR “professional role”</p>
3.1.7.2	<p><b>Models to guide the provision of sexual support</b></p> <p><b>Inclusion criteria</b></p> <ul style="list-style-type: none"> <li>- Flexible date criteria</li> <li>- Models which had an assessment and support components to guide sexual support</li> </ul>	<p>Sexuality OR sexual* OR fertility OR “sexual wellbeing” OR sex* OR “sexual side*effect* OR sexual function OR sexual dysfunction* OR psychosexual disorder* OR intimacy OR body image OR “sexual satisfaction” OR “interpersonal relationships” <b>AND</b> “pleasure model” OR “pleasure communication framework” OR “pleasure framework” OR Auchincloss</p>

	<p><b>Exclusion criteria</b></p> <ul style="list-style-type: none"> <li>- Models which only assessed sexual concerns e.g. ALARM (Anderson 1990)</li> </ul>	<p>OR “ex-plissit” OR “5 A’s model” or “5 A’s framework” OR “better model” OR “better framework” OR “better communication model” OR “plissit” OR “assessment model” OR “communication model” OR “communication framework” OR “assessment framework”</p>
3.1.7.3	<p><b>Educational interventions combined with model to guide HPs in the provision of sexual support</b></p> <p><b>Inclusion criteria</b></p> <ul style="list-style-type: none"> <li>- Interventions which explicitly combined education / training component with a model to support HPs to assess and support sexual support needs of patients and partners</li> <li>- Restricted to articles from 2010 - current</li> </ul> <p><b>Exclusion criteria</b></p> <ul style="list-style-type: none"> <li>- Interventions with no explicit model to support the assessment and support of sexual support needs of patients and partners</li> <li>- Interventions without any educational component</li> <li>- Articles prior to 2010</li> </ul>	<p>Sexuality OR sexual* OR fertility OR “sexual wellbeing” OR sex* OR “sexual side*effect*” OR sexual function OR sexual dysfunction* OR psychosexual disorder* OR intimacy OR body image OR “sexual satisfaction” OR “interpersonal relationships” <b>AND</b> education OR training OR eLearning OR “online learning” OR intervention OR “education intervention” <b>AND</b> healthcare professional OR nurse* OR doctor* OR physician* OR oncologist* OR radio* OR physio* OR psycho* OR counsel* OR “health* personnel” OR “allied health professional” OR “professional role”</p>

The following sections will now critically explore each of the themes within Table 2.

### 3.1.2 Impact of a cancer diagnosis and cancer treatment on sexuality

Sexuality is one of the most fundamental and enduring aspects of daily life that can be affected by a cancer diagnosis and cancer treatment through a variety of interacting biopsychosocial aspects (Bober and Varela 2012). For some, physical effects can present prior to diagnosis, for example, fatigue, blood loss or a lump which can suddenly create psychosocial problems. This can result in fears about cancer and the future; subsequently changing a person’s sense of sexuality and how they interact with their partner (Gianotten and Reisman 2017). However, for many, sexual challenges arise from the treatment(s)

they receive to manage or cure their cancer (Milbury *et al.* 2013; Incrocci and Jensen 2013; Bregendahl *et al.* 2015). These challenges may present immediately following treatment, or later and persist for many years into survivorship (Ratner *et al.* 2010). At diagnosis and during active treatment, patients may give less priority to sexual concerns, however as they adjust to life with and beyond cancer, these challenges often become more prominent and problematic (Olsson *et al.* 2012; Reese and Haythornthwaite 2016).

Epidemiological data on the prevalence of sexual concerns after treatment varies significantly; partially due to the variation in effect of tumour type, location and treatment (Traa *et al.* 2012). For example, in relation to a variation in surgical procedure, patients receiving a total laryngectomy following cancer of the larynx were observed to experience more sexual problems and depression in comparison with patients receiving a partial laryngectomy (Batioğlu-Karaaltın *et al.* 2017). Similarly, as outlined by a review of the effects of different treatment modalities for colorectal cancer, sexual function outcomes were found to be better for patients receiving a laparoscopic total mesorectal excision (TME) rather than an open resection after rectal cancer, however, for women the outcomes are not as well understood after rectal cancer surgery perhaps linked to an historic lack of validated scoring systems for female sexual problems (Breukink and Donovan 2013).

Several studies have made attempts to reflect the prevalence of sexual concerns for different tumour groups. An important landmark study recruited a large cohort of men with prostate cancer (n=35823) and reported poor sexual function for over 80% of men (Downing *et al.* 2019). A systematic review which evaluated sexual concerns after colorectal cancer identified that concerns for men ranged between 5% and 88% and approximately 50% for women (Traa *et al.* 2012). Of the 82 studies included in this review (Traa *et al.* 2012), 39 were measuring sexual dysfunction and/or quality of sexual life as a

secondary outcome and approximately half of the studies were cross-sectional, thus limiting a full understanding of the changes to sexuality over the course of treatment (Traa *et al.* 2012). Milbury *et al.*'s (2013) analysis of six colorectal studies also proposed variation between men and women's reporting of sexual challenges after colorectal cancer. This disparity in prevalence rates of reporting sexual challenges between male and female colorectal patients is possibly related to the underrepresentation of women in these colorectal studies. Sadovsky *et al.* (2010) review of the literature supports this premise, as they highlighted that women were more reluctant to complete questionnaires about sexuality in comparison to men. Furthermore, Milbury *et al.* (2013) reported that many postmenopausal women were not sexually active at cancer diagnosis or had stopped sexual activity after colorectal cancer treatment. Many of the studies investigating the prevalence of sexual concerns after colorectal cancer have certain methodological limitations such as small sample sizes and the use of a range of non-standardised data collection tools. There are a range of standard validated data collection tools available to assess sexual concerns (a brief overview of these tools is provided by Grover and Shouan 2020), although they may not be validated for use with specific tumour groups and may not capture the nuances of sexual concerns experienced as a result.

Studies recruiting women with breast cancer estimated the rates of sexual concerns as ranging up to 85% (Panjari *et al.* 2011; Ussher *et al.* 2012b; Di Mattei *et al.* 2020). The literature reports significant variation on the extent to which sexuality is affected by gynaecological cancer. Some studies report low numbers (Barlow *et al.* 2014; Kim *et al.* 2015), some report that half of women are affected (McCallum *et al.* 2014; Carr 2015) and others suggest that most or all women report experiencing sexual difficulties (Cleary *et al.* 2011; Lara *et al.* 2012). This may be due to differences in how sexuality is defined, with studies working with a more holistic definition reporting more difficulties (Williams *et al.*



2017). Rates of sexual concerns for patients with head and neck cancer (HNC) can range from 24-100% (Singer *et al.* 2008; Low *et al.* 2009; Moreno *et al.* 2012). A recent study of 134 head and neck cancer survivors, with a range of tumour locations and tumour staging, at baseline indicated that 76.1% of patients were experiencing sexual challenges (Schutte *et al.* 2021). As mentioned earlier, the literature is divergent in respect to which patients across and within tumour groups are more likely to experience sexual problems, relating this to age, tumour location and gender (Singer *et al.* 2008; Moreno *et al.* 2012; Rogers *et al.* 2015). This is primarily due to a lack of validated tools designed to measure the sexual challenges faced by specific tumour groups such as body image after breast cancer related to breast shape (Dalton *et al.* 2009) or compromised function of the lips or tongue, xerostomia, trismus, or presence of a stoma in patients with HNC (Hoole *et al.* 2015). Thus, it is highly likely that the full extent of sexual challenges faced by patients with cancer or cancer survivors is not known and understood.

The overriding conclusion drawn from studies on the prevalence of sexual problems for people with cancer signifies this as a frequent issue confronted by many. Although cognisant of the complex interplay between many factors which contribute to sexual difficulties, the following sections will appraise the literature on the physical, psychological and social impact of a cancer diagnosis and treatment on the patient and their partner.

### **3.1.2.1 Physical impacts of treatment on sexuality**

Treatment for cancer can include surgery, radiotherapy, chemotherapy or hormone therapy or a combination of these, each of which present physical challenges that can affect an individual's sexuality. Table 2 provides an overview of how common treatments can have a physical impact on patient's sexuality. This table is followed by a detailed presentation of how these specific treatment modalities impact sexual wellbeing for

patients across cancer care. This evidence base was used to inform the content and structure of advice provided within the MSW: CC eLearning resource, on treatment-related sexual challenges.

**Table 3: Summary of cancer treatments and potential physical impact on sexuality (adapted from Mercadante et al. 2010; Bober and Varela 2012; Schover 2019)**

<b>Treatment</b>	<b>Physical impact on sexuality</b>
<b>General treatment-related effects</b>	Pain, fatigue, nausea, vomiting, hair loss (including pubic hair with chemotherapy and pelvic radiotherapy), weight changes, lymphoedema
<b>Surgery</b>	Difficulty experiencing pleasure and reaching orgasm Erectile dysfunction Loss of sensation
<b>Radiotherapy involving pelvic region (neurological or vascular damage)</b>	Difficulty experiencing pleasure and reaching orgasm Erectile dysfunction Vaginal atrophy, dryness and pain Fertility problems Early menopause Loss of sensation
<b>Chemotherapy</b>	Temporary/early menopause Fertility problems
<b>Hormone therapy</b>	Vaginal atrophy, dryness and pain Menopausal symptoms Erectile dysfunction Loss of desire for sex

### **Effects of surgery on sexual wellbeing**

Using models of benchmark surgical use based on clinical guidelines across 183 countries it is estimated that 58% of newly diagnosed patients with cancer need at least one surgical treatment as part of their disease management (Perera *et al.* 2021). It is therefore important that the evidence surrounding the specific effects of surgery on sexual wellbeing are reviewed across different tumour groups. For example, after a range of surgical procedures for gynaecological cancer including cervical, vulvar, uterine and ovarian, a high proportion (around 80%) of woman (aged  $52 \pm 13.4$  years) report sexual dysfunction, which is commonly due to changes to bodily functions and damage to pelvic nerves, through the removal of the uterus, fallopian tubes, ovaries and or cervix (Aerts *et al.* 2009; Carter *et al.* 2013; Jeppesen *et al.* 2015). These surgeries are associated with

vaginal dryness and vaginal atrophy, pain during sex and issues surrounding lubrication and infertility, all of which can affect sexuality, with increased significance for patients whose treatment causes early menopause (Aerts *et al.* 2009; Jeppesen *et al.* 2015; Vermeer *et al.* 2016; Seske *et al.* 2017). Gynaecological studies are not without methodological limitations, inhibiting their generalisability due to small sample sizes (n=50 (Aerts *et al.* 2009), n=30, (Vermeer *et al.* 2016), n=129 (Seske *et al.* 2017) and heterogeneity of gynaecological subgroups represented – cervical (Vermeer *et al.* 2016; Seske *et al.* 2017), vulvar, uterine and ovarian (Aerts *et al.* 2009; Seske *et al.* 2017). In addition, most of these studies are retrospective in nature, but despite this, patients reported symptomology over a lengthy period (18 months, Aerts *et al.* 2009 and 1 - 12 years Vermeer *et al.* 2016). Although retrospective studies could be subject to recall difficulties, these findings do point towards the ongoing effects of gynaecological surgery's impact upon sexuality.

For patients having surgery for colorectal cancer, sexual dysfunction is also commonly reported (Traa *et al.* 2012; Almont *et al.* 2019a), with more profound effects after radical rectal surgeries, because of damage to important nerves (Breukink and Donovan 2013). This nerve damage can cause erectile dysfunction (ED) or ejaculatory dysfunction (EJD) in men, while for women, it can disrupt blood flow to the vagina and vulva, reducing vaginal lubrication and sensation and decreasing orgasm (Breukink and Donovan 2013; Bregendahl *et al.* 2015). Lange *et al.* (2009) compared 990 patients treated for colorectal cancer who had radiotherapy and surgery (n=497) to those having surgery only (n=493); these researchers concluded that radiotherapy was not an independent risk factor for ED or EJD, but that sexual dysfunction was mainly caused by surgery. Other studies of men and women with colorectal cancer (77% colon, 23% rectal) have similarly reported surgery as being independently associated with a decrease in sexual activity (Almont *et al.* 2019a). What is clear from the literature is the surgical procedures for colorectal cancer have a

direct impact on both the type and severity of sexual challenges experienced. For women, in a nationwide cross-sectional retrospective study with a median follow-up time from surgery  $n=55$  months, Bregendahl *et al.* (2014) found risks of dyspareunia twice as likely for patients who had an abdominoperineal resection (APR) when compared with low anterior resection (LAR). Furthermore, they found LAR to be associated with a lack of sexual desire, sexual inactivity and dissatisfaction with sex life or a lack of sex life. For rectal surgery resulting in an ostomy, patients of both genders reported greater sexual problems compared to those having an anastomosis (Sun *et al.* 2016). Participants ( $n=575$ ) in this study also note that decreased or loss of sexual activity after an ostomy was one of their greatest post-treatment challenges. After such surgery, women with a mean age of 74.9 years (range 43.5 – 100.3) reported difficulties with vaginal strictures and vaginal pain, which persisted many years after treatment (at least 5 years after surgery). Whereas men with a similar mean age of 72.4 years (range 36.2 – 96.5) reported problems getting and maintaining an erection, although this problem did appear to reduce over time.

A large study of men with prostate cancer ( $n=35,823$ ) from the UK found that 83.7% of men after surgery alone, reported their overall sexual function was poor or very poor (Downing *et al.* 2019). After surgery for prostate cancer most men report a range of significant treatment effects, including urinary continence, erectile dysfunction due to damaged muscles and nerves and reduced sexual pleasure (Hanly *et al.* 2014; Danemalm *et al.* 2019; Downing *et al.* 2019). Similar to colorectal patients, when surgery forms part of the treatment plan for prostate cancer, this has a direct, more intense effect on sexual wellbeing, compared to having radiotherapy alone, up to five-years following treatment. This was borne out in a long-term (15 year) longitudinal cohort study (Prostate Cancer Outcomes Study (PCOS)), comparing patients receiving either surgery alone or radiotherapy alone across different timepoints (Resnick *et al.* 2013). In this study, patients

having surgery alone were twice as likely to experience ED and five times more likely to have urinary incontinence, five-years post-surgery. Interestingly, these findings suggest that the prevalence of these sexual difficulties were similar for both treatment types at 15 years (87% and 93.9% respectively). Thus, one can infer that prostate cancer patients, irrespective of treatment experience longer-term effects. However, some of these physical effects could be related to a combination of the aging process (men in the study were diagnosed between 55 and 74 years of age and followed up over 15 years) and other factors linked to the cancer and its treatment, as side-effects were relatively stable between 2 and 5 years but declined after 5 years (Resnick *et al.* 2013).

Recent studies illustrate the evolution of surgical techniques and the possible impact on sexual wellbeing. This includes the use of nerve sparing surgery on men who have had erectile function prior to surgery. Importantly, this nerve sparing surgery for prostate cancer has been reported to increase the chance of a return to baseline erectile functioning (Avulova *et al.* 2018; Mullins *et al.* 2019). One study assessing patients' perceptions of postprostatectomy erectile function to preoperative status reported that bilateral nerve-sparing surgery was the only significant predictor of a return to baseline function (15.5% of patients compared to 3.3% of patients who had not undergone bilateral nerve sparing surgery) (Fode *et al.* 2016). However, these conclusions were based on a small number of men (n=14). Surgical interventions for prostate cancer usually involve the removal of the seminal vesicles, therefore men can no longer ejaculate when having an orgasm, become infertile and orgasms themselves may be delayed. In several studies, gay men report that the lack of semen at orgasm was concerning, as it is removing a sense of 'proof' to the man and partner that sexual pleasure had been achieved (Wassersug *et al.* 2013; Hart *et al.* 2014; Danemalm *et al.* 2019). Findings from an earlier study (Danemalm *et al.* 2016) with heterosexual men however found men to be less

concerned about the loss of ejaculate, highlighting potential differences in prioritising concerns.

Patients who have had surgery for HNC reported sexual difficulties arising from reduced mouth movement, tongue movement, dental loss, reduced range of neck and shoulder movement and highly visible changes to facial shape and communication (Parahoo *et al.* 2019, Semple *et al.* 2019). Reduced mouth and tongue movement combined with dental loss, can make kissing and oral sex difficult (Moreno *et al.* 2012, O'Brien *et al.* 2012; Semple *et al.* 2019). Some caution is necessary regarding the generalisability of these findings, as HNC studies exploring the impact of sexuality after surgical intervention have reached their conclusions based on small sample sizes with an underrepresentation of women. For example, O'Brien *et al.* (2012) used a stratified quota sample of n=16 patients, with only n=4 female participants, stratified across ear, nose and throat or maxillofacial cancers. Moreno *et al.*'s (2012) sample comprised of mainly white (83%), male (74%) patients, while Batioğlu-Karaaltın *et al.*'s (2017) Turkish study of n=108 participants purposefully excluded females to create a homogenous group given that not many females would meet the inclusion criteria. While most HNC patients are male (1.4 : 1 for cancers of the oral cavity and 4.4 : 1 for cancers of the larynx, although this varies with geographical location) (Braakhuis *et al.* 2014), these findings may not be representative of female patients, nor address the challenges faced by their partners (Badr *et al.* 2016). Changes to the head and neck, a result of treatment which can introduce pain, eating and drinking difficulties and can cause altered speech which may affect the patient's sense of self, communication and important daily essential functions (Badr *et al.* 2016, Semple *et al.* 2019). The requirement of feeding tubes or support with breathing can prove challenging to negotiate during sex and intimacy (Badr *et al.* 2016). Of note, patients with HNC in a study with a larger sample size than most (n=206),

reported the lack of physical strength after surgery as having a greater impact on their sexuality than managing sputum or changes to appearance (Singer *et al.* 2008).

Surgical treatment for breast cancer may result in changes to or the loss of a breast resulting in scarring, pain, lost sensation in breast and/or nipple tissue and lymphoedema (Bitzer and Hahn 2017; Panjari *et al.* 2011). In keeping with previous research (Beckjord and Compas 2007; Markopoulous *et al.* 2009), Aerts *et al.* (2014) a prospective case-controlled study (n=149 women with n=149 age-matched controls) found a significant negative impact on sexual function based on the type of breast surgery. This study demonstrated that women who had a mastectomy reported more problems with sexual desire, arousal and orgasm; than prior to surgery, or when compared to women without breast cancer (Aerts *et al.* 2014). Women who had received breast conserving surgery experienced better sexual adjustment compared to those who underwent a mastectomy. However, the participants for Aerts *et al.*'s (2014) study were heterogeneous in terms of adjuvant treatment. This study had significantly more women in the breast conserving group receiving radiotherapy and significantly more in mastectomy group receiving chemotherapy, which has a well-known impact on sexual functioning (Ganz *et al.* 2011). It is possible that the significant negative impact relating to mastectomy detailed by Aerts *et al.* (2014) could be related to adjunctive chemotherapy rather than the surgical intervention.

For women with hormone positive cancers, surgery for breast cancer may include removal of the ovaries, for some this can be a relief as it signals a reduced risk of cancer in the future, but for others the loss of fertility can be devastating (Perz *et al.* 2014). Previous studies have also reported that cancer-related infertility is associated with feelings of depression and the resultant early menopause is distressing for patients with cancer (Schover 2008; Tschudin *et al.* 2010). Although not undertaken by all, women who have

had reconstruction surgery either as part of surgery to remove cancer or at a later point, or a lumpectomy, tend to report better sexual adjustment than those who have a mastectomy without reconstruction surgery (Markopoulous *et al.* 2009; Manganiello *et al.* 2011; Neto *et al.* 2013). Specifically, Markopoulous *et al.* (2009) reported that n=207 women from Greece with stage 1 or 2 breast cancer who had breast reconstruction were the group most satisfied with their sexual life (81.3%), reporting that breast cancer surgery was not affecting their sexual life (75%). Those in the breast-conserving surgery group demonstrated a greater satisfaction with their sexual life (57.8%) than those in the mastectomy without reconstruction group (37%). Woodbury *et al.* (2017) systematic review and meta-analysis of 104 studies has supported these findings, nonetheless, they have noted that the evidence is confounded due to the lack of compatibility of validated measures across studies.

Although these studies are not exhaustive in terms of representative tumour groups, it is evident that the location of cancer and type of surgery can physically disrupt patients' experience of sexuality. These problems are not confined to what has previously been described as 'sexual cancers' such as breast, prostate or gynaecological cancers, for which much research centres around, but are challenges experienced by patients across tumour groups. This section has highlighted sexual challenges due to surgical intervention, which are unique to specific tumour groups while identifying others, such as pain, which is experienced by patients across tumour groups.

### **Effects of radiotherapy on sexual wellbeing**

Pelvic radiotherapy used in prostate, colorectal and gynaecological cancer treatments is associated with infertility, urinary and bowel problems, fatigue, erectile and ejaculatory dysfunction, vaginal dryness, stenosis and atrophy and lymphoedema (Rodrigues *et al.* 2012; Incrocci and Jensen 2013; Bregendahl *et al.* 2015). Bruheim *et al.* (2010a; 2010b)



investigated the impact of radiotherapy on the sexual function of men and women with rectal cancer and compared it to a non-radiotherapy control group. These studies adjusted for confounding factors, such as a greater number of radiotherapy patients having a localised advanced cancer and tumours positioned closer to the anal verge. For men, Bruheim *et al.* (2010a), reported significantly poor scores for erectile function, orgasmic function, intercourse satisfaction and overall satisfaction with sex life compared to controls. For women, they reported an increased risk of dyspareunia and vaginal dryness compared to surgery alone (Bruheim *et al.* 2010b). Further highlighting some of these struggles, was a small phenomenological study of 10 Canadian women aged between 40 and 60 years old who were treated with radiotherapy for cervical cancer (Bilodeau and Doucard 2011). The study reported that these women struggled with having no sexual desire and foul-smelling discharge which made intercourse uncomfortable. Other women experienced vaginal stenosis which made intercourse painful and difficult and which required them to adjust sexual positions.

For women with breast cancer, treatment for radiotherapy may cause scarring, burns, lymphoedema and breast skin thickening, presenting both physical and psychosocial problems to sexuality (Bitzer and Hahn 2017). When controlling for the effects of systemic treatments, Bantema-Jobbe *et al.* (2015) study of women in the Netherlands with breast conserving surgery and radiotherapy found sexual function challenges to be more significant for older than younger women, indicating the need for further research to understand more fully the reasons for this. Patients with HNC requiring radiotherapy may need to have some, or all teeth removed (Hancock *et al.* 2003). If extractions are performed after radiotherapy, there is an increased risk of osteoradionecrosis, although there is no evidence from RCTs to support or refute the extraction of teeth prior to radiotherapy for the reduction of subsequent dental complications (Eliyas *et al.* 2013; Parahoo *et al.* 2019). However, as indicated by Parahoo *et al.*'s (2019) small study (n=15,

men and women) of the impact of multiple dental loss as a consequence of treatment for head and neck cancer, the removal of teeth can result in difficulties relating to speech, eating and social interactions, together with challenges to physical intimacy through kissing.

Importantly, the side effects following radiotherapy, irrespective of tumour group, may present gradually and persist for several years post-treatment, therefore having an enduring effect on relationships and sexuality (Rodrigues *et al.* 2012; Incrocci and Jenson 2013). Siglin *et al.* (2010) illustrated this, as men (n=143) who received external beam radiotherapy for prostate cancer, reported significant declines in sexual function (sex drive, erectile and ejaculatory function and overall satisfaction) up to 24 months following treatment which stabilised thereafter. In contrast, Lange *et al.* (2009) noted from their study of 990 Dutch patients (63.1% male) that sexual decline after preoperative radiotherapy for rectal cancer, improved in females over time, though it remained worse for male patients. However, the authors do point out that the assessment of female sexual dysfunction is difficult, as simple endpoints equivalent to erectile function and ejaculation are not available and sexual intercourse often remains technically possible even when sexual dysfunction is present. Akin to surgery, the physical sexual challenges for radiotherapy are varied as they depend on factors such as the location of treatment on body.

#### **Effects of chemotherapy on sexual wellbeing**

Chemotherapy is a systemic cancer therapy associated with indirect effects on patient sexuality such as nausea, vomiting, bowel changes, hair loss, weight gain and peripheral neuropathy. Among these, nausea and vomiting are viewed as the most distressing, which can have a considerable effect on sexual desire and body image (Ganz *et al.* 2011; Limoncin *et al.* 2017). Fatigue has been reported by up to 99% of patients following

chemotherapy and/or radiotherapy (Radbruch *et al.* 2008). Mackereth *et al.*'s (2015) UK-based study of 40 women's experience of fatigue after chemotherapy for breast cancer, suggested that fatigue was responsible for a reduction in sexual activity, sexual drive and intimacy with partner. However, it is difficult to ascertain if these findings only related to chemotherapy as patients often receive multiple treatments, therefore it is possible that other treatments contributed to fatigue levels. In a Turkish mixed methods study of 79 women with ovarian cancer, women reported that chemotherapy treatment made them feel incomplete as a woman (20.6%), 62% refrained from sexual intercourse and 56% stated that chemotherapy negatively affected their sexuality (Akkuzu and Ayhan 2013). However, it was not clear in this study how researchers controlled for the effects of surgery on sexuality. Furthermore, a large Italian survey of 761 patients who had a diagnosis of cancer in the previous 6 years (84%) as a result of varied tumours (predominantly breast (56%) and female (77.6%)), reported that 60% of patients experienced an altered sexual life associated with their chemotherapy treatment (Lorusso *et al.* 2017). For 50% of these patients, sexual challenges were confined to the chemotherapy treatment cycle, while such challenges extended beyond the cycle for the remainder of the sample (Lorusso *et al.* 2017). In a study of 487 patients (258 male, 229 female) with colorectal cancer (77% colon, 23% rectal), chemotherapy was positively associated with decreased frequency of intercourse and reduced satisfaction with the frequency of hugging and kissing (Almont *et al.* 2019a). Conversely, Mayer *et al.* (2019) found that chemotherapy did not influence sexual function and wellbeing of 396 sexually active women with breast cancer and reported that hormone therapy could account for the changes. This discrepancy may be due to the gender differences, or variation of validated tools used across the two studies. The tools used by Mayer *et al.* (2019) appeared to be more comprehensive as they considered additional partner-related factors potentially influencing sexuality. These related to having no partner, a partner experiencing physical problems which could make sexual relations difficult or a partner's

lack of sexual desire. The literature has suggested that the effects of chemotherapy often improve post-treatment, but for women it may have longer lasting direct effects, by increasing vaginal dryness and pain during sex, reduce sexual pleasure and a risk of temporary or early menopause (Boswell and Dizon 2015; Limoncin *et al.* 2017), which can lead to infertility. Ganz *et al.*'s (2011) prospective longitudinal study of women with breast cancer (n=558) at 4 timepoints, first timepoint within 4 weeks of treatment commencing, then at 3, 6 and 12 months, echoes this finding. Women reported significantly more problems, such as hot flushes, nausea, vaginal problems, musculoskeletal pain, cognitive problems and weight problems for women who received chemotherapy, compared to those without. While this study benefited large study sample, non-responders at 12 months were more likely to be older and use Tamoxifen. This could have potentially skewed the data, underrepresenting the extent of the sexual challenges encountered given Tamoxifen's reported negative effect on sexual wellbeing (Buijs *et al.* 2009).

It is recommended that women should not get pregnant during or for a short time after chemotherapy treatment (Limoncin *et al.* 2017), therefore, studies investigating the therapeutic challenges of chemotherapy while pregnant are limited and involve only a small number of patients (Esposito *et al.* 2016). In their systematic review on neonatal outcomes, Esposito *et al.* (2016) suggest that chemotherapeutic agents have a dangerous effect, particularly in the first trimester, with a risk of pregnancy loss or malformations. These problems are much reduced after 12 weeks. However, Esposito *et al.* (2016) adds caution to these findings for several reasons. They reported that many of the chemotherapy drugs given to pregnancy women show lower blood concentrations when compared to nonpregnant women, suggesting that women who are pregnant would require a higher dosage. Furthermore, pregnant women treated with chemotherapy

have a greater risk of severe neutropenia, but the safety and effectiveness of the treating agent for this condition during pregnancy is not well established.

For men, chemotherapy may cause erectile problems and reductions in sperm count due to higher levels of follicle-stimulating hormone, luteinizing hormone and a reduction in testosterone (Wiechno *et al.* 2007; Meistrich *et al.* 2009). A multicentre prospective longitudinal study of 129 men aged between 20 and 44 years with testicular cancer with a control group of 257 fertile men identified lowest sperm count values at 3 and 6 months after chemotherapy treatment commenced (Bujan *et al.* 2013). However, their study identified that semen characteristics recovered to pre-treatment values at 12 months when there was fewer than two cycles of chemotherapy. Following chemotherapy treatment, erectile function usually improves, however, as pointed out by an earlier study of semen analysis following allogeneic bone marrow transplantation where patients were aged between 9 and 50 years, sperm count may not usually improve (Anserini *et al.* 2002) which may indicate a need to consider fertility preservation in advance of treatment. However, given the timelapse between studies it is possible treatments have become more refined. Furthermore, Anserini *et al.* only had baseline data for n=8 patients in their study. From the evidence base, it appears that chemotherapy treatment can have an enduring impact on sexuality, however, for others it can have a shorter-term impact. Nonetheless, the experiences discussed can induce or increase patient and partner concerns around sexuality.

#### **Effects of hormone therapy on sexual wellbeing**

Hormone therapy such as androgen deprivation therapy, selective oestrogen receptor modulators (e.g., Tamoxifen) or aromatase inhibitors are commonly used for hormone sensitive tumours (breast, uterine or prostate), either to prevent hormones reaching cancer cells or to stop their production. This is an important factor which can influence

sexual function and QoL (Mayer *et al.* 2019). In men, androgen deprivation therapy may cause a loss of sexual desire, erectile dysfunction, hot flushes, weight gain, enlarged and tender breasts, reduced semen volume, trouble with orgasms and emotional instability; all of which affect self-image, perceived identity and the experience of masculinity (Donovan *et al.* 2018; Corona *et al.* 2021). Even when androgen deprivation therapy is discontinued, a study of 167 men receiving treatment for localised prostate cancer which compared the effects of radiotherapy and radiotherapy plus androgen deprivation therapy reported those receiving androgen deprivation therapy had worse erectile dysfunction (Joyce *et al.* 2021). Women with breast and gynaecological cancers, on the other hand, have reported side-effects from hormone therapy such as vaginal dryness, pain during sex, loss of desire, hot flushes, problems with orgasm along with fatigue and bowel problems (Tucker *et al.* 2016; Carter *et al.* 2020). Studies comparing the effect of aromatase inhibitors and Tamoxifen on sexual function have reported that aromatase inhibitors can cause significantly greater severity of sexual symptoms (Baumgart *et al.* 2013; Tucker *et al.* 2016). Schover *et al.* (2014) highlighted (n=129) that during the first 2 years of adjuvant treatment with aromatase inhibitors, many women (93%) with breast cancer scored as dysfunctional on the Female Sexual Function Index (FSFI); moreover 75% of these women were distressed about sexual problems, finding them difficult to resolve, with some choosing to cease sexual activity as a result (Schover 2014). However, Buijs *et al.*'s (2009) earlier review of prospective randomised studies, into the influence of endocrine treatments for pre and post-menopausal women with breast cancer contradicts this finding, suggesting that aromatase inhibitors often have less impact than Tamoxifen on sexual wellbeing. This picture is complex as many studies have included patients with prior chemotherapy. Effects therefore may not be due to the hormone treatment itself and patients may have found ways to cope and adapt because of the many challenges they have faced to date, which could result in a lower response of sexual issues (Buijs *et al.* 2009). However, post-menopausal women using aromatase inhibitors

are more likely to experience increased menopausal symptoms that negatively affect sexuality due to the disruption in the primary source of oestrogens (Derzko *et al.* 2007; Mok *et al.* 2008; Van Londen *et al.* 2014).

### **3.1.2.2 Psychosocial impact of a diagnosis of cancer and treatments**

There is a complex relationship between the physical and psychosocial aspects of sexuality after diagnosis or treatment for cancer (Boquiren *et al.* 2016). Painful intercourse, due to vaginal dryness, can lead to feelings of anxiety and avoidance of sexual contact while hair loss, weight gain and bodily scarring can interrupt a person's sexual identity, reduce perceptions of attractiveness and act as a visible reminder of the cancer (Cleary *et al.* 2013; Gilbert *et al.* 2013; Vermeer *et al.* 2016). These treatment-related effects can reduce levels of sexual desire and pleasure which can also negatively affect sexual identity (Gilbert *et al.* 2013; Tracy *et al.* 2016). The loss of body parts can change perceptions of sexual identity, for example, Ussher *et al.* (2012a; 2015) in two large surveys (breast cancer n=1965, reproductive and non-reproductive tumour groups n=657) using quantitative and qualitative items described the negative psychosocial impact from having no breasts, particularly when they were important to a partner or as part of physical pleasure. Furthermore, a study of 381 women with breast cancer, whose treatment led to the early onset of menopause and infertility, described women's feelings of inadequacy in their role as a partner, due to not being able to conceive children (Perz *et al.* 2014). Farthmann *et al.* (2016) in a prospective study of 79 women from Germany (mean age = 47 years old: SD 9.75) who received chemotherapy treatment for breast cancer reported greater levels of distress (health related QoL and sexual function) in premenopausal women compared to older women. They concluded that this was due to the increased importance placed on fertility and having a family at that life stage. Yet, for some patients, the experience of cancer and treatment although life changing can produce feelings of empowerment and confidence (Gilbert *et al.* 2013). Gilbert *et al.*

(2013) reported that 21 Australian men from a range of tumour types including prostate, leukaemia, bowel, bladder and brain, who were more accepting of the sexual changes did not feel that their sexual identity was affected. Furthermore, for some patients, the removal of sexual organs can bring a sense of relief (Juraskova *et al.* 2003; Sekse *et al.* 2010). For example, in patients with gynaecological cancer, these body parts have been associated with the cancer diagnosis, pain and bleeding which was experienced prior to surgery (Juraskova *et al.* 2003; Sekse *et al.* 2010).

Nonetheless, the psychological impact of cancer can be experienced through feelings of fear, loss, guilt, shame, sadness, anger and depression (Wittmann *et al.* 2011; Begovic-Juhant *et al.* 2012; Baxi *et al.* 2013; Vermeer *et al.* 2016). Patients with cancer can experience many fears related to mortality, a preoccupation with cancer recurrence, or partner abandonment, each of which may affect their levels of sexual desire (White *et al.* 2013; Boquiren *et al.* 2016; Vermeer *et al.* 2016). A qualitative study with women aged between 36 and 62 years of age investigated the meaning women with breast cancer (n=10) from Brazil attributed to their diagnosis and its impact on sexuality. Even at diagnosis women identified the proximity of death and fears of bodily alterations which could be caused by treatments as having a negative impact on sexuality (Cesnik *et al.* 2013). For some patients, the anticipation of alopecia and changes to breasts had resulted in the end of intimate relationships (Cesnik *et al.* 2013). Furthermore, a small study of 30 patients with cervical cancer treated in the Netherlands within the previous 12 years reported that half of patients attributed feelings of embarrassment, guilt and sadness to the sense of loss associated with impairments to sexual function (Vermeer *et al.* 2016). Embarrassment, guilt and sadness was consequently attributed to lower levels of sexual desire affecting their sexual relationship and leaving them feeling a sense of guilt towards their partner. Interestingly, of the 44% of those approached to participate in this study but who declined, with most reporting their decision was based upon the topic being



considered as too intimate or intimidating. Guilt and embarrassment were also evident in a qualitative study of men with HNC (n=10) (Baxi *et al.* 2013). This study described how patients with an HPV-related cancer diagnosis expressed a sense of stigma and embarrassment associated with their diagnosis of a sexually transmitted infection. Patients had concerns about engaging in sexual activity due to worry related to passing on HPV to their partner (Baxi *et al.* 2013). Other studies, however, demonstrate patients adaptive coping mechanisms in response to the psychological impact of an HPV-related HNC cancer diagnosis. Dodds *et al.* (2019) reported that patients with HNC in their study coped better by focusing on the improved prognosis implied by an HPV-related HNC and by developing an understanding of HPV-virus prevalence. Partners too can be fearful about engaging in sexual activities. This fear was described by Taylor (2014) in their study (n=4) recruiting partners of patients with cancer from outpatient, community and hospice inpatient units in the UK, who in relation to fear of the toxicity of patient's chemotherapy treatment impacting upon themselves, were reluctant to engage in sexual activity (Taylor 2014). It is evident that without open communication, partner avoidance of sexual activity can reduce the intimate emotional connection between partners and increase patient distress (Tracy *et al.* 2016).

Patients can experience emotional distress in relation to changes to sexual identity, body image and relationships (de Vocht 2017). Poor body image, lower feelings of attractiveness, challenges with sexual identity and lower sexual function are positively correlated with depression and have negative effects on overall QoL (Begovic-Juhant *et al.* 2012, Bae and Park 2016). Begovic-Juhant *et al.*'s (2012) quantitative study assessed body image, physical attractiveness and femininity of 70 women with breast cancer post-treatment (most within 6 years of treatment), aged between 23 to 79 years and investigated the relationship between body image, depression and QoL. Their findings, based on questions from a series of validated questionnaires including the European

Organisation for the Research and Treatment of Cancer QoL Questionnaire – Breast Cancer (EORTC QLQ-BR23) (Sprangers *et al.* 1996) showed that poor body image and a negative perception of attractiveness and femininity contributed to higher depressive symptoms and lower QoL. In fact, body image was responsible for the greatest variance in depression. However, caution is required with interpretation of these findings, as it is unclear if depression contributed to the poorer perception of body image, attractiveness and femininity or this was resultant from poor body image or depression prior to diagnosis (Begovic-Juhant *et al.* 2012). In contrast with these findings was Zimmermann *et al.*'s (2010) study of 98 couples in which the women had breast cancer surgery and were receiving adjunctive treatment. They found positive body image to be a consistent and robust predictor of women's adjustment to breast cancer and that women's self-acceptance was dependent on the extent of depressive symptoms experienced. Feelings of unattractiveness and poor body image have been described in a small qualitative study of patients with HNC (n=11) (Rhoten *et al.* 2020). For this tumour group, patients reported not only difficulties adjusting to appearance-related changes but also due to the presence of a percutaneous endoscopic gastrostomy (PEG) tube or stoma; as such they avoided intimacy with their partners, experienced emotional distress and wanted to be alone (Rhoten *et al.* 2020). Furthermore, patients may experience anger because of the changes to their body. Ussher *et al.*'s (2015) study of 535 women and 122 men from a range of tumour groups (85% of women had breast cancer, 72% of men had prostate cancer), indicated that the loss in size of penis after treatment for prostate cancer and the changes to breasts after breast cancer treatment left patients feeling angry at the disturbances to their experiences of sexuality after cancer. However, it is not clear if they were angry because the changes were unexpected or as part of the grieving process for the losses incurred (Wittman *et al.* 2011). The evidence provided thus far has indicated that the psychological impact of cancer and its treatment is real and complex, for which patients

and partners require significant support, alongside addressing the physical treatment-related sexual challenges (Sears *et al.* 2018).

Relationship quality is also an important predictor to one's experience of sexuality and continued sexual activity is positively associated with greater relationship satisfaction (Zimmerman *et al.* 2010; Tucker *et al.* 2016; Gianotten 2017). Furthermore, a healthy supportive relationship has a positive impact on individuals' QoL, as patients with strong support systems, particularly a spouse or partner, tend to live longer (Aizer *et al.* 2013; Dahl *et al.* 2020) and adapt and cope better with sexual changes (Zimmerman *et al.* 2010; Emilee *et al.* 2010; Brédart *et al.* 2011; Male *et al.* 2016). Dahl *et al.*'s (2020) study of 523 cancer survivors who had treatment for cervical cancer in Norway between 2000 and 2007 were followed up in 2015 and identified that sexually inactive survivors had significantly lower mean scores on most cancer-related quality of life measures than sexually active ones. Sexual inactive survivors were older, more often were single, had low education, were not in paid work and were overweight. There are many potential interacting factors which could have influenced sexual inactivity and quality of life, regardless of cancer and treatment. For some, however, cancer along with its treatment can introduce new problems into a relationship but, for others, it can exacerbate existing relationship difficulties (Tracy *et al.* 2014).

### **3.1.2.3 Partners**

A diagnosis of cancer can have a significant psychological and social impact not only on the patient, but also the partner (Collaço *et al.* 2018). Often there is a greater awareness of dyadic adjustments by both the patient and their partner, as they deal with changes to daily life, concerns for the future and sexual challenges as a result of treatment (Rottmann *et al.* 2014; Collaço *et al.* 2018). Couples can often experience changes to mutual roles, family and social relationships. A meta synthesis of existing qualitative literature (n=37

studies) on the experiences of couples affected by prostate cancer (Collaço *et al.* 2018) identified that pivotal to coping with these changes for many was acceptance of the loss of sexual intercourse by the patient and partner. Those couples who were unable to accept the loss of sexual intercourse showed poorer adjustment to their circumstances (Beck *et al.* 2013). Couples who adapted well often renegotiated or redefined sexual practices, incorporating mutual genital touching, massage and kissing. Although many partners may accept the changes to their relationship, they may simultaneously experience resentment to the changes and experience feelings of anger, confusion and sadness (Gilbert *et al.* 2009) at their 'reduced' circumstances (Abbott-Anderson *et al.* 2019). In other studies, partners reported a more positive outcome, describing an admiration for how their partner was managing, along with increased closeness and opportunities to establish a new relational balance (Paulwels *et al.* 2012; Preau *et al.* 2013; Drabe *et al.* 2013). Drabe *et al.* (2013) study of 149 patients and 156 partners identified in their surveys that most couples reported growing closer through their cancer experience but a small, sizeable percentage observed negative changes which resulted in increased psychological distress and reduced quality of life. For the partner, however, adapting to the changes in the relationship can be exhausting (Abbott-Anderson *et al.* 2019), especially if the patient has an uncertain future, with a poor prognosis. This can result in potential changes to mood and depression not only for the patient but the partner, alike (Gianotten 2017).

For some male partners of cancer patients, changes of mood and reporting of depression have been associated with physical difficulties, such as erectile difficulties (Alacacioglu *et al.* 2014; Enzlin *et al.* 2017). Alacacioglu *et al.*'s (2014) study of partners of breast cancer patients in Turkey identified higher scores of depression, sexual communication, avoidance and erectile dysfunction on the Golombok-Rust Inventory of Sexual Satisfaction (GRISS), when compared to partners with lower depression scores. Interestingly, an

earlier study by Milbury and Badr (2013) found that partners (mean age  $54.4 \pm 10.85$  years) of patients with advanced breast cancer who had greater sexual problems had more depressive symptoms regardless of communication patterns.

Changes to sexuality for the couple may include reduced frequency or total abstinence from sexual intercourse and decreased intimacy (Cleary *et al.* 2013; Vermeer *et al.* 2016; Grondhuis Palacios *et al.* 2019). Such changes can result in increased friction and tension within the relationship and less touch or signs of affection. In a small qualitative study considering partners' (n=6) unmet needs and relationship challenges after HNC, partners reported decreases in expressions of physical intimacy such as kissing, hugging, or touching and that physical sexual relationships had ceased (Badr *et al.* 2016). A larger study which included 174 partners of men with prostate cancer, described how half of the partners had found it difficult to cope with their altered situation regarding sexuality (Grondhuis Palacios *et al.* 2019). For some partners, sexual activity can serve as a means of reducing tension, but changes to the relationship due to cancer and its treatment may limit this outlet (Vermeer *et al.* 2016), which then contributes to higher levels of conflict or resentment.

Partners however reported a wariness when it comes to initiating sexual activity. In a qualitative study of partners (n=20) of patients with breast or gynaecological cancers, this was a result of their awareness of the struggles their partner (the person with cancer) was facing, such as the loss of sexual desire, stress, exhaustion and changes to their body (Gilbert *et al.* 2009). Many partners were reluctant to cause pain to their partner (the patient), they did not want to be perceived as inappropriate and they feared being rejected (Gilbert *et al.* 2009). To address this, in another study of 12 partners of women with cervical cancer, some partners reported that they wanted to leave the initiative for sexual contact up to the patient, however some worried that this approach would reduce

their sexual contact (Vermeer *et al.* 2016). Vermeer *et al.* (2016) described the changes to a partner's sexual behaviour within the relationship could cause the patient to worry that their partner had lost sexual interest in them and create further tension and concern within the relationship. This has highlighted the complexities of decision making about sexual behaviour and its potential effect on relationships, which couples with cancer may have to navigate. These findings have briefly summarised some of the difficulties experienced by partners/couples and highlighted the importance of providing sexual support for couples to aid improvement of communication patterns. The literature indicates that in addition to the challenges that patients face, partners also face many challenges across the physical, psychological and relational domains.

#### **3.1.2.4 Other specific sexual challenges for population groups**

Some patient subgroups (and partners) may experience specific challenges in relation to cancer and sexuality. This may include, lesbian, gay and bisexual and transgender (LGB & T) patients (and partners), older patients, patients with advanced cancer or those from ethnic minority cultures. While LB women often reported lower sexuality concerns, GB men reported specific functional and psychosocial challenges (Asencio *et al.* 2009; Rose *et al.* 2017; McInnis and Pukall 2020). A series of focus groups with 36 ethnically diverse GB men, aged between 37 and 70, from a mix of professional and unskilled backgrounds from America identified the significance of the loss of penile function, ejaculation anal pleasure as a result of prostate cancer treatment suggesting it could have a deep effect emotionally, physically and socially (Asencio *et al.* 2009). After prostate cancer treatment, erections may be weaker, which can be problematic for men wishing to engage in anal intercourse, as firm erections are required (Goldstone *et al.* 2005). McInnis and Pukall's (2020) summary of the literature on sex after prostate cancer in gay and bisexual men identified that gay and bisexual men when compared to heterosexual men reported greater ejaculatory problems and changes to their sexual role. The impact of post-

treatment erectile dysfunction varied depending on the role of the man in the relationship. Those who were insertive partners had more concerns about erectile function while those who were receptive partners were more concerned about pain and discomfort (Asencio *et al.* 2009). Furthermore, for GB men these changes to sexuality can leave them feeling an outsider within their community (Rose *et al.* 2017).

For older patients (65+), a fairly recent systematic review (18 studies – qualitative and quantitative) highlighted that sexuality continued to be important for this patient group (Bauer *et al.* 2016), with an English study of n=6690 men and women identifying that many older people remaining sexually active (Jackson *et al.* 2016). However, for older people it is more likely that comorbid conditions, partner health and sexual function can present challenges (Mercadante *et al.* 2010; Ussher *et al.* 2012a; Sawin 2012). A study investigating women's adjustment to sexuality changes after gynecological cancer identified in their study that many older people were accepting of the changes to sexuality, (Abbott-Anderson *et al.* 2019), and akin to Murillo *et al.*'s (2017) study findings, emotional intimacy remained important to them. Patients with advanced cancer retained a desire for intimacy even when they were very ill (Bond *et al.* 2019). In fact, for those with advanced cancer a large Danish survey (n=1447) of patients with tumour stages III to IV, (n=961 completing sexuality items) indicated there can be a stronger need for physical closeness, intimacy and touch at this time (Bond *et al.* 2019). Despite a paucity of studies into the sexual needs of patients with advanced cancer, one quantitative study (n=65) recruited patients admitted to an acute pain relief and palliative care unit (Vitrano *et al.* 2011). They investigated the sexual needs of patients receiving palliative care, although excluded those who were too ill or confused. Findings indicated that most patients (72.8%) viewed sexuality as 'very important' or 'important' to their psychological wellbeing (Vitrano *et al.* 2011). Furthermore, Taylor's (2014) qualitative study of patients recruited from outpatient, community and hospice inpatient units, described the

importance that patients with advanced cancer placed on non-sexual touch and emotional attachment. They identified that a disconnection can occur in sexual relationships due to a lack of physical intimacy, a disconnection which could be exasperated by the lack of privacy and provision of single beds in hospital and hospice settings (de Vocht 2017).

This is not just a concern for couples, as unpartnered patients often express fears about dating again after cancer and the fear of rejection by a new partner (Shortt 2016; Tracy *et al.* 2016; Reese *et al.* 2017a). In these studies patients' concerns centred around how and when to tell a new partner about their experience with cancer and the resultant changes to their body, which then turned to finding a way to manage those reactions.

Finally, the experience and expression of sexuality between and within cultures varies significantly. Cancer in some cultures may signal a threat to the relationship and undermine sexuality identity as illustrated by Bamidele *et al.* (2019). In this UK-based study which included 28 men and 11 partners, Bamidele described that black African and black Caribbean men saw disclosure of their illness as a sign of weakness and vulnerability which did not align with their stoic masculine identity. Bamidele *et al.* highlighted that some men in their study did not allow their wives to disclose their diagnosis, which then limited their wives' supportive networks. Furthermore, the lack of autonomy apparent in many African and Asian cultures such as Afghanistan, Iraq, Somalia, Sudan, Sri-Lanka and India may make women's decision-making relating to sexuality after cancer difficult, affecting decisions such as when to engage in sexual intercourse or family planning (Metusela *et al.* 2017). The taboo nature of sexuality can make it difficult to discuss sexual concerns in the presence of a partner or family member, which undoubtedly makes the provision of HP-led sexual support more challenging.



This section has demonstrated the range of physical and psychosocial treatment-related effects which are experienced by patients across tumour groups when diagnosed with cancer and having treatment. It is evident that these effects are not limited to 'sexual cancers' but have been demonstrated to be a challenge for people with other cancers, including HNC and colorectal cancer. The type and location of the surgical intervention or treatment often has a bearing on the type and severity of the challenge faced. For many, the experience of these challenges will improve with time, however, for others they may present later and persist for many years. Not all patients regard these issues as bothersome, with some more accepting of the changes affecting sexuality. For some patients the treatment changes indicate a relief at knowing that there is less risk of cancer in the future. Given the challenges faced by patients and partners it is important to consider what is expected of HPs in relation to providing sexual support.

### 3.1.3 What do healthcare guidelines recommend in relation to the provision of sexual support for patients with cancer and partners across cancer care?

More recent healthcare guidelines have provided clarity to the HP's role, regarding the provision of sexual support in cancer care. The American Society of Clinical Oncology recommended that HPs initiate the provision of sexual support for patients (and partners if the patient does so wish). This includes addressing the physical and psychosocial challenges that patients face across the treatment trajectory and by providing access to resources or referral information for the patient and partner (Carter *et al.* 2018). Similarly, guidelines in Australia and the UK have supported this position (NHS 2016; Cancer Australia 2019). Specific tumour group guidelines within the UK developed by the National Institute for Health and Care Excellence (NICE), have addressed sexual support across several tumour groups including colorectal, prostate and ovarian cancer (NICE 2011, NICE 2019, NICE 2020). The provision of sexual support is omitted from the breast cancer care guidelines, although they do recommend that support is provided for women

experiencing menopausal symptoms and infertility (NICE 2002, 2009, 2018). Absent within NICE guidelines for HNC management is the recommendation of sexual support for this tumour population (NICE 2004); this seems a significant oversight given the considerable sexual challenges experienced by these patients and partners.

#### 3.1.4 Prevalence of sexual support needs of patients with cancer and their partners

The literature clearly demonstrates that most patients with cancer need sexual support and points to the majority of patients with cancer across many age groups and partners placing importance on receiving sexual support and information from HPs routinely across the treatment trajectory (Albers *et al.* 2020a; 2020b). Patient interest in receiving sexual support is evidenced by Flynn *et al.* (2012) in their large survey (n=819) of patients, across a range of tumour groups, who reported that 78% of patients would welcome sexual support. Similar findings have been reported in studies within smaller heterogeneous tumour populations (Sporn *et al.* 2015) and across studies that are tumour specific (Downing *et al.* 2019). For example, 62% and 60-70% of patients with gynaecological and breast cancer respectively wanted to receive sexual support (Ussher *et al.* 2013; Den Ouden *et al.* 2019; Hubbs *et al.* 2019). When looking at cancer groups that were not gender specific, that is, not breast, prostate or gynaecological, Hautamäki-Lamminen *et al.*'s (2013) Finnish study of 177 patients with a range of tumours which included, gastrointestinal, lymphoma, respiratory cancer, brain, skin, kidney did not find differences in how patients ranked the importance of receiving sexuality related information. When breast, gynaecological and prostate cancers were included in the analysis (n=505), men with prostate cancer ranked access to sexuality-related information more important than patients with other cancer type. This identifies the importance placed on receiving sexual support across all tumour groups.

The discussion of sexual support with an HP can present as a challenge for some patients, as also illustrated in the above studies, however there is evidence that patients can manage initial shock of the HP raising the topic and benefit from the sexual wellbeing discussion. A study which investigated patients' feelings about their general practitioner (GP) discussing sexuality, found that most patients reported that they were able to overcome the surprise of the topic by giving it a medical or contextual meaning (Zéler and Troadec 2020). They achieved this by attributing the discussion as related to their medical history, or enquiry into sexual experiences was the role of the GP. Some patients conveyed that the discussion strengthened the patient/GP relationship and 81% of patients expressed the wish for sexual assessment to be an integral part of their GP patient consultation (Zéler and Troadec 2020). Patients have reported that the provision of sexual support helped them to make informed treatment choices, reduce risk, normalise the treatment effects on sexuality experienced, facilitate sexual rehabilitation, reduce sexual distress and promote psychosocial adjustment (Laurence and Rousset-Joblonski 2012; Hanly *et al.* 2014; Canzona *et al.* 2016; Reese *et al.* 2017a; Walker *et al.* 2021a).

The literature has identified that sexual support is highly individualised and complex and cannot be perceived as a 'one size fits all'. When demographic characteristics are examined, such as gender and age as potential factors that influence individual's wish for sexual support, it would appear from two large-scale studies, with mixed cancer populations (n=819; n=4349) that men and younger participants placed greater value and were more willing to discuss sexual concerns than women and older patients (Flynn *et al.* 2012; Charif *et al.* 2016a). Such findings were echoed, in part, in the aforementioned Finnish study, which reported that men ranked sexual support higher than women, but there was no statistical difference in interest in receiving sexual support across age groups (Hautamäki-Lamminen *et al.* 2013). These findings may be explained by these studies

having a high proportion of men with prostate cancer, who often have significantly higher rates of sexual dysfunction following treatment, with a propensity to rank access to sexuality-related information higher than other tumour groups (Hautamäki-Lamminen *et al.* 2013). Furthermore, a recent study of culturally diverse women (n=144) surveyed from a breast cancer outpatient clinic, identified that women who sought help for sexual concerns were younger, more likely to be partnered and sexually active (Reese *et al.* 2020). Whereas those not seeking help and those who sought help from outlets other than HPs such as a partner, family and/or friends, had significantly lower self-efficacy which related to their confidence levels to talk or ask about sexual concerns (Reese *et al.* 2020). Furthermore, Ussher *et al.* (2013) reported from their study of Australian women with breast cancer (n=1965) that most often they had not spoken to anyone about the changes to their sexuality after cancer. The most common reasons given by 1323 participants were that the women often preferred to discuss sexual problems with their partner (38%), they felt embarrassment (36%), tried to cope on their own (32%), were unaware of how anyone could help (32%) and believed sex was a private matter (23%) (Ussher *et al.* 2013). These findings echo other studies which have highlighted that women perceive there to be little value to raising sexual concerns due to a lack of awareness of efficacious treatment methods (Charif *et al.* 2016b; Reese *et al.* 2017b). However, there are many support options available for women to promote coping with sexual challenges, with an evidence-base rapidly growing (Reese *et al.* 2017b) with research suggesting a need to gain a better understanding of patient concerns and how best to address them.

Many partners wish to be included in the provision of sexual support (Traa *et al.* 2014; Vermeer *et al.* 2016; Albers *et al.* 2020b; 2020c), which many patients are in favour of, as it is believed this would help to open future communication about sexual concerns with their partner (Flynn *et al.* 2012; Leonardi-Warren *et al.* 2016; Abbott-Anderson *et al.* 2019;

Den Ouden *et al.* 2019; Albers *et al.* 2020c). However, for some patients as identified in a qualitative Dutch study with patients with cervical cancer (n=30) there may be a reluctance for sexual support to be offered in the presence of their partners as it may make it more difficult for them to articulate their concerns (Vermeer *et al.* 2016) or there may be potential for a negative impact on the patient's relationship. Furthermore, as mentioned earlier, there are cultural variations as to how cancer could potentially negatively impact intimate relationship, of which HPs should be cognisant. Bamidele *et al.* (2019) reported that black African and black Caribbean men from their UK-based study did not wish for their partners to be informed of their diagnosis or included in consultations, because of fears about how such knowledge of sexual challenges may cause problems within their relationship, with concerns that a partner may leave the relationship.

Variability in partners desire for sexual support was further illustrated by Gilbert *et al.* (2016), with a large study population of patients (n=657), across a range of cancers and their partners (n=148). This study indicated that male partners of women with cancer had a greater reluctance to seek help than female partners of men with cancer. This may be explained by an increased likelihood that sexual intercourse continued when the woman was the patient, despite pain or absence of desire (Gilbert *et al.* 2016; Tracy *et al.* 2016), resulting in less support needs for some male partners (Hawkins *et al.* 2009). Conversely, it may be that male partners in these studies were more acceptant of the sexual changes faced and adjusted more easily. Despite this, Albers *et al.* (2020c) reported that partners (n=76) of women with breast cancer aged 33-79 years who had received a range of treatments, recommended that sexual support should be provided routinely to partners, with only a minority disagreeing (22.7%). These studies have identified that the wish for sexual support from partners also appears to be variable; it is often confounded too, as partners are not always included in the consultation or in attendance at appointments

(Forbat *et al.* 2012; Albers *et al.* 2020c). Furthermore, in some relationships, partners may be in denial about the cancer diagnosis and to cope try to distance their thoughts from it (Olson 2011), while other partners may not be supportive due to pre-existing relationship difficulties or personal health concerns (Sawin 2012).

Having highlighted many unique complexities associated with the desire for sexual support for patients with cancer and their partners, nonetheless, a sentiment echoed through many studies, is the need for individualised support as a standard part of care (Traa *et al.* 2014; Canzona *et al.* 2016; Reese *et al.* 2017a; Albers *et al.* 2020b).

#### 3.1.5 Current provision of sexual support in cancer care

Professional standards (General Medical Council 2013; Medical Board of Australia 2014; Nursing and Midwifery Council 2015;) outline that HPs should prioritise the care of patients, ensure professional knowledge and skills are up-to-date, adequately assess and promptly provide or arrange suitable advice, investigation and treatment and take steps to alleviate pain and distress. However, research extensively reports that sexual challenges resulting from a cancer diagnosis and or treatment, are not routinely addressed by HPs (Lindau *et al.* 2011; Zeng *et al.* 2011; Zeng *et al.* 2012; Oskay *et al.* 2014; Ferreira *et al.* 2015; Vermeer *et al.* 2016; Canzona *et al.* 2016; Reese *et al.* 2019b, Albers *et al.* 2020a; 2020b). Illustrating this, Oskay *et al.* (2014) study of 87 nurses within Turkish oncology departments reported that the majority (87%) of nurses agreed it was their responsibility to provide sexual support, yet 88.5% did not perform any sexual care assessment. A similar level of sexual support provision was demonstrated in a multi-centred, Chinese study of nurses (n=202) working in gynaecological cancers units, with nearly 80% of nurses never, rarely, or occasionally addressing patient's sexuality concerns or making referrals to counselling services (Zeng *et al.* 2012).

A recent systematic review has provided a wider representation of the prevalence of sexual support for patients with cancer (Reese *et al.* 2017b). This review included 29 studies, many of which were from Western countries (n=24), examining both patient and HP perspectives on accessing and delivering sexual support. From both the patient and HPs viewpoints, the findings illustrated that HPs more readily provide sexual support when discussing the potential impact of treatment on sexual dysfunction, rather than assessing sexual problems or addressing them following treatment. This is evident from patient data, which demonstrated that 50% of HPs provided information on the potential impact of cancer treatment on sexual dysfunction but only 22% of HPs addressed sexual concerns. HP data mirrored this trend, with higher levels of HPs reporting the provision of information, but lower levels addressing sexual concerns (88% vs 17%). This may be due to the perceived complexities in assessing and addressing sexual challenges when they arise (Reese *et al.* 2017b). These discrepancies between patient and HP data on the degree of support provided may be attributed to the use of self-reported data (with different data collection approaches used for patients and HPs); and some studies relying on participants recalling their experiences of receiving sexual support over an extended period (Reese *et al.* 2017b). Moreover, findings from a large multi-centre study of men (n=35823) with prostate cancer in the UK, a group who are much more likely to receive sexual support, demonstrated that despite 80% of men experiencing sexual difficulties, 55.8% were not offered interventions or support for the sexual dysfunction they encountered (Downing *et al.* 2019). Similarly, in a recent study of n=64 breast cancer survivors, 71.9% of patients declared they were not adequately informed about the side effects of treatments on sexuality (Di Mattei *et al.* 2020). These findings are of particular note, given that these two tumour groups are considered 'sexual cancers' and are more likely than other tumour groups to report receipt of sexual support (Gilbert *et al.* 2016). Most recently, Aptecar *et al.*'s (2021) prospective study of n=103 women with breast cancer receiving hormonal treatment over a 12-month period, identified a low sexual

satisfaction at baseline, yet poor HP communication about sexuality. Twelve months later, although there was an improvement in HP communication related to sexual challenges, this was still at a low level. The literature identifies a need for enhanced communication between HPs and patients to address the current gap in sexual care for patients with cancer and their partners. These findings have demonstrated a significant unmet need for patients and partners worldwide. Given this, it is important to understand the barriers which have prevented patients and partners receiving sexual support.

### 3.1.6 What are the perceived barriers to HPs providing sexual support in cancer care?

In the last 10 years, there have been several systematic reviews and literature reviews on the barriers to the provision of sexual support in cancer care (Dyer and das Nair 2013; Wang *et al.* 2018; Reese *et al.* 2017b; Vassão *et al.* 2018; O'Connor *et al.* 2019; Papadopoulou *et al.* 2019). These reviews identified many factors impinging on the provision of sexual support, including personal and societal factors, patient characteristics and those at organisational level such as strategy, policy, or funding. The next sections focus specifically on the key barriers affecting the provision of sexual support.

#### **3.1.6.1 Personal and societal factors affecting HPs routine provision of sexual support**

Prominent within the literature, HP barriers to the provision of sexual support are personal embarrassment, discomfort and fears of causing offence (Fitch *et al.* 2013; Moore *et al.* 2013; Mansour and Mohamed 2015). Even for HPs who provided sexual support as part of gynaecological cancer care, sexuality was considered a taboo subject (Vermeer *et al.* 2015). For many HPs from China, Canada and Ireland, sexuality was viewed as private, personal and complex (Zeng *et al.* 2012; Fitch *et al.* 2013; Moore *et al.* 2013). For others in Sweden and Brazil, sexuality was considered as something that older people do not discuss (Olsson *et al.* 2012; Vieira *et al.* 2013). While studies identified sexuality as 'too private', Zeng *et al.* (2011) argued that this is more apparent within



conservative cultures like that of Chinese culture based on Confucian philosophy, where sexuality is viewed for the purpose of procreation with any discussion of sexual issues outside of marriage considered to be highly inappropriate (Khoo 2009). Afiyanti (2017) corroborates this viewpoint, reporting that over 85% of Indonesian nurses in their study viewed sexuality as private and taboo. Despite this, many nurses in this study did report making time to discuss sexual concerns with patients (63.3%), which starkly contrasts with Zeng *et al.* (2011) Chinese study, where 77.9% did not make time to discuss sexual concerns. Although both cultures are considered conservative (Woo *et al.* 2009; Khoo 2009; Oetomo and Boellstorff 2014) and the studies reported that education and training on talking about sexuality with patients was not part of their nursing curriculum, nurses within the Afiyanti (2017) study reported greater levels of confidence (68.9%) when compared to Zeng *et al.* (2011) study (30.7%). The reasons for disparities in levels of confidence are not clear especially given the similar cultural backgrounds and lack of education, however nurses from the Afiyanti (2017) study had more year's clinical experience. Other studies have identified less clinical experience as a barrier in the provision of sexual support which may explain the contrast (Oskay *et al.* 2014; Krouwel *et al.* 2015b).

HPs who are younger, with less experience, report that they provide less sexual support to patients with cancer and their partners and experience higher levels of discomfort discussing sexual concerns (Zeng *et al.* 2011; Zeng *et al.* 2012; Oskay *et al.* 2014, Krouwel *et al.* 2015b). This premise was supported by Krouwel *et al.* (2015b) who noted that Dutch nurses who were over 44 years old, with greater than 10 years in oncology practice, discussed sexual concerns with patients significantly more often compared to younger nurses. Numerous other nursing studies have echoed these findings, reporting that older and more experienced oncology nurses are more likely to discuss sexual concerns with their cancer patients (Zeng *et al.* 2011; Zeng *et al.* 2012; Oskay *et al.* 2014). What is clearer

from the current body of literature, is that greater levels of discomfort in providing sexual support is associated with HPs who have less clinical experience. The literature also notes that HPs working in cancer care with less than 10 years clinical experience are more likely to report a 'lack of time' as a barrier to providing sexual support (Huang *et al.* 2013; Krouwel *et al.* 2020). This could indicate a link between those HPs who perceive there is a lack of time to discuss sexual concerns with those experiencing a greater degree of discomfort in providing support, however this would need to be investigated.

Evidence has suggested that HPs find some aspects of sexual support more comfortable to discuss than others. Moore *et al.* (2013) surveyed 89 HPs who supported men with testicular cancer and discovered greater comfort discussing the impact of treatment on sexuality and addressing fertility concerns; but more discomfort when discussing the specific impact of impotence, ejaculatory and erectile difficulties. Many HPs in that study indicated that their discomfort was a result of a lack of knowledge in this area. Although Canzona *et al.*'s (2016) qualitative study of n=40 HPs and n=40 patients with breast cancer identified differing perspectives with regards to HP levels of discomfort when exploring factors that mitigated the provision of sexual support in cancer care. They reported that evidence of HP discomfort was largely absent from the HP's transcripts, however, patients in the study reported that they perceived HPs to be uncomfortable through nonverbal cues or the HP shifting the conversation away from sexuality. The authors suggest that HPs may be unaware of the impact of their behaviours (Canzona *et al.* 2016), but this may point more to the tension between HPs experiencing discomfort and HPs viewing the topic as important and within the remit of their role to provide sexual support.

### **3.1.6.2 Patient specific characteristics which HPs perceive as barriers to providing sexual support**

Further to the personal and societal barriers, HPs reported significant patient-related barriers to the provision of sexual support, including fear of patient embarrassment, phase of care, the specific illness, the likely patient perceptions and difference in characteristics between the HP and patient (Moore *et al.* 2013; O'Connor *et al.* 2019). The fear of causing the patient embarrassment was found to be as significant as personal embarrassment for the HP, with one study identifying that some HPs reported that this fear was reflective of their own personal embarrassment (Olsson *et al.* 2012). This Swedish study of 10 HPs who provided care for patients from mixed tumour groups at various points on their treatment trajectory, identified HP concerns that patients who were in active treatment phases or who they considered 'too ill', would question the HPs treatment priorities if they were to begin to explore patients' sexual concerns. This was a sentiment echoed in other studies, where HPs felt that talking about sexual concerns could be viewed as taking attention away from treatment or curing the disease (Fitch *et al.* 2013; Frederick *et al.* 2019a). Some HPs from a variety of disciplines and tumour groups identified within a qualitative Australian study, viewed patients who were single, older or have a non-reproductive cancer to be 'asexual', 'disinterested in sex' or sexual support to be 'irrelevant' (Ussher *et al.* 2013). Other HPs, similarly, from a range of disciplines and tumour groups, expressed concerns about how a patient may react to the topic being raised, particularly LGB & T patients or those who have a non-reproductive cancer; with HPs reporting fears of such discussion being viewed by patients as inappropriate, being perceived as an infringement of privacy (Ussher *et al.* 2013; Moore *et al.* 2013; Williams *et al.* 2017). Furthermore, Moore *et al.* (2013) study of 89 Irish nurses comfort related to discussing sexuality concerns with men diagnosed with testicular cancer identified several potential patient related barriers. These included patients with a mental health problem (46%) and patients who differed from the

attending HP in terms of culture (29%), religion (27%), age group (23%) or gender (21%), although there were many in this study who disagreed with these latter barriers (40-60%).

### **3.1.6.3 Professional and organisational factors influencing the provision of routine sexual support**

The reviews which examined barriers to providing sexual support in cancer care found an extensive number of factors which were related to professional and organisational factors (Dyer and das Nair 2013; Reese *et al.* 2017b; Wang *et al.* 2018; Vassão *et al.* 2018; O'Connor *et al.* 2019; Papadopoulou *et al.* 2019). The professional factors included HPs lack of awareness of the sexual challenges faced by patients and role uncertainty relating to providing sexual support in cancer care.

HPs frequently reported a lack of knowledge of the sexual challenges faced by patients and their partners and strategies which could offer support (Huang *et al.* 2013; Mansour and Mohamed 2015; Krouwel *et al.* 2015b; Bedell *et al.* 2017; Lynch *et al.* 2018; Wright *et al.* 2018). These studies reflected that the lack of knowledge is an issue across HP roles, including nurses, surgeons, oncologists, radiotherapists and other roles. Bedell *et al.* (2017) surveyed 124 HPs, most of whom were oncologists working with patients with cervical cancer who were trained in the US (90%), however, only 29% of HPs had previously received education on sexual dysfunction. Both those HPs who had received previous training (72%) and those who had not (72%) identified interest in receiving education about the treatment-related effects on cervical cancer. Unfortunately, most of the studies in this area do not investigate HPs' prior engagement in sexual awareness, education and training programmes; therefore, it is difficult to ascertain whether education and training have had minimal impact or whether there has been a gap in accessing training on this aspect of care. However, when HPs access education and training, findings have often demonstrated increases in self-reported knowledge,

although the provision of sexual support provided for patients and their partners remains low (Jonsdottir *et al.* 2016). The impact of sexual wellbeing education interventions in cancer care is reported in Section 3.1.7.3. These studies do not always detail the theoretical basis for their educational intervention to enable inquiry into whether the intervention was flawed or there were external influencing factors such as workplace culture affecting the implementation of the intervention. Although in contrast of these findings, Almont *et al.* (2019b), reported that HPs from a mix of disciplines with greater knowledge of sexuality after cancer did provide higher levels of sexual support. Some caution should be given to this finding, as HPs in their study had intensive training to national diploma level in sexology, which probably led to greater confidence in this area.

A minority of HPs, again from a range of locations, Netherlands, Iceland and Wales, expressed that providing sexual support was not their role or may position this as the role of another HPs (Krouwel *et al.* 2015a; Jonsdottir *et al.* 2016; Gleeson and Hazell 2017). Studies have identified that HPs view of their role in providing sexual support was at times, related to a narrow understanding of holistic care (Zeng *et al.* 2012; Ussher *et al.* 2013; Frederick *et al.* 2019a). An earlier study demonstrated this problem, in which it was reported that those HPs who struggled to define the breadth of sexuality, were less likely to provide sexual support to patients (Lavin and Hyde 2006). On the other hand, HPs who have a broader definition of intimacy and relationships may use this as a rationale to avoid engaging patients in sexual support conversations about the functional aspects of sexuality (Olsson *et al.* 2012). More recent studies in the Netherlands, have identified commonality in the views of doctors and radiotherapists who are less likely to regard the provision of sexual support as their role when compared to nurses (Krouwel *et al.* 2015a; Krouwel *et al.* 2015b). This viewpoint is also more commonly held in primary rather than secondary care (Gleeson and Hazell 2017). Further to the uncertainty of whether it is the HP's role to provide sexual support is a lack of clarity on which member(s) of the multi-

disciplinary team should provide this support. This is illustrated through a series of studies in the Netherlands led by Krouwel *et al.* (2015a; 2015b; 2020), which considered the frequency of differing HP roles provision of information on possible treatment-related effects on sexuality. In these studies, 17.9% of medical oncologists reported discussing sexual function with at least half of their patients daily (Krouwel *et al.* 2020), while surgical oncologists report this to be 19% (Krouwel *et al.* 2015a) and nurses 48.5% (Krouwel *et al.* 2015b). The lower rate of sexual support provided by medical oncologists may be explained by their view that although they had responsibility to address concerns, that this responsibility was shared with nursing colleagues. Moreover, some believed it should be the patient that identifies the need for sexual support (Krouwel *et al.* 2020). On the other hand, the higher rates of nurses providing sexual support may be related to nurses holding a view that oncologists would not regularly provide sexual support, nor would patients raise the topic (Krouwel *et al.* 2015b) and a viewpoint that patients may prefer to discuss this aspect of care with a nurse (Albers *et al.* 2020a; 2020c). In contrast, Oskay *et al.* (2014) reported that from 87 oncology nurses in a Turkish study, all HPs recognised that patients with cancer experience sexual problems and most of those surveyed considered the provision of sexual support as part of their role (87%), but only 11.5% of HPs evaluated the sexual concerns of patients. Many nurses in this study (67%) stated the responsibility to initiate sexual support lay with the doctor or the patient. It would appear that the uncertainty about who will provide sexual support, increases the likelihood that patients will have unmet sexual support needs.

Organisational factors influencing the provision of sexual support include a lack of time to address sexual concerns, a lack of private space for sensitive conversations and HPs' perceptions of workplace culture on the acceptability of providing sexual support. For some HPs, discussing patient and partner sexual concerns can be viewed as disorganising and elongating the clinical appointment. This is important given the large numbers of

patients seen at most routine cancer review clinics (Fitch *et al.* 2013; Depke and Ontilio 2015; Ferreira *et al.* 2015; Williams *et al.* 2017; Benoot *et al.* 2018; Canzona *et al.* 2018). Canzona *et al.* (2018) described how time pressures precluded multidisciplinary HPs in an American study from adequately addressing sexual concerns for breast cancer patients due to a predominant focus on addressing success of cancer treatment or acute treatment-related toxicities. When under time constraints, HPs report the need to prioritise what they discussed with patients, with the result that sexual support is often side-lined.

HPs have reported how care delivery involving sensitive communication in shared workspaces, can restrict the discussion of sexual concerns (Hautamäki-Lamminen *et al.* 2013; Ussher *et al.* 2013; Ferreira *et al.* 2015). Ferreira *et al.* (2015) identified from a study in a hospital in Sao Paulo, Brazil that the lack of private space acts as an obstacle preventing HPs from raising the topic and HPs perceive that the lack of privacy patients from talking freely about sexual concerns. They described nurses providing advice and support in a ward environment with many other people present. This coupled with the discomfort around the topic could further prevent the provision of sexual support. In addition, HPs reported the presence of a family member or friend as limiting or curtailing the discussion of sexual concerns with patients, with HPs viewing it as not an appropriate time to bring sexual concerns up and opting to potentially discuss these at a future appointment instead (Ussher *et al.* 2013). For some HPs from multi-disciplinary backgrounds providing care across a range of tumour groups, the presence of the partner also inhibited the discussion with HPs citing the need to get prior permission to raise the subject with the patient (Moore *et al.* 2013; Ussher *et al.* 2013).

Although not reported as a major barrier, some studies alluded to a perceived workplace culture, that deemed it inappropriate to routinely provide sexual support for patients with

cancer and their partners. Mansour and Mohamed (2015) reported 63.9% of oncology nurses in an Egyptian hospital setting who provided care to women with gynaecological cancer presumed that colleagues may have a negative reaction to them providing sexual support. This may be indicative of the cultural setting as the authors describe Egypt as a place where sexuality is a taboo in the family and education system, synonymous with shame and guilt (Mansour and Mohamed 2015). Further studies have investigated this, identifying concern for colleagues' perceptions of impinging on patient privacy (Moore *et al.* 2013; Leonardi-Warren *et al.* 2016). The perceived lack of support within healthcare teams needs to be addressed from a leadership perspective (Moore *et al.* 2013). The lack of availability of support resources and formalised care pathways for patients may perpetuate this culture, facilitating the absolution of responsibility to provide support (Ussher *et al.* 2013; Oskay *et al.* 2014; Traa *et al.* 2014; Mansour and Mohamed *et al.* 2015; Frederick *et al.* 2018). Such normative beliefs could have a major impact on HPs intention to provide sexual support in cancer care (Ajzen 1985).

The literature has demonstrated a substantial range of barriers relating to personal and societal factors, patient characteristics, organisational and professional factors which need to be addressed to facilitate the routine provision of sexual support in cancer care. From this evidence, it is clear that HPs across many cultures and contexts face similar barriers. Alongside the identification of these barriers, these reviews have also examined what HPs have perceived would facilitate the provision of sexual support with patients and partners. The next section provides an overview of potential facilitators to the provision of HP-led sexual support and explores their impact within the literature. This informed the rationale for the approach taken to address the lack of provision of sexual support in cancer care in this current study.



### 3.1.7 What are the perceived facilitators to HP-led provision of sexual support in cancer care?

Previous research has established the key facilitators that HPs perceive would help them to overcome the barriers to providing sexual support in cancer care. Throughout the literature four predominant facilitators are identified by HPs. The first of these is the provision of education and training (Albers *et al.* 2020a). Education and training should be directed towards increasing HPs knowledge of sexual concerns for patients and partners and strategies to address them, while challenging attitudes and increasing self-efficacy to provide sexual support (Moore *et al.* 2013; Mansour and Mohamed 2015; Canzona *et al.* 2018; Albers *et al.* 2020b). This is discussed in more detail in the next section (3.1.7.1). Second, HPs identified the need for a framework or model to tailor communication, assessment and interventions in relation to patient (and partners) sexual concerns (Frederick *et al.* 2018). Further considerations of existing frameworks are provided in Section 3.1.7.2, which is followed by a critique of interventions which combine education and a communication model. Third, HPs require support resources which can further inform patients about how treatment could impact on their sexual wellbeing, normalise the potential treatment-related effects of cancer on sexuality and provide strategies to help to manage these effects (Fitch *et al.* 2013; Vermeer *et al.* 2015; Albers *et al.* 2020a). These support resources should be tailored to the cancer type and treatment the patient is receiving (Fitch *et al.* 2013; Vermeer *et al.* 2015). HP studies have suggested that these support resources could assist patients beyond their appointment and act as a tool for patients to have conversations with their partner (Fitch *et al.* 2013; Traa *et al.* 2014; Vermeer *et al.* 2015; Leonardi-Warren *et al.* 2016; Gleeson and Hazell 2017; Frederick *et al.* 2019a). The main consensus within the literature is for written resources (Fitch *et al.* 2013; Gleeson and Hazell 2017), however, some HPs have suggested the benefit of online resources (Fitch *et al.* 2013). HPs in the Fitch *et al.* (2013) Canadian study of multidisciplinary HPs (n=34), although mainly doctors (n=11) and nurses (n=12),

identified that the supportive resources could be used both to focus a conversation with a patient as well as providing patients with important take-home information. Due to the COVID-19 pandemic, a large proportion of patient consultations have been conducted remotely and failure to adapt to provide educational material remotely could negatively impact patients with cancer and their partners and disease management (Turkdogan *et al.* 2021). Finally, HPs advocate for knowledge of and access to referral pathways (Fitch *et al.* 2013; Traa *et al.* 2014; Gleeson and Hazell 2017; Williams *et al.* 2017; Frederick *et al.* 2019a). Referral pathways to specialist services dealing with challenges such as ED, or vaginal pain could maximise the specialist sexual support available for patients with cancer and their partners, while encouraging HPs across cancer care to assess the need for sexual support (de Vocht *et al.* 2011; Papadopoulou *et al.* 2019).

#### **3.1.7.1 Education and training**

Although the provision of education and training is often reported as being key to supporting HPs address sexual concerns in cancer care, there is a lack of detail on the specific elements required (Papadopoulou *et al.* 2019). HPs perceive that increases in knowledge, through the access to education and training, could have a positive effect on the provision of sexual support in cancer care (Moore *et al.* 2013; Mansour and Mohamed 2015; Canzona *et al.* 2018). Indeed, HPs with more self-reported knowledge have been found to discuss sexual function more often (Almont *et al.* 2019b; Krouwel *et al.* 2020). Almont *et al.* (2019b) have suggested that to improve the efficacy of education and training, interventions need to be specific to the sexual issues relating to cancer care. Their study of 165 HPs in across a range of HP roles in all French regions, examined practices, attitude and knowledge of HPs in oncology following completion of an intense training programme in generic sexology and concluded that more tailored education focused to cancer care was required. Fitch *et al.*'s (2013) study of Canadian multi-disciplinary HPs (n=34) working across tumour groups indicated that education should

help HPs to identify specific sexual issues concerning patients and provide opportunities for HPs to role play practical aspects of care. Others have described a need for education and training to equip HPs, through knowledge and communication skill development to enable HPs to discuss the potential treatment-related effects and management strategies relating to sexual functioning (Krouwel *et al.* 2015a, 2015b, 2020; Vermeer *et al.* 2015; Canzona *et al.* 2018; Lynch *et al.* 2019; Frederick *et al.* 2019a). HPs within these studies focused on education related to the physical effects of sexual functioning and less on other psychosocial issues, such as body image. Training needs to be broader than physical issues alone, as is evident within the earlier parts of this chapter, patients struggle with psychosocial needs related to sexual loss or relationship dynamics and require support for the difficulties they experience adjusting to these (McClelland *et al.* 2016; Boquiren *et al.* 2016).

Furthermore, there is a need to couple education with training to promote good communications skills. This could facilitate HPs to establish a rapport with patients when providing sexual support (Canzona *et al.* 2018), a key priority identified by HPs providing care to patients with breast cancer who view rapport as important to alleviate potential patient discomfort around sexuality. Moreover, a qualitative study of 17 nurses providing support to women with gynaecological cancer in Australia highlighted the need for enhanced confidence to communicate well about sexual concerns (Williams *et al.* 2017). The study concluded suggesting the need for training strategies such as peer mentoring and opportunities to observe colleagues in practice as advantageous (Williams *et al.* 2017). Such strategies can work to build confidence, which is in keeping with an established body of evidence on the benefits of role modelling and experiential learning for other cancer related topics (Kurtz and Cooke 2017).

### **3.1.7.2 Models to guide provision of sexual support**

In conjunction with education and training, HPs have suggested that models to guide communication, assessment and interventions to address sexual concerns would help with the delivery of sexual support in routine practice (Gleeson and Hazell 2017; Canzona *et al.* 2018). One study which surveyed 121 HPs in Wales, including nurses, doctors, healthcare support workers, surgeons and AHPs, reported that approximately half the HPs in secondary care and one-third in primary care had perceived significant benefit to utilising an assessment model to guide sexual wellbeing care (Gleeson and Hazell 2017). Despite, the perceived benefit of an assessment model to guide sexual support in clinical practice, over 80% of HPs in their study did not use any model in practice (Gleeson and Hazell 2017). Furthermore, following assessment, HPs require a model to facilitate the provision of tailored advice and information to patients and their partners.

The literature describes a range of models, developed over the last 50 years, which have been depicted as helpful to both assess and provide sexual support. There are four popularly cited models which offer support to HPs in terms of both assessing and addressing sexual concerns (PLISSIT, BETTER, Ex-PLISSIT and Five A's) spanning three decades, from the 1970s to 2000s; followed by two more recent models in the past five years (CARD and EASSi). Table 4 presents an overview of these models, which is followed by a discussion of these models.

**Table 4: Models for HPs to guide communication, assessment and interventions on sexual concerns with patients and partners in cancer care**

<b>Name/Author</b>	<b>Main components</b>
<b>PLISSIT (Annon 1976)</b>	Permission, Limited Information Specific Suggestions Intensive Therapy
<b>BETTER (Mick and Cohen 2003)</b>	Bringing up the topic Explain importance of sexuality Tell patient about resources/access Timing Educating the patient about side effects of treatment and Record
<b>Five A's Model (Whitlock <i>et al.</i> 2002)</b>	Assess Advise Agree Assist and Arrange
<b>Ex-PLISSIT (Davis &amp; Taylor 2006)</b>	Uses the 4 themes from PLISSIT with each stage now supported with permission giving and self-reflection
<b>CARD (Wang <i>et al.</i> 2015)</b>	Initiating conversation about Cancer and sexual wellbeing Assessing concerns Referrals and resources Documenting conversation
<b>EASSi (McCaughan <i>et al.</i> 2020)</b>	Engagement Assessment Support Signposting

The PLISSIT model has 4 distinctive stages: permission giving (P), limited information (LI), specific suggestions (SS) and intensive therapy (IT). The initial phase of permission-giving involves HPs initiating the conversation, by doing so they are communicating that it is normal to discuss sexual concerns. Some HPs have misinterpreted this first stage and have viewed this as seeking permission from the patient to discuss sexual concerns (Davis and Taylor 2006). This was not Annon's intention; permission giving was instead an activity undertaken by the HP (Annon 1976). The model is based on the premise that HPs should be able to offer brief sexual support to many patients in the early stages of the model, with fewer patients then requiring specialist support which is provided in the latter

phases of the model (Annon 1981). PLISSIT was developed in the 1970s, however, this model has been further progressed through a more participative approach with patients, with the revised version known as Ex-PLISSIT (Taylor and Davis 2007). This updated model provides greater flexibility, moving away from its previous linear model. The Ex-PLISSIT model features permission-giving as a common thread throughout each stage and encourages reflective practice. The model permits the HP to move patients straight to intensive therapy or onward referral for complex issues rather than working through brief intervention stages unnecessarily. This element has allowed the model to be more responsive to need. Mick and Cohen (2003) developed 'BETTER', a model primarily for a cancer setting. The literature has provided descriptive accounts, which outline its framework, however there is no detailed information on the rationale or evidence base for its components or evaluation findings from the HPs perspective. Finally, 'Five A's' is a stepped care model for HPs to use to support patients with behaviour change. This model has been used successfully across many health conditions and settings (Sim *et al.* 2009), having originated with smoking cessation (Fiore *et al.* 2008). More recently this model has received attention as good practice for those addressing sexual wellbeing with patients after cancer within a primary care setting (Zhou *et al.* 2015). However, studies with other health conditions have found HPs focus on the initial steps, by merely raising the issues but do not adequately address the issues or refer on (Simmons *et al.* 2012; Martínez *et al.* 2017). Adopting such a model would be counter intuitive as it would be unhelpful to identify such concerns resulting from disease or treatment and not provide the necessary support to address these sexual difficulties.

Despite these models being developed since the 1970s, there is a lack of clear evidence as to why they have not been implemented into routine clinical practice, even with numerous intervention studies detailing positive outcomes for patients when used (Ayaz and Kubilay 2009; Rostamkhani *et al.* 2012; Farnam *et al.* 2014; Perz and Ussher 2015;

Saboula and Shahin 2015; Khakbazan *et al.* 2016; Faghani and Ghaffari 2016; Daneshfar *et al.* 2017; Demir and Aslan 2018; Asadi *et al.* 2018). An obvious gap in the literature, which may help to address lack of implementation in practice is the paucity of studies capturing the HPs' view of using the models. One qualitative study of 14 nurse participants working in a mental health hospital setting in Australia, was identified, which assessed HPs views on using the BETTER model (Quinn *et al.* 2012; 2013a; 2013b). Their study demonstrated that HPs did not adhere strictly to its framework and although HPs felt the model provided some structure, they recounted that attendance at the training session was the primary factor in improving the provision of sexual support.

More recently two other models have been introduced and evaluated from an oncology HP perspective, namely, CARD (Wang *et al.* 2015) and EASSi (McCaughan *et al.* 2020). Each of these models have taken cognisance that HPs' lack of knowledge of cancer and sexuality issues after cancer was a pivotal barrier to integrating sexual support into routine clinical care. First, the CARD model (Wang *et al.* 2015) was designed to encourage HPs working in breast cancer care, with variable levels of confidence and sexual health knowledge to provide sexual support by: initiating conversations, assessing sexual concerns and patients' comfort to discuss, coordinating care and documenting concerns. This model was evaluated as part of a small pre-post-test intervention study, although the evaluation placed greater focus on the training element of the intervention. The study was subject to high attrition rates (survey 1 n=71, survey 2 n=36). Irrespective of this, the authors reported that the model was well-received by HPs and has been incorporated as a model for sexual health screening by participating breast cancer centres in the United States.

More recently, McCaughan *et al.* (2020) provided a detailed outline of the development of the EASSi conceptual framework to improve sexual wellbeing communication in

prostate cancer care. The Theoretical Domains Framework (French *et al.* 2012) guided its development through a multi-phase process, which included a review of the literature to identify patient needs (Parahoo *et al.* 2013; McCaughan *et al.* 2015; Parahoo *et al.* 2017) and perceived barriers among HPs to providing sexual support (O'Connor *et al.* 2019). Furthermore, the research team engaged many key stakeholders throughout the optimisation and evaluation of the framework (McCaughan *et al.* 2020). The evaluation reported that HPs found the framework valuable to their practice; widening the scope of current supportive conversations by providing a helpful framework to guide conversations, which are sometimes difficult to initiate and sustain (McCaughan *et al.* 2020). While there are other models to assess and address sexual concerns in the literature, this model has adopted a person-centred approach. By promoting a shared conversation to initiate discussions, it provides the opportunity to address barriers to the provision of sexual support and normalise sexual concerns that patients and partners often encounter. The EASSi conceptual framework therefore demonstrates benefits over previous models through robust and transparent planning and development of the intervention. It is underpinned by a theoretical and evidence base and was optimised by key stakeholders through a person-centred approach. Qualitative findings from key stakeholders in prostate cancer care reported EASSi to create an appropriate context to discuss sexual concerns and establish a degree of trust with patients and partners (McCaughan *et al.* 2020). Furthermore, the approach promoted active patient and partner involvement in sexual wellbeing discussions (McCaughan *et al.* 2020).

The models to support HPs communication, through assessment and addressing of sexual concerns, have demonstrated positive effects for patients, experts in the field and HPs working in cancer care, to facilitate the provision of sexual support. Despite this, there is little evidence to suggest that these models are integrated into routine cancer and there is a paucity of research to explain this disconnect. Given HPs reported lack of knowledge



about sexual concerns and strategies to support patient to cope it is now important to consider the impact of the more recently evaluated interventions which have sought to combine education and training with models to support the provision of sexual support in cancer care.

### **3.1.7.3 Education and training combined with a model to guide the provision of sexual support**

The literature describes eight intervention studies which have combined an education and training intervention with a model to guide HP communication, assessment and provision of sexual support to patients and partners (Lee *et al.* 2012; Wang *et al.* 2015; Afiyanti *et al.* 2016; Jonsdottir *et al.* 2016; Merriam *et al.* 2018; Quinn *et al.* 2019; Reese *et al.* 2019a, 2019b; McCaughan *et al.* 2021a). These studies differed significantly on their design, most utilised pre-test and post-test surveys (Wang *et al.* 2015; Afiyanti *et al.* 2016) while one study also reviewed audio from clinical consultations (Reese *et al.* 2019b). The interventions themselves varied significantly in term of timeframe, with some using a brief one-off session (approximately 1-2 hrs) (Wang *et al.* 2015; Reese *et al.* 2019a McCaughan *et al.* 2021a), while others took a more intensive approach over 5 days (Afiyanti *et al.* 2016) or weekly sessions (60-90 mins) over 8 weeks (Quinn *et al.* 2019). Most of the interventions included a communication skills-based element, however, two online interventions provided HP/patient sexual wellbeing consultation demonstrations and identified frameworks to help HPs structure future sexual support conversations (Quinn *et al.* 2019; McCaughan *et al.* 2019a). Furthermore, there were a range of survey instruments used to evaluate these intervention studies. They included versions of the SABS (Reynolds and Magnan 2005), adaptations of a surveys developed by Hautamaki *et al.* (2007) and Horden *et al.* (2009), or self-deployed surveys by study authors. Given the heterogeneity of these studies it is not possible to do a like-for-like comparison, instead this section will provide an overview of key findings.

A key aim of each intervention was to improve HPs knowledge of sexual issues for patients with cancer. In this domain, studies demonstrated a significant impact on self-reported (Lee *et al.* 2012; Wang *et al.* 2015; McCaughan *et al.* 2021a) or assessed levels of knowledge (Afiyanti *et al.* 2016; Merriam *et al.* 2018; Quinn *et al.* 2019) post intervention. Only one of the studies, the evaluation of an eLearning resource for HPs working in prostate cancer, provided a breakdown of mean scores between timepoints and despite statistically significant increases to HPs self-reported knowledge and understanding of sexual issues for patients initially post-intervention, this significance was not maintained 4 weeks post-test (McCaughan *et al.* 2021a). This may demonstrate the need to bolster education to embed learning through opportunities for further discussion, reading material and practice.

Small to medium increases in perceived self-efficacy or professional confidence to provide sexual support were found in some studies (Afiyanti *et al.* 2016; Quinn *et al.* 2019; Reese *et al.* 2019a 2019b; McCaughan *et al.* 2021a). Reese *et al.*'s (2019a) intervention for HPs providing breast cancer care, although not powered to test for significance, noted that communication barriers to providing sexual support tended to reduce with increased HP confidence; however, the actual communication barriers were not specified in the study. McCaughan *et al.*'s (2021a) eLearning resource developed for men with prostate cancer demonstrated significant improvements in perceived confidence of HPs to address sexual concerns and confidence in knowing what to say to patients and partners, with the latter being sustained at the 4-week post intervention follow up.

Three studies, using questionnaires constructed by study authors (Wang *et al.* 2015; Merriam *et al.* 2018) or adapted from a previous study (Jonsdottir *et al.* 2016), examined the effect of the intervention on HPs level of comfort to provide sexual support. Findings

indicated that in two studies the educational workshop and skills training increased HP comfort related to providing sexual support. However, one study seeking to improve HP communication with female patients on sexual dysfunction had only n=21 participants, 38% of who were doctors and 62% were advanced practice providers and provided no detail on the validation of the questionnaire used (Merriam *et al.* 2018). The other study, also a multidisciplinary study of 74 HPs, 16% of whom were oncologists and surgeons and 84% were nurses and other allied HPs, was subject to high attrition rates (49%) particularly in relation to nurses and allied HPs (39%) (Wang *et al.* 2015). This high attrition introduces bias, as HP who are more comfortable will more likely respond to follow up evaluation. Wang *et al.*'s (2015) study did show statistically significant increases in relation to HP comfort to approaching the topic, assessing, addressing and co-ordinating care for sexual concerns, although these findings were most prominent in the areas of approaching the topic and co-ordinating care. On the other hand, Jonsdottir *et al.* (2016) Icelandic study identified slightly higher rates of discomfort following their intervention with 'sexual concerns as difficult to discuss' remaining the second most common HP barrier. The study design for this educational intervention, makes these assertions challenging, given inherent methodological flaws surrounding intervention fidelity. Jonsdottir *et al.* (2016) surveyed all nurses and doctors employed in the Icelandic hospital at the time of the study as part of a comprehensive long-term educational intervention programme over 2 years. This education intervention comprised of two workshops, developing a sexuality counselling service, conducting educational meetings with staff champions and developing resources suitable for HPs and patients. This before and after research design surveyed over 200 participants at each timepoint, however only 40 of these participants attended the workshops. It is possible that if all participants recruited attended the workshops, there may have been a greater reduction in the discomfort barrier reported.

Interventions which sought to target HP attitudes in areas such as discomfort in providing sexual health care, feeling uncertain about patient's response, fear of a colleague's negative response and lack of environmental support were found to have had little impact. The aforementioned Jonsdottir *et al.* (2016) study reported no significant change in attitudes of HPs relating to their role to provide sexual support, HPs views on having adequate time to discuss sexual concerns with patients or views on how the environment inhibited HPs provision of sexual support (Jonsdottir *et al.* 2016). However, as noted above, the study design may have masked the impact on HPs who were more involved in the study.

These studies do suggest that in tandem with challenging attitudes, HPs need to develop confidence in this area and have other environmental barriers, such as a lack of privacy addressed. Of the two studies that did report significant changes in attitudes to providing sexual support, one did not provide any data pertaining to this (Merriam *et al.* 2018) while the other had similar pre-test and post-test intervention scores (Afiyanti *et al.* 2016). These studies have suggested that changing HPs attitudes is a more challenging aspect of educational interventions which warrants attention.

The time commitment to complete education and training varied significantly in studies from a brief one-off education and training session (Wang *et al.* 2015; McCaughan *et al.* 2021a) to longer commitments of up to 8 weeks (Quinn *et al.* 2019). More in-depth training may result in greater levels of knowledge and confidence, but it is likely that interventions with longer commitments may make it more difficult for HPs to attend, given the reports of a lack of time and busy clinics. Providing training that can be completed at a time and pace of the participants (i.e., asynchronous and web-based) can address this issue. In doing so, one web-based study received positive feedback from participants who regarded the approach taken to be conducive to learning. HPs

highlighted that they would recommend the course to other HPs and had a high positive regard for the intervention's interactive design, communication framework, downloadable resources and demonstration video (McCaughan *et al.* 2021a).

Overall, interventions within the literature to date have made moderate progress in addressing the barriers to the provision of sexual support, with most success evident in improving knowledge. It appears that future interventions need to pay more attention to challenging attitudes, improving self-efficacy and embedding the provision of sexual support into routine clinical practice. Many of the interventions discussed in this section have been delivered using a face-to-face approach, which limits their accessibility and replicability while other interventions are limited by their specificity to a tumour group (for example, prostate or breast), or issue of concern such as fertility. The key facilitators to help HPs routinely provide sexual support include the provision of HP education and training, models to guide the provision of sexual support, support resources for HPs to give to patients (and partners) and establishing referral pathways. However, studies from across the globe, have highlighted that even when training, resources and referral pathways are in place, many HPs continue to struggle with limited private space in healthcare settings to have conversations with patients (Zeng *et al.* 2011; Moore *et al.* 2013; Mansour and Mohammed 2015). Therefore, future implementation of sexual support interventions needs to be cognisant of the perceived environmental constraints within which HPs practice.

#### 3.1.8 Literature review conclusion

This literature review has demonstrated that the sexual effects of a cancer diagnosis and its treatment can have a significant impact on patients and their partners across physical, psychological and relational domains. It does appear that the psychological stressors associated with having a cancer diagnosis, compounded with how cancer-related

treatments can change the structure and function of the body, can collectively lead to difficulties in relationships and roles, contributing to sexual difficulties. Current guidelines across cancer care position the HP as the person to initiate and provide adequate support for the challenges patients and their partner's encounter. However, HPs across cancer care do not routinely provide routine sexual support, as HPs identify that they are often uncomfortable with the topic of sexuality, lack the knowledge of the impact of treatment on sexuality and strategies to provide support while working in busy clinics which often lack adequate privacy. Further impeding the provision of sexual support are the perceived barriers in patient characteristics including the age or gender of the patient and their phase of care. This review has demonstrated that there are many similar challenges to the provision of sexual support experienced by HPs across cancer care, in many countries, that are akin to the challenges faced by HPs working in prostate cancer. These are: the HPs lack of knowledge, difficulties knowing how to approach the sexual support conversations, uncertainty over role to provide sexual support and a lack of resources and referral options to further support patients and partners. HPs have consistently identified the need for educational support to improve their awareness of sexual challenges patients face and strategies to offer support, a guide to structure sexual support conversations with patients and partners, supportive resources and referral pathways. Several interventions have been designed which have shown potential for addressing these barriers to the provision of sexual support in cancer care. However, there is currently no available intervention which addresses these barriers for HPs working across cancer care.

### **3.2 Moving forward**

Globally, there is a lack of sexual support routinely provided in cancer care and a workforce that feels ill-equipped to address the sexual concerns of patients and partners. To address this evident gap in cancer care; HPs need access to an educational resource, a communication framework, alongside supportive resources. There is potential and scope

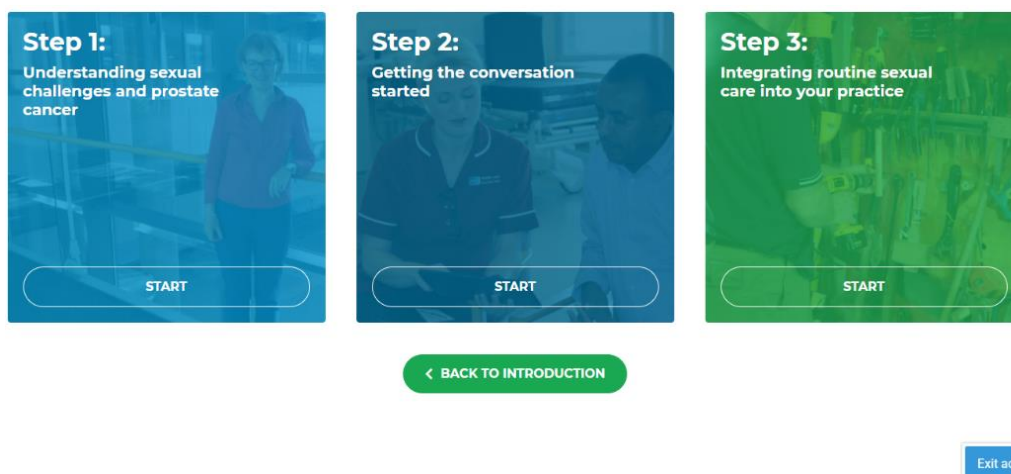
to adapt the MSW: PC eLearning resource for use across cancer care. The next sections of this chapter briefly outline background information about the MSW: PC eLearning resource and detail the theoretical framework used to develop the MSW: PC eLearning resource and its underpinning theories (Sections 3.3 and 3.4). Thereafter, this chapter will detail how these both relate to the adaptation process of the MSW: CC eLearning resource. Then the process used to establish an expert group which co-produced the MSW: CC eLearning resource is noted (Section 3.5), before finally presenting the guiding principles which informed the intervention development process (Section 3.6).

### **3.3 Background information about the MSW: PC eLearning resource**

The MSW: PC eLearning resource (McCaughan *et al.* 2021a) was developed by members of this research team to support the embedding of the EASSi framework into routine clinical practice. To do so, the eLearning resource addressed many attitudinal barriers affecting the lack of HP-led sexual support available for men with prostate cancer. The MSW: PC eLearning resource aimed to provide HPs with the skills and awareness to deliver routine sexual support to men with prostate cancer and their partners; through the provision of language, structure and content to guide sexual wellbeing conversations. Details of the development processes related to the MSW: PC eLearning resource (McCaughan *et al.* 2021a) and the EASSi framework, (McCaughan *et al.* 2020) have been previously published.

The MSW: PC eLearning resource is a brief intervention, designed to take HPs one to two hours to complete. Initially, the MSW: PC eLearning resource provides a clear rationale for the inclusion of HP-led sexual support for patients with prostate cancer and their partners, raising awareness on the importance of this aspect of holistic care. The MSW: PC eLearning resource content is clearly presented in 3 steps (Fig. 5). An overview of these 3 steps within the MSW: PC eLearning resource has been presented in Table 5.

**Figure 5: Screen shots from MSW: PC eLearning resource**



**Table 5: Overview of MSW: PC eLearning resource**

<p><b>Step 1</b></p> <p><b>Understanding sexual challenges and prostate cancer</b></p>	<ul style="list-style-type: none"> <li>• Research on sexual challenges for men with prostate cancer</li> <li>• Exploring HP attitudes about sexuality after prostate cancer [Interactive]</li> <li>• Patient and partner stories [Video]</li> <li>• Exploring needs of different populations</li> <li>• Difficulties men face discussing sexual concerns</li> <li>• Identify the need for support, barriers to support and support resources/referral pathways</li> </ul>
<p><b>Step 2</b></p> <p><b>Getting the conversation started</b></p>	<ul style="list-style-type: none"> <li>• Introduction to the EASSi Framework</li> <li>• EASSi Framework: rationale and application</li> <li>• Information on sexual challenges for prostate cancer arising from surgery, radiotherapy, hormone therapy, or combined radiotherapy and hormone therapy</li> <li>• Demonstration of EASSi framework in use [Video]</li> </ul>
<p><b>Step 3</b></p> <p><b>Integrating routine sexual care into your practice</b></p>	<ul style="list-style-type: none"> <li>• Strategies to move HPs from knowledge to practice</li> <li>• Resources to support practice including downloadable EASSi quick guide and signposting sheet</li> <li>• Links to support resources and online self-management resource for patients with prostate cancer and partners</li> </ul>

This section now presents the theoretical frameworks which guided the development of the MSW: PC eLearning resource and subsequent MSW: CC eLearning resource. This is followed by the theoretical framework used for the development of new content for the MSW: CC eLearning resource.



Key components of the MSW: PC eLearning resource were identified using the Theoretical Domains Framework (French *et al.* 2012). Barriers and facilitators known to mediate the provision of sexual support (O'Connor *et al.* 2019) were identified and mapped to the relevant theoretical domain (McCaughan *et al.* 2020). To address these barriers, several behaviour change techniques (Michie *et al.* 2013) which were relevant and perceived as feasible to implementing the intervention in practice (McCaughan *et al.* 2020) were then mapped to the relevant theoretical domain. These behavioural techniques included: information about consequences, instruction on how to perform the behaviour, demonstration/modelling of behaviour, use of prompts and cues, social comparison and restructuring of the environment.

Underpinning the MSW: PC eLearning resource were several theoretical frameworks, namely, the Theory of Planned Behaviour (TPB) (Ajzen 1985) and Social Cognitive Theory (SCT) (Bandura 1986), which could address the attitudinal, professional and organisational barriers affecting the provision of sexual support. Furthermore, the Biopsychosocial Model (BPS) (Engel 1977) was used to scaffold the content to ensure it addressed the range of sexual challenges faced by patients and partners.

The central concept of the TPB is that attitudes, subjective norms and a person's sense of how difficult or easy a behaviour is to perform (perceived behavioural control) determines behavioural intentions. The stronger the behavioural intention is, the more likely the behaviour will occur. The constructs within the TPB held relevance to the MSW: PC eLearning resource, as they directed focus to address key barriers to provision of sexual support, for example, HPs perception that it is not their role to provide sexual support (Jonsdottir *et al.* 2016), that colleagues or patients would find discussions of sexual concerns in cancer care inappropriate (Mansour and Mohamed 2015) or that HPs did not have the knowledge and skills necessary to provide sexual support (Krouwel *et al.* 2015b;

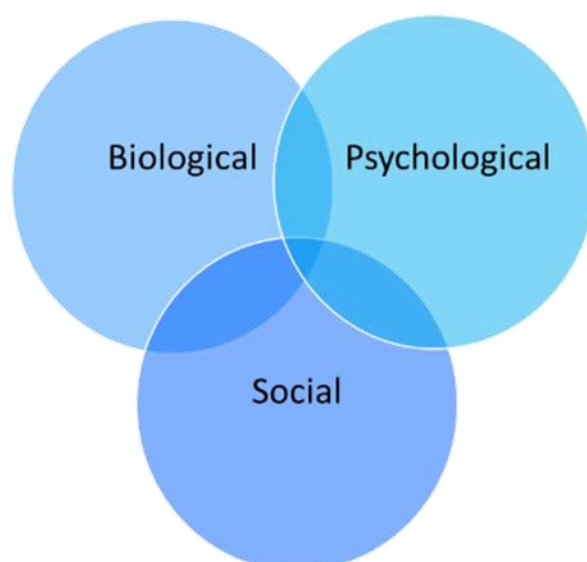
Bedell *et al.* 2017; Wright *et al.* 2018). However, this theory does not take into account influence of HPs past experiences or environmental barriers and assumes that the person has the opportunity and resources to successfully engage in the behaviour (Ajzen 2011).

The SCT, a theory of motivation, can mitigate some of these limitations. This theory seeks to maximise HPs' motivation to engage with the eLearning resource (Bandura 1986). The SCT acknowledges the interplay between a person's thoughts, behaviour and environment (Bandura 1986). The key concept within the SCT is that of self-efficacy (a person's judgement of their capability to learn or perform at a specific level), which is considered a primary driver to motivate a person to action. Pre-task self-efficacy levels can be determined by past experiences of online learning, aptitude and social support (Cook and Artino 2016). Through engagement in the learning process and action through conducting sexual support conversations with patients or alternatively practicing the provision of sexual support with colleagues, can improve one's sense of self-efficacy and make the behaviour more likely to occur. Other key SCT concepts are that of outcome expectancies, the belief that certain outcomes will result from given actions, and self-regulation, a cyclical process by which individuals use self-generated feedback about their learning or performance to manage their pursuit of personal goals (Cook and Artino 2016). Both concepts are evident within the eLearning resource. For example, through the promotion of strategies to embed learning and through the challenging of pre-conceived attitudes that prevent the provision of sexual support, such as, HPs perceiving that the provision of sexual support could be viewed as inappropriate by patients (Afiyanti 2017).

Prior to the development of the EASSi framework a series of qualitative interviews and 3 stakeholder workshops with men with a lived experience of prostate cancer and HP participants (combined total n=76), were conducted (McCaughan *et al.* 2020). Participants reported that HP-led sexual support often was biomedical in focus, centring

on medication for erectile dysfunction with limited support or onward referrals to address any other emerging issues (McCaughan *et al.* 2020). As a result, the MSW: PC eLearning resource with its EASSi communication framework strengthened the HP-led assessment and support for the physical and psychosocial sexual issues identified. The BPS model (Engel 1977) (Fig. 6) addresses the limitations of the dominant biomedical model and therefore reflected the holistic perspective that the intervention required, encouraging HPs to pay attention the interactions between physical, psychological and social elements of illness (Engel 1977). The BPS is not a theory but rather a philosophy of clinical care and a practical clinical guide (Borrell-Carrio *et al.* 2004). By supporting person-centred care, which often improves patient outcomes (Weiner *et al.* 2013), the model predicts that the consequences of physical issues such as erectile dysfunction, could be ameliorated through the provision of cognitive based support strategies (Wade and Halligan 2017). Despite receiving some criticism for being vague about how the physical, psychological and social elements within the model interact, the BPS is widely recognised throughout healthcare literature as a model of best practice and has been recommended to guide interventions in sexuality and cancer care by many authors in the field (Brotto *et al.* 2010; Traa *et al.* 2012; Wittmann *et al.* 2015; Sears *et al.* 2018).

**Figure 6: Engel's (1977) BPS Model**



The development, evaluation and implementation of any intervention can require use of several theories to enable a comprehensive examination of the potential barriers and enablers and possible mechanisms which link them to target HP behaviour (French *et al.* 2012). As such, the researcher has noted that there is evidence of other theories at work within the MSW: PC eLearning resource however these have not been documented. One such example is Goal Setting Theory (Locke and Latham 1990) which has suggested that effective performance is dependent on specific and challenging goals, underpinned by two cognitive determinants, values and intentions. An example of this is the inclusion of strategies which sought to move HPs from a position of knowledge into action in Step 3 of the MSW: PC eLearning resource. Furthermore, the Stress and Coping Theory (Lazarus and Folkman 1984) is evident through attentiveness to the potential grief and loss related to sexuality, cognitive restructuring of sexual concerns and sexual rehabilitation utilising behavioural strategies. The Stress and Coping Theory has emphasised the importance of two processes: appraisal and coping. Appraisal is the continuous evaluation of the situation by the person and coping refers to strategies used to manage distress. These include emotion-focused (for example, addressing grief and loss relating to sexual dysfunction or body image), problem-focused (for example, cognitive or behavioural strategies as a means to address sexual concerns) or meaning-focused (for example, adjustment to the centrality of the sexual concerns) (Lazarus and Folkman 1984). This theory is visible through Step 2's advice for HPs to share with patients and partners after prostate cancer. Furthermore, there is some evidence that implementation theories have been considered, such as the Normalising Process Theory (May *et al.* 2009) which through application of four components: coherence, cognitive participation, collective action and reflexive monitoring supports the embedding of interventions into routine practice. Application of this theory is evident through the prioritisation of HPs and patient input into the development process of the MSW: PC eLearning resource, alongside the provision of a clear rationale for the eLearning resource and the elements within the

communication framework, and the inclusion of a printable communication framework and printable signposting sheets.

### **3.4 Theoretical frameworks for the MSW: CC eLearning resource**

Until recently, there was limited literature to guide researchers on what elements of an intervention could be adapted and at what point extensive adaptation is denoted as a new intervention (Evans *et al.* 2021). However, findings from a systematic review have indicated that adaptation frameworks often draw on the concept of 'core components' to define which parts of an intervention cannot be modified (Movsisyan *et al.* 2019). These core components are thought to be based upon the components that encapsulate an intervention's key ingredients (Greenhalgh and Papoutse 2019). Moreover, Evans *et al.* (2021) reported findings from a consensus study panel who were considering the what, why and when of adapting interventions for new contexts. They questioned whether it would be possible to disentangle core and non-core components of interventions, questioning why an intervention would have components which are not supported by its theory of change. Recent guidance published by the Centre for Development, Evaluation, Complexity and Implementation in Public Health improvement (DECIPHer) has since advocated that when an evidence and theory-based intervention is being adapted, the underpinning theoretical basis for the intervention should not change (Moore *et al.* 2021b). To do so would risk the intervention not working in its new context and may step outside the definition of adaptation into 'de novo' intervention development (Moore *et al.* 2021b). It is considered that if the same theory of change can be activated in the new context, then activities can be substituted and components adapted without interfering with the causal logic of the intervention (Evans *et al.* 2019). Given a recent evaluation of MSW: PC eLearning resource identified the eLearning intervention was effective at reducing attitudinal barriers to enhance the provision of sexual support in the prostate

cancer setting (McCaughan *et al.* 2021a), it is prudent that the underpinning theoretical basis should remain the same for the adapted intervention in this study.

The MSW: PC eLearning resource, as part of this study, went through a planned adaptation. This focused on the adaptation of its content for use by HPs working across cancer care and the development of new treatment-related advice content, supportive resources and signposting to address the patient and partner needs of a mixed cancer population. In keeping with the theoretical underpinning of the MSW: PC eLearning resource, the researcher applied the BPS Model (Engel 1977) to scaffold all new content and modifications. Similar to the experience of patients with prostate cancer (discussed in Section 3.1.2), sexual challenges for patients from wider tumour groups varied across the BPS domains, reinforcing the BPS model's relevance for this study. The BPS could offer support to promote HPs' understanding of the impact of cancer and treatment on patients with cancer (and partners) and to support the researcher to construct advice, identify supportive resources and referral pathways to address the physical, cognitive, emotional and social sexual concerns.

### **3.5 The expert group**

The third element presented in this chapter discusses the establishment of an expert group. Setting up of an expert group was the second part of Phase 1, intervention planning. Recently, PBA authors have advocated for the integration of patient and public involvement (PPI) approaches alongside PBA to maximise the diversity of feedback (Muller *et al.* 2019) rather than relying on input or qualitative approaches alone. The PPI contributors did not provide 'data' like that from qualitative interviews (Rai *et al.* 2021), instead, their involvement provided valuable oversight on the design, methods and conduct of the research study. As noted earlier, due to the expansive literature on support and cancer, no further empirical qualitative studies were required during the

planning phase of this study. Therefore, the primary function of the carefully selected and diverse expert group for this study was to review the new content generated from the evidence base for the MSW: CC eLearning resource and to inform of its relevance and applicability to cancer care settings. Furthermore, members of the expert group were involved throughout all steps of the intervention development process, which included guidance and assistance with study set-up in HSCTs, and study recruitment. Table 6 displays the delineation of roles for the current study between the researcher, the research team, which included two original developers from the MSW: PC research team and the expert group.

The expert group comprised of multi-disciplinary HPs working across cancer care from Health & Social Care Trusts (HSCTs) in NI and patients and a partner, representing varied cancer populations (see Table 7). The researcher liaised with the Macmillan Services Manager from one HSCT, who then contacted potential HP expert group members via email to ascertain interest. HPs who were interested and had capacity to participate in an expert group for this research study contacted the researcher for further information. Those HPs who agreed to participate identified potential patient and partner members and approached those they felt might have an interest in advising on the development of content for the resource. The researcher received contact details of those who were willing to become involved. Despite efforts to include patients and partners in two expert group meetings, they were unable to attend. This prompted the researcher to adopt an asynchronous approach to communication with the expert group. Subsequently, some patients and partners were able to contribute and advise on content improvements remotely via email and post, while another existing group of patients invited the researcher and member of the research team (EM) to attend a local meeting. The expert group met as a group on two occasions, June 2019 and January 2020, however there were a series of one-to-one or small group meetings with the researcher throughout the study

period. These meetings and communications varied over the project's lifespan, some of which were focused on refining content, others were advisory in terms of recruitment and study procedures. The development of new content benefited significantly from the individual expertise available from HPs across tumour groups and disciplines and patients. They provided a depth of insight into specific cancer and treatment-related effects while also increasing awareness of the practicalities of support strategies to address the sexual challenges after cancer. The expert group members were valuable in helping to guide recruitment and encourage uptake of the study, particularly given the challenges imposed by COVID-19 restrictions.

**Table 6: Delineation of the researcher, research team and expert group member roles**

<b>Activity</b>	<b>Researcher</b>	<b>Research team, CS, CF, LD and EM (CF and EM original developers)</b>	<b>Expert group HPs</b>	<b>Expert group Patients</b>
<b>Phase 1: Literature review</b>	Conducted literature review	Reviewed and challenged literature review		-
<b>Phase 2: Prototype development and refining</b>	Reviewed content and suggested refinements, implement refinements	Reviewed content and suggested refinements prior to expert group involvement	Reviewed and refined content prior to optimisation study	
<b>Optimisation recruitment</b>	The researcher developed and conducted the recruitment strategy in collaboration with the research team and expert group members			
<b>Optimisation study</b>	Conducted and analysed TA interviews	Reviewed and independently analysed TA interviews	Participated in testing phase (n=2)	-
<b>Phase 3: Evaluation recruitment</b>	The researcher developed and conducted the recruitment strategy in collaboration with the research team and expert group members			
<b>Evaluation study</b>	Collected and analysed results	Reviewed and independently analysed results	Unknown	-



**Table 7: Members of the expert group**

Role represented by expert group members	Tumour group(s) represented	Number of experts per role involved
Patients	HNC, Breast & Colorectal	9
Partners	HNC	1
Clinical Nurse Specialist (CNS)	HNC, Breast, Gynaecological, Colorectal, Lung, General/Palliative	11
Speech & Language	HNC	1
Psychologist	General	1
Physiotherapist	Gynaecological & Colorectal	1
Medical Consultant	Gynaecological	2
Macmillan Service Improvement Manager	General	1

### 3.6 Developing guiding principles

Guiding principles act as a blueprint for intervention development and offer a succinct summary of the crucial ways in which the intervention is intended to support change in behaviour by improving engagement with the intervention content (Yardley *et al.* 2015b). The guiding principles consist of two elements: the intervention design objectives and the intervention's key features to achieve these aims. By identifying the key features of the intervention, the guiding principles capture the intervention characteristics, which should optimise its acceptability, feasibility and effectiveness (Yardley *et al.* 2015b). The PBA guiding principles for the study were based in evidence, guided by the theory and informed by insights from the expert group. The literature provided the researcher with a concise overview of the behavioural issues that the MSW: CC eLearning resource needed to address. From this, key design objectives and intervention features were identified, which would target each behavioural issue. These principles needed to be established early in the development process. However, the iterative approach inherent within the PBA, supported continued revisions of the guiding principles throughout the intervention optimisation (Phase 2) and evaluation phases (Phase 3), associated with new evidence which challenged the current evidence base (Yardley *et al.* 2015a).

To develop the guiding principles for this study, it was necessary to state the objective of the study intervention, as noted below.

The objective of the intervention is to enable (*behaviour*) HPs working across cancer care to provide routine sexual support (*outcome*) to patients and partners, by adapting the disease-specific (MSW: PC) eLearning resource to an e-Learning resource for HPs working across cancer care (MSW: CC).

Using a combination of the literature, learning from the MSW: PC research team and input from the expert group, the researcher identified five fundamental behavioural issues that the intervention needed to address. These were similar to the behavioural issues denoted for the MSW: PC eLearning resource and are detailed in column one of Table 8. Subsequently, the researcher identified design objectives that would address each of the behavioural issues. Following this, the integral intervention features were identified, which, in turn, addressed each of the key design objectives (Yardley *et al.* 2015a) (See Table 8, columns 2 and 3). Through this process, it was apparent that the MSW: PC eLearning resource addressed many of the key behavioural issues that the MSW: CC eLearning resource needed to address, with a range of appropriate design and intervention features feasible for the cancer care setting. The guiding principles were created and refined over a series of meetings with the research team. These guiding principles provided the foundation to manage the adaptation of the MSW: PC eLearning resource and subsequent optimisation of the MSW: CC eLearning resource (Phase 2). This study made a unique contribution to many key intervention features, which have been highlighted in grey within Table 8.

Yardley *et al.* (2015b) based on their experience of ensuring that digital interventions are engaging, relevant and feasible for their intended settings have pointed out a set of common guiding principles which should be used alongside specific guiding principles to support intervention development. These have been provided in Table 9 alongside

examples of how they are evident with the original MSW: PC eLearning resource and reference to what was retained or changed for the MSW: CC eLearning resource.

**Table 8: Guiding principles for MSW: CC – an intervention to enable HPs working across cancer care to provide routine sexual support to patients and partners**

Key behavioural issue to be addressed	Design objectives that address each key issue	Key intervention features relevant to each design objective
<p>HPs do not routinely provide sexual support to patients and partners* in cancer care due to:</p> <p>a) limited knowledge of impact and strategies, resources and referral pathways that can support</p>	<p>i) Increase HPs knowledge and understanding of:</p> <ul style="list-style-type: none"> <li>- the impact of cancer on sexuality</li> <li>- practical strategies to support patients with cancer and partners</li> <li>- supporting resources</li> <li>- referral pathway options</li> </ul>	<ol style="list-style-type: none"> <li>1. Provide relevant and trustworthy information on the key sexual challenges that patients with cancer and their partners face.</li> <li>2. Outline sexual support strategies for HPs to use when tailoring support for patients with cancer and partners.</li> <li>3. Provide links to resources available online relevant for across cancer care.</li> <li>4. Develop signposting sheets for general cancer care and one for each specified tumour group, retaining the prostate cancer version.</li> <li>5. Provide information on accessible and universal referral pathways for HPs to signpost patients with cancer and partners to.</li> <li>6. Include referral options on signposting sheets as patients may wish to revisit these with HP at a later stage.</li> </ol>
<p>b) lack of access to relevant training</p>	<p>ii) Provide an accessible platform for HPs to access an engaging, positive and interactive education and training on sexual challenges faced by patients with cancer and partners.</p>	<ol style="list-style-type: none"> <li>1. Create the MSW: CC eLearning resource using the structure of the MSW: PC eLearning resource, ensuring that the new resource can be accessed by HSCT staff.</li> <li>2. Retain user autonomy through offering choices within the resource, such as information to view, goals to set and give flexibility when to complete training.</li> <li>3. Adapt the rationale for advice, acknowledging concerns and addressing barriers to be relevant across cancer care.</li> <li>4. Build on the interactive components, avatar and multimedia aspects of MSW: PC resource ensuring relevance across cancer care.</li> </ol>

Key behavioural issue to be addressed	Design objectives that address each key issue	Key intervention features relevant to each design objective
c) ambiguity regarding the HP role to provide sexual support to patients with cancer and partners	iii) To persuade HPs that providing routine sexual support to all cancer patients and partners is part of their healthcare role	<ol style="list-style-type: none"> <li>1. Provide research evidence that patients across cancer care and partners wish to be supported.</li> <li>2. Provide patient perspective videos which describe the sexual challenges faced and the importance of sexual support across cancer care.</li> </ol>
d) HPs lack of confidence in their ability to provide sexual support	iv) Provide an intervention which can enhance self-efficacy of HPs in relation to providing sexual support to patients with cancer and partners.	<ol style="list-style-type: none"> <li>1. Integrate the new content within the EASSi framework to support both assessment of sexual concerns and tailored support.</li> <li>2. Broaden information which acknowledges the personal barriers to providing sexual support, to reflect wider evidence base.</li> <li>3. Provide the information HPs need to increase knowledge and understanding on the impact of cancer and treatments on sexuality</li> <li>4. Retain the opportunities in Step 3 to build skills such as practicing with colleagues, target setting, team debriefing.</li> <li>5. Replace existing video demonstrating an HP assessing and supporting a patient with cancer without the use of an electronic tablet resource (was specifically designed for prostate cancer).</li> </ol>
e) a lack of time and other priority care issues	v) Provide an intervention with information tailored to suit a range of multidisciplinary HPs working within time-limited appointments	<ol style="list-style-type: none"> <li>1. Ensure that tailored content is succinct for staff with busy schedules.</li> <li>2. Equip HPs with advice relevant across cancer care which HPs can use to open conversations about sexual concerns with signposting options available to address concerns which are outside their role or expertise.</li> </ol>

\* and partners, only when applicable and not a pre-requisite

**Table 9: Common guiding principles for digital intervention development (adapted from Yardley et al. 2015b)**

<b>Intervention design objective</b>	<b>Key intervention features</b>	<b>Examples of application within MSW: PC eLearning resource</b>	<b>Variation within MSW: CC eLearning resource</b>
To improve acceptability and engagement in digital interventions	Offering users choice where possible (E.g., use of goals, tools, timing, method of implementation).	<ul style="list-style-type: none"> <li>• Flexibility of access to resource</li> <li>• Flexibility in how HPs navigate resource</li> <li>• Range of treatment-related advice and patient stories for HPs to select</li> <li>• Provides a range of strategies to implement knowledge into practice</li> <li>• Printable signposting sheets and EASSi framework to support clinical practice</li> </ul>	Retained  Retained  Retained  Retained  Expanded
	Providing clear structure and (optional) guidance, examples, stories modelling desired behaviour, graded goal setting, minimising conscious effort and lifestyle disruption where possible.	<ul style="list-style-type: none"> <li>• EASSi framework to structure sexual support conversations</li> <li>• Organised over 3-step structure with key messages building and supported by additional resources</li> <li>• Demonstration of HP/patient sexual support conversation</li> <li>• Variety of implementation strategies to embed learning</li> <li>• Printable framework to act as a prompt in clinical practice</li> </ul>	Retained  Retained  New video  Retained  Retained

Intervention design objective	Key intervention features	Examples of application within MSW: PC eLearning resource	Variation within MSW: CC eLearning resource
	<p>Using positive language throughout, giving rationale for advice, acknowledging and addressing concerns</p> <p>Ensuring all communications provide something interesting, enjoyable, relevant and helpful for the user</p> <p>Reciprocating intervention usage by providing immediately rewarding feedback</p> <p>Following best practice to maximize accessibility, usability and trust.</p>	<ul style="list-style-type: none"> <li>• Key barriers to provision of sexual support challenged</li> <li>• Interactive elements with immediate feedback</li> <li>• Relevant information ready to use in clinical practice</li> <li>• Rationale provided for each step in EASSi framework</li> <li>• Intuitive design, with ongoing access supported</li> </ul>	<p>Retained</p> <p>Retained</p> <p>Retained</p> <p>Retained</p> <p>Adjustments made to enhance</p>

### 3.7 Conclusion

This chapter has presented the findings from four key elements that contributed to the PBA's intervention planning phase. Initially, the literature review established the extent and variation of sexual challenges confronted by patients, the lack of sexual support available and the key barriers that need to be overcome to facilitate the provision of sexual support in cancer care. The review of the literature provided a rationale and informed the adaptation of the MSW: PC eLearning resource. This chapter considered the theoretical framework used to guide the development of the MSW: PC eLearning resource and its theoretical underpinnings were presented alongside a justification on the importance of retaining these as core elements for the MSW: CC eLearning resource. Next, this chapter outlined the rationale for and detailed the processes employed to establish an expert group to co-produce the MSW: CC eLearning resource. Finally, this

chapter has concluded by demonstrating how the evidence and theory base, alongside input from the research team and the expert group have been combined into a practical blueprint (guiding principles) to guide the adaptation of the MSW: PC eLearning resource to the MSW: CC eLearning resource and to provide a basis from which modification decisions could be challenged during the optimisation phase (Chapter 4).

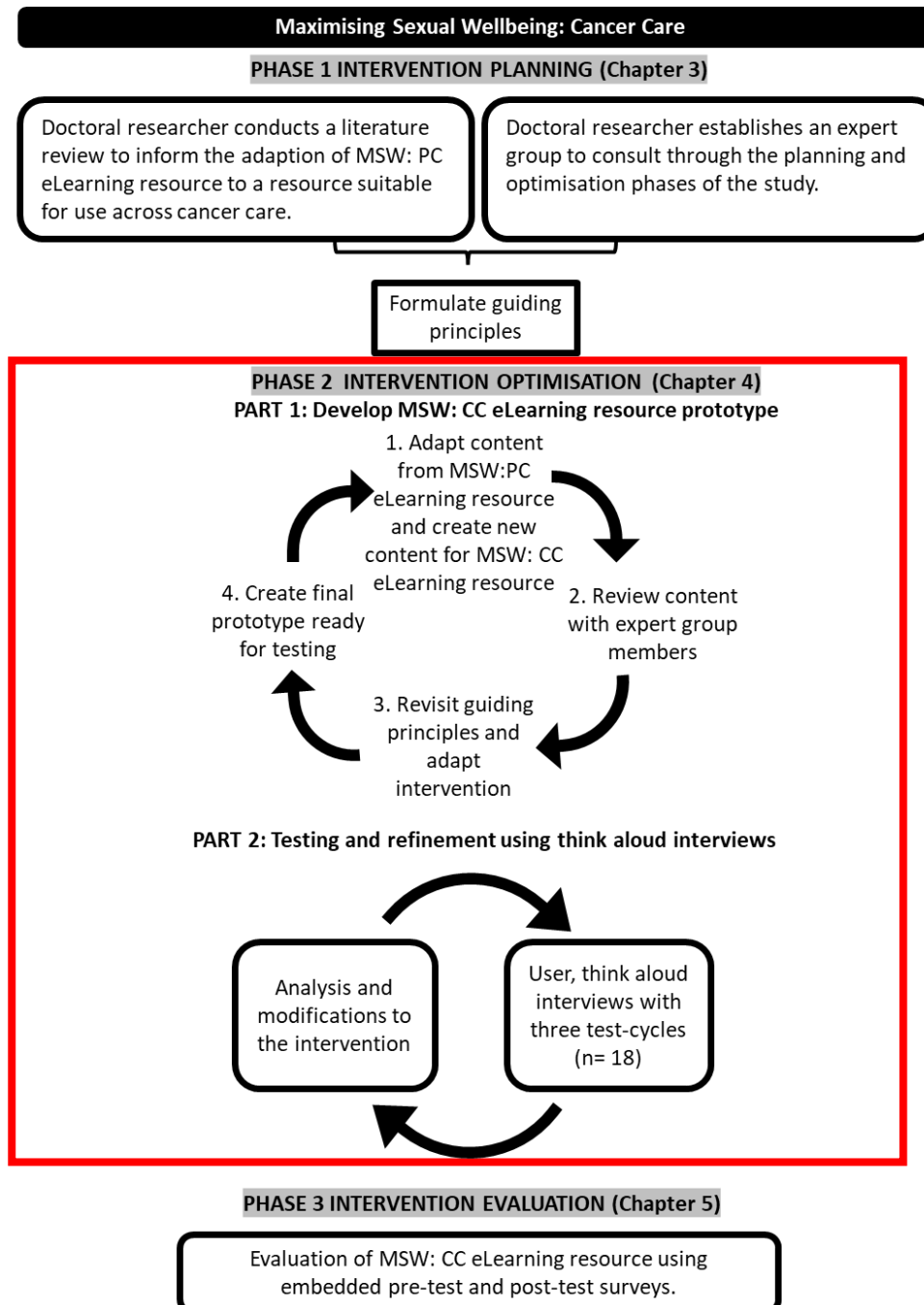


## CHAPTER FOUR: PHASE 2 - INTERVENTION OPTIMISATION

### 4.1 Introduction

This chapter presents Phase 2 of the PBA: Intervention Optimisation. The intervention optimisation will be presented in two parts as highlighted below in Figure 7.

**Figure 7: PBA phases of study, highlighting the Intervention Optimisation phase**



Part 1 of the Intervention Optimisation involved adapting the MSW: PC eLearning resource to the MSW: CC eLearning resource. This included creating new content to address the sexual support needs of a mixed cancer population. This chapter outlines the expert group and research team input, which, together with the guiding principles (Table 8, pp.108-109), informed the content and shaped the appearance, navigation and functionality of the new eLearning resource. Part 2 then presents the methods, analysis and results of iterative testing, using TA interviews with HPs working across cancer care. Finally, the refinement process, which culminated in the production of a final prototype of the MSW: CC eLearning resource, is included. The final prototype of the MSW: CC eLearning resource went 'live' for evaluation in November 2020. The evaluation is presented in Chapter 5.

## **4.2 Study objectives**

Research objectives 1 and 2 were aligned to Part 1 and 2 of this phase, respectively:

- 1) Adapt the content of the MSW: PC eLearning resource to a resource suitable for HPs working across cancer care (MSW: CC eLearning resource), providing core information for general use with some additional information for specific issues related to breast, colorectal, head and neck, gynaecological and prostate cancers.
- 2) To iteratively test and refine the content and design of the eLearning resource.

## **4.3 INTERVENTION OPTIMISATION (PART 1)**

### **4.3.1 Adapting content from the MSW: PC eLearning resource to create the MSW: CC eLearning resource**

To start, the researcher met with two original developers from the MSW: PC collaborative research team. The meeting involved a thorough review of each step within the existing MSW: PC eLearning resource. Agreement was reached on which elements of the MSW:

PC eLearning resource would apply to the new MSW: CC eLearning resource. It was decided to retain the 3-step structure of the resource as it addressed many of the design objectives for the study. With adjustments, it was evident that a considerable amount of the content was suitable for HPs working across cancer care. All decisions made during the adaptation stage were evidence-led, informed by the guiding principles and input from the expert group. These adjustments included changing 'men' to 'men and women' or 'prostate cancer' to 'cancer'. There were, however, slides<sup>2</sup> from each of the three steps which required more substantial changes. Specific gaps in content were also identified and are outline in the next section. An overview of these changes and an accompanying rationale are detailed in Appendix 5.

#### 4.3.2 Development and review of new content for the MSW: CC eLearning resource

The next stage involved developing and reviewing new content to address gaps in the MSW: CC eLearning resource. Using the literature, the guiding principles (Table 8, pp.108-109) and input from the expert group and research team, the researcher identified and sought agreement on the main areas within the MSW: CC eLearning resource which required additional content. These areas included:

1. Treatment-related sexual challenges and advice suitable for use with patients across different cancer types.
2. Additional video content to address broader sexual challenges faced by women and other tumour groups, as the MSW: PC eLearning resource was designed to address only prostate cancer and its male population group. Furthermore, the MSW: CC eLearning resource required a new introduction video to introduce HPs to the topic of sexuality and its relevance across

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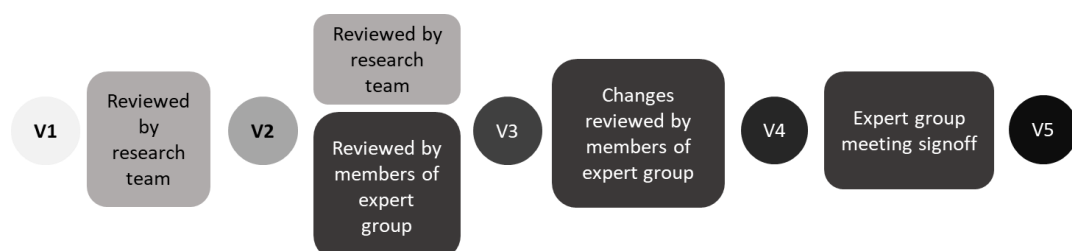
<sup>2</sup> The term 'slide' used in this study is to denote offline content equivalent to that of an online web page.

cancer care and an updated demonstration of an HP providing sexual support.

3. Relevant resources to signpost patients and partners to further support.
4. Referral pathways for more complex sexual challenges faced by different cancer populations.

The new content evolved iteratively over five versions (Fig. 8) with the researcher, seeking feedback and clarity from the research team and expert group members on suggested improvements to the content. This consultation process for content development enabled critique from the expert group and research team, ensuring that all content was relevant and practical for HPs working in cancer care. In some instances, the suggested coping strategies for patients within the literature were deemed impractical for patients. For example, to avoid embarrassment from urinary incontinence issues resulting from cancer treatments, one suggested strategy was to have sexual intercourse in the shower (Reese *et al.* 2010). However, given the advanced age of many patients with colorectal cancer, this advice was not practical and therefore withdrawn. An excerpt from the overview of the feedback provided by expert group members is presented in Table 10 with the complete overview of the feedback from the expert group and rationale for action taken by the researcher in conjunction with the established guiding principles available in Appendix 6.

**Figure 8: Outline of consultation process used in the development of content for MSW: CC eLearning resource**



**Table 10: Excerpt from meetings with expert members providing an overview of feedback**

<b>Versions reviewed, tumour Group, perspective represented, &amp; type of contact</b>	<b>Overview of feedback</b>	<b>Action taken by researcher</b>
<p>Version 2 and 3 HNC</p> <p>Multidisciplinary regional group (n=8) (In-person mainly with few on teleconference)</p> <p>CNS (and supervisor) (In-person)</p> <p>Speech and Language Therapist (In-person)</p> <p>Nurse (In-person)</p> <p>Partner of patient (Email)</p>	<p>Language</p> <ul style="list-style-type: none"> <li>•Clarity around language such as ‘jaw opening’.</li> <li>•Be careful advice does not seem glib: ‘having a positive attitude and confidence can help’.</li> <li>•Change reduced movement to read ‘reduced jaw, neck and shoulder movement’.</li> </ul> <p>Content</p> <ul style="list-style-type: none"> <li>•HPV scares people and needs to be acknowledged as part of the resource</li> <li>•Do not localise the resource by adding specific shops, although there are products which can help people manage symptoms.</li> </ul> <ul style="list-style-type: none"> <li>•Be mindful of neck breathers</li> <li>•For those with a tracheostomy, include that patients and partners can agree a signal to stop if needed</li> <li>•Familiar places do not always help</li> <li>•Remove reference to regular dental check-ups as this will vary depending on the patient</li> <li>•Acknowledge the fear of dislodging the peg tube</li> <li>•Remove advice on oral contact concerning teeth cleaning/mouthwash</li> <li>•Impact of full dental clearance on speech, isolation and libido</li> <li>•Importance of creating time away from where you are known can help you to relax as a couple.</li> <li>•The importance of giving your relationship time.</li> </ul>	<ul style="list-style-type: none"> <li>• Wording amended</li> <li>• Language revisited and amended</li> <li>• Change amended</li> <li>• HPV section added</li> <li>• Removed any local references</li> <li>• Decision not to introduce specific products as advice can change on these</li> <li>• New category: Tracheostomy laryngectomy and sexuality</li> <li>• Removed</li> <li>• Dental check-ups removed as not always relevant</li> <li>• Included</li> <li>• Removed</li> <li>• Communication difficulties included</li> <li>• Emphasis on being patient and giving yourself time is addressed in resource</li> <li>• Included</li> </ul>

The remainder of this section details the decision-making processes in developing and organising the new content. First, the development and organisation of treatment effects and advice on sexual challenges are considered, followed by the deliberations which related to the development of new video content, supporting resources and referral pathways.

#### ***4.3.2.1 Treatment effects on sexual wellbeing***

Some of the treatment-related effects on sexual wellbeing as a result of prostate cancer applied to the new MSW: CC eLearning resource, however there were significant gaps that needed to be addressed, to ensure this eLearning resource met the needs of other cancer populations. A literature review equipped the researcher with the evidence base on which to draft the key effects that cancer and its treatment can have upon patient and partner sexuality. This section provides an insight into the decisions and challenges of finding an effective structure to present the new content, followed by a detailed overview of the process used to develop new supporting information and advice.

##### Developing a structure to present treatment effects

The literature review identified that many cancer populations face similar sexual challenges (see Section 3.1.2). Using this insight, the researcher combined the physical sexual challenges that were common across tumour groups. This led to the creation of two discreet sections. One, a 'core' section of sexual challenges. Examples of treatment effects in this section included body changes, loss of desire, hot flushes, vaginal dryness, erectile dysfunction and pain (as a physical symptom) or fear of pain or injury. However, it was evident that some tumour groups required further tailored advice; these included, breast, colorectal, gynaecological, head and neck and prostate. This tailored advice was included in a second section. These tumour groups were selected on criteria that included

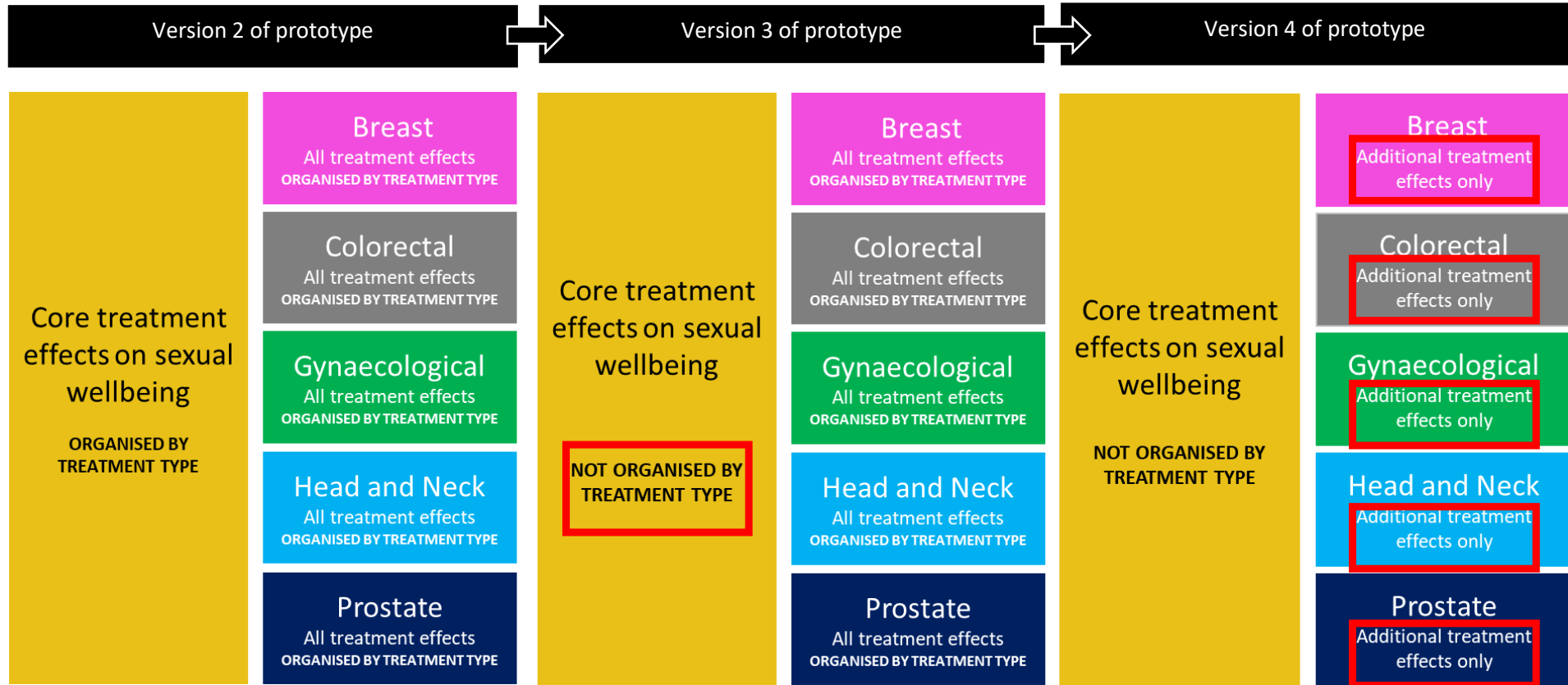
higher prevalence of cancer incidence within the specific tumour type or tumour specific treatment-related effects to sexuality. For example, some of these specific sexual challenges faced by patients with HNC may include body image problems arising from facial disfigurement affecting sense of attractiveness and reduced jaw movement, impacting communication and kissing (Moreno *et al.* 2012, O'Brien *et al.* 2012; Semple *et al.* 2019). Furthermore, patients with gynaecological cancers may have problems with vaginal stenosis and experience pain and bleeding (Aerts *et al.* 2009; Jeppesen *et al.* 2015). Those with colorectal cancer may find bowel or stoma issues challenging in terms of leakage and body image (Sun *et al.* 2016). Patients with breast cancer experience loss of or changes to their breast(s), which may reduce sensation, make it difficult for patient to look at their breast area or for the patient to let their partner see and potentially require decisions relating to reconstruction surgery (Markopoulous *et al.* 2009; Manganiello *et al.* 2011). Men receiving treatment for prostate cancer often encounter problems due to damage to nerves, which can result in poor erections, reduced ability to reach orgasm and cause urinary and bowel leakage, while hormone treatments can trigger hot flushes and weight gain (Downing *et al.* 2019). Sexual support for prostate cancer was included within the MSW: CC eLearning resource, despite HPs having access to detailed information and advice within the MSW: PC eLearning resource. This was in recognition that while some HPs only support patients with prostate cancer and their partners, other HPs work across multiple cancer populations and require broader content.

In early iterations, the 'core' and 'specific tumour group' sections, presented all relevant sexual challenges that patients and their partners may confront. Each section was organised by treatment type (as was applicable), for example, surgery, radiotherapy, chemotherapy and hormonal therapy, each of which also contained all relevant sexual challenges. Figure 9 displays three approaches used to organise the treatment-related effects section. The changes made between the approaches have been highlighted in red

boxes. A disadvantage of categorising by treatment type was the repetitiveness of treatment effects section, as many treatments within and across tumour groups had a similar impact. For example, vaginal dryness results from both chemotherapy and pelvic radiotherapy and affect patients with colorectal, gynaecological and many other cancers. There was a risk of HPs having to view large amounts of repetitive information as they moved between tumour group sections. Thus, expert group members advised on a more succinct structure; presenting the core treatment effects on sexuality section for all HPs to view, with the tumour specific sections presenting bespoke, tailored effects and advice alone. For example, a breast care nurse using the eLearning resource would view most of the relevant information within the 'core' section, then move to the breast cancer-specific section to find additional items: 'changes to my breast' and 'reconstruction, prosthesis or going flat' (see Fig. 10, slide 4). However, this approach only had limited benefit to reducing the repetitiveness of the content. The 'core' and 'tumour specific' sections were still organised by treatment type and therefore HPs would be viewing some content on several occasions.



Figure 9: Flow diagram of the organisation process of 'core' and 'tumour-specific' treatment-related effects on sexual wellbeing



**Figure 10: Screenshots of treatment-related effects on sexual wellbeing for 'core' and 'tumour-specific' sections of eLearning resource - Version 5**

1




### Key messages to include when providing emotional support....

- ✓ Changes to your sexuality may feel like a loss. It is normal to grieve for this.
- ✓ These changes can be difficult for you and your partner; be patient; most people adapt to these changes in time.
- ✓ Try not to compare yourself to how you were before.
- ✓ Regular exercise and a good sleep routine can help.
- ✓ Keep talking to your partner.
- ✓ Find ways to remain close to your partner.
- ✓ There is support if you need it.

NEXT

2

### Core Treatment Effects on Sexual Wellbeing




Click on each box to explore how treatment effects sexual wellbeing and see some basic information and advice to help guide meaningful conversations with patients.

- Body changes
- Hot flushes and vaginal dryness
- Penis not getting hard (erections)
- Sex, Fertility and Pregnancy
- Pain and fear of pain/injury
- Changes to orgasm

NEXT

3

### Treatment Side-Effects for Tumour Groups



In addition to the common sexual side-effects patients with cancer and their partners may face, some tumour groups have further challenges.

Please select any tumour groups you would like further information on.

- Breast
- Colorectal
- Gynaecological
- Head and Neck
- Prostate

4

### Breast Cancer – Specific challenges to sexual wellbeing

Click box to explore each challenge further and see some basic information and advice you can give.

- CHANGES TO MY BREAST(S)
- RECONSTRUCTION, PROTHESIS OR CHOOSING TO GO FLAT

[BACK TO TUMOUR GROUPS](#) [MOVE ON](#)

5

### Colorectal Cancer – Specific challenges to sexual wellbeing

Click box to explore each challenge further and see some basic information and advice you can give.

- PENIS NOT GETTING HARD (ERECTIONS)
- VAGINA MAY FEEL SHORTER, TIGHTER OR SORE
- URINARY/BOWEL CHANGES
- ADJUSTING TO STOMA
- BODY CHANGES

[BACK TO TUMOUR GROUPS](#) [MOVE ON](#)

6

### Gynaecological Cancer – Specific challenges to sexual wellbeing

Click box to explore each challenge further and see some basic information and advice you can give.

- VAGINA FEELS SHORTER, TIGHTER OR SORE
- FEAR OF PAIN/INJURY
- URINARY/BOWEL CHANGES
- VAGINAL DISCHARGE/POST-COITAL BLEEDING
- FEAR OF DILATORS

[BACK TO TUMOUR GROUPS](#) [MOVE ON](#)

7

**Head and Neck Cancer – Specific challenges to sexual wellbeing**

Click box to explore each challenge further and see some basic information and advice you can give.

- DIFFICULTY COMMUNICATING
- CHANGES TO APPEARANCE
- PROBLEMS WITH MOUTH/KISSING
- PEG TUBE AND SEXUALITY
- TRACHEOSTOMY, LARYNGECTOMY AND SEXUALITY
- REDUCED JAW, NECK AND SHOULDER MOVEMENT
- HPV AND CHANGES TO MY SEX LIFE

BACK TO TUMOUR GROUPS      MOVE ON

8

**Prostate Cancer – Specific challenges to sexual wellbeing**

Click box to explore each challenge further and see some basic information and advice you can give.

- LEAKING URINE WHEN AROUSED
- BOWEL SENSITIVITY

BACK TO TUMOUR GROUPS      MOVE TO SIGNPOSTING

In order to resolve these issues, two alternative approaches were trialled to find an appropriate structure for treatment types. First, treatment types were removed from the ‘core’ section but retained in the tumour specific sections (Fig. 9, Version 3). This approach preserved some tailoring of information by treatment type for HPs and while this was valued, the treatment effects on sexuality section was still too repetitive. Second, based on consistent feedback from expert group members, the tailoring of treatment-related effects on sexual wellbeing by treatment type within all the tumour group sections was removed (Fig. 9, Version 4). Members of the expert group supported these changes as the information was presented in a more concise way. One example of how this structure improved the presentation is demonstrated in the section considering ‘hot flushes and vaginal dryness’. These treatment-related effects could have featured in

any of the core, breast, colorectal and gynaecological sections and within these sections be listed under treatment types: chemotherapy, hormone therapy and pelvic radiotherapy. However, with the final changes applied, 'hot flushes and vaginal dryness' appear only once in the 'core' section and are removed from all other sections.

To balance the removal of tailored information by treatment type, the advice provided for sexual challenges was enhanced to specify which treatment may cause sexual challenges. This is in keeping with the guiding principles that stipulated the need to provide HPs with information that would facilitate tailored support and advice (p.100, See i(2)). For example, the advice on 'vaginal dryness' was enhanced with a statement that identified, "chemotherapy, pelvic radiation or hormone therapy may cause vaginal dryness." These actions supported HP's access to relevant, specific and succinct information, relating to sexual challenges faced by patients and partners.

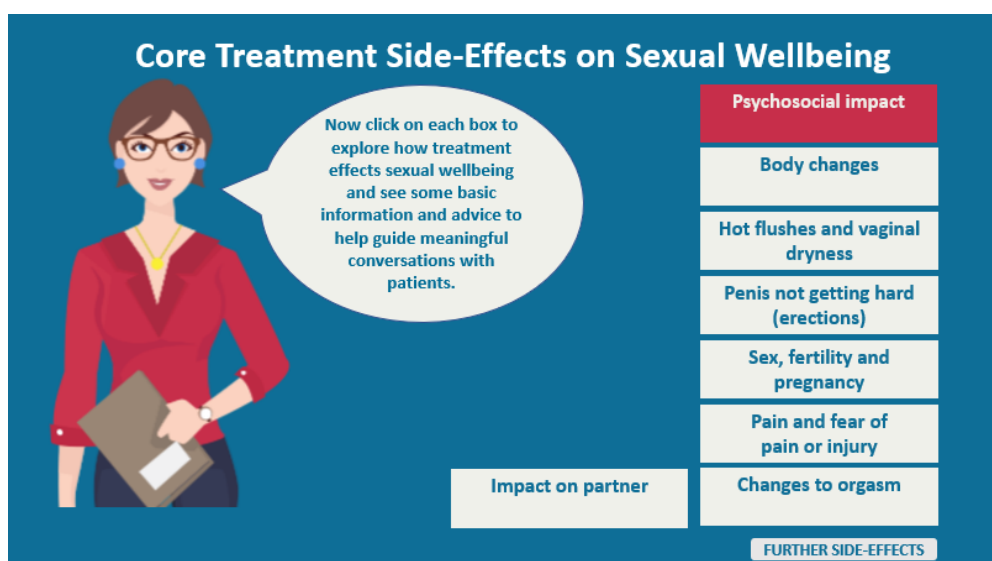
Alongside decision-making on the structure of the physical treatment-related effects on sexuality, the positioning of psychosocial sexual concerns also needed to be addressed. The patient representative within the expert group emphasised that the psychosocial challenges that patients and partners face often present the greatest difficulty. This perspective, supported by recent evidence (Wittmann *et al.* 2015; Sears *et al.* 2018), indicated that the psychosocial impact of treatments should have a prominent position within the resource.

Within the 'treatment-related effects' section, there were two approaches trialled to organise the psychosocial challenges and advice. Initially, psychosocial concerns arising from cancer and treatment effects were embedded alongside the physical challenges, which reflected an equal status and acknowledged how these issues were interrelated. However, following feedback from patients within the expert group, this approach was

restructured, creating a specific slide, 'Key messages when providing emotional support to patients and partners'. The psychosocial slide was placed before 'core treatment effects on sexuality – physical challenges'; thus, making it a mandatory slide for all HPs to view, by embedding it within the linear flow of the resource (Fig. 10, Screenshot 1). The second change to the organisation of psychosocial challenges related to improving the flow of the 'treatment-related sexual challenges' section within Step 2. This change was included following a pilot TA interview with a research team member (EM). The psychosocial challenges were changed to be accessed as part of the 'core treatment effects on sexual wellbeing' rather than having HPs navigating additional slides. To give it prominence, it was placed as the first category and brightly coloured (Fig. 11).

The researcher was aware that making elements of the resource mandatory to view removed some user autonomy, which Yardley *et al.* (2015b) have suggested could reduce HPs motivation to use the resource. To address this, all the other treatment effects included in each section ('core' and 'tumour-specific') were optional to view. This enabled HPs who did not work in an aforementioned tumour specific group(s) permission to move from the 'core treatment effects on sexual wellbeing – physical challenges' to the 'Signposting' section of the resource.

**Figure 11: Screenshot of 'core treatment effects on sexual wellbeing' from eLearning resource - Version 6**



### Developing the new content

Once an initial draft of the treatment effects on sexual wellbeing was established (see Fig. 10, slides 2-8), the researcher began the process of creating content to cover advice on informative and supportive coping strategies. Also, the researcher considered the language HPs could use when providing patients and partners with sexual support. Generating this content on advice and language was iterative in nature, going between many sources of evidence. Examples of the range of sources are outlined below:

- Evidence base including research articles, systematic reviews and books (see Chapter 3)
- International guidelines, for example, Guidelines on Vaginal Dilatation after Radiotherapy (National Forum of Gynaecological Oncology Nurses 2012) and Interventions to address sexual problems in people with cancer (Carter *et al.* 2018).
- Evidence-based eLearning resources, for example, Cancer Australia (2019) on the psychosexual care of women affected by gynaecological cancers.

- Podcasts by experts in the field, including 'Sex, intimacy and breast cancer' (O'Riordan 2019) and 'Communicating about sexuality and fertility' (Schover 2012).
- Reputable cancer support websites, for example, Macmillan Cancer Support (2020), American Cancer Society (2020)
- Booklet information provided by healthcare organisations, for example 'Going home after major gynaecological surgery' (National Health Service 2019) and cancer charities; for example, 'Managing the late effects of pelvic radiotherapy in women' (Macmillan Cancer Support 2018).
- Patient stories on Macmillan You Tube video channel, for example Helen discussing 'Sex and relationships after having a mastectomy' (Macmillan Cancer Support 2014) and Rebecca and Scott sharing their experiences about 'Sex, fertility and internal radiotherapy' (Macmillan Cancer Support 2009).

Initially, the advice and coping strategies contained within the treatment-related effects on sexuality were extensive and repetitive. This was partly due to the advice being similar across some of the treatment-related sexual effects. To address this, the researcher identified treatment effects that could be collated under one suitable heading. An example of this was grouping 'pain' and 'fear of pain or injury' into one category. By combining these two categories, the advice addressed the relevant physical and psychological issues by acknowledging 'fears and worries', encouraging patients to 'maintain sexual intimacy, with or without sexual intercourse' and talking to a 'healthcare professional'. Furthermore, the researcher carefully considered the appropriate tone and language so that HPs could easily implement the conversations in routine clinical practice. This proved effective, as feedback from the expert group identified that the advice, language and tone provided a helpful tool to facilitate sexual support conversations.



Expert group members reflected that some elements of the suggested advice could be more specific. It was necessary to balance this suggestion with maximising the eLearning resource's relevance over time and geographical locations. For example, particular details about retail outlets providing bra fitting services, reportedly effective products to manage a dry mouth, or psychosexual support services could potentially be presented. However, a decision was taken not to incorporate these as they were not aligned with the guiding principles which stipulated the need to include accessible, relevant and universal advice and information (p.100, i(1, 5)). To include these may have localised the reach of the resource, making it only relevant for HPs in Northern Ireland (NI). Secondly, as products change and improve, references to specific products may cause HPs to view the resource as outdated and irrelevant, which could impact the trustworthiness of the resource and reduce HPs' motivation to use it. Finally, the provision of services such as psychosexual counselling is limited, so it was necessary not to raise expectations by highlighting support resources for which access was limited. Instead, the resource directed HPs to refer to available relevant healthcare services for particular issues. For example, with bra fitting after breast surgery, the breast nurse could advise on potential services offered by local retailers or local cancer charities.

The findings from the evidence base informed the development of the content of the 'treatment-related effects' section. The expert group and research team provided helpful critique to improve the content and develop a suitable organisational structure to scaffold the content.

#### ***4.3.2.2 Developing new video content***

The use of videos to promote learning can complement other approaches within eLearning interventions (Moffett 2015). Videos can powerfully convey expert and patient perspectives that enhance intervention objectives and assist HPs to grasp the importance

of providing sexual support to patients in their clinical practice (Moffett 2015; Sinclair *et al.* 2017). The MSW: PC eLearning resource contained six video files, each reviewed by the research team. The first video introduced the topic of sexuality and referred to the sexual challenges faced by men and their partners and videos 2-5 provided HPs with various insights into the patient/partner experience of sexual challenges, including helpful coping strategies. The last video file demonstrated an HP facilitating a sexual support conversation with a patient following treatment for prostate cancer. Two of these six videos were retained in their original format for use in the MSW: CC eLearning resource due to their relevance to a broader cancer population. These were video file no. 2: 'Colin', a man with prostate cancer describing how he and his partner adapted to using sexual aids and no. 5 'Lorna's' perspective of coping with sexual challenges as a partner of a man with prostate cancer.

Two additional video files were modified: the introductory and the HP/patient clinical consultation demonstration video. For the introductory video, minor changes were made to the script and re-recorded, with the researcher providing alternative graphics to accompany the new audio. The result was an introductory video covering the sexual challenges after cancer aimed at HPs working with a mixed cancer population. The HP/patient clinical consultation demonstration video was also modified. The earlier version, included within MSW: PC eLearning resource, used an electronic tablet to guide the sexual support conversation which was prostate cancer specific. The script for this video file was appropriately modified, removing the use of the electronic tablet, and instead depicted an HP facilitating a sexual support conversation informed by the EASSi framework without the use of external aids.

The two video files removed from the MSW: PC eLearning resource had tumour and gender-specific content from no. 3 'Martin's' perspective as a gay and single guy with

prostate cancer and no. 4 'Alonzo's' experience of having prostate cancer from a BAME cultural perspective. The video files which remained in both the MSW: PC eLearning resource and the MSW: CC eLearning resource addressed a man's and a female partner's perspective of adapting to sexual challenges following PC. As such, there was a need to increase the relevance of content to sexual challenges facing women including the management of menopausal symptoms and to address both genders wider psychosocial issues such as body image. The researcher identified two potential existing video clips available online, one in which 'Helen' (Macmillan Cancer Support 2014) discussed her challenges with coping with the body image issues after breast cancer and being single. A second video where 'Rebecca and Scott' (Macmillan Cancer Support 2009) focused on the challenges of pain during sex and fertility concerns after gynaecological surgery. When presented to the research team as potential content, there were some reservations around the usefulness of these videos. First, the team shared concerns relating to 'Helen's' focus on the importance of her breast reconstruction as the coping mechanism. In addition, with 'Rebecca and Scott,' the focus on fertility outcomes did not provide insight into how the couple managed painful dry sexual intercourse, a common issue raised within the literature for female patients after cancer treatment. It was agreed that further opinion would be sought from the wider group of HPs during the optimisation study using TA interviews. This feedback is detailed in Section 4.4.5.1 (pp.163-164).

#### ***4.3.2.3 Support resources and referral pathways***

The specific need to increase HP knowledge of supporting resources and referral pathways was reflected in guiding principle (i), as this was a key barrier to providing sexual support identified within the literature (Fitch et al. 2013; Traa et al. 2014; Gleeson and Hazell 2017; Williams et al. 2017; Frederick et al. 2019a). The MSW: CC eLearning resource supporting materials were provided as hyperlinks to other evidence-based, reputable booklets, websites and organisations providing further sexual support and

information. This content was populated through many rigorous online searches of expert organisations in cancer care and recommendations from the expert group and research team. However, the process of locating high-quality content for the resource section highlighted the lack of easily accessible information and advice on sexual support strategies across cancer populations. In contrast, HPs who used the MSW: PC eLearning resource benefited from being able to signpost their patients and partners directly to an extensive self-management patient and partner resource<sup>3</sup> (O'Connor *et al.* 2021). The original MSW: PC eLearning resource printable signposting sheet for patients detailed potential referral pathways, useful weblinks with supporting resources, top tips to remember and included a communication activity. This was retained for the HPs engaging with the MSW: CC eLearning resource who provided care to patients with prostate cancer. Five additional signposting sheets were also created, a general one and one for each tumour group. The signposting sheets' content was reviewed by members of the expert group and research team who suggested minor improvements. These improvements, when applicable, were applied to the "Support resources" section of the eLearning resource. As an example, the general signposting sheet has been included in Appendix 7.

Finally, referral pathways suitable for a mixed cancer population were considered and added accordingly to the MSW: CC eLearning resource. These included a pelvic physiotherapist, erectile dysfunction clinic, incontinence clinic, 'look good, feel better' workshops and a psychological therapist/counsellor. The expert group deliberated over the timing of patient access to support when they encountered problems using vaginal dilators. Members of the expert group reported that radiotherapists usually discussed

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<sup>3</sup> Although not connected to this study, it is of note that members of the research team have since adapted the self-management resource for prostate cancer to one suitable for a mixed cancer population. The new MSW: CC self-management programme for patients' and partners resource has been developed, in part, using the content generated from this study, although does not form part of this study. The MSW: CC self-management resource was not completed in time to include as a link within the MSW: CC eLearning resource during the study period, however, this will be added thereafter.

the use of dilators with patients. However, for many patients, difficulties related to vaginal stenosis (for which the dilators are used) do not present until after radiotherapy is completed, when they are no longer receiving support from radiotherapists. Despite this, the expert group's consensus was that, if a problem was identified by an HP or patient, HPs could request specific advice from a specialist nurse or physiotherapist. Direction for HPs within the eLearning resource was improved to reflect this.

This detailed section has provided an overview of the process of adapting the MSW: PC eLearning resource to the MSW: CC eLearning resource, the development and organisation of new content. Relevant examples highlight the considerations, decisions and challenges experienced by the researcher. This development process culminated in the production of the MSW: CC eLearning resource, version 6, which encompassed feedback from pilot TA interview.

#### **4.4 INTERVENTION OPTIMISATION (PART 2)**

Part 2 outlines the testing process for the MSW: CC eLearning resource prototype, which informed modifications and explored HPs views of the eLearning resource, through TA interviews. This section has detailed the research design for Phase 2, part 2 and has included the researcher's preparation for data collection using TA interviews. Following this, the results from the TA interviews are presented and discussed.

##### 4.4.1 Methods

###### **4.4.1.1 Sample and sampling procedures**

The MSW: CC eLearning resource, was tested with a sample of multidisciplinary HPs who provided direct care to patients from a mixed cancer population, the target audience for the eLearning resource. This cohort was designed to ensure that those involved in the testing were substantially appraised of the sexual challenges men and women with cancer

confronted, and therefore best placed to advise on modifications and acceptability of the resource within their clinical setting. In addition, participants had to be employed in one of the five Health and Social Care Trust (HSCT) organisations in Northern Ireland (NI). The decision to exclude those outside NI, at the time of study set-up, was to enable ease of access to participants for face-to-face qualitative data collection. A summary of the inclusion and exclusion criteria is provided in Table 11.

**Table 11: Inclusion and exclusion criteria for intervention optimisation study**

Inclusion Criteria	Exclusion Criteria
<ul style="list-style-type: none"> <li>• Multidisciplinary HPs providing care to patients from mixed cancer population</li> <li>• Provide direct cancer care as part of routine practice</li> <li>• Employed in one of five HSCTs in NI</li> </ul>	<ul style="list-style-type: none"> <li>• Not providing routine cancer care</li> <li>• Not employed in HSCT in NI</li> </ul>

A non-probability purposeful maximum variation sampling procedure was employed to ensure end-users would be represented across healthcare disciplines and tumour groups, to maximise the breadth of knowledge and depth of experience (Van Hoeven *et al.* (2015; Etikan *et al.* 2016). The researcher also identified a range of professional roles, working with specific tumour groups, who would be beneficial to the study, for example, a pelvic floor physiotherapist and a breast cancer specialist nurse.

The inclusion and exclusion criteria, target HP disciplines and tumour groups was shared with each HSCT local collaborator<sup>4</sup> (LC). Upon consideration of this information, LCs advised the researcher on the accessibility of HPs, as not all HSCTs provide care for all tumour groups or provide a full range of treatments. The LC then selected HPs who they believed would have an interest in participating. Whilst it was acknowledged that this

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<sup>4</sup> A local collaborator is an HP who volunteered or who has a clinical research role in the HSCT who the contact point between the researcher and participants.

sampling procedure was likely to create participant bias in selecting HPs with an interest, knowledge and expertise in sexual care, it was deemed necessary to ensure that those participants recruited were knowledgeable in the field of interest, to maximise the quality of the final resource.

#### **4.4.1.2 Recruitment**

LCs contacted potential participants via email, enclosing a Participant Information Sheet (PIS) and consent form (Appendix 8 and 9). The PIS provided participants with a short rationale for the study, research expectations of participants and contact details of the researcher. The LCs from each HSCT and the researcher liaised regularly to support the recruitment process. After one week, if potential participants from the HSCT had not approached the researcher, the LC contacted potential participants with a further reminder via email reminder and asked for feedback on any issues in contacting the researcher. On a few occasions (n=3), those identified as potential participants declined to take part due to personal circumstances: maternity leave or workload. In these instances, the LC discussed a suitable alternative role within their HSCT with the researcher and another potential participant was approached. HPs who declared interest in study participation usually contacted the researcher directly, however, this interest was confirmed through the LC on two occasions. The researcher subsequently liaised with each participant and the LC to arrange a suitable date, time and venue for the TA interview.

#### **4.4.1.3 TA interviews: Background and rationale**

The researcher used TA interviews as the qualitative data collection method. The TA interview requires participants to verbalise their thoughts, cognitive processes and strategies employed as they engage with a task in real-time (Ericsson and Simon 1998). The PBA views the TA interview as an effective data collection method to elicit views on

all elements of a digital intervention and to understand the range of ways it may be used (Yardley *et al.* 2015a; Morrison *et al.* 2018). The data can inform modifications and refinement of an intervention through iterative test cycles (Yardley *et al.* 2015b). The real-time feedback provided by the TA interview has a significant benefit over alternative methods such as retrospective verbal reports. Specifically, asking participants to recall issues with the intervention content or navigation could be subject to memory loss or bias (Leighton 2017). In previous studies, the TA interview was a valuable method to ascertain how an intervention will be used in its intended context. For example, in relation to estimating physical activity levels, Morrison *et al.* (2018) used TA interviews, which subsequently identified a fundamental problem with participants' interactions with their digital physical activity resource. Participants were found to overestimate their physical activity levels, which rendered the tailored feedback provided to the participant incorrect. In this example, and as part of the PBA iterative approach, the TA interviews provided researchers with an early opportunity to address the problem of overestimation, retest a solution and ultimately ensure the intervention could successfully influence behaviour change. Despite the proven benefits of using TA interviews as an integral component within intervention optimisation, it is not without criticism.

The objective analysis of the content of one's thoughts was largely rejected as unreliable in the early 20<sup>th</sup> century (James 1890). This has since changed (Cotton and Gresty 2006) with a greater acceptance of the method being attributed to improved data collection accuracy. For example, TA interviews have been argued to be reliable when participants engage in a 'well-structured task'. A well-structured task is understood to be when the focus is on the way a participant manipulates and transforms information from working memory towards the generation of a solution to a given problem (Eccles and Aarsal 2017; Leighton 2017). Leighton (2017) has provided a criterion for developing of a well-



structured task. The researcher considered each criteria to ascertain how the current study could address these (see Table 12).

A further issue raised in the literature concerns the 'reactivity' of the TA interview, where providing verbal feedback may change how a participant interacts with the same problem when compared to silent conditions (Eccles and Arsal 2017). Participant reactivity could potentially undermine the usefulness of the process, providing a less accurate understanding for researchers of how their interventions will be used in real time. However, in a meta-analysis of n=94 studies, Fox *et al.* (2011) provided evidence to show that the verbal reports produced in the TA interviews resulted in little or no reliable differences in performance when compared across verbal report and silent conditions. The findings from this meta-analysis provided the researcher with confidence that the data to be collected as part of this study would be valid, as it was an accurate representation of how HPs use the resource.

**Table 12: Criteria for a well-structured task and evidence of application from the MSW: CC eLearning resource TA interviews**

	<b>Criteria for a well-structured task (Leighton 2017)</b>	<b>Evidence of application from the MSW: CC eLearning resource TA interviews</b>
1	Ability to represent the problem and what the proposed solution might require	The eLearning resource was presented using Microsoft PowerPoint, which simulates a web viewing experience or via a webpage. To focus attention, participants viewed and commented on each slide/web page as presented.
2	Apply actions incrementally to the original problem to get increasingly closer to the desired solution	Participants viewed the version of the eLearning resource they were presented, making comments on what they viewed. Participants incrementally contributed to the final version of the MSW: CC eLearning resource through the test cycle iterations.
3	Describe or apply the actions to transform states to solve the problem	Participants reviewed each slide and said aloud their reflections on content, structure, language/tone, which contributed to the refinement of the eLearning resource.
4	The problem can be solved with knowledge and skills that are accessible and operational within the human information processing system	The purposeful selection of HP ensured that those with relevant knowledge and skills participated.
5	True problem-solving task of medium difficulty so that participants are reporting on verbal processes rather than interpretations of recall from long term memory.	Participants were required to read/view new and previously unseen content to provide immediate reactions from working memory.

Finally, the researcher's provision of prompts or interference have been considered by some in the field of research to interrupt the participants thought processes during TA tasks. Ericsson and Simon (1980) advocate that researchers must not interfere with participant's thought processes; this is to ensure that the cognitive processes of the participant have not been changed to any measurable degree by researcher interference. They do, however, support the use of basic prompts to remind participants to 'keep talking'. Nevertheless, other researchers, for example, Cotton and Gresty (2006) have supported the prompting of participants to provide clarity on verbalisations as they

engage in the task, suggesting that this approach can meaningfully increase the usefulness of the data (Cotton and Gresty 2006). Evidence from the literature has supported this latter claim, demonstrating that the use of prompts in TA interviews has no significant negative impact on participants and improves the richness of the data collected (Cotton and Gresty 2006; Whitehead *et al.* 2015; Semple and McCaughan 2019). To be cognisant of both schools of thought, the protocol adopted by this study ensured interruptions to participant thought processes were kept to a minimum, with the view that the researcher was able to establish difficulties relating to functionality or navigation. When it was necessary to gain further clarity, for example, on challenges to content, the researcher explored this with the participants at a suitable point.

The TA interview can provide a valid and reliable method to collect data from participants in real-time. This approach can provide researchers with meaningful observations related to how an intervention is used and audible data on participants views of the intervention. Reviewing the issues raised by other researchers in the field was essential to establish a replicable protocol for the TA interviews, conducted as part of this PhD (see Appendix 10). This action ensured that both the task and researcher behaviour supported the integrity of the research.

#### **4.4.1.4 TA interview procedures**

The TA interviews were conducted face-to-face or online using video conferencing software following a TA protocol (Appendix 10). The LC selected a quiet and comfortable room, to enable participants to remain 'on task'. Participants were provided with water during the face-to-face interviews and encouraged to bring water to the video conferencing interviews. As with other types of psychological research, these were important considerations when the interview was going to take some time and be tiresome for the voice and throat of the participant (Albers 2015; Alhadreti 2021).

Immediately before each TA interview, the concept of the TA interview was outlined. This specified the need for participants to verbalise all thoughts as they progressed through the MSW: CC eLearning resource. Participants were encouraged to provide critical feedback, particularly in relation to the eLearning resource's content, navigation, appearance and functionality. The researcher outlined her role, which included making notes on participants' responses and observations related to their interactions with the MSW: CC eLearning resource. At the end of the TA interview, a short semi-structured interview followed which explored participants overall impressions of the eLearning resource as an educational tool and its usefulness to HPs in cancer care settings. Audio or video recordings (in TA interviews using video conferencing software) were used to collect data for transcription. Participants were reminded that they were free to stop or withdraw from the interview if they so wished and given the opportunity to ask any questions. The data handling procedures were also reiterated.

The interview was kept to a maximum of 1 hour; this was to ensure the quality of the feedback as participants may tire (Eccles and Arsal 2017) and to maximise engagement with the study. Due to the limited interview time, along with knowledge of the additional time required to think aloud (Ericsson and Simon 1993; Fox *et al.* 2011) and experience of conducting the pilot TA interview (discussed later in Section 4.4.4.1), the researcher allocated specific sections of content to each HP. This aligned with the HPs discipline and or tumour group(s). For example, a nurse specialising in colorectal cancer could view both the 'core' treatment effects on sexuality and the colorectal tumour sections alongside general content from Steps 1 and 2. A chemotherapy nurse, alternatively, may view the 'core' treatment effects on sexuality alongside general content in Steps 2 and 3. The purposeful selection of participants supported this procedure, as it ensured that all aspects of the eLearning resource were reviewed thoroughly by relevant HPs. During the

TA interview, if participants were silent for a prolonged time, the researcher reminded them to keep talking aloud. The researcher, on suitable occasions, asked participants to further explain their comments, for clarification. Once the TA interview was completed, the researcher asked participants if they had any final comments or questions and thanked the participant for their participation. At the end of each interview, the researcher took some time to note personal reflections that could support subsequent data analysis in the development of initial codes.

The TA interviews were conducted over three test cycles, with the method used to present the eLearning resource varying throughout the cycles. In test cycle 1, participants viewed a mock-up of the online resource using Microsoft® PowerPoint®. After analysis of data and relevant modifications, an online version of the eLearning resource was created and used by participants during test cycle 2. For test cycle 3, to keep project costs to a minimum whilst allowing the researcher to respond flexibly by implementing necessary navigational changes, participants reviewed the resource using a combination of a Microsoft® PowerPoint® mock-up version and the unedited online version. The TA interviews continued until no significant new concerns or critiques were raised. The decision to stop collecting data at this point differs from that of 'data saturation', which can be considered a 'logical fallacy' (Low 2019) given that further interviews could potentially generate new themes or indeed develop codes further within themes. Instead, the endpoint was a pragmatic decision, based on when the researcher and research team believed the objective to refine the eLearning resource was met and the eLearning resource was ready to move to the evaluation phase. In support of this decision was the surface-level nature of the data pursued, from a relatively homogenous group of HPs who worked in a cancer care setting (Braun and Clarke 2021). Furthermore, the content they reviewed had already benefited from significant input from the evidence

base and expert group. After final modifications were agreed upon, the online version of the MSW: CC eLearning resource was finalised.

#### 4.4.2 Analysis of TA interviews

Interviews were transcribed very shortly after they were conducted by the researcher, SB. The process of transcribing was beneficial as it provided the researcher with an opportunity to become familiar with the data and deepen her understanding of the participants' perspectives (Lester *et al.* 2020). The transcriptions were independently reviewed by two other members of the research team (CJS and CF). The researcher used Microsoft<sup>®</sup> Excel<sup>®</sup> to assist in the analysis process. Two objectives informed the data analysis of this part of the study. First, the researcher sought to identify barriers to HPs' engagement with the MSW: CC eLearning resource that could be iteratively modified to optimise acceptability and usability. Second, the researcher wanted to explore HP's views of the MSW: CC eLearning resource.

##### **4.4.2.1 Objective 1: Identify modifiable barriers to HPs engagement with the MSW: CC eLearning resource**

Following transcription of each interview, the researcher reviewed the transcript and combined all negative and positive critiques of the MSW: CC eLearning resource into a table of changes format (Yardley *et al.* 2015b; Bradbury *et al.* 2018). The table of changes was reviewed at the end of each test cycle by research team members (test cycle 1, participants 1-4, test cycle 2 – participants 5-12 and test cycle 3 – participants 13-18). To meet objective 1, analysis of the transcribed data was deductive in its approach, which was appropriate to inform the modifications required (Polgar and Thomas 2013). Critiques were grouped as they applied to appearance, content, navigation and functionality of the MSW: CC eLearning resource. Table 13 has provided an example of the table the researcher presented to the research team. The researcher used modification criteria adapted from Bradbury *et al.* (2018) (see Table 14 Section 1) to aid

decision-making. Their criteria provided a guide to identify if a modification would likely influence behaviour change or act as a precursor to behaviour change, for example, accessibility, feasibility, persuasiveness, motivation and engagement (Bradbury *et al.* 2018). Furthermore, the decision to implement a modification was influenced by PBA common guiding principles (Yardley *et al.* 2015b) and the specific guiding principles for this study (Table 8, pp.108-109). Modifications were prioritised using the MoSCoW (Must have, Should have, Could have, Would like) criteria (Bradbury *et al.* 2014) (Table 14 Section 2). The refinement process was an iterative process, as the researcher moved between data collection and analysis, identifying the modifications that might be needed, then modifying the eLearning resource followed by further data collection (Bradbury *et al.* 2018). Recently, Morton *et al.* (2021) utilised this method when optimising an online handwashing intervention during the COVID-19 pandemic. They reported this method improved the speed and efficiency of adaptation and optimisation which is in line with calls for more rapid, pragmatic health research methods (Morton *et al.* 2021).

**Table 13: Excerpt of table of changes used by research team when making modification decisions**

Slide No	Negative comments	Positive comments	Possible change	Reason for change	Agreed change	MoS coW
	<b>Step 2</b>					
<b>5</b>	<b>E-Why/E-How</b> 'How to engage' section is repeatedly missed. Your eye is at the bottom of text and needs guided up to the next section. Requires a directive prompt.	<b>E-Why/E-How</b> Layering of information is good  Continuity of Eilís throughout resource is nice, keeps it altogether.	<b>IMP</b>	Key information to assist in behaviour change is being missed.	Number the sections Include a direct prompt at end of Why section to How section	<b>Must have</b>
<b>8</b>	<b>Treatment Side-Effects on Sexual Wellbeing</b>  Treatment side effects concentric circles physical/psychological/social... text is blurry and small.  Low feelings would be better as low mood. This sentence needs reworded.  Title doesn't really make sense, a lot of words without meaning.	<b>Treatment Side-Effects on Sexual Wellbeing</b> Positive feedback on inclusion of BPS model and the message of how the issues are interwoven.	<b>EAS</b>  <b>EAS</b>  <b>IMP</b>	Improve Readability  Improve readability  To prepare users for information	Make circles and text size larger and text less blurry.  Reword sentence to A cancer diagnosis and treatments for cancer can cause low mood, anxiety or change people's feelings about sex.  Reword title 'Treatment Effects on Sexual Wellbeing'	<b>Must have</b>  <b>Should have</b>  <b>Should have</b>
<b>9</b>	<b>Psychosocial Treatment Side-Effects on Sexual Wellbeing</b>  Title doesn't read well, combination of words that don't say or do anything.	<b>Psychosocial Treatment Side-Effects on Sexual Wellbeing</b> Relevant and powerful	<b>IMP</b>	To prepare users for information	Reword to 'Psychosocial Effects on Sexual Wellbeing.'	<b>Should have</b>



**Table 14: Criteria for making modifications to the MSW: CC eLearning resource (adapted from Bradbury et al. 2018)**

Criteria		Means
<b>Section 1: Criteria for deciding whether to make modifications</b>		
<b>IMP</b>	Important for behaviour change	The modification is likely to impact behaviour change or a precursor to behaviour change (e.g., acceptability, feasibility, persuasiveness, motivation, engagement).
<b>GP</b>	Consistent with guiding principles	The modification is in line with the guiding principles of the MSW: CC eLearning resource.
<b>EXP</b>	Experts	For example, HPs in cancer care agree that this would be an appropriate change.
<b>EAS</b>	Uncontroversial and easy	An uncontroversial and easy to implement solution that is in keeping with the evidence base and guiding principles for the MSW: CC eLearning resource.
<b>REP</b>	Repeated by several participants	This point was made by more than one participant and is in line with the evidence base and guiding principles for the MSW: CC eLearning resource.
<b>NC</b>	Not changed	It was decided not to make this change.
<b>NCON</b>	Does not contradict	This does not contradict experience, or the Guiding Principles.
<b>Section 2: Criteria for prioritising which modifications to make (MoSCoW)</b>		
<b>Must have</b>		This modification must be made in order for the MSW: CC eLearning resource to be effective in changing HPs behaviour (given what is known from the evidence base).
<b>Should have</b>		This modification should be made if possible as it may impact effectiveness but may be able to be delivered in a different way or is in some way less critical than a Must have.
<b>Could have</b>		This modification would be useful but may be less critical to behaviour change than a 'Should have' and may only be implemented if time and resources are available.
<b>Would like</b>		This modification is not needed to support behaviour change but could be useful if time and resources allow.

#### **4.4.2.2 Objective 2: To explore HPs views of the MSW: CC eLearning resource**

A different data analysis approach was required for Objective 2. Therefore, when transcription of the last TA interview was in hand, the researcher conducted a thematic analysis of data relating objective 2 for this study, namely 'HPs views of the eLearning resource.' An inductive approach was applied, using Braun and Clarke (Braun and Clarke 2006, 2013) which was considered appropriate for this objective and was also fitting for the data collected. Thematic analysis is not tied to any epistemological or theoretical perspective. It was used for this part of the study as it is a flexible method useful to exploring an individual's experiences, perspectives and opinions, as well as similarities, differences and unanticipated insights (Braun & Clark 2006; Nowell *et al.* 2017). Other general inductive approaches exist, such as Miles and Huberman (1994) which has many similar and suitable features to aid a systematic and rigorous analysis of data. Nonetheless, Braun and Clarke have a clear six-step approach and was deemed fitting to meet this research objective (Braun and Clarke 2006). Braun and Clark's (2006) framework provided a six-step guide to conducting thematic analysis: (1) become familiar with the data, (2) generate initial codes, (3) search for themes, (4) review themes, (5) define themes and (6) write-up. The six-steps were not linear and was possible to move forward and back between them (Maguire & Delahunt 2017; Nowell *et al.* 2017).

The researcher's application of Braun and Clarke's six-step approach to thematic analysis will now be presented.

##### Familiarisation with the data collected

As Braun and Clarke (2006, 2013) have advocated, the data analysis was inductive, in keeping with a qualitative paradigm, beginning with the researcher becoming familiar with the data. This first step involved immersion into the data, which included the researcher

reading and reread the transcriptions, reviewing her notes (excerpt provided in Appendix 11) and personal reflections (example provided in Appendix 13) to understand the breadth and depth of the content (Braun and Clarke 2013; Nowell *et al.* 2017). During this phase the researcher made initial notes to help to inform the generation of codes.

The researcher was mindful of the personal and professional journey she embarked upon when taking up her previous role of Specialist Health Improvement Manager for sexual health, held prior to the PhD study. To develop a language and confidence to talk openly in the subject area with HPs colleagues and staff across the statutory and community sectors, she required education, communication skills practice and time immersed in the subject area, learning from colleagues more experienced in the field. This experience made her acutely aware of the potential challenges sexuality could present to other professionals. Yet, with full acknowledgement that with proper exposure to information and support, skills were developed, making it is possible to communicate about sexual issues with confidence. Recognising this, the researcher was aware that her views and experience could have impacted the interpretation of the data. Therefore, the researcher took a deliberate choice to try to hold no preconceived idea of codes, ensuring that codes were directly tied to segments of data as far as possible.

#### Generation of initial codes

For this step, the researcher coded the TA interviews by identifying relevant data and tagging them with a few meaningful words or a short phrase (Braun and Clarke 2013). Codes identified a feature of the data and were generated from semantics in the text, for example “*very relevant topics*” resulting in the code “relevance – content” or based on a latent feature such as “*everything in a nutshell*” as “content – all-encompassing” (Braun and Clarke 2006, 2013). Care was taken to ensure that context was not lost within the

extracts, ensuring enough of the extract was included to code more accurately. The credibility of the analysis at this stage was enhanced with two members of the research team who independently analysed the initial codes from the transcribed data and challenged the researcher's initial codes (Nowell *et al.* 2017), as discussed below.

#### Search for themes within codes

A 'theme' in thematic analysis is understood to capture something important about the data in relation to the research question posed and represents some level of meaning within the data (Braun and Clarke 2006). Theme development involved the researcher collating all potentially relevant coded data extracts (Braun and Clarke 2006). The researcher used tables and mind maps to create a web-like network to organise codes and themes (Terry 2016). The researcher reviewed code descriptions and critiqued decisions to establish coherent themes that brought meaning and identity to the data (Braun and Clarke 2006). This process was iterative, with the researcher working to provide the best way to represent the HPs views. Initially, a series of codes were reviewed and grouped into themes. Upon discussion with the research team, changes were made to bring better clarity to the themes.

During the process of developing themes, it was evident that some of the grouped codes did not fully capture the meaning of the data, nor concurred with the initial themes developed. This prompted the researcher to revisit these codes (Braun and Clarke 2013). The researcher and wider team considered changes made to these codes to be a more accurate representation of the data.

Two research team members (CS and CF) reviewed the final themes independently from the researcher, with general agreement that the themes were representative of the data.

### Review themes

Next the researcher reviewed the coded data extracts for each theme to consider if they appeared to form a coherent pattern (Nowell *et al.* 2017) and determine if the themes accurately reflected the meanings evident in the data (Braun and Clarke 2006). To ensure that the themes reflected the raw data, the researcher compared the themes with the codes (Nowell *et al.* 2017). To present the most coherent story, it was apparent that it was necessary to group themes into two main themes. These themes are presented in Section 4.4.5.2.

### Definition of themes

To define the themes, the researcher moved away from a summative position to an interpretive orientation (Braun and Clarke 2017). This involved a refinement of the themes and the identification of what each theme was about (Braun and Clarke 2006). As such, the researcher wrote a detailed analysis of each theme, identifying the story it told while considering how each of the themes fitted into the overall story about the entire data set about the research questions (Braun and Clarke 2017; Nowell *et al.* 2017). It was important for the researcher to identify overarching themes and understand how they interact and relate to the sub-themes (Braun and Clarke 2006; 2012). To determine suitability and comprehensibility, overarching and sub-themes were verified and refined through discussion with the researcher's supervisory team.

### Write up

The researcher ensured the writeup of results provided a coherent, concise, logical and interesting account of the data (Nowell *et al.* 2017). Direct quotes were to aid understanding and demonstrate the prevalence of the themes and subthemes (Braun and Clarke 2006; Nowell *et al.* 2017). To ensure rigour and trustworthiness, the findings were

linked back to the literature (Nowell *et al.* 2017). Findings have been written up for dissemination in academic peer reviewed journals and abstracts for international conferences.

The Braun and Clarke (2006) framework provided a flexible, step by step guide for the analysis of the findings of the study. It allowed the researcher to review and challenge coding decisions and supported more comprehensive deliberation and challenge from the research team. In addition, there were many other processes involved to ensure the scientific rigour of the study. These are now presented, followed by a review of the ethical considerations made in relation to this phase of the study.

#### 4.4.3 Scientific rigour, trustworthiness and ethical considerations

Qualitative research has been criticised as merely an assembly of anecdote and personal impressions, strongly subject to research bias, lacking reproducibility and generalisability (Mays and Pope 1995). It is vital that qualitative researchers employ quality standards (Parahoo 2014). Among others, Tracy (2010) and Lincoln and Guba (1985) have provided a set of criteria for researchers operating outside a positivist quantitative approach, which can address these issues and contribute to qualitative research's scientific rigour and trustworthiness. Criteria of credibility, dependability, confirmability and transferability (Polit and Beck 2014) have been established to guide researchers in the pursuit of high-quality research. As such, Table 15 outlines the provisions made by the researcher in this study to address the four-quality criterion specified by Lincoln and Guba (1985).

**Table 15: Provisions to address scientific rigour and trustworthiness of qualitative component of this study (informed by Lincoln and Guba 1986, Shenton 2004, Forero et al. 2018)**

Quality criterion	Purpose	Provision made by researcher
<b>Credibility</b>	To establish confidence that the results are true, credible and believable.	<ul style="list-style-type: none"> <li>• Peer review of optimisation study prior to ethics submission</li> <li>• Study methodology received ethical approval</li> <li>• Adoption of PBA which is used extensively in the development of robust digital interventions</li> <li>• Time spent with expert group and research team to understand the culture of the participating organisations prior to data collection</li> <li>• Purposeful sampling method to ensure a wide range of perspectives were accounted for</li> <li>• TA interview tested at pilot interview</li> <li>• Researcher had required research skills to perform the role</li> <li>• Regular debriefing sessions with the research team</li> <li>• Independent analysis of transcribed data by two members of the research team</li> <li>• Quotes were used to provide ‘thick descriptions’ in the reporting of the data from TA interviews</li> </ul>
<b>Dependability</b>	To ensure the findings of this study are repeatable if the study was repeated with the same cohort of participants, researchers and context.	<ul style="list-style-type: none"> <li>• Detailed research protocol</li> <li>• Ongoing observation of HPs using the MSW: CC eLearning resource prototype during TA interview</li> <li>• Triangulation of data between the expert group, research team, participants and guiding principles derived from theory and evidence base</li> <li>• The researcher documented reflective thoughts after each interview and throughout the data analysis process</li> <li>• An audit trail was kept on key methodological decisions within the study, as documented in minutes of supervision meetings</li> </ul>

Quality criterion	Purpose	Provision made by researcher
<b>Transferability</b>	To extend the degree by which the results can be generalised or transferred to other contexts or settings.	<ul style="list-style-type: none"> <li>• Study procedures reported in detail</li> <li>• Data confirmed that no further major modifications were required</li> </ul>
<b>Confirmability</b>	To extend the confidence that the results would be confirmed or corroborated by other researchers	<ul style="list-style-type: none"> <li>• Provision of a review of the literature to establish research context</li> <li>• Provision of the detailed description of inclusion/exclusion criteria, number of participants, previous training, length of service, data collection methods, number and length of TA interviews and the period over which data collection occurred</li> <li>• Setting out the researcher's philosophical assumptions</li> <li>• Use of a reflective commentary throughout data collection and analysis</li> <li>• Data collection ceased when no further major modifications were identified through data analysis.</li> <li>• Detailed audit trail provided of modifications and rationale</li> </ul>

In further support of the scientific rigour of research, Miles and Huberman note:

“we must consider the rightness or wrongness of our actions as qualitative researchers in relation to the people whose lives we are studying, to our colleagues and to those who sponsor our work. . . . Naiveté [about ethics] itself is unethical.” (Miles and Huberman 1994, p.288).

To this end, the researcher attended to ethical considerations in advance of the study and throughout, considering different factors relating to procedure, situation, relations and exiting the study (Tracy 2010). These following sections present the ethical considerations relating to the optimisation phase of the study.



#### **4.4.3.1 Procedural ethics**

Procedural ethics refers to the ethical actions dictated as universally necessary by governing bodies and includes participant anonymity, confidentiality, autonomy and informed consent, beneficence and non-maleficence. Anonymity refers specifically to removing or obscuring the names of participants or research sites and not including information that might lead participants or research sites to be identified (Walford 2005). Data for this study were managed in accordance with the General Data Protection Regulations and the Data Protection Act (2018). To protect the anonymity of potential participants, the LC in each HSCT made initial contact with participants. Only upon potential participants demonstrating an interest to participate in the study verbally or via email to the LC, were their details shared with the researcher. At the point of data collection, the researcher used a coding system to label notes pages which related to the participant number in the study, HP role or tumour group (for example, PHY for physiotherapist or HNC for head and neck cancer) and the test cycle number (for example, TC3). These same codes were used to label the transcripts and to present findings from the study. The participant's employing HSCT was not identifiable.

Confidentiality refers to the management of private information 'that has been communicated in trust of confidence, such that disclosure would or could incur particular prejudice' (Giordano *et al.* 2007, p.264). Initial TA interviews took place in a private room within the clinical setting with the researcher present, with later interviews conducted using video conferencing software with the researcher and participant in two separate locations. To ensure confidentiality in the online environment, a series of adjustments were approved relating to the use of passwords, video recording and storage. Participants who were interviewed via video conferencing required appropriate equipment and a suitable private room. The researcher used a private study room in her own home. All

study data was kept in securely and safely stored on UU encrypted software or in a secure cabinet with access restricted only to the researcher and supervisors. In line with UU policy for the governance of research involving human participants (2018), participants were advised that study data would be kept for ten years after the end of the study and then securely destroyed.

Informed consent is one way to ensure the autonomy of research participants (Fouka and Mantzorou 2011). According to the Health Research Authority (HRA) (2020), informed consent is when a person with capacity, who is adequately informed, voluntarily under no undue influence, gives their consent. On the other hand, weak consent jeopardises the quality of data collected as respondents may try to protect themselves in a mistrusted relationship (Miles and Huberman 1994). For this study, potential participants were approached by email and provided with a PIS for the study (Appendices 8 and 9). The PIS detailed the background, purpose, recruitment procedures, research procedures, risks and benefits to participating in the research, methods used to protect anonymity and manage confidentiality, contact details for further enquiries, a non-coercive disclaimer and acknowledgement of the right to withdraw at any stage without consequence. Eligible participants interested in taking part in a TA interview either notified the LC who contacted the researcher or directly contacted the researcher themselves. Before the in-person TA interview, the researcher recapped the information within the PIS with the participant, discussed and obtained written consent. For those using video conferencing software, completed participant consent forms were forwarded in advance of the TA interview to the researcher, although the researcher, reviewed this with participants at the start of the TA interview, seeking confirmatory verbal consent.

The ethical principles of beneficence and non-maleficence refer to the Hippocratic Oath “be of benefit, do not harm” (Fouka and Mantzourou 2011, p.5). According to Burns and Grove (2005), discomfort and harm can be physiological, emotional, social and economic. When considering the beneficence and non-maleficence of this part of the study, the MSW: CC eLearning resource can bring about change in the way HPs address the sexual wellbeing needs of patients following a diagnosis and treatment of cancer. A benefit to participation in the intervention optimisation, was the understanding that the data would be used to improve the MSW: CC eLearning resource, thus enhance its utility for HPs providing sexual support to patients with cancer (and partners). While it was recognised early in research planning that the provision of sexual support should already be an integral component of holistic healthcare, it was clear that sexuality discussions were avoided in part due to a perceived discomfort (Moore *et al.* 2013; Canzona *et al.* 2016). For HPs, the TA interview may cause them to reflect on their previous limited provision of sexual support to patients, which could give rise to concerns of unmet patient care needs. To minimise potential distress, the recruitment procedure through the LC was suitable ensuring that only those with an interest in the topic area and willingness to participate, did so. Participants were also reminded of the focus of the TA interviews, namely, to inform modifications to the eLearning resource and explore their views of the resource. Furthermore, at the start of the TA interviews, all participants were reminded of their right to withdraw at any stage. Finally, there was a small risk resulting from the researcher of lone working. As such the researcher worked in accordance with UU’s Lone Working protocol ensuring that all in-person interviews took place on HSCT premises and kept in regular communication with research team regarding the interview schedule. The researcher also considered how to maximise the quality of the research out of respect for HPs participation in the study. The thematic analysis framework offered by Braun and Clarke (2006) provided a robust and systematic method for data analysis. However, the quality of qualitative research relies on

the skill of the researcher (Watts 2014). Training therefore was undertaken on topics including ethics and qualitative interviewing to enhance the researcher's skill in data collection and analysis. In addition, the researcher conducted a pilot TA interview with a member of the research team who had expertise utilising TA interviews as a research method. Throughout the study the researcher worked under regular supervision with the research team, who each had extensive experience and expertise in mixed methods studies and working in the field of cancer care and sexuality.

#### **4.4.3.2 *Situational ethics***

Situational ethics requires the researcher to exercise a higher degree of reflexivity to respond in an ethical manner to ongoing, unanticipated challenges which arise beyond gaining approval for the study (Tracy 2010). In this study, the 'TA' interviews commenced in February 2020 and paused in March 2020 due to the COVID-19 pandemic. Accordingly, the researcher was required to adjust the study methodology to consider COVID-19 lockdown restrictions, alongside the health and wellbeing of both participants and researcher. Following ethical approval for changes to move the TA interviews online, the researcher had to adapt to a variety of situations regarding access to suitable accommodation, appropriate video technology, low broadband issues and varying levels of participants' proficiency using the video conferencing software. On one occasion this called for an interview to be rescheduled and on other occasions the researcher relied on using multiple devices, such as mobile phones and tablets or computers, to facilitate the interview. Researcher reflexivity ensured that the study could proceed ethically and rigorously, within its timeline, without compromising on the quality or quantity of data collection or causing harm or distress to participants.

The primary focus for the TA interviews was to identify HPs views of the MSW: CC eLearning resource. Through this process, some of the HP participants elaborated on their reactions to the resource content, connecting the content to the current provision of sexual support and factors influencing it, as they understood. These comments were offered freely as a response to parts of the resource being viewed. The researcher was acceptant of the variable detail elicited, as it was evident participants had naturally varying approaches to the process.

#### **4.4.3.3 Relational ethics**

Relational ethics involve an ethical self-consciousness; therefore, the researcher was mindful of her character, actions and consequences on others (Tracy 2010). This included recognising and valuing mutual respect, dignity and connectedness between the researcher and the researched (Ellis 2007). Taking cognisance of this, the researcher ensured commitments to the expert group and TA participants through adherence to meetings and interview bookings and providing HPs with flexibility to meet the demands of their role. This facet also provided participants with timely communication of study progress and dissemination of findings.

There was an interdependence between the researcher and participants, with the participants guiding the researcher, while the researcher sought to address an identified research gap (Meloni *et al.* 2015). From the outset of the study, the expert group was fundamental to developing the eLearning resource. Throughout the testing phase, the study participants were open and honest and provided rich feedback to modify the eLearning resource. As such, the researcher, through the adapting and testing the MSW: CC eLearning resource, employed methods to ensure the study made a significant contribution to knowledge, alongside the creation of a quality eLearning resource, with the

potential to enhance HP provision of sexual support and assist current and future policy implementation. Ongoing communication with the expert group members and study participants to share the progress of the study and the link to the final eLearning resource, which they could freely access, was key to retaining mutual respect.

#### **4.4.3.4 *Exiting ethics***

In preparation for completing the study, the researcher considered how the findings were presented and how the study was exited. The researcher communicated regularly with LCs from each HSCT throughout the study, via telephone and email and was purposively closed at a final exit meeting. The researcher has planned to published findings from the study in peer review journals and provide LCs with signposting to researcher outputs and highlight the study findings via social media.

This section has outlined many considerations made by the researcher and the research team to ensure scientific rigour and trustworthiness of the study. In addition, the researcher's thoughts relating to exiting ethics are presented within the discussion section (see Section 4.4.6). The next section discusses the researcher's preparation for conducting the TA interviews which included developing a mock version of the eLearning resource and a pilot TA interview with a member of the research team.

#### **4.4.4 Preparation of eLearning resource for TA Interviews**

To prepare for the testing of the MSW: CC eLearning resource with participants, the researcher created a Microsoft® PowerPoint® mock-up version of the content, presenting each web page on a slide. The expert group previously had used paper copies of content, however, the testing needed to take account of the usability of the wider resource. Using the 'link' and 'transitions' functionality, it was possible to simulate a navigational

experience for participants via Microsoft PowerPoint, similar to how users would engage with the online resource. While this provided the researcher with insights into how participants would use the resource, there were limitations due to the scroll function of the 'mouse' which did override some of the functionality. However, this approach was instrumental in testing some potentially costly web design aspects.

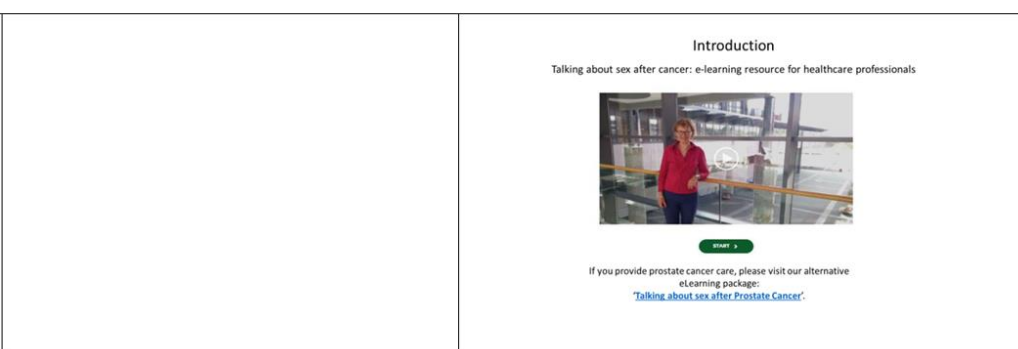

The Microsoft® PowerPoint® of version five of the MSW: CC eLearning resource was used for the pilot TA interview described in the next section.

#### **4.4.4.1 TA interview pilot**

In advance of the TA interviews, the researcher conducted a pilot TA interview to trial the TA protocol with a member of the research team, who both specialised in cancer care and was trained as a sexual health counsellor. At the commencement of the interview, the researcher briefly outlined the study and described the process of the TA interview, which was followed by the completion of the consent form. As agreed at an earlier research team meeting, the researcher used a printed table in paper format, which displayed each slide being viewed by the participant and provided space for the researcher to take additional notes on participant's comments (Fig. 12). During the pilot interview, it became apparent that the one-hour period allotted for the interview would not allow enough time for participants to review the entire resource. As a result, it was agreed that future participants would review pre-determined parts of the resource to include a) the generalist content in Steps 1 and 3, b) the 'core' treatment-related content and c) content related to their area of expertise or discipline. This ensured that all parts of the resource were reviewed throughout the testing phase with the appropriate subject experts. The feedback provided on the eLearning resource via this pilot TA interview allowed the research team member

to identify potential areas for improvement. This feedback was incorporated into the MSW: CC eLearning resource, forming version 6 (feedback discussed in 4.3.2.1, p.126).

**Figure 12: Example of TA interview note-taking sheet**

eLearning resource Test v1 all slides [29 01 2020] PARTICIPANT ID DATE TEST CYCLE	1
Intro Page	
Home page	

**4.4.5 Results**

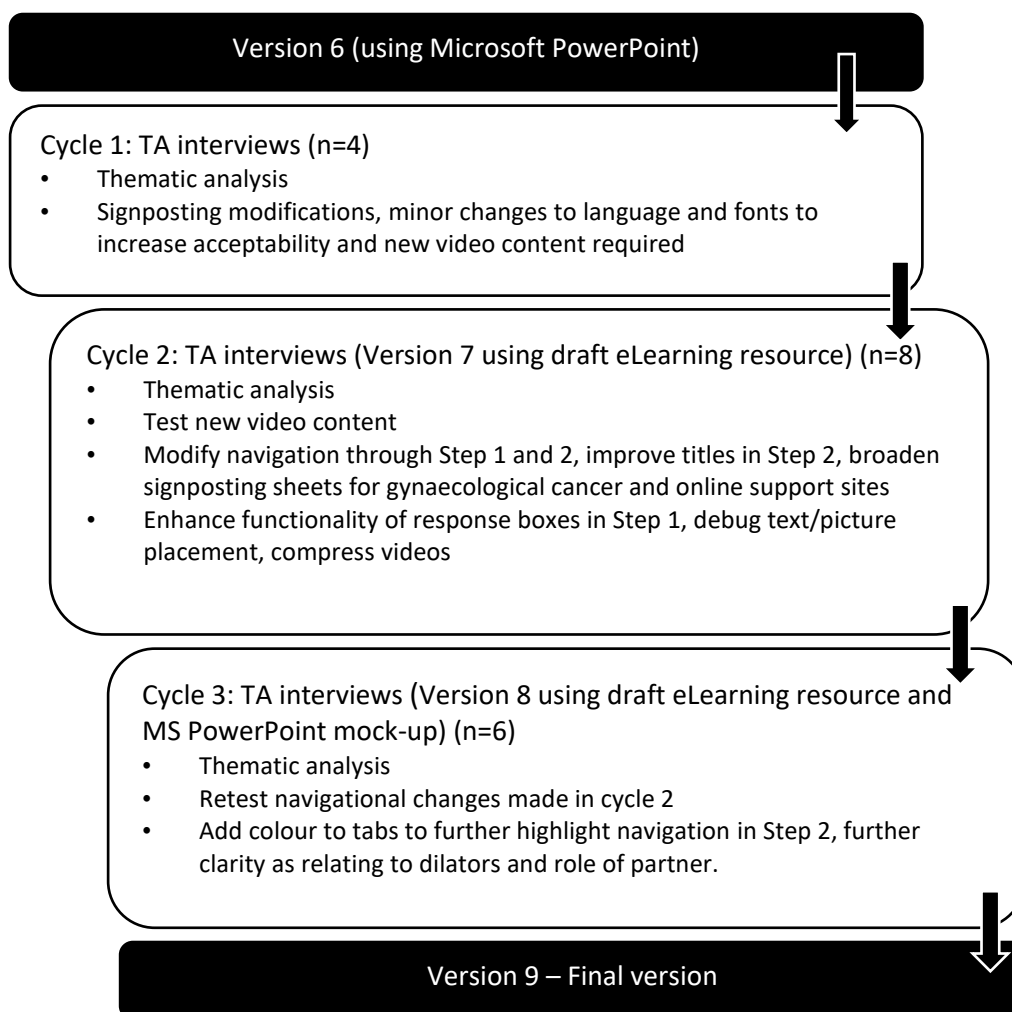
The researcher conducted one-to-one TA interviews (n=18). Table 16 has provided demographic information relating to those who participated in TA interviews. The interviews took place over three testing cycles (see Fig. 13), with n=4 participants in the first cycle, n=8 in second and n=6 in third. The findings from the TA interviews provided data which (1) informed modifications to the MSW: CC eLearning resource and (2) explored HP views of the MSW: CC eLearning resource. The findings from each of these objectives will be presented in the following two sections.



**Table 16: TA interview participant demographics**

<b>Healthcare Professionals</b>		
<b>Participant Identification Number</b>	<b>Gender</b>	<b>Job Title</b>
101 CRC TC1	Female	Clinical Nurse Specialist (Colorectal)
102 GYN TC1	Female	Clinical Nurse Specialist (Gynaecological)
103 RAD TC1	Female	Radiotherapist
104 PHY TC1	Female	Oncology Physiotherapist
105 HNC TC2	Female	Clinical Nurse Specialist (Head and Neck)
106 GYN TC2	Female	Clinical Nurse Specialist (Gynaecological)
107 BRC TC2	Female	Breast Care Nurse
108 CHE TC2	Female	Chemotherapy Nurse
109 PEd TC2	Female	Practice Education Nurse
110 GYN TC2	Male	Consultant Surgeon (Gynaecological)
111 PHY TC2	Female	Oncology Physiotherapist
112 HNC TC2	Female	Clinical Nurse Specialist (Head and Neck)
113 PHY TC3	Female	Oncology Physiotherapist
114 HNC TC3	Male	Nurse Practitioner (Head and Neck)
115 CHE TC3	Female	Chemotherapy Nurse
116 CRC TC3	Female	Clinical Nurse Specialist (Colorectal)
117 CHE TC3	Female	Chemotherapy Nurse
118 HNC TC3	Female	Clinical Nurse Specialist (Head and Neck)

**Figure 13: Testing phase of intervention development using TA interviews**



#### 4.4.5.1 Utilisation of data to inform modifications to the MSW: CC eLearning resource

##### Objective 1: Identify modifiable barriers to HPs engagement with MSW: CC eLearning resource

An overview of the utilisation of data generated from the TA interviews across the three testing cycles has been presented in Appendix 13. HP's feedback relating to modifications balanced across four main themes: appearance, content, navigation and functionality. Appearance issues were minor, relating to font consistency and spacing, all of which were easily addressed. Therefore, the three remaining issues of content, navigation and

functionality were appraised using criteria from Table 14 (p.137). The specific utilisation of data generated from TA interviews is presented in Table 17 (pp.169-170), with some exploration of the issues presented below.

### *Content*

The changes to the detail of the content were essentially minor, often relating to improving clarity and as such were easy to implement. One issue was a tension between the evidence base and accepted practice. The 'Sex, fertility and pregnancy' section included a statement supported by the literature that chemotherapy can pose risks to an unborn child, primarily in the first trimester of pregnancy (Esposito *et al.* 2016). However, current practice, recognising the challenges related to the management of cancer during pregnancy, strongly advised against pregnancy during any stage of treatment and for a period thereafter. If a patient does conceive during the treatment phase of care, it is likely that treatment may have to be stopped or the multidisciplinary team would consider alternative options such as delaying treatment or preterm delivery. HPs wished that the advice was made suitable for use with women across the pregnancy trimesters. While this issue was raised by one participant early in test cycle one, it was decided that if left unchanged it could have a considerable impact on the credibility of content within the eLearning resource. Therefore, this element was modified to state that 'getting pregnant during chemotherapy or radiotherapy is NOT advised; if you are pregnant, treatment may have to be stopped', advising patients that if they do get pregnant during treatment 'it is important to tell your healthcare professional at the earliest opportunity.'

In some instances, participants' views of the content were subjected to further testing before applying a modification. For example, a participant suggested that the advice on treatment effects in Step 2 could be reduced significantly to save HP reading time, which

supported a key feature within the guiding principles - 'ensure that tailored content is succinct'. The participant suggested that "*reducing the room temperature and placing a fan beside your bed can help*" could be amended to read "*↓room temperature, fan at beside*"(104 PHY TC1). However, this view was not held by any other HPs, with many participants expressing value in how the advice could be lifted directly from the eLearning resource and used during clinical encounters, "*as an HP you don't always know what to say...*" (117 CHE TC3) and "*nice that you are giving us the advice to say*"(118 HNC TC3). The decision not to make this change was in keeping with the key features within the guiding principles (Table 8, pp.108-109) which identified the need to equip HPs with advice to help to open conversations about sexual concerns.

Some aspects of content were highlighted by several participants, for example signposting content. Participants reported that the Cancer Research UK (2018) weblink contained helpful information, however, some reported that they were unsure initially of why they were taken to this link, as the relevant information was not immediately apparent and required participants to scroll down to find it. In addition, this link provided details of support organisations that were accessible only in certain parts of the UK, which was problematic. As a result, the researcher amended the weblink to include access to the National Cancer Institute's (2018a; 2018b) web pages on treatment effects for men and women. These weblinks provided access to a greater range of information, including information relevant to the United Kingdom (UK), American and Australia. These changes were found to be acceptable in test cycle 3.

Early in test cycle 1, it became apparent that the research team's concerns about the content of the patient videos were also reflected by participants. Two of the four patient videos from the MSW: PC eLearning resource had been retained and two new patient

videos had been added (details provided in Section 4.3.2.2, pp.129-130). Participants' critique of the first new video, depicting Helen's story, identified that HPs would find the inclusion of strategies to support women when breast reconstruction was not performed would be more helpful, as for many women reconstruction was not part of their treatment pathway. Additionally, HPs reported that the Rebecca and Scott story lacked important detail which could help HPs support patients to manage menopausal symptoms such as vaginal dryness. The researcher was unable to identify alternative suitable video clips. Consideration was given to creating new videos using actors with scripts written from the experiences of members in the expert group. However, with the COVID pandemic and related restrictions imposed, this was not possible. Instead, EM, a research team member, approached a professional contact, Liz O'Riordan, a Consultant Breast Surgeon, author, broadcaster and speaker who kindly agreed (without charge) to contribute two short video clips. O'Riordan, who herself has had recurrent breast cancer, has an active social media presence and advocates for sexual wellbeing after breast cancer. Her knowledge and expertise as a patient and surgeon made a significant contribution to the MSW: CC eLearning resource, providing detailed advice for HPs, to equip patients to manage distressing and enduring sexual challenges. The first video file presented 'sex tips and hints' which can help to alleviate symptoms of menopause, such as vaginal dryness to enhance intimacy. The second video shared tips about improving emotional connectedness with a partner and sex, after a breast cancer diagnosis, which also included advice on coping with changes to body image. Participant feedback relating to the inclusion of new videos is provided in the next section (Section 4.4.5.2, pp.180-181) which investigated the HPs' perceptions of the MSW: CC eLearning resource.

### *Navigation*

Test cycle 2 used the online version of the MSW: CC eLearning resource which flagged significant navigation. The online build of the MSW: CC eLearning resource mainly utilised a scroll-down function, however, on occasion, participants were required to move to the left for additional information, or to click on tabs to view layered information (see Fig. 13). Participants consistently missed these large sections of the content as their attention was focused on using the primary scroll-down function. These additional navigation requirements (arrows and tabs) to access the layered information did not appear to be noticeable. During the TA interviews, when participants were asked to move back, the missed slides were highlighted. Participants reported that *“scrolling was a new approach”* (109 PEd TC2), that they *“wouldn’t have thought about this (moving sideways)”* (108 CHE TC2) and that the navigation was *“not clear”* (111 PHY TC2). The researcher used Microsoft® PowerPoint®, to make refinements to the MSW: CC eLearning resource [v8] for test cycle 3, as the software had the capacity to test the most effective ways to improve the flow of information prior to more costly changes by LMS developers. For example, in Step 1, rather than expecting participants to click on the arrow to view the next slide, this choice was removed and participants were automatically moved to the next statement. Furthermore, in Step 2’s sections with layered information, written navigational instructions had enhanced visibility, as this was subsequently positioned below the text and header tabs were coloured to make them clearly seen (see Fig 14). These changes were tested in test cycle 3. These modifications proved successful, with participants moving through the resource as expected by the research team and not missing the layered information.

Figure 13: Examples of webpages with navigational difficulties

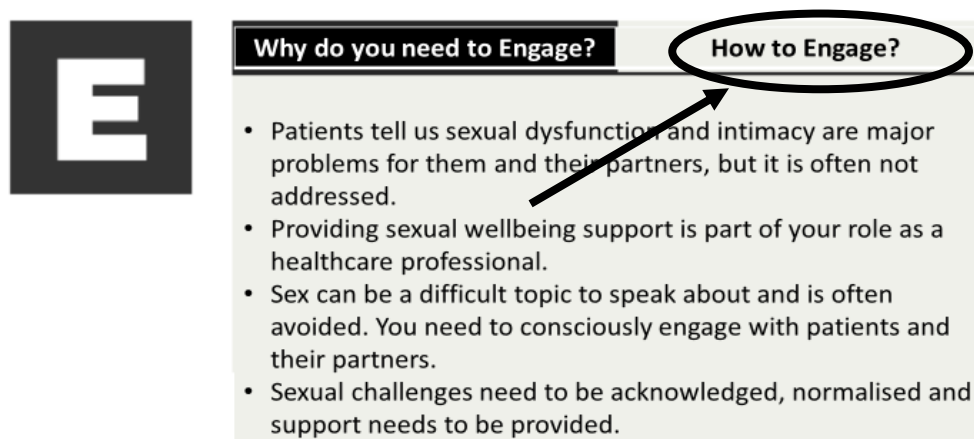
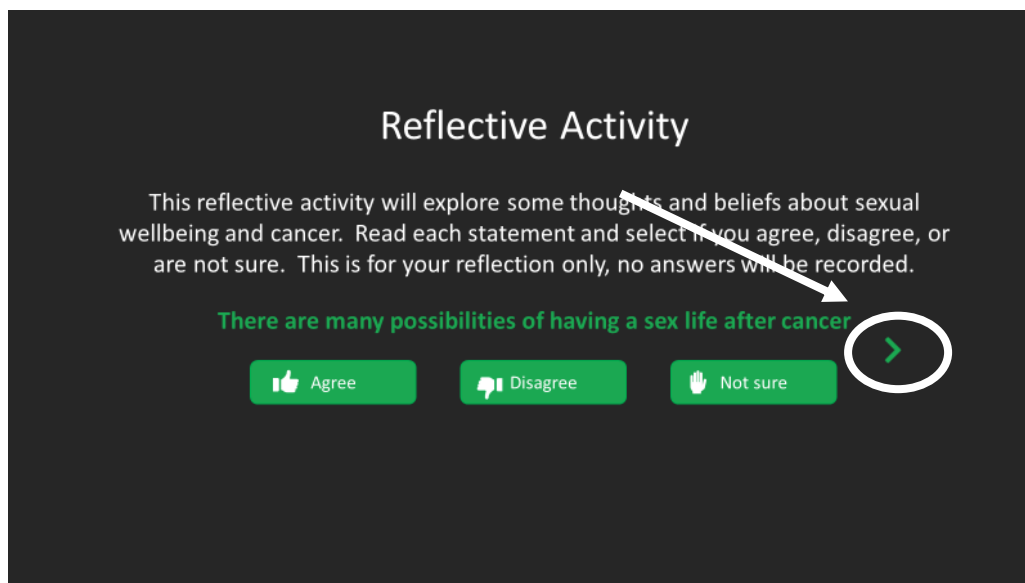
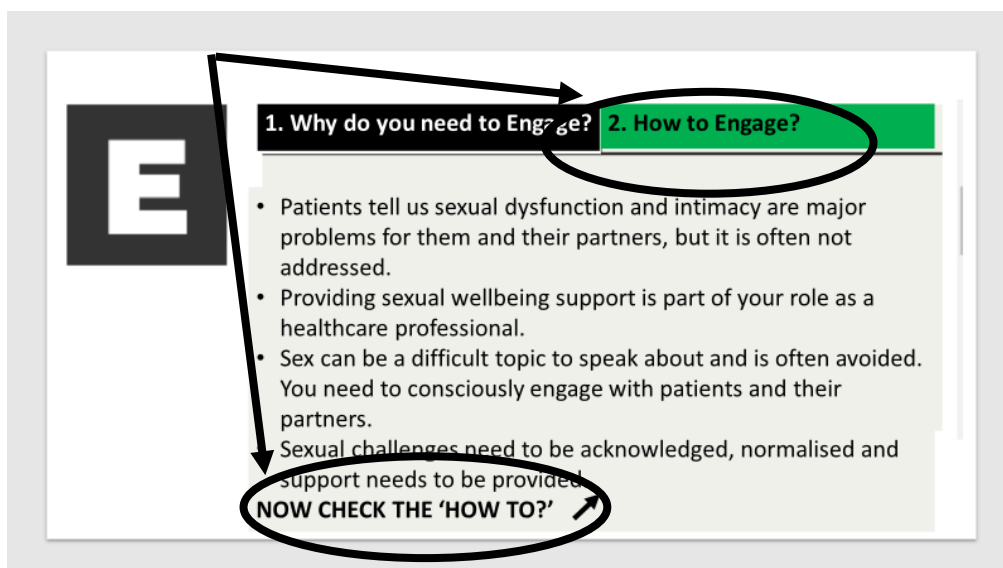


Figure 14: Additional navigational instructions in Version 8 of MSW: CC eLearning resource



### *Functionality*

Finally, there were four issues relating to the functionality of the resource. Three of these were technical issues quickly resolved after discussion with the web developers. These issues involved advice boxes in Step 2 running off the right-hand side of the screen, icons appearing on top of content and videos unable to play in places with low bandwidth. The remaining issue related to the design of the reflective activity in Step 1. Although the responses to the reflective question in Step 1 were not recorded, the exercise provided an opportunity for reflective practice regarding potential barriers to providing sexual support. Some participants reported that although they saw the value in reflecting on the barriers they faced, it was unlikely that they would complete this task. On the other hand, those who did submit text comments were confused by the non-responsive action and unsure of what to do next. To enhance this section, functionality was added to the reflective activity 'Enter' button. This meant that when 'clicked' participants were automatically taken to the next section, which explained and challenged the barriers to the provision of sexual support from the literature. Participants were positive regarding this change; however, this did not address the potential lack of motivation to complete the activity. The researcher discussed this tension with the LMS developer and research team as to whether to apply completion criteria, which would necessitate participants completion of the activity to proceed through the eLearning resource. A decision was taken not to implement this to support of PBA's common guiding principle which prioritises user autonomy; this action avoided dissuading engagement by frustrating users. It was deemed more beneficial that HPs continued to move forward through the resource rather than insist on participant reflection.

During the third phase of testing, a small number of minor issues were identified, which although applied, were deemed not to have a substantial effect on the effectiveness or acceptability of the intervention. As a result, no further test cycles were conducted.



Although the researcher had ranked all modifications using 'Must have, Should have, Could have, Would have' (see Table 14, Section 2, p.145), in reality, all of the changes identified were in keeping with the guiding principles and were implemented. Furthermore, they were achievable within the resource and time allocation for the intervention development phase.

**Table 17: Utilisation of data generated from TA interviews**

	Cycle 1 (MS PowerPoint)	Cycle 2 (Online version)	Cycle 3 (Online resource and MS PowerPoint)
Appearance	Split larger paragraphs on common myths and HP perspective to improve readability on a large screen.	Increase text size and improve layout in Step 2 Specific tumour section response slides as suboptimal to other content.  Check font consistency throughout the resource.	
Content	Extend examples of good practice relating to specific populations in single and LGBT as is provided in 'end of life' section.  Remove repetitive slide at the beginning of Step 2 describing EASSi Framework.  Language (1) Increase acceptability (should to may, should to could). (2) Reflect clinical practice, e.g. remove specific advice relating to treatment and pregnancy, ask patients to avoid pregnancy and speak to HP if there are any concerns. (3) Facilitate HP autonomy on recommendations for individual treatment e.g. do not specify hormonal or non-hormonal vaginal moisturisers, instead suggest 'designated vaginal moisturisers.'	Include disclaimer relating to the products mentioned in Patient video (Liz Part 1).  Improve online support options as not relevant to all areas in the UK and users lack clarity on relevance of content.  Improve title clarity in Step 2 Support section.  Remove repetitive slide in Step 2 Support prior to Psychosocial Effects on Sexual Wellbeing.  Broaden Gynaecological signposting sheet resources on increase relevance across types of tumours.	Change wording relating to 'main role of partner' as not reflective of the point being made.  Increase clarity for HPs in Step 2 Support section on: where patients can access dilators support (GYN), timing of intimacy in relation to stoma activity (CRC) and use of Heat Moisture Exchange filters (HNC).  Reorganise ordering of 2 questions in couple communication activity on Signposting sheets to encourage progression in thinking towards couples trying new things.

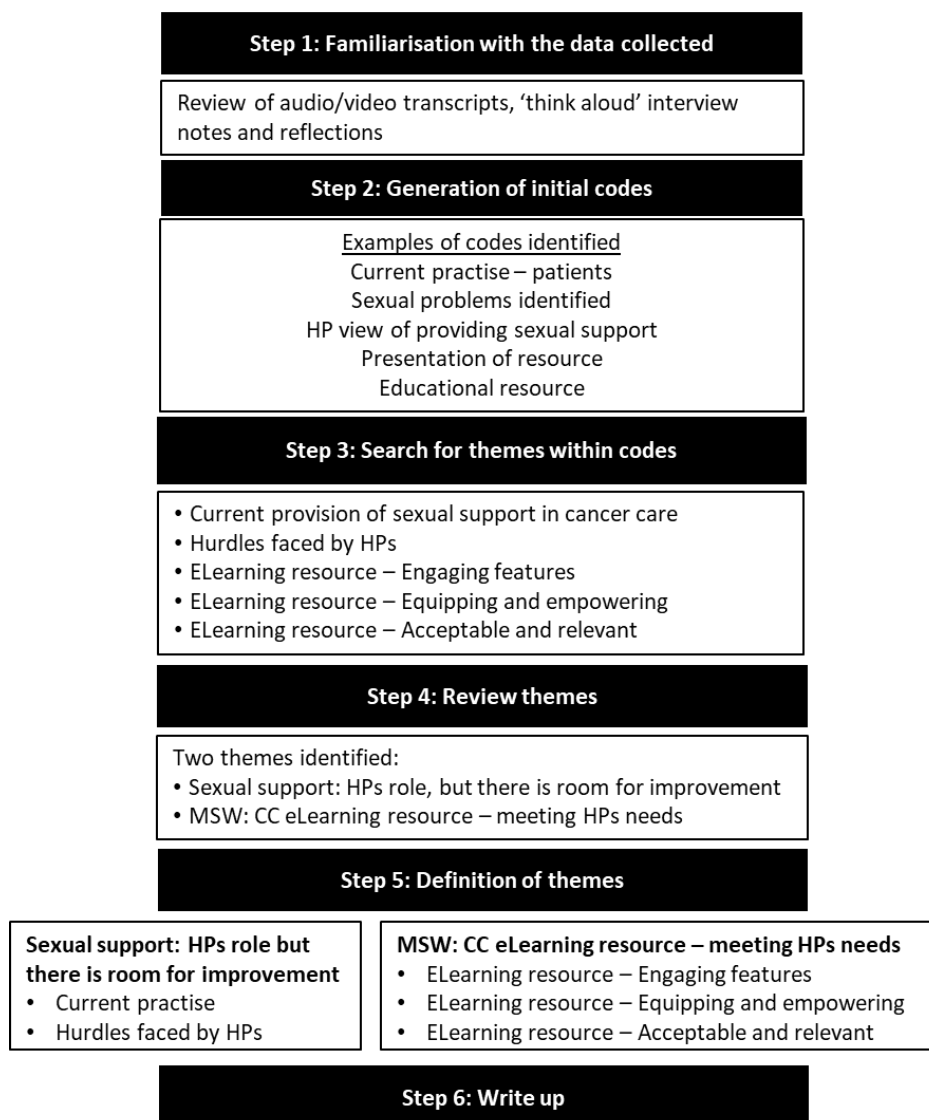
	Cycle 1 (MS PowerPoint)	Cycle 2 (Online version)	Cycle 3 (Online resource and MS PowerPoint)
Navigation	Improve the relevance of video content on emotional concerns, body image and coping with menopausal symptoms.	Minor changes to provide clarity to advice.	
	Remove irrelevant signposting instructions from 'advice slides' in Step 2 Support section.	<p>Improve side-way navigation in Step 1 as most users miss information.</p> <p>Improve signposting within the layered sections of the EASSi framework in Step 2 as users overlook content.</p> <p>Provide clarity to navigation, changing 'Back to Start' to 'Back to previous section' in Step 2</p>	Add colour to the tabs in layer information sections in Step 2 to enhance navigation.
Functionality		<p>Add functionality to Step 1 Response activity, as nonresponse confusing to users.</p> <p>De-bug the Step 2 Support section 'advice boxes' as the information runs off the page meaning users cannot view all text.</p> <p>Ensure icons do not appear over text in Step 1 response screens.</p> <p>Compress videos to ensure they can be accessed when bandwidth is limited.</p>	

#### 4.4.5.2 Thematic analysis on HPs' views of the MSW: CC eLearning resource

##### Objective 2: To explore HPs views of the MSW: CC eLearning resource

Further to the modifications identified and presented above, thematic analysis of the TA interviews with HPs (n=18) using Braun and Clarke's six-step framework identified five subthemes, which were further categorised into two overarching themes: 1) Sexual support – it's the HP's role, but there is room for improvement and 2) the MSW: CC eLearning resource - meeting HPs' needs. Figure 15 presents the researchers application of thematic analysis using the Braun and Clarke (2006) approach.

**Figure 15: Outline of process for thematic analysis of the TA interviews**



*Theme 1 – Sexual support – it’s the HPs’ role, but there is room for improvement*

The current provision of sexual support in cancer care was reported by HPs to be limited, described as a topic often “*side-lined*” (114 HNC TC3, see p.161 for information on participant codes), “*shied-away from*” (110 GYN TC2) and “*brushed over*” (109 PEd TC2). In routine clinical care, sexual support was often confined to the consent process for treatment, with patients left to navigate sexual challenges later in the treatment trajectory, without support and guidance from their cancer team. HPs recognised personal shortcomings when it came to providing sexual support for patients and partners although, in doing so, HPs acknowledged this was indicative of the limited sexual support culture within cancer care. When sexual support was provided, it was considered inadequate, given the sexual challenges patients and partners face. On reflection, disappointment was expressed by HPs.

*“I just feel I have let all my patients down in the past few years... how many are feeling and going through this [sexual challenges] and we are not addressing it.” (115 CHE TC3)*

Yet, HPs identified sexual challenges resulting directly from the treatments provided in cancer care, as valid support needs, with one participant highlighting “*they [patients] need to know the potential impact so that they are not shocked later down the line should it [sexual problems] occur*” (116 CRC TC3). Furthermore, HPs were cognisant that despite patients having the potential to achieve sexual satisfaction after cancer, that for many it was unlikely to be achieved or maximised, with the same participant saying, “*I agree they can [have a satisfying sex life after cancer] but whether they [patients] do is another thing*” (116 CRC TC3).

Despite this, HPs stated they viewed the provision of sexual support as an important and integral part of their role, understanding that these discussions were necessary to obtain informed consent from patients before treatment. This was to ensure that patients

realised the potential impact of treatment on sexuality, to normalise symptomology, to make onward referrals for patients requiring more help and to provide support strategies to *“help patients cope at an earlier stage”* (111 PHY TC2); so that presenting sexual challenges do not *“hit them as hard mentally later on”* (117 CHE TC3). The dyadic nature of sexual challenges of cancer on couples was acknowledged by HPs, with one HP highlighting specifically the significance of psychological challenges within the relationship.

*“Intimacy is a huge thing... I hear that time and time again, where one partner just can't come to terms with it and it's not usually the partner that has come through the treatment, it's the other one, which leaves the partner coming through the treatment feeling worthless... and I hear that quite regularly.”* (116 CRC TC3)

HPs viewed themselves as *“ideally placed”* (110 GYN TC2) to provide sexual support, with HP-led sexual support enabling patients to take an active role in their sexual care and to engender a sense of empowerment with patients as *“sometimes just engaging will give them [patients] confidence to bring it up at the next appointment”* (111 PHY TC2). However, for the HP, the provision of sexual support was fraught with challenges; particular difficulty was experienced by HPs in the initiation of a sexual support conversation. Another challenge reported was providing sexual support in the presence of a partner or family member, where they feared being considered intrusive or offensive. Participants reported, *“I suppose people are worried about offending a patient...”* (118 HNC TC3) and *“you don't want to be intrusive...it can be difficult when the partner is there as patients don't want to speak out of turn about private relationship”* (108 CHE TC2). The reasons for challenge were varied, with factors relating to the HP, patient characteristics and the organisational setting, as discussed below.

*HP-related factors*

HPs strongly expressed feeling ill-equipped to address the sexual problems patients and partners faced. They identified gaps in their knowledge, which negatively impacted their capacity to provide sexual support and articulated clearly the need for an intervention to help. While identified at an individual level, the lack of knowledge and need for support, was also characterised as a requirement for HPs working across cancer care.

*“As HPs we don’t have support for this [providing sexual support], sometimes we get asked questions, but we need help.” (117 CHE TC3)*

The gap in HP’s knowledge related to numerous facets, including how to approach the topic of sexuality sensitively, especially when caring for older patients, uncertainty of the correct language to use, lack of strategies to offer to patients to help them to cope and to achieve sexual pleasure, and knowledge of referral pathways for additional support. The sense of disablement experienced by HPs arising from a lack of knowledge on sexual support was starkly contrasted by one HP who felt equipped with knowledge and a sense of self-efficacy; demonstrating the potential value of equipping HPs in this area.

*“I’ve learned about some sexual dysfunction issues that I have never known about before I came into this role, so it has been a big learning curve.... It’s been great learning and being able to tell people that you can orgasm without or without penetrative intercourse.” (116 CRC TC3)*

Addressing knowledge deficits in isolation was perceived to have a limited effect, without an accompanying development in skills and self-efficacy to provide sexual support. Skill development and self-efficacy was deemed necessary to address feelings of awkwardness, embarrassment, or shame perceived to be experienced during patient-professional consultations.

Findings highlighted that for the HP, discomfort in initiating sexual support could be reduced by adopting a team approach. It was suggested that those in medical roles providing salient background patient information, with those in roles such as nursing to

direct the provision of sexual wellbeing support. Although there was debate around which HPs would proactively provide support, more often the findings highlighted the view that medical roles may be more exclusively focused on treatment progress and less on psychosocial issues. Participant quotes that demonstrated this view included, *“Consultants would find it hard to explore this I imagine as they are focused on the medical. Many wouldn’t follow up,”* (118 HNC TC3) while the CNS may be a more appropriate professional to address this aspect of care with a participant reporting, *“[discussing sexuality is a ] nurse specialist kind of role or I would see as part of my role [nurse practitioner] too, but I’d be more directing them towards the CNS”* (114 HNC TC3). This view was not exclusively adopted. To circumvent the challenges HPs encountered providing sexual support, some HPs reported that sexual support needs could instead be addressed by those working in the voluntary/community sector.

*“It’s not an easy thing for HPs to talk to patients about sexuality so you can signpost to Macmillan for more information.”* (113 RAD TC1)

Despite these self-identified HP-related challenges, many HPs communicated a willingness and eagerness to redress the lack of knowledge and skills and personal discomfort experienced so that they could support patients to enhance QoL. This attitude is evident in the following quote, *“We need to have this. We are not educated, so we cannot help patients”* (107 BR TC2).

#### *Patient characteristics*

Some patient characteristics, such as sexual orientation, gender identity including being transgender, older age and an age gap between HP and patient, where the HP was younger, were found to influence decision-making relating to the provision of sexual support. First, HPs reported that support for same-sex partners was viewed as less available than that for heterosexual couples and only approached if *“HPs felt forced to”*



(114 HNC TC3), with a feeling that this may be reflective of the more culturally conservative locale. HPs also appeared more reluctant to initiate sexual support with older patients, believing that the topic had less relevance for older people, “ *if someone is older, I don’t bring it up because I don’t think that there is any need....*” (102 GYN TC1). Furthermore, HPs reported a fear of being perceived as inappropriate by enquiring into current sexual relations with an older patient, especially when there could be a risk of that patient’s partner “*having dementia or being deceased*” (102 GYN TC1).

*“I worked with a consultant one time... who... a woman ... she was maybe 78/79 and the consultant said to her... ‘how’s your sex life’ and the woman said, ‘my husband died 10 years ago’ and she said, I know, but ‘how’s your sex life’ and she said, ‘look I repeat my husband died 10 years ago’. ...as if she was anticipating that this woman was gonna meet a new partner and be having loads of sex. It was really embarrassing for her; her daughter was embarrassed ... I was embarrassed. It didn’t take a flinch out of the consultant, but I’ll never forget that how embarrassed that woman was.”* (110 GYN TC2)

Despite the encounter, this HP and others were challenged by their reluctance to provide sexual support to older patients; identifying those assumptions based on age could be incorrect.

*“I have one patient in their 80’s who has a very active sex life and others in their 60’s who are not interested...your assumptions should go out the window.”* (110 GYN TC2)

Finally, the age and gender differences between HP and patient were seen as problematic to the provision of sexual support. There was a view that younger HPs would be uncomfortable providing sexual support to patients who were older. Equally it was also suggested that older patients would find it embarrassing to speak to a younger HP. To reduce the perceived embarrassment experienced by patients, it was considered by the HP that retaining a focus on the healing of body parts, was more appropriate than discussions of attaining sexual stimulation and pleasure, although this could serve to protect the HP from potential embarrassment. “*Stimulation and pleasure... I think women are embarrassed because I am younger man in my 30’s, my focus tends to be more on*

*healing after surgery rather than stimulation and pleasure*" (110 GYN TC2). Furthermore, HPs perceived that if HP gender-matched that of the patient, patient embarrassment could be reduced.

From the results, it appears that patient characteristics were an essential influence on HPs decision making on the provision of sexual support, along with HPs levels of confidence to provide support adequately.

### *Organisational factors*

There were three organisational challenges identified, time, privacy and the change to virtual appointments due to Covid-19 restrictions. First, concerning time, there were discrepancies between HPs views on the time available to provide what was considered *"in-depth sexual support"* (114 HNC TC3). One viewpoint expressed that there was a lack of time, however an alternative view was the *"[lack of] time can often be used as an excuse"* (118 HNC TC3) to avoid addressing an uncomfortable topic. Instead, examples of adequate time and opportunity to provide sexual support were described, such as during appointments for physiotherapy massage, administration of intravenous chemotherapy, or holistic needs assessment consultations. It is important to acknowledge there was a sense of autonomy apparent within the specialist roles of these HPs, which may not be indicative of all roles of HPs within cancer care.

*"I allow patients extra time to talk... physio has the opportunity during massage... there is time to chat."* (111 PHY TC2)

*"I'm very lucky I run a holistic needs clinic and my patients get an hour of my time so there is never a lack of appointment time."* (116 CRC TC3)

The delivery setting also seemed to impact on HP's view of privacy when providing sexual support, with the lack of privacy afforded by a curtained cubical seen to inhibit conversations. Furthermore, with the transition to virtual appointments, due to COVID-

19 restrictions on patients attending healthcare settings for appointments, a decrease in sexual support conversations was noted with a view that “*patients were more reluctant to participate in sexual support discussions*” (116 CRC TC3) on a virtual forum and partners were less likely to attend virtual appointments. While noted that the presence of a partner was a barrier to HPs and patient’s communication about sexual concerns, there may have been other factors at play influencing whether discussion took place virtually, which are unknown.

The current levels of sexual support reported and the reflection of HPs on the challenges they faced in the provision of sexual support endorsed the need for an educational resource to support sexual wellbeing communication across cancer care settings.

#### *Theme 2: MSW: CC eLearning resource - meeting HPs’ needs*

The feedback provided by HPs through the testing phase suggested that the MSW: CC eLearning resource has potential to address many of the barriers identified by HPs and to enhance the provision of sexual support in cancer care. Evidence to support this position was identified over three subthemes; the MSW: CC eLearning resource 1) has engaging features, 2) it equips and empowers HPs and 3) is relevant to practice.

#### MSW: CC eLearning resource: Engaging features

HPs expressed that the presentation of the eLearning resource was easy to read with well-written content, which addressed sexual challenges faced by patients from the outset. The multimedia interactive elements of the resource were “*immediately engaging*” (109 PED TC2) and reported to support reflective practice; nonetheless a few HPs were unsure if they would engage in the reflective activities. The pictures and statements used throughout the resource, for example, of an older couple on a park bench, were identified as both “*memorable*” and “*contemplative*”(109 PED TC2). HPs found navigation through

the eLearning resource to be *“straightforward and easy to use, quite intuitive”* (114 HNC TC3), the layout of the information encouraged users to consider and reflect on questions and subsequent sections provided helpful and simple answers. This promoted onward engagement. Progression within the resource was evident with *“same messages but building information through layers”* (109 PEd TC2) through the resource, maintaining the balance of informing users without being overwhelming. HPs regarded the resource to be one that HPs would want to spend time on, rather than rushing through to mark as a task completed, as reported by this participant’s final thoughts,

*“this is an important piece that needs highlighted, the training exercises, the length is very appropriate, straight to the point, clear, gives you a lot to think about, it’s not something that you will be clicking forward through to get to the end, you are going to stop and read it, it is a taboo subject but one HPs are interested in.”* (105 HNC TC2)

HP viewed the eLearning resource as credible, with its content grounded in a clear evidence base with participants valuing the inclusion of references to authorship, *“I like that references are there”* (109 PEd TC2). In addition, the use of up-to-date statistics on the extent of issues faced by patients and limitations of support and relevant supporting references enhanced its acceptability, with one participant highlighting *“love that... research shows with patient and persistence... we can bring in statistics there....”* (114 HNC TC3). The supporting references were considered to add weight to key messages, potentially offering patients and partners a sense of *“hope”* (118 HNC TC3), although the reference detail, for some HPs, was viewed as unnecessary. HPs valued the patient video content acknowledging the patient voice as *“the best learning tool we have”* (118 HNC TC3). Specifically, the video content provided by Liz O’Riordan, the Consultant Surgeon and breast cancer patient, was considered *“powerful”* (118 HNC TC3) as she spoke from the lived patient experience and as a medical expert, with one HP describing

it as a *“honest, frank and lived experience”* (113 PHY TC3). The websites to which the resource linked to were perceived as *“sound”* (101 CRC TC1) and *“reputable”* (116 CRC TC3), as they were well-known for high quality information by those working in cancer care.

MSW: CC eLearning resource: Equips and empowers

The MSW: CC eLearning resource was found to be informative, extending HP’s knowledge of the level of sexual challenges faced across cancer care and population groups, the need and desire for sexual support across treatment trajectories. It also provided relevant advice, resources and referral pathways. HPs identified that it broadened the definition of sexuality, with one participant reporting *“it [the eLearning resource] introduces to the HP that there are many issues beyond the act itself”* (103 RAD TC1). Frequently, HPs reported *“I hadn’t thought about this before”* (110 GYN TC2) or *“I did not know that”* (107 BR TC2), with examples relating to psychosexual challenges, navigating new relationships, sexuality issues at the end of life and specific challenges within tumour groups such as managing a PEG tube or a colostomy/ileostomy.

The content was perceived to support HP practice by normalising sexual challenges for patients irrespective of relationship or treatment status, for example, patients in a relationship, those pursuing new relationships and sexual challenges across treatment types and treatment trajectories. One participant’s quote demonstrated this,

*“good that there is the acknowledgement for the person who has undergone treatment, the partner and looking to the future for the person who is maybe going to pursue a new relationship. Great things in here, really normalises.”* (112 HNC TC2)

Also, the resource normalised the provision of sexual support by clearly and directly identifying the HP’s role, which HPs *“can’t duck and dive”* (112 HNC TC2). HPs were also

able to clearly identify the importance of providing sexual support as a means to promote open communication between patients and partners, with one participant highlighting *“it [sexuality] is a difficult topic for a patient to raise with a partner, I think the communication activity could help to open the conversation”* (113 PHY TC3). Furthermore, the importance of providing sexual support was seen as a way to further develop HP self-efficacy, with this perspective demonstrated in these quotes, *“[EASSI Framework] you see this is what I need help with... saying the right words...”* (102 GYN TC1) and *“[signposting sheet] really really like this ... will be useful to help to lead a conversation”* (116 CRC TC3).

HPs suggested there was a need for the EASSi framework. This was clearly articulated, with a strong rationale for its application to promote active engagement with patients. One participant reported *“it is clear what it is.... ... it allows nurses to buy into the rationale, very good...if you have a rationale, it helps you to apply it...”* (117 CHE TC3). This proposed brief framework provided HPs with reassurance and support for skill development through its step-by-step approach. It also normalises sexual issues, addresses expectations and provides appropriate support, which could be used in clinical practice.

The “Support” element of the EASSi framework equipped HPs with succinct yet *“practical”* advice (109 PEd TC2) which was *“comfortable”* (115 CHE TC3) and considered within the reach of HPs. The advice provided within the support section, was seen as equipping HPs with tools that could address current communication difficulties as it *“puts difficult things into words”* (109 PEd TC2). Also, wider aspects of the resource played a key role in supporting HPs to find a way to approach sexual support conversations, including the demonstration video and patient videos. HPs welcomed being able to print off the one-page EASSi framework to keep in their diary as a reference point or to place on a wall. Furthermore, the EASSi framework was regarded as suitable for further adaptation to help early career HPs to explore challenging healthcare issues.

Signposting within the resource, which included the hyperlinks to webpages, referral pathways and signposting sheets, was described as helpful to support the provision of sexual support. Information accessible through weblinks offered HPs an alternative way to share information with patients, especially if the patient appeared *“too embarrassed to talk”* (117 CHE TC3). The inclusion of the General Practitioner (GP) was noted as helpful, as GPs have a broader knowledge of patient treatment needs and many of the sexual challenge’s patients may face continue beyond the active treatment phase. The printable signposting sheets were considered a valuable resource, as they offered HPs (1) a guide when providing sexual support, with one participant reporting *“I could anticipate and pull out as items in my toolkit to help me navigate conversations”* (112 HNC TC2). (2) Pointed to and reminded HPs and patients to onward referral options, with one participant highlighting the need for this support, *“yes, where do we signpost when they need professional help... [I] wouldn’t have thought of continence service or physio but very relevant”* (118 HNC TC3). (3) Reinforced key sexual support messages and (4) offered a tool to facilitate communication between partners (couples communication activity). One participant suggested that a couple could be given a few copies of the communication activity *“so that they could do the couples activity separately then come together and do”* (114 HNC TC3). That said, a small number of participants were less in favour of the signposting sheet. One concern related to the detail of support provided for HPs rendering the appearance of the printout as *“very busy”* (109 PED TC2). Second, some HPs thought the couple’s communication activity included on the printout could be unexpected and *“quite challenging [for patients and partners]”* (110 GYN TC2). That said, there was an acknowledgement that the couple’s communication activity could have potential benefits, acting as a vehicle to promote communication between patients and partners.

There were a range of strategies to assist HPs to gain self-efficacy and move from transfer of knowledge to practice, such as role-play with a colleague, goal setting, incorporating into department training and mentoring. HPs perceived these activities to enhance their confidence and self-efficacy, although HPs identified varying personal preferences for these strategies. The eLearning resource fostered a sense of empowerment, with HPs reporting increased motivation and readiness to put into action their new knowledge.

*"...see reading through that like ... I would go for it now like." (117 CHE TC3)*

*"[its] good to know what tool kit as an HP I have. Learning does empower you." (118 HNC TC3)*

#### MSW: CC eLearning resource: Acceptable and relevant resource

The MSW: CC eLearning resource content was accepted by each of the HPs in the study. Key messages were described as *"positive"* yet *"realistic"* (108 CHE TC2) while communicating key points. A few examples included recognising that patients and partners may face continued challenges; persistence was often required to address sexual challenges; and when in a relationship, the partner plays a key role in maximising sexual wellbeing. The resource was considered *"true to life"* (117 CHE TC3) reflecting relevant issues which regularly present in the clinical environment. For example, changing levels of sexual desire, change in roles in the household *"my wife has become my carer"* (118 HNC TC3), difficulty communicating about cancer treatment in new relationships and concerns about sexual desirability after a stoma or erectile dysfunction. The messages within the resource were found to be all-encompassing, covering issues HPs encountered with patients and partners across the biopsychosocial domains demonstrated by a participant comments, *"very relevant topics, with no topics missing..."* (105 HNC TC2).

HPs found the advice provided to be in line with current best practise, such as promoting expert strategies and taking into account the impact of specific surgical decisions on



sexuality, including women choosing to or having to 'go flat' after breast cancer. One participant reported, *"I wouldn't have realised that [earlier in career] .... be proud to go flat... it's good to have the flat option promoted as this is something that women choose"* (117 CHE TC3). While advice relating to treatment effects contained within the support section of the resource was not equally applicable to all HPs, the structure facilitated HPs ease of navigation to sections relevant to their role. Overall, the advice was seen as acceptable; however, two areas were highlighted, one requiring some extra investigation and the other requiring some sensitivity by HPs working in gynaecology. The first related to the promotion within the resource of a product unknown to some HPs - 'Ohnut', which HPs felt hesitant to recommend based on a lack of knowledge, with one participant suggesting *"I would have reservations about bringing this (Ohnut device) out to say to patients 'put this on your partner's penis'"* (110 GYN TC2). However, HPs reflected an openness to explore the product further for the purposes of recommendation. The second concerned the promotion of the use of dilators with gynaecological patients, particularly those receiving treatment for cervical cancer who tended to be younger and perceived to have a greater interest in discussing sexual intercourse. HPs recognised that dilators were a recommended course of action; however, they emphasised the need for sensitivity with cervical patients due to the stigma of dilators as part of the patient's recovery to promote muscle integrity and flexibility. One specialist nurse conveyed,

*"gynae patients see dilators as part of their treatment and that causes stigma with dilators, they don't use them to help with intercourse, they are using them because that's what they are told to do after treatment and that has that whole stigma with them and they hate using them...."* (106 GYN TC2)

Overall, however, the MSW: CC eLearning resource was found to be an engaging resource, capable of equipping and empowering HPs working in cancer care with relevant information in an acceptable format.

#### 4.4.6 Discussion

The planning and development of digital interventions are not often reported in detail, offering little insight into key design decisions or indeed the fundamentals of how the intervention was informed by both theory and the evidence-base (Bradbury *et al.* 2018). This is considered critical information for researchers, policy makers and commissioners, to build a scientific understanding of what effective interventions need to contain (Michie and Abraham 2004; Abraham and Michie 2008). This study has addressed this evident gap, by methodically detailing the systematic and iterative application of the PBA which optimised the MSW: CC eLearning resource, to include the rationale for fundamental decisions made throughout the process. As a result, this account has provided a transparent guide to support future intervention development.

A feature of best practice when developing healthcare resources is Patient and Public involvement (PPI), alongside the systematic application of the theory and evidence base (Craig *et al.* 2008). Although PPI was not a key feature in the original PBA model, currently, PBA researchers emphasise the importance of this component to maximise the diversity of feedback, helping to achieve more engaging interventions (Muller *et al.* 2019). This was embedded at the inception of this study. Co-design (Sanders and Stappers 2008) and, more recently co-production, have been promoted as an PPI approach to research that emphasises the importance of power-sharing to promote inclusive research practices, valuing and respecting knowledge from different sources (Allen *et al.* 2020). Co-production has gained considerable momentum throughout public services and public policy worldwide, to improve collective health and wellbeing (Department of Health (DoH) 2018). For this study, substantial effort was directed to bring experts with experience (patient, carers and HPs) into the research process, being a key co-production principle. This goal was achieved by iterative collaboration between academics and non-academics to co-produce knowledge within a context-specific focus, being goal-

orientated and interactive (Norström *et al.* 2020). For example, there was extensive iterative involvement of an expert multi-professional stakeholder group (n=27), during the adaptation and testing phases of the MSW: CC eLearning resource, representing the contribution of HPs as the end-users of the intervention and patients and partners who were best placed to advocate for the optimal sexual support. The range of viewpoints was fundamental to the development process of the MSW: CC eLearning resource, as they provided expertise and insightful perspectives on the evidence base, reiterating the importance of the biopsychosocial content, advising on tone, clarity of language and identifying additional supporting resources and need for referral pathways. Co-production can be more inclusive, less tokenistic and offers more opportunities for meaningful use of expertise from experience than an approach based only on PPI (Jackson *et al.* 2020).

Establishing representative PPI and/or co-production can be challenging, as researchers ensure inclusivity of a range of views, perspectives and experiences, depending on each member's variable time, skills and interest (Muller *et al.* 2019). Based on previous recommendations advocated by Coulman *et al.* (2020), the researcher had to be clear on what expertise the different group members brought, given the diversity of the membership and how it would be applied to new knowledge generated. Trust was also essential to relationship building. Furthermore, it was inherently important to value viewpoints to address any perceived imbalance between professional/clinical/patient and partner/academic viewpoints. Consideration was given to research management and delivery to maximise contributions from each expert group member. Thus, the researcher adopted a flexible approach to communication, meeting with HPs as a group as well as with a series of individual meetings. Patients/partners were met on a small group basis, or by direct communication with the researcher via email/written to delve into specific aspects of the content. The planning agenda was insufficient without constant

communication and reflection of how to utilise collective stakeholder expertise. As part of the co-production process, the researcher was transparent, communicated clearly and had a commitment to reflection and learning. Adopting this approach enriched engagement with the expert group, which helped to strengthen the relevance and quality of the intervention before qualitative testing, potentially reducing optimisation test cycles (Coulman *et al.* 2020).

The TA interview, through the capture of real-time observable and audible reactions of HPs (Van den Haak *et al.* 2007) advocated by the PBA, complemented the input of the expert group by providing an in-depth understanding of the perspective of people who will use the intervention and their context (Band *et al.* 2017; Morrison *et al.* 2018). There is some debate within the literature about the use of prompts during TA interviews (Ericsson and Simon 1998; Cotton and Gresty 2006). Ericsson and Simon (1998) purported that interruptions during TA interviews via prompts may impact the validity of research findings. However, the use of prompts within this study proved beneficial and essential to identify key navigational problems and potential solutions. TA interviews proved invaluable during the optimisation phase to resolve navigation difficulties prior to more costly implementation and evaluation. Employing an alternate retrospective interview approach which would have involved participants verbally recalling problems they had with the intervention, would not have alerted the researcher to these navigational issue (Yardley *et al.* 2015a). However, retrospective approaches can be helpful later in the development of interventions to identify any further problems occurring when people use the intervention alone (Bradbury *et al.* 2014).

The PBA's qualitative optimisation method can be seen as labour intensive (Morrison *et al.* 2018), yet the researcher would advocate that it is a necessary process to ensure that interventions achieve target outcomes, avoiding future investment in large-scale

evaluation studies of sub-optimally designed solutions (Blanford *et al.* 2018). Not engaging in a thorough and robust process to intervention optimisation can risk the development of interventions with modest effects or no effect at all (Lau *et al.* 2016). More specifically, this is often attributed to a lack of regard for ensuring an intervention will fit into its intended context (Lau *et al.* 2016). The value of TA interviews within the optimisation process was discussed by Morrison *et al.* (2018) whose team identified how and why end users of a physical activity planner were overestimating their self-reported physical activity levels. The insights gained through the TA interviews in this study, allowed the researcher to iteratively adjust and test the impact of each change until the intervention was feasible for evaluation (Chapter 5). Such an approach is paramount, as studies that have used an iterative optimisation phase, have repeatedly shown intervention effectiveness at the subsequent evaluation phase (Little *et al.* 2013; Anthierens *et al.* 2014; Little *et al.* 2015; Little *et al.* 2016).

Although the use of TA interviews afforded a time investment, this study's optimisation phase was managed within in a succinct timeframe, utilising three iterative test cycles. To promote efficiency through the optimisation process, the researcher adhered to the research guidance framework (HRA 2017). This ensured clear designation of research responsibilities between researcher and local collaborators, established communication pathways between researcher, research team and research sites, with roles agreed at the outset of each study phase. Despite this action, internal and external influences, delayed governance team approvals and data collection with HPs across research test sites. These included priority being given to clinical trials during the COVID-19 pandemic, staff sick leave and change of personnel, extending the time required for this phase of the study. To counter these challenges, an effort was made to maximise participation and keep the study on schedule. These endeavours included the local collaborator championing the research within the test site, while the researcher ensured flexibility within the interview

schedule and approach to data collection to meet the demands of the changing healthcare environment due to the pandemic (Baier *et al.* 2021). Furthermore, timely set-up of interdisciplinary collaborations with LMS developers was fundamental to the study to ensure the intervention met scientific and technical standards (Biagianti *et al.* 2017). Building upon existing collaborative networks was advantageous along with employing 'team science' principles (Börner *et al.* 2010), which promoted discussion between developers and researchers and supported early agreements on issues like payment, storage and security (Biagianti *et al.* 2016; 2017). Using the same LMS involved in the MSW: PC eLearning resource developed for prostate cancer (McCaughan *et al.* 2021a) further contributed to the efficiency of optimisation phase, as there were established pathways of communication developed.

The TA interviews produced comprehensive insights from HPs reflections on the eLearning resource, which at times revealed variances in perspective and opinions. The use of systematic test cycles supported a methodical and robust approach to decision making. This approach facilitated the collection of a range of views from HPs to inform decision-making, which was supported by a system that classified the relevance of changes based on specific criteria (Table 14, p.145). The criteria included: intervention guiding principles, expert recommendation and call from participants to adjust content (Bradbury *et al.* 2018). Adopting these criteria ensured a sound rationale for potential modifications while supporting clear communication on proposed changes with the wider research team. Alongside this, further criteria were used to support communication within the research team around the prioritisation of modifications to promote feasibility and acceptability of the intervention for end-users (Bradbury *et al.* 2014; 2018). The 'Must have, Should have, Could have, Would have' criteria focused discussion, but proved to be an unnecessary process, as all modifications agreed could be addressed within resources. This approach may be more beneficial for a more complex digital intervention, or for

those exceeding allocated resources, which require decisive action from the research team, related to decisions on which elements of the intervention to adjust.

The MSW: CC eLearning resource has met the identified need for transformative educational opportunities for HPs across cancer care. It can provide flexible access to learning content to support continuing professional development and mitigate for geographic barriers (Carolan *et al.* 2020). Existing interventions targeting the provision of sexual support in cancer care had limitations in reach, due to adopting a face-to-face approach (Wang *et al.* 2015; Jonsdottir *et al.* 2016, Afiyanti *et al.* 2016; Reese *et al.* 2019a; 2019b). To ensure quality and engagement with an asynchronous eLearning programme, the MSW: CC eLearning resource's learning content addressed key principles (Sinclair *et al.* 2017). First, the use of the PBA, through the expert group and TA interviews ensured that the content's level of detail and tone were appropriate, given HPs limited awareness of the sexual challenges faced by patients with cancer and challenges HPs faced providing sexual support (Sinclair *et al.* 2017). Next, the MSW: CC eLearning resource's intuitive design, with ease of navigation, has been shown to be necessary to promote engagement and satisfaction with the learning experience (Palmer and Holt 2009). Finally, to capture HP's attention, the resource utilised an expert-led introduction and patient stories to help convey the importance of providing sexual support routinely (Sinclair *et al.* 2017). The testing process allowed HPs to independently engage with multiple devices, which revealed appearance and functionality issues. Given the range of devices available to users, this approach was essential to avoid implementation issues arising from cross-device incompatibility (Husmann *et al.* 2016). The LMS developers were able to address each issue, which ensured the eLearning resource's capability to operate on various devices.

The researcher's reflections on the data collection and analysis of TA interviews prompted some discussion surrounding the scientific credibility of this study's data, specifically related to creating a fair representation of HP views (Cavallerio *et al.* 2019). This provoked consideration of the reflexivity relating to the presenting situational and relational ethics of the study (Tracy 2010). Despite the researcher communicating the objectives of the TA interviews, according to an agreed TA interview protocol (Appendix 10); which were (1) to inform modifications to the eLearning resource and (2) to explore HPs views of the resource, HP's provided reflections on current practice and barriers faced providing sexual support. For example, when presented with webpage content, which highlighted the importance of sexual support for older people, HPs commented that this was "good," or "relevant," and shared examples such as "I would have only approached this [sexuality] with people under 60..."(104 PHY TC1). This data enriched the meaning of the verbalisations for the researcher. Upon reflection, it could be argued that these comments were not systematically collected so therefore could possibly reduce the scientific credibility of data, with a potential for underrepresentation of some points of view within the study. This was evident as some HPs adhered more rigidly to the TA protocol instructions, reporting only their views of the content, appearance, functionality and navigation, while for others, fuller explanations appeared to be a natural extension on verbalised thoughts (Ericsson and Simon 1998). Upon consideration of a commentary that explored participants' negative reaction to published works (Cavallerio *et al.* 2019), the researcher was wary of wider readership's interpretation of the study's presented findings. The researcher ruminated on how the presentation of data on the lack of provision of sexual support in NI may cause upset to HP participants, who may not expect these elements of data to be presented and could lead to distrust of the researcher. Yet, further deliberation on these personal reflections, these findings provided a stronger rationale for the eLearning intervention. An example of how this data enhanced the rationale for the intervention content was illustrated through HPs comments, "we don't



know what to say” relating to providing sexual support to patients and partners and further comments made by participants after reviewing the tailored sexual support advice “this gives us what to say.” While it could be argued that the resource was viewed as equipping, with or without the reflection on current practice, this additional data provided a clear impetus that this educational resource is necessary for HPs. Upon personal reflection and thorough discussions with the research team, it was agreed to thematic analyse and report on HPs reflections on current practice. This data provided a more comprehensive insight into the importance and relevance of the MSW: CC eLearning resource and also addressed one of the study’s research objectives. Excluding this data from the study would have been a discredit to the richness of the information willingly provided by HPs.

Many of this study’s reflections on the lack of provision of sexual support and hurdles faced by HPs, supported findings of previous studies in the field extensively documented (Dyer and das Nair 2013; Wang *et al.* 2018; Reese *et al.* 2017b; Vassão *et al.* 2018; O’Connor *et al.* 2019; Papadopoulou *et al.* 2019) although it is important to be cautious as to the generalisability of the data. Future qualitative studies could consider the inclusion of member reflections, that is, to revisit participants with the findings from the study, to enhance the confirmability and rigour of the findings (Cavallerio *et al.* 2019). In keeping with the pragmatic philosophy for this study, that is, recognising that there is not one truth to be confirmed, member reflections, supported by Braun and Clarke (2013, p.285) could provide an “opportunity for a ‘reflexive elaboration’ of the results rather than testing if the researcher ‘got it right’.”

Although the optimisation process of the MSW: CC eLearning resource was embedded within a wide variety of multidisciplinary HPs, patients and partner perspectives, guided by the PBA, there were three noteworthy limitations to the study’s approach. First, the

purposely selected, broad representation of disciplines and tumour groups was not fully representative of all potential end users, given the over representation of mainly white, females all from Northern Ireland. Tumour groups such as haematological or testicular were not accounted for, nor were minority ethnic groups or cultures fully represented. A broader representation may have raised additional sexual challenges, or nuances in the provision of sexual support, which would enhance the relevance of the intervention to specific groups. However, this study was supported with an extensive global evidence base, together with the detailed development processes used for the EASSi framework and the MSW: PC eLearning resource which may have helped to alleviate representation issues. Furthermore, the mainly female study sample somewhat balanced the male input into the MSW: PC eLearning resource. Second, similar to the development of the EASSi framework (McCaughan *et al.* 2020), it could be argued that those who participated in the development of the MSW: CC eLearning resource had a strong clinical interest in the area of practice, which may have positively biased the feedback during the TA interviews. However, the researcher would argue that this expertise, interest and commitment of HPs was integral to the success of the study. Finally, it is possible that the presence of the researcher, who was pivotal to the development and optimisation of the content, may have positively biased elements of the critique. That said, this is unlikely as the researcher at the outset stipulated that critique was welcome and all participants providing a range of positive and negative comments on various elements of the eLearning resource.

#### **4.5 Conclusion**

This chapter has provided a transparent guide optimising an eLearning resource which sought to enhance the provision of sexual support across cancer care, providing a detailed picture of decision-making throughout. By doing so, this study has demonstrated how intervention planning activities, through the application of the guiding principles, were brought to life to adapt the MSW: PC eLearning resource to create the MSW: CC eLearning

resource for use by multidisciplinary HPs working across cancer care. Such detail could instruct the future development of similar engaging and acceptable interventions, which address the known barriers to the provision of sexual support across other chronic conditions (Papadopoulou *et al.* 2019), including cardiovascular disease, stroke and rheumatic disease (D'Eath *et al.* 2013; Mellor *et al.* 2013; Helland *et al.* 2013). The usability testing involved iteratively moving between data collection, analysis and modifications, which was steered by the guiding principles, theory and evidence base. The positive feedback on the MSW: CC eLearning resource relating to appropriateness, usability, engagement and relevance, points to its acceptability in cancer care. However, it is still to be determined if this intervention successfully reduces barriers to providing sexual support in cancer care. The next step is to conduct a single-arm evaluation of the MSW: CC eLearning resource, investigating the MSW: CC eLearning resource's impact on the sexual attitudes and beliefs of HPs related to the provision of sexual support in cancer care. This evaluation is detailed in Chapter 5.

## CHAPTER FIVE: PHASE 3 - EVALUATION OF MSW: CC ELEARNING RESOURCE

### 5.1 Introduction

Assessing the impact of healthcare interventions is critical to inform practice, policy direction and future research (Clarke *et al.* 2019). National guidance such as that of the Medical Research Council (MRC) for evaluating interventions (Moore *et al.* 2015) has advocated for a 'mixed methods process evaluation' which seeks to understand "can" and "how" interventions work. In line with recommendations, a mixed methods process evaluation has been embedded within Phase 3 of the PBA (Morrison *et al.* 2018). Within the confines of this PhD thesis, Phase 3 (evaluation phase) solely addressed the question of outcomes investigating, "does the intervention work?" using a quantitative research approach. A subsequent qualitative study has been planned to inform "how does it work?" (Orsmond and Cohn 2015) but due to time factors, it sits outside the remit of this PhD project. The future qualitative study is important, as intervention evaluation studies, which only seek to establish if an intervention works, may undermine future research efforts by failing to address early problems of acceptability, compliance, delivery of the intervention with integrity and recruitment and retention (Bowen *et al.* 2009; Tickle-Degnen 2013).

### 5.2 Study objectives

For the evaluation phase of this study, the objectives were to:

1. To determine the impact of the MSW: CC eLearning resource on HPs sexual attitudes and beliefs related to the provision of sexual support in cancer care.
2. To ascertain the acceptability and usability of the MSW: CC eLearning resource for use by HPs in the cancer care setting.

## 5.3 Methods

### 5.3.1 Study design

The mixed methods approach to this study was described in Chapter 2 (pg. 18). As with an exploratory sequential mixed methods approach, the quantitative evaluation element of the study builds on the analysis of the data from Phase 2 (Chapter 4) – the optimisation phase of the PBA. The data from Phase 2 informed the final version of the eLearning prototype. This evaluation of this prototype will be described in this chapter.

The evaluation study was a single arm pre-test and post-test survey design. The single-arm study design has been used in most interventional research in this field, with no inclusion of a control group (Lee *et al.* 2012; Wang *et al.* 2015; Afiyanti *et al.* 2016; Merriam *et al.* 2018; Reese *et al.* 2019; Quinn *et al.* 2019; McCaughan *et al.* 2021a). A single-arm study design using pre-test and post-test surveys can be a good method to identify causality, particularly when demonstrating the immediate impacts of short-term interventions (Ip *et al.* 2013), as there are less threats to external validity such as policy or department protocol changes, influences from work colleagues or attrition albeit, attrition can occur immediately post-test. However, attributing causality without a control group cannot be done with a high degree of certainty, as completing pre-test measurement of a behavioural determinant such as sexual beliefs, may inspire a participant to reflect on beliefs which could result in changes to post-test scores rather than those changes being solely attributable to the intervention (Marsden and Torgerson 2012; Jhangiani *et al.* 2019). Furthermore, there is a risk that a pre-test and post-test survey design could mask the impact of the intervention, as at the pre-test survey stage, participants *do not know what they do not know*. Consequently, participants may award higher Likert scale ratings to statements pre-test than post-test, which may indicate their increased awareness of their lack of knowledge before engaging in the intervention (Hiebert and Magnusson 2014). That said, this choice of research method has provided

HP-orientated sexual support intervention studies with useful measurable data to identify potential elements within resources, which may need further strengthening prior to larger scale evaluation using a randomised controlled trial (Ainesworth *et al.* 2017).

### 5.3.2 The intervention

The MSW: CC eLearning resource was designed to enhance the HP-led provision of sexual support in cancer care. The eLearning resource is presented in three steps (see Fig. 16). *Step 1 is aimed at increasing HPs awareness* of the impact of a cancer diagnosis and treatment on sexuality for both patients and partners, plus their desire for sexual support. This encompasses a range of tumour groups and populations (for example, end of life and LGB & T). This step also identifies key barriers for HPs in providing sexual support, reflecting the importance of sexuality to patients and partners across the lifespan, HP role to address sexual concerns and acknowledge potential embarrassment with the topic, lack of knowledge, skills and time. Included within this step are links to resources and potential referral pathways which could support clinical consultations. *Step 2 of the resource is aimed at equipping HPs with the knowledge and skills to engage effectively with patients and their partners.* To achieve this, it introduces an Engagement, Assessment, Support and Signposting (EASSi) framework developed by McCaughan *et al.* (2020), see Figure 17.

**Figure 16: Outline of each step within the MSW: CC eLearning resource**

**Step 1:**  
**Understanding sexual challenges and cancer**

- Cancer and treatment effects on sexuality
- Patient and partner videos on managing sexual challenges
- Barriers preventing the provision of sexual care

**START**

**Step 2:**  
**Getting the conversation started**

- Communication framework to guide sexual support conversations
- Treatment effects on sexual wellbeing advice
- Demonstration of sexual care conversation

**START**

**Step 3:**  
**Integrating routine sexual care into your practice**

- Strategies to integrate routine sexual care into practice
- Supportive resources, referral pathways and signposting sheets which HPs can share with patients.

**START**

**Figure 17: Overview of the EASSi conceptual framework (McCaughan et al. 2020)**



‘Engagement’, the first component, is focused on ensuring that routine discussions take place with patients facing a cancer diagnosis, underlining the significant impact on sexual wellbeing. The ‘Assessment’ component encourages the HP to begin to consider the difficulties patients and partners may face related to cancer and treatment type, time from treatment and relationship status. This is fundamental to tailoring ‘Support,’ the next component, which aims to equip HPs with information on common sexual challenges and strategies to support patients and partners to cope, necessary for patients regardless of cancer type (Albers *et al.* 2020b). Finally, the ‘Signposting’ component, seen as a critical resource to equip HPs (Palacios *et al.* 2018), provides a range of support options for HPs and patients, including links to further information online, referral pathways and introduces the signposting sheets available for download. Step 2 closes with a practical video demonstration of an HP using the EASSi framework to guide a sexual support conversation with a patient following treatment for prostate cancer. *Step 3* of the eLearning resource seeks to move HPs from knowledge to action and through the provision of suggested activities is aimed at supporting HPs to develop skills and confidence to discuss sexual concerns with patients and partners. This approach stops short at providing a real time training opportunity for HPs to ‘role-play’ the provision of sexual support in a safe environment. Nevertheless, tools and guidance are provided within the resource, mitigating a potential missed training experience arising from an asynchronous eLearning approach. Furthermore, the eLearning resource includes a



simplified A4 poster version of the EASSi framework for the HPs to have at hand when using the framework in routine practice, see Appendix 14.

The intervention, namely MSW: CC eLearning resource was accessed by HPs participating in the study at <https://talkingaboutsex-cancercare.org> using any device, including a personal computer, electronic tablet, or phone. The eLearning resource was purposefully designed for self-directed learning with the intention that participants would not require any additional assistance. The resource was estimated to take approximately 1 hour to complete, with recognition that there are individual differences in learning styles, so this time may be significantly shorter for some, while for others, they may wish to progress at a slower pace.

### 5.3.3 Participants

The evaluation, aligned with PBA methodology, was targeted at end users of the intervention (Yardley *et al.* 2015b); therefore, eligible participants were HPs who provided routine care to patients with cancer and their partners. There were no exclusion criteria in terms of location base, professional group, or years of clinical experience, as this study wanted to be reflective of the diverse cancer care workforce. A minimum sample of n=34 participants for this phase of study was calculated in G\*power, a flexible statistical power analysis program (Faul *et al.* 2007) for use in behavioural sciences. This calculation was based on use of a repeated measures t-test using a power 0.8 and a medium effect size of 0.5 with the alpha value set at 0.05. A planned sample size of n=41 participants was selected to allow for missing data at follow up. This was based on 20% attrition rate experienced by McCaughan *et al.* (2021a) in the evaluation of the MSW: PC eLearning resource.

#### 5.3.4 Recruitment procedures

The recruitment approach was a convenience non-probability sampling method to target accessible HPs with an interest and willingness to participate (Dörnyei 2007). The recruitment process used two approaches. First, the researcher recruited through established links with LCs in each HSCT in NI. HSCT participants were approached by the LC via email, with an invitation to participate on the study. This email included a copy of the PIS; this information was also contained within the MSW: CC eLearning resource. The PIS provided details of the eLearning resource, how to access it, the time commitment involved and outlined the required completion of the pre-test and post-test surveys. To maximise participant variation, LCs were instructed to recruit across disciplines and tumour groups. Additionally, the researcher provided a video promoting the study aimed at HPs across cancer services. Nonetheless, there were compatibility difficulties in sharing a video file within the HSCTs, which meant this approach was not utilised. Participants could opt to take part without notifying LCs, thus protecting their anonymity.

Local recruitment was augmented by a second approach which used social media to recruit to the study. This was not the original intention for the study but given the impact of COVID-19 on the cancer care workforce, including the re-deployment of staff and reduced opportunities for the researcher to promote the study at multidisciplinary forums, social media proved helpful to maximise participant numbers. Specifically, the second approach used the social media platform Twitter, which enabled high visibility of posts and retweets of posts to wider audiences. Targeted use of social media in healthcare has been found to substantially aid recruitment as an adjunct to traditional methods (Khatri *et al.* 2015) and has been reported as an accessible, low-cost and high-yield strategy (Bethel *et al.* 2021). A social media approach can overcome barriers to recruiting HPs, such as survey fatigue, 'gatekeepers' monitoring access to HP participants and homogeneity of participants at a single healthcare organisation or country (Bethel *et*

*al.* 2021). Furthermore, social media recruitment has been reported as a cost-effective means of recruitment with potentially difficult-to-reach populations and provided participants with anonymity and a more accessible method by which to engage in health research (O'Connor *et al.* 2014; Khatri *et al.* 2015). Both Facebook and Twitter have been demonstrated as successful recruitment (Khatri *et al.* 2015) although it has been argued that with a carefully considered marketing strategy, Twitter could be used as the sole platform to collect data with clear evidence demonstrating high levels of uptake in short time periods (O'Connor *et al.* 2014; Bisset *et al.* 2020). That said, recruitment of research participants via social media is relatively new and there is an evident need for guidelines to address issues arising from self-identification by research participants in comments and messages posed to the researcher (Bethel *et al.* 2021).

For this study, a tweet was crafted and posted (following review and approval by ethics panel, IRAS ID 259926 Amendment 2, Appendix 4) from the lead researcher's Twitter account and retweeted by the research team and UU's Cancer Care Research group over the course of the data collection period. Key cancer care providers, cancer charities and cancer care researchers were tagged in the posts. Experts in the field retweeted and promoted the opportunity to become involved in the study via their own networks. Examples of cancer care organisations targeted to promote availability of the MSW: CC eLearning resource and the evaluation included United Kingdom Oncology Nursing Forum (UKONs), European Oncology Nursing Forum (EONs) and the Irish Cancer Society. The tweet signposted potential participants via a link to the MSW: CC eLearning resource page, where they could view the PIS prior to completing the pre-test survey.

#### 5.3.5 Measures

Participants completed surveys immediately pre and post use of the MSW: CC eLearning resource. At pre-test, all participants completed demographic questions (n=4), which

included information about role, years in practice, frequency of providing cancer care and previous sexual wellbeing communication training. This was followed by the primary outcome measure, a 12-item a modified version of the existing validated 'Sexual Attitudes and Beliefs Survey' (SABS) using a four-point Likert scale (McCaughan *et al.* 2021a) to identify HPs sexual attitudes and beliefs related to the provision of sexual support in nursing practice (Reynolds and Magnan 2005). The pre-test survey concluded by establishing the reasons behind participation on the eLearning resource. At the post-test timepoint, in addition to the same 12-items of the modified SABS, all participants also completed four items which assessed HPs views of their acceptability and usability of the MSW: CC eLearning resource, similarly measured using the four-point Likert scale. As part of the post-test survey there were three optional questions with free-text response option; these questions investigated the elements of the eLearning resource most and least liked and areas for improvement.

The SABS (Reynolds and Magnan 2005) was originally developed by a group of USA-based multidisciplinary specialist and oncology nurses and researchers to identify barriers to incorporating sexuality assessment and counselling into nursing practice. The authors evaluated its validity and reliability and found SABS to be an internally consistent measure of barriers to integrating sexual assessment and support into routine nursing practice with Cronbach alphas of 0.75 and 0.82 over two separate administrations. Further studies have concurred with these findings demonstrating that SABS achieved good reliability and validity (Ayhan *et al.* 2010; Zeng *et al.* 2011). Specifically, the instrument was found to provide a stable measure of attitudes with good test-retest reliability over a 7-10-day period ( $r=.85$ ;  $p<.001$ ). There are other valid and reliable scales to evaluate attitudes towards sexual health care in oncology. For example, the Sexual Knowledge and Attitudes Test (SKAT) (Miller and Lief 1979), a scale used for over 40 years within the nursing field, assesses knowledge and attitudes about physical aspects of sexuality and specific sexual

behaviours rather than attitudes to sexuality in relation to nursing practice (Aguiar Frias *et al.* 2021). Furthermore, the Sexual Health Care Attitude scale for nurses (SHC – A) (Kim *et al.* 2011), is a 36-item scale which has demonstrated good validity and reliability at assessing attitudinal barriers and to develop and test educational interventions for the improvement of sexual health care however, given the length of the survey, it was dismissed over concerns that it may present recruitment and retention challenges. The SABS has been used as a measuring tool in similar studies investigating the impact of an educational intervention on the HP provision of sexual support (Afiyanti *et al.* 2016). To enable a more direct comparison of findings between the MSW: PC and MSW: CC eLearning resources, the researcher used the modified version of the SABS with minor amendments to ensure applicability across cancer care (McCaughan *et al.* 2021a).

The modified SABS, used in both the MSW: PC eLearning resource and MSW: CC eLearning resource studies, like the original SABS tool, consisted of twelve single-item statements. Short measurement tools can reduce participant burden and increase the response rate (Fan and Yan 2010). The main modification to the SABS for the MSW: PC eLearning resource evaluation study was the reduction of Likert scale points, from six-points in the original survey to four-points in the modified survey, to ascertain the extent to which the participant agreed or disagreed with the presenting statement. This change was made to the scale by the MSW: PC research team to simplify the measure, by reducing number of categories the differentiation between points was increased to aid decision-making, for example, combining '*very strongly disagree*', '*strongly disagree*' and '*disagree*' into more simply '*strongly disagree*' and '*disagree*' (Chang 1994). It could be argued that reducing the Likert scale points may affect the accuracy of HP responses, although the authors of the SABS (Magnan *et al.* 2005), along with others (Saunamaki *et al.* 2010; Afiyanti 2016), have advocated alternate simplified dichotomised scale as sufficient to reflect the levels of 'agreement' (values 1-3) or 'disagreement' (values 4-6). Also, the McCaughan *et al.*

(2021a) version of the SABS had modified three statements and made minor adaptations to language. The modified statements were more aligned with the objectives of the intervention, for example, one sought to determine if HPs found it difficult to talk to older people about sexual concerns and another asked HPs to identify if they knew the right language to use when discussing sexual concerns. The language changes adopted for the MSW: PC eLearning resource study aligned the survey with the language used in the MSW: PC eLearning resource and was relevant to HPs providing care for men with prostate cancer. For example, "Discussing sexuality is essential to patient's health outcomes," became "Sexual concerns are an important topic to discuss with men living with cancer." Furthermore, clarity was increased within several statements, for example, the statement from the original SABS, "I am uncomfortable talking about sexual issues," was targeted specifically to communication with patients and was modified to read, "I am uncomfortable talking about sexual issues with men with prostate cancer." The modified survey is available in McCaughan *et al.* (2021a) Supplement Table 1. The Cronbach's Alpha measure for internal consistency of the 12 items was reported to be acceptable at 0.69 (McCaughan *et al.* 2021a). For this current study, the only change made to the McCaughan *et al.* (2021a) modified SABS was any references to 'men' and 'prostate cancer' which were changed to read 'patients' and 'cancer'. The internal consistency of this scale is presented in Section 5.3.7 (p.200).

The Likert scale is frequently analysed as an interval scale, although there is some controversy relating to appropriateness of considering Likert ordinal data as an interval data (Harpe 2015). By considering ordinal data as an interval scale, researchers can encounter challenges related to the normal distribution of data, an assumption required for parametric tests (Wu and Leung 2017). By increasing the anchors points in the scale, it is possible to improve normal distribution of data (Leung 2011; Wu and Leung 2017). However, Leung (2011) reported that a comparison of psychometric properties of four,

five, six and eleven-point Likert scales identified no differences in means and standard deviations. A decision was taken to retain the four-point scale to prioritise the ease of completion of the survey along with ensuring comparability of outcome measures with the MSW: PC eLearning resource evaluation study (McCaughan *et al.* 2021a). Test of normality for this study have been presented in Section 5.3.10 (p.203).

#### 5.3.6 Procedure for moving through the MSW: CC eLearning resource

Completion of all pre-test survey items was mandatory for HPs to gain access to the eLearning resource; responses to all Likert-scale items (which included the SABS and the questions on acceptability and usability) in the post-test survey were required to gain a CPD certificate. This action was taken to avoid incomplete data sets. Answering the free-text comments was optional, this was to help reduce participant perceived burden and to hopefully increase participant engagement and completion. It was important to determine the impact of the MSW: CC eLearning resource on HPs attitudes to providing sexual support; thus, an algorithm was used to permit participants to complete the post-test survey once they had viewed each step of the eLearning resource. Patient videos, links and downloads of signposting sheets and EASSi quick guide were not included within this algorithm as the relevance of each of these to specific participants could not be pre-determined. This meant each participant who provided evaluation data has engaged to some degree with each step (outlined in Fig. 16) within the eLearning resource.

To make it easier for HPs to navigate between the resource and the final survey, an additional quick link to the post-test survey was included on the eLearning resource main page. This was a new feature from the MSW: PC eLearning resource study, which the researcher thought may improve post-test survey completion rates by reducing burden on participants locating the post-test survey. Akin to the MSW: PC eLearning resource study, no reminder emails or financial incentives were used. Data from the questionnaires

were made accessible to the researcher only, through the Moodle open-source learning platform which hosted the eLearning resource.

#### 5.3.7 Scoring and reliability of the modified SABS

To facilitate scoring, five survey items (questions 2, 4, 8, 9, 12) were reversed during scoring. Survey responses were scored collectively, similarly to other studies (Magnan *et al.* 2005; Julien *et al.* 2010), with a potential total score of between 12 and 48 points. The lower values indicated greater barriers to providing sexual support. Statistical significance was defined as  $p < 0.05$ . A reliability analysis was conducted to ascertain the degree to which the items on the modified SABS scale were all measuring the same underlying construct. The reliability analysis of the pre-test surveys of  $n=157$  multi-disciplinary HPs, working routinely in cancer care, demonstrated the 12 -item modified SABS had good internal consistency, with a Cronbach alpha coefficient reported of 0.78.

#### 5.3.8 Determining acceptability of the MSW: CC eLearning resource

Guidance provided by the originators of PBA (Yardley *et al.* 2015b) and the MRC (Craig *et al.* 2008; Moore *et al.* 2015) on the development of complex interventions emphasised the importance of determining social validity or acceptability of healthcare interventions. Although *acceptability* is considered a legitimate concept to assess, often involving end-users throughout the intervention development processes (Yardley *et al.* 2015b), it is a term not well defined and often conflated with other constructs such as satisfaction, perceptions of usefulness, or behaviour such as response and attrition rates (Dennison *et al.* 2010; Humphris and Ozakinci 2008; Sharp *et al.* 2013; Powell *et al.* 2015). Sekhon *et al.* (2017) in a review of definitions used in healthcare intervention literature, identified various underlying theoretical basis for acceptability, including attitudinal (Pechey *et al.* 2014), sense-making (Cohn 2016), behavioural (McGowan *et al.* 2018) and related to context (Yardley *et al.* 2015a). Sekhon *et al.* (2017, 2018) have recently proposed the



Theoretical Framework of Acceptability (TFA) which they have argued detangles *behaviour from acceptability*; behaviours, like attrition, could be due to factors such as technical difficulties. Acceptability is therefore defined as:

“a multi-faceted construct that reflects the extent to which people delivering or receiving a healthcare intervention consider it to be appropriate, based on anticipated or experienced cognitive and emotional responses to the intervention (Sekhon *et al.* 2017, p.4).”

With the exception of two of the earlier studies discussed in Chapter 3 (Section 3.1.7.3, p.89), educational sexual support intervention studies in cancer care had not measured acceptability *per se*, but rather had focused their attention on related constructs, such as perceived usefulness, satisfaction and rates of enrolment (Lee *et al.* 2012; Jonsdottir *et al.* 2016; Quinn *et al.* 2019). One of these studies sought to determine acceptability using a 13-item survey assessing ease of participation, satisfaction with the programme, perceived clinical relevance and impact (Reese *et al.* 2019a), which was aligned to constructs from the Theoretical Framework of Acceptability, affective attitude, self-efficacy and perceived effectiveness. Definitions of Theoretical Framework of Acceptability component constructs can be found in Table 18. The second study by Lee *et al.* (2012) stated that their intervention was acceptable, however they did not define what acceptability related to nor how it was determined. As acceptability is a necessary, albeit not singular, condition for the effectiveness of an intervention, which could have a significant influence on the future embedding of the eLearning resource into cancer care, it is paramount to determine and address any issues raised (Sekhon *et al.* 2017). This study used Likert scale statements and free-text comments to determine HPs views related to affective attitude, burden, intervention coherence, perceived effectiveness and self-efficacy constructs.

**Table 18: Definitions of the component constructs in the Theoretical Framework of Acceptability (Sekhon et al. 2017)**

<b>TFA construct</b>	<b>Definition</b>
<b>Affective attitude</b>	How an individual feels about the intervention.
<b>Burden</b>	The perceived amount of effort that is required to participate in the intervention.
<b>Ethicality</b>	The extent to which the intervention has good fit with an individual's value system.
<b>Intervention coherence</b>	The extent to which the participant understands the intervention and how it works.
<b>Opportunity costs</b>	The extent to which benefits, profits, or values must be given up to engage in the intervention.
<b>Perceived effectiveness</b>	The extent to which the intervention is perceived to be likely to achieve its purpose.
<b>Self-efficacy</b>	The participant's confidence that they can perform the behaviour(s) required to participate in the intervention.

#### 5.3.9 Ethical considerations

Many of the ethical principles applied to this study have been discussed in detail in Chapter 2, Section 2.5 and Chapter 4, Section 4.4.3. For this phase of study, there were some additional considerations made in relation to data collection and analysis. Access to the eLearning resource required participants to register their name and email address at log-in. This data was necessary to link the pre-test and post-test survey data, to enable participants repeated access to the content, picking up from where they had left off and to provide data to automatically populate a CPD certificate. To protect anonymity, this data was only accessible by the researcher, who downloaded it to a secure computer at the close of the evaluation period in the form of two excel spreadsheets. The participant's name/email address were used to match the pre-test and post-test survey data, following which the identifiable data were then removed from matched survey data and replaced with an identification number prior to analysis. Participant autonomy and informed consent was supported by the recruitment process. To support this process, LCs in each HSCT provided a copy of the PIS to potential participants, to avoid direct contact between

researcher and participant. Those participants recruited using social media, could access the PIS as the first viewable document after log-in to the eLearning resource. Informed consent was assumed if survey questionnaires were completed, as it was deemed participants could freely access the resource anonymously and were free to decide to engage or withdraw at any time (Whitehead 2007; Alessi and Martin 2010). Finally, to support the principle of beneficence and non-maleficence, the researcher participated in several quantitative training courses to update knowledge and skills relating to quantitative data processing and analysis and she was further supported by research supervisors who verified the correct processing and analysis of findings.

#### 5.3.10 Data analysis

The Statistical Package for Social Science (SPSS®) v26 supported the analysis of the quantitative data from the questionnaires. Descriptive analysis was used to report the demographic characteristics of the study sample. It is well established that for repeated measure data, the dependent t-test has a power advantage for normal distributions, with Wilcoxon being appropriate for data which has skew or kurtosis (De Winter and Dodou 2012). Shapiro-Wilk's test ( $p > 0.05$ ) (Shapiro and Wilk 1965; Razali and Wah 2011) and a visual inspection of histograms, normal Q-Q plots and box plots showed that the modified SABS scores were approximately normally distributed at both timepoints with a skewness of 0.299 (SE=0.258) and a kurtosis of -0.243 (SE=0.511) for timepoint 1 and a skewness of -0.139 (SE=0.258) and a kurtosis of -0.480 (SE=0.511) for timepoint 2 (Cramer 1998; Cramer and Howitt 2004; Doane and Seward 2011). This indicated the suitability of parametric tests, namely the t-test to identify total mean differences in HPs sexual attitudes and beliefs relating to the provision of sexual support at two timepoints. Independence of observation, that is, that data collected was not influenced by other participants behaviour, was achieved as the intervention was developed for use independently by HPs across varied settings (Pallant 2020).

## 5.4 Results

### 5.4.1 Participants

Between November 2020 and April 2021, n=157 participants registered on the eLearning resource Moodle page and completed the pre-test survey, timepoint 1. Post-test surveys were completed following use of the eLearning resource (timepoint 2) by n=89 participants, however data from 2 participants were removed as they did not routinely provide support to patients with cancer, selecting the 'not at all' option in the drop-down box in response to the question, "How often do provide support for patients living with cancer?" Most participants were from nursing (n=40, 46%) and radiotherapy roles (n=20, 23%), with the majority having over 12 years experience providing cancer care (n=47, 54%) and no previous formal training in communication relating to providing sexual support. According to responses, the main reason for undertaking the eLearning resource was to increase knowledge of sexual concerns (n=51) and to equip HPs with tools to provide sexual support in cancer care (n=49). Table 19 provides an overview of participant demographics. Google analytics used alongside the intervention, identified that the resource was accessed in countries including United Kingdom (UK), United States of America (USA), Ireland, Finland, Netherlands, Austria, France, Australia, Brazil and Canada, however, it is unknown if the survey data pertaining to the study is representative of each of these countries.

**Table 19: Participant demographics**

Participant characteristic	Number (%) Total n=87	
<b>Profession</b>	Nurse	40 (46%)
	Physiotherapist	3 (3%)
	Psychologist/Counsellor	10 (11%)
	Radiographer	20 (23%)
	Doctor	5 (6%)
	Support worker	4 (5%)
	Other	5 (6%)
<b>Years in practice</b>	0-4 years	20 (23%)
	5-12 years	20 (23%)
	More than 12 years	47 (54%)
<b>Days per week providing care for patients with cancer</b>	1-2 days per month	5 (6%)
	1-2 days per week	19 (22%)
	4-5 days per week	63 (72%)
<b>Previous training in sexual health or wellbeing communication</b>	No	70 (80%)
	Yes	17 (20%)
<b>Primary reason for undertaking the eLearning resource*</b>	To increase knowledge	n=51
	To equip to address topic	n=49
	Applicable to role	n=11
	Request to complete	n=2
	Supporting research	n=2

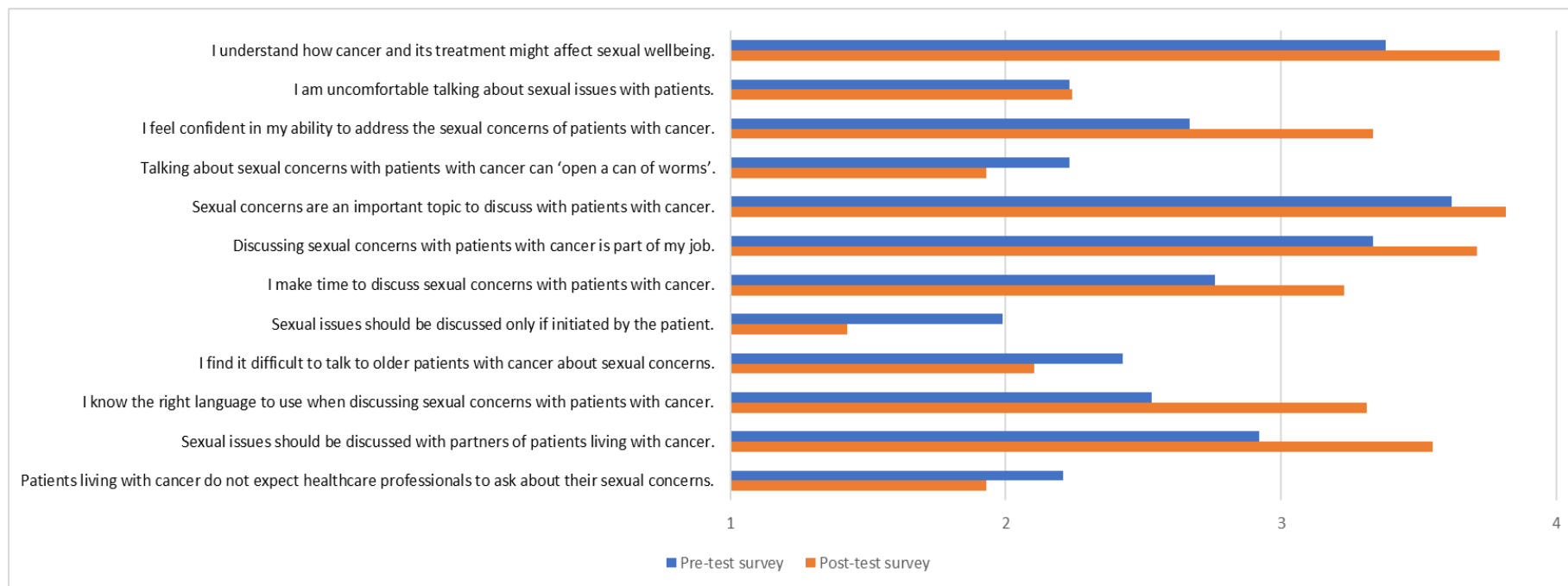
\*Note that participants were permitted to report more than one response

#### 5.4.2 Impact of the intervention on HP's sexual attitudes and beliefs relating to the provision of sexual support in cancer care

HPs responses mean scores to SABS statements at each timepoints have been provided in Figure 18. From Figure 18 it is evidenced that HPs at timepoint 2 (post-test) had a greater understanding of how cancer and its treatment might affect sexual wellbeing, however, it was also clear that many HPs reported this to be the case at timepoint 1. At timepoint 2, following the intervention, HPs reported greater levels of confidence in their ability to address patient sexual concerns and knowledge of the right language to use when discussing sexual concerns with a patient, yet their perceived comfort levels relating to talking about sexual issues with patients remained somewhat unchanged. It was clear that after engaging with the MSW: CC eLearning resource (post-test at timepoint 2) more HPs believed sexual concerns should be discussed, with a greater awareness of their role to initiate the provision of sexual support.

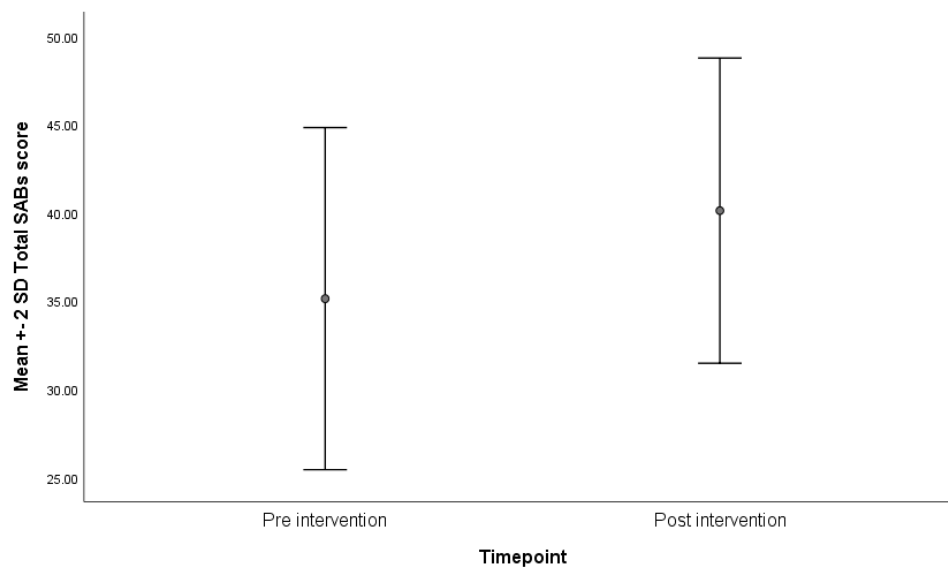
A paired samples t-test was conducted to evaluate the impact of the eLearning resource on HPs sexual attitudes and beliefs relating to the provision of sexual support in cancer care using the modified SABS. There was a statistically significant increase in the modified SABS scores from Time 1 (M=35.1, SD=4.8) to Time 2 (M=40.1, SD=4.3),  $t(86) = -10.2$ ,  $p < 0.001$  (two-tailed). The mean increase in SABS scores was 5 with  $p < 0.001$ . The eta squared statistic (0.55) indicated a medium effect size (Cohen 1988). These results indicate that there was a significant decrease in the barriers to the provision of sexual support in cancer care following use of the eLearning resource. Figure 19 provides a visual representation of the SABS means and standard deviations at each timepoints.

**Figure 18: HPs responses to SABS statements based on mean scores at pre and post survey timepoints**



Each question or statement was scored /4 based on the following criteria:  
 [1] = Strongly Disagree; [2] = Disagree; [3] = Agree; [4] = Strongly Agree.

**Figure 19: Mean and standard deviations of total SABS scores at pre-test and post-test survey timepoints**



#### 5.4.3 Acceptability and usability

Following completion of the eLearning resource, at timepoint 2, participants rated the eLearning resource as containing relevant information that will equip in practice (3.77/4; SD 0.5) and reported that the eLearning resource was easy to use (3.8/4; SD 0.42). The results are summarised in Table 20. Free text comments on HPs' experiences of using the resource were summarised into similar categories. There were variable responses to each of these questions; this is indicated by the differing denominator used to describe these findings. Sixty-one participants provided data on the most liked features. These were the patient and partner video content (n=28/61: 46%) and the provision of signposting links to resources and referral pathways (n=16/61: 26%). Further feedback is detailed in Figure 20.

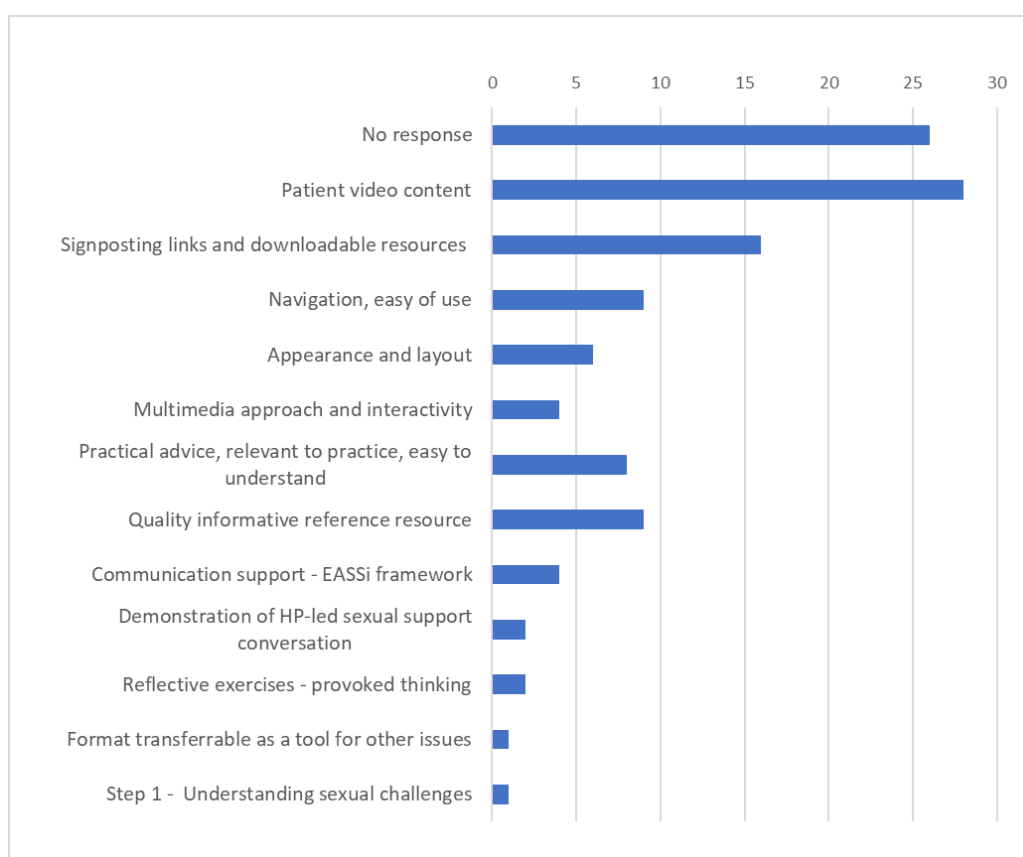


**Table 20: Participant views on acceptability and usability of the MSW: CC eLearning resource**

Question	Mean (SD)
The eLearning resource included information that will be useful for my practice	3.77 (0.5)
I would recommend others use the eLearning resource	3.78 (0.5)
I will use the eLearning resource as a resource	3.78 (0.5)
I thought the eLearning resource was easy to use	3.8 (0.42)

Each question or statement was scored /4 based on the following criteria:  
 [1] = Strongly Disagree; [2] = Disagree; [3] = Agree; [4] = Strongly Agree.  
 SD = Standard Deviation

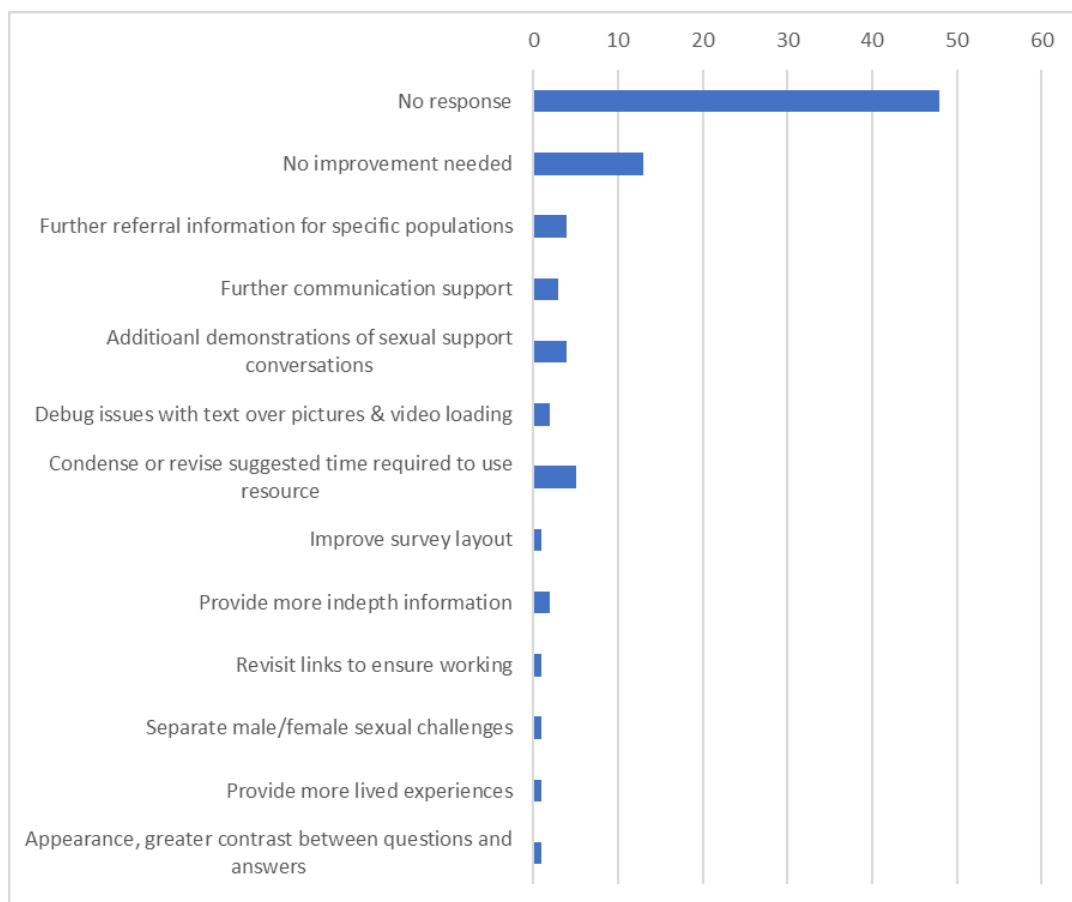
**Figure 20: Most liked aspects of the MSW: CC eLearning resource**



Most participants did not identify the need for improvements to the eLearning resource (n=48/87: 55%), however some participants suggested that further HP-led demonstrations of patient consultations with differing sexual issues, with women and other tumour groups could enhance the resource (n=4/39: 10%). A minority of participants requested further information and referral pathways for population groups

including those with learning disability/difficulties, autism and dementia, groups which had not been considered in the identification of supporting resources (n=4/39: 10%). A small number of respondents who felt they knew little about the topic area, suggested the time frame for completion of the resource was an underestimation. They reported that it would be helpful to notify participants that some HPs may require more time to complete the resource and that there is the option to dip in and out of resource as necessary (n=2/39: 5%). Only a few further participants (n=2/39: 5%) reported, in contrast, that the content should be condensed. Figure 21 details further suggested improvements.

**Figure 21: Suggested areas of improvement for the MSW: CC eLearning resource**



Sixty-two percent of HPs participants (n=54) either did not respond to the survey question about 'least liked aspects' or reported that there was no aspect disliked. A small number (n=2/33: 6%) of participants indicated that one of the least liked aspects of the MSW: CC eLearning resource was the scroll function, regarding this approach as unclear. One (n=1/33: 3%) participant reported content display issues and video loading issues, suggestive of unresolved problems with the eLearning resource on a particular web browser or device. Three of the 33 participants offering free text comments on disliked features of the eLearning resource reported the resource as too long, with a further participant specifically suggesting a reduction in the duration of patient videos. Improvements to layout of survey were suggested by one participant, who asked for the scale descriptors to be more clearly aligned with the Likert scale, such action may avoid participants making incorrect assumptions about the direction of the scale.

## **5.5 Discussion**

The MSW: CC eLearning resource has demonstrated potential as an acceptable intervention, capable of reducing attitudinal barriers to the provision of sexual support in cancer care. This eLearning resource shows promise at being able to support the delivery of global cancer care guidelines that stipulate the provision of routine sexual support for patients and partners across the treatment trajectory (NHS 2016; Carter *et al.* 2018; Cancer Australia 2019). For the first time, the MSW: CC eLearning resource offers cancer care HPs working with mixed tumour groups an opportunity to access free education to improve the provision of sexual support, which works at the pace of the learner and does not require training co-ordinators with specific expertise in sexual care.

Although both the MSW: CC and MSW: PC studies have indicated a reduction in the barriers to the provision of sexual support in cancer care settings, the mean SABS scores for the MSW: PC study were not statistically significant (McCaughan *et al.* 2021a) unlike

this study. Such a finding might be due to HPs who work in prostate cancer care being more familiar with patient sexual concerns given the direct impact on erectile dysfunction (Flynn *et al.* 2012), meaning that they were more informed at timepoint 1 (mean score 35.14), hence showed lowered increased learning at timepoint 2 (mean score 37.08). However, this positive shift in attitudinal scores in both this study and that of McCaughan's original study, are in keeping with Papadopoulou *et al.*'s (2019) recent review reporting that cancer nurses' sexual support provision was impacted by a lack of professional confidence and complicated by unhelpful views and beliefs towards providing sexual support. It would, however, be remiss to suggest that a brief online educational intervention would be the sole answer to reducing attitudinal barriers, which are more often subject to reinforcement by wider system level barriers (Moore *et al.* 2013; Winterling *et al.* 2020). The MSW: PC eLearning resource study (McCaughan *et al.* 2021) had a third data collection timepoint, 4-weeks post intervention; this was not a feature of the current study, hence it has not possible to determine if the positive effects from engaging with MSW: CC eLearning resource have been sustained over time.

Analysing mean scores of individual statements within the SABS tool identified that despite the reduction in attitudinal barriers, there was no improvement in perceived comfort levels to providing sexual support. It is unclear from this study as to why this might be the case, but an important question to be addressed in a subsequent qualitative study. Other sexual support studies evaluating education interventions in cancer care, such as Jonsdottir *et al.* (2016) also reported reductions in attitudinal barriers related to knowledge and training. Despite this, Jonsdottir and colleagues reported that 'difficult to discuss' (HPs discomfort) remained the second most common barrier to HPs providing sexual support which is noted in other studies as a key barrier to providing sexual support (Huang *et al.* 2013; Krouwel *et al.* 2015b; Vermeer *et al.* 2015). Future implementation of sexual wellbeing educational interventions in cancer care should be mindful of this

challenge and consider strategies to further support HPs to address this issue of personal discomfort. This could include workshops where HPs can role play providing sexual support with expert patient volunteers or other colleagues, reflective practice through clinical supervision and use of sexual wellbeing champion roles who can support staff to address organisational barriers.

The MSW: CC eLearning resource could support the delivery of training for all clinical cancer care staff, which has been stipulated as an important facet within recent quality improvement initiatives seeking to embed the provision of sexual support into routine practice in Canada (Duimering *et al.* 2020) and England, UK (Nisbet *et al.* 2021). Nonetheless, the MSW: CC eLearning resource addresses a current training gap for the cancer care workforce, as the literature recognises the limited provision of sexual support within cancer care (Flynn *et al.* 2012; Charif *et al.* 2016a, Sporn *et al.* 2015, Reese *et al.* 2017b; Frederick *et al.* 2018), alongside the identified need for access to disease and treatment specific education, plus tools to support the provision of sexual support (O'Connor *et al.* 2019).

The online approach used by the MSW: CC eLearning resource was advantageous. HPs could easily, readily and repeatedly access information contained within this resource to improve their understanding of sexual challenges faced by patients and partners, gain advice for many common sexual challenges, access links to supportive resources and referral pathways. Most previous intervention studies seeking to enhance sexual support provision in cancer care used a face-to-face mode of delivery, which although identified reductions of attitudinal barriers to the provision of sexual support, had limited reach (Afiyanti *et al.* 2016; Reese *et al.* 2019a). It is important to find methods to provide accessible education to enhance HP-led sexual support to help healthcare organisations implement clinical guidelines which explain that HPs should initiate sexual support

conversations. Akin to the content encapsulated for HPs within the MSW: CC eLearning resource, the aforementioned clinical guidelines have indicated that HPs should, inform, assess and support patients through the biopsychosocial effects of cancer on sexuality, have knowledge of and access to supportive resources and referral pathways for both the patient and the partner (Carter *et al.* 2018). To the researcher's knowledge, this is the first HP-focused eLearning intervention which aligns with the approach emphasised within global cancer care guidelines.

The evaluation data indicated that most HPs who engaged with the MSW: CC deemed it to be an acceptable eLearning resource. HPs reported the MSW: CC eLearning resource provided practical and evidence-based advice and resources, within a high-quality online learning experience, which was easy to use, all of which are important for end users (Sekhon *et al.* 2017). Previous studies have also identified HPs acceptability of their face-to-face and online approaches to sexual wellbeing education interventions in cancer care (Reese *et al.* 2017b; Quinn *et al.* 2019; McCaughan *et al.* 2021a). This is an important and promising finding from this study at this stage, although research now must establish if this acceptable intervention can effectively enhance the provision of sexual support in cancer care. There were a few participants (radiographers) who raised minor issues with the resource, reporting it as too detailed, which could be perceived as adding unnecessary burden to HPs in terms of length of time to undertake the eLearning resource. As HPs working in cancer care have many competing survivorship priority areas to support, therefore, it is important to explore HP views in more depth, on time to complete training and content provided within the resource, which could act as future contextual and environmental constraints to implementation of the eLearning resource (Bowen *et al.* 2009). Reducing the content, given the extensive iterative development and testing, may affect the integrity of the resource. Rather it may be more constructive to indicate that some users may require a potentially longer time to view all content. This would ensure

that those who may have less knowledge and experience do not get frustrated if they are moving more slowly through the resource. Furthermore, it could be advantageous to draw users' attention to the progress bars provided in each step of the resource which can provide a sense of the amount of content left to view.

As indicated by the pre-survey, the majority of HPs participated in the MSW: CC eLearning resource out of a desire to increase their knowledge and understanding of sexual and intimacy issues for cancer patients and to improve their communication skills, so they could confidently approach the provision of sexual support. HPs in the post-test survey indicated that the eLearning resource overwhelmingly and successfully met these specific expectations. This finding lends further support for the multifaceted PBA development phases, which employed strategies to ensure the intervention was acceptable to HPs, as informed by the guiding principles (Table 8, pp.108-109) (Yardley *et al.* 2015b). Evidence from free text comments indicated that HPs highly evaluated the eLearning resource and benefited from the diverse range of tools, with particular emphasis on the patient stories, supportive resources and referral pathways (Fig. 17). Many HPs identified the resource as able to support clinical practice (99% agreeing or strongly agreeing), with free text comments suggesting favour for the provision of relevant informative content, support for reflective practice and the demonstration of an HP/patient sexual support conversation. Some HPs suggested the need for additional HP/patient video demonstrating HP-led sexual support conversations beyond the one within the MSW: CC eLearning resource which addresses the sexual concerns of a man with prostate cancer. It could be helpful to demonstrate a further HP-led sexual support conversation looking at issues for women, for example, breast and gynaecological cancers. Furthermore, HPs' competent use of the resource was evident with participants having reported the resource as '*easy to use*' (3.8/4, SD 0.42) which indicated that the PBA planning and optimisation phases, which sought to gain an in-depth understanding of end-user's

requirements and context was effective (see Chapter 3, Review of the Literature and Chapter 4).

The completion of the eLearning resource survey and certificate download could have been deemed a demonstration of both acceptability of the intervention and ability to navigate the resource effectively. First, by completing the resource and participating on the post-survey could have indicated that HPs found the content as informative and relevant and therefore wished to complete the resource and provide feedback; the converse is also possible. However, if the resource was very unacceptable it would be unlikely that many HPs would have completed the resource. Second, to participate in the post-test survey indicated that HPs had choose to complete the resource and managed to do so successfully. Although, Sekhon (2018) warns against determining acceptability through a behavioural lens. With the higher number of pre-test versus post-test surveys completed, there may have been practical aspects of the eLearning resource which impinged upon HPs completion of the intervention and affected its future acceptability in cancer care settings such as technical difficulties. This may have prevented participants from providing potentially negative feedback. There was little indication of usability issues with the MSW: CC eLearning resource, except for a picture/text overlapping issue and a video loading issues for one participant and a navigational issue for another. The evaluation did not capture which device and software specifications to which these problems related. Future research should explore areas of potential problems with participants to ascertain the hardware and software specifications used. This would enable researchers to effectively communicate with the LMS developers about the fixes required.

This study commenced recruitment in November 2020 just prior to the second wave of the COVID-19 pandemic. At that time, most oncology staff faced additional challenges,



while the reallocation of resources put additional strain on existing overburdened oncology services (Paterson *et al.* 2020). This could have impinged upon recruitment to this study. While the study did surpass the minimum sample required (n=41) achieving n=157 at baseline, it highlighted the need to re-evaluate the initial recruitment protocols, to include a social media strategy to enable study completion within the agreed timeframe. Topolovec-Vranic and Natarajan (2016) conducted a scoping review, which identified social media to be an effective recruitment method for studies with harder-to-reach populations. The social media recruitment approach utilised posting recruitment advertisements on Twitter and linking to key cancer organisations and researchers in the field alone. While this did enhance recruitment, given the reach of social media, this could have been further enhanced through the adoption of more targeted and active approaches. McRobert *et al.* (2018) have identified several actions which could optimise the use of Twitter as a recruitment tool, suggesting the use of the free versions of software such as Followerwonk (Moz Inc. Washington, USA) to support target tweets to potential participants who meet the inclusion criteria and have high social capital and Hootsuite (Hootsuite Media Inc. Vancouver, Canada) to ensure that research invitations feature regularly on the stream of tweets. Furthermore, they suggested the use of interchangeable hashtags on tweets to promote visibility. If adopting these targeted approaches, it would be important for researchers to monitor Twitter metrics throughout the recruitment period to make further adaptations to their recruitment strategy if required.

To further enhance data collection, it would be important to reduce the attrition rate at the post-test timepoint. This study's response rate from pre-test to post-test surveys dropped by 44%. Participants were informed, akin to the MSW: PC evaluation that a CPD certificate would be offered on completion of the post-test survey. This incentive does not appear to be an important motivating factor. Furthermore, the integration of the

quick link to the post-test survey on the home screen did not appear to boost completion rates of the post-test survey. The MSW: PC eLearning resource did not have this function yet only identified a drop of 19% of participants completing surveys from pre to post intervention timepoints (McCaughan *et al.* 2021b). However, the evaluation context for each of these studies were drastically different, with reduced ability to promote the study in person and the many changes the cancer care workforce faced during the second wave of the COVID-19 pandemic. Previous studies identified recruitment attrition challenges also throughout their study period (Lee *et al.* 2012; Jonsdottir *et al.* 2016; Merriam *et al.* 2018; Wang *et al.* 2015; Quinn *et al.* 2019). While studies have suggested limited effectiveness, the use of reminder emails could enhance recruitment (Wang *et al.* 2015; Jonsdottir *et al.* 2016; McCaughan *et al.* 2021b). Furthermore, monetary incentives could enhance response rates (Cho *et al.* 2013; Quinn *et al.* 2019; Reese *et al.* 2019a) with Quinn *et al.* (2019) retaining all study participants at follow up (Quinn *et al.* 2019). Missing or incomplete data can also affect participant data. This issue meant an Icelandic 2-year educational intervention to enhance sexual support at a hospital base required the removal of n=16 (20%) participant's data (Jonsdottir *et al.* 2016). The current study successfully mitigated for the problem of missing data by making completion of all Likert scale questions mandatory to access the resource and completion certificate. Cho *et al.*'s (2013) meta-analysis of healthcare survey response rates over the last 50 years appears to reflect that response rates from HP sexual support intervention studies are in keeping with other healthcare research. Nonetheless, the smaller numbers of participants engaging in sexual support intervention studies does highlight the importance of maximising participant retention and fine-tuning recruitment protocols prior to larger scale studies. Survey implementation measures such as partnering with healthcare organisations to maximise on their communication and dissemination systems could increase interaction and the digital visibility of studies and establish trust with participants (Hlatshwako *et al.* 2021). The MSW: PC eLearning resource evaluation study identified

the potential value of this approach with their low attrition rates; however, the COVID-19 restrictions during this study's data collection, prevented this study from meaningful engagement with cancer care teams. Despite the lead researcher and LCs efforts to use opportunities through HSCT team meetings and regional forums to increase the visibility of the study, provide a rationale for the study and establish trust with potential participants, this was not achieved. This may, in part, have resulted in greater attrition rates for this study when compared with the MSW: PC eLearning resource study. Dunleavy *et al.* (2018) systematic review of the barriers to study recruitment has highlighted the need for careful messaging when promoting a study which can address participant concerns, the need for repeated contact with referral sources throughout the lifetime of the study and the value of having enthusiastic study champions. It could be argued, however that those who did participate in this study provided more objective data, given they had no association with the researcher (Parahoo 2014).

#### 5.5.1 Limitations

While this study points to a potentially effective educational intervention for multidisciplinary HPs, several limitations should be considered. First, intervention fidelity was unknown, albeit for participants to gain access to the post-test survey and CPD certificate they had to view a significant amount of content in each of the eLearning resource's three steps. This study was not able to determine which videos were watched, which links were accessed, what material was downloaded or how long participants meaningfully engaged with the content. This intervention was built on a Moodle open-source platform using a single webpage, therefore exact participant activity could not be tracked accurately. Tracking options do exist on this platform and coding could have been incorporated earlier in the process to account for aspects of participant behaviour. However, the researcher was unaware of this option and therefore this facility had not been part of the agreed contract. This highlights the importance of early, clear,

documented discussions with LMS developers, stipulating the research outputs required, to avoid unexpected costs and delays to research projects. Alternatively, PBA authors have suggested that researchers could build interventions using LifeGuide (Williams *et al.* 2010). Lifeguide is an open-source software platform that allows researchers with no previous programming experience, to either develop interventions from inception or modify interventions (Yardley *et al.* 2015b). This option of using Lifeguide was not selected for this study, given that much of the structure and design already existed online in the form of the MSW: PC eLearning resource and it was therefore advantageous to utilise this both in terms of maximising the design quality and reducing the time it would take to build the intervention on another platform.

Second, the recruitment method used a non-probability sample which prevented generalisability across multi-disciplinary HPs in cancer care. It was possible that this study's sample participants may have been more aware of the importance of sexual wellbeing support for patients and were more likely to want to provide sexual support in the future, than those who choose to not participate. The variability and bias inherent within the study sample could not be measured or indeed controlled for, given the anonymity of participation (Acharya 2013) and the single-arm study design.

The study design did not lend itself to attributing causality of findings to use of the eLearning resource as there was no control group to account for external factors. As acknowledged at the study outset, it was possible that the pre-test survey had a positive influence on attitudes of HPs towards providing sexual support or that those submitting data had positive bias towards the intervention, each of which could be somewhat mitigated for through a randomised control trial. Furthermore, the use of an active control group, one where HPs would receive an alternate form of information/resources should be an ethical consideration for future study. It is well-established that HPs do

require education, training and resource support to provide sexual support, but there is a lack of clarity on the best implementation method. Use of an active control group would enable the study to determine the comparative benefit of the eLearning resource on attitudes and beliefs related to the provision of sexual support against a less intense intervention while upholding the ethical principle of beneficence (DoH 2014).

## **5.6 Conclusion**

The provision of HP-led sexual support in cancer care is stipulated in current healthcare guidelines as an important part of patient-centre care (NHS 2016; Carter et al. 2018; Cancer Australia 2019). However, HPs across cancer care have lacked access to suitable training to address the barriers they face providing routine sexual support. Findings from this evaluation have suggested that the MSW: CC eLearning resource was an acceptable and usable resource, with potential to reduce the attitudinal barriers affecting the provision of sexual support in cancer care. The MSW: CC eLearning resource has received positive feedback, however, a more detailed process evaluation is indicated and planned. This will include exploring HPs time spent with eLearning resource, HPs' perceptions on the length of resource, resource appearance and any technical issues. Furthermore, HPs views will be sought on their perceptions of the need for further role-play demonstrations of sexual support, any other specific tumour group information or sexual challenges required and supporting resources or referral pathways to offer support to patients managing sexual challenges such as those with when they have learning disabilities, difficulties, or dementia.

## CHAPTER SIX: DISCUSSION

### 6.1 Introduction

This thesis has described the process used to adapt, test and evaluate an eLearning resource for HPs to enhance the provision of sexual support to patients and partners in cancer care. A literature review identified the extent of sexual challenges faced by patients and partners after a cancer diagnosis and treatment, the gaps in provision of sexual support and the barriers to the provision of HP-led provision of sexual support. The researcher in collaboration with an expert group of HPs, patients and partners adapted the MSW: PC eLearning resource to an eLearning resource suitable to enhance the provision of HP-led sexual support across cancer care. The same theoretical frameworks were retained from the original MSW: PC eLearning resource (TDF (French *et al.* 2012), underpinned by the TPB (Ajzen 1985) and SCT (Bandura 1986)). Following the comprehensive review of the literature and development of PBA guiding principles, the new content was devised using the BPS model (Engel 1977). The MSW: CC eLearning resource was initially optimised through expert group critique of the new content. Next, all aspects of the eLearning resource were tested using TA interviews to identify the necessary refinements to improve acceptability and usability. After optimisation, the eLearning resource was evaluated to determine ‘does the intervention work?’ and to ascertain HPs’ perceptions of the eLearning resource’s acceptability and usability for cancer care settings. The aim of this chapter is to discuss the key findings, highlight limitations of the study and the study’s unique contribution to knowledge. Furthermore, this chapter makes recommendations for future policy, education, clinical practice and research. At the conclusion of this chapter, a proposal for the future direction of this work is provided.

## 6.2 Discussion of key findings from the study

A discussion of the study findings is presented at the end of each study phase; however, this chapter provides an overall collective discussion of all the findings. Table 21 outlines the key findings from this study and highlights the relevant data and its location within the thesis supporting these claims. Following this, the key findings are discussed in detail.

**Table 21: Key study findings and supporting data**

<p><b>1. The MSW: CC eLearning resource as an acceptable, usable and efficacious approach to address a gap in cancer care.</b></p> <p><b>Phase 2 (Chapter 4) Qualitative TA interviews</b> identified the MSW: CC eLearning resource as an acceptable resource to HPs providing cancer care. They identified the resource as much-needed, relevant, informative, engaging, user-friendly and intuitive to use.</p> <p><b>Phase 3 (Chapter 5) Quantitative pre-test post-test survey data</b> identified that after engagement with the MSW : CC eLearning resource HPs reported a reduction in the attitudinal barriers preventing the provision of sexual support in cancer care. Furthermore, HPs rated the eLearning resource as easy to use and would recommend to other colleagues alongside providing free-text comments highlighting the utility of the patient videos, signposting sheets and supporting resources.</p>
<p><b>2. Inherent benefits to adapting an intervention.</b></p> <p><b>Phase 2</b> adaptation and optimisation process of the MSW: CC eLearning resource identified inherent benefits to adapting an intervention. The adaptation process capitalised on the extensive evidence and theory base used to develop the MSW: PC eLearning resource. Involvement of the original MSW: PC eLearning resource research team ensured fidelity to the original intervention by providing insights into the intervention development beyond that in published papers. Furthermore, this study realised a cost-benefit through utilisation of well-established and successful communication with LMS developers, which ensured timely, specific communication on all changes required, keeping within the agreed contract.</p> <p><b>Phase 3 Quantitative pre-test post-test survey data</b> identified that the MSW: CC eLearning resource, retaining the theoretical underpinning of the original resource did have a similar impact on the reduction of attitudinal barriers to the provision of HP-led sexual support, further supporting the rationale for adapting efficacious resources.</p>
<p><b>3. Asynchronous approaches to co-production can maximise meaningful PPI.</b></p> <p><b>Phase 2</b> documents the application of an asynchronous approach to engage a diverse range of key stakeholders throughout the adaptation and optimisation of the eLearning resource. The use of a flexible approach ensured meaningful engagement with experts throughout the study period. Each meeting or correspondence was directly related to the member's area of expertise, reducing the cost-time burden on research involvement.</p>

<p><b>4. Rapport with potential participants can enhance study recruitment.</b></p>
<p>The data collection process used for <b>Phase 3</b> identified problems with recruitment and attrition. Despite access to the MSW: CC eLearning resource study taking a similar approach to that of the MSW: PC eLearning resource, the slow uptake to recruitment and greater than expected attrition rate highlighted the potential importance of building rapport with potential participants. A key difference between the two studies was the in-person promotion of the MSW: PC eLearning resource evaluation at a wide range of meetings and conferences locally and nationally. Based on the experience of this study, it is the researcher's belief that addressing the barrier to promoting the study remotely will enhance future data collection.</p>
<p><b>5. Good project management is key to maximising the success of the intervention development.</b></p>
<p><b>Phase 2</b> identified challenges working across research and LMS developer agendas. Given the competing agenda of ensuring a quality intervention and keeping within an agreed contract, there is a need to build in flexibility into the contract in order to meet the needs of the research agenda. Researcher ingenuity to problem solve navigational issues outside of the contract that could be replicated by LMS developers was key to keeping the study on time and within contract.</p> <p><b>Phase 3</b> denoted the challenges and frustrations relating to the capturing of the usage analytics for the study; this highlighted the need to for the researcher to adapt her expectations and note important learning for future digital intervention developments. Ensuring clear communication, working within the confines of the agreed contract with LMS developers, conveying the meaning of the eLearning resource for HPs to LMS developers and flexibility were key attributes highlighted.</p>
<p><b>6. Quality of feedback can moderate for a small sample size in the PBA's optimisation phase.</b></p>
<p><b>Phase 2 qualitative TA interviews</b> used a purposefully selected sample of HPs working in cancer care. Many of those, depicted through their roles, were specialist within their field. HPs in test cycle 2 were the first to use the online version of the resource, yet data collected was of considerable quality feedback that it informed key navigational refinements which were acceptable to HPs during test cycle 3. Furthermore, after application of refinements from two test cycles, the feedback in test cycle 3 involved only minor changes, pointing to the quality of feedback already received.</p>
<p><b>7. Investing in optimisation phase can promote effectiveness of intervention.</b></p>
<p>This optimisation phase (Chapter 4) of the study built upon elements within the planning phase, that is the literature review, review of theoretical underpinning of MSW: PC eLearning resource, establishing an expert group and developing the guiding principles. To optimise the intervention, the expert group reviewed the content and challenged aspects of it in terms of relevance and priority areas for population group, ensuring relevance for all advice included. The TA interviews, under research conditions, provided the opportunity to test the content and the usability of the eLearning resource with HP from diverse roles. The data collected informed refinements of the content, navigation, functionality and appearance of the resource. The success of this optimisation process was apparent through the qualitative feedback provided in <b>Chapter 4</b> and the findings from the modified SABs survey data and free text comments, presented in <b>Chapter 5</b>.</p>



6.2.1 The MSW: CC eLearning resource as an acceptable, usable and efficacious approach to address a gap in cancer care.

The optimisation and evaluation phases of this study have identified the MSW: CC eLearning resource as acceptable, usable and effective; equipping HPs with the necessary tools to support patients and partners with the sexual challenges they confront. The provision of HP-led sexual support can bring many benefits for patients and partners, these include increased knowledge of treatment risks and benefits, important for informed consent, greater cooperation with treatment-related advice, better psychosocial adjustment, reduced sexual distress and improved wellbeing (Laurence and Rousset-Joblonski 2012; Hanly *et al.* 2014; Maslow *et al.* 2014; Tracy *et al.* 2016; Canzona *et al.* 2016; Reese *et al.* 2017a; Walker *et al.* 2021a). HP-led sexual support can mitigate patient discomfort with the topic of sexuality while normalising the provision of sexual support as part of holistic care in cancer care settings (Tracy *et al.* 2016). Alongside the physical and psychological treatment-related challenges, intimate relationships are at risk of break-up, consequently diminishing important support systems for patients (Boquiren *et al.* 2016; Tracy *et al.* 2016; Farthmann *et al.* 2016; Rhoten *et al.* 2020). This is an important consideration, given that healthy relationships, particularly with a spouse or partner can be key factor promoting a longer life after cancer (Aizer *et al.* 2013; Dahl *et al.* 2020) and QoL (Brédart *et al.* 2011; Emilee *et al.* 2010; Hanly *et al.* 2014; Male *et al.* 2016).

The MSW: CC eLearning resource has demonstrated potential for effectiveness to enhance the provision of routine sexual support in cancer care. Underpinned by the TPB (Ajzen 1985) and the SCT (Bandura 1986), the target of the intervention was to address the attitudinal barriers preventing the provision of sexual support in cancer care. The literature, alongside findings from this study, reported that in some cases HPs believed

that the provision of sexual support was not within their remit to provide (Gleeson and Hazell 2017; Jonsdottir *et al.* 2016; Krouwel *et al.* 2015a), while other HPs, despite seeing the value and need for sexual support, failed to provide support due to a lack of knowledge, perceived skill and a lack of access to resources and referral pathways. The evaluation findings have indicated success in reducing the attitudinal barriers related to the provision of sexual support, similar to findings reported by the MSW: PC eLearning resource. Moreover, the current study echoes the findings of McCaughan *et al.* (2021a) in relation to HP's level of discomfort surrounding the provision of sexual support. Akin to their study, there was little change to the HP's levels of discomfort related to providing sexual support. Other educational interventions have reported greater success in this area by adopting a skills-based element, such as role-play, within their model prior to post-intervention data collection (Lee *et al.* 2012; Wang *et al.* 2015; Merriam *et al.* 2018). The study by Lee *et al.* (2012) identified from a multidisciplinary group of HPs in cancer care that the combination of theory and skills helped to build confidence, noting that the role-play exercises were useful, encouraging reflection and initiation of communication in a challenging area. This suggests the need to strike a balance between theory and skills training (Lisko and O'Dell 2010). The asynchronous approach utilised with the MSW: CC eLearning resource did not support the integration of a skills-based element, although the resource did suggest several ways for HPs to gain this experience. However, it is unclear if HPs availed of such suggestions, as no follow-up data was collected on this specific area or for the SABS at a third timepoint. These findings indicate that future implementation of the MSW: CC eLearning resource should consider the effect of a potential adjunct skills-based workshop to further support skill development or further video demonstrations of HP-led patient sexual wellbeing consultations, which was requested by participants completing the post-test survey.

This study did not examine the impact of the resource on clinical practice, although early indications from findings of the MSW: PC eLearning resource study have suggested that the MSW: CC eLearning resource has potential to make a difference. Over one-third of participants at 4-weeks post-test (n=14/44) in the prostate study provided examples of when they had applied learning from the resource in their clinical practice (McCaughan *et al.* 2021a). Previous interventions (Quinn *et al.* 2018; Reese *et al.* 2019b), based on similar theoretical underpinning – SCT (Bandura 1986), have likewise identified a positive change in clinical practice. Reese *et al.*'s (2019b) study reviewed audio transcription of clinical encounters, which demonstrated that HPs' sexual health communication behaviours increased from baseline to post-test for raising the topic (28% vs 48%), assessment (33% vs 45%) and providing information (18% vs 24%). The findings from the MSW: CC eLearning resource study and that of the published MSW: PC eLearning resource (McCaughan *et al.* 2021a) have identified changes to SABS statements which related to key constructs within the TPB (attitudes towards the behaviour, subjective beliefs and self-efficacy). Previous interventions which have successfully addressed these beliefs and self-efficacy have demonstrated a positive effect on behavioural intentions, key to increasing the likelihood of a target behaviour (Steinmetz *et al.* 2016). There is a need to investigate further the strength of the impact on these beliefs, identifying the impact on behavioural intentions and the clinical practice outcomes.

The EASSi framework used to structure the eLearning resource and to provide a framework for routine brief HP-led sexual wellbeing conversations, was accepted by HPs as a suitable tool to support HPs to routinely address patient and partner sexual concerns across the treatment trajectory. The EASSi framework was grounded upon a strong evidence base and behaviour change components which have been clearly detailed in peer-reviewed publications for the MSW: PC eLearning resource (McCaughan *et al.* 2020;

2021a). The optimisation and evaluation phases of this study further validate support for the EASSi framework. HPs in the optimisation study deemed the EASSi framework as providing a sound rationale for the provision of sexual support, which could support application in practice, while HPs reported a higher level of confidence to address sexual support needs at the post-survey timepoint. As already discussed in Chapter 3, previous communication models within the literature had some concerning shortcomings which the EASSi framework addressed. For example, the PLISSIT model used a sexual counselling approach which involved HPs providing support beyond the knowledge and expertise of some HP roles (Annon 1976). Furthermore, HPs perceived that they needed to gain permission from patients to discuss sexual concerns. In contrast, the EASSi framework was designed to be used by multidisciplinary HPs without any specific training in sexual counselling and explicitly states that all patients should be routinely provided with sexual support (McCaughan *et al.* 2020). As such, EASSi has a distinct advantage over the BETTER model (Mick and Cohen 2003), which brings with it a risk that HP-led sexual support for patients could be overlooked, as the framework stipulates HPs are responsible for deciding the most appropriate timing of sexual support conversations. Given that patients need to be informed about the consequences of treatment and that patients identify that the early provision of sexual support promotes better outcomes, this is problematic (Olsson *et al.* 2013; Traa *et al.* 2014; Albers *et al.* 2020). Furthermore, the option not to provide sexual support on occasions could serve to alleviate HPs discomfort and perpetuate unmet sexual care needs.

The qualitative and quantitative findings from this study, akin to others (Wang *et al.* 2015), identified that HPs lacked knowledge of resources and referral pathways. The resources and services included within the intervention existed prior to the development of MSW: CC eLearning resource; however, participating HPs were largely unaware of their

availability (Chapter 4, Section 4.4.5.2, p.183). This study has highlighted a need to increase awareness of the supportive resources and referral pathways available to help patients navigate sexual concerns offered by clinical and voluntary/community sector services to maximise effective and efficient referrals and improve patient outcomes. Dissemination of the MSW: CC eLearning resource could address this gap in knowledge, however HPs working to translate this information to a local context could utilise existing technologies to maximise reach. Podcasts (an episodic digital audio recording) have been used to communicate key knowledge about services provision and referral pathways using downloaded files and online streaming (Lichtenheld *et al.* 2015). The 'on-demand' educational content can be useful, as although many people could access this information upon release, with shift-working and staff leave, the content could be accessed at a later suitable date (Patrick *et al.* 2019). This low-cost approach which can provide easy to access information could ensure that helpful information about potential support for sexual challenges is available to HPs across clinical services.

The PBA approach suggests that users of interventions must feel motivated and confident to use an intervention on their own; elements akin to those within the Self-Determination Theory (SDT) (Deci and Ryan 2000; Ryan and Deci 2000). As such, Yardley *et al.* (2015) identified key features of digital interventions aligned to these constructs, namely autonomy, competence and relatedness (Ryan and Deci 2000). There is supporting evidence for these constructs from the optimisation and evaluation phases. Support for *autonomy* was evident through reports of a well-designed structure which supported navigation and selection of information pertinent to the HP's role. For example, the treatment-related advice in Step 2 presented in 'core' and 'tumour-specific' sections and the provision of a variety of patient stories and a diverse range of helpful resources and referral pathways. Support for HPs' *competence* was visible throughout the TA interviews,

as the researcher observed HPs successful navigation through the eLearning resource. HPs reported there was a clear rationale for the intervention and the elements within the EASSi communication framework. Subsequently at evaluation, completion of the final survey identified a level of competence to navigate each of the 3 steps successfully. Furthermore, HPs reported that the MSW: CC eLearning resource was intuitive, easy to use and when used, HPs felt that providing sexual support was achievable. Finally, *positive experience and relatedness* were evident throughout both optimisation and evaluation phases where HPs reported through the TA interviews (Phase 2) and free text comments (Phase 3) that the resource was enjoyable, interactive, engaging and contained relevant quality information. Likert scale items indicated that HPs would use the resource in the future and recommend it to other colleagues. Creating an autonomous learning environment is thought to be key to achieving positive learning outcome and enhancing patient-related outcomes (Orsini *et al.* 2016). Therefore, there are elements of the eLearning resource that require further exploration, for example, the length of the content, applicability of content across HP roles and minor technical issues. Addressing these issues could further enhance HPs' motivation and confidence to engage with the eLearning resource.

The BPS model (Engel 1977) offered a helpful scaffold to ensure HPs were furnished with relevant information and advice. The literature on sexual concerns after cancer (Matthew *et al.* 2018) and the provision of HP-led sexual support, has previously been critiqued as too medically orientated (Vermeer *et al.* 2016; McCaughan *et al.* 2020). Psychological support is considered a key element to improving patient outcomes related to poor treatment adherence, for example, in relation to vaginal dilation, use of erectile aids, emotional avoidance of sexual activity or sexual treatments (Matthew *et al.* 2005; McCallum *et al.* 2012; Law *et al.* 2015). More recently, psychological issues arising from

body image difficulties, sexual identity, perceptions of sexual QoL and the presence of psychological distress have been accepted within the discourse of sexual dysfunction (Schover *et al.* 2014; McClelland *et al.* 2015; Boquiren *et al.* 2016). It has been well established that the provision of biopsychosocial sexual support can make a difference both to QoL (Laurence and Rousset-Joblonski 2012; Hanly *et al.* 2014; Canzona *et al.* 2016; Reese *et al.* 2017a; Walker *et al.* 2021b) and patients' perceptions of quality of care (Nisbet *et al.* 2021; Walker *et al.* 2021a). Healthcare guidelines, globally, have recognised the importance of providing biopsychosocial sexual support to patients and partners across the treatment trajectory (NICE 2019; Carter *et al.* 2018; Cancer Australia 2019). Integrating these elements of support can help to support the sexual concerns of patients as they present within clinical practice (Walker *et al.* 2021b). The MSW: CC eLearning resource can support the provision of an integrated person-centred approach to sexual support.

At the outset of this study, it was identified that eLearning was an essential approach to consider in the development of CPD programmes. This study identified that HPs regarded the online approach acceptable and usable. The motivation for adopting an eLearning approach included wider reach of the intervention, easy access and improved usability while having a comparable level of efficacy as face-to-face in-person approaches and being more cost-effective (Atreja *et al.* 2008; Du *et al.* 2013; Kirana *et al.* 2020). In the UK during March 2020, this approach became more meaningful as HPs navigated the impact of COVID-19 restrictions, to include social distancing. With much in-person training cancelled, many HP educators were working at pace to develop online programmes to prepare HPs to address COVID-19 challenges (Bushell *et al.* 2020). This study benefited from its online approach, as it permitted continuing testing and evaluation processes, and overcame challenges introduced by the recent pandemic. The

use of an asynchronous approach to eLearning further facilitated access to the resource at a suitable time, whether that be during day or night shift and regardless of time zone. While there are advantages to engaging with users in real time, such as peer support from other learners and instructors being able to address barriers and concerns (Rege Colet 2017), this needs to be weighed up against providing flexible learning which can help maximising reach of information, tools and resources to HPs who are juggling education, clinical practice, family and other commitments (Hrastinski 2008).

### 6.2.2 Inherent benefits to adapting an intervention.

This study validates the rationale for researchers to adapt existing interventions rather than 'reinvent the wheel' (Copeland *et al.* 2021) and has identified that the PBA has utility to ensure a successful adaptation process. Adaptation of an intervention is the intentional modification of an intervention to meet the needs of a new context, where there is evidence of that intervention's effectiveness in its original context (Evans *et al.* 2021). It is postulated that adapting an intervention can prove more efficient and less resource intensive, meaning more likelihood that efficacious interventions will be generated (Copeland *et al.* 2021).

There were several benefits to the MSW: CC eLearning resource study realised by the adaptation approach. First, this study was able to capitalise on the evidence related to the empirical research and literature reviews of the biopsychosocial sexual challenges which men with prostate cancer faced and barriers and facilitators to the provision of HP-led sexual support that informed MSW: PC eLearning resource (McCaughan *et al.* 2013; McSorley *et al.* 2014; O'Connor *et al.* 2019). This information provided a clear basis from which the researcher could review the wider literature (see Chapter 3) to ascertain any further barriers encountered or key components which could facilitate the provision of



sexual support in cancer care. Next, the original developers of the MSW: PC eLearning resource provided their expertise throughout the development of the MSW: CC eLearning resource. This expertise provided additional detail on the intervention beyond published materials, which helped to aid replication of its mechanisms in the new context (Campbell *et al.* 2020). There is a risk to involving the original developers in adaptation projects, as it can cause a conflict of interest (Moore *et al.* 2021a). However, it was the researcher's perception that the reflexivity demonstrated in research team meetings was indicative of the original developers' commitment to high quality research and to maximising successful interventions to improve patient reported outcomes in cancer care.

The involvement of the original developers helped to ensure intervention fidelity, that is controlling the extent to which the key elements of the intervention were replicated despite adaptation of other components (Movsisyan *et al.* 2019). This included deliberations about the basis of all new content, ensuring it was commensurate with the theoretical frameworks. When adapted interventions fail, it can be difficult to determine if it stems from the intervention's fit with the new context, an implementation failure, or as a result of the adaptation violating the intervention theory (Evans *et al.* 2019). This issue was exemplified in a study which implemented an adapted version of the United States Strengthening Families Programme in Sweden, which demonstrated no effect (Skärstrand *et al.* 2014). Although authors had attributed this largely to differences in context, commentators argued that the local adaptations to the interventions application in Sweden had violated the intervention's causal pathway (Segrott *et al.* 2014). This related to the removal of sessions where parents and children worked together to practise skills, and the loss of interaction between families during programme activities and meal breaks. The authors concluded that while cultural adaptation for local contexts is important, interventions need to retain fidelity to their original theory (Segrott *et al.* 2014). To support intervention fidelity through the adaptation process, the Cancer

Prevention and Control (CDC) Research Network have proposed the use of a traffic light tool (Rolleri *et al.* 2014). This tool can guide researchers to achieve a balance between intervention fit, that is making the intervention compatible with the target population/context and maintaining fidelity, implementing the intervention as prescribed in the original protocol. The traffic light framework allows a clear and practical way to define appropriate and inappropriate adaptations which could be used when constructing the PBA guiding principles to ensure any adaptations have minimal negative impact on intervention effectiveness. With this tool, green symbolises elements of the intervention which can be changed such as pictures and wording to make it readable and appropriate to target group. Yellow identifies elements of the intervention which could be changed with caution, such as shifting or expanding the primary audience, adding activities to address other behaviours while red indicates aspects which cannot be changed such as communication models and theoretical basis, which emulated decisions made within this study. For this study, 'green' elements were changes to layout of paragraphs to make them more readable and pictures to depict the resource was for both women and men. Yellow related to the broadening of the resource to other tumour groups and women as patients, however this was completed within the framework, so as not to change the way in which the resource communicated key messages and advice. As with adaptation guidance, the red element related to the theoretical underpinnings which remained the same, namely the TPB (Ajzen 1985), SCT (Bandura 1986) and BPS Model (Engel 1977) alongside the conceptual framework Engagement, Assessment, Support and Signposting (EASSi) (McCaughan *et al.* 2020) used to structure the information and advice. This traffic light tool could help support other researchers seeking to adapt interventions while maintaining fidelity to the original intervention protocol. Some researchers take a more dynamic view of interventions as system disruptions with an interplay between the intervention theories, intervention components and the system in which they operate (Hawe *et al.* 2009; Rutter *et al.* 2017; Moore *et al.* 2019). This perspective would call for

both an adherence to core components of the intervention, that is its theoretical underpinning and a need for functional fidelity, that is fidelity of the application of the intervention (Hawe *et al.* 2009; Moore *et al.* 2017; Evans *et al.* 2021) for the successful adaptation of interventions.

Finally, there was a cost-benefit to adapting the MSW: PC eLearning resource which had also been developed using a Moodle platform, as much of the layout, navigation, functionality and content could be transferred across to the MSW: CC eLearning resource. The transfer of these elements to the new resource saved researcher and developer time and therefore reduced the cost of intervention development. This contrasts with previous concerns raised as to time-consuming nature of intervention adaptation (Copeland *et al.* 2021). Realising the cost-benefit to adaptation is redundant if the intervention does not produce clinically significant changes, as illustrated by other healthcare eLearning interventions (Harris *et al.* 2011). The process of adaptation not only saved time and cost, but it also identified a potential improvement to be considered for the MSW: PC eLearning resource, that was, better signposting through Step 2 to avoid HPs missing key information. Future studies which seek to adapt an intervention could potentially yield benefits to both the current intervention and suggest improvements to the original intervention.

### 6.2.3 Asynchronous approaches to co-production can maximise meaningful PPI.

PPI co-production approaches offer a complementary function, alongside the iterative and systematic PBA qualitative approach to intervention development (Muller *et al.* 2019). The asynchronous approach to the involvement of an expert group was fundamental to maximising engagement and ensuring a high-quality eLearning resource. Expert group members' perspectives were vital to ensuring the resource was acceptable,

usable, meaningful and engaging. Taking this flexible approach enabled a broader representation of views which undoubtedly saved study time by advancing the relevance and presentation of the prototype. Often there is critique for the lack of representativeness of PPI involvement in research studies (Rai *et al.* 2021), yet the purposeful selection of participants for qualitative research as representative of wider population is well accepted (Locock and Boaz 2019). This study sought to maximise the variation of PPI involvement, which was supported by a Macmillan Service Improvement Manager who suggested potential roles and contacted personnel. While similar variation was sought in patient and partner representatives, there was less willingness in those approached, as a result only three tumour groups were represented (breast, gynaecological and head and neck). It was quickly realised that those recruited would not be free to meet as a group when required and HPs would prefer to meet to discuss only issues relevant to their discipline or tumour group. Previous PBA healthcare interventions have used various models for involving PPI contributors, with numbers ranging from 4 to 30 people. In addition, contributions to PPI have included individuals being involved throughout studies and others, selecting specific parts of a study to which they would contribute (Muller *et al.* 2019; Rai *et al.* 2021). This study has added to these approaches, suggesting proposed value in applying an alternate asynchronous approach to PPI involvement which to date has not been published for PBA methodology. Asynchronous approaches have been used in more recent forms of co-production (Sorrentino *et al.* 2018). In the current study, such an approach made it possible to involve a larger PPI representation, with members involved throughout intervention adaptation, testing and evaluation, maximising input in line with each person's specific expertise. This strategy provided support to the key co-production principles of diversity and accessibility by facilitating group meetings with those who could attend and individual meetings, emails, or postal communication approaches with others, as preferred. Careful use of participants' time meant that HPs, patients and partners were able to avoid attendance

at meetings where the discussion was not related to their area of expertise. The involvement of the expert group in the planning and producing of the MSW: CC eLearning resource has recognised and realised the vital contribution that HPs, patients and partners can make to improving healthcare interventions.

#### 6.2.4 Rapport with potential participants can enhance study recruitment.

The contrast in recruitment approaches between the MSW: PC eLearning resource study and the current study illuminated potential value in building rapport with future participants. Rapport with potential participants has been reported in the literature as a key strategy to facilitating better recruitment (Felsen *et al.* 2010). The evaluation of the MSW: PC eLearning resource took place prior to the COVID-19 pandemic at a time when people were permitted to meet in groups, alongside unrestricted access for researchers to meet in-person with healthcare teams. As such the MSW: PC team, with leverage support from Prostate Cancer UK, introduced the MSW: PC eLearning resource at a series of high-profile events including a Urology Specialist Nursing Education Forum, Birmingham, UK, two Institute of Psychosexual Medicine in Newry, Northern Ireland (NI) and London, UK and to an Oncology Specialist Nursing conference held at Queen's University, Belfast, NI. This was in addition to smaller presentations to local teams in HSCTs in NI. These events provided opportunities for potential participants to hear directly from the expert researchers, who provided detail on the intervention, participation expectations and benefits, an outline of time commitment and addressed any barriers raised in real time. It could be argued, however, that as this information is clearly presented on the PIS, this effort is a potentially unnecessary cost. Irrespective of the evaluation study design being set up with a detailed online PIS, on two occasions participants sought out dialogue with the researcher. These two recruitment related enquiries, out of a potential 160 who registered to participate during the study period,

was in stark contrast to the many conversations to clarify research expectations with each participant during the Phase 2 TA interview recruitment period. Phase 2 used a similar, detailed PIS. Specifically, the dialogue for Phase 2 often sought to alleviate participant concerns about their contribution to the study and restating the expected time commitment. Furthermore, some participants required reminders to attend TA interviews, or wished for the researcher to confirm arrival at location ahead of their TA interview (see excerpt from reflective diary - Appendix 12). Salvy *et al.* (2020) compared the effectiveness of virtual and in-person recruitment methods to a self-management clinical trial and found that in-person recruitment was overall the most cost-effective strategy. However, once recruited, in-person approaches often do not yield any difference to study completion rates (Salvy *et al.* 2020). However, it is possible that in-person approaches to recruitment could have increased rapport with potential participants and reduced the data collection timeframe.

#### 6.2.5 Good project management is key to maximising the success of the intervention development.

The research team's previous experience working with the LMS provider proved advantageous to the cost and timeframe of the study. Primarily, this saved construction time as much of the layout, colour scheme, images and functionality could transfer to the new resource. Prior experiences ensured that the MSW: PC eLearning resource research team members and LMS developers had clear and established methods of communication relating to timeframe, change iterations and project sign-off.

Aligned with PBA, user testing was an integral part of the optimisation process of the MSW: CC eLearning resource. This required a flexible timeframe, agreed in advance, between intervention build and final LMS modifications to facilitate data collection and

the application of iterative modifications. Despite previous experience gleaned from team members who developed the MSW: PC eLearning resource, there remained several challenges. These challenges primarily centred on required modifications, arising from the data generated from the TA interviews that were perceived as more expensive and outside the agreed budget. For example, the LMS developers considered communication to explore the resolution of navigational difficulties during test cycles as an unreasonable expectation and not part of the agreed service package. Nonetheless, the researcher was able to explore a suitable modification with participants to address the identified problem. The LMS developers were subsequently able to implement the modification as per agreed work package timeframe. As noted earlier (Chapter 5, Section 5.5.1, pp.226-227) the quality of usage analytics presented another challenge. The research team however had to concede that it was not possible to address the usage analytics issues at this stage as this was beyond the original scope and would have a major impact on both project cost and timeframe. This was a key learning point for the research team. It had been assumed that the reliable and detailed usage analytics provided by platforms such as Lifeguide (Williams *et al.* 2010), which the research team based initial conversations with the current LMS provider upon, would be available through the Moodle, but this was not the case. The research team and LMS developers, in fact, through the planning for the build, had each been talking about two quite different system outputs. It could have been advantageous to have co-opted an expert in LMS systems onto the research team, enhancing a shared understanding of both the system and the research project (Bond 2017) or if the LMS provider had been clearer with the research team in terms of available usage analytics.

Hence, project success has two key components: managing the project and managing the client (Pinto and Slevin 1988). Therefore, project management is a key element of project

success (Han *et al.* 2012). There were two project management perspectives at play in this study, the LMS developer perspective who were seeking to keep their agreed project within time, cost and delivery of a quality product; and that of the research team who were also prioritising these elements to ensure end user acceptability of the intervention. To enhance project success, building rapport as part of good project management can improve performance and reduce costs. This can include no-blame culture, joint working, communication, problem solving and continuous improvement (Meng 2012). Furthermore, the researcher reflected on the how communicating the shared goal and vision of the intervention to the LMS team is crucial to ensure the sign-off of a high-quality resource and related usage data. This resonates with a large body of literature, demonstrating the importance of a clear strategic vision, total alignment to vision and goals and good communication to project success (Shenhar and Holzman 2017). This study found the key to both a good working relationship with the LMS developer and the production of a high-quality resource for HPs working in cancer care were dependent on four points. These were (1) clear communication of the prototype build expectation for each section of content of the eLearning resource, (2) the research team working within the confines of the agreement with LMS developers, (3) the research team conveying the meaning of the project to end users and (4) the research team being prepared to concede on usage data requirements when it was realised that expectations would move outside the timeframe for the study.

#### 6.2.6 Quality of feedback can moderate for a small sample size in the PBA's optimisation phase.

The findings from the evaluation phase confirmed support for the timepoint at which recruitment ceased in the optimisation phase (Phase 2, Chapter 4). The estimated sample size presented for ethical approval for the optimisation phase (n=20) was a pragmatic



decision, based on the extensive experience of the research team and their perceptions of the quality of the prototype being presented to HPs for testing. It could be contested that this sample size was unrealistic, given the range of tumour groups and HP disciplines identified as end-users of the intervention. A priori research protocols for ethical approval necessitate researchers to detail the number of expected participants in a proposed study yet determining such a number is very dependent on the researcher's assurances of the quality of data that will be generated (Braun and Clarke 2021). Sim *et al.* (2018) have recommended that researchers should provide a provisional range of participants that could potentially generate adequate data to tell a rich, complex and multi-faceted story about the phenomenon of interest. Arguably, it could be suggested that to claim validity of findings, a study must claim data saturation, but given the reflexive nature of thematic analysis, there is always a potential for further participant viewpoints and the researcher's interpretation of data to generate further codes if not themes (Braun and Clarke 2021). It is, therefore, important for researchers to articulate with clarity the basis for these decisions. As noted, the primary objective for the data collected at this point in the study was to refine the MSW: CC eLearning resource, which generated relatively concrete data upon which to base decision making (Braun and Clarke 2021). The decision to stop collecting data was based upon no further identification of major modifications, that is, modifications which would be important to address behavioural issues. The original estimate appears to have been appropriate, with the diverse range of participants providing high quality interview feedback, which allowed important changes to be actualised after test cycle 1 and 2 and minor changes only in test cycle 3. Analysis of the feedback of HPs' views of the eLearning resource, provided support for this decision, with themes illuminating the MSW: CC eLearning resource as having engaging features, the potential to equip and empower HPs with information which is relevant and acceptable for practice. Furthermore, the analysis of Phase 3, evaluation data, provided support for this decision, as it confirmed that many participants reported that no further

improvements were required and the few improvements suggested were minor in nature. The clear communication of the rationale for ceasing data collection and providing evidence to support the appropriateness of this decision, has provided readers of this thesis with helpful detail upon which to objectively verify the validity of findings.

The quality of the feedback and thereby the adequacy of the sample size was further influenced by a pragmatic decision made during test cycle 2, when it was discovered that most participants were missing large and integral sections of content due to a lack of navigational tools. When this was evident, deliberation was given as to redirecting participants attention to the missed content during the TA interviews or to allow the participant to continue, obtaining a sense of how HPs would use the resource in the real world. At the study outset, the researcher anticipated the use of minimal prompts. These would be to remind the participant to keep talking, given that some people find the task of thinking aloud more challenging than others (Ericsson and Simon 1980); and to clarify participant comments, to provide a clear rationale upon which to base modifications. However, the unexpected navigational difficulties in test cycle 2 meant that without taking action to redirect participants, feedback on parts of the content would be compromised and would necessitate further participant interviews. A decision was taken to utilise prompts during TA interviews, thus redirecting participants, which reduced the number of test cycles required in the study. It is important to note that this more flexible approach to TA interviews is not without controversy. Despite some (Rubin and Chisnell 2008) advocating the use of prompts, to seek explanations and additional details from participants, others fear that by altering participants' interaction with a task during thinking aloud there is a risk of compromising validity of data pertaining to the usability of the intervention (Hertzum *et al.* 2009). Earlier seminal work on TA (Ericsson and Simon 1993) concluded that it is wiser, safer and cheaper to follow Ericsson and Simon's (1993)

classical approach. However, if researchers are considering an alternate method, they should weigh up the pros and cons of choosing a TA method, clearly articulate the approach adopted and if interrupting participants, should allow additional time for the task (Alhadreti and Mayhew 2017). This current study argues that the flexible approach to TA data collection was justified as it maximised the quality of feedback and reduced the recruitment demand to the study, thereby optimising study timeframe and reducing unnecessary cost to HSCTs.

#### 6.2.7 Investing in optimisation phase can promote effectiveness of intervention.

The third phase of the PBA, intervention evaluation, provided evidence for the ‘ecological validity’ of the findings from the TA interviews during the optimisation phase. Previous studies have identified the need to attend to the ecological validity of a study, to ensure that findings are meaningful and applicable for their intended settings (Kent *et al.* 2018). However, the term ecological validity is shrouded in both conceptual and methodological confusion (Hollerman *et al.* 2020). For this study, ecological validity is defined as research that resembles “the situation and task demands that are characteristic of the real-world rather than rely on artificial laboratory settings and tasks so that results will generalise to the real-world” (Ashcraft and Radvansky 2009 p.511). This definition differs to that of external validity, which is assessing whether data collected under one set of conditions with one group of participants can also be generalised to other people, tasks and situations (Campbell 1957), yet ecological validity can be conflated with generalising across samples (Hollerman *et al.* 2020). Data collected during the optimisation phase, although gathered within the cancer care setting, was generated from TA interviews in the presence of the researcher. This, therefore, presented a somewhat artificial situation being one “specifically designed for research” (Hoc 2001, pp.282-283). The evaluation phase (Phase 3) used a single arm, pre-test post-test survey design with HPs who provided

routine cancer care. Each HP had autonomy regarding participation, with freedom to choose the time and space to engage with the resource between November 2020 and April 2021 and being able to choose to exit the study prior to completing the second survey. Participation on eLearning courses (Sinclair *et al.* 2017) and completion of surveys are somewhat commonplace within the clinical context. Despite these elements being viewed as a natural condition in participants' routine environment, one could equally argue that an artificial condition was simultaneously introduced, given that the topic of sexual support is not one regularly discussed in cancer care settings (Reese *et al.* 2017b). Nevertheless, the positive evaluation findings from HPs' pre-test and post-test surveys concurred with positive findings on acceptability and usability identified during the optimisation process. These findings lend support for the MSW: CC eLearning resource's ecological validity. It is possible however, that participants through both phases of the study lacked contextual representativeness, which could impact on the generalisability of findings beyond the sample. This issue is discussed in the next section.

### **6.3 Study limitations**

There were two key study limitations, which are now discussed relating to sampling and usage data generation.

#### **6.3.1 Sampling**

The study sample, across all phases, was evidently diverse in terms of HPs' roles and tumour groups. This supports the conclusion that the resource is suited for use by HPs across cancer care. Nonetheless, it is important to acknowledge the potential for inherent bias when reflecting on sampling. For example, the study is likely to have attracted HPs who were more positive and motivated about the integration of sexual support into cancer care and were more likely to engage in the provision of sexual support. This may

have overestimated the ability of the eLearning resource to impact HPs' attitudes and beliefs relating to the provision of sexual support in cancer care. Many of the participants in Phase 2 and Phase 3 were from a nursing background. A greater variation of participating HPs could have provided feedback, which would have further enhanced the eLearning resource's relevance for the diverse cancer care workforce. Furthermore, all members of the expert group and Phase 2 participants were Caucasian, potentially limiting the insight into challenges and sexual advice requirements of minority ethnic groups. Also, most of those involved in the development of the MSW: CC eLearning resource were female, however, given that the MSW: PC eLearning resource was developed with input from many men, the sample for this study may have provided a balance. Specifically, the purposeful sample in Phase 2 did not include HPs from primary care. HPs in primary care provide ongoing holistic care to patients during and beyond the cancer diagnostic and treatment phases, when many sexual concerns may present or indeed at a time when patients and partners are ready to receive support (Sisler *et al.* 2012). Organisation of follow-up care between healthcare providers is complex and variable and the interface challenges between primary and secondary cancer care well-documented (Dahlhaus *et al.* 2014; Sampson *et al.* 2015). There have been repeated calls from both providers for improved communication to better inform care. As such, primary care input could have added further perspective to the qualitative findings, enhancing or raising important considerations regarding referral sources for patients who have completed treatment. That said, it is possible that participants in Phase 3 included representation from primary care, as demographic data did not distinguish whether the nurse or doctor was from primary or secondary care. The acceptability, usability and effectiveness of the MSW: CC eLearning resource for HPs providing sexual support to cancer patients in primary care should be explored in subsequent studies.

### 6.3.2 Usage data generation

The lack of meaningful usage data obtained from data analytics limits the objective understanding of how participants used and engaged with different aspects of the intervention (Kazanidis *et al.* 2016). Future investigations determining how the intervention is used will need to rely on qualitative or self-reported quantitative feedback from users, which could be subject to bias due to participant recall problems or social desirability responding. Retrospective reports of how participants used a resource tend to have limitations, due to participants producing rather vague and generic insights (Cotton and Gresty 2008). A potential way to overcome this could be asking participants to make brief notes as they progress through the resource recording, for example, the elements of the resource they spent more time on, the videos viewed, resources downloaded and highlights. As noted earlier, gaining retrospective feedback could be at risk of social desirability bias, that is, where participants inflate their participation to appear to have used to the resource according to their perception of the developer's intention. A review of 14,275 studies established that only 0.2% (n=31) of studies used a social desirability scale to detect, minimise and correct for this potential methodological flaw (Van de Mortel 2008). Of these 31 studies, 43% found that social desirability influenced the responses provided. Authors therefore recommended that future research pertaining to socially sensitive subject matters should consider the impact of social desirability responses, influencing the validity of their research. To mitigate against this, a social desirability scale could be included to detect and control for bias (Van de Mortel 2008).

#### 6.4 Unique contribution to knowledge

This study has made tangible contributions to knowledge through the presentation of findings at conferences within NI, the UK and internationally and planned peer-reviewed publications (see Table 22 and 23).

**Table 22: Presentations related to MSW: CC eLearning resource**

Date	Conference title	Type of Presentation	Presentation Title
April 2019	Ulster University Festival of Research	Poster	Sexual wellbeing: online resources to support healthcare professionals in cancer care.
May 2019	UU/QUB Annual Doctoral Collaborative Conference	Poster	Sexual wellbeing: online resources to support healthcare professionals in cancer care.
May 2019	Cancer Care Research Group PBA Workshop	Oral	Improving patient sexual wellbeing in cancer care.
April 2021	RCN Education Forum	Poster	Adapting, developing and testing an eLearning resource for healthcare professionals to enhance the provision of sexual support in cancer care.
April 2021	Scientific Network on Female Sexual Health and Cancer	Audible poster	Adapting, developing and testing an eLearning resource for healthcare professionals to enhance the provision of sexual support in cancer care, including common female cancers.
June 2021	Multinational Association of Supportive Cancer Care Annual Meeting	Oral	Talking about sex after cancer: adapting and testing an eLearning resource to enhance the provision of sexual support in cancer care.
June 2021	Ulster University 3MT Final <a href="https://www.youtube.com/watch?v=nrIVkVW2e4k&amp;feature=youtu.be">https://www.youtube.com/watch?v=nrIVkVW2e4k&amp;feature=youtu.be</a>	Oral	The elephant in the room: Talking about sex after cancer.
November 2021	UKONS Caring Connections Conference	Oral and Poster	'Talking about sex after cancer': Evaluation of an eLearning resource to enhance the provision of healthcare professional-led sexual support in cancer care.

**Table 23: Planned peer-reviewed publications related to the MSW: CC eLearning resource**

<b>Progress</b>	<b>Journal</b>	<b>Article title</b>
Submitted to journal for peer review	Supportive Care in Cancer	Adapting and usability testing of an eLearning resource to enhance healthcare professional provision of sexual support across cancer care
Initial draft being reviewed by co-authors	Psycho-Oncology	Enhancing healthcare professional-led sexual support in cancer care: Acceptability, usability and preliminary outcomes of an eLearning resource.

Other specific contributions of this study to knowledge are now outlined. First, this study has successfully adapted the MSW: PC eLearning resource to create the MSW: CC eLearning resource for HPs working with mixed cancer populations, to enhance the provision of sexual support to patients with cancer and partners. To the best of the researcher's knowledge, this is the first intervention of its kind, providing accessible education and supportive resources to HPs working across cancer care. The MSW: CC eLearning resource has demonstrated potential capability at reducing the attitudinal barriers impacting the provision of sexual support in cancer care. Furthermore, HPs have identified the MSW: CC eLearning resource as not only an acceptable and usable resource, but an engaging, informative and much needed intervention to support HPs working routinely in cancer care. The eLearning resource has been widely promoted by the researcher, but also by expert academics and leading practitioners in the field through presentations at national and international meetings and use of social media which targeted international networks. These networks have included the European Oncology Nursing Society (EONS), the European Society of Gynaecological Oncology, the International Psycho-Oncology Society (IPOS) and the Scientific Network on Female Sexual Health and Cancer. As a result, Google Analytics has identified the resource as being accessed in over 30 countries. Furthermore, United Kingdom Oncology Nursing Society (UKONS), in July 2021 agreed to provide a direct link from their new sexual health and



wellbeing webpages (UKONS 2021) to the MSW: CC eLearning resource. Further dissemination opportunities are being explored.

Second, this study has validated previous findings that it is possible to successfully adapt existing interventions for use with a different population and identified the PBA as offering a suitable step-by-step approach to ensure that the intervention is meaningful, engaging, acceptable, usable and effective in the new context. This finding can provide both a rationale for exploring the potential of adapting existing effective interventions for new contexts and provide future researchers with a systematic and iterative approach to the optimisation and evaluation processes.

Third, this study has identified important lessons learned when combining a LMS company and research agenda around usage data generation. As the study progressed, the differences in understanding became more apparent, however due to cost and time, it was not possible to address all the variances to meet the researcher's agenda. Therefore, this study has identified learning for future researchers seeking to develop and evaluate interventions using Moodle outputs. First, it could be advantageous for the research team to include a member with specific knowledge of both the study outputs and capabilities of LMS systems. This may identify problems early in the project planning and costing stage with LMS developers and facilitate clearer communication. Second, it is important to establish what the Moodle constitutes as a view. To facilitate this, it may be more advantageous to build the intervention on different pages or use section breaks to facilitate a more objective count of what content was viewed. Third, it could be useful to position videos on an external site, for example, You Tube and create links to these from the resource. This would allow researchers to identify more easily how often videos were accessed. Finally, the researcher should ensure LMS developers make provision for an

objective count of external links that have been accessed and the resources downloaded. These actions could ensure the researcher would have access to objective data that could be used to understand more clearly how the intervention might work. Alternatively, researcher may wish to avail of the Lifeguide open-source software platform advocated by Yardley *et al.* (2015b). Albeit this could improve insight into how the intervention was used, it may increase the time required for the study to allow the researcher to learn to use the platform and build and modify the intervention.

Lastly, this study's review of the literature identified a wide range of sexual challenges faced by patients and partners across cancer care which could be presented in a structured way for HPs to access relevant information to support patients and partners. In pursuit of an understanding of the sexual challenges after cancer, the researcher identified further literature which attested to a similar problem across chronic conditions. Using the MSW: CC eLearning resource as a starting point, researchers could adapt this resource for use by HPs supporting patients with other chronic conditions.

## **6.5 Recommendations**

Several policy, clinical, educational and research recommendations are now outlined.

### 6.5.1 Policy

Policymakers should recognise HPs' pivotal role in the provision of routine sexual support for cancer patients and their partners, across the cancer trajectory. The Cancer Strategy for NI 2021-2031 released in August 2021 (DoH 2021) for consultation has recognised the devastating physical and psychological consequences on sexuality for many people. It points out that while the full impact of cancer on sexuality is likely to be underreported, there is a lack of formal, coordinated services or pathways for patients and partners. The

MSW: CC eLearning resource could support the Cancer Strategy (DoH 2021) by increasing HPs' awareness of the importance of such services and by guiding HPs who seek to coordinate services and develop appropriate pathways to enhance the sexual wellbeing of patients and partners.

There is a need to update existing cancer care guidance documents to reflect the impact of cancer on sexuality and make recommendations for the provision of sexual support as part of holistic care. This guidance should clearly identify the role of the HP to initiate the sexual wellbeing conversation, assess, support and refer to suitable specialist services when required to address biopsychosocial sexual concerns for patients and partners. To support HPs to achieve this, guidance documents could signpost HPs to resources such as the MSW: CC eLearning resource, to help with the implementation of sexual support into clinical practice.

#### 6.5.2 Educational

HPs working in cancer care have specified the need for an increased awareness of the sexual challenges encountered by patients with cancer and their partners. HPs need to be equipped with the information and skills to embed the provision of sexual support into routine practice across cancer care settings. Papadopoulou *et al.* (2019) suggests a two-level competency chart for nurses working in cancer care and hold the view that this approach would be equally applicable to other HP roles across cancer care. The MSW: CC eLearning resource could lend support to provide HPs with post-qualification entry level training. This could be supported through the successful implementation and embedding of the MSW: CC eLearning resource into HP training. For those already based in clinical practice, whether that is primary or secondary care, this education could form part of their CPD. To support the application of learning, HPs should seek out opportunities to

develop their confidence to engage in sexual support conversations with patients and partners. The behavioural strategies outlined in Step 3 of the MSW: CC eLearning resource could support this process. These included scenarios where HPs could engage in role play with colleagues to practice providing sexual support or creating opportunities to learn from colleagues' experiences and patient feedback in clinical practice. In future, students at pre-registration level and those post-qualifying could be signposted to this resource in preparation for implementing sexual support as part of holistic care provision. To support the development of skills, course directors responsible for undergraduate and postgraduate primary and secondary care training should build in opportunity for learners to role play and provide constructive feedback to maximise the likelihood that sexual support will be provided when in clinical practice.

### 6.5.3 Clinical

The MSW: CC eLearning resource could support the implementation of a tiered model of sexual care provision as suggested by Duimering *et al.* (2020), which would address the need for coordinated services as highlighted by the Cancer Strategy for NI (DoH 2021). Sexual support at the lower tiers would provide patients with general information on sexual challenges and would have HPs trained to address sexual concerns during routine clinical care, which could sufficiently address sexual challenges for most patients. Engagement, the first component of the MSW: CC eLearning resource EASSi communication framework (McCaughan *et al.* 2020) seeks to standardise the routine clinical provision of sexual support in cancer care. The embedding of this approach within practice could address the evident clinical bias influencing who receives sexual support, for example, HPs avoiding the provision of sexual support to older, LGB & T and single people. For patients with more persistent and complex concerns, the higher-tiered, more specialist services could provide necessary support.

Work is required in localities to identify specific referral pathways and services within NI HSC organisations to support HPs with the signposting element. First, there is a need to establish which pathways already exist and can be accessed by patients within the organisation. Pathways should be promoted to ensure HPs across cancer care are aware of what services they provide, which patients can be referred and the preferred mechanism of referral. Second, gaps in sexual support service provision need to be identified. Upon identification of gaps, important consideration needs to be given to which providers or potential collaborations are best positioned to effectively address the gap, alongside identification of funding to enable adequate service provision. As funding streams are changeable, existing services may undergo change, for example moving from a local service to a regional service. Such changes could raise significant access problems for patients and partners; services need to be carefully monitored to ensure patients' needs are met and that HPs are kept fully abreast of changing services provision.

Alongside addressing policy issues, training needs, communication models and referral pathways there is a need to address system-level challenges. The provision of sexual support in cancer care needs to be normalised by organisations from the top-down to avoid HPs feeling that the provision of sexual support is not deemed appropriate by other colleagues. In addition, consideration should be given to the layout of the healthcare environment, seeking opportunities to address the lack of privacy which prevents the provision of sexual support.

#### 6.5.4 Research

The research findings have illuminated the MSW: CC eLearning resource's potential to reduce the HP's attitudinal barriers to the provision of sexual support in cancer care. Future evaluation needs to determine how the intervention works. To this end a

qualitative study has been planned to explore HPs experiences of using the eLearning resource which could inform future implementation of the resource into practice. Qualitative research should consider an analysis of the variance of HP perceptions of the MSW: CC eLearning resource across the tumour groups to identify problem areas that could be addressed during implementation. It would be helpful to further explore the lack of change to HPs levels of discomfort and ascertain what may help to address this aspect further. On this point, it may be useful to investigate the relevant question on the SABS scale to ascertain if the way the question is posed was problematic. It would also be prudent to ascertain primary care HPs perceptions of the MSW: CC eLearning resource, as they have been underrepresented in the development of the resource.

Following an exploration of how the intervention works, it will be important to establish the effectiveness of the intervention through a randomised controlled study. This could determine the impact of the e-learning resource on HPs' attitudes and beliefs and self-efficacy, which have been theorised as key to increasing the likelihood of sexual support being provided and enhancing patient sexual wellbeing outcomes. Furthermore, a qualitative study could explore the impact of the MSW: CC eLearning resource at baseline and at subsequent timepoints utilising an objective analyse of clinical charts or audio from patient-clinician dialogue (Reese *et al.* 2019b) to explore the relationship between provision of sexual support and engagement with the MSW: CC eLearning resource.

Sexual support interventions in the field of cancer care are very much in their infancy, with a great variety in design and approach to content and evaluation and require more robust testing to determine what design, content, duration of intervention will have the optimal impact on enhancing the provision of sexual support in cancer care. Future study should also determine the optimal implementation method of the MSW: CC eLearning

resource which will maximise the provision of sexual support across cancer care. To this end, a second study has been planned. This study will compare the impact of HPs' attitudes and beliefs related to the provision of sexual support and explore levels of confidence to provide sexual support following either use of the eLearning resource alone or use of the eLearning resource accompanied with participation in roleplay workshop to practice providing brief sexual support. This will illuminate important considerations for the implementation of MSW: CC eLearning resource into healthcare settings.

The MSW: CC eLearning resource like the MSW: PC eLearning resource utilised a range of behaviour change techniques such as information about health consequences, instruction on how to perform behaviour and demonstration of the behaviour. To inform future adaptations of the intervention there is a need to accurately describe the 'active ingredients' of the intervention, detailing how the content and activities link with behavioural change techniques identified and defined by the behavioural change technique taxonomy v.1 (Michie *et al.* 2015).

The slow recruitment to the study has indicated that recruitment for future research with the MSW: CC eLearning resource should consider methods to maximise recruitment uptake. The CPD certificate, as an incentive for completion of eLearning resource and the two surveys, had a limited motivating factor to enhance recruitment; further complementary strategies to reduce attrition would be warranted. In future, it is recommended that the researcher seeks ways to maximise the visibility of the study, overcoming the restricted access to healthcare teams either virtually or in-person. It could be advantageous to maximise on existing collaborative partnerships through research team members and local collaborators in Trusts. Second, effort should be made to understand and reduce attrition between timepoints. It may be useful to compare

characteristics of those who completed both surveys to those who did not and contact HPs who did not participate on the final survey to explore potential barriers. Additionally, future study should include the use of reminder emails to participants between timepoints to promote participation.

Finally, given that HP-led provision of sexual support for other chronic conditions is also problematic, with HPs reporting similar barriers preventing the routine provision of sexual support, the MSW: CC eLearning resource could be successfully adapted to support HPs working in these contexts.

## **6.6 Future direction**

Recently there has been a growing body of work implementing sexual support interventions into hospital settings (Duimering *et al.* 2020; Walker *et al.* 2021a; Nisbet *et al.* 2021). This further identifies considerable need for sexual care across tumour groups and a high regard for sexual support, with 100% of patients likely or extremely likely to recommend the piloted services. Nisbet *et al.* (2021) developed a radiotherapist-led intervention to address specific challenges patients encountered after radiotherapy for cancer treatment. The authors reported that to improve this intervention, it was essential that adequate training was provided for all cancer care HPs to ensure sexual issues are addressed. A further quality improvement study reported congestion problems within a tiered model of sexual care initiative with patients experiencing unnecessary waiting times (Duimering *et al.* 2020). This study concluded with similar recommendations; all cancer care HPs required training to provide sexual support (Duimering *et al.* 2020). The MSW: CC eLearning resource has the potential to offer healthcare organisations a cost-effective approach to upskilling HPs to deliver sexual support across cancer care, allowing



funds to be concentrated on development of specialist services for patients and partners with complex sexual support issues.

This PhD researcher embarked upon this study to offer more to the Sexual Health Promotion strategy. This strategy sought “to improve, protect and promote the sexual health and wellbeing of the population in Northern Ireland” (DHSSPS 2008), although its related actions stopped short of recognising the sexual challenges for those living with a chronic condition. In preparation for a return to employment at NHSCT and seeking to move this research into meaningful action, the PhD Researcher has submitted a pilot project proposal to the NHSCT, to advance a tiered model of sexual care. Informed by Duimering *et al.* (2020) it seeks to utilise the MSW: CC eLearning resource to support HPs to provide sexual support as part of the first tier of the model. This proposal is provided in Appendix 15. If adopted, it is the intention that work from this proposal would continue to be aligned to the UU Cancer Care Research Group’s programme of work to ensure high quality research outputs to inform policy and practice.

## 6.7 Conclusions

Patients and partners face enduring and difficult sexual challenges after a cancer diagnosis and treatment. Many patients and partners wish for HPs to provide sexual support across the treatment trajectory, with HPs often avoiding addressing sexual concerns due to personal discomfort, a lack of awareness of the sexual challenges faced, strategies to help patients and partners cope, alongside a lack of resources and referral pathways. This study sought to address this gap by adapting an eLearning resource which had been developed to enhance the provision of HP-led sexual support in prostate cancer care. This resource was optimised, then evaluated to determine its effectiveness and utility for HPs working across cancer care. It is the researcher's experience that theory and evidence-based effective interventions developed for one population can be successfully adapted for another population. Key to the adaptation success was the iterative and asynchronous involvement of expert group members as part of the PBA process, whose contributions maximised the quality of the prototype ahead of optimisation with study participants. Project success was in part attributed to good working relationships with LMS developers, maximised through conveying the meaning of the intervention to HPs and patients, clear communication, flexibility and working within confines of agreements. This study has provided a widely accessible foundational level eLearning resource for HPs working with patients and partners from mixed tumour groups, which has been deemed as acceptable, usable, informative, engaging and relevant by a diverse range of HP roles. This resource, available at <http://talkingaboutsex-cancercare.org>, can help to meet global healthcare guidelines that stipulate the provision of biopsychosocial sexual care across the treatment trajectory as part of holistic cancer care.

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**APPENDICES**

## Appendix 1: MSW: PC eLearning resource: Resource structure and logic model

1. Service gaps [Identified problems] and resource aim[s]
  - Inadequate provision of care and support around sexual health after prostate cancer diagnosis [Patients not receiving minimal standard of care as per current guidelines [NICE, 2014]; resulting in unmet patient and partner needs and limited professional recognition of sexual health concerns after prostate cancer diagnosis.
  - Conversations about sensitive issues such as sexual health do not happen routinely in practice.
  - Different clinical roles during care pathway after prostate cancer diagnosis result in patient and HP uncertainty over who initiates sexual health conversations and when.
  - Focus during initial treatment centred on prognosis.
  - Patients report that information/advice and support often come too late, if at all.
  
2. Overall aims
  - To develop a brief, accessible, usable and interactive online training module for HPs which provides:
    - a) Increased HP awareness around importance of sexual health after prostate cancer diagnosis [including impact on patients when sexual health concerns are not adequately addressed]
    - b) A foundational level of training which includes skills and strategies allowing HPs to effectively engage with men (and partners).

The overall aims will be achieved by:

  - Providing strategies to overcome common barriers to effective engagement, promoting an approach whereby HPs are confident in their role opening an effective conversation and discussing sexual health after prostate cancer diagnosis.
  - Promoting an approach whereby HPs can provide a minimal level of support for all patients in line with current clinical guidelines and provide relevant, practical sign-posting and patient follow-up.
  - Introducing the overall EASSi framework [Engagement, Assessment, Support and Sign-posting Instrument] as an effective approach / structure to SH conversation after prostate cancer diagnosis [At end of the training, the module will provide a link to the online version of the resource [the EASSi tool which follows this framework].
  - Providing sufficient CPD resources and usable resources to support HPs after completion of the training module [e.g., downloadable documents or tools, links with other staff, including more experienced HPs and/or a 'buddy' system, interactive elements, practical advice/support suggestions (i.e., reflective practice after clinical encounter), use of 'active', evidence-based behaviour change methods for influencing clinicians' practice (i.e., use of goal setting techniques etc.).

Following completion of the training module, HPs should be able to:

  - Demonstrate knowledge/understanding/around sexual health communication after prostate cancer diagnosis.
  - Engage in an effective ongoing support conversation with the patient (and their partner) after prostate cancer diagnosis.
  
3. Target[s] for change
  - Routine engagement/meaningful conversation around sexual health [between HP + patient and patient + partner]



- HP perceptions/beliefs regarding importance of sexual health after prostate cancer diagnosis.
  - HP/patient/partner discomfort regarding sexual health conversations.
  - Addressing [Challenge!] barriers preventing sexual health conversations including clinical setting, privacy, lack of time, values, initial 'bio-medical' focus, difficulty with effective engagement.
  - Increasing patient/public awareness regarding sexual health after prostate cancer diagnosis [via overall branding of project resources].
4. Factors to facilitate change ['Guiding Principles']
- Increased HP confidence, knowledge and awareness around sexual health after prostate cancer diagnosis.
  - Promoting use of effective patient engagement and communication approaches and methods.
  - Providing structure to sexual health conversations [based on EASSI model].
  - Promoting importance of clinician's role in sexual health conversations with patients + partners during all phases of care [based on patient need]
  - Promoting HP 'autonomy'
5. Mediating factors [Features that will help deliver on 'Guiding Principles']
- HP confidence/beliefs/attitudes/level of knowledge around sexual health after prostate cancer diagnosis.
  - HP and patient/partner personal thoughts/beliefs/cultural values about sexual health in general [and how they can influence clinical encounter].
  - HP communication style and approaches used during clinical encounter [e.g., focus on bio-medical model model].
  - HP and patient understanding/interpretation of commonly used terminology relevant to SH.
  - Setting / environment in which clinical encounters takes place [including issues around presence of partners or others at appointment].
  - HP and patient perceptions on professional roles in sexual health.
  - HP and patient knowledge and understanding around effectiveness of available interventions.
  - Provision of sufficient time to discuss sexual health fully as a sensitive topic during brief clinical encounter.
  - HP and patient priorities at different phases of care.
  - Access to sexual health advice throughout different phases of care and timing of support / advice.
  - PTs previous sexual health, sexuality and presence of co-morbidities.
  - Providing simple, usable, engaging module format.
  - Reinforcing importance of HP role in holistic care
  - Use of behaviour change techniques / practices
  - Providing examples of 'success' / best practice
  - Providing high quality supporting evidence for support interventions /approaches for patients.
6. MSW: PC eLearning resource components [scrolling page structure vs. clicking to next page [as per family centred training module]
- i. Landing page
- Log-in page
  - Contact us section
  - About us section

- Introduction [Including aim, target population, time to completion, CPD credits available, endorsements]
- ii. Background / Introduction
  - Content of module [Sections]
  - Welcome video
  - What will be provided [Downloadable content etc.]
- iii. Why is it important/ what is the impact on patients + partners? [Emphasize aims in visual / interactive way +/- 5 key points / reasons]
- iv. Why does a sexual health conversation sometimes not take place? – HP and patient barriers [Include self-reflection section +/- barriers identified using turn around photos and quotes +/- identify most important factor]
- v. Summary of section / page iv [include questions]
- vi. The EASSi conversation
- vii. Engagement [list of 'terminology' to use]
- viii. Assessment questions [brief]
- ix. Support [link to guidelines]
- x. Signposting [local / national / global resources]
- xi. Evidence of effectiveness
- xii. Managing difficult conversations
- xiii. Meeting different patient needs
- xiv. Evidence of impact
- xv. Take home messages [? including quiz element]
- xvi. Resources [including links / downloads]
- xvii. Next steps [using in practice; hints / tips to support practice [e.g., link to 'buddy' scheme etc.].

## 7. Outcomes

- 1. Pre-use questionnaire [HP]
- 2. Immediate post use questionnaire
- 3. Follow up questionnaires [HP]
- 4. Follow-up and qualitative interviews with sub-sample of participants
- 5. Analytic / usage data
- 6. Usability testing [cognitive task analysis of v1 of module using 'think aloud' method]
- 7. Usability questionnaire [measuring user satisfaction]

\*Evaluation = focused on core aspects e.g. not QoL

**Appendix 2: Ethical approval for study**

*Office for Research Ethics Committees  
Northern Ireland  
(ORECNI)*

Customer Care & Performance Directorate  
Lissue Industrial Estate West  
5 Rathdown Walk  
Moira Road  
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Tel: 028 95361407

[www.hscbusiness.hscni.net/services/orecni.htm](http://www.hscbusiness.hscni.net/services/orecni.htm)  
Health & Social Care Research Ethics Committee A (HSC  
REC A)

09 October 2019 (re-issued from 03 October 2019)

Dr Cherith Semple  
Ulster University / South Eastern Health & Social Care Trust  
Ulster Hospital, Upper Newtownards Road,  
BELFAST,  
BT16 1RH

Dear Dr Semple

Study title:	Adapting, testing and evaluation of educational/facilitative resources to enable healthcare professionals working in cancer care to support patients and partners with sexual wellbeing.
REC reference:	19/NI/0175
Protocol number:	19/0067
IRAS project ID:	259926

Thank you for your letter of 30 September 2019, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

#### Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or NHS management permission (in Scotland) should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA and HCRW Approval (England and Wales)/ NHS permission for research is available in the Integrated Research Application System.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations.

### Registration of Clinical Trials

It is a condition of the REC favourable opinion that all clinical trials are registered on a publicly accessible database. For this purpose, 'clinical trials' are defined as the first four project categories in IRAS project filter question 2. Registration is a legal requirement for clinical trials of investigational medicinal products (CTIMPs), except for phase I trials in healthy volunteers (these must still register as a condition of the REC favourable opinion).

Registration should take place as early as possible and within six weeks of recruiting the first research participant at the latest. Failure to register is a breach of these approval conditions, unless a deferral has been agreed by or on behalf of the Research Ethics Committee (see here for more information on requesting a deferral: <https://www.hra.nhs.uk/planning-and-improving-research/research-planning/research-registration-research-project-identifiers/>).

As set out in the UK Policy Framework, research sponsors are responsible for making information about research publicly available before it starts e.g. by registering the research project on a publicly accessible register. Further guidance on registration is available at: <https://www.hra.nhs.uk/planning-and-improving-research/research-planning/transparency-responsibilities/>.

You should notify the REC of the registration details. We will audit these as part of the annual progress reporting process.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

### After ethical review: Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study, including early termination of the study

- Final report

The latest guidance on these topics can be found at <https://www.hra.nhs.uk/approvals-amendments/managing-your-approval/>.

Ethical review of research sites

NHS/HSC sites

The favourable opinion applies to all NHS/HSC sites listed in the application subject to confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or management permission (in Scotland) being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS/HSC sites

I am pleased to confirm that the favourable opinion applies to any non-NHS/HSC sites listed in the application, subject to site management permission being obtained prior to the start of the study at the site.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Covering letter on headed paper [1 Cover letter for IRAS]	v2	22 August 2019
Covering letter on headed paper [Response to provisional opinion]	v1	30 September 2019
Interview schedules or topic guides for participants [Appendix 8 Phase 3 Topic Guide HP R2]	v2	22 August 2019
Interview schedules or topic guides for participants [Appendix 10 Phase 3 Topic Guide Patient R2]	v3	30 September 2019
IRAS Application Form [IRAS_Form_23082019]		23 August 2019
IRAS Checklist XML [Checklist_23082019]		23 August 2019
IRAS Checklist XML [Checklist_01102019]		01 October 2019
Letter from sponsor [Sponsorship for project reference 19/0067]	v2	22 August 2019
Non-validated questionnaire [Appendix 5 Phase 3 R1 Pre and post questionnaires]	v2	22 August 2019
Non-validated questionnaire [Appendix 6 Phase 3 Pre R2 questionnaire]	v2	22 August 2019
Non-validated questionnaire [Appendix 7 Phase 3 Post R2 Questionnaire]	v2	22 August 2019
Non-validated questionnaire [Appendix 9 Phase 3 R2 Patient Research Pack]	v3	30 September 2019
Other [Appendix 2 Phase 2 Think Aloud Interview Overview]	v2	22 August 2019
Other [Appendix 13 Distress Protocol for interviews]	v2	22 August 2019
Other [Appendix 14 Patient Support Sheet]	v2	22 August 2019
Other [Appendix 15 Lone Worker Protocol]	v2	22 August 2019
Participant information sheet (PIS) [Appendix 3 Phase 2 HP Cover letter PIS and Consent R1 & R2]	v2	22 August 2019
Participant information sheet (PIS) [Appendix 4 Phase 2 Patient Cover letter PIS and Consent R2]	v2	22 August 2019

Participant information sheet (PIS) [Appendix 11 Phase 3 HP cover letter PIS R1]	v2	22 August 2019
Participant information sheet (PIS) [Appendix 12 Phase 2 HP Cover letter PIS & Consent R2]	v2	22 August 2019
Participant information sheet (PIS) [Appendix 20 PIS and Consent form for Partner]	v1	30 September 2019
Research protocol or project proposal [Appendix 1 Research Protocol]	v2	22 August 2019
Summary CV for Chief Investigator (CI) [Appendix 19 CSemple cv]	v2	22 August 2019
Summary CV for student [Appendix 17 SBingham cv]	v2	22 August 2019
Summary CV for supervisor (student research) [Appendix 16 EMcCaughan cv]	v2	22 August 2019
Summary CV for supervisor (student research) [Appendix 18 C Flannagan cv]	v2	22 August 2019

#### Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

#### User Feedback

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

#### HRA Learning

We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities— see details at: <https://www.hra.nhs.uk/planning-and-improving-research/learning/>.

19/NI/0175
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Please quote this number on all correspondence
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With the Committee's best wishes for the success of this project.

Yours sincerely



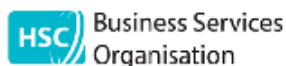
pp Dr Alastair Walker  
Chair

Email: [RECA@hscni.net](mailto:RECA@hscni.net)

Enclosure: After ethical review – guidance for researchers

Copy to: Mr Nick Curry, Ulster University

### Appendix 3: Ethical approval for amendment to study (19.076 Amend 1 (S))



Office for Research Ethics Committees  
Northern Ireland (ORECNI)

Customer Care & Performance Directorate  
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HSC RECA:

**Please note: This is the favourable opinion of the REC only and does not allow the amendment to be implemented at NHS sites in England until the outcome of the HRA assessment has been confirmed.**

07 August 2020

Mrs Sharon Bingham  
80 Ballywillin Rd  
Portrush  
Co Antrim  
BT56 8JN

Dear Mrs Bingham

<b>Study title:</b>	<b>Adapting, testing and evaluation of educational/facilitative resources to enable healthcare professionals working in cancer care to support patients and partners with sexual wellbeing.</b>
<b>REC reference:</b>	<b>19/NI/0175</b>
<b>Protocol number:</b>	<b>19/0067</b>
<b>Amendment number:</b>	<b>19/NI/0175/AM02</b>
<b>Amendment date:</b>	<b>03 August 2020</b>
<b>IRAS project ID:</b>	<b>259926</b>

The above amendment was reviewed at the meeting of the Sub-Committee held on 07 August 2020 by the Sub-Committee in correspondence.

#### Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

REC Ref 19-NI-0175-AM02

## Approved documents

The documents reviewed and approved at the meeting were:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Completed Amendment Tool [259926_19.0067 Amend 1 (S)_03Jul2020_Locked03Jul20_141723]	1	03 July 2020
Other [Appendix 22 Phase 2 Think Aloud Interviews using Zoom Data]	1	03 July 2020
Participant information sheet (PIS) [Appendix 3 Phase 2 HP Cover letter PIS and Consent R1 & R2]	2	22 August 2019
Participant information sheet (PIS) [Appendix 21 Phase 2 HP Cover letter PIS and Consent R1 R2]	1	02 July 2020

## Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

## Working with NHS Care Organisations

Sponsors should ensure that they notify the R&D office for the relevant NHS care organisation of this amendment in line with the terms detailed in the categorisation email issued by the lead nation for the study.

## Amendments related to COVID-19

We will update your research summary for the above study on the research summaries section of our website. During this public health emergency, it is vital that everyone can promptly identify all relevant research related to COVID-19 that is taking place globally. If you have not already done so, please register your study on a public registry as soon as possible and provide the HRA with the registration detail, which will be posted alongside other information relating to your project.

## Statement of compliance

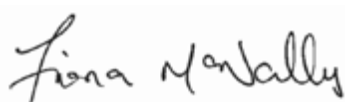
The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

## HRA Learning

We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities– see details at: <https://www.hra.nhs.uk/planning-and-improving-research/learning/>

*IRAS Project ID - 259926: Please quote this number on all correspondence*

Yours sincerely



pp Dr Alastair Walker Chair



REC Ref 19-NI-0175-AM02

E-mail: RECA@hscni.net *Enclosures:*

*List of names and professions of members who took part in the review*

HSC REC A

Attendance at Sub-Committee of the REC meeting on 07 August 2020

Committee Members:	<i>Profession</i>	<i>Present</i>	<i>Notes</i>
<i>Name</i>			
Ms Rosemary Kelly	Registered Nurse	Yes	
Dr Alastair Walker (Chair)	Retired Head of Education Services, CCEA	Yes	

Also in attendance: *Name*

*Position (or reason for attending)*

Mrs Tamla Ervine (Minutes)

REC Manager

Ms Fiona McNally

REC Assistant

## Appendix 4: Ethical approval for amendment to study (19.076 Amend 2 (S))



Office for Research Ethics Committees  
Northern Ireland (ORECNI)

Customer Care & Performance Directorate  
Lissue Industrial Estate West  
5 Rathdown Walk  
Moirá Road  
Lisburn  
BT28 2RF  
Tel: 028 95361400  
www.orecni.hscni.net

HSC REC A:

**Please note: This is the favourable opinion of the REC only and does not allow the amendment to be implemented at NHS sites in England until the outcome of the HRA assessment has been confirmed.**

12 October 2020

Mrs Sharon Bingham  
80 Ballywillin Rd  
Portrush  
Co Antrim  
BT56 8JN

Dear Mrs Bingham

<b>Study title:</b>	<b>Adapting, testing and evaluation of educational/facilitative resources to enable healthcare professionals working in cancer care to support patients and partners with sexual wellbeing.</b>
<b>REC reference:</b>	<b>19/NI/0175</b>
<b>Protocol number:</b>	<b>19/0067</b>
<b>Amendment number:</b>	<b>19.0067 Amend 2 - Substantial</b>
<b>Amendment date:</b>	<b>01-10-2020</b>
<b>IRAS project ID:</b>	<b>259926</b>

The above amendment was reviewed at the meeting of the Sub-Committee held on 12 October 2020 by the Sub-Committee in correspondence.

### Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

### Approved documents

REC Ref 19-NI-0175-AM02

The documents reviewed and approved at the meeting were:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Completed Amendment Tool [259926_19.0067 Amend 2 - Substantial_30Sep2020_Locked01Oct20_141041 v1]	v1	01 October 2020
Copies of advertisement materials for research participants [Appendix 23 Phase 3 HP social media recruitment v1 [250920]]	1	30 September 2020
Participant information sheet (PIS) [Appendix 11 Phase 3 HP cover letter PIS R1 [25.09.20v3]]	v3	25 September 2020
Research protocol or project proposal [Appendix 1 Research Protocol v3 [25.09.20]]	v3	25 September 2020

#### Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

#### Working with NHS Care Organisations

Sponsors should ensure that they notify the R&D office for the relevant NHS care organisation of this amendment in line with the terms detailed in the categorisation email issued by the lead nation for the study.

#### Amendments related to COVID-19

We will update your research summary for the above study on the research summaries section of our website. During this public health emergency, it is vital that everyone can promptly identify all relevant research related to COVID-19 that is taking place globally. If you have not already done so, please register your study on a public registry as soon as possible and provide the HRA with the registration detail, which will be posted alongside other information relating to your project.

#### Statement of compliance

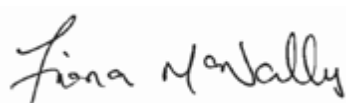
The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

#### HRA Learning

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*IRAS Project ID - 259926: Please quote this number on all correspondence*

Yours sincerely



pp Chair Mr Barry Mimmagh

E-mail: [RECA@hscni.net](mailto:RECA@hscni.net)

REC Ref 19-NI-0175-AM02

*Enclosures:*

*List of names and professions of members who took part in the review*

*Copy to:*

Mrs Sharon Bingham

HSC REC A

Attendance at Sub-Committee of the REC meeting on 12 October 2020

Committee Members:	<i>Profession</i>	<i>Present</i>	<i>Notes</i>
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*Name*

Mr James Cooke	Student	Yes	
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Mr Barry Mimmagh (Chair)	Pharmacist	Yes	
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Also in attendance: *Name*

*Position (or reason for attending)*

Mrs Tamla Ervine (Minutes)

**Appendix 5: Overview of significant changes made when adapting the MSW: PC eLearning resource to create the MSW: CC eLearning resource**

Slide No.	MSW: PC Content to be adapted	MSW: CC New content – Test Version [1]	Rationale
<b>Step 1</b>			
Intro	Intro video	To be scripted and filmed to address sexuality across cancer care.	Ensure content relevance across tumour groups. Design objective i.
1	<ul style="list-style-type: none"> <li>Prostate cancer is the most common cancer among men</li> <li>In the UK, 1 in 8 men will be diagnosed during their lifetime</li> <li>For black men, 1 in 4 will be diagnosed</li> </ul>	<ul style="list-style-type: none"> <li>1 in 2 people will be diagnosed with cancer during their lifetime.</li> <li>Survivorship is improving but men and women face many challenges to their quality of life including sexual wellbeing.</li> <li>Changes to sexual wellbeing can have a profound effect on both the patient and their partner after a diagnosis of cancer and its treatment.</li> </ul>	Ensure content relevance across tumour groups. Design objective i.
3R [a]	Full erectile function may not be possible for all men after prostate cancer, but there are many other ways of experiencing sexual pleasure.	Sexual function may not return to how it was before cancer due to physical and psychological changes but there are many other ways of experiencing sexual pleasure.	Ensure content relevance across tumour groups. Design objective i.
3R [b]	Evidence shows that men can also 'underplay' the problem.	These include embarrassment about sexual issues, a lack of appointment time, or a feeling that sexual wellbeing is not an appropriate topic to raise.	Making specific reference to the barriers faced by HPs. Design objectives ii, v.

<b>Slide No.</b>	<b>MSW: PC Content to be adapted</b>	<b>MSW: CC New content – Test Version [1]</b>	<b>Rationale</b>
3 [c]	Men can reach orgasm without an erection after prostate cancer	Men and women can have a satisfying sex life after cancer.	Ensure content relevance across tumour groups. Design objective i.
3R [c]	It is still possible for most men to reach orgasm, but it may take longer and feel different. They may not have semen, so they will not ejaculate. This is called a 'dry-orgasm'.	Sex life may be different after cancer, but it is still possible for most men and women to have a satisfying sex life. This may require both patients and their partners to think differently about sex. Patients and partners need to be supported to be persistent, motivated and to try new things. It is still possible for both men and women to orgasm despite erectile or vaginal changes. Men and women can also achieve orgasm without penetration; it can help to explore other parts of the body.	Ensure content relevance across tumour groups. Design objective i.
3R [d]	For most men, sex will be different after prostate cancer. Desire can be affected more by some treatment types including hormone therapy and by having a cancer diagnosis. However, for many men, the desire is still as strong, but they are unable to achieve full erectile function. This can be frustrating. It is important that men are informed	Desire can be affected more by some treatment types and by having a cancer diagnosis. However, for many, their desire is still as strong, but they are unable to achieve their previous full sexual experience and may experience pain and discomfort. This can be frustrating. It is important that both men and women are informed about ways to get sexual stimulation and pleasure.	Ensure content relevance across tumour groups. Design objective i.

Slide No.	MSW: PC Content to be adapted	MSW: CC New content – Test Version [1]	Rationale
	about ways to get extra sexual stimulation and pleasure.		
6	<p>Black Men Black men’s experiences after treatment can be quite different. They are usually younger when diagnosed. There is a higher risk of being diagnosed with advanced prostate cancer. Treatment can have a different and major impact on men’s sense of masculinity. There is also evidence that black men have less access to and uptake of support from healthcare professionals.</p> <p>[Reference: Bamidele O <i>et al.</i> (2018) Eur J Cancer Care]</p> <p>Gay Men The impact of prostate cancer treatment on the sex lives of gay men can be substantial. For example, depending on their roles within the sexual partnership (e.g. receptive or insertive) changes to erectile and bowel function may</p>	<p>End of life A decline in function towards the end of life does not always imply that sexual activity stops. Although most patients will stop being sexuality active; intimacy is still important. Cuddling, kissing and spooning may be ways in which a couple can stay connected. Finding ways to support patients to remain close can reduce fear, pain and loneliness. Examples include ensuring some time for privacy, lowering the side of the bed.</p> <p>[Reference: de Voght (2017) in Reisman &amp; Gianotten Cancer, Intimacy &amp; Sexuality]</p> <p>Lesbian Gay Bisexual &amp; Transgender (LGB &amp; T) The impact cancer treatment on the sex lives of LGBT men and women can be substantial. For men, depending on their roles within the sexual partnership (e.g. receptive or insertive) changes to erectile and bowel function may result in not being able to continue with their previous sexual practice. For women, their needs may not differ</p>	To reflect issues relating to population groups across tumour groups. Design objective I, iii.

Slide No.	MSW: PC Content to be adapted	MSW: CC New content – Test Version [1]	Rationale
	<p>result in not being able to continue with their previous sexual practice. This can be temporary or permanent depending on treatment. Research shows that gay men have significant psychological distress, more challenging couple communication and lower masculine self-esteem.</p> <p>[Reference: Ussher <i>et al.</i> (2017) J Sex Med.]</p>	<p>from heterosexual, but they feel more reassured when information given is relevant to their sexual orientation. Additionally, there are concerns around disclosure, assumptions made on sexual practices, or fears about how treatment will affect their masculinity or femininity.</p> <p>[Reference: Margolies (2014) Clin J of Onco Nurs.]</p>	
10R	<p>Around half of men are not offered any interventions to support sexual concerns and for most it is inadequately addressed.</p> <p>[Reference: Downing <i>et al.</i> (2019) Lancet Onco.]</p>	<p>Around half of patients are not given information on the impact of treatment on sexual function and only 22% of patients have their sexual concerns addressed.</p> <p>[Reference: Reese <i>et al.</i> (2017) J Cancer Surviv.]</p>	<p>Provide evidence relating current levels of HP support across cancer care. Design objective ii.</p>
11	<p>[Reference: Downing <i>et al.</i> (2019) Lancet Onco.]</p>	<p>[References: Sporn <i>et al.</i> (2015) Psycho-oncology; Downing <i>et al.</i> (2019) Lancet Onco.]</p>	<p>Reflect the broader evidence base relating patients wish for sexual support. Design objective ii.</p>



Slide No.	MSW: PC Content to be adapted	MSW: CC New content – Test Version [1]	Rationale
14	<p>What else can you do?</p> <ul style="list-style-type: none"> <li>• Referral to an erectile dysfunction (ED) clinic</li> <li>• Online support – Maximising Sexual Wellbeing   Prostate Cancer: Sexual Recovery Programme:</li> <li>• Online support – Prostate Cancer UK website</li> <li>• Ongoing support from healthcare professionals</li> <li>• Referral to specialist support include relate or psychosexual counselling by a trained counsellor</li> </ul>	<p>What else can you do?</p> <ul style="list-style-type: none"> <li>• Online support – Information and resources</li> <li>• Ongoing support from healthcare professionals</li> <li>• Referral to specialist services</li> </ul>	<p>To increase knowledge of further support for patients and partners across cancer care. Design objectives i, iv.</p>
14	<p>Referral to specialist support include Relate or psychosexual counselling by a trained counsellor.</p> <p>Counselling services are an important support for any man or partner who feel they need more intensive specialist care. Men can self-refer or be referred to these</p>	<p>Erectile Dysfunction (ED) These clinics offer different treatments for erection problems and are run by urologists and CNSs.</p> <p>Specialist Pelvic Physiotherapy This service supports men and women to manage urinary or bowel incontinence, pelvic pain or dysfunction.</p>	<p>To increase knowledge of further support for patients and partners across cancer care. Design objectives i, iv, v.</p>

Slide No.	MSW: PC Content to be adapted	MSW: CC New content – Test Version [1]	Rationale
	services by a healthcare professional.	<p>Continence Service Their role is to provide treatment and management options for patients with bladder and bowel dysfunction.</p> <p>Psychological Therapist or Counsellor Psychological therapy and counselling services are an important support for any patient or partner who feel they need more intensive specialist care. Patients can self-refer or be referred to these services by a healthcare professional.</p>	
<b>Step 2</b>			
7 [a]	New slide	<p>-Type of cancer The type and location of cancer will have a direct impact on the sexual challenges a patient and their partner may face. Example A patient with breast cancer may experience challenges with body image and changes to sense of femininity, while patients with head and neck cancer may have difficulty communicating with their partner or kissing.</p>	Ensure content relevance across tumour groups and to support tailoring of advice. Design objectives i.

<b>Slide No.</b>	<b>MSW: PC Content to be adapted</b>	<b>MSW: CC New content – Test Version [1]</b>	<b>Rationale</b>
7 [b]	- Type of treatment Example One possible side effect of treatment is a change to sex drive. For men receiving hormone therapy, libido (sex drive) can be reduced significantly. However, for men who have had surgery, their libido (sex drive) should stay the same.	-Type of treatment Example One possible side effect of treatment is a change to sex drive. For patients receiving hormone therapy, libido (sex drive) can be reduced significantly. However, for patients who have had surgery their libido (sex drive) should stay the same.	Ensure content relevance across tumour groups and to support tailoring of advice. Design objectives i.
7 [c]	-Time from treatment Example Erectile function will usually be lost immediately after surgery; some function may return over the next 2 – 3 years. However, men receiving radiotherapy will not usually experience erectile changes for weeks, months or even years after treatment is completed.	-Time from treatment Example Immediately after bowel surgery patients may experience bleeding, discharge and the surgical site may feel very raw. However, this does improve with time.	Ensure content relevance across tumour groups and to support tailoring of advice. Design objectives i.
8 [c]	Speech bubble Research shows most men give up trying to have sex within two years of treatment.	Speech bubble As a healthcare professional, it is important to make sure the focus is not on sexual intercourse only.	Ensure content relevance across tumour groups. Design objective i.

<b>Slide No.</b>	<b>MSW: PC Content to be adapted</b>	<b>MSW: CC New content – Test Version [1]</b>	<b>Rationale</b>
	<p>It is important to help men understand that approaches aimed at improving sexual recovery may need to be tried at least eight times before considering another sexual aid.</p> <p>As a healthcare professional, it is important to make sure the focus is not on erectile function only.</p>		
11	<p>Example of the EASSi Framework in use</p> <p>Video file demonstrating patient and HPs using the electronic tablet version of EASSi</p>	<p>Example of the EASSi Framework in use</p> <p>Replacement video demonstrating patient and HPs using the EASSi framework to guide a conversation.</p>	<p>Provide a brief framework to support communication, assessment and interventions with patients with cancer and partners and enhance self-efficacy of HPs in the provision of sexual support. Design objectives iv and v.</p>
<b>Step 3</b>			
6	EASSi online programme link	Remove EASSi online programme link	Resource was specific to HPs working with men with prostate cancer and their partners

Slide No.	MSW: PC Content to be adapted	MSW: CC New content – Test Version [1]	Rationale
7	Download the EASSi Sign-posting Sheet	<p>Download the EASSi Sign-posting Sheet CLICK THE SIGNPOSTING YOU WISH TO DOWNLOAD</p> <p>General Gynaecological Breast Head and neck Colorectal Prostate</p>	Provide general and tumour specific signposting information. Design objectives i.
New Slide 10		<p>Thank you to all patients and healthcare professionals who contributed to the design and content of this eLearning resource.</p> <p>Belfast Health &amp; Social Care Trust Northern Health &amp; Social Care Trust Southern Health &amp; Social Care Trust South-Eastern Health &amp; Social Care Trust Western Health &amp; Social Care Trust</p> <p>© Ulster University 2020</p>	Acknowledge contributions of HSCTs to the study.

**Appendix 6: Detailed overview of expert group member feedback on new content for the MSW: CC eLearning resource**

<b>Versions reviewed; tumour group; HP or patient perspective; &amp; type of contact</b>	<b>Overview of feedback</b>	<b>Action taken by researcher</b>
	<p>General comments made throughout feedback by HP and patients</p> <ul style="list-style-type: none"> <li>• Sexuality is a sensitive topic for staff and patients</li> <li>• For some HPs, patients more often raised psychosocial issues</li> <li>• Content of resource repetitive</li> <li>• Considered to cover the key issues</li> <li>• Patients felt strongly that this was a part of life that cannot be forgotten about and wish that they had received support in this area.</li> <li>• Advice should be focused on positive action</li> <li>• Patients may have a lack of time to process major challenges such as loss of breasts and fertility changes, needing support to manage these challenges.</li> <li>• Encourage HPs to ask specific questions about sexual concerns.</li> <li>• Amount of information is appropriate. HPs will skim read but need to feel reassured with more rather than less information. Key to providing sexual support is to ask the question. Patients often just wish for a discussion.</li> <li>• Telling patient to relay HP/patient discussion can enabling communication about sexuality between patient/partner.</li> <li>• Women who are same sex attracted may still have penetrative sex and gay men may not have anal sex.</li> <li>• Letting people know that if they decide sex isn't a priority initially and that changes, there is support.</li> </ul>	<ul style="list-style-type: none"> <li>• Use alternative means to tailor resource than treatment types to reduce repetitiveness</li> <li>• Advice reviewed to ensure it is positive, action orientated and hopeful</li> <li>• Addressed</li> <li>• Addressed</li> <li>• Addressed</li> <li>• Addressed</li> </ul>

<b>Versions reviewed; tumour group; HP or patient perspective; &amp; type of contact</b>	<b>Overview of feedback</b>	<b>Action taken by researcher</b>
<p>Version 2 and 3 Head and neck cancer</p> <p>Multidisciplinary regional group (n=8) (In-person mainly with few on teleconference)</p> <p>CNS (and supervisor) (In-person)</p> <p>Speech and Language Therapist (In-person)</p> <p>Nurse (In-person)</p> <p>Partner of patient (Email)</p>	<p>Language</p> <ul style="list-style-type: none"> <li>• Clarity around language such as ‘jaw opening’.</li> <li>• Be careful advice does not seem glib: ‘having a positive attitude and confidence can help.</li> <li>• Change reduced movement to read ‘reduced jaw, neck and shoulder movement’.</li> </ul> <p>Content</p> <ul style="list-style-type: none"> <li>• HPV scares people and need to be acknowledge as part of the resource</li> <li>• Do not localise the resource by adding specific shops, although there are products which can help people manage symptoms.</li> <li>• Be mindful of neck breathers</li> <li>• For those with tracheostomy, include that patients and partners can agree a signal to stop if needed</li> <li>• Familiar places do not always help</li> <li>• Remove reference to regular dental check-ups as this will vary depending on patient</li> <li>• Acknowledge the fear of dislodging the peg tube</li> <li>• Remove advice on oral contact in relation to teeth cleaning/mouthwash</li> <li>• Impact of full dental clearance on speech, isolation and libido</li> <li>• Importance of creating time away from where you are known can help you to relax as a couple.</li> <li>• The importance of giving your relationship time.</li> </ul>	<ul style="list-style-type: none"> <li>• Wording amended</li> <li>• Language revisited and amended</li> <li>• Change amended</li> <li>• HPV section added</li> <li>• Removed any local references</li> <li>• Decision not to introduce specific products as advice can change on these</li> <li>• New category: Tracheostomy, laryngectomy and sexuality</li> <li>• Included</li> <li>• Removed</li> <li>• Dental check-ups removed as not always relevant</li> <li>• Included</li> <li>• Removed</li> <li>• Communication difficulties included</li> <li>• Emphasis on being patient and giving yourself time is addressed in resource</li> </ul>

Versions reviewed; tumour group; HP or patient perspective; & type of contact	Overview of feedback	<i>Action taken by researcher</i>
Version 2 and 3 Breast cancer  Nurse Practitioner (In-person)  Support Group meeting (n=7) (In-person)	Content <ul style="list-style-type: none"> <li>• Reconstruction will leave patient with no sensation in breast</li> <li>• Patients may experience shooting pains because of breast surgery for up to 2 years</li> <li>• Include reference to Cancer Focus shops</li> <li>• Breast Care nurses offer prosthesis fitting</li> <li>• Important not to get pregnancy when on treatment</li> <li>• Use barrier contraception after chemotherapy to protect partner</li> <li>• Complementary therapies, exercise and low does anti-depressants can help with hot flushes</li> <li>• Vaginal moisturisers should be non-hormonal</li> <li>• If ongoing pain during sex experienced should be checked for possible infection</li> <li>• Fatigue management workshops</li> <li>• Fatigue will lessen over time</li> <li>• Hair loss is <i>almost always</i> temporary</li> <li>• Include a 'changes to body' section which addresses joint pain, weight gain and menopause</li> <li>• Low mood should be included in effect on emotions</li> <li>• Information relating to fertility issues</li> <li>• Awareness of impact of medication on sexual desire</li> <li>• Include take away printed resources to support</li> <li>• Provide an option of partner counselling</li> </ul>	<ul style="list-style-type: none"> <li>• Text amended to include issue of no sensation</li> <li>• Not specifically mentioned as information about pain management in 'core' section</li> <li>• Decision not to localise resource by adding shop names</li> <li>• Clarify about where to access prosthesis fitting given</li> <li>• No specifics given in relation to pregnancy and contraception, advice is dependent on treatments given and patients are to talk to HP</li> <li>• All suggestions included</li> <li>• Amended to read non-hormonal products</li> <li>• Rather than being specific about infection, recommend patients to talk to HP if experiencing problems</li> <li>• Decision not to localise the resource</li> <li>• Included</li> <li>• 'Almost' added</li> <li>• Body changes section included in 'core' section of resource</li> <li>• Included</li> <li>• Addressed</li> <li>• Included</li> <li>• Signposting information available to patients and partners</li> </ul>



Versions reviewed; tumour group; HP or patient perspective; & type of contact	Overview of feedback	<i>Action taken by researcher</i>
Version 2 and 3 Gynaecological cancer  Consultant (In-person)  CNS (In-person)  Consultant (In-person)  Specialist Pelvic Physiotherapist (In-person)  Patient (Email)	Content <ul style="list-style-type: none"> <li>• In response to direct query about pregnancy and guidelines about the length of time to wait after receiving chemotherapy, signposted to Greenbook guidelines which stipulate that patients should wait 2 years. This is based on risk of reoccurrence as opposed to the impact the chemotherapy drugs have.</li> <li>• In response to query about significance of fear of bleeding after cancer, feedback suggested this was an issue presenting in clinics and important as women link bleeding with their cancer diagnosis.</li> <li>• Change 'sex and chemotherapy' to 'talk to your HP about pregnancy and sex' as there are many individual factors</li> <li>• Include radiotherapy as effecting fertility</li> <li>• Include hair thinning with hair loss as some drugs do not cause hair loss</li> <li>• Numbness and tingling as issues are important to retain as many patients struggle with the impact on touch and feel</li> <li>• Fear of dilator – remove reference to sex aids as it is perceived that culture is changing and people do not have same issues</li> <li>• A dilator can help apply vaginal lubricants and moisturisers</li> </ul>	<ul style="list-style-type: none"> <li>• No specifics given in relation to pregnancy and contraception, advice is dependent on treatments given and patients are to talk to HP</li> <li>• Retained</li> <li>• Changed to read 'sex, fertility and pregnancy' and placed in 'core' section</li> <li>• Included</li> <li>• Included</li> <li>• Removed. Decision to keep resource focused on sexual issues that HPs find difficult to discuss</li> <li>• Removed</li> <li>• Included</li> <li>• Removed</li> </ul>

Versions reviewed; tumour group; HP or patient perspective; & type of contact	Overview of feedback	<i>Action taken by researcher</i>
	<ul style="list-style-type: none"> <li>• Delete 'regular sexual activity' can help with vaginal dryness as this may put unhelpful pressure on relationships</li> <li>• Physiotherapists can help with use of dilators</li> <li>• Advocate the use of both vaginal lubricants and moisturisers</li> <li>• Discuss the use of dilators in a positive way as about 'supporting good skin care' and that use of a dilator may improve confidence to return to sexual intercourse.</li> <li>• Include lymphedema as a body image issue</li>   <li>• Provide information on psychosexual counselling as this may not be an area that HPs know exists</li>   <li>• Sex may be painful and impossible as a result of the emotional impact of cancer and treatment.</li> <li>• Remove vaginal reconstruction from surgery section as not common.</li> <li>• Women should not feel pressured into a sexual relationship... it should be when they are ready</li> <li>• Partners section needs expanded with more emphasis on partner to provide support, go back to early days of relationship – hugging/cuddling, partner needs to realise the emotional impact, it would be useful if couples attended post-operative review were this was discussed</li> <li>• Online support groups and peer support can help</li> </ul>	<ul style="list-style-type: none"> <li>• Included</li> <li>• Included</li>   <li>• Included</li>   <li>• Included in 'core' section of resource as is applicable to other tumour groups</li> <li>• This is not available to all so not specifically mentioned however counselling and psychological therapists can signpost.</li> <li>• Included</li>   <li>• Removed</li>   <li>• Partners section was initially amended to encourage more support for patient however, this was subject to further change as the aim of this section was to address partner sexual needs rather than patient needs</li> </ul>

Versions reviewed; tumour group; HP or patient perspective; & type of contact	Overview of feedback	<i>Action taken by researcher</i>
		<ul style="list-style-type: none"> <li>The signposting sheets contain information and organisations which offer further support, as online groups change and specific groups are not included</li> </ul>
Version 2 and 3 Colorectal cancer  CNS (In-person)  Specialist Pelvic Physiotherapist (In-person)  Patient (Email)	Content <ul style="list-style-type: none"> <li>HSCTs do offer biofeedback therapy</li> <li>Surgery section: remove pain during sex (more relevant for radiotherapy patients) and fear of dilator (not as relevant as maybe is for gynae patients)</li> <li>ED: include talk to your GP</li> <li>Include counselling as an option for body changes</li> <li>Fatigue management workshops are an option or speaking to a specialist OT</li> <li>Chemotherapy section: barrier method of contraception should be used throughout (verified by Consultant), no pregnancy for 6mths to 1 year after treatment</li> <li>Remove hot flushes as majority older and post-menopausal</li> <li>Include hair thinning due to some chemotherapy drugs</li> <li>Remove numbness and tingling section</li> <li>Remove reference to sex in the shower</li> <li>Some people struggle with dilators, could include that people could alternatively give their body</li> </ul>	<ul style="list-style-type: none"> <li>Reference to specific treatment removed and kept general to allow for HP to collaborate with patient to find most suitable approach</li> <li>Treatment sections were removed. Pain during sex is included in 'vagina may feel shorter, tighter or sore' and fear of dilator was removed as felt this was not as relevant.</li> <li>Included</li> <li>Included</li> <li>Not referenced as avoiding localising the resource to NI</li> <li>No specifics given in relation to pregnancy and contraception, advice is dependent on treatments given and patients are to talk to HP</li> <li>Removed as not as relevant</li> <li>Included</li> <li>Removed</li> <li>Removed</li> </ul>

Versions reviewed; tumour group; HP or patient perspective; & type of contact	Overview of feedback	Action taken by researcher
	time to naturally and gradually allow penetration to get easier	<ul style="list-style-type: none"> <li>This was not included as HPs strongly recommend the use of dilators. Also, there is a fear of putting additional pressure on relationships at a difficult time</li> </ul>
Version 2 and 3 Across tumour groups  Specialist Pelvic Physiotherapist (In-person)  Clinical Psychologist (In- person)  Lung and Palliative Care CNS (In-person)	Content <ul style="list-style-type: none"> <li>Normalise sense of loss both for patients and partners as they both go through grieve process for sexual life, they have lost</li> <li>Try not to be self-critical, avoid comparing self to before cancer</li> <li>Fear of death is normal</li> <li>Low mood and low sex drive are correlated</li> <li>Don't focus on vaginal penetration</li> <li>The importance of time to adjust</li> <li>Loss of fertility can affect those whose family is complete also</li> <li>Normal to feel self-conscious with changes to body image</li> <li>Discussion around sexuality at 'end of life'.</li> <li>Resource should encourage HPs to think of side rooms, pulling curtains to give couples privacy, encouraging couples to hold hands/hug.</li> <li>Include reference to 'Move more' funded exercise scheme available across NI</li> <li>Think about times in the day when less fatigued</li> <li>Shortness of breath/oxygen tubing are specific issues for patients with lung cancer.</li> </ul>	<div style="border-left: 1px solid black; border-right: 1px solid black; padding: 10px; margin-bottom: 10px;"> <p>Feedback woven throughout the categories to acknowledge more fully the psychosocial issues faced.</p> </div> <ul style="list-style-type: none"> <li>Section 1 on the resource amended to reflect end or life rather than palliative issues around sexuality</li> <li>Relevant to section 1 of resource</li> <li>Not implemented as to not localise resource, exercise encouraged however</li> <li>Included in body changes in 'core' section</li> <li>Lung cancer is not a specific group in the resource as for the most much of the resource addresses concerns.</li> </ul>

<b>Versions reviewed; tumour group; HP or patient perspective; &amp; type of contact</b>	<b>Overview of feedback</b>	<b><i>Action taken by researcher</i></b>
Version 4 Expert group meeting (n=5)  In-person	<ul style="list-style-type: none"> <li>• Changes discussed in terms of who to contact in relation to dilator support</li> <li>• Signposting sheets to be adapted to have a more general approach</li> <li>• Remove references to 'good vaginal skin care' in general signposting</li> <li>• Ensure 'be patient' and 'take time' are on all signposting sheets.</li> </ul>	<ul style="list-style-type: none"> <li>• Patients are encouraged to speak to an HP/physiotherapist in relation to dilator issues as not all will have access to radiotherapy support given that many problems exist beyond treatment</li> <li>• Removed</li> <li>• Signposting sheets revised</li> </ul>

## Appendix 7: General signposting sheet from MSW: CC eLearning resource

### Maximising Sexual Wellbeing | Cancer Care



#### Signposting Sheet - General

The following resources can provide useful sexual wellbeing support for men and women and their partners living with cancer.

Referrals to discuss:

- Look Good, Feel Better  
Confidence boosting workshops for people undergoing cancer treatment, including make-up and skin care.  
[https://www.lookgoodfeelbetter.co.uk/support-advice/group-session/#find\\_location\\_area](https://www.lookgoodfeelbetter.co.uk/support-advice/group-session/#find_location_area)
- Physiotherapist/Specialist Pelvic Physiotherapist  
Referral information and contact details for physiotherapy support.
- Incontinence clinic information.  
Referral information and contact details for your local incontinence clinic.
- Erectile dysfunction [ED] clinic information.  
Referral information and contact details for your local ED clinic.
- Psychological therapist or a counsellor  
Provide information on HSC and local community/voluntary support services.

Useful weblinks:

Information and support for relationships, sexuality and cancer

<https://www.cancer.gov/about-cancer/treatment/side-effects/sexuality-men>

<https://www.cancer.gov/about-cancer/treatment/side-effects/sexuality-women>

<https://macmillan.org.uk/information-and-support/coping/relationships/your-sex-life-and-sexuality>

A self-management online programme to help you with your sex life after prostate cancer

[prostate.lifeguidewebsites.org](http://prostate.lifeguidewebsites.org)

Sexual Advice Association

Factsheets and resources written by expert sexual health professionals.

<https://sexualadviceassociation.co.uk>

LGBT Discussion Forum

A discussion forum for LGBT or any other minority sexuality/gender identity to share their experiences.

[https://community.macmillan.org.uk/cancer\\_experiences/lgbt/discussions](https://community.macmillan.org.uk/cancer_experiences/lgbt/discussions)

### Top tips to remember

- The journey is not a straight path - there will be ups and downs
- You will have to try new things.
- It is important to keep connected as a couple, talking and touching.
- Be patient, it will take time to adjust.
- Try not to compare yourself to how you were before.
- Research shows if you have patience and persistence you can still have a satisfying and pleasurable sex life.

---

### Couples Communication Activity

Think about and write down one question to ask your partner about how cancer has affected him/her.

\_\_\_\_\_

Share with each other and discuss each other's responses.

Think and write down one activity (that you already do) that makes you feel physically close.

\_\_\_\_\_

Share with each other and discuss each other's responses.

Think about and write down one activity you would like to do to stay physically close.

\_\_\_\_\_

Share with each other and discuss each other's responses.

- 
- This activity can help to understand each other better.
  - It can be used as often as you decide.
  - Putting a date in your calendar can help make it happen.

**Appendix 8: PIS (in person)**

Ulster University  
Room 12J03  
Shore Road  
Jordanstown  
Co. Antrim  
BT37 0QB

Date: DATE TO BE INSERTED

Dear Sir/Madam

*Research Study:* Adapting, testing and evaluation of educational/facilitative resources to enable healthcare professionals working in cancer care to support patients and partners with sexual wellbeing.

Please find included a participant information sheet for the proposed research. Please read this information carefully before you decide whether you wish to consent to participating in the testing of these resources through a Think Aloud Interview.

Thank you for your time.

Yours sincerely,

---

Sharon Bingham  
PhD Researcher  
(on behalf of the research team)



Title of research:

Adapting, testing and evaluation of educational/facilitative resources to enable healthcare professionals working in cancer care to support patients and partners with sexual wellbeing.

What is the research study about?

Cancer and its treatment impact many aspects of life including health. Sexual wellbeing is one aspect that is often affected. Patients tell us that they want support for the sexual wellbeing issues they face and that they want this support from Healthcare Professionals (HPs). HPs face many challenges to providing this support including lack of awareness, embarrassment and supportive resources.

You are being invited to participate on research which has 'adapted educational/facilitative resources to enable healthcare professionals working in cancer care to support patients and partners with sexual wellbeing.' These resources were originally designed for Prostate Cancer. This study is funded by the Department for the Economy (DfE).

We are now ready to test these resources. We are asking you to provide us with feedback on the content and structure of the e-learning module and the electronic tablet-based facilitative tool.

Why you have been chosen?

You have been chosen because you provide routine clinical care to patients with cancer.

What will this involve?

This will involve reviewing of a prototype of each of the online resources using a Think Aloud interview. This will involve you meeting with the researcher. During the review of the resource, you will be asked to say aloud everything you think as you use the resource. This will be audio recorded and used to identify the improvements required.

Participants involved in this phase will be involved in 1 test cycle with an interview of 1hr approximately. Participants may be asked to participate in a further test cycle. They can decline to do this. Interviews will take place at a convenient location and time within the healthcare setting.

Why should you take part?

By participating in the Think Aloud Interviews you will help in the refinement of these resources which aim to support healthcare professionals to provide routine sexual wellbeing care for all cancer patients and partners.

It is entirely up to you whether to take part.

Will people be able to identify you from this study?

**Everything you tell us will be treated with strict confidentiality (nobody apart from the research team will be able to access the data). The researcher will ensure that no identifying information is included in the transcripts and that no participant is identified in the final report. Any further reports or publications stemming from this study will not contain any identifying features.**

Where will the information be stored?

Audio-files will be transcribed on to a password protected computer belonging to Ulster University which only the research team will have access to. Once transcribed the audio-

file will be deleted. Once the study is complete all the information will be destroyed in accordance with research protocol.

Is there any risk involved in taking part in the research?

It is important for you to know that in the unlikely event of you telling us something that would make us worry about your safety or the safety of someone else we will make sure that we pass on this information to those who need to know. If you have any concerns or worries about what we are asking you to do you can contact one of the researchers whose contact details are given at the bottom of this information sheet.

What happens if something goes wrong? This research has received ethical approval from Ulster University, research governance from the NHS trusts and Office for Research Ethics Committees NI (OREC NI). It is very unlikely that anything will go wrong. The Ulster University has procedures in place for reporting, investigating, recording and handling adverse events. Further details of the University's complaints procedure can be found at <http://research.ulster.ac.uk/rg/0208ResearchVolunteerComplaintsProcedure.pdf>

If you wish to make a complaint you can also contact either the Chief Investigator as detailed at the end of this Information Sheet.

What happens after the study finishes?

We will then publish and present the findings as widely as we can and we will try our best to make sure that everyone who has taken part will have access to the results.

What do I do now?

Thank you for taking time to read this Information Sheet. If you have any further questions about the study, please do not hesitate to contact the lead researcher named below. If you are willing to participate in the Think Aloud Interviews let your manager know and contact the lead researcher.

Privacy notice and sponsor compliance with GDPR and the Data Protection Act 2018

Ulster University is the sponsor or managing organisation for this study and we will use information gathered from you in order to carry it out.

We will act as the data controller, which means that we are responsible for looking after your information and using it properly, as stipulated in GDPR and the Data Protection Act 2018.

Ulster University will keep identifiable information about you for 10 years after the study has finished/September 31.

You can find out more about how we look after your information at:

<https://www.ulster.ac.uk/about/governance/compliance/gdpr>

As a university we use personal identifying information to conduct research to review and improve people's health, wellbeing and care, the services they use and our understanding of the world in which we live. As a publicly funded organisation, we have to ensure that it is in the public interest when we use personal identifying information from people who have agreed to take part in research. This means that when you agree to take part in a study, we will use your data to conduct the research and analyse the information and findings.

We need to manage your information in specific ways in order for the research to be reliable and accurate and therefore your rights to access, change or move your information are limited.

You should note that if you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personal identifying information possible.

Health, care and other human research should serve the public interest, which means that we have to demonstrate that our research serves the interests of society as a whole. We do this by following University and appropriate UK policies and codes of practice.

The only people in the University who will have access to your personal identifying information will be those who need to contact you for the study or to carry out audits of the research.

If you wish to raise a complaint on how we have handled your personal data, you can contact our Data Protection Officer who will investigate the matter. If you are not satisfied with our response or believe we are processing your personal data in a way that is not lawful you can complain to the Information Commissioner's Office (ICO).

Our Data Protection Officer is Eamon Mullan; you can contact him at [e.mullan@ulster.ac.uk](mailto:e.mullan@ulster.ac.uk).

For further information regarding the research please contact:  
Sharon Bingham (Lead Researcher) at [Bingham-s4@ulster.ac.uk](mailto:Bingham-s4@ulster.ac.uk)

Dr Cherith Semple (Chief Investigator) at [Cherith.Semple@setrust.hscni.net](mailto:Cherith.Semple@setrust.hscni.net)

Adapting, testing and evaluation of educational/facilitative resources to enable healthcare professionals working in cancer care to support patients and partners with sexual wellbeing.

### Consent Form

Please tick and initial each box to show your agreement with the following:

1. I confirm that I have read and understand the Information Sheet (DATE TO BE INSERTED) for the above study. I have had the opportunity to consider the information and ask questions.	
2. I understand that any participation is voluntary and that I can choose not to participate in the research, without giving any reason and without my legal rights being affected.	
3. I understand that all the information provided by me will be stored confidentially at the University of Ulster and that I will not be identifiable in any data published in relation to this project.	
4. I am willing to participate in a Think Aloud Interview with a member of the research team which will be audio-taped.	

Name of participant      Date      Signature

\_\_\_\_\_

Person taking consent      Date      Signature  
[if different from  
researcher]

\_\_\_\_\_

Name of researcher      Date      Signature

\_\_\_\_\_

One copy for participant, one copy for researcher.

**Appendix 9: PIS (adapted for use with video conferencing)**

Ulster University  
Room 12J03  
Shore Road  
Jordanstown  
Co. Antrim  
BT37 0QB

Date: DATE TO BE INSERTED

Dear Sir/Madam

*Research Study:* Adapting, testing and evaluation of educational/facilitative resources to enable healthcare professionals working in cancer care to support patients and partners with sexual wellbeing.

Please find included a participant information sheet for the proposed research. Please read this information carefully before you decide whether you wish to consent to participating in the testing of these resources through a Think Aloud Interview.

Thank you for your time.

Yours sincerely,

A handwritten signature in black ink that reads 'S. Bingham'.

---

Sharon Bingham  
PhD Researcher  
(on behalf of the research team)

Title of research:

Adapting, testing and evaluation of educational/facilitative resources to enable healthcare professionals working in cancer care to support patients and partners with sexual wellbeing.

What is the research study about?

Cancer and its treatment impact many aspects of life including health. Sexual wellbeing is one aspect that is often affected. Patients tell us that they want support for the sexual wellbeing issues they face and that they want this support from Healthcare Professionals (HPs). HPs face many challenges to providing this support including lack of awareness, embarrassment and supportive resources.

You are being invited to participate on research which has 'adapted educational/facilitative resources to enable healthcare professionals working in cancer care to support patients and partners with sexual wellbeing.' These resources were originally designed for Prostate Cancer. This study is funded by the Department for the Economy (DfE).

We are now ready to test these resources. We are asking you to provide us with feedback on the content and structure of the e-learning module and the electronic tablet-based facilitative tool.

Why you have been chosen?

You have been chosen because you provide routine clinical care to patients with cancer.

What will this involve?

This will involve reviewing of a prototype of each of the online resources using a Think Aloud interview. This will involve you communicating with the researcher via ZOOM technologies. During the review of the resource, you will be asked to say aloud everything you think as you use the resource. This will be video recorded and used to identify the improvements required.

Participants involved in this phase will be involved in 1 test cycle with an interview of 1hr approximately. Participants may be asked to participate in a further test cycle. They can decline to do this. Interviews will take place at a convenient location and time within the healthcare setting.

Why should you take part?

By participating in the Think Aloud Interviews you will help in the refinement of these resources which aim to support healthcare professionals to provide routine sexual wellbeing care for all cancer patients and partners.

It is entirely up to you whether to take part.

Will people be able to identify you from this study?

**Everything you tell us will be treated with strict confidentiality (nobody apart from the research team will be able to access the data). The researcher will ensure that no identifying information is included in the transcripts and that no participant is identified in the final report. Any further reports or publications stemming from this study will not contain any identifying features.**

Where will the information be stored?

Video-files will be transcribed on to a password protected computer belonging to Ulster University which only the research team will have access to. Once transcribed the video-file will be deleted. Once the study is complete all the information will be destroyed in accordance with research protocol.

Is there any risk involved in taking part in the research?

It is important for you to know that in the unlikely event of you telling us something that would make us worry about your safety or the safety of someone else we will make sure that we pass on this information to those who need to know. If you have any concerns or worries about what we are asking you to do you can contact one of the researchers whose contact details are given at the bottom of this information sheet.

What happens if something goes wrong? This research has received ethical approval from Ulster University, research governance from the NHS trusts and Office for Research Ethics Committees NI (OREC NI). It is very unlikely that anything will go wrong. The Ulster University has procedures in place for reporting, investigating, recording and handling adverse events. Further details of the University's complaints procedure can be found at <http://research.ulster.ac.uk/rg/0208ResearchVolunteerComplaintsProcedure.pdf>

If you wish to make a complaint you can also contact either the Chief Investigator as detailed at the end of this Information Sheet.

What happens after the study finishes?

We will then publish and present the findings as widely as we can and we will try our best to make sure that everyone who has taken part will have access to the results.

What do I do now?

Thank you for taking time to read this Information Sheet. If you have any further questions about the study, please do not hesitate to contact the lead researcher named below. If you are willing to participate in the Think Aloud Interviews let your manager know and contact the lead researcher.

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We will act as the data controller, which means that we are responsible for looking after your information and using it properly, as stipulated in GDPR and the Data Protection Act 2018.

Ulster University will keep identifiable information about you for 10 years after the study has finished/September 31.

You can find out more about how we look after your information at:

<https://www.ulster.ac.uk/about/governance/compliance/gdpr>

As a university we use personal identifying information to conduct research to review and improve people's health, wellbeing and care, the services they use and our understanding of the world in which we live. As a publicly funded organisation, we have to ensure that it is in the public interest when we use personal identifying information from people who have agreed to take part in research. This means that when you agree to take part in a study, we will use your data to conduct the research and analyse the information and findings.

We need to manage your information in specific ways in order for the research to be reliable and accurate and therefore your rights to access, change or move your information are limited.

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Our Data Protection Officer is Eamon Mullan; you can contact him at [e.mullan@ulster.ac.uk](mailto:e.mullan@ulster.ac.uk).

For further information regarding the research please contact:  
Sharon Bingham (Lead Researcher) at [Bingham-s4@ulster.ac.uk](mailto:Bingham-s4@ulster.ac.uk)

Dr Cherith Semple (Chief Investigator) at [Cherith.Semple@setrust.hscni.net](mailto:Cherith.Semple@setrust.hscni.net)



Adapting, testing and evaluation of educational/facilitative resources to enable healthcare professionals working in cancer care to support patients and partners with sexual wellbeing.

## Consent Form

Please tick and initial each box to show your agreement with the following:

1. I confirm that I have read and understand the Information Sheet (DATE TO BE INSERTED) for the above study. I have had the opportunity to consider the information and ask questions.	
2. I understand that any participation is voluntary and that I can choose not to participate in the research, without giving any reason and without my legal rights being affected.	
3. I understand that all the information provided by me will be stored confidentially at the University of Ulster and that I will not be identifiable in any data published in relation to this project.	
4. I am willing to participate in a Think Aloud Interview with a member of the research team using ZOOM technologies which will be video-recorded.	

Name of participant	Date	Signature
_____	_____	_____
Name of researcher	Date	Signature
_____	_____	_____

Please return signed copy of consent form to researcher  
[Bingham-s4@ulster.ac.uk](mailto:Bingham-s4@ulster.ac.uk)

## Appendix 10: Protocol for TA interviews

- Welcome participant
- Provide introduction to the study and review details provided on the participant information sheet
- Explain the process for thinking aloud. (1) Ask participants to say aloud any thoughts as they move through the resource which can include thoughts about the content, appearance, navigation and functionality. (2) Explain that the researcher will remain quiet throughout interview. (3) Ask participants to use resource as they might in normal practice. (4) Tell participants that the researcher will offer minimal prompts to remind participant to keep talking if they are quiet and may ask questions relating to comments for clarification purposes (5) Remind participants that the study welcomes all opinions, with the objective of improving the resource for healthcare professionals in the future.
- Restate that the interview will take a maximum of 1 hour, however participants are free to withdraw or stop the interview at any time.
- Explain to participants that they will only review specific parts of resource, so at times they will be asked to move to another section within the resource
- Remind participants that the session will be recorded, highlighting data storage, retention and destruction is in accordance with UU regulations and explain how data will be used
- Ask participant if they have any questions or concerns
- Ensure eLearning resource is open on participant computer
- **Ensure recording function is on**
- Begin interview
- Finish interview, thank participant, ask if they have any questions or comments.
- **Exit recording and save.**

### Required for each interview

- List of elements of resource to be viewed by each participant
- Researcher feedback sheet

### Additional protocols for interviews using video conferencing

#### *In advance of Zoom interview:*

- Send Meeting ID and passcode in advance
- Send URL for MSW: CC eLearning resource
- Signed consent form received (will be reviewed at beginning of video conferencing interview)

#### *Process for Zoom call*

1. Open Zoom
2. Enable video and audio
3. Enable screen share
4. Optimise sound to share video content (if participant cannot access due to low bandwidth)

**Appendix 11: Excerpt of notes taken during TA interviews**

eLearning resource Test v3 all slides [02 10 2020]  
 PARTICIPANT ID 109 PEd TC2  
 DATE 5 Oct 20  
 TEST CYCLE 2

<p>2</p>	<p>Like interaction. Immediately engaging</p>	
<p>2R</p>	<p>Not immediately apparent that the 'x' will take you back... but participant did figure out what to do.</p> <p>Would like functionality of 'x'.</p> <p>Missed the scroll sideways function.... Suggested to include 'next question' with arrow.</p>	

## Appendix 12: Excerpt from reflective diary

I arrived at the HSC building for the 2<sup>nd</sup> think aloud (TA) interview however, staff were unsure of where I should be located, despite my explanation. We were able to contact the local collaborator (LC) and established the correct room for the interview to which I then made my way. Prior to the TA interview there had been emails back and forward between the participant, the LC and me about the details of the interview. However, 102 GYN TC1 arrived late to the TA interview and was annoyed that I had not notified them of my arrival, despite the prior arrangements to meet at the room at a certain time. The lateness caused no additional pressure or inconvenience to me that annoyed me, I was simply happy to have participant number 2 attend. However, there was a prickly feeling within the room although I did try to remain open and flexible whilst feeling reprimanded. I did consider the irritation was possibly more about 102 GYN TC1 being late rather than their belief that I failed to prompt them, so I set about to try to ensure the interview was upbeat and that I tried to reflect an openness to move on and hear their responses to the interview.

Their initial reflections on the video content again, I felt came across prickly, however this may have been because of the above-described arrival. Their challenge to the content provoked frustration within me that the videos were not of the quality they needed to be to address the information needs of HPs. I sought clarity at this point as to their perspective and remained open to listen to their perspectives. As 102 GYN TC1 continued, it did feel like they warmed to me and became more friendly which helped to facilitate a sense of rapport. This sense of rapport is clearly especially important to me as a researcher, maybe one that I rely on too much to achieve my aim. I find it interesting that this frustrated me about the start to this interview. I did not mind she was late to the interview, but I did mind that she regarded my behaviour as not meeting her expectations, which was extended by the feeling that the video within my eLearning resource was not meeting her information needs.

As the interview progressed there were key messages with which the participant connected. The participant discussed her need to know the patient's context prior to providing sexual support to avoid being inappropriate. They reflected, for example, if the patient is older, was it appropriate to bring up the conversation given there is a risk that the partner is dead or has dementia. At the same time, they reflected a sense of ambiguity about this, suggesting that this may be incorrect and maybe the patient would want support. This conversation highlighted for me the potential for this eLearning resource (1) to tackle assumptions about who to provide support to and (2) to maximise on the opportunity to broaden HPs view of the biopsychosocial nature of sexual challenges and avoid limiting sexual support to only those in a sexual relationship.

102 GYN TC1 did show an awareness of the enormity of the physical and the emotional sexual challenges which treatment could pose to some patients' sexuality and showed a good knowledge of the use of dilators and provided examples of sexual care communication. They shared a framework of questions in response to the EASSi framework which they would use to work through with patients which has helped build their confidence in this area. It was reassuring to be told that sexual care is provided to some patients, but this spoke to the potential enabling value of providing HPs with a framework. As the eLearning resource is framed around the EASSi framework, this hopefully would be the key to moving new knowledge into practice... which is the ultimate hope for this resource, so to improve patient-reported outcomes.

The participant highlighted that the resource was adequately scripted however would have liked to see more in the way of conversation starters. I feel that this is a fair point and should have some further consideration if this resource is going to support the known barriers to initiating a sexual support conversation with a patient and partner.

Appendix 13: Overview of utilisation of data generated from TA interviews

	Cycle 1 (MS PowerPoint)	Cycle 2 (Online version)	Cycle 3 (Online resource and MS PowerPoint)
<b>Appearance</b>	Improve readability: Split larger paragraphs (Step 1)	Increase text size (to enhance presentation of Step 2 Specific tumour section response slides)  Ensure font consistency	
<b>Content</b>	<p>Extend examples of good practice (single and LGBT as is provided in 'end of life' section).</p> <p>Remove repetitive slide (Step 2 describing EASSi Framework).</p> <p>Language</p> <p>(1) Increase acceptability (should to may, should to could).</p> <p>(2) Reflect clinical practice, e.g. remove specific advice relating to treatment and pregnancy, ask patients to avoid pregnancy and speak to HP if there are any concerns.</p> <p>(3) Remove specific mention on hormonal or non-hormonal vaginal moisturisers, rather suggest 'designated vaginal moisturisers.'</p> <p>Improve relevance of video content (include emotional concerns, body image and coping with menopausal symptoms).</p>	<p>Include product disclaimer (Liz video Part 1).</p> <p>Amend online support options – UK wide relevance and immediate relevance content.</p> <p>Improve title clarity in Step 2: Support.</p> <p>Remove repetitive slide (Step 2 Support prior to Psychosocial Effects).</p> <p>Broaden Gynaecological signposting to increase relevance across types of tumours.</p> <p>Minor changes (Improve advice clarity.)</p>	<p>Change wording relating to 'main role of partner' to enhance relevance.</p> <p>Increase clarity for HPs in Step 2 Support: dilator support (GYN), timing of intimacy (stoma activity (CRC)) and use of Heat Moisture Exchange filters (HNC).</p> <p>Reorganise ordering of 2 questions in couple communication activity (Signposting sheets) to encourage progression in thinking.</p>

	<b>Cycle 1 (MS PowerPoint)</b>	<b>Cycle 2 (Online version)</b>	<b>Cycle 3 (Online resource and MS PowerPoint)</b>
<b>Navigation</b>	Remove unnecessary signposting from advice pages in Step 2.	<p>Enhance navigation (poor use of side-way navigation).</p> <p>Improve signposting to avoid missed layered sections (Step 2.)</p> <p>Reword 'Back to Start' to 'Back to previous section' (Step 2.)</p>	Colour tabs in layer sections (Step 2) to enhance navigation.
<b>Functionality</b>		<p>Add functionality to Step 1 Response activity (No response confusing.)</p> <p>De-bug Step 2 Support advice boxes (Information disappears off page)</p> <p>Ensure icons/text do not overlap (Step 1 response screens.)</p> <p>Compress videos for low bandwidth.</p>	

## Appendix 14: EASSi Quick Guide, to assist HPs sexual support conversations in clinical practice



### Maximising Sexual Wellbeing | Cancer Care

Engagement, Assessment, Support & Signposting | EASSi

#### Quick Guide

EASSi is a framework for healthcare professionals to guide routine, brief sexual care discussions with patients (and partners) living with cancer.

Engage	<p><b>Why Engage?</b> Sexual dysfunction is a major problem for patients (and partners) and is often not addressed.</p>	<p><b>How to Engage?</b></p> <ul style="list-style-type: none"> <li>• Take the lead</li> <li>• Normalise the conversation</li> <li>• Explain you are going to have a brief conversation about sex and cancer</li> </ul>
Assess	<p><b>Why Assess?</b> A basic assessment is needed to provide tailored support (based on type of cancer, treatment and relationship status).</p>	<p><b>How to Assess?</b></p> <ul style="list-style-type: none"> <li>• Ask about ...</li> </ul> <p>Type of Cancer Type of treatment Stage of Treatment Relationship status</p>
Support	<p><b>Why Support?</b></p> <ul style="list-style-type: none"> <li>• There are many sexual side-effects of each treatment.</li> <li>• Patients need to know how treatment will affect their sex life.</li> <li>• There are things that can be done to help</li> <li>• You are ideally placed</li> </ul>	<p><b>How to Support?</b></p> <ul style="list-style-type: none"> <li>• Provide information about what sexual challenges may be expected (based on treatment)</li> <li>• Acknowledge sex life will change</li> <li>• Give brief advice on ...</li> </ul> <p>What can be done Widening understanding of sex The need to have patience and persistence</p>
Sign-posting	<p><b>Why Signpost?</b> After providing sexual support you then need to signpost to specialist services/resources.</p>	<p><b>How to Signpost?</b> Point towards...</p> <ul style="list-style-type: none"> <li>• Online resources</li> <li>• Referral to physiotherapy, psychological therapist or counsellor, ED or Continence clinics</li> </ul>

This document has been adapted from the TrueNTH Maximising Sexual Wellbeing Project, which is funded by the Movember Foundation, in partnership with Prostate Cancer UK, as part of the TrueNTH programme. © Copyright Ulster University 2020



## Appendix 15: Enhancing the provision of HP-led sexual care in the NHSCT

### Background

The provision of routine HP-led sexual support in cancer care is at best ad-hoc although often avoided<sup>1,2</sup> despite being a priority survivorship area in many healthcare guidelines.<sup>3-5</sup> Patients (78%) across tumour groups wish for HP support to deal with enduring and difficult sexual challenges.<sup>6</sup> However, the provision of HP-led sexual care is fraught with barriers, including HP discomfort with the topic, a lack of knowledge of sexual challenges and strategies to support, resources and referral pathways.<sup>7</sup> Yet, sexual care brings benefits, with patients and partners reporting that it helps to normalise the sexual side effects experienced, facilitates sexual rehabilitation, promotes psychosocial adjustment and informs treatment choices.<sup>8-12</sup>

Having identified that a passive approach to including sexual concerns on a screening form is insufficient,<sup>13</sup> the proposal is to develop a tiered model to engage all patients and partners (when appropriate) in a sexual support conversation to proactively ensure that they have knowledge of and access to appropriate HP-led sexual support across the treatment trajectory as required. This approach is supported by the Cancer Recovery Plan<sup>14</sup> which prioritises ensuring equitable access and support to adequately address the holistic needs of people living with cancer whom it recognises have been living with high levels of anxiety due to the pandemic. Training the cancer care workforce to address sexuality proactively throughout patients' care could reduce the number of post-treatment referrals made for specialist services such as psychology or sexual health services, thereby reducing waiting times and improving access for patients who do require more intensive treatments.<sup>15</sup>

### Aim

To pilot and evaluate a 3-tiered sexual care model into Northern Health and Social Care Trust cancer care services to enhance the provision of HP-led sexual care and improve patient reported outcomes.

### Activities

- Scoping exercise to explore the HP-led sexual care provision for patients and partners from HP and patient viewpoints. To explore the frequency, experience and quality of sexual health care provision across tumour groups, communication framework used to guide conversations, referral pathways utilised, supportive resources for patients.
- Develop and implement a three-tiered model of sexual care, Level 1, proactive level of sexual support for all patients and partners extending from pre-treatment across treatment trajectory, Level 2, signposting to patient online self-management resources and Level 3, referral on for more complex sexual concerns. (See Fig. 1.)
- Upskill cancer care workforce to provide routine sexual support.
- Develop signposting to patient online self-management resources.
- Develop, promote and embed onward referral pathways for more complex sexual concerns including sexual health services, psychology, counselling, specialist physiotherapy.
- Evaluate to determine the feasibility of embedding the model into cancer care, identifying
  - the utility of an eLearning resource at supporting the integration of sexual support into routine cancer care, ascertaining benefits and shortcomings to inform

- modifications ahead of a randomised control trial determining intervention effectiveness
- the impact of the tiered model on the provision of sexual care in clinical practice, measuring the sexual support provided and onward referrals across tumour groups
  - the impact of the tier model on patient reported outcomes relating to sexual wellbeing
  - recommendations to refine an implementation model ahead of regional rollout to health and social care organisations.
- Partner with Ulster University to ensure high-quality research outputs to inform policy and practice.

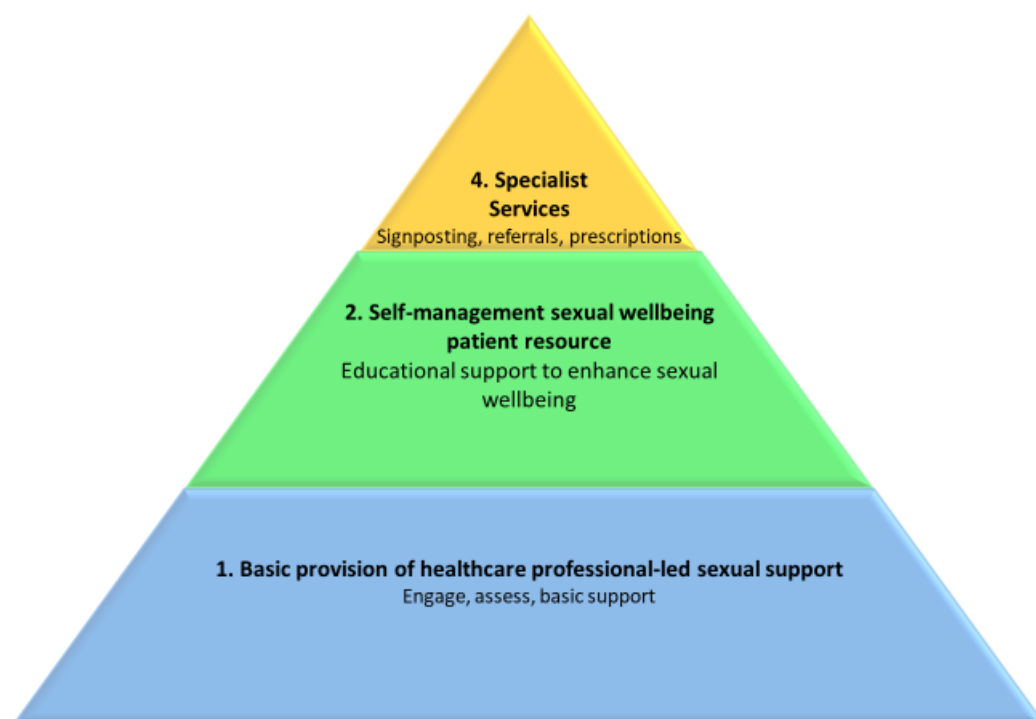


Figure 1: Proposed model of sexual care adapted from the Oasis programme.<sup>15</sup>

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