Paradoxical Support: Exploring Use of the Holistic Needs Assessment and its Contribution to Meaningful Support for Women with Breast Cancer

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Abstract

Breast cancer is a widespread disease, with rapidly increasing numbers of people living with or beyond this diagnosis (Breast Cancer Care, 2018a). The disease is associated with a complex array of physical, psychological and social impacts, which may continue long after treatment (National Cancer Institute, 2014). The concept of ‘personalised care’ (formerly the ‘recovery package’) was introduced in the UK as part of a nation-wide agenda to support women with breast cancer, of which holistic needs assessment (HNA) is a core element (National Health Service (NHS), 2019). These assessments give people opportunities to raise their concerns and have these addressed through a meaningful discussion and subsequent care plan (National Cancer Survivorship Initiative, 2013). Across the UK, implementation of the HNA varies significantly in its approach and delivery methods. Although various types of HNA tools exist, few studies have explored the perspective of either healthcare professionals or individuals with cancer around use of these tools. However, there is some indication that the HNA’s contribution to addressing concerns arising from cancer diagnoses is complex, and often minimal.

The current study aimed to understand the contribution of the HNA in assessing and supporting the needs of women with breast cancer, and understanding the barriers and enablers to use of the assessment. The study adopted a multiple case-study approach, including two acute NHS Trusts and four hospital sites. In total, 24 women with breast cancer and 24 staff were recruited. Data collection involved face-to-face interviews with all participants, follow-up interviews with women and observations of HNA completion wherever possible. Furthermore, HNA care plans and other key documentation were analysed to compile a case around use of the HNA in each NHS Trust, with the primary focus being Macmillan Cancer Support’s electronic HNA (eHNA). A Framework

Analysis approach was adopted to identify key categories and explanations within the data.

Findings showed that the HNA’s contribution in supporting women’s needs was complex, and dependent on multifactorial influences. Framework analysis identified a trio of key factors which affected participants’ perceptions of the (e)HNA’s contribution, which were how women’s views and judgements influenced these perceptions, how the staff member’s views and judgements influenced these perceptions, and the influence of the broader context and culture within their organisations. An apparent superficial implementation of HNAs in these case studies seemed to facilitate cultures of achieving targets over the value of meaningful conversations. Therefore, rather than providing support to women, the HNA's contribution appeared paradoxical in many cases, through eliciting either indifferent or negative feelings among women. However, there were notable differences observed between case studies, with more negative views towards the assessment expressed by participants at Case Study 1 compared with Case Study 2.

Women perceived the HNA as meaningful ‘in principle’, as this provided an opportunity to have their needs met, and the care plan offered a valuable safety net and physical reminder of the conversation. However, challenges and room for improvement were noted by both staff and women in HNA implementation processes. A series of recommendations for practice settings were developed to support the delivery of increasingly personalised HNAs, focusing around: introductions to the HNA, the practicalities of arranging the HNA and maximising the value of each element of the HNA process.

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Chapter One: Introduction

1.1 Overview

This thesis explores the ‘Holistic Needs Assessment’ (HNA), an intervention focused on recognising and supporting concerns within all aspects of people’s lives following a diagnosis of cancer (Macmillan Cancer Support, 2016). The HNA aims to provide early intervention in supporting needs, alongside encouraging an individual’s ability to self-manage their condition (Macmillan Cancer Support, 2016). The primary aim of this thesis is to understand the contribution of the HNA in assessing and supporting the needs of women with breast cancer. However, this exploration highlighted the significance of wider, underlying factors which may influence the successful implementation of any healthcare innovation into practice settings.

In this introductory chapter, my own background and experience are discussed to display the lens through which I approached the study. Subsequently, the chapter provides an overview to situate the thesis in the context of the HNA’s background and its function in healthcare settings.

1.2 Motivation for Choice of Subject Matter

With a background in cancer nursing, my training and core values focus on ensuring those in receipt of care are well supported. Upon receiving a cancer diagnosis, individuals are often frightened, alongside having their own families, existing worries and priorities to consider. My motivation for choosing HNAs as the topic for this thesis originates from these concepts, as I believe a deeper understanding of the wider features of a person’s life can enhance support and outcomes. Therefore, care can be provided which not only manages an individual’s physical condition, but also supports them to be the very best version of themselves.

As a junior nurse prior to commencing this study, I was involved in the delivery of HNAs to women with breast cancer in a hospital ward environment. During this time, I encountered many challenges and barriers to delivery of HNAs (such as increased workload and lack of interest from other staff), and the assessments I conducted often felt superficial. I believed that if my knowledge and skill to undertake HNAs were greater, the contribution this made to the individual would be more valuable. I began to network with other NHS organisations and identified similar patterns of challenges and disengagement from staff. I developed an interest in understanding these barriers, which would enable me to create recommendations for practice, to increase the value of HNAs. Consequently, I undertook my Master of Arts (MA) in Research Methods, including a small HNA-focused study. This revealed a level of complexity in the assessment’s delivery that was beyond the scope of the MA study to explore. When situating my MA findings in a broader evidence base, this highlighted that few studies had examined whether HNAs were used to their maximum potential, and their value in practice settings.

1.3 Breast Cancer

As described in this chapter’s overview, the thesis aims to explore the HNA’s contribution to supporting the needs of those with cancer, specifically women with breast cancer. Within this section, the rationale for this choice of cancer type is presented, emphasising the prevalence of breast cancer within the population and the associated physical, emotional and social concerns, which often persist after treatment.

Breast cancer affects one in eight women during their lifetime, with over two million new diagnoses occurring in 2018 alone (World Cancer Research Fund, 2020). The disease has many forms, including invasive, lobular, ductal and inflammatory cancer (Cancer Research UK, 2014). Nine in ten women survive over five years beyond their diagnosis, with 691,000 of these individuals residing in the United Kingdom (UK) alone (Breast Cancer Care, 2018a). Breast cancer occurs from uncontrolled cell growth, which becomes malignant and leads to tumour formation (American Cancer Society, 2017). This process can transpire in various parts of the breast, and may spread to other areas of the body if left untreated (known as metastatic cancer) (American Cancer Society, 2017). UK national objectives focus on achieving a ‘two-week wait’ target, for individuals to receive a specialist review if cancer is suspected (Cancer Research UK, 2018). Furthermore, emphasis is also placed on a 62-day pathway from initial hospital referral to commencing cancer treatment, with a view to reducing incidence of metastatic cancers (Cancer Research UK, 2018). Based on the need to rapidly treat cancers, individuals undergo intensive investigations prior to diagnosis, involving scans, examinations and invasive procedures (National Institute for Health and Care Excellence, 2015). Once diagnosed, patients may have potentially radical treatments, including combinations of surgery, chemotherapy, radiotherapy or hormone therapy (Breast Cancer Care, 2018b). Collectively, these processes often amount to a life-changing experience (National Cancer Institute, 2014).

A significant body of literature suggests the cancer journey feels interminable, with one in four women reporting the period after cancer treatment as the most emotionally challenging time (Breast Cancer

Care, 2018a). However, complex physical, psychological and social needs can arise at various points along this journey (Campbell-Enns & Woodgate, 2017; Pauwels et al., 2013; Sherman et al., 2012; Williams & Jeanetta, 2016). Physical concerns that may occur include altered appearance, fatigue, pain, menopausal symptoms, sexual dysfunction and infertility (Aranda et al., 2005; Arndt et al., 2005; Boehmke & Dickerson, 2006; Bower, 2008; Campbell-Enns & Woodgate, 2017; Ganz et al., 2004; Mols et al., 2005). Furthermore, frequently reported psychological concerns include anxiety, depression, fear of cancer recurrence, loss of control, altered body image, uncertainty, guilt and isolation (Aranda et al., 2005; Armes et al., 2009; Arndt et al., 2005; Burg et al., 2015; Campbell-Enns & Woodgate, 2017; Mols et al., 2005). Additionally, other aspects of life can be affected, such as changing familial and career roles (Aranda et al., 2005; Armes et al., 2009; Arndt et al., 2005; Campbell-Enns & Woodgate, 2017), or financial issues due to loss of income, and increased day-to-day living costs resulting from debilitating treatments (Macmillan Cancer Support, 2013). Although concerns are variable between individuals, research has highlighted a relationship between these ‘unmet needs’ and quality of life, with greater needs correlating with poorer outcomes (Cheng et al., 2016). Despite this, support from healthcare professionals appears to reduce towards the end of treatment, and needs are often left unaddressed (Armes et al., 2009).

Although the thesis focuses on individuals with breast cancer, the following sections provide a general background to the concept of HNAs across all types of cancer, considering why and how the tools were developed, and how they function to support needs.

1.4 The Case for Change

Beginning with why the HNA was developed; the inadequacy of support provided following a cancer diagnosis was initially recognised in the UK’s Cancer Reform Strategy (National Health Service (NHS), 2007). This report highlighted the complex needs of individuals, leading to the formation of the National Cancer Survivorship Initiative (NCSI). The NCSI focused on promoting individualised support, and encouraging self-management (Richards et al., 2011), which involves empowering patients to take ownership of managing their health condition (Taylor et al., 2014). In 2013, NCSI’s policy for taking action was released, followed by the National Cancer Strategy for England several years later, which centred on understanding patients' needs and improving care provision (Independent Cancer Taskforce, 2015; NCSI, 2013; NHS, 2007).

Once improving outcomes for those with cancer was identified as a priority, this stimulated the development of the ‘recovery package’ interventions (now referred to as ‘personalised care’) (NHS, 2019). These interventions were targeted at each individual diagnosed with cancer, and included HNA and care planning as a key component (plus treatment summaries, cancer care reviews, and access to health and wellbeing information and support, as additional constituents) (NCSI, 2013; NHS, 2019). These ‘personalised care’ interventions are defined as follows:

- The HNA is an assessment focused on identifying and supporting areas of life which hold the greatest need for people. This is subsequently formulated into a care plan, to illustrate actions required to address these needs.

- Treatment summaries give opportunity for general practitioners (GPs) and those with cancer to have increased awareness of their diagnosis details, treatment plan, and any follow-up actions required.

- The cancer care review is undertaken in a GP practice setting, to check the individual's progress and prompt actions, such as medication reviews.

- Health and wellbeing information and support (including personalised information or general health promotion) encourages empowerment and individuals taking an active role in their recovery.

(NCSI, 2013)

The HNA (and care plan) have been referred to as the 'heart' of personalised care (Doyle & Henry, 2014), and are therefore adopted as the primary focus within the thesis.

1.5 The Concept of Holistic Needs Assessment

Having established why the HNA was introduced, this section focuses alternatively on what the HNA is. The concept of 'holistic' is defined as considering each person as a whole, made up of body, mind and spirit (Thompson et al., 2008). The holistic approach requires acknowledgement of factors such as autonomy and self-management within care provision (Thompson et al., 2008). Additionally, holistic needs vary significantly between individuals, and a designated HNA tool can assist with identifying needs and action planning to support these (National Cancer Action Team (NCAT), 2011). Additionally, use of an HNA enables greater prioritisation of needs by ensuring all areas of holism are considered (NCAT, 2011). HNAs can also be categorised as a form of patient reported outcome measures (PROM), which is an umbrella term for self-reported questionnaires that assemble information about an individual's health outcomes (Valderas & Alonso, 2008). A similar branch of questionnaires - patient reported experience measures (PREMs) - are also frequently adopted, but alternatively focus on people's experiences of the care received. For example, a PROM may measure side effects following cancer surgery, whereas a PREM might consider experiences of communication with staff and adequacy of analgesia during their hospital stay.

Many forms of the HNA tool exist, which are explored within Chapter Two. For this thesis, the primary focus is Macmillan Cancer Support's HNA, also known as the 'Concerns Checklist'. The unique approach taken by Macmillan Cancer Support places the Concerns Checklist and five other HNA tools under the umbrella term 'eHNA' (electronic holistic needs assessment). The eHNA represents a virtual platform where any of these six tools can be completed and stored.

1.5.1 Technological Platform: eHNA Development

Within this section, an overview describes how the HNA was developed, with a specific focus on Macmillan Cancer Support's eHNA platform. This represents the most widely adopted method for HNA completion throughout the UK. As of September 2018, 103 out of 152 Acute NHS Trusts in England, six Trusts from Wales, Scotland and Northern Ireland, and 15 out of 35 community Trusts were implementing this to some degree, with others planning to follow (eHNA Support Officer, 2018). The eHNA platform aimed to simplify the HNA process, and facilitate completion of more assessments (Rowe et al., 2014). In order to achieve this, the eHNA system allows the individual to complete assessments at home, which is especially applicable during the COVID-19 pandemic, which encouraged global maturation in technology usage (Bayram et al., 2020). The electronic platform has therefore enabled HNAs to continue throughout the pandemic, without the additional risk to patients from hospital visits. Adoption of electronic methods also supports the NHS IT strategy, which aimed to assist staff with tracking patients' progress, empower people to take control of their own health and use virtual platforms to integrate care services (NHS, 2014; Swindells, 2017).

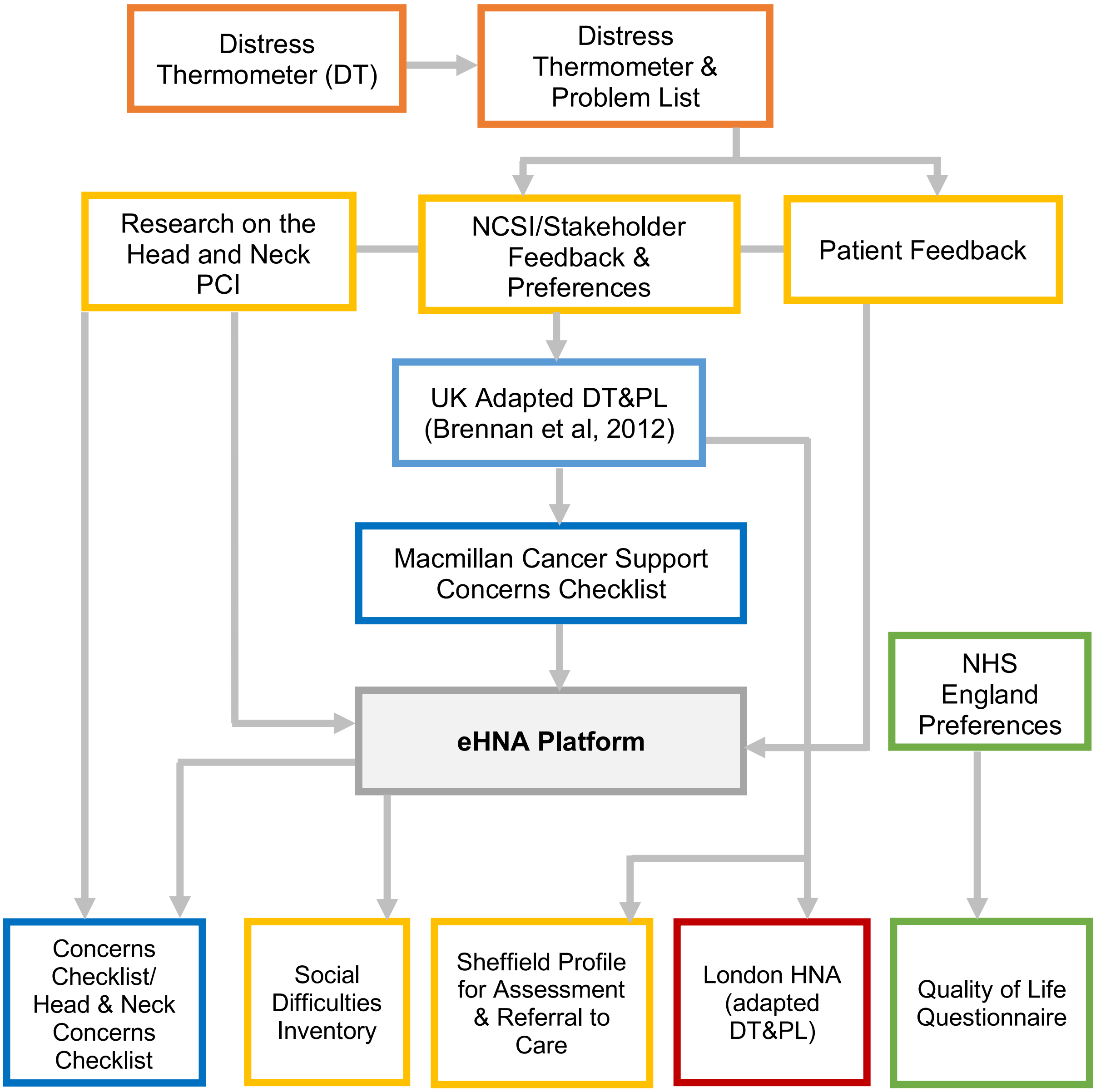
As of July 2020, the eHNA platform enabled staff to administer any of the following six HNA tools: Sheffield Profile for Assessment and Referral to Care (SPARC) (Ahmedzai et al., 2005), Quality of Life Questionnaire (QoLQ) (EORTC Quality of Life Group, 1995; EuroQol Research Foundation, 2019), Social Difficulties Inventory (SDI) (Wright et al., 2011), London HNA (O'Donnell et al., 2013), Concerns Checklist (Brennan et al., 2012) and the Head and Neck Concerns Checklist, based up on the work completed around a Head and Neck HNA tool called the 'Patients Concerns Inventory' (Macmillan Cancer Support/NCSI Professional, 2019; Rogers et al., 2009). Further context surrounding the development and content of these tools is provided in Appendix A. However, minimal information exists to explain why the above HNA tools were chosen for inclusion in the eHNA platform, and others were excluded. Moreover, much of what is known about this platform was derived from a telephone interview with a senior Macmillan Cancer Support employee who had involvement in the eHNA design process, therefore providing only a single perspective (Macmillan Cancer Support/NCSI Professional, 2019). As an overall summary, the Macmillan Cancer Support team envisioned a central HNA tool as the basis of the eHNA, originally proposed as the 'Distress Thermometer and Problem List' (DT&PL) (Roth et al., 1998). However, during the eHNA’s online construction, the DT&PL was deemed too vague for understanding the needs of individuals with cancer (Macmillan Cancer Support/NCSI Professional, 2019), thus leading to the alternate focus on the similar ‘Concerns Checklist’ tool (Macmillan Cancer Support/NCSI Professional, 2019).

As a brief background to these central tools, the DT&PL was originally designed as the Distress Thermometer (DT) (Roth et al., 1998), and was later adapted by the National Comprehensive Cancer Network to add the Problem List (PL) (O'Donnell et al., 2013). Subsequently, the PL was refined and largely became the basis for Macmillan Cancer Support’s Concerns Checklist, alongside stakeholder feedback and patient involvement (Brennan et al., 2012). The Concerns Checklist provides a more detailed version of the DT&PL, containing 56 items as opposed to 40. Furthermore, both tools require concerns identified to be rated out of ten for severity. In order to achieve this, the DT&PL provides a 0-10 scale, rated from no distress to extreme distress. Alternatively, the Concerns Checklist simply requests users to score the concern between 0-10, omitting the term ‘distress’.

Considering the various tools within the eHNA platform, data from Macmillan Cancer Support showed that the Concerns Checklist is the most commonly performed assessment, accounting for 77% of 30,065 assessments undertaken across the UK in an eight-month period (eHNA Support Officer, 2018). Of the other tools included in the eHNA platform, the London HNA (an adaptation of the DT&PL) covered a further 22% of the total assessments, and SPARC, QoLQ and SDI collectively represented <1% of the overall HNAs completed during that period (eHNA Support Officer, 2018). Macmillan Cancer Support’s data did not record rationale for the choice of HNA type, and it is therefore unclear as to why these variations exist.

The predominant use of the Concerns Checklist by users of the eHNA platform informed the decision for the thesis to focus on this tool. As the Concerns Checklist was developed from other HNA tools and stakeholder feedback, the focus on this assessment may also enable a broader understanding of the impact of HNA tools more generally. Figure 1 provides a visual representation of the eHNA platform's construction.

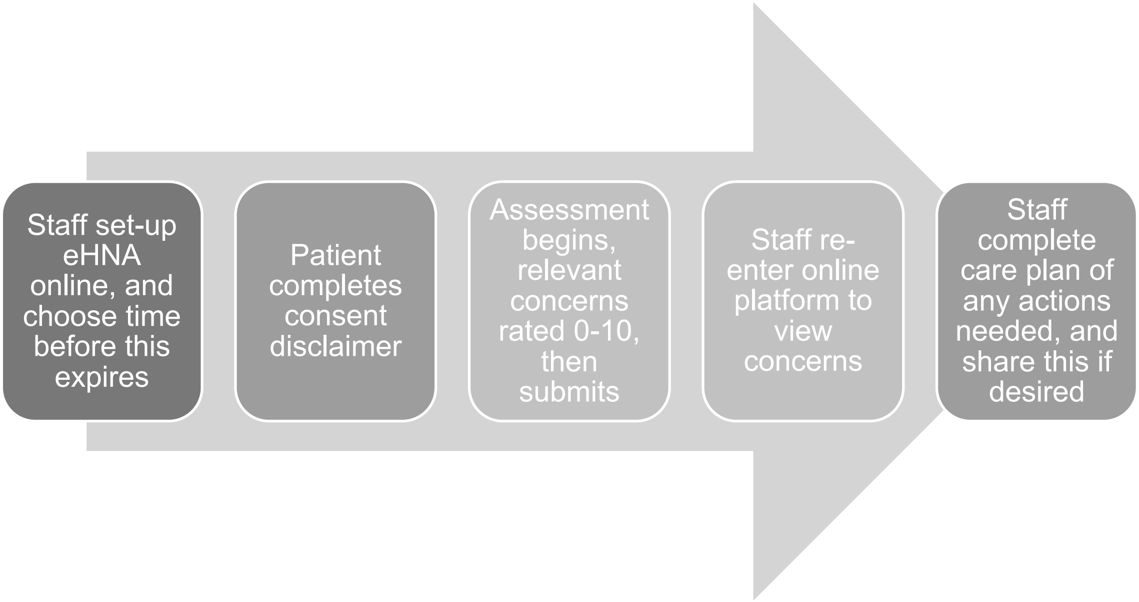
Figure 1. Development of the eHNA Platform



1.5.2 Technological Platform: eHNA Use

As a final introduction to the HNA, this section considers how the assessments function within the eHNA platform. Broadly, variations exist between NHS Trusts in the approaches to HNA delivery. Therefore, Figure 2 provides a basic example of how the Concerns Checklist is completed within the eHNA platform. The key milestones within this process are the individual’s receipt of an online assessment, allowing them to highlight their concerns and score these out of ten for severity. Subsequently, these concerns are discussed with a healthcare professional, and a care plan is developed with an action plan to address these (where applicable). A more detailed illustration of this process and the basic structure of the care plan are available in Appendix B and C.

Figure 2. Process of eHNA Completion



Staff set-up eHNA online, and choose time before this expires

Patient completes consent disclaimer

Assessment begins, relevant concerns rated 0-10, then submits

Staff re-enter online platform to view concerns

Staff complete care plan of any actions needed, and share this if desired

Although Figure 2 illustrates key points within the HNA process, many specific details appear to be determined by each organisation. Whilst no evidence provides a national overview of the methods adopted to implement HNAs, the following aspects of delivery may be variable:

- When the HNA is offered within the cancer journey
- How the HNA is offered (verbal introduction, letter, upon request)
- Where this is offered (home assessment, hospital environment)
- Which member of staff completes the care plan
- How actions taken on the care plan are determined
- How scores are interpreted and prioritised
- Whether the care plan is shared with the individual or other staff

Despite these variations, attempts have been made to standardise the HNA process. Consequently, both local and national objectives highlighted milestones for when in the cancer journey HNAs should be offered. Originally, documents recommended HNAs were undertaken "at or near diagnosis, and at the end of treatment" (NCSI, 2013, p63). However, guidance has become less specific in recent years, alternatively recommending HNAs are delivered at "key points" (Independent Cancer Taskforce, 2015) or simply "during the cancer journey" (NHS, 2019, p61). Despite this lack of specificity in national policy, recent local strategies have demonstrated a continued focus on offering HNAs at diagnosis and the end of treatment (Doncaster and Bassetlaw Hospitals NHS Foundation Trust, 2017; University Hospitals of Leicester, 2019; West Midlands Cancer Alliance, 2019).

Regardless of the inevitable differences in HNA delivery, some key concepts are understood and utilised by all users of the eHNA platform, and therefore appear throughout this thesis. These concepts include HNA 'expiry' and scoring 'cut-offs', which are defined below.

1.5.3 Key eHNA Terminology

Firstly, when HNAs are set-up on the eHNA platform, the staff member is required to enter a period for how long the assessment invitation will remain active (maximum of 12 weeks). During this time, the individual receives no automatic prompts to complete their assessment, so reminders only occur if this is part of the organisation's local delivery process. Following expiry of the HNA, this cannot be retrieved and an additional HNA would need setting-up for the individual to access. Moreover, individuals with cancer can also opt to decline their (e)HNA, which is formally recorded on the eHNA system.

Secondly, some organisations utilise 'cut-off' scores when addressing concerns, which employ the tools' 0-10 scoring system to influence actions taken to provide support. For example, scores of above five might be addressed by staff registered with a professional body (such as nurses), and those below five addressed by unregistered staff. As with other decisions, these choices similarly appear to be locally determined within each organisation. The eHNA platform also contains some pre-programmed actions which can be added to care plans, such as 'follow up ongoing with Clinical Nurse Specialist (CNS)', 'discussed concern', 'advice given', 'information given' or 'signposted to a local support service'.

1.6 Chapter Summary

In summary, complex individual needs can result from a breast cancer diagnosis, and HNAs provide a process to ensure these are identified and addressed. Macmillan Cancer Support's online eHNA platform is a widely adopted method of undertaking and storing HNAs. Although this platform incorporates six different HNA tools, the Concerns Checklist is the most widely adopted tool in the UK. However, significant variations in HNA implementation methods exist between organisations, and many specific processes appear to be decided locally. Considering the diversity of individual needs, alongside the range of possibilities for how to implement HNAs, this indicates that variation may also be present in the assessment's benefits to individuals with cancer. Therefore, this thesis explores views of women with breast cancer and staff, to explore how HNAs contribute to the support women receive, and the impact of the HNA implementation and delivery methods.

Figure 3. Chapter One Key Points

Chapter One Summary: Key Points

- This chapter has explored the significance of concerns facing those with breast cancer, presenting the case for support and change, which was nationally recognised.

- The concept of HNA was described, providing background and context to the development of the tool adopted in the current study.

- Variations in HNA delivery were outlined, including a standard delivery process. These processes are explored in more depth within Chapter Two.

Chapter Two: Literature Review

2.1 Introduction

The overarching aim of the thesis is to explore the contribution of holistic needs assessments (HNA) in assessing and supporting the needs of women with breast cancer. Therefore, reviewing the wider literature on this topic was essential, to assess what research has been undertaken that might contribute the study's aims. Furthermore, reviewing the literature enables the adequacy and methodological rigor of this body of research to be assessed, and identifies evidence gaps. Therefore, this chapter presents a scoping review of research considering the benefits, limitations and impact of HNA tools from user perspectives, and displays which HNA tools have been frequently adopted in recent years. Following this, key themes identified through the scoping review are considered in the context of wider literature. Primarily, this chapter sets a foundation for the broader factors involved in the implementation of healthcare innovation, including the introduction of HNAs into settings which may not have been equipped to use them.

Many approaches to reviewing literature exist, traditionally separated into systematic and unsystematic methods (Aveyard, 2014; Ferrari, 2015; Green, 2006). A systematic scoping review adds value when a topic has not been meticulously reviewed, and aims to present a general overview of the subject area (Munn et al., 2018; Peters et al., 2015). This scoping review is structured according to the Joanna Briggs Institute (JBI) guidance for conducting and presenting scoping reviews (Peters et al., 2015). Initially, a background section situates the review, thus providing context for decisions made in the review's design (Peters et al., 2015).

2.2 Situating the Review

As described in Chapter One, HNAs assess needs and consequently support individuals with cancer (Macmillan Cancer Support, 2016a). The long-term support needs of those with cancer were incorporated into national policy, including the National Cancer Survivorship Initiative's (NCSI) work that prompted wider exploration of these issues from 2010 onwards (NCSI, 2013). Therefore, the scoping review focused on published studies from 2010 to the present. Existing research evaluating HNAs has concentrated on tools designed for adults and children with cancer, or those with caring responsibilities. However, the content of children's and carer's tools focus on highly specific issues, such as coping emotionally with a relative whose health is deteriorating (Ewing et al., 2015). Therefore, these tools were excluded from the review, based on the challenges of comparing these HNAs against those targeted at adults with cancer.

Chapter One highlighted that few restrictions exist around the methods used to deliver HNAs in practice (Macmillan Cancer Support, 2019). This flexibility enables HNAs to cover a broad spectrum of individuals with cancer, to be undertaken by any health or social care professional with relevant skills, in any healthcare or home-based setting (Macmillan Cancer Support, 2019). However, the ambiguity in guidelines has led to implementation disparities between different organisations, or between different cancer teams in the same organisation (Macmillan Cancer Support, 2019; Macmillan Cancer Support/NCSI Professional, 2019).

The content of HNA tools also vary in 'domains of need' they encompass (the categories of concerns the questions refer to). Many tools incorporate several domains listed below, which have been identified as key (Fitch, 2008; Young et al., 2012). Furthermore, these domains are included within Macmillan Cancer Support's Concerns Checklist, the tool of focus for this thesis.

- **Physical concerns** - General physical issues, side effects of treatment or those appearing long after treatment.

- **Practical concerns** - Wider aspects of life affected by a cancer diagnosis, for example caring responsibilities or work.

- **Family/Relationship concerns** - Key people in an individual's life, and factors which might become challenging (for example sexual relationships).

- **Emotional concerns** - Psychological elements of a cancer diagnosis and feelings that might surface or worsen, including loneliness or isolation.

- **Lifestyle or information needs** - Areas where an individual might identify changes needed, such as improvements in exercise or smoking cessation.

- **Spiritual concerns** – Either religious needs or change of perceptions, for example loss of meaning of life.

- **Informational needs** - Knowledge gaps identified, for example understanding of symptoms, procedures and treatment.

Many HNA tools do not encompass all domains outlined above, and users report varied opinions of which areas are most significant

(Macmillan Cancer Support, 2016a). Many versions of the HNA include a total of four of these domains (Fitch, 2008; Young et al., 2012). Therefore, this scoping review focuses on tools encompassing any four (or more) of the above domains.

Finally, variations in the appearance of the HNA acronym appear throughout this review. Therefore, the headings ‘HNA’, ‘eHNA’ and ‘(e)HNA’ have been described and defined as they appear in the context of this thesis (Figure 4).

Figure 4. HNA Acronym Definitions

Acronym	**Definition**
HNA	Holistic needs assessment (any tool assessing holistic needs in those with cancer, the term most commonly used within this scoping review).
eHNA	Electronic holistic needs assessment (Macmillan Cancer Support’s online platform for HNAs).
(e)HNA	Representing Macmillan’s Concerns Checklist as a whole, either on paper or via the eHNA platform, which is used throughout the thesis. This includes in the context of the research study undertaken, particularly where information is not present as to whether the assessment occurred online or on paper.

2.2.1 Existing Reviews

This scoping review considered the range of literature available on HNAs, yet several reviews already exist relating to specific components of this evidence base. For example, one systematic review described the implementation and impact of HNA tools, and acknowledged an absence of patient perspectives on HNA outcomes (Johnston et al., 2019). This review identified studies which focused on quantifiable outcomes of HNAs (such as frequency of concerns raised), and also restricted search results to six HNA tools (Johnston et al., 2019). Moreover, Johnston et al's (2019) findings highlighted the crucial role of the staff in HNAs, due to the importance of delivery methods in successful implementation. A further systematic review on brain cancer HNA tools identified four in use, but none that performed strongly in terms of their psychometric properties, including; reliability, validity and interpretability (Afseth et al., 2018). These reviews emphasised a requirement to focus the scoping review on less specific HNA tools (those which cover every type of cancer), and to consider associations between HNA delivery processes and their perceived success (Afseth et al., 2018). Therefore, the current scoping review concentrates on both individuals with cancer and staff perspectives, and includes tools adopted worldwide for any cancer type.

2.3 Review Methodology

2.3.1 Review Questions

The scoping review had multiple aims and questions to provide a foundation for the study. The broad questions adopted in scoping reviews allow exploration of the topic as a whole (Peterson et al., 2016), which enabled studies to be identified despite the limited evidence base that exists around HNAs. Overall, this thesis seeks to understand the HNA's contribution in assessing and supporting needs, alongside barriers or facilitators to its implementation. With this in mind, three scoping review questions were chosen, and the rationale for this choice is explained below.

1. Which HNA tools have been in use since 2010, and how much literature exists on each?

2. Are the ‘domains of need’ represented in Macmillan Cancer Support’s (e)HNA reflective of the domains in other HNA tools?

3. What perceptions exist around benefits, limitations and impact of HNA tools, from the perspectives of staff or individuals with cancer?

The initial question provides an avenue to understand how widely Macmillan Cancer Support’s (e)HNA (and other tools utilised in its design) have been researched, due to this being the tool of focus for this thesis. Secondly, question two considers whether the domains of need in Macmillan Cancer Support’s (e)HNA appeared evidence-based. This was assessed through examination of domains present in other tools, which may be absent in the (e)HNA. However, question three was the primary focus for the review, considering the perceptions of HNAs from individual with cancer and staff who deliver them. Collectively, these questions generated an overview of HNA literature, through identifying evidence gaps, implementation variations and users’ experiences, thus creating a foundation for this thesis by refining the focus for the research.

2.3.2 Inclusion and Exclusion Criteria

When considering inclusion criteria for a review, JBI recommend creation of a PICo chart (population, phenomena of interest, context) (JBI, 2020). Broadly, the inclusion criteria for this scoping review were research undertaken from 2010-present (as discussed in Section 2.2), the population sample of healthcare professionals and individuals with cancer, the phenomenon of interest as adult HNA tools, and the context as healthcare or home-based settings. More detailed criteria are presented in Appendix D.

2.3.3 Search Strategy

The search for eligible articles was undertaken in October 2020 using the databases Cumulative Index to Nursing and Allied Health Literature (CINAHL), Medline (OVID), PsycINFO and ProQuest. These databases are frequently used to identify healthcare literature, and ProQuest allowed the addition of grey literature (research which is unpublished or published in non-commercial formats) (Adams et al., 2016). The search terms selected were extremely broad in line with the review questions, and were refined based on some terms identifying irrelevant or no results.

The main excluded search terms were 'HNA' (keyword) and 'eHNA' (keyword), which generated irrelevant results (for example, 'eHNA' is the name of a chemical compound and produced literature on this topic). Furthermore, combining these terms with 'cancer' or other Medical Subject Headings (MeSH) yielded no search results. The terms 'Distress Thermometer' and 'Concerns Checklist' were chosen due to these tools being the primary basis for the eHNA platform's design, and the Concerns Checklist being the most frequently adopted tool. The only limit placed on the searches was the date range. Articles focused on children's HNA tools were excluded by hand, as were those targeted solely at relatives/carers of individuals with cancer. Final search teams utilised were:

Needs Assessment (MeSH Heading) AND Cancer (MeSH Heading)

Holistic Needs Assessment (Keyword)

Distress Thermometer (Keyword)

Concerns Checklist (Keyword)

Needs Assessment Tools (Keyword)

The search strategy incorporated two stages, in light of the review questions. The initial search produced 123 articles that met the inclusion criteria. However, many of the studies only answered the initial two review questions (information about which tools were in use, and which domains of need they covered), but did not highlight information regarding user opinions of the HNA's benefits, limitations or impact. Alternatively, most studies focused on aims such as the feasibility or psychometric properties of HNA tools in detecting patient distress, patterns of HNA concerns raised by study participants, or a comparison between tools in their ability to identify distress. Therefore, the third review question was answered by reducing the 123 articles to 27, to include studies that incorporated user opinions (even if this was a minor component of the study). Appendix E provides a Preferred Reporting Items for Systematic Reviews and Meta-Analyses diagram (PRISMA) (Moher et al., 2009), to demonstrate the process undertaken in both stages of the search strategy.

2.4 Findings

2.4.1 Range of Evidence

The scoping review provided an overview of 36 HNA tools in recent use, including the types of tools, how frequently these appeared in the literature, and domains of need they incorporated (Appendix F).

Overall, the Distress Thermometer and Problem List (DT&PL) was the most common tool used in research, with n=56 (42%) of studies incorporating this. The DT&PL has also been translated and validated in a significant number of countries. The Supportive Care Needs Survey (SCNS) was the second most common at n=15 (11%). Only two studies considered the Concerns Checklist, or the eHNA itself. Overall, the majority of studies were conducted in the United Kingdom (22.3%, n=27), Australia (18.2%, n=22) and the USA (12.4%, n=15).

Furthermore, of the 36 HNA tools identified, the domains of need covered within these were comparable. The majority of tools included questions about psychological concerns (n=33, 92%), family or social considerations (n=31 (86%), physical concerns (n=30, 83%), quality of care or communication received during their experience of care n=22 (61%), and practical considerations such as financial issues (n=21, 58%). Other domains covered within the tools comprised of; information needs, spiritual needs, quality of life, cultural issues and others (more details are available in Appendix F). The domains of need covered in Macmillan Cancer Support's (e)HNA are physical, practical, emotional, relationship, lifestyle, spiritual, and information needs. This demonstrates that the (e)HNA includes the majority of key domains which exist in other HNA tools, with the exception of quality or experiences of care.

2.4.2 User Experiences of the HNA

The final review question aimed to understand users' perceptions of the benefits, limitations and impact of HNA tools. As previously described, the 123 articles were reduced to 27 for inclusion in this detailed discussion, because they included content about perceptions of HNAs. The focus of each study is outlined in Table 1, which is laid out to highlight key information in line with JBI recommendations (Peters et al. 2015). The full name and explanation of each HNA tool included in Table 1 is available in Appendix F.

As an overall impression of the included studies, most incorporate only staff perceptions of the HNA's value, rather than those of individuals with cancer. Moreover, the findings typically highlight barriers and limitations of HNAs, with only small sections suggesting notable benefits. Although the scoping review identified many validated HNA tools, users' opinions of these depicted a somewhat different image of their value and contribution to supporting needs. Therefore, the studies trialling HNAs indicated their feasibility in principle, but staff opinions highlighted implementation challenges.

Findings on user perspectives are presented based on three key stages of the HNA process: set up, day-to-day activity, and outcomes. Each heading is structured around barriers of the HNA, as most literature reflected challenges, as opposed to benefits of the tools. However, the small amount of available evidence suggesting the benefits of HNAs is also included within this discussion of findings. The main headings are:

- Barriers influencing initial HNA set-up
- Barriers influencing day-to-day HNA delivery
- Barriers influencing HNA outcomes

Table 1. Studies included in the HNA Scoping Review

	Author	Year	Methodology	Aims/Objectives	Sample Size	Country	Cancer Type	HNA Type	Key Findings
1	Biddle, et al.	2016	Interviews	To understand how HNA tools are experienced by patients and improve future use.	15 patients 7 healthcare professionals	UK	Various	DT&PL	• Perceived benefits include identification of concerns and opportunity to discuss/address these. • Patients withhold concerns due to perceptions of staff being unable to address these and their lack of time.
2	Briggs, et al.	2019	Interviews	To understand experiences of having breast cancer. To understand experiences of completing HNAs.	15 patients	UK	Breast	eHNA	• Patients withhold concerns due to pressure on staff, or fear of repercussions. • Perceived value of HNAs was sometimes low and many did not understand its purpose.
3	Clarke, et al.	2019	Interviews	To identify perceived barriers/ enablers to implementation of sHNA.	16 Patients, 4 Staff	UK	Prostate	sHNA	• Both staff and patients saw benefits to HNAs. • Staff felt this increased their confidence in caring, but lack of training was available

									• Age, visual impairment, IT competency and desire to make decisions were barriers.
4	Gamlen & Arber.	2013	Ethnography (observations and Interviews)	To explore how staff carry out community HNAs and their perceptions of these.	6 patients (observations only) 6 healthcare professional	UK	Various	SCC	• Staff felt HNAs prompted discussions around psychosocial concerns. • HNAs perceived as a barrier to relationship building at first meeting.
5	Garvey, et al.	2012	Interviews	To adapt and evaluate an HNA tool.	29 Patients	Australia	Various	SCNS-SF34	• Patient concerns that wording would cause negative feelings, such as 'cancer'. • Some concerns were not considered culturally applicable by patients ('thinking/uncertainty about future').
6	Garvey, et al.	2016	Surveys and Interviews	To evaluate the implementation of an HNA tool.	10 Healthcare Professionals 36 Patients	Australia	Various	SCNAT-IP	• Patients found the tool helpful and acceptable. • Most staff found it acceptable and useful in care.
7	Hatta, et al.	2014	Surveys	To consider effectiveness of HNAs for	72 Patients 17 Healthcare Professionals	Malaysia	Oral	PCI	• All surgeons referred to HNA prior to consultations which helped conversations but

				assessing concerns.					prolonged this, they recommended future use. • Half of receptionists felt it was unsuitable at registration (prolonged this).
8	Hughes, et al.	2011	Surveys (including open-ended)	To understand acceptability of telephone HNAs.	18 healthcare professionals (Total in study) 7 (Completed Questionnaire)	Australia	Various	DT&PL	• Benefits of HNAs were having objectives, structured approach to screening/ referral to services. • HNAs were sometimes inappropriate due to extreme distress, or staff training gaps.
9	Ipsos Mori.	2015	Process and impact evaluation- various methods (surveys, interviews)	To examine HNA processes, impact and cost/benefits analysis.	Pre: 127 healthcare professionals, 482 patients. Post: 180 healthcare professionals, 250 patients	UK	Various	eHNA	• Staff reported barriers included lack of time/staff, Wi-Fi issues, lack of management buy-in or targets • Staff enablers related to willingness to change, previous use of paper HNAs and clinic restructuring.
10	Kotronoulas, et al.	2017	Feasibility Trial	To assess feasibility, acceptability and	18 Patients	UK	Skin	DT SCNS-SF34	• Patients found HNAs easy to use, and helped to prioritise needs.

				perceived value of HNAs.					- Staff viewed as structured and useful for tailoring support.
11	Lambert, et al.	2018	Observations	To understand HNA implementation processes, potential to identify concerns and impact on consultation length	20 patients	Australia	Various	PC-NAT	- Administration methods were sub-optimal (no explanation of purpose, jargon, not integrated into consultation). - Doctors mainly focused on physical concerns with minimal responses to emotional. - No increase in consultation time.
12	Lo, et al.	2016	Surveys	Before and after review of supportive service referrals from HNAs, and staff opinions.	27 healthcare professionals	USA	Various	Modified DT	- Patient language, literacy skills and time were key implementation barriers. - Many staff felt DT was helpful in deciding where to refer. Many felt patient interview would be more effective.
13	Lynch, et al.	2010	Audit	To investigate patient compliance to HNA and the impact on psychology referral rates.	34 Patient Records	UK	Various	DT	- HNAs opened up discussions about psychological status, and provided communication to other professionals.

									- Did not lead to increased referrals for psychological support.
14	Mitchell. (Poster abstract only)	2017	Interviews	To identify staff perceptions of introducing HNAs.	8 healthcare professionals	UK	Various	Not specified	- Staff raised concerns around when/where to do HNA, where to refer, time constraints, confidence to address concerns, but some value in HNAs noted. - Positive attitudes, forum to share experiences were important enablers
15	Mitchell, et al.	2012	Surveys	To examine staff perceptions of benefits to HNA screening.	50 Healthcare Professionals	USA	Various	DT ET	- Half of staff found HNAs useful, which sometimes changed their clinical opinion, supported communication and improved detection of psychological issues. - HNAs were impractical for routine use (nursing view).
16	O'Donnell, et al.	2013	Interviews	To evaluate effectiveness of introducing HNAs.	16 Patients 10 Healthcare Professionals	Ireland	Various	DT	- All staff and patients saw the value of HNAs highlighting psychological concerns, and to process their concerns.
17	Oktay, et al.	2012	Focus Groups	To explore social worker	15 healthcare professionals	USA	Various	DT&PL	- Decision-making around when, where and how to

				experiences of HNAs.					measure distress, and how to refer to services was challenging. • Concerns about being overwhelmed with referrals.
18	Rogers & Lowe.	2014	Tool pilot and Interviews	To evaluate use of HNAs.	81 Patients (used tool), 6 interviewed 9 Healthcare Professionals	UK	Head & Neck	PCI	• Patients found easy to use, did not negatively affect quality of consultation, supported communication, and most wanted to continue using HNAs. • Small proportion of patients felt they may lead to unmet expectations. • Most staff felt beneficial but some practical, administrative and educational issues.
19	Rooney, et al.	2014	Surveys	To development and evaluate new HNA tool.	53 Patients 21 Healthcare Professionals	UK	Neurological	Brain PCI	• New HNA captured additional issues not present on generic HNA tools. • Patients and staff found this useful.
20	Sterba, et al.	2017	Interviews	To identify key end of treatment issues in patients,	17 Patients 14 Caregivers	USA	Head and Neck	SNAP	• Positive patient perceptions of HNA, easy to use (including electronic).

				develop HNA and evaluate feasibility.	14 healthcare professionals				• Co-ordinating HNAs with pre-planned visits was essential for time constraints. • Patients and staff preferred to complete later in cancer pathway.
21	Snowden, et al.	2012	Interviews	To analyse patient experience of the assessment process.	16 Patients	UK	Various	DT	• First impressions of HNAs were important for attitudes and actions. • Engagement determined by perceived relevance. • Different experiences of actions (and whether they were taken up) determined positive or negative experience.
22	Taylor, et al.	2012	Document Analysis	To provide an overview of how a service implemented HNA and patient views.	18 Patient Records	UK	Colorectal	London HNA	• Additional concerns identified by staff which were not raised on HNAs. • In some cases referrals were offered but declined.
23	Thayssen, et al.	2017	Interviews	To understand GP use and introduction of HNAs.	11 Healthcare Professionals	Denmark	Various	DT IT	• Use of HNAs provided supportive structure to consultation, prompted

									raising issues which may not have been mentioned. • Some found constraining, detracting from patient focus and limiting usual practice.
24	Thewes, et al.	2016	Interviews	To assess patient and staff attitudes towards acceptability of HNA.	10 healthcare professionals 34 patients	Australia	Various	SCNAT-IP	• Patients felt HNA easy to understand and they felt listened to. • Staff felt it was comprehensive and systematic, opportunities for early intervention, improved team communication, triggered referrals. • Staff barriers: time, response format, language barriers but did not outweigh benefits.
25	Van der Meulen, et al.	2018	RCT	To investigate the feasibility of using an HNA tool.	110 Patients	Netherlands	Head & Neck	DT&PL	• Patients satisfied with care, attention paid to all domains of their concerns and duration of the conversation. • No effects on patient outcomes seen whether HNA used or not.

26	Wells, et al.	2015	Surveys	To understand staff views of follow-up and survivorship care, alongside HNAs.	74 Healthcare Professionals	UK	Head & Neck	PCI, DT&PL, Concerns Checklist, SPARC, Pepsi-Cola	• Gaps and variation were found in how support and HNAs were provided. • Staff lacked confidence, skills and knowledge in some cases, and reported barriers to survivorship care or HNAs through lack of time, privacy, services to refer to or lack of patient desire for this input.
27	Williamson, et al.	2020	Interviews	To explore views of staff about barriers/ facilitators in implementing the Recovery Package.	19 Staff	UK	No specific	No specific	• Staff felt Recovery Package implementation was unsustainable, but HNA could be implemented better with financial support. • Lack of clarity about best HNA timing and who would do this if care was spread across multiple organisations.

2.4.2.1 Barriers Influencing Initial HNA Set-up

The scoping review highlighted key themes that influenced the original set-up of HNAs in an organisation. Senior management support was identified as essential for the assessment's successful introduction, acting as a catalyst to influence buy-in at an early stage (Ipsos Mori, 2015). The need for support similarly extended to peers, where being able to share experiences proved invaluable for the HNA's implementation (Mitchell, 2017). Collectively, the findings above (seeking management oversight and communal support from colleagues) may indicate confidence issues among staff, which require support for the HNA's successful implementation. Furthermore, these confidence concerns may partially explain staff resistance to the deployment of HNAs, alongside their views that the tool was unsustainable (Williamson et al., 2020).

A further barrier to implementation related to the timing chosen to administer HNAs. National recommendations have historically suggested HNAs should be undertaken at the point of diagnosis (NCSI, 2013). However, staff often viewed this timing as unsuitable, and recommended alternatives ranging from one to six months post-diagnosis (Ipsos Mori, 2015; Kotronoulas et al., 2017; Sterba et al., 2017; Thewes et al., 2016). Despite their views, many staff continued to undertake HNAs at diagnosis (Ipsos Mori, 2015; Wells et al., 2015). Moreover, decisions are also made regarding how often HNAs should be repeated, because stand-alone assessments may fail to represent a true reflection of the individual's feelings (Oktay et al., 2012; Thewes et al., 2016). Decisions around timing and frequency of delivery have been reported as especially challenging when care is shared between multiple organisations (Williamson et al., 2020).

2.4.2.2 Barriers Influencing Day-to-Day HNA Delivery

When considering day-to-day use of the HNA, barriers identified predominantly related to high workload pressures on staff, and challenges with progressing to a digital format of the HNA from a paper-based approach.

The absence of sufficient time to deliver HNAs was a commonly raised issue within the scoping review literature (Biddle et al., 2016; Ipsos Mori, 2015; Lo et al., 2016; Mitchell, 2017; Sterba et al., 2017). Biddle et al's (2016) study reported qualitative experiences from staff and patients involved in a larger randomised controlled trial (RCT), which considered the cost-effectiveness of HNAs in reducing distress. Biddle et al's (2016) study showed that insufficient time negatively affected HNA implementation, due to the inability to explore concerns. Therefore, protected time is considered important for HNA delivery, and Ipsos Mori (2015) suggested the value of altering working practices to accommodate workload (Ipsos Mori, 2015). Of the two studies referred to above, Biddle et al.'s (2016) study collected the qualitative experiences of only a small number of patients, yet Ipsos Mori's (2015) findings supported these views with a wider range of participants. The HNA may also contribute to staffs' workload pressures due to its length. However, different studies highlighted staff experiences of both time pressures and time savings from HNA use (Biddle et al., 2016; Ipsos Mori, 2015; Thewes et al., 2016; Hatta et al. 2014). Although, the HNA tool adopted in Thewes et al's (2016) study contained 27 items, versus 40 on the DT&PL (Biddle et al., 2016) and 56 within the (e)HNA (Ipsos Mori, 2015) which may have contributed to the varied length of time to complete these found by staff.

An additional barrier to HNA use involved the format of delivery, whether this was online or paper-based. Electronic methods presented issues of poor Wi-Fi functionality and barriers due to staff’s own lack of confidence with technology (Clarke et al., 2019; Ipsos Mori, 2015; Wells et al., 2015). However, explanations for low confidence were twofold, with physical use of electronic devices being one, and the other relating to general lack of confidence in undertaking HNAs. This was demonstrated through staff’s greater confidence in implementing electronic HNAs if a paper version was embedded prior to this (Ipsos Mori, 2015). From the perspective of individuals with cancer, HNAs were frequently set up for completion in their own homes, due to challenges in obtaining private space to undertake them in hospital (Biddle et al., 2016; Ipsos Mori, 2015). Nevertheless, some individuals felt that home-based, online HNAs were unfeasible (Ipsos Mori, 2015), and preferred paper-based assessments (Rogers et al., 2018). These views were not echoed among all individuals with cancer, as some regarded online methods as simpler or more useful in meeting their needs (Ipsos Mori, 2015; Sterba et al., 2017; Thewes et al., 2016). However, the majority of interviewees indicating preferences for online assessments in Ipsos Mori’s (2015) study were young participants who had successfully completed an eHNA, so this finding may not be generalisable across all age groups.

Within the scoping review, one staff member also suggested that HNAs disrupted the flow of conversation, and they therefore preferred to assess needs without one (Gamlen & Arber, 2013). Furthermore, some general practitioners (GP) felt that HNAs tended to encourage a ‘task-orientated’ approach among staff (Thayssen et al., 2017). The concept of task-orientation refers to a focus on the completion of tasks as a measure of success (Collins Dictionary, 2021). Thayssen et al’s (2017) study utilised data triangulation methods through inclusion of interview and observation data, allowing greater confidence in the study conclusions (Thurmond, 2001). However, several other studies indicated that HNAs facilitated communication by providing opportunities for patients to be listened to (Lynch et al., 2010), enabled identification of issues which may have been missed (Mitchell, 2017; Rooney et al., 2014; Taylor et al., 2012) and supported them to self-manage (Ipsos Mori, 2015).

2.4.2.3 Barriers Influencing HNA Outcomes

As a final theme, barriers also had an impact on the outcomes of HNAs. Primarily, these were either actions resulting from the assessment, or where the HNA's outcome was affected by a specific factor, (for example an individuals' reluctance to disclose their concerns).

Beginning with the actions which resulted from HNAs, staff reported lower confidence when the services they required for patients were absent, or where they feared overrunning them with referrals (Oktay et al., 2012). Moreover, this absence of services could lead to concerns left unaddressed and subsequent feelings of disappointment (Rogers & Lowe, 2014). Despite these issues, HNA use was found to result in increased numbers and uptake of referrals to external services (Lo et al., 2016).

Variations were also reported in how staff reacted to concerns based on their professional role. For example, nursing staff have declared reduced confidence when addressing psychological or social concerns (Biddle et al., 2016; Mitchell, 2017). Furthermore, nursing staff completed more onward referrals for supportive care than psychologists, although this may be due to the types of concerns raised within this study (for example, if these were practical rather than psychological concerns) (Musiello et al., 2017). The differences in actions by staff may also indicate varied knowledge levels, including knowledge of when and where to refer individuals for support. Moreover, individuals with cancer have detected gaps in staff's ability to provide support, and have reported not disclosing their concerns because they deemed them irrelevant to the professional undertaking their assessment in some cases (Biddle et al., 2016).

Patients’ non-disclosure of concerns on HNAs emerged as a theme within the scoping review. Firstly, some patients felt that staff would be unable to address their concerns. For example, concerns were not always disclosed on HNAs conducted by social workers and nurses, based on the patient’s fear of a particular outcome, such as hospital readmission or increased social services intervention (Briggs et al., 2019; O'Donnell et al., 2013). Secondly, individuals with cancer suggested that disclosing emotional concerns wasted staff time, especially when they felt able to cope independently (Biddle et al., 2016; Briggs et al., 2019; Taylor et al., 2012). Factors such as HNA timing also influenced disclosure of concerns, through affecting the development of the relationship between staff and patients, or forcing the individual to open up before they were ready to (Biddle et al., 2016; Gamlen & Arber, 2013; Hughes et al., 2011). Lastly, a further barrier to openness can originate from misunderstanding the HNA’s purpose (Briggs et al., 2019; Snowden et al., 2012). These misunderstandings could include lack of confidence in using the HNA’s scoring system (Hughes et al., 2011), and incorrect assumptions about what to expect as a result of the assessment, due to lack of explanation (Snowden et al., 2012).

Despite the above barriers to use of HNAs and disclosure of concerns, several included studies reported positive views of the assessment from the perspective of individuals with cancer (Garvey et al., 2012; Ipsos Mori, 2015; Kotronoulas et al., 2017; van der Meulen et al., 2018; Garvey et al., 2016). However, most of these opinions were displayed in Ipsos Mori’s (2015) evaluation, with other studies only providing brief comments regarding patients’ views. Despite this, reasons for these positive opinions towards the HNA included their value in helping individuals remember to raise concerns within a consultation (Kotronoulas et al., 2017) and enabling them to feel more supported (Ipsos Mori, 2015).

2.4.3 Quality of the Evidence

The 27 studies included in the above discussion had varying aims, but primarily intended to explore participants’ experiences of HNAs, or the feasibility of implementing a new HNA tool in various settings. The studies were also quality appraised wherever possible, which enables the reader to judge the reliability of the research, alongside its value within the context it was conducted (Morrison, 2017). The specific critical appraisal tools adopted (from the Critical Appraisal Skills Programme, (CASP), 2018a, 2018b; Centre for Evidence-based Management (CEBM), 2014; and Pluye, Robert et al., 2011) were chosen due to being widely recommended for use (National Collaborating Centre for Methods and Tools, 2020; Royal College of Nursing, 2020; University of South Australia, 2018). Moreover, use of critical appraisal tools allow methodological rigour and high-quality reporting to be assessed against structured criteria (University of South Australia, 2018). Of the 27 scoping review articles discussed, 13 were critically appraised from a qualitative perspective (CASP, 2018a), which highlighted issues in methodological approaches. These included small samples of participants, brief interviews preventing depth of understanding, analysis undertaken by a single researcher (risking bias in interpretation), and underreporting of the qualitative methods and findings (for example, stating interviews were the primary data collection method but results provided only a brief section on qualitative findings). Moreover, one study adopted a focus group method, which can lead discussions to be dominated by opinionated individuals, or views concealed in the presence of colleagues (Leung & Savithiri, 2009). When reporting the research, many of these studies did not explore ethical issues, or the influence of the researcher on data collection and interpretation. Further information regarding the individual critical appraisal of each study is provided in Appendix G.

For the seven survey studies included in the review, their appraisal displayed similar methodological challenges (CEBM, 2014). These studies were included in the scoping review because part of each study included questions regarding users' perspectives of HNAs. However, in many cases, these viewpoints were only a minor aspect of the research, with the primary measure focusing on concerns elicited by the HNA tool. Therefore, the survey questions used to gauge the opinions of users were often unclear. Furthermore, the single study appraised using the randomised controlled trial (RCT) tool (CASP, 2018b) aimed to assess the feasibility of HNAs and their effect on patient outcomes, but reported not attaining the required sample size to achieve statistical power. Therefore, it was difficult to assess if the sample size was adequate, and these calculations are essential in identifying any false-positive results which might emerge from data gathered (Biau et al., 2008). Lastly the mixed-methods critical appraisal tool (Pluye et al., 2011) enabled assessment of one feasibility study, which contained a very small number of participants, thus making it challenging to transfer these results to other populations.

The final five studies were not appraised using a structured tool, because they were service evaluation/audit studies, or conference abstracts only. The service evaluation (Ipsos Mori, 2015) contained the greatest depth regarding perceptions of HNAs, and was conducted during the early stages of HNA implementation. However, this evaluation was commissioned by Macmillan Cancer Support and may therefore be subject to a conflict of interest in outcome reporting. Furthermore, two further studies adopted audit methods, which could not provide explanation regarding why phenomena occurred, such as why increased use of HNAs did not lead to increased service referrals. Additionally, the success of audit methods are dependent on the accuracy and completeness of information documented (Bowen, 2009). Overall, although the scoping review studies had some positive attributes in relation to methodological and reporting quality, the aspects most central to the aims of this scoping review were lacking. Many studies contained small samples or insufficient detail, and user opinions were often a secondary aim of the research and were therefore underreported. This caused challenges in concluding how far the views highlighted were representative of the whole sample, which questions were asked to obtain these responses, and whether these were considered in-depth.

2.4.4 Review Summary and Evidence Gaps

Overall, the scoping review highlighted a clear theme around perceptions of HNAs, which concentrated on the barriers to their use. The evidence indicated that challenges exist throughout each component of the implementation process (set-up, delivery and outcomes). Furthermore, some practical considerations were not captured during the development and piloting of HNA tools, for example in-depth motives as to why individuals may be reluctant to disclose concerns, and practical decisions around timing/location that can influence the assessment’s value. Staff appeared to have low confidence in using HNAs in some cases, due to technological abilities, expertise, and belief in the delivery methods adopted. Therefore, HNA implementation appears to require skill and consideration of complex factors to be successful, which was not explored in the scoping review studies. The review highlighted a need for further understanding of these complex factors, and the impact these may have on individual experiences of the HNA. Participant perceptions of HNAs (such as their value and how well they work) were not widely represented within the literature, particularly from the perspective of those with cancer.

The few studies that considered the impact of HNA tools primarily measured this by quantifying referrals made to supportive services, and did not consider how meaningful the outcomes were to participants. Furthermore, many studies in the review focused on feedback about the HNA in its early stages of implementation or during development, as opposed to barriers that persisted or improved over time.

In conclusion, whilst HNAs evidently provide value in assessing the concerns of individuals with cancer, it is possible that methods used to evaluate the HNAs differed from those adopted when routinising this (for example, some research provided temporary, increased resource to support a pilot of the tool). Additionally, many studies considered the effectiveness of HNAs in terms of quantifiable outcome measures (for example referral to specific services, number of concerns elicited), which limits conclusions regarding how valuable users felt these outcomes were. The few studies exploring staff views of HNAs highlighted that many of the challenges to embedding the assessments had not been overcome. The studies included in the review therefore highlighted significant gaps in understanding about the contribution of HNA tools to support those with cancer.

2.5 Discussion

Following the detailed discussion of scoping review studies, this section provides an overview of wider literature related to the above themes. These concepts include the implementation of innovation, use of technology in healthcare, influences on patients’ reporting of HNA concerns, self-management and the relevance of a commonly used social action theory to the key findings of the review- Normalisation Process Theory (NPT).

2.5.1 Normalisation Process Theory

The scoping review highlighted many considerations that influenced the delivery of HNAs, such as the mode of assessment, the timing of delivery, and the role of the member of staff undertaking the HNA. The influence of these factors on the success of the innovation's implementation strongly correspond with NPT, an influential theory in healthcare research (May et al., 2015). NPT focuses on embedding innovations within healthcare settings (McEvoy et al., 2014), and was devised from studies on the intricacies of healthcare systems (May et al., 2015). Within NPT, the framework considers some rationalisation for behaviours, for example, how knowledge is communicated between groups, and the effort required to translate knowledge into practice (McEvoy et al., 2014). Traditionally, NPT is used to help explain factors affecting the implementation of complex interventions, presenting barriers or enablers to these becoming 'business as usual'. NPT consists of four overarching constructs, each containing four sub-components (McEvoy et al., 2014).

Table 2. Core Constructs Framework in NPT

Core Constructs	**Components of Core Construct**			
Coherence	Differentiation	Communal Specification	Individual Specification	Internalisation
Cognitive Participation	Initiation	Enrolment	Legitimation	Activation
Collective Action	Interactional Workability	Relational Integration	Skill set Workability	Contextual Integration
Reflexive Monitoring	Systematisation	Communal Appraisal	Individual Appraisal	Reconfiguration

Each construct is central to representing social actions which occur to implement a new practice (May et al., 2015). Initially, ‘coherence’ focuses on making sense of the intervention, ‘cognitive participation’ considers relational aspects of building team engagement and buy-in, ‘collective action’ around operationalisation of the innovation and ‘reflexive monitoring’ for the intervention’s appraisal and perceived value (May et al., 2015). Collectively, the constructs provide an overview of the actions undertaken around a new practice in order to implement this (May et al., 2015).

Despite extensive use of NPT in practice, one criticism describes the overlap in its constructs, which can cause challenges when applying the theory (Atkins et al., 2011). However, views of NPT overall are largely positive, due to its value as an explanatory framework, and ability to highlight key factors influencing interventions becoming business-as-usual (McEvoy et al., 2014). When broadly considering the scoping review findings in the context of NPT, this highlights further gaps in understanding around the HNA’s implementation. For example, no studies focused on the role of individual staff in the HNA’s application or provided examples of how the staff themselves made sense of the tool and its value (coherence construct). Therefore, NPT is relevant to understanding the HNA’s implementation from a staff perspective, and is used within the current study to aid analysis and understanding of key findings.

Following this, wider research is presented below, relating to the key themes identified in the scoping review, beginning by building on NPT to consider the implementation of innovation more generally.

2.5.2 Implementation and Resistance to Change

The HNA’s implementation raised various challenges evident throughout the scoping review, and manifests in themes relating to staff resistance, lack of confidence and the challenges staff experience in using technology. As discussed in Section 2.5.1, the key constructs of NPT are embedded within the challenges of introducing innovation and enabling these to become business as usual. However, the challenges of implementing new interventions are apparent in wider literature, and are based upon wider resources, staff buy-in (both frontline and management) and economic considerations which are disrupted as a result of introducing a change (Repenning & Sterman, 2001). Therefore, several factors are deemed significant in influencing these well-known challenges to implementation. Firstly, strong leadership is fundamental for success in implementing interventions, including the need for individuals who consistently support use and embedding of the innovation, often known as ‘champions’ (McInnes et al., 2015). Secondly, communicating the intervention’s vision and strategy to stakeholders can reduce challenges with staff engagement towards this (Lorden et al., 2014). Thirdly, staff workload is a key influence on successful integration of innovation in healthcare settings. Consequently, additional time pressures on staff can be detrimental to the quality of care given by the intervention (Waring and Bishop, 2010).

The three issues above are applicable to the scoping review findings, particularly where staff’s workload was found to restrict their time to deliver high-quality HNAs, resulting in staff preferences to conduct their supportive conversations without use of a tool. Moreover, these pressures on staff led to some resistance towards the HNA’s use, yet the reasons for this were not explored in-depth by the studies reviewed. Within wider literature, some broader reasons for resistance to change within healthcare have been explored, and are often multifactorial. For example, resistance can occur due to individual personality traits (such as the desire for control), having no stake in the outcome of using an intervention, previous negative experiences with implementation of interventions and hierarchical management structures affecting staff's independence to influence changes (King & Anderson, 1995; Meston & King, 1996). Considering the above reasons resistance to change may occur, these can also lead to reactions among staff. These reactions include a sense of threat to staff's job roles if the intervention's benefits are not understood (Chihung et al., 2012), 'change fatigue' (continuous changes cause resistance towards the concept of change itself) (McMillan & Perron, 2013), or blaming staff for the resistance (which often falls upon individual staff opposing change) (Brown & Cregan, 2008; Meston & King, 1996; Rogers, 1983). However, an alternative perspective views resistance to change as a positive notion, as staff opposing the change may have in-depth knowledge of their service, and can therefore produce more efficient ideas for improvement (Ford & Ford, 2010).

Resistance to the HNA was noted within entire teams (as opposed to individuals) in some scoping review studies, and senior management support was deemed necessary to enable the HNA's successful implementation. These findings highlight the relevance of what is termed 'organisational culture'. Organisational culture is a phenomenon that is consistently reinforced by interactions within a particular group, alongside overarching leadership influence (Schein, 2004). Within an organisational culture, there are routines, customs and rules, which both restrict and stabilise the behaviours of those within them (Schein, 2004). Additionally, there are three levels of culture, based upon the degree to which behaviours or views can be observed by outsiders (Schein, 2004). The first level is 'artefacts' (aspects which can be seen/heard when observing the culture), followed by 'espoused beliefs and values' (which emerge through the leader's own values, ultimately determining the group's goals) and finally the deepest level of organisational culture, relating to ‘unconscious beliefs and feelings’ (Schein, 1985). Therefore, these considerations may have influenced the dynamics present in the scoping review studies, such as negative views of the HNA that were echoed by entire teams.

Within the scoping review, several studies reported staff’s low confidence in addressing patients’ psychological concerns, and staff evaded discussion of these in some cases. Within wider research, ‘blocking behaviours’ have been identified in staff and patient interactions, such as staff changing the subject during consultations, or avoiding patient cues to discourage discussions about strong emotions (Maguire et al., 1996). These blocking behaviours may be due to staff anxiety and low confidence in having difficult conversations, or their own self-awareness of utilising these behaviours (Maguire et al., 1996; Wilkinson, 1991). In some cases, blocking behaviours led to patient consultations which were deemed superficial, through preventing the possibility of exploring patients’ concerns in-depth (Wilkinson, 1991). Considering the similar blocking behaviours enacted within some scoping review findings (evading discussion of psychological concerns), staff’s declaration of low confidence in addressing these concerns may have contributed to this behaviour.

2.5.3 Technological Innovation

As described in Chapter One, HNAs can be viewed as a form of patient reported outcome measure (PROM), which are self-reported questionnaires collecting information about health outcomes (Valderas & Alonso, 2008). PROMS can also appear in electronic formats, known as ePROMs, such as the electronic HNA (eHNA). Within the scoping review, low uptake of online HNAs was found, although the reasons for this were not explored in the studies.

Overall, various benefits have been attributed to technology use in healthcare, including the ability of ePROMS to enable data comparison (demonstrating progress or changes between multiple assessments), alongside the paperless feature and ease of use (Meirte et al., 2020). However, optimism or uncertainty towards the use of technology in healthcare are common opinions among staff, with optimism being the main driver and determinant of perceived usefulness (Kowitlawakul, 2011; Kuo et al., 2013). Despite the benefits of technology use in healthcare, many factors present challenges in its use, including the quality of Wi-Fi connectivity (Tubaishat, 2018), ease or complexity of webpage logins (Nordan et al., 2018), how well the innovation integrates into an existing service (Chau & Hu, 2002), or perceived self-efficacy and anxiety towards use of computers (Beenkens, 2011). With this in mind, barriers to patients' use of technology may also be due to specific characteristics. For example, individuals of an older age range are generally reported to have less experience and self-assurance in using computers (McCleary et al., 2013; Richter et al., 2008; Wintner et al., 2015). As a further example, certain characteristics have been found to influence completion of PROMS, such as being over 75 years old and having a history of hospital admissions for similar conditions (Schamber et al., 2013). Nevertheless, various methods exist to facilitate the acceptance of technology and promote its use. These methods include; adaptability of the technology to the service (as opposed to requiring service redesign) (Chau & Hu, 2002), and providing clear context (such as purpose and expectations) when introducing ePROMS (Nordan et al., 2018).

2.5.4 Concerns about External Perceptions

Within the scoping review, several studies highlighted patients' adjustments to their behaviour based on how they felt they might be perceived by others. These adjustments often manifested as non-disclosure of concerns in HNAs (for reasons such as patients feeling they would add to staffs' workload, or that disclosure could lead to repercussions in some cases). In the context of broader literature, attempts to avoid repercussions or judgement from others may indicate the desire to be characterised as a 'good patient' (Frosch et al., 2012). This desire to be viewed positively can affect patients' behaviour, such as complying with all recommendations or instructions from healthcare staff (Frosch et al., 2012), feeling obligated to respond to questions in a particular way (Tmobranski, 1994), or feeling that responding negatively to surveys about their experience of care could be detrimental to their future care (Tadic et al., 2012). With this in mind, the scoping review considered 'domains of need' covered by the identified HNA tools, which highlighted 'experiences or quality of care' as the only common domain absent in Macmillan Cancer Support's (e)HNA. However, Tadic et al's (2012) findings (described above) suggest that questions about care experiences can cause concern for some patients. Furthermore, staff communication surrounding patient experience surveys can affect patients' engagement with these, particularly if their purpose is not understood (Black, 2014; Llanwarne et al., 2013). Additionally, care quality questions may also affect patients' perspectives of the HNA's purpose, particularly as the scoping review highlighted some patients' opinions that HNAs to exist for research or data collection purposes (Briggs et al., 2019). Therefore, the addition of care quality questions in HNAs may exacerbate patients' feelings of pressure and alter the questionnaire's focus to one of service improvement, rather than the patient's care and support.

2.5.5 Self-Management

Alongside the reasons for non-disclosure of concerns on HNAs discussed above, patients who felt more confident to self-manage their condition appeared less likely to raise their concerns on the HNA.

However, use of a structured HNA was also seen to encourage the self-management process in other scoping review studies. Although healthcare professionals' practices for encouraging self-management can vary, these can include providing education about the condition, physical and emotional coping strategies, action plans to respond to worsening symptoms and social support (Taylor et al., 2014).

Various benefits of self-management interventions have been noted across several conditions. Examples of these benefits include: facilitating behavioural change in diabetes management (Clark et al., 2004), improved perceptions of self-efficacy following a stroke (Jones et al., 2009), increased focus on goal attainment in cardiac rehabilitation (Scholz et al., 2006), and improved emotional coping in those with breast cancer (Cimprich et al., 2005). However, limitations in self-management interventions have also been noted, both in patients' ability to perform the required tasks and the outcomes of these. For example, a study allowing individuals to assess their own need for hospital appointments identified patients' lack of understanding and confidence in their own assessment skills, or feelings of rejection through being compelled to lead their own follow-up (Mejdahl et al., 2018). Additionally, some self-management methods have been deemed ineffective based on the outcomes they produced, such as no improvement to the individuals' perceived self-efficacy or health-related quality of life (Kennedy et al., 2013).

The above examples demonstrate that the impact of self-management interventions can vary between patients, which may relate to their personal circumstances. Firstly, the impact of self-management may be due to the individual scenario, such as the quality of support delivered by staff (two-way communication, shared decision-making, information provision), which in turn empowers individuals to enact self-management behaviours (Corben & Rosen, 2005). However, personal characteristics and circumstances may also influence patients' ability to enact self-management practices, and their perceived value of these. These include the patient's acceptance of their condition (Naranjo et al., 2014), age and educational background (Kawi, 2014), social support network and faith in the benefits of the self-management practice (Skinner et al., 2000). Furthermore, another personal factor affecting self-management is connected to 'locus of control', which can be internal (beliefs that positive outcomes originate from one's own behaviour) or external (beliefs that positive outcomes are unrelated to one's own actions) (Crisson & Keefe, 1987). In the context of healthcare, locus of control can reflect the individual's view of how much they can influence their own fate, or are reliant on other significant individuals (such as doctors) (Schneider et al., 2006). Moreover, locus of control has been found to affect patients' preferences to delegate decision-making to healthcare professionals, based on their personal characteristics of autonomy and desiring shared decision-making (Schneider et al., 2006). A higher internal locus of control has been associated with greater competency in patients' self-management of their health, shown by their willingness to access support and regularly initiate use of physiotherapy services (Wahl et al., 2018). Although locus of control was not directly discussed in scoping review studies, there were indications that some individuals would be less likely to raise concerns on their HNAs if they felt able to self-manage. This may suggest that the level of internal locus of control was relevant to patients' self-management behaviour, alongside the various other characteristics which can affect this on a personal level.

2.6 Chapter Summary

Overall, the scoping review followed JBI guidance to present evidence in answer to three identified research questions. This included the identification of 36 HNA tools in use over the past ten-years, which broadly covered ‘domains of need’ representative of those present in Macmillan Cancer Support’s (e)HNA. Furthermore, 27 studies were discussed in detail, to present an overview of evidence relating to perceptions of HNAs and their implementation. Many of the claims outlined in the results section were supported by small amounts of data, and provided insufficient depth to understand why particular views were held. A strong thread which emerged from the literature highlighted the complex factors involved in HNA implementation and its subsequent success. Consequently, the review indicated an evidence gap in understanding why particular behaviours occur in relation to HNA implementation, and whether these lead to HNAs which are meaningful to the individuals receiving these. The gaps highlighted in this review provide a foundation to explore the contribution of HNAs to individuals with cancer, alongside barriers to its implementation and use.

Figure 5. Chapter Two Key Points

Chapter Two Summary: Key Points

- The scoping review summarised the existing evidence surrounding the implementation and opinions of HNAs, identifying key themes of barriers in each aspect of the delivery process (set-up, day-to-day use and outcomes).

- The review highlighted evidence gaps for experiences of the HNA from a patient perspective, and depth of understanding about the issues which were found. Quality assessment of the studies also highlighted that data was often from minor, secondary aims of the studies, with small samples and lack of explanation for why opinions were held.

- The scoping review findings were situated in wider literature, including the introduction of NPT as a theory relevant to the identified implementation barriers of HNA delivery.

Chapter Three: Methodology and Methods

3.1 Introduction

This chapter presents an overview of methodological procedures undertaken in the current research study. Within Chapter Two, the scoping review highlighted evidence gaps and complex factors involved in the successful implementation of holistic needs assessments (HNAs), which led to the development of the current study. This study seeks to determine the HNA's contribution to assessing and supporting the holistic needs of women with breast cancer, including a focus on understanding barriers and facilitators to its use, and the value of care plans. A qualitative, multiple case study approach is adopted to achieve these aims. Within this chapter, content is divided into four main sections to consider the significant aspects of the study's development: methodology, study design, methods and ethical considerations.

3.2 Methodology

In this section, the philosophical basis for the thesis is explained, emphasising that the study is influenced by interpretivism and elements of a constructivist view, both of which are defined and justified within this section. Following this, a section on reflexivity is presented (adopting critical reflection techniques when interpreting research findings) (Flick, 2014). This discussion of philosophical approaches and reflexivity illustrates the lens through which the study was developed and approached, to enhance rigour (Given, 2008).

3.2.1 The Positivist and Interpretivist Paradigms

Within research, a study’s philosophical assumptions aim to influence how data is gathered to answer research questions (Creswell, 2011). These assumptions are grounded in ontology (beliefs held about the nature of reality), and epistemology (beliefs about how knowledge is known) (Creswell, 2011). The research questions and approach required to effectively address these therefore dictate the choice of ‘paradigm’ (the analytic lens through which the researcher views the world) (Flick, 2014). Historically, social science disciplines have endorsed a natural sciences approach, generating outcomes such as cause and effect, and measurement via quantitative methods (Flick, 2014). This approach aligns with the positivist paradigm, which suggests that evidence and scientific verification are required to generate understanding (Pham, 2018). Positivism is therefore traditionally associated with quantitative research (Pham, 2018). However, positivism has been contested based on the challenges of controlling variables in human studies, and whether it is appropriate to disregard behavioural information (such as individual attitudes, perceptions and beliefs) (Snape & Spencer, 2005). For example, survey questions may be reliable and congruent with the methodology, yet this does not ensure the reliability of participant’s responses (Fielding & Fielding, 1986).

However, this thesis concentrates on the actions and experiences of individuals, and is therefore influenced by an alternative paradigm known as interpretivism. This paradigm has become increasingly adopted due to the limitations of positivist enquiry (Snape & Spencer, 2005). Interpretivism is grounded in the view that knowledge about social sciences and human participants cannot be obtained through scientific verification, as individual interpretations of the world that influence behaviour and opinions are variable (Hammersley, 2013).

Interpretivist epistemology is based upon the view that multiple realities exist, and knowledge is gained through individual understanding (Garfinkel, 1967). This view is strongly opposed by positivism, which concentrates on society as an external structure, which dictates the actions of individuals (Hollis, 1994).

As such, interpretivism traditionally aligns with qualitative research, which aims to generate understanding through exploring beliefs, motivations and feelings which influence individual behaviour (Berkwits & Inui, 1998). Furthermore, qualitative approaches are suitable if the research question seeks to understand meaning and experiences from the participant’s viewpoint, rather than numerical or factual information (Hammarberg et al., 2016). Qualitative methodology has a number of key strengths, including the ability to elicit rich, detailed information (Lancaster University Management School (LUMS), 2016). Additionally, the in-depth, narrative experiences reported in qualitative research are useful to improve understanding of a phenomenon (Rahman, 2017; Von Wright, 1971). However, criticisms of qualitative research include the inability to generalise findings to broader populations, due to small participant sample sizes used, (which may be entirely different in different participant groups) (LUMS, 2016). Furthermore, although qualitative and quantitative paradigms can be combined, use of solely qualitative methods is appropriate when the subject involves understanding complex phenomena (Ormston et al., 2013). Within the current study, the interpretivist approach is consistent with the aims of producing understanding of individuals’ complex views, behaviour and decision-making. Alongside interpretivism, elements of constructivism were also adopted to influence how the study was approached, as discussed below.

3.2.2 Constructivism

The constructivist approach to research suggests that knowledge is socially constructed by each individual (Guba & Lincoln, 1982). Therefore, constructivists believe that the construction of knowledge is influenced by interactions, leading to a complex array of beliefs and meanings (Berger & Luckmann, 1967). However, despite individuals having unique interpretations, these may correspond with the views of others in some cases, thereby constructing a somewhat universal reality (Stake, 1995).

In line with the constructivist approach, those reading a research study report should arrive at their own understandings and generalisations, which is facilitated by the presentation of detailed, narrative accounts of subjects' experiences (Stake, 1995). For example, when considering constructivism in the context of innovation in healthcare, a person's understanding of a new intervention may be shaped by their prior experiences of implementing interventions, alongside the explanation given by the person introducing the innovation (Thomas et al., 2014). Some nursing research has been described as aligned to the constructivist paradigm, which views the nursing profession as socially-constructed (Latimer, 2008). This construction includes divisions in the social positions held by those involved in interactions (for example, power dynamics) such as those between doctors and nurses, nurses and patients, and how the world of nursing is socially organised (Peplau, 1989).

However, critics of the constructivist approach highlight its potential to be reductionist in explaining different phenomena (Schmidt, 2001). For example, the principles of constructivism can undermine theories of knowledge and the credibility of any epistemological conclusions, on the basis that every individual has a different understanding of reality

(Schmidt, 2001). Furthermore, this diversity of perspectives creates challenges in comprehending cross-cultural differences (Schmidt, 2001). Despite this, constructivism has been deemed robust as an approach to research, which increases understanding of a phenomena through emphasis on individual agency (Jung, 2019).

Although a significant proportion of constructivist research traditionally focuses on theories of learning, the approach has also been utilised within healthcare contexts to consider knowledge translation (Thomas, 2014). This concept refers to the exchange, amalgamation and moral application of knowledge to improve healthcare services (World Health Organisation, 2021). With this in mind, constructivism views knowledge as a communally constructed social context (for example, in interactions between patient and staff) with understandings formed by each individual (Thomas, 2014). Therefore, elements of the interpretivist-constructivist approach influence the current research study, which are revisited in the discussion of findings in Chapter Seven.

Furthermore, Chapter Two introduced ‘Normalisation Process Theory’ (NPT) as an influential theory in healthcare research, which can be used to consider study findings around the implementation of innovations (May et al., 2015). The theory has been deemed congruent with a constructivist approach, through its focus on how individual and shared understandings influence the success or failure of implementation (De Brún et al., 2016). Therefore, NPT is revisited in Chapter Seven, and is used to present an additional lens for understanding key study findings.

3.2.3 Reflexivity

Constructivism highlights that understandings are unique to each individual, dependent on a range of factors such as their experiences and knowledge (Stake, 1995). An example of this individuality is highlighted within the image below.

Figure 6. Image to Represent Perspective

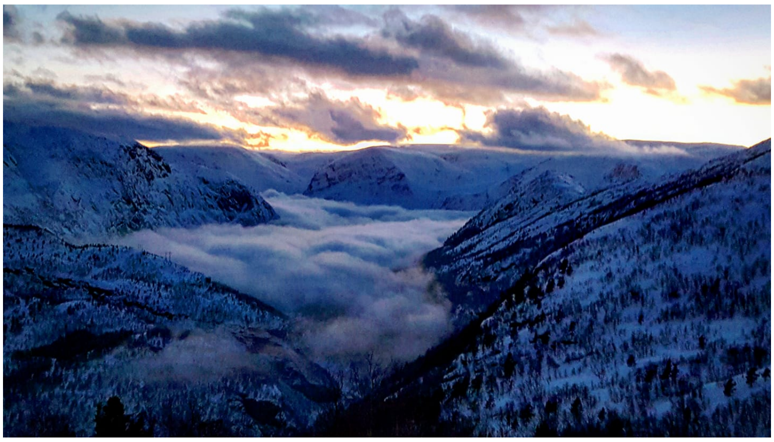


Image taken by and property of the researcher

An individual's experiences and knowledge might influence their perception of the above image, to show idyllic beauty, a climbing challenge, a reminder of a treasured childhood memory, an escape from a stressful life situation, or a sense of peace from being above the clouds. This image may elicit feelings of happiness, sadness, fear or excitement. Our experiences shape our perspective and world view to some extent, and therefore influence our interpretations and behaviour.

With this in mind, an essential aspect of qualitative research is the researcher's ability to critically reflect on their study to interpret findings, a process commonly known as reflexivity (Flick, 2014). Furthermore, reflexivity emphasises that the researcher must consider themselves and how their personal identity may shape relationships and wider views (Clarke, 2006; Sanjari et al., 2014). Consequently, an important consideration for this study was how my own pre-conceptions may have influenced design, outcomes, or my interpretation of data. As outlined in Chapter One, I have experience as a cancer nurse, I have been involved in HNA delivery, and I have networked with other professionals in relation to challenges identified with the HNA's implementation. Therefore, this study was approached with significant frontline experience and knowledge around the topic, thus requiring critical reflection to minimise biases arising from this.

Finlay (2002) outlines five variants of reflexivity in research, including 'introspection' (using one's own reflection and thinking as primary evidence), 'intersubjective reflection' (exploring how unconscious processes facilitate mutual meanings within the research relationship), 'mutual collaboration' (enlisting participants as co-researchers), 'social critique' (acknowledgement of the tensions around social roles and power imbalances) and 'discursive deconstruction' (noting ambiguity in how language is used, and how this impacts interpretations). In the current study, the primary approaches used were reflexivity as social critique and discursive deconstruction, which were used to encourage more relaxed research encounters (where participants were at ease to disclose their opinions). The concepts of reflexivity are interwoven throughout the chapter, to highlight how critical reflection has influenced study procedures.

3.3 Study Design

In this section, the case study design is explained, aligning with the style of Robert Stake (Stake, 1995), an influential approach within qualitative research (Yazan, 2015). Initially, the background to case study research is presented, followed by an overview of the study's research questions, case selection, structure, and other defining features of the design process, such as patient and public involvement and engagement (PPIE).

3.3.1 Case Studies

Case studies allow observation and data collection in a phenomenon's natural environment (Zainal, 2007), to support theory development and exploration of research questions (Eisenhardt, 1989, Baxter and Jack, 2008). Despite the individuality of each case study, two approaches are commonly used to guide the process, from Robert Yin and Robert Stake (Yazan, 2015). In Yin's (2018) approach, case study design assumes a logical sequence, adopting five key principles. These principles are identification of key questions, propositions of the study, units of analysis, linking the data to the propositions, and the criteria for interpreting the findings. Traditionally, Yin's approach aligns with positivism, and encourages the use of both quantitative and qualitative data sources (Yazan, 2015). Alternatively, Stake's (1995) approach offers increased flexibility in design and analysis, and greater congruence with an interpretivist-constructivist epistemology (Yazan, 2015). Therefore, Stake's approach was chosen as a framework for how the current study's design was developed.

3.3.2 Type of Case

In Stake's (1995) method, three design techniques are differentiated. The approach taken to unique (single) case study is influenced by its purpose, either as intrinsic (the need to understand a specific situation), or instrumental (the need to generate understanding of a broader phenomenon, illustrated by use of a specific case). A third type of case study introduced by Stake (1995) is collective case study, made up of several instrumental cases, selected for their ability to explore the phenomenon under study (for example, these could be several typical cases, or a typical case combined with an unusual option). The collective case study provides increased opportunities for learning beyond what is achievable from a single case (Stake, 1995). As highlighted in Chapter Two, much about the implementation and contribution of HNAs to patients' experiences of support remains unknown. Consequently, this study's selection of collective case study allowed the diversity in use and delivery of HNAs to be explored in-depth, and provided the basis for comparison between cases.

Stake also emphasises the different focus of single and collective case study approaches (Stake, 1995). Within a single case, research questions concentrate on understanding the specific circumstances and content of one case (Stake, 1995). Alternatively, the focus changes in a collective case study approach, where cases are selected because they hold shared characteristics, opposing characteristics, or because they provide examples of a specific phenomenon (Stake, 1995). Collectively, Stake (1995) labels this focus the 'quintain', which involves designing research questions to understand what the cases show collectively, rather than only what they show independently (Stake, 1995). In the context of the HNA, a single case might concentrate on the tool's content, how it functions in practice, and how individuals interact with it. By contrast, collective case study might explore these factors, but also investigate the local aspects of HNA delivery within the organisation more deeply, highlighting variations between cases and the impact these have. The collective case study approach aligned with the aims of the thesis' study, which centred on understanding the HNA's contribution and use within the chosen NHS organisations. Following choice of case study type, Stake then describes processes for developing and refining the research questions (Stake, 1995).

3.3.3 Research Questions

Prior to specifying research questions, Stake (1995) describes that key issues (known as ‘issue statements’) should be identified to highlight subjects for investigation and provide direction for the study. When constructing these issue statements, these can be categorised into; cause and effect, general representation of a problem, and evaluative questions (Stake, 1995). The questions presented in Figure 7 were generated from Chapter Two’s literature review findings, and broader practical experience.

Figure 7. Issue Statements/Questions

Type	Questions
Cause and Effect	Do the practical barriers for staff implementing HNA tools affect the delivery of these? Does staff confidence in delivering HNAs affect outcomes? Are some methods of HNA implementation more successful in meeting the needs of women than others? Which factors lead women to decline/not engage with HNAs?
Evaluative	How useful are HNAs to women with cancer and staff? How well do women understand the HNA at the point of completion?
General	Do specific factors cause women's non-disclosure of concerns on HNAs? Are recommended actions undertaken from care plans? Are enough referral resources and services available, in order to address women’s concerns?

The issue statements were refined to develop the research question. They also directed data collection in terms of the initial interview content, and determining where and when to undertake observations.

Defining a research question can be a rigorous and challenging aspect of study design (Stake, 1995) and involves detailing boundaries to limit the scope of the chosen question (Baxter & Jack, 2008; Yin, 2018; Stake, 1995). These boundaries can include; activities, context, time, place or definitions (Baxter & Jack, 2008). The boundaries presented in Figure 8 were determined by the scoping review and the issue statements above.

Figure 8. Defining Boundaries

Boundary	Details
Context	NHS Trusts and any outpatient clinical or non-clinical areas within these that routinely offer HNAs to women with breast cancer.
Participants	Women with breast cancer, staff in the chosen NHS Trust involved in HNA delivery.
Methods	Non-participant observations of HNAs being undertaken, semi-structured interviews with women with cancer and staff, analysis of care plan documents (these methods are defined in Section 3.4).
Time	The women with cancer identified at any point within their cancer journey following diagnosis, providing they had not been fully discharged from care by their NHS Trust.

Further refinement of questions enabled development of the overarching question and objectives for the study. The HNA was termed ‘(e)HNA’ within these objectives, which represents Macmillan Cancer Support’s Concerns Checklist as either a paper assessment or using the online electronic HNA (eHNA) platform, as was described in Chapter Two.

Therefore, the term (e)HNA will be used consistently throughout the thesis from this point, to represent all references to the tool throughout the data collection and analysis processes.

3.3.3.1 Study Aims and Objectives

Based on the above considerations from Stake's (1995) approach to case studies, the following research question and objectives were determined:

> **How does the (e)HNA contribute to the assessment and support of the holistic needs of women living with or beyond breast cancer?**

Objectives

- To gather accounts of women's experience of undertaking (e)HNAs, and their perceptions of its contribution (if any) to their experiences of support throughout their cancer journey.
- To identify facilitators or barriers to use of the (e)HNA, and staff perceptions of its contribution to women's experiences of support.
- To explore the contribution of the care plan component of the (e)HNA in relation to supporting women's needs, alongside any factors which rendered this more or less meaningful to women.

3.3.4 Selection of Cases

Following explanation of the type of case study adopted (collective case study), alongside its boundaries and questions, Stake emphasises the importance of selecting appropriate cases (Stake, 1995). Each case should be chosen based on how it might facilitate or hinder learning opportunities (Stake, 1995). However, diversity and resources are important to consider when choosing cases, such as how many cases to include, the geographical locations of these, and the practicality of access to these locations (Stake, 1995).

In the context of the current study, site selection involved choosing NHS Trusts which deliver the (e)HNA to women with breast cancer. In order to identify these sites and establish diversity in cases, data were obtained from Macmillan Cancer Support, showing the highest users of the (e)HNA in England. These data reflected sites which were in similar stages of (e)HNA implementation (several years post-(e)HNA introduction), rather than those newly trialling this. The aim in selecting cases was to obtain two organisations with high (e)HNA use, which still provided diversity due to the sites' variable processes for delivering (e)HNAs, the staff involved in these and their general views. Specific details regarding the sites are discussed in Section 3.4.1.

3.3.5 Patient and Public Involvement and Engagement Strategy

A further influence on study design originated from a patient and public involvement and engagement (PPIE) group, used to inform various stages of the study. This group consisted of ten individuals with a current or previous diagnosis of breast cancer, recruited from a breast cancer support group in a separate organisation. The aim of the group was to facilitate the research process from initial design through to dissemination of findings, providing a unique perspective from patients who had experiences of care relevant to those of study participants (as opposed to my own perspective as a healthcare professional and researcher). A comprehensive PPIE strategy is recommended by the National Institute for Health and Care Excellence (NICE), Economic and Social Research Council (ESRC) and National Institute for Health Research (NIHR) (ESRC, 2017; NICE, 2013; NIHR, 2014) due to its numerous benefits. These benefits include the contrasting perspective which promotes critical reflection on decisions, and increased understanding of the condition under study (NIHR, 2014). Details regarding the PPIE group sessions are provided in Table 3.

Table 3. PPIE Meetings

Meeting Type	Discussion	Changes Based on Discussion
Face-to-face Meeting 1 (10 Participants)	Introductions to the topic and general feedback on (e)HNAs	Helped develop issue questions/statements and structure.
Face-to-face Meeting 2 (9 Participants)	Refining research question	Research question refined and helped identify key actions within the (e)HNA process (assessing and supporting concerns).
Face-to-face Meeting 3 (9 Participants)	Considering practicalities of delivering the study	Discussion around challenges at different points in the cancer journey, which led to broadening of criteria for the time point to recruit participants.
Email Contact 1 (6 Participants)	Refining interview guides	Changes to wording for the women with cancer interview guides that supported clarity.
Email Contact 2 (5 Participants)	Refining participant information sheets and consent forms	Changes to wording for the women with cancer information sheet that supported clarity.
Group Video Call 1 (5 Participants)	Discussion around analysis and interpretation of findings	Minor changes to interpretation of example quotations in the context of undergoing treatment, these principles were applied to other manuscripts when indexing.

Group Video Call 2 (3 Participants)	Refining recommendations and dissemination plans	Supported development of final study recommendations and added an additional one.

Overall, this section has emphasised the key components of study design associated with Stake's (1995) approach. This included explanation of the type of case study adopted, how the research questions and objectives were determined, how specific case selection was approached, and how PPIE influenced the decisions made at each stage of the study design and methods.

3.4 Methods

The structure of the methods section focuses on processes that enabled the development of study findings. These are identification of, and access to study sites, selection of participants, data collection and data analysis procedures. As described in Section 3.3.3, all subsequent uses of the term HNA or eHNA are collectively described as (e)HNA from this point onwards.

Detail regarding the data collection processes and participants recruited are outlined in Sections 3.4.2-3.4.4. As an overview, the study methods involved exploring (e)HNA use within two NHS Trusts, from the perspectives of women with breast cancer and staff involved in the delivery of (e)HNAs. For women with cancer, the study aimed to conduct an observation (where possible) of a hospital appointment where they completed an (e)HNA, a face-to-face interview, and a brief, follow-up telephone interview about their (e)HNA, approximately one month after its completion. Additionally, the women's care plan(s) resulting from their (e)HNA were accessed wherever possible. These methods of collecting data were chosen to provide a comprehensive overview of women’s (e)HNA experience. Staff participants were invited for a face-to-face interview, and an observation if they performed an (e)HNA hospital appointment with one of the women recruited.

During the study’s conduct, variations were expected in the numbers of possible observations and accessible documents, based on situations where (e)HNAs might be offered in privacy at home, completed over the telephone, completed unplanned, or did not result in a care plan for any reason. Therefore, interviews were chosen as the most significant component of data collection.

3.4.1 Site Identification and Access

As previously discussed, site selection required a balance of diversity and practical feasibility. Seven possible sites were identified, approached, and assessed for suitability, based on the data obtained from Macmillan Cancer Support highlighting the highest users of the (e)HNA platform. Table 4 explores the benefits, limitations and the final decision regarding each site. In Table 4, although selected sites were classified as ‘high’ usage from Macmillan Cancer Support’s data, one of the sites approached reported ‘low’ use of the (e)HNA with breast cancer patients (the sixth Trust). Ultimately, the choice was made to use two sites, as this provided an opportunity to compare the (e)HNA processes in different NHS Trusts, but also allowed time to consider each in sufficient depth, given the PhD timescale. Initial site access agreement was obtained from Lead Cancer Nurses (contacted through existing networks, or through the study’s clinical supervisor), and meetings were arranged to discuss the finer details of data collection with the breast care nurses (BCNs).

Table 4. Site Matrix

	HNA Usage	Benefits	Limitations	Decision
1	High	Geographical location, well established	Researcher acquainted with breast team and has conducted research in this Trust (prior knowledge of (e)HNA's implemented)	Researcher decided not to proceed based on the desire to explore un-researched areas
2	High	Well established user, high volume of women with breast cancer	Issues with access, Lead Cancer Nurse felt BCNs would not want to participate	Researcher decided not to proceed
3	High	Highest (e)HNA user, staff seemed to dislike (e)HNAs, possible useful findings	Issues with access and contacts indicated staff compliance with research can be problematic	Initial contact made but researcher decided not to proceed
4	High	Well established user and supportive network of staff	Geographical location problematic due to financial budget	Initial Case Study 1 (research department stopped)
5	High	Well established user, supportive of the study and engaged staff	Geographical location problematic due to financial budget	Case Study 1
6	Low	Support from key individual to facilitate access	Low (e)HNA user, location problematic due to financial budget	Researcher decided not to proceed
7	High	Geographical location, some key staff supportive of study	Some staff less supportive of study	Case Study 2

Initially, the fourth Trust in Table 4's list was chosen as Case Study 1 for the study, based on positive engagement from organisational management and possessing the highest (e)HNA use nationally. Consequently, several visits to the site were undertaken. However, the study later failed to obtain local Research and Development (R&D) department approval, due to the high workload of staff. Therefore, Trust numbers five and seven became the study sites and local R&D

approval was obtained accordingly. The characteristics of these sites are outlined in Section 3.4.1.1 and 3.4.1.2. Relationships were built with key stakeholders at each site before commencing the study, including those with project oversight for (e)HNA delivery, breast cancer consultants, and the ‘breast teams’, made up of BCNs and support workers (SW). Throughout data collection, the primary contact at both sites was a SW, based on their increased time capacity to assist with the study. As demonstrated above, site access, study facilitation and participant recruitment involved a number of staff with specialist roles. Therefore, Figure 9 provides an overview of these roles, alongside the input of Macmillan Cancer Support.

Figure 9. Key Roles in Case Study Sites

Role

Breast Care Nurse (BCN)

BCNs are specialist nursing roles, involving information provision, emotional support, treatment advice, clinical procedures and conducting HNAs (Cancer Centre London, 2020). BCNs are deemed ‘clinical experts’, with advanced communications skills and the ability to address highly challenging emotional situations (Oakley, 2019). In some organisations, BCNs are referred to as clinical nurse specialists (CNS).

Support Worker (SW)

Many SWs nationally are funded by Macmillan Cancer Support to work alongside specialist nursing staff. They undertake non-complex tasks to allow registered staff to focus on more challenging care needs. They are able to co-ordinate care, and signpost/refer individuals to support services (Macmillan Cancer Support, 2016b). National variations are used in SW job titles, and they are collectively referred to as SWs throughout the current study to avoid identification of specific NHS Trusts.

Other Macmillan Cancer Support Roles

Many Trusts received funding from Macmillan Cancer Support for project/programme managers to oversee the implementation of personalised care. Many organisations also have a Macmillan Cancer Information and Support Service hub, containing staff who regularly has supportive/signposting conversations. Many of these roles are Macmillan Cancer Support ‘adopted’, referring to the partnership between Macmillan and the host organisation (and allowing individuals to access benefits, such as training courses) (Macmillan Cancer Support, 2014).

3.4.1.1 Case Study 1

The site chosen for Case Study 1 was a large, acute NHS Trust in England with two primary hospital sites delivering cancer care, including a day unit, four cancer inpatient wards and a specialist outpatient breast cancer centre. The Trust delivered various treatments on site, including chemotherapy, radiotherapy and surgery. Most staff involved in cancer services worked across both hospital sites. There were many different supportive services in the geographical area covered by this organisation, many of which were independent or community based. These services offered support for challenges people with cancer might face, such as financial support, drop-in centres and support groups. Accessibility to these services was postcode dependent in some cases, so availability varied according to where individuals lived. Case Study 1 also had a strong link to its Macmillan Cancer Information and Support Service.

3.4.1.2 Case Study 2

Case Study 2 was also a large, acute NHS Trust consisting of two hospital sites that delivered cancer care, including a day unit, various cancer inpatient areas and a specific outpatient area for breast cancer. The Trust also delivered a variety of treatments on site, including chemotherapy, radiotherapy and surgery. However, due to significant variations in process between the two hospitals and the absence of cross-site working between staff, these hospitals were divided in data reporting to some extent. As an overview, one of the hospitals (Hospital 1) was much larger than the other (Hospital 2). There were many different support services in the area covered by the Case Study 2 NHS Trust, some of which differed. Access to these services was post code dependent in many cases, and some of the supportive services offered were somewhat different between the two areas. Further details regarding the processes within each site are explored within the findings in Chapters Four and Five.

3.4.2 Selection of Participants: Women with Cancer

3.4.2.1 Sampling Strategy

When recruiting participants, women with cancer were purposively sampled based on having been offered an (e)HNA, and the study successfully recruited 12 individuals from each site. Purposive sampling increases the likelihood of gathering useful data, through accessing participants with suitable knowledge to answer the research question (Benoot et al., 2016). As a process, purposive sampling involves deliberate selection of participants with knowledge about the phenomenon of interest, or important characteristics to answer the research question (Battaglia, 2008) (for example, women having experience of being offered an HNA, or being in a job role that involves (e)HNA delivery). Purposive sampling adopts non-probability sampling methods, and is often undertaken by applying expertise of the target population to deliberately select individuals representative of this group (Battaglia, 2008). When establishing sample size in qualitative research, this is traditionally based upon the concept of data saturation (when data collection ceases at the point no new data is discovered, and additional collection of data is therefore unnecessary) (Mason, 2010). However, quantifying an exact recommended sample size within qualitative research can be challenging. Previous social sciences research has made suggestions of appropriate participant numbers to recruit, such as 6-12, 5-25 and >15 participants (Guest et al., 2006; Mason, 2010). With this in mind, the total of 24 women with cancer in the current study (12 per site) was congruent with these perspectives.

Inclusion and exclusion criteria for participants recruited are highlighted in Figure 10. The primary emphasis of the chosen criteria was to focus on a broad range of women whose treatment aimed to cure their cancer (as opposed to untreatable cancer), and who were cognitively able to engage with the (e)HNA and the study. This appropriateness and ability to participate was decided by the BCNs during participant screening. These staff also determined whether women had cognitive capacity to provide fully informed consent -an ethical requirement of research participation (Fields & Calvert, 2015).

Figure 10. Women with Cancer - Inclusion/Exclusion Criteria

Participant Criteria

Inclusion

1. Females aged 18 and above
2. Diagnosis of breast cancer (any stage, type)
3. Ability to give informed consent
4. Recent or planned completion of an HNA
5. Treatment included (or planned) surgery (this could also include other treatments, such as chemotherapy, radiotherapy or hormone therapy)
6. Any stage in their cancer pathway (for example end of treatment)

Exclusion

1. Women whose treatment did not/would not include surgery
2. Significant co-morbidities, including distant metastasis
3. Those undergoing preventative surgery for possessing high-risk breast cancer genes (no cancer diagnosis)
4. Cognitive impairments affecting the ability to give informed consent
5. Individuals who have not/will not be offered an HNA

The broad inclusion criteria encouraged recruitment of participants with diverse experiences of (e)HNAs, due to the variety of treatments they were undergoing, varying age groups, and the differing stages in their cancer journey at the point of recruitment. The rationale for the focus on breast cancer was highlighted in Chapter One, due to its global prevalence and associated physical, emotional and social concerns which persist in those diagnosed (Breast Cancer Care, 2018a). Furthermore, the choice to include those undergoing surgery as part of their treatment was based on the fact that surgery is recommended to almost all patients diagnosed with breast cancer (Breast Cancer Care, 2017). The exceptions are those whose general health or severity of diagnosis is deemed inoperable, therefore aligning them with the exclusion criteria for significant co-morbidities (the presence of multiple diseases) (Valderas et al., 2009) or distant metastasis (cancer which has spread from the original site) (American Cancer Society, 2020). Those with metastatic disease were excluded based on the complex nature of their condition, where palliative care (e)HNA tools may be more suitable to address their needs (Ahmed et al., 2015).

3.4.2.2 Recruitment

Each site's breast team (SW or BCN) undertook screening and recruitment of women with cancer for their possible involvement in the study. These staff provided letters of invitation/reply slips (Appendix H) to prospective participants, alongside a participant information sheet (Appendix I), and a pre-paid envelope for their reply slip if they wished to participate. In order to maintain accurate records of participants screened and invited to the study, each site was provided with participant screening logs, and taught how to complete these. Unfortunately, data were recorded inaccurately despite these arrangements, regarding the numbers of women invited to participate at both sites. Based on these records and further discussion, approximately 60 women appear to have been sent letters of invitation in Case Study 1, and 30 in Case Study 2.

Figure 11. Women with Cancer - Recruitment Process

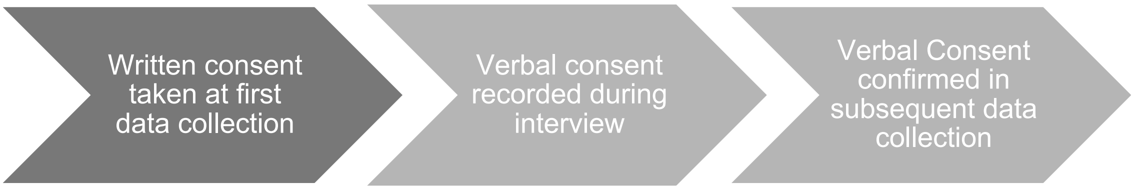
During the recruitment process, challenges occurred within both sites. For example, I initially sought to recruit women with a recent diagnosis in Case Study 1, as there would likely be more opportunities to conduct observations and follow-up interviews if participants were recruited at an early stage. However, of the approximately 60 women invited to join the study, around two thirds were newly diagnosed with breast cancer, and only one responded. Based on this ineffectiveness, additional participants were alternatively sought from later points in their cancer journeys, such as during treatment or post-treatment. From this learning in Case Study 1, initial recruitment in Case Study 2 was aimed at individuals at different points in their cancer journey, as opposed to exclusively looking at the point of diagnosis. However, the (e)HNA delivery processes at Case Study 2 also meant that few participants were offered (e)HNAs around diagnosis, and therefore no individuals were recruited at this point.

At both sites, further recruitment challenges occurred due to engagement from the staff responsible for screening and recruitment. The researcher was unable to access patients' information prior to their agreement to participate, and it was therefore the breast team's responsibility to identify and approach those who were eligible. Staff's high workload often meant the study was considered a low priority, and many visits were undertaken by the researcher to improve engagement through visibility. Overall, visits to sites varied, but often occurred two-three times per week over a two-month period, with additional visits occurring as and when required to collect data or prompt recruitment. Within the initial visits, presentations were scheduled with a variety of staff to encourage buy-in, and subsequent visits were undertaken to answer questions about the study, clarify details, discuss recruitment and collect data.

3.4.2.3 Consent

The consent process began with the letter of invitation and participant information sheet sent by the breast team. These provided potential participants with clear descriptions of the study and its purpose, alongside contact details for any questions. The principles of informed consent are discussed within Section 3.5 of this chapter.

Figure 12. Women with Cancer - Consent Process



Following provision of the study information, participants completed a written consent form before initial data collection, alongside verbal consent at subsequent points of data collection (recorded on interview audio recordings). Beside the consent form, participants received a verbal explanation of the voluntary nature of study participation, and freedom to withdraw at any time.

3.4.2.4 Participant Characteristics

Participants were at varying stages in their cancer journeys, with the majority recruited whilst undergoing some form of treatment (n= 13, 54%), at the end of treatment (n=7, 29%) or several months post-treatment (n=3, 13%). Only one individual was pre-treatment when recruited. The actual treatments undergone (or planned) for participants were comparable between sites, with 25% receiving chemotherapy (Case Study 1 n=4, Case Study 2 n=2), 88% radiotherapy (Case Study

1 n=11, Case Study 2 n=10), 8% a course of cancer drug injections (Herceptin) (Case Study 1 n=1, Case Study 2 n=1), and 58% hormone therapy (Case Study 1 n=5, Case Study 2 n=9). Furthermore, 17% of participants were unsure of their full treatment plan and may therefore have received additional treatments after the study concluded.

The collection of demographic information is essential in research reporting, as this provides a sample overview to interpret conclusions, and consider findings within other populations (Marchant, 2018). The participants themselves had diverse characteristics, including an age range of 48-81 (average 60). Almost all participants were of a White, British ethnicity (one White, Australian), and most were married (71%). For employment status, eight were retired (34%), six were full-time employed (25%), six part-time (25%), two self-employed (8%) and two unemployed (8%). Further information is provided in Appendix J.

In order to protect confidentiality, each participant (staff and women) was provided with a unique study identifier such as ‘0101S’ dependent on the number of the site (01 or 02), the order in which they were recruited (01-12) and whether they were ‘staff’ or ‘patients’ (‘S’ or ‘P’). Furthermore, the women were allocated a pseudonym, utilised to present their data. This is discussed further in the ethical considerations section of the chapter. The individual pseudonyms and a background summary for each participant is provided in Chapters Four and Five.

Alongside demographic information, data on support offered to individuals during their cancer pathway were also recorded. Within this, the number of (e)HNAs offered and completed for each participant were documented, alongside any additional telephone calls with the breast team that the participant initiated. This information was captured with the aim of highlighting whether participants had declined or not completed an (e)HNA, but took it upon themselves to seek support through alternate means. For example, participant number 0104P completed no HNAs, but sought advice for financial support directly, and several participants requested support for physical or emotional concerns, alongside having completed (e)HNAs (shown in Table 5).

Table 5. Women with Cancer - Contacts Initiated and HNA History

No.	No. of contacts with breast team	Nature of contact	HNAs Offered	HNAs Completed
0101P	0	Not applicable	1	1
0102P	0	Not applicable	1	0
0103P	0	Not applicable	1	1
0104P	1	Financial Concerns	1	0
0105P	1	Financial Concerns	1	1
0106P	0	Not applicable	2	0
0107P	0	Not applicable	2	1
0108P	3	Physical Concerns	2	2
0109P	0	Not applicable	2	2
0110P	0	Not applicable	2	2
0111P	0	Not applicable	2	2
0112P	3	Emotional Concerns	2	2
0201P[1]	1	Treatment Questions	2	1
0202P[1]	0	Not applicable	3	1
0203P[1]	0	Not applicable	2	1
0204P[1]	0	Not applicable	3	2
0205P[1]	2	Physical Concerns	3	2
0206P[1]	1	Emotional Concerns	4	2
0207P[2]	2	Physical /Emotional	2	2
0208P[2]	1	Treatment Questions	3	2
0209P[2]	1	Treatment Questions	3	2
0210P[2]	1	Physical Concerns	1	1
0211P[1]	1	Emotional Concerns	2	2
0212P[1]	0	Not applicable	1	1

[1] Hospital 1, [2] Hospital 2 (Case Study 2 participants)

3.4.3 Selection of Participants: Staff

3.4.3.1 Sampling Strategy

For staff, a similar purposive sampling technique was adopted based on their participation in (e)HNA delivery, and 12 individuals were successfully recruited from each site. However, staff involved indirectly in (e)HNA delivery (such as service managers) were also included, to provide perspectives on the (e)HNA's overall implementation. Therefore, the inclusion criteria were broad (Figure 13), to include any staff whose role related to the principles of (e)HNA delivery, or broader implementation of this from a management perspective.

Figure 13. Staff - Inclusion/Exclusion Criteria

Participant Criteria

Inclusion

1. Aged 18+ (no upper age limit)
2. Any staff role (of any duration) which involves either:
   - Direct delivery of (e)HNA to patients (or the principles of assessing holistic needs)
   - Some involvement in the process of (e)HNA implementation (e.g. project managers, service leads)

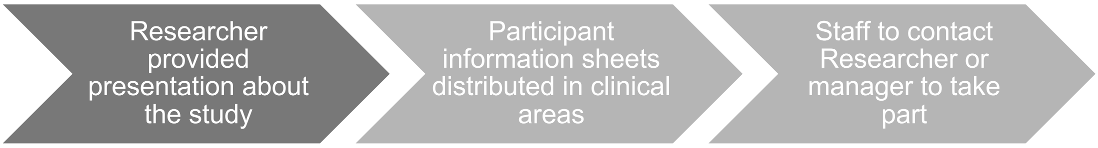
Exclusion

1. Staff with roles which had no relation to delivery or implementation of (e)HNAs, or the principles of assessing holistic needs.

3.4.3.2 Recruitment

Recruitment of staff was facilitated through the researcher's visibility within their clinical areas, and undertaking group presentations outlining the structure and purpose of the study. Individuals in roles such as service management were contacted by the lead BCNs to invite them to attend these presentations, and a copy of the participant information sheet was sent to them directly. It was the staff member’s responsibility to make contact with the researcher if they were interested in participating, and then interviews dates were arranged.

Figure 14. Staff - Recruitment Process



3.4.3.3 Characteristics

Predominantly, staff recruited were BCNs, and one advanced nurse practitioner (ANP) (whose role in (e)HNA delivery functioned in the same way as a BCN in Case Study 1) (n=13, 54%). Additionally, individuals in service management roles were also recruited from both sites. Four SWs were involved (two per case), and a staff member from Case Study 1’s Macmillan Information and Support Service was a further participant. In Case Study 2, a radiographer and radiotherapy nurse agreed to participate. Length of experience as a healthcare professional or worker ranged from five months to 22 years. BCNs/ANP had a notably higher average length of time in roles (eight years) than the other staff recruited (two years). More demographic information is available in Appendix J.

Table 6. Staff- Characteristics

No.	Age	Ethnicity	Employment	Role	Time in role
0101S	28	White British	Full-time	BCN	6 mnths
0102S	56	White British	Full-time	BCN	9 yrs

0103S	28	White British	Full-time	Programme manager	6 mnths
0104S	46	White British	Full-time	Macmillan Information and Support Service staff member	1 yr
0105S	45	White British	Full-time	SW	9 mnths
0106S	55	White British	Full-time	Project manager	3 yrs
0107S	60	White British	Full-time	SW	2.5 yrs
0108S	52	White British	Full-time	Lead BCN	9 yrs
0109S	53	White British	Full-time	BCN	22 yrs
0110S	41	White British	Part-time	BCN	1.5 yrs
0111S	55	White British	Full-time	Advanced nurse practitioner	18 yrs
0112S	51	White British	Part-time	BCN	10 yrs
0201S^1	49	White British	Full-time	Radiotherapy nurse	1.5 yrs
0202S^1	56	White British	Full-time	Project manager	2.5 yrs
0203S^1	50	White British	Part-time	SW	5 mnths
0204S^1	39	White British	Full-time	BCN	6 yrs
0205S^1	26	White British	Full-time	Senior radiographer	4 yrs
0206S^1	47	White British	Part-time	BCN	2.5 yrs
0207S^2	56	White British	Full-time	BCN	7 yrs
0208S^2	48	White British	Part-time	BCN	4 yrs
0209S^2	62	White British	Part-time	Project manager	3.5 yrs
0210S^1	49	White British	Full-time	Lead BCN	10 yrs
0211S^2	34	White British	Part-time	BCN	5 yrs
0212S^2	N/D	White British	Full-time	SW	3 yrs

N/D- Not Disclosed, the numbers indicated after Case Study 2 ’s participant identifiers refer to the hospital in which they were based.

3.4.4 Data Collection

Following recruitment of participants, data collection took place between May 2019 and December 2019. When conducting data collection, variations in how the (e)HNA was delivered were expected between study sites (based on the findings from previous (e)HNA research in Chapter Two). Therefore, the order of data collection activities was determined by what was most suitable for staff in each site.

This section outlines the details of data collection processes for interview, observational and documentary data, incorporating reflexive learning throughout. Prior to exploring each component individually, Table 7 and 8 display the planned data collection figures, compared with the reality of data obtained. The reasons for variations between expected and actual numbers of observations and follow-up interviews are explored in the relevant sections.

Table 7. Planned Data Collection

Interviews	**Observations**	**Documents**
16-24 x face-to-face interviews with women (8-12 per case)	Up to 24 observations of women's (e)HNAs (8-12 per case), for any women participants who completed the (e)HNA	16-48 care plans completed for women (8-12 participants per case, up to two care plans each)
16-24 x follow-up telephone interviews with women (8-12 per case)		2-4 local Trust letters of invitation for (e)HNA completion sent to women (1-2 per case)
16-24 x face-to-face interviews with staff (8-12 per case)		1 x generic Macmillan Cancer Support (e)HNA leaflet and 1 x generic (e)HNA access card (same at both case)

Table 8. Actual Data Collection

Interviews	Observations	Documents
24 x face-to-face interviews with women (12 per site)	7 observations of women's (e)HNAs (1 Case Study 1, 6 Case Study 2)	33 care plans completed for women (14 Case Study 1, 19 Case Study 2)
3 x follow-up telephone interviews with women (2 Case Study 1, 1 Case Study 2)		3 local Trust letters of invitation for (e)HNA completion sent to women (2 Case Study 1, 1 Case Study 2)
24 x face-to-face interviews with staff (12 per site)		1 x generic Macmillan Cancer Support (e)HNA leaflet and **1** x generic (e)HNA access card (same in both cases)

3.4.4.1 Interview Data

Beginning with the interview aspect of data collection, research interviews can be classified into three primary categories: structured, semi-structured and unstructured (Given, 2008). Where structured interviews utilise a rigid, closed-question approach to generating data, the unstructured approach alternatively avoids prearranged questions (Warren, 2001). In contrast, a semi-structured method uses several predetermined questions, yet allows scope for unplanned discussions and requires no fixed responses (Given, 2008). Semi-structured interviews encourage a conversational style to data collection, allowing participants to speak freely about their experiences, which are conveyed in their own words (Warren, 2001). This approach therefore enables individual perspectives to be presented and recognises the differing world views of participants (Peck & Mummery, 2019). A potential limitation of this method is its reliance on the skill of the researcher to elicit in-depth information, and avoid bias in interpretation (Given, 2008). With this study, use of semi-structured interview were suitable in guiding the interview topics, whilst maintaining flexibility for broad discussions of the (e)HNA. This flexibility was important, considering how much about user experiences of the (e)HNA were unknown (outlined in Chapter Two).

Three topic guides were adopted for interviews, made up of main and associated questions (DiCicco-Bloom and Crabtree, 2006). The three guides were different for the three types of interviews occurring (women face-to-face, staff face-to-face and women follow-up interviews). These guides were developed in collaboration with the study's PPIE group, and the final versions are included in Appendix K.

The face-to-face interviews were the primary component of data collection, and aimed to explore a range of topics related to experiences of (e)HNA use. Considering the variations in how (e)HNAs were delivered between study sites, women's interviews were scheduled around their availability and (e)HNA appointments, rather than at a specific time within their cancer journey. Additionally, in all but one case, women's interviews occurred following the observation of their (e)HNA (where an observation was possible), as discussed further in Section 3.4.4.2. All participants recruited to the study (staff and women) underwent a face-to-face interview. Overall, women's interviews ranged in length from 18 minutes to 77 minutes, with 18 of these being undertaken in the individual's own home (Case Study 1 n=10, 83%, Case Study 2 n=8, 67%) and six in hospital at their request (Case Study 1 n=2, 17%, Case Study 2 n=4, 33%). For staff, interview length was 20 minutes to 69 minutes, and all were undertaken in a hospital.

The second interview component of data collection was the women's follow-up telephone interview, to explore experiences of their recent (e)HNA, approximately one month following its completion. The purpose of this interview was to understand if any action was taken since this interaction occurred (for example, if they had received further correspondence, received their care plan or had taken steps to complete recommendations themselves). Telephone interviewing was offered for the second interview, based on the inconvenience of undergoing two interviews in person. However, the practicalities of organising the initial face-to-face interview (including geographical location, the point in their cancer journey at which participants were recruited, or participant preferences) often meant that more than one month had already passed since the (e)HNA's completion (approximately 4-6 weeks in many cases) by the time the face-to-face interview was undertaken. Furthermore, the follow-up interview was unnecessary for several participants, who either did not complete their (e)HNA, or raised no concerns within this. Therefore, only three follow-up telephone interviews took place out of the intended 24 (n=2 in Case Study 1, n=1 in Case Study 2). Despite this deviation to the aim of conducting follow-up interviews with all women, participants had good recall of their (e)HNAs. Therefore, in their face-to-face interviews, most women were able to describe both their experience of undertaking (e)HNAs, alongside whether any actions had subsequently occurred within the month after this. With this in mind, the absence of a follow-up interview did not appear detrimental to data gathered overall. The follow-up interviews which did occur ranged in length from 14 minutes to 24 minutes, were conducted within 4-6 weeks of women completing their (e)HNAs, and were undertaken over the telephone. All interviews were audio-recorded with consent, and were transcribed using an intelligent transcription method (involving minor editing to remove speech disruptions such as ‘erm’ or other fillers, whilst maintaining the essence and tone of a transcript) (New Media Services, 2020).

The concept of reflexivity was considered throughout the interview data collection, particularly related to the potential impact of being a dual nurse-researcher. Within the interviews, Finlay’s (2002) ‘social critique’ aspect of reflexivity was relevant, which focuses on social positions (such as power dynamics), and how these can be managed within an interaction. Finlay (2002) outlines potential approaches to managing this, including the interviewer’s use of humour to avoid appearing detached, or adopting language which encourages being viewed as part of a group, and thus a more natural and relaxed situation (Finlay, 2002; Gough, 1999).

In the current study, my dual nurse-researcher role may have complicated the power dynamics in research interactions. For example, a staff member in one interview apologised for saying she disliked the (e)HNA. When reflecting on this scenario, I attempted to understand why this individual felt obliged to apologise for her opinion, and whether my introductions had indicated that I desired her views to be positive. From my own nursing experience of administering the (e)HNA, I imagined a reverse scenario if I was asked to participate in an (e)HNA study with a nurse. I concluded that the staff member in question was aware of my nursing background, but may have also viewed me as an expert in (e)HNAs, due to this being the focus of my PhD. Alongside this, considering the local targets in place for (e)HNA completion, and a stranger asking questions about the assessment and audio-recording their answers, this may have created fears that staff’s professionalism or compliance was being tested. Therefore, staff may have felt I was holding them accountable for (e)HNA completion, and that I was in a position of authority. In order to reduce this dynamic, I pointed out the staff member's apology for disliking the (e)HNA, using humour and giving permission for her to provide an honest opinion. I also spent additional time building rapport with the staff member and discussing my own experiences of nursing, to encourage a more relaxed atmosphere and reduce being viewed as an authority figure. From this encounter, I adopted the same technique at the beginning of subsequent interviews, through explaining my positive view of their service and clarifying that my capacity in their environment was to understand their opinions, which they were free to divulge openly without any impact on their work.

Additionally, staff appeared to justify their actions in some cases, such as explaining why (e)HNA care plans were not shared with general practitioners (despite the (e)HNA platform encouraging staff to do this). The staff member's defence of their decision not to share care plans may suggest they felt obligated to justify this, and that I may perceive them to be acting incorrectly. In this situation, Finlay's (2002) reflexivity concept of 'discursive deconstruction' is applicable, (situations where language use can impact conversation, and participants present an the image of themselves that may need to be deconstructed to gauge their meaning) (Finlay, 2002). Considering the example above, staff described information in a way which presented their actions as understandable, suggesting they may have felt the desire to defend and justify these actions. It was important to also consider the view I was presenting to participants, being conscious to avoid body language that might imply I was judging their actions, or expected specific answers to interview questions. This also included awareness of the language used to describe the (e)HNA, as women participants appeared to deconstruct the meaning of the phrase 'holistic needs assessment' in some cases, and arrive at an incorrect interpretation (discussed in Chapters Four and Five).

3.4.4.2 Observational Data

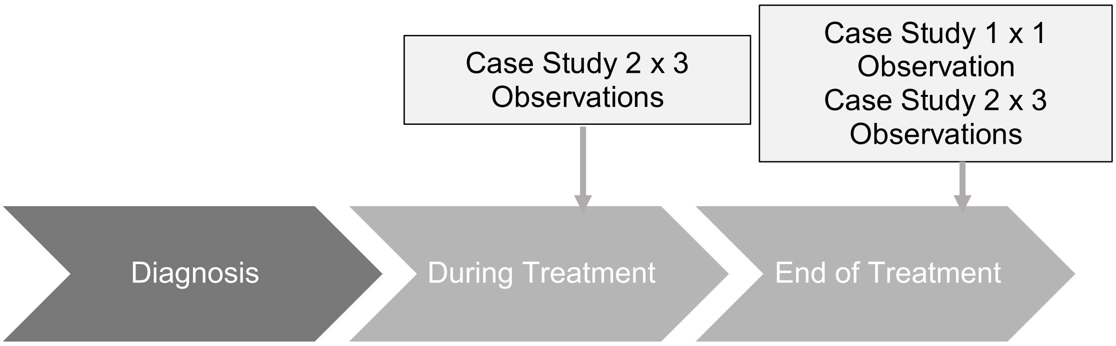
Observations were also included within the study, utilising a non-participant observation approach, in which the researcher is separate from (rather than involved in) the behaviour being observed (Mills et al., 2010). Observation in research may be overt (participants are aware of their research involvement) or covert (participants are unaware of their involvement) (Mills et al., 2010). When used, observations capture detailed information focused around interaction and communication between participants (Mills et al., 2010). An overt, non-participant observation technique was chosen for the study, as a useful mechanism for understanding how holistic needs are assessed, particularly where communication techniques facilitated use of the (e)HNA. However, a key limitation of the observation method is the observer effect, in which the presence of the researcher causes a participant reaction which would not ordinarily have occurred (Mills et al., 2010). This issue leads to challenges in eliciting a true reflection of normality (Mills et al., 2010).

When conducting observations in the current study, staff's delivery of the (e)HNA was variable, which presented challenges in identifying opportunities to observe (e)HNAs in progress. For example, variations included staff's last-minute decisions to undertake assessments at geographically distant sites, staff's decisions to undertake care planning conversations over the telephone (rather than scheduled face-to-face discussions) and booked telephone calls not being answered by women. Consequently, only one observation was possible in Case Study 1, and six in Case Study 2 (out of the possible 24 for all participants). This difference between sites primarily occurred because some (e)HNAs in Case Study 2 were undertaken in scheduled, face-to-face clinic appointments, which made it possible to plan my attendance.

Furthermore, the scheduled clinic appointments in Case Study 2 had staff automatically assigned to them, and it was therefore not possible to predict which staff would be participants in the observation encounters. As a result, the variety of staff involved in these observations was limited, as half were undertaken with the same staff member in Case Study 2, and only one observation was undertaken in Case Study 1.

As with the interview component of the study, an observation guide was developed, adapted from two examples (Roller & Lavrakas, 2015; University of Sheffield, 2015) (Appendix L). This guide provided a broad structure to allow flexibility within the observations. Observational data were not recorded or transcribed, and were alternatively gathered in field note form using the guide's structure. Of those undertaken, observations occurred at different time points within the participant's cancer journey, based on when they were recruited and when an (e)HNA was offered, as shown in Figure 15.

Figure 15. Women with Cancer – Timing of Observations



Further details on the observation contexts and content are provided in Chapters Four and Five.

The concept of social critique as a reflexivity tool was also applicable to observational data (Finlay, 2002). For example, the approach acknowledges the varying researcher-participant positions (such as positions of authority), and the complex task of deconstructing the researcher’s authority to reduce the participant’s perceived power imbalances (Finlay, 2002). One individual with cancer highlighted an example of power dynamics present in the researcher-participant relationship. During an interview, the participant sought advice on her treatment side effects from me, and expressed clear reluctance to criticise her experiences of care. This suggested that the participant perceived me as a caregiver and authority figure, and I took steps to reduce this view by explaining my role as a researcher, alongside use of humour and informal conversation to relax the atmosphere. Consequently, the participant appeared increasingly comfortable in my presence during her follow-up interview, where comments alluding to my nursing background did not occur, and she seemed to speak more freely.

3.4.4.3 Documentary Data

A final component of data collection was documentary data, which provides value in case study research through the stability it maintains over time, the unchangeable nature of the information, and the unobtrusiveness of gathering the data (Yin, 2018). However, use of documents in research is also subject to limitations, including reporting being subject to the opinions of the document’s author and the difficulty with accessing the required information (Yin, 2018). Documents were used in the current study to provide a further means to triangulate data (combining use of several research methods to explore the same concepts) (Stake, 1995).

In the current study, the documents collected were; letters of invitation to complete the (e)HNA (sent to most participants), a Macmillan Cancer Support (e)HNA information leaflet and a small (e)HNA online access card (which were the same at both sites, described further in Chapters Four to Six), and care plans completed for the women recruited.

Figure 16. Documentary Data Sources

Documents were analysed alongside interview and observational data. However, the content of care plans was also considered with specific patterns in mind:

- Staff actions taken in response to women's concerns raised in the (e)HNA, and if a relationship existed between the score women assigned to the concern and the action taken (for example, whether only high scores were acted upon).
- Staff descriptions of women's concerns documented in the care plan (the care plan requires the healthcare professional to include these in the women's own words).
- Use of 'cut-off scores' (described in Chapter One, p26) such as whether the actions reflected the cut-off scores for escalation that staff had stated existed in their interviews.
- Quality of the care plan, for example how this was written and key positive or negative features.

Considering documents in this way also enabled triangulation of data between interview responses and care plans, to determine what participants felt were strengths and weaknesses of these documents. Within the letters of invitation participants received to complete an (e)HNA, specific attention was paid to how the information was written, or what was deemed as priority information to convey by staff at the two sites. This is explored further in Chapters Four and Five.

Alongside analysis of these, all documents were also used as memory prompts in women's face-to-face interviews by showing these to participants, particularly when time had passed since the participant had completed their (e)HNA. For example, in Case Study 1, the Macmillan Cancer Support leaflet and online access card (which was conspicuous due its size, bold images and colour scheme) was shown to women. These were often useful as memory prompts, as women confirmed that they recalled receiving these leaflets, even if the name of the assessment could not be recollected. Furthermore, where available, care plans were shown to participants during their interviews so that these could be re-read and prompt recall of the discussion, which was often successful.

3.4.5 Data Analysis

Following data collection, Framework Analysis was adopted, which is an increasingly used approach to data analysis in health and social research (Gale et al., 2013).

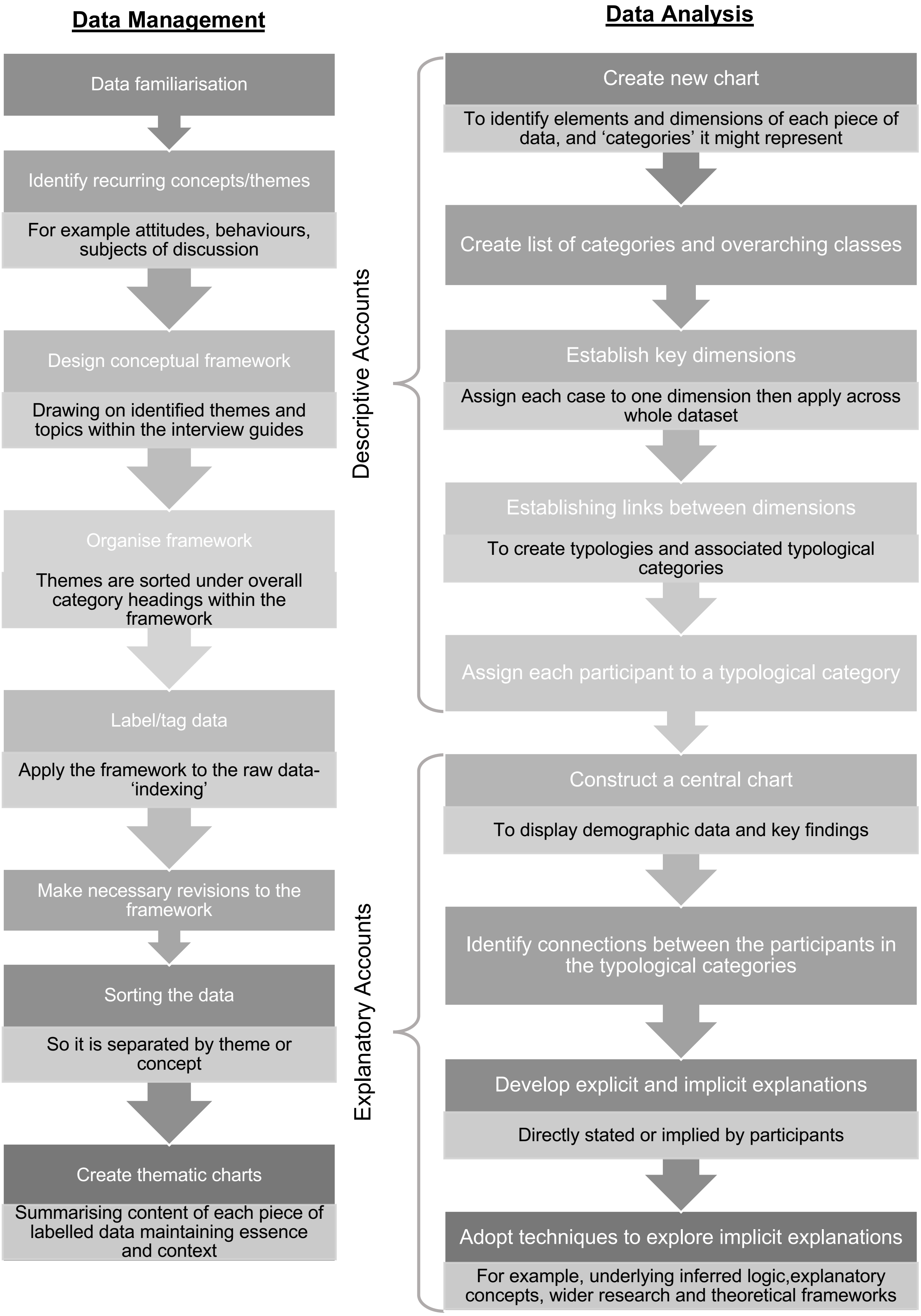
Generally, efficient qualitative analysis should, maintain the essence of data, facilitate ordering of data for comparison between different cases or participants, enable systematic coverage of the data, and transparency in reporting of findings (Spencer et al., 2013). With this in mind, key strengths of the Framework Analysis approach are its grounding within the original accounts of participants, its adaptability, clear structure, comprehensiveness, and ability to easily retrieve data for cross-case analysis (Gale et al., 2013). The epistemological roots of Framework Analysis draw on a variety of approaches, including elements of positivism, interpretivism and pragmatism (Spencer et al., 2013). However, the Framework Analysis method does not exclusively align with a specific epistemological position, and is therefore adaptable to many qualitative approaches (Gale et al., 2013; Spencer et al., 2013). Critics of the Framework Analysis approach have highlighted its time-consuming nature, and the risk that using systematic charts may lead to quantification of data (Gale et al., 2013). However, Spencer et al. (2013) highlight the complex nature of case study analysis, due to the challenges of accurately mapping concepts within large amounts of data, in a way which can be revisited and compared between cases. Overall, the systematic and comprehensive processes within Framework Analysis provide a robust structure in which to undertake this complex analysis, and this method was therefore chosen for the current study.

According to Spencer et al. (2013), the five key stages of Framework Analysis are familiarisation, identifying a thematic framework, indexing, charting, mapping and interpretation. These are divided between ‘data management’ and ‘data analysis’ procedures. Figures 17 and 18 summarise key Framework Analysis terminology and processes.

Figure 17. Framework Analysis Terminology (Spencer et al., 2013)

Term	Definition
Classes and Categories	Part of the 'descriptive accounts' phase of analysis, where charted data are taken to the next level of abstraction to identify 'categories' which summarise the data. When this has been applied to all data, the categories can then be grouped into further thematic 'classes' which represent broader groups.
Indexing	Applying a framework of early categories (a 'thematic index') to the whole dataset during data management. This is known as indexing as opposed to coding, based on the absence of abstraction (identifying key dimensions) at this stage, and referring more to labelling the data to determine which components of the index apply.
Matrix	Following the process of indexing from early categories, matrices are ways of grouping the data into systematic charts where data can be explored. In this context, each early theme with its associated subcomponents would be charted within a separate thematic matrix, also known as a 'thematic chart'.
Typology	The combination of two or more dimensions identified through the process of sorting and analysing data, which provide a more complex depiction of a phenomenon or characteristic, often relating to groups of people or phenomena.
Explanatory Accounts	This refers to the analytic process of detecting patterns within the data which enables a more in-depth understanding between various phenomena, and use of associations to develop explanations.

Figure 18. Processes in ‘Framework Analysis’ (Spencer et al., 2013)



3.4.5.1 Data Management

The initial data management process begins with the researcher's immersion in the data, providing a foundation of understanding prior to identifying early themes and concepts (Spencer et al., 2013). Using a cross-section of data is recommended for this initial procedure (Spencer et al., 2013), and thus six interview transcripts from staff, six from women, six care plans and two observations were selected. The concepts highlighted were then assembled under broader headings to develop a 'thematic index', consisting of five categories and 48 sub-categories. The thematic index was then applied to the whole dataset (known as 'labelling' or 'tagging' the data), which included some pieces of data placed within multiple categories. As recommended by Spencer et al. (2013), when new concepts were identified, the whole dataset was revisited to ensure these had not surfaced elsewhere within the transcripts. The process was undertaken using Nvivo 12 software, a data management programme which enables organisation, and supports activities such as indexing (QSR International, 2020). Use of Nvivo also allowed for each category and its component data to be revisited at later stages of data management.

Figure 19. Initial Data Management Processes

Subsequently, the data within each section were explored more thoroughly to reduce overall quantity, which led to development of a matrix representing each of the broader themes (an excerpt from which is provided in Appendix M). Within these matrices, each participant was plotted against each theme to map out their individual data in a format which could be revisited. The following step ‘synthesising or summarising the data’ involved maintaining the essence of each piece of data within these matrices (often using the original language and no interpretive analysis), which served to further reduce data quantity (Spencer et al., 2013). A total of five matrices were developed using Microsoft Excel.

3.4.5.2 Data Analysis

Following the principles of ‘data management’ within Spencer et al.’s (2013) Framework Analysis approach, these are succeeded by data analysis processes, separated into ‘descriptive accounts’ and ‘explanatory accounts’.

3.4.5.3 Descriptive Accounts

Firstly, Framework Analysis’ data analysis begins with descriptive accounts, referring to a general unpacking of content and dimensions within phenomena or concepts (Spencer et al., 2013). This process involves detection, categorisation and classification of data, to create a system of meaningful ‘classes’ and ‘categories’ which group data. As with the development of the thematic index, this categorisation and classification of data allowed creation of a newly refined framework where data could be assembled.

Secondly, establishing typologies is a key element within the Framework Analysis process, defined as multidimensional groupings in which ‘types’ of phenomena are divided and organised (such as groups of people) (Collier et al., 2012). Typologies are created through identifying key dimensions within study data, and combining these to provide a more complex portrayal of the phenomenon (Spencer et al., 2013). Overall, typologies make significant contributions to analysis in the social sciences, through refining key concepts and understanding (Collier et al., 2012).

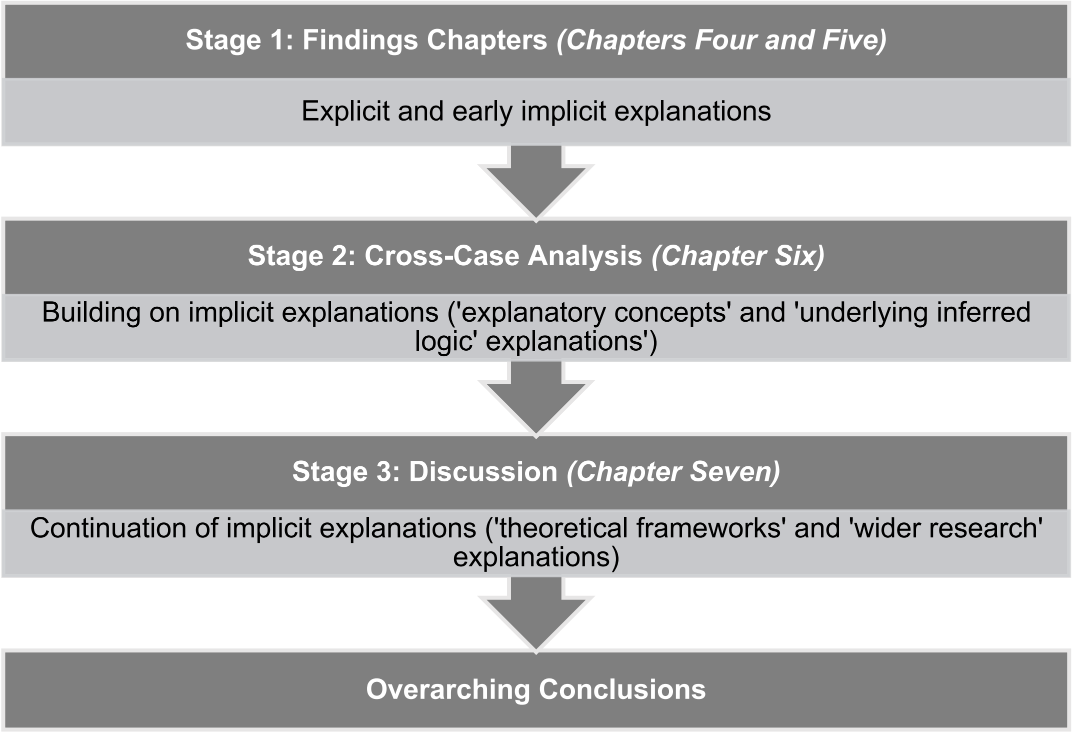
As displayed in Figure 20, the initial step in typology development is to undertake further data immersion to understand the various elements of a dimension or phenomenon. Subsequently, 'typological categories' are formed, which group participants (or other phenomena) according to patterns in the data. The process requires continuous refinement of the classes and categories, to accommodate each participant into one typological category, rather than overlapping between multiple categories (Spencer et al., 2013). In this study, two overarching typologies were developed in response to the research question, with one grouping women with cancer into typological categories, and the same process for staff. The two dimensions involved in construction of the typologies were identified through data immersion and mapping out summaries of key data reported by each participant using the matrices. More detail concerning the typologies is given in Chapters Four and Five.

Figure 20. Typology Development

3.4.5.4 Explanatory Accounts

The explanatory accounts component of Framework Analysis focuses on identifying connections within the data, to develop ‘explicit’ and ‘implicit’ explanations which provide greater depth of understanding (Spencer et al., 2013). Explicit explanations are derived from the views directly stated by participants, whereas implicit explanations build upon explicit comments to consider inferences made by the researcher (elements not openly stated by participants) (Spencer et al., 2013). To identify implicit explanations, several techniques are recommended. These are: ‘explanatory concepts’ (the development of phrases to explain a phenomenon, and variations in behaviour or views which result from this), ‘underlying inferred logic’ (exploring connections in the data which use well-known patterns or simply make sense as explanations) and use of wider research or theoretical frameworks (Spencer et al., 2013). The process of identifying these connections was facilitated through construction of a central chart, to highlight links and patterns (a section of which is presented in Appendix N). Within this thesis, implicit explanations are explored over Chapters Four-Seven, and are divided into three stages (shown in Figure 21).

Figure 21. Presentation of Explanatory Accounts Analysis



3.4.5.5 Cross-Case Analysis

As outlined at the outset of this chapter, Stake (1995) emphasises that cases should be considered in isolation prior to the merging of findings (Stake, 1995), and this process was facilitated by Framework Analysis (see Chapters Four and Five). However, despite Framework Analysis providing a way to manage and analyse data across and within cases, this process provides few details for how to present cross-case comparison.

Following single case analysis, Stake (1995) describes the need to triangulate findings both within and between case studies, to ensure meanings are clearly understood and reduce the risk of bias through use of multiple research methods (Stake, 2006). To provide a comparison between cases, various approaches can be adopted, including the development of what Stake (2006) refers to as ‘worksheets’ (charts containing key themes from each case so comparison can occur), which both refine and strengthen themes identified through comparison. When conducting cross-case analysis, common findings should be combined whilst maintaining the independent circumstances of each case (Stake, 2006). Therefore, following individual case analysis, variations of Stake’s (2006) worksheets were adopted to report and compare the cases. This process was facilitated by using Framework’ Analysis’ matrices, which capture and maintain the uniqueness of participants and cases.

3.4.5.6 Ensuring Rigour

Throughout qualitative data collection and analysis, rigour should be maintained (Stake, 1995). Fossey et al. (2002) focus on the concepts of ‘methodological rigour’ (standards of research planning, conduct, analysis and reporting) and ‘interpretive rigour’ (trustworthiness of interpretations made), which are required to ensure studies are robust in their development and procedures (Fossey et al., 2002). Methodological and interpretive rigour can be achieved through triangulation of multiple evidence sources to corroborate conclusions (Fossey et al., 2002). For interpretive rigour, Stake (1995) emphasises the importance of focusing on detail to understand each unique case, as opposed to generating findings applicable to a broader range of cases. However, the learning from a unique may inform understanding of broader concepts or different cases, despite this not being the key priority (Stake, 1995). To improve rigour, Stake (1995) emphasises the value of triangulation, and the challenges of this notion from a constructivist perspective. Constructivists consider that no one perspective is superior or correct, and the aim of triangulation is therefore to represent the data as participants themselves have presented it (Stake, 1995). Several variations of triangulation are differentiated between in Figure 22.

Figure 22. Stake's (1995) Classifications of Triangulation

Type	Definition
Data Source Triangulation	Whether a phenomenon remains the same at different times, locations or between individuals.
Investigator Triangulation	Obtaining views of the same data from other researchers.
Theory Triangulation	Similar to investigator triangulation but relating to differing theoretical stances of researchers, for example varying perspectives between nurse and psychologist researchers.
Methodological Triangulation	Comparison of findings between data sources (such as interviews and documents)

This study attempted to consider all aspects of triangulation, to give greater confidence in findings generated. For instance, data source triangulation was considered through identifying whether delivery and contributions of the (e)HNA were consistent across differing points in the cancer journey, between locations (such as face-to-face or home assessments) or between individuals (such as when this was delivered by a SW or a BCN). Secondly, robust and critical discussions took place with the thesis' supervisors to determine approaches and outcomes in analysis, and provided differing interpretations of data in some cases, due to experiential and theoretical backgrounds distinct from my own. Finally, methodological triangulation was undertaken via multiple data sources to understand the (e)HNA's use, for example comparing participant experiences of an (e)HNA interaction reported through their interview, with an observation I witnessed from the same interaction. This triangulation can improve understanding, particularly where certain influences on an outcome are not witnessed (for example, reasons for non-disclosure of concerns on the (e)HNA).

3.5 Ethical Considerations

The final section of this chapter concentrates on potential ethical issues arising when undertaking research in general, and in this study specifically. The ESRC outlines that research should provide maximum benefits to the target population and minimise risk of harm to participants, alongside upholding individual rights (ESRC, 2017). Therefore, many possible issues should be considered when designing a study (World Medical Association, 2008).

3.5.1 Ethical Approval Process

Due to the study focusing on individuals with cancer as well as health care staff, full ethical approval from the Health Research Authority (HRA) (obtained 16/04/2019, IRAS ID for HRA approval: 259760), Research Ethics Committee (REC) (obtained 12/04/2019, reference: 19/EM/0076), and local Research and Development departments (R&D) (Case Study 1 reference: 19/023/GHT; Case Study 2 reference: UHDB/2019/057) were required prior to commencing the study. This process involved significant planning to ensure the details of the study were accurate, whilst maintaining some degree of flexibility to allow for small, site-specific differences in the delivery of (e)HNAs.

The key potential ethical considerations within this study were deemed to be informed consent, dual-identity (nurse-researcher), confidentiality and anonymity, and vulnerability or distress. These issues are discussed below.

3.5.2 Informed Consent

A fundamental component of conducting high-quality research is obtaining informed consent from participants (ESRC, 2017). The process of gaining informed consent goes beyond a simple agreement to participate, and involves awareness of the methods, purpose and uses of study findings, alongside potential risks introduced (ESRC, 2017). Consequently, this study's participant information sheets and consent forms provided detailed explanation of the above, to ensure clarity of understanding when consent was given. Additionally, these forms presented a clear description of the voluntary nature of the study, emphasising that non-participation would not be detrimental to their care (shown in Appendix I). However, although understanding of the study was an essential consideration, it was important for participants to also recognise that participation was optional. This can be especially problematic when the researcher has a clinical professional background, as discussed below.

3.5.3 Dual Identity

It is widely acknowledged that a therapeutic relationship exists between nurses and those in receipt of care, which can lead to complications when nurses are also researchers (Judkins-Cohn et al., 2014). In this instance, individuals may view the researcher as a caregiver, thus potentially influencing decisions to participate in the study, or the nature of information they divulge in research encounters (for example, sharing medical concerns) (Judkins-Cohn et al., 2014). In the current study, separation between the roles was explicitly clarified when obtaining consent, emphasising that my role functioned as researcher, and that participation was entirely voluntary and would not affect their care.

A further issue with the nurse-researcher identity is the nursing profession’s duty of care obligation to report issues surrounding poor practice or risk of harm (Judkins-Cohn et al., 2014; Sanjari et al., 2014). Therefore, this responsibility was disclosed to participants in the study consent forms (Appendix O). The above considerations also highlight the essential nature of reflexivity, to produce ethical research practice through contemplating how personal identity may influence interactions with participants (Clarke, 2006; Sanjari et al., 2014).

3.5.4 Confidentiality and Anonymity

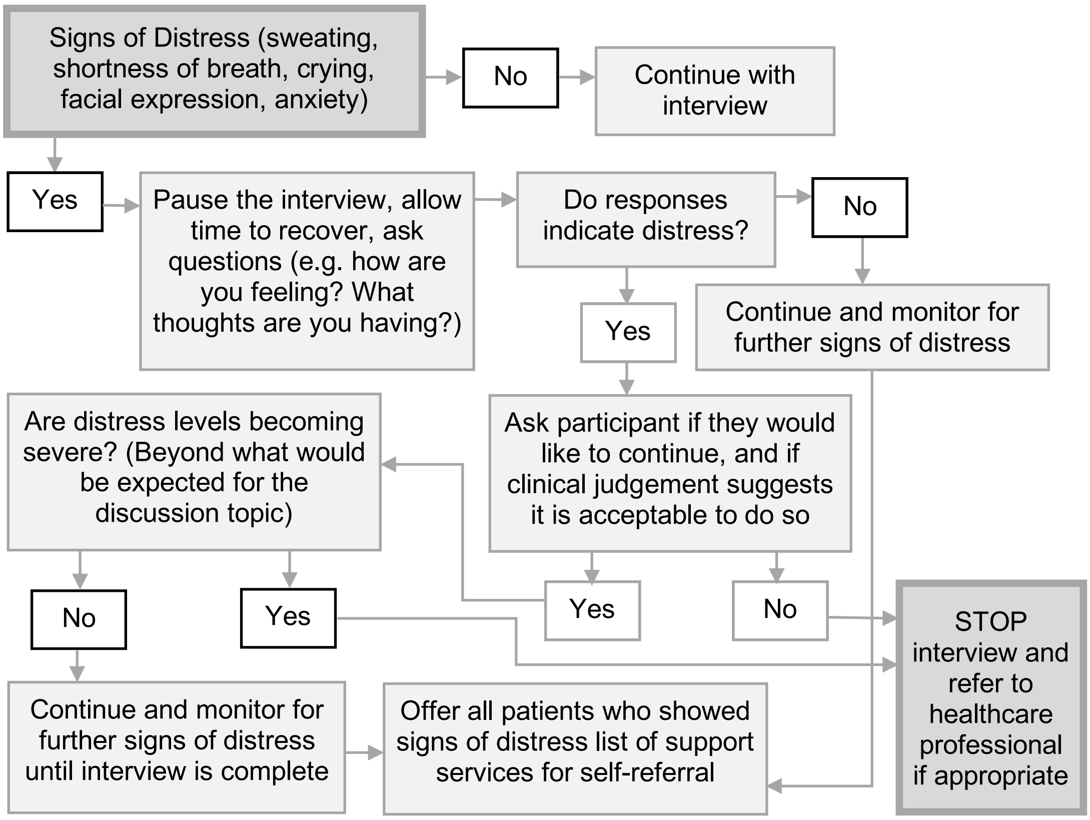
Thirdly, confidentiality is described as a basic human right, however much research conducted in healthcare environments requires access to personal information (Medical Research Council (MRC), 2014). Therefore, study participants should have a comprehensive understanding of how their personal information and research data will be used, a process facilitated by obtaining informed consent (MRC, 2014). Confidentiality also extends to data protection (MRC, 2014), which was upheld by securely storing the case report forms, consent forms, data transcripts, audio files and participant identifiers, in a locked room at the University of Nottingham (for paper files), and on a secure, password protected database (for computerised files). Access to the research data is limited to the researcher and academic supervisors, and is retained for a period of seven years, as per local policy. In this study, the issue of confidentiality is also applicable to several kinds of personal information, including having knowledge of the individual’s medical diagnosis and treatment plans, and their completed (e)HNA and care plan. Maintaining confidentiality amongst the study team was therefore essential in upholding the rights and dignity of those recruited.

As for anonymity, this process was supported by the use of anonymous personal identifiers and pseudonyms to present study findings, in order to protect individual identities. Alongside this, staff recruited indicated negative views of the (e)HNA on occasion, which could result in negative reactions or conflict among team members if widely known. In the reporting of findings, measures were taken to avoid identification of specific participants through labelling by job title. However, a potential issue relating to ‘internal confidentiality’ was considered, where the small number or uniqueness of individuals in a particular context could enable others within the group to identify participants from their quotations (Saunders et al., 2014). In this situation, it is important to maintain a balance between anonymity and sufficient context and integrity in data reporting, so as not to influence how findings may be interpreted (Saunders et al., 2014). Although steps were taken to mitigate this risk through the removal of staff names and departments, the small team focusing on breast cancer (e)HNAs in the Trusts meant that the use of job title might reveal identities in roles. Therefore, every attempt was made to make role titles more generic, such as ‘support worker’ instead of breast navigator, and ‘project manager’ instead of Macmillan Improvement Lead or other official job titles held by participants.

3.5.5 Vulnerability and Distress

The ESRC’s ethical principles highlight the importance of protecting participants from harm (ESRC, 2017). However, this can be especially challenging when the research conducted involves vulnerable individuals, such as those with cancer (Slowther et al., 2006). Consequently, the discussion of sensitive issues during data collection may potentially lead to distress, or have a negative emotional impact. In the current study, discussions did not directly focus on the cancer diagnosis, however sensitive issues (such as feelings at diagnosis and concerns raised on the (e)HNA) often surfaced during conversations. As a researcher with a nursing background in cancer, I am accustomed to both recognising and responding to distress related to cancer, through communication skills and appropriate referrals for support if needed. However, risk of distress was further mitigated using a distress protocol, which provides an action plan for the researcher’s use (including when to stop an interview, and when to seek external support), with the aim of minimising harm or distress from a research encounter (Draucker et al., 2009; Haigh & Witham, 2015).

Figure 23. Distress Protocol (Adapted from Draucker et al., 2009)



Throughout the course of data collection, no severe distress was noted. However, in two situations where a participant became tearful, the digital recording device was paused and supportive questions asked as per the protocol. In both situations, the participant was keen to continue the interview, and experienced no further distress. Participants were also provided with a list of key contacts should they experience distress following their interview, as per the protocol (such as contact details for local support groups, the hospital BCNs and Macmillan Cancer Support). The lists of key contacts were developed and adapted at each site, in collaboration with the BCNs.

3.6 Conclusion

This chapter has presented an overview of methods and procedures undertaken during the study, under the four headings of methodology, study design, methods, and ethical considerations. Concepts of reflexivity and rigour are interwoven throughout the chapter, providing a reflective focus and justification for decisions. The explanations provided have highlighted detail regarding processes, and have set the scene for presentation of study findings. The findings are structured according to each individual site (Chapter Four - Case Study 1 findings, Chapter Five - Case Study 2 findings), prior to cross-case analysis in Chapter Six. This choice of reporting allows each case to be understood in-depth within its original context, before considering overarching conclusions resulting from the study.

Figure 24. Chapter Three Key Points

Chapter Three Summary: Key Points

- The study’s methodology was described, describing a qualitative approach influenced by elements of an interpretivist-constructivist stance.

- Research design was also explored, including an overview of case study research and Stake’s (1995) approach, and how the notion of reflexivity was interwoven to shape the study.

- Discussion of methods included exploration of the interlinking data collection components of interviews, observations and document analysis, alongside the in-depth Framework Analysis (Spencer et al., 2013) technique to manage and interpret the data.

- Ethical considerations explored the protection of participants from a data management and recruitment perspective (such as confidentiality and informed consent), followed by study-specific issues such as the risk of distress, and considerations from having a dual nurse-researcher role.

Chapter Four: Case Study 1 Findings

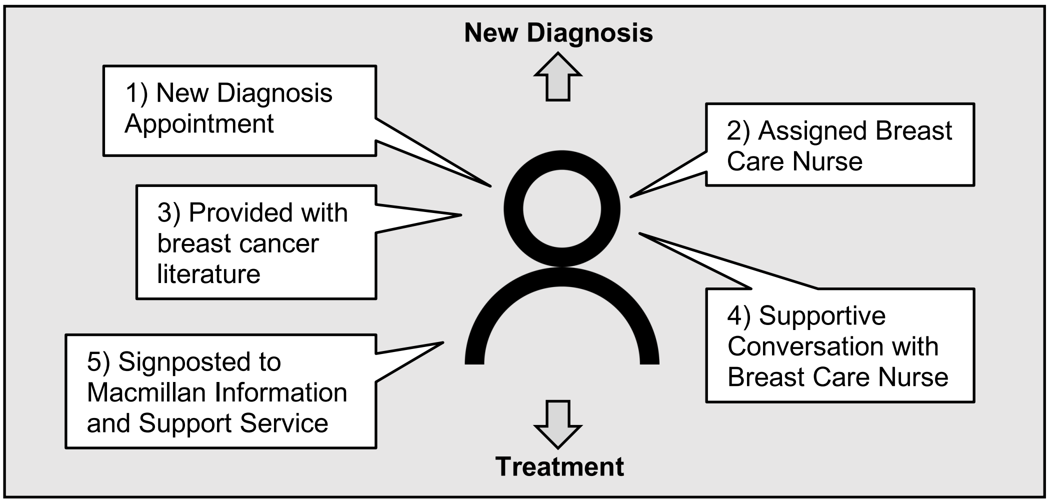
4.1 Introduction

This chapter presents findings from Case Study 1 (Site 1). As discussed in Chapter Three's explanation of methods, the Framework Analysis approach began with data management, before progressing to analysis which featured 'descriptive accounts' and 'explanatory accounts'. Initially, this chapter highlights the context of Case Study 1, followed by the findings from descriptive accounts analysis. Within this section, the framework of classes and categories is explored, and presentation of the typologies and typological categories that grouped participants. Subsequently, the explanatory accounts process is described, with Stage 1 discussed in this chapter, and Stages 2 and 3 continued in Chapter Six and Seven. The term '(e)HNA' is used throughout the discussion of findings to cover all holistic needs assessment types used within the case studies.

4.2 The Case

The acute NHS Trust chosen as Case Study 1 contained two main hospital sites that delivered cancer care through a day unit, cancer inpatient wards, and a specialist, outpatient breast centre. For all women newly diagnosed with breast cancer, the process of 'routine care' included their initial appointment to receive their diagnosis (in the presence of a breast care nurse (BCN) where possible), followed by a supportive conversation with the BCN. Ordinarily, BCNs would relay information or treatment options in this conversation, and emotional support was provided where necessary. The BCN then became the individual's primary contact, and endeavoured to attend appointments with the consultant throughout their cancer journey. The majority of staff in this team worked across both hospital sites. At diagnosis, most women were also routinely signposted to the local Macmillan Information and Support Service, as a way to access further support.

Figure 25. 'Routine care' in Case Study 1



4.2.1 Local (e)HNA Usage

In the context of the (e)HNA, Case Study 1 aligned with the national targets (discussed in Chapter One), which meant they aimed to offer (e)HNAs around diagnosis and at the end of treatment. Delivery of this goal was primarily driven by the Macmillan Cancer Support-funded project manager, whose role was focused on (e)HNA implementation.

In Chapter One, definitions were provided for instances of (e)HNA non-completion and how these are reported, for example 'expired[1]' or

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[1] The (e)HNA is not completed in the time period the healthcare professional set it up for (for example 12 weeks), and the online link becomes invalid.

'declined'. Table 9 presents a breakdown of (e)HNA figures in 2019 (obtained from Case Study 1's project manager), including which stage in the cancer pathway these occurred.

Table 9. Case Study 1 (e)HNA 'Expired or Declined' by Pathway Stage Figures 01/01/2019-31/12/2019

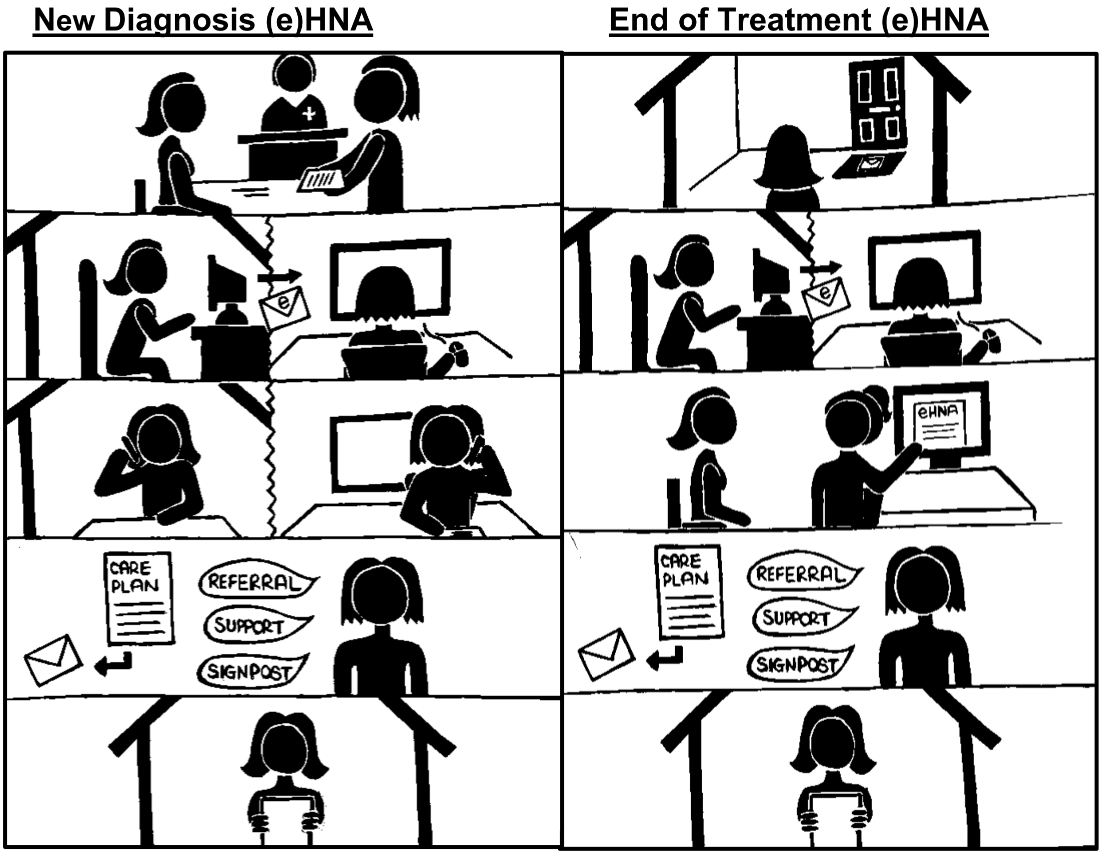
Initial Diagnosis			**During Treatment**			**End of Treatment**		
Total Offered	**Expired/ Declined**	**Total Completed**	**Total Offered**	**Expired/ Declined**	**Total Completed**	**Total Offered**	**Expired/ Declined**	**Total Completed**
569	138 (24%)	431 (76%)	177	46 (26%)	131 (74%)	206	50 (24%)	156 (76%)

As demonstrated above, the study site reported generally high (e)HNA completion rates in 2019. Cases of expired or declined (e)HNAs were fairly evenly distributed across pathway stages.

4.2.1.1 (e)HNA Offers

The study site aimed to uphold a 'gold standard' delivery process when offering (e)HNAs. However, informal discussions with staff revealed challenges with the reality of delivering this. At the point of data collection, the standard process of (e)HNA delivery is reflected in Figure 26.

Figure 26. Image Representing ‘Gold Standard’ (e)HNA Delivery Process



New Diagnosis (e)HNA

End of Treatment (e)HNA

Image drawn by and property of the researcher

Figure 26 shows an information pack being given to the individual at their new diagnosis appointment, which contained three elements:

- A letter inviting them to complete the (e)HNA (Document 1).
- A Macmillan Cancer Support HNA leaflet (Document 3).
- A small, Macmillan Cancer Support card which provided (e)HNA online accessibility details (Document 4).

Further detail about these three items is explored in Section 4.2.3, alongside Document 2, which is a similar (e)HNA invitation only given to individuals being offered an additional (e)HNA during chemotherapy. Because these documents were central to many women's initial impression of the (e)HNA, they were chosen for analysis as part of the case study's data.

Following receipt of the information pack, the standard (e)HNA process at diagnosis enabled individuals to complete their (e)HNA online at home. The system then sent an automatic notification to the support worker (SW) to inform them of the (e)HNA's completion. Subsequently, the SW and woman discussed the concerns raised on the telephone, from which a care plan was created and posted to the individual.

For the end of treatment (e)HNA, the same information pack was posted to the individual, prompting similar methods of completion online at home. Afterwards, the woman was invited to an end of treatment appointment, in which a BCN talked through their concerns face-to-face, generated a care plan and posted this to the individual. Although Figure 26 represents standard processes for offering (e)HNAs in Case Study 1, these also occurred at unplanned times at the staff member's discretion, or during chemotherapy.

4.2.1.2 Addressing (e)HNA Concerns

When addressing the concerns raised within an (e)HNA, the process was individualised for each woman, including actions such as referral to internal services (for example, psychology), signposting to external services (such as benefits advice and support groups) and general advice.

Locally, decisions were made to apply ‘cut-off scores’ when addressing concerns raised through (e)HNAs (defined in Chapter One). This policy determined that concerns rated as four or below were dealt with by a SW, but those above four required a BCN to decide the appropriate course of action. Within this organisation, the rationale for implementing cut-off scores appeared related to the responsibilities assigned to different roles, for example non-registered staff (no formal nursing qualification) did not address higher-level concerns, due to their responsibility level. In further discussion, staff indicated that the cut-off score of ‘four’ was a figure determined by the project manager, yet it is unclear how this decision was made.

4.2.2 Participant Demographics

4.2.2.1 The Women

In Case Study 1, 12 individuals with breast cancer were recruited, ranging in age from 50-78 years, with an average age of 60 years. All were of a White, British ethnicity (despite individuals from diverse ethnic backgrounds being invited to join the study) and had varied characteristics in terms of their education, employment and marital status (Appendix J). The women lived in different locations within the area covered by the Trust, and had varying personal circumstances, priorities, worries and experiences. Some contextual information about each individual is provided in Table 10, alongside the pseudonyms they were assigned.

Table 10. Women with Cancer: Pseudonyms and Context

No.	Pseudonym	Context
0101P	Jane, 69	Jane had just obtained her diagnosis when she was interviewed but had an unclear treatment plan. She

		was retired, lived alone and had a good social support network. Her hobbies included walking her dog and she was a member of a choir. Jane was educated to degree level. Her research interview was conducted in her home after completion of the (e)HNA, and no observation was possible.
0102P	Marie, 63	Marie was widowed and living alone. She was unemployed and stated she had few hobbies due to financial difficulties, which also prevented trips to the hospital to access supportive services. Many services available were geographically distant from her home. She had a small social support network, and she supported other members of her family who had medical conditions. Her research interview was completed in her home, and no opportunity for observation was possible.
0103P	Kate, 51	Kate was single, living alone, and employed in a health and social care job (but was off work at the point of interview due to ongoing treatment). She was educated to university level and had her interview conducted in her home. No opportunities were presented for an observation.
0104P	Ruth, 58	Ruth was married and in full-time employment, although she was on sick leave at the point of data collection due to ongoing treatment. Her interview was home-based, and she completed no (e)HNAs, therefore no observation opportunities were presented.
0105P	Laura, 64	Laura was married and also in full-time employment, although she was on sick leave at the point of data collection. Laura’s interview was conducted in her home whilst her husband was in another room, and she was intentionally lowering her voice during certain parts of the discussion. No observation was possible.
0106P	Paula, 57	Paula was single and in full-time employment (on sick leave due to ongoing treatment) when she was interviewed in her home. She had a good social support network through her family. No observation opportunities were presented.
0107P	Sarah, 50	Sarah was married, self-employed and educated to degree level, with a good social support network. Her teenage children took up a lot of her time. She was a regular runner and enjoyed keeping active, which continued during treatment. She was interviewed at home, but had a prior commitment that meant she had to shorten the interview to accommodate this. No observation opportunities were available.

0108P	Rose, 56	Rose was married and in full-time employment. She was at the end of treatment when we met and had returned to work. Colleagues were a great source of emotional support for her. Rose enjoyed keeping active but was struggling to do so due to her treatment side-effects. Rose's interview was conducted in the hospital at her request, as she was attending to see the BCN for an end of treatment (e)HNA appointment, which was then observed.
0109P	Joan, 78	Joan was married and retired, living with her husband at home. Joan was the carer for her husband who had dementia, and had been trying to increase social care for him, as he required all of her attention. Her interview was conducted in her home whilst her husband was asleep, and she regularly went to check on him during the interview. No observation was possible, as Joan had completed her treatment at the point of interview.
0110P	Harriett, 57	Harriett was married and unemployed. She emphasised her great social support network through her family and had a comfortable financial situation. She was having ongoing treatment at the point of interview. The interview was conducted in her home. No observation was possible.
0111P	Claire, 56	Claire was divorced and employed part-time in a healthcare profession. She was beyond treatment at the point of interview, and was feeling positive about the support she had received from work. Her interview was hospital-based at her request. No observation opportunity was presented.
0112P	Tina, 55	Tina was married, part-time employed and felt that she had received poor support from healthcare professionals and her social support network. She was looking for new cancer support groups and other resources. Her interview was conducted in her home and she was beyond treatment when we met. She had not been offered an end of treatment (e)HNA appointment (and so observation was not possible).

4.2.2.2 The Staff

As previously outlined, women with cancer were routinely allocated one BCN, although staff provided cross-cover in the event of sickness absence or planned leave. The SWs also frequently dealt with tasks that did not require input from a BCN (such as administrative tasks).

Of the 12 staff participants recruited for Case Study 1, half were BCNs and there was one advanced nurse practitioner (ANP) (n=6, 50%) whose role in (e)HNA delivery echoed the BCN's role. Two participants were SWs (n=2, 16%). As part of the Macmillan Cancer Support funding offered to organisations to support delivery of (e)HNAs, a project manager and programme manager were employed within Case Study 1, and also took part in the study. Another participant worked within the Macmillan Cancer Information and Support Service, who regularly assessed individuals with cancer in a less structured way, (these assessments had similarities to (e)HNA discussions). The project and programme managers and the SWs were reasonably new in their roles, ranging from six months to three years in their positions (averaging 1.5 years). The BCN/ANP team were more experienced, ranging from 6 months to 22 years, and averaging 11.5 years of experience. Most staff were employed full-time (n=10, 83%), and further demographic details are available in Appendix J. For the presentation of data in this chapter, staff were provided with participant identifiers denoting their job role, to display their role in the delivery of (e)HNAs (for example direct delivery or service oversight).

Table 11. Staff Participant Identifiers (used to present findings)

No.	Age	Role	Referred to as:
0101S	28	BCN	BCN 1
0102S	56	BCN	BCN 2
0103S	28	Programme manager	Programme manager
0104S	46	Macmillan Information & Support Service staff member	MCISS staff member
0105S	45	SW	SW 1
0106S	55	Project manager	Project manager
0107S	60	SW	SW 2
0108S	52	Lead BCN	Lead BCN

0109S	53	BCN	BCN 3
0110S	41	BCN	BCN 4
0111S	55	Advanced nurse practitioner	ANP
0112S	51	BCN	BCN 5

4.2.3 Contextual Data

Prior to presenting Case Study 1's findings, contextual information for observations and documents collected in this case study is presented. This enables background understanding of the data collection scenarios as they are introduced throughout the chapter, alongside the information provided in Chapter Three. Initially, Table 12 provides a summary of the only observation undertaken in Case Study 1, with Rose (0108P) and BCN 2 (0102S).

Table 12. Case Study 1 Observation Context

Rose's (0102S) Observation
Context: End of treatment clinic appointment, face-to-face. **Summary:** BCN 2 received Rose's completed (e)HNA prior to the appointment, and concerns raised were discussed within the appointment, alongside recommendations made. **Rose's (0108P) Behaviour:** Rose adopted closed body language throughout her observation. Within the discussion, she displayed periodic tearfulness alongside making jokes, defensiveness and explaining why she could not enact the BCN's suggested behavioural changes. **BCN 2's (0102S) Behaviour:** BCN 2 had open body language initially, which became progressively more closed throughout the observation. She did not react to Rose's episodes of tearfulness until the eighth occasion, at which point support was offered.

Additionally, care plans were obtained for all the women recruited. Table 13 provides details of the number of care plans completed for each individual, alongside the number and scoring of concerns raised, and which staff member completed the document. This information provides context for the comments women made in their interviews.

Table 13. Case Study 1 Care Plan Context

Participant	No. of Care plans	No. of Concerns	Average Score of Concerns	Staff Role
Jane	1	1	11	SW
Marie	1	2	3	SW
Kate	1	9	3	SW
Ruth	0	N/A	N/A	-
Laura	1	7	8.7	SW
Paula	0	N/A	N/A	-
Sarah	1	2	1	SW
Rose	2	Care plan 1) 10 Care plan 2) 24	4.4 7.5	SW BCN
Joan	2	Care plan 1) 0 Care plan 2) 10	N/A 7.1	SW BCN
Harriett	1	0	0	-
Claire	1	5	6	BCN
Tina	2	Care plan 1) 20 Care plan 2) 32	6.2 5.4	SW SW

Section 4.2.1.1 highlighted the information pack women received when they were offered (e)HNAs, which often acted their initial introduction to the tool (either partly or entirely). Table 14 provides a summary of content for each of the documents routinely provided.

Table 14. Case Study 1 Generic Documents Context

Document	Summary of Content
Document 1: Case Study 1 Letter 1 (Main letter from breast team, offered at diagnosis) **(Appendix P)**	• Introduces SW who can offer practical support and signpost. • Describes the (e)HNA as beneficial and describes its content, states it will help to identify support. • Requests completion of the (e)HNA even if they have no concerns. • Explains leaflet is enclosed containing ‘pass code’ and provides web address for access.

	• States SW will contact them if they do not complete the (e)HNA.
Document 2: Case Study 1 Letter 2 (Main letter of invitation if undergoing chemotherapy) **(Appendix Q)**	• Explains the (e)HNA is being offered for support and there will be opportunity to discuss concerns with staff. • Emphasises that the (e)HNA is in two parts, includes paper version and option to complete online. • Asks to complete even if have no concerns, and outlines this can be done again if situation changes. • Explanation of the (e)HNA (focuses on concerns experienced over past week) to encourage a more detailed discussion around support. • Disclaimer about information provided being owned by Macmillan Cancer Support but not identifiable, stored securely and will not affect their care if they choose not to complete it.
Document 3: Macmillan HNA Booklet **(Not included as an appendix due to length of booklet)**	• 18-page booklet with image of friendly healthcare staff on cover. • Describes the (e)HNA as opportunity to reflect and discuss solutions. • Provides link to video for more information, image of the (e)HNA screen on tablet device. • Explains what usually happens in the (e)HNA appointment (answer questions, discuss answers, create care plan together). • States the care plan will include contact details for organisations signposted to, will be given copy of the care plan. • States (e)HNA takes approximately 30 minutes but should take as long as they need, will be done in private, comfortable setting or over the phone. • Small disclaimer about cancer registry and data held, and to talk to healthcare professional if questions. Document available to view at: https://be.macmillan.org.uk/Downloads/CancerInformation/ResourcesForHSCP/InformationResources/MAC12957HNAE04LowresPDF20190115HS.pdf
Document 4: 'Extra Support' Card **(Appendix R)**	• Small card that provides cancer patient quotation to emphasise all areas of life can be affected by cancer. • States the (e)HNA will help to provide support. • Includes information on how to complete the (e)HNA, including website address, date, pass code, the (e)HNA expiry date and the details of their key worker. • Includes Macmillan Cancer Support contact information and branding.

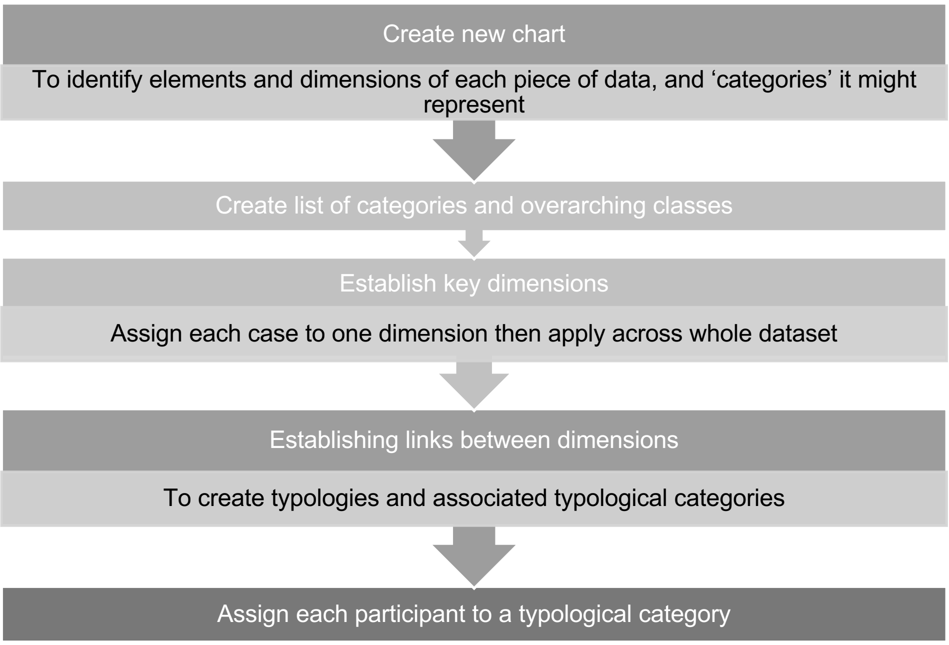
This section has presented an overall description of the context for Case Study 1. The subsequent sections outline findings in terms of descriptive accounts (including the overarching class-category framework and typologies), followed by explanatory accounts (separated into three stages across Chapters four to seven).

4.3 Findings: Descriptive Accounts

4.3.1 Overview of Findings

Presentation of the study's findings is structured around Spencer et al.'s (2013) Framework Analysis approach, described in Chapter Three. Due to the significant volume of data, this section provides a summary of all 'descriptive accounts' findings, prior to more detailed discussion of each aspect individually. Figure 27 shows an excerpt from Chapter Three which provides further detail on the descriptive accounts process.

Figure 27. Descriptive Accounts Analysis



The initial outcome from the Framework Analysis process was to development of an overarching framework of classes and categories using data from the matrices (Spencer et al., 2013), which is presented in Figure 28. The central overarching classes were ‘perceived contributions’ (the contributions of the (e)HNA to women’s experiences of support) and ‘wider influencing factors’ (wider contextual influences on the perceived contributions). These headings are further defined in Figure 29.

Figure 28. Overarching Classes and Categories

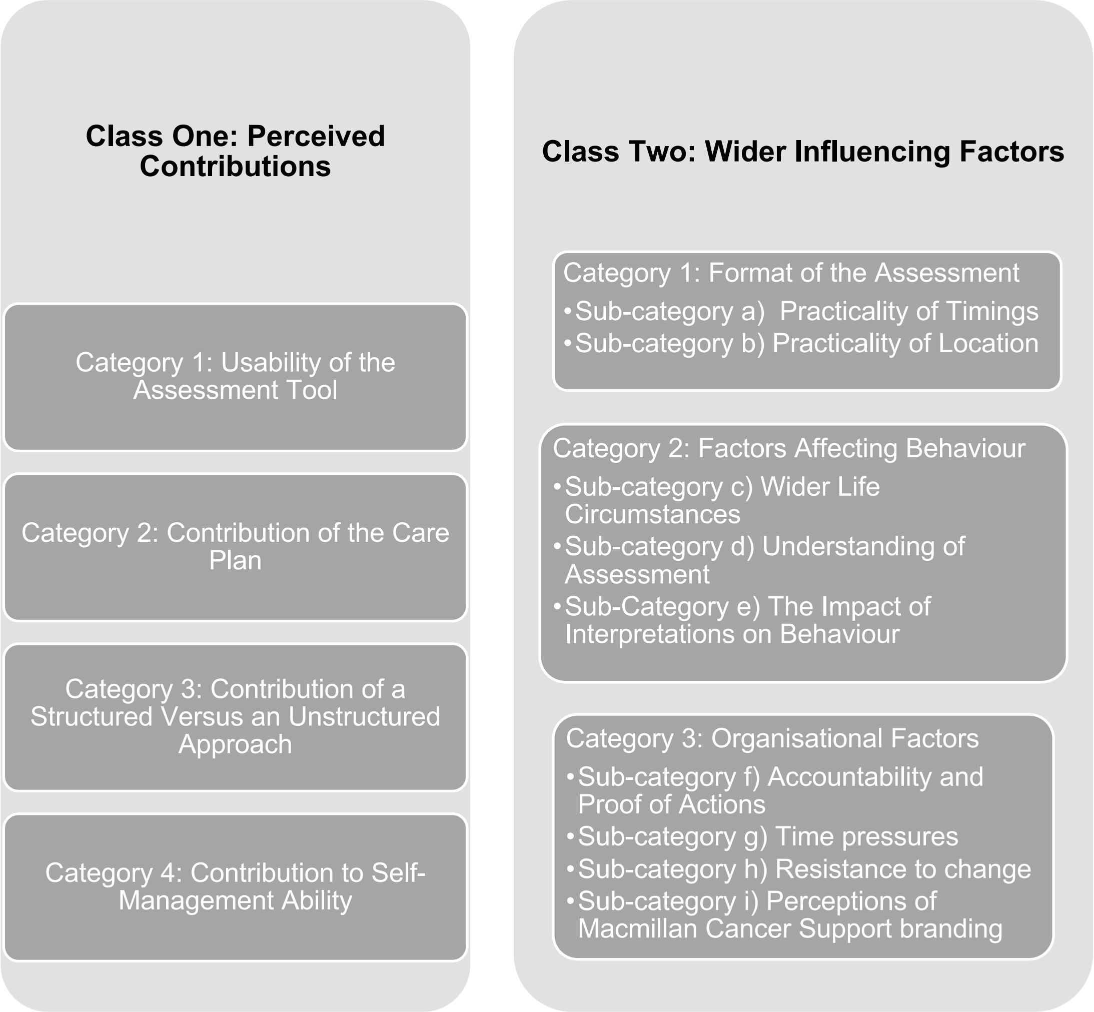


Figure 29. Definitions of the Overarching Classes

Definitions of the Classes

Perceived Contributions

Use of the term ‘perceived’ emphasises how participants regarded or understood the (e)HNA, in relation to its contributions to women’s experience (from a staff or women’s viewpoint). The term ‘contributions’ refers to what participants felt the (e)HNA added to their experience (for example, the value of the care plan, or the contribution of the (e)HNA beyond a general conversation, without a structured (e)HNA tool.

Wider Influencing Factors

As with ‘perceived contributions’, the term ‘perceived’ displays how participants regarded the (e)HNA, but alternatively focuses on ‘influencing factors’ for what the assessment contributed to women’s experiences. This phrase is used throughout Chapters Four-Eight to denote the variety of factors which frequently affected the (e)HNA’s contribution to women (such as location and timing of assessments, or staff resistance).

Once the class-category framework was assembled, the process of developing typologies began. Typologies are multidimensional groupings, which provide increased depth and understanding in analysis, and allow the social world to be divided (for example, groups of people, or groups of phenomena) (Spencer et al., 2013). The process of creating typologies includes identifying key dimensions in the data, which are combined to provide a more complex depiction of the phenomenon (Spencer et al., 2013). In the current study, data for women and staff were analysed together due to similarities in the themes that arose, but are presented separately. The above class-category framework (Figure 28) was used to generate central typologies and typological categories, through identifying two key dimensions which underpinned the framework:

1. Views of the (e)HNA’s use and delivery process

2. Views about the (e)HNA’s contribution to women’s experiences of support (or a staff perspective on how they viewed this).

Women’s ‘experience’ referred to specific elements of the research question, such as whether the (e)HNA process facilitated assessment of their needs, or contributed to a more positive experience of supporting these needs.

These dimensions enabled identification of connections, which grouped participants by their perceptions towards the (e)HNA. These groups are known as typological categories. Each typological category was given a label as per Spencer et al.’s (2013) approach, and contained a statement outlining participants’ shared perspectives related to the two dimensions (for example positive or negative opinions). These labels highlighted the variation in perceptions between the typological categories. The principal typological categories for women with cancer and staff are displayed in Figure 30 and Figure 31. A key difference between the two sets of typological categories is reference (in some cases) to either ‘expectations’ or ‘experience’. This differentiation refers to the second dimension above, which focuses on the (e)HNA’s contribution. Therefore, women’s typological categories relate to their ‘experience’ of this, and for staff this was their ‘expectations’ of the contribution.

Figure 30. Typological Categories: Women with Cancer

1. "Positive in Principle"
   - The (e)HNA's use and delivery process is positive in principle, but there was little or no contribution from this to the overall experience.
2. "Paradoxical Experience"
   - The (e)HNA's use and delivery process is positive in principle, but had a negative contribution to the overall experience.
3. "Disconnection"
   - The process of (e)HNA was not engaged with, and had no contribution to the overall experience.

Figure 31. Typological Categories: Staff

1. "Paradoxical Expectations"
   - The (e)HNA's use and delivery process is positive 'in principle', but they perceived that it contributed something negative to the overall experience.
2. "Comprehensively Negative Expectations"
   - The (e)HNA's use and delivery process is negative or has little benefit, and they perceived that it contributed something negative to the overall experience.
3. "Positive in Principle"
   - The (e)HNA's use and delivery process is positive in principle, but there was little or no contribution from this to the overall experience.
4. "Comprehensively Positive Expectations"
   - The (e)HNA's use and delivery process is positive, and they perceived that it contributed something positive to the overall experience.

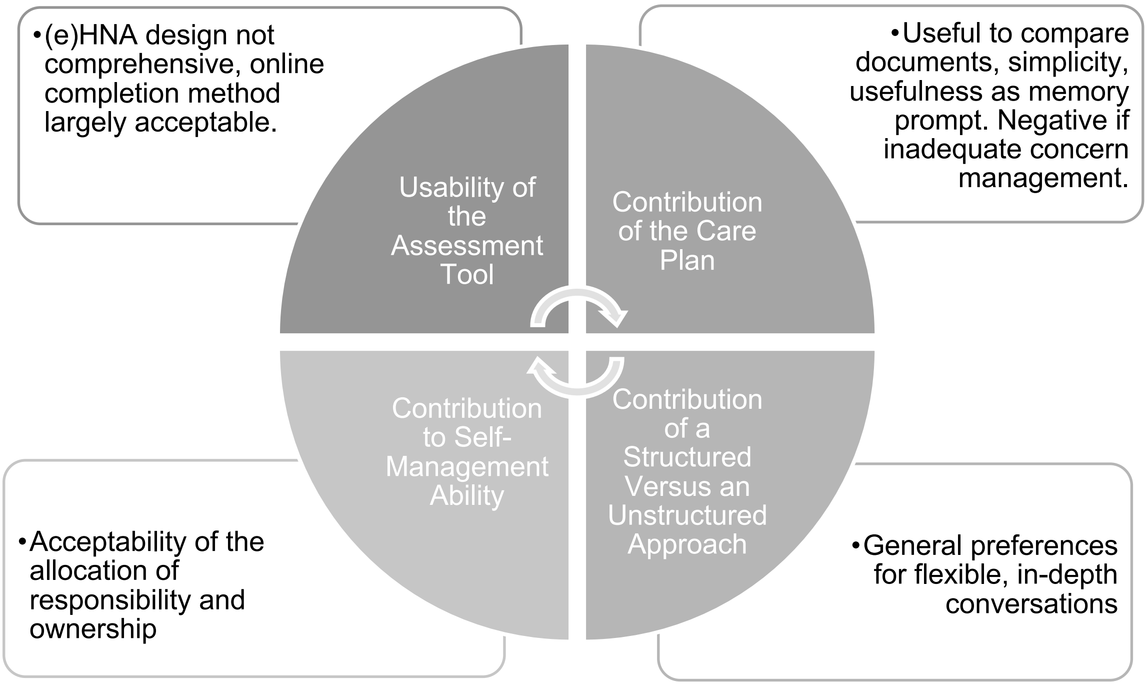
This section has presented an overview of findings for descriptive accounts analysis. However, the two elements within this (class-category framework and typologies) are discussed in more depth, before considering explanatory accounts analysis. Initially, the framework of overarching classes and categories is presented, using data that supported its structure in participants’ own words. Secondly, the seven typological categories are explored, once the background of participant data is better understood from the class-category framework.

Throughout discussion of data, the views of women with cancer are separated from staff to highlight the variations between the two groups, (despite the classes and categories being very similar across both participant groups). Data from observations and care plans is interwoven with interview quotations. To present data from observations and care plans, this is labelled with the participant’s name and data source (for example, ‘Rose’s care plan’). Interview data are labelled with the participant’s name and identifier, following a direct quotation.

4.3.2 Class One: Perceived Contributions: Women with Cancer

Class One relates to the perceived contributions of the (e)HNA, divided into four categories. The key findings within each category are outlined throughout this section, supported by verbatim extracts from interview data.

Figure 32. Perceived Contributions: Women with Cancer: Key Points



4.3.2.1 Usability of the Assessment Tool

Women discussed the usability of (e)HNAs in terms of the tool's design and structure, and their apparent desire to provide flexible responses:

> *"I can't remember whether there were any free text boxes on there… If I remember rightly I thought I don't really think there's an answer there that I want to tick but I probably want to say something, so having a few free text boxes, that's more difficult because you can't standardise what you're doing, but that might have been helpful." (Kate, 0103P).*

Although this demonstrates that the (e)HNA's content did not entirely encompass Kate's needs, it also highlights her beliefs about the overall purpose and aim of the assessment. Kate's acknowledgement that free-text responses would introduce difficulty, implies she may have perceived data analysis as a key goal of the (e)HNA process.

The online method of (e)HNA completion was also discussed by participants, which appeared largely acceptable to women despite their varied age groups and backgrounds:

> *“At least somewhere you’re in the system… I think it's helpful in that it shows there is a sort of care system around you potentially ready to help you, so I think from that point of view it's helpful.” (Jane, 0101P).*

> *"That online assessment is dead easy to complete, isn't it?" (Kate, 0103P).*

Although one participant reported connectivity issues with the online system, none indicated a negative view of the online method of completion itself. Jane’s words also highlight an expectation of future (e)HNA encounters, signifying that online completion brought her into a ‘safety net’ of structured support, should she need to use this.

4.3.2.2 Contribution of the Care Plan

The care plan component of the (e)HNA process was generally perceived as useful, including its simplicity, and function as a memory prompt:

> *“I can remember most of it but I don't know whether I'll remember it in a week because I only had the conversation with her last*

> *week. So, getting some information, understanding where you can go is helpful." (Kate, 0103P).*

> *"There might be an occasion where I think oh my gosh, what did she say about those exercises again, let me see what she put and I would read it, I will refer back to it at some point." (Rose, 0108P).*

> ***Observation of Rose's (e)HNA (0108P):*** *The BCN emphasised that she was writing on the care plan that Rose needed to make contact with a particular support service, which prompted Rose to write her own notes.*

Despite the care plan's ability to prompt action, this may be contingent on the type of recommendations made within it. For example, if staff explicitly allocated responsibility to the individual to act upon recommendations (as in Rose's case), the care plan appeared more likely to function as a prompt. Participants also emphasised wanting to retain the document for future use, which shows the importance placed on the advice and information staff provided. Moreover, many individuals expressed views that revisiting the care plan at least once during their cancer journey would be beneficial for comparison between two time points:

> *"Actually, you almost want to revisit it, don't you… because, a) then you get a sense of whether the care plan's working and whether the things that you've recommended are actually changing stuff and making people move to a different place but, b) also this does change." (Kate, 0103P).*

Kate’s view demonstrates an understanding that the (e)HNA ought to lead to outcomes which could be monitored by repeating the assessment. However, despite views of this ideal scenario, participants predominantly felt such an opportunity was unlikely to be presented:

> *"I didn't get a sense that you can revisit this." (Kate, 0103P).*

> *“It almost seems an isolated incident.” (Laura, 0105P).*

Alongside the benefits summarised above, two participants suggested negative perceptions of the care plan. These views were primarily based on omissions in the actions of staff, as opposed to the document itself (for example the way staff had written the document, or the negative memories it provoked):

> *"Reading that one again, I’m then thinking do you know what was the point of that, ’cause a lot of it is actually got the same paragraph in every one." (Tina, 0112P).*

> ***Tina’s care plan (0112P) (2 of 2):*** *Plan of Action: “Follow-up short-term with CNS” (Clinical Nurse Specialist) repeated in five boxes.*

> *"I thought right okay then, because it was bringing back to me all the issues of the appointment, which I walked away feeling not particularly positive, so I thought okay then right that’s it, and I folded it up and I put it in my breast care file, and that’s where it still is." (Rose, 0108P).*

Tina’s words demonstrate the lack of support she experienced from her care plan. Tina raised multiple concerns in her two (e)HNAs, many of which had actions documented such as ‘referred to BCN’, although these did not actually happen. Tina described use of medical jargon and repetition throughout the care plans, which did not meet her support needs. Furthermore, receiving the care plan appeared to raise Tina’s expectations of support, but these were unmet because written actions remained unfulfilled.

4.3.2.3 Contribution of a Structured Versus an Unstructured Approach

The third category relating to perceived contributions of the (e)HNA was the contrast between informal, unstructured conversations and use of a structured (e)HNA tool. For the discussion of this category, the phrase unstructured assessment is used to describe conversations in which staff provided support or assessed women through an informal, unstructured conversation (without an (e)HNA), whereas structured assessment represent use of an (e)HNA tool. Primarily, positive and negative perspectives on these approaches were related to the individual’s understanding of the (e)HNA. For example, structured assessment was sometimes perceived as referring solely to the questionnaire element of the (e)HNA process, and the separate face-to-face conversations were assumed to be unrelated to this. Although this raised challenges in differentiating between assessment types when interviewing participants, there was an apparent preference for flexible, in-depth methods:

> *"The conversation’s more flexible than written for me… because you can elaborate on things." (Claire, 0111P).*

> *"I think I feel like the formal assessment is like a beginning, and then if you want more it should be a conversation, because it's the development of that." (Laura, 0105P).*

The desire for depth and flexibility suggests that both structured and unstructured components of the (e)HNA process are beneficial. One participant highlighted that despite completing a structured (e)HNA and raising emotional concerns, it was an unconnected, unstructured conversation (not prompted by completion of an (e)HNA), which initiated the offer of support:

> *"That was a sort signing off appointment, and we talked for a little while and she said you know are you okay? And I said well no actually I don't think I am really, and she said would you like counselling, and I said yes I would." (Laura, 0105P).*

This example prompts a series of considerations, such as why one approach elicits action when another does not, and whether the trajectories of addressing concerns stem from staff or women's behaviour. These possibilities are explored in the discussion of Class Two.

4.3.2.4 Contribution to Self-Management Ability

Finally, the (e)HNA was deemed to contribute to women's self-management ability, through the transfer of responsibility and ownership for wellbeing on to the women themselves:

> *"It's sort of quite self-directed support rather than somebody referring me on and actually, I'm quite happy to do that." (Kate, 0103P).*

> *"I felt that she made the recommendations, and I thought they were valid, and at the time I thought, "yes, they're doable." (Laura, 0105P).*

> ***Laura's care plan (0105P):*** *Plan of action for feelings of uncertainty "We discussed visiting [support service] and taking part in one of their light exercise programmes or just dropping in for a cuppa and a chat. Laura will consider this."*

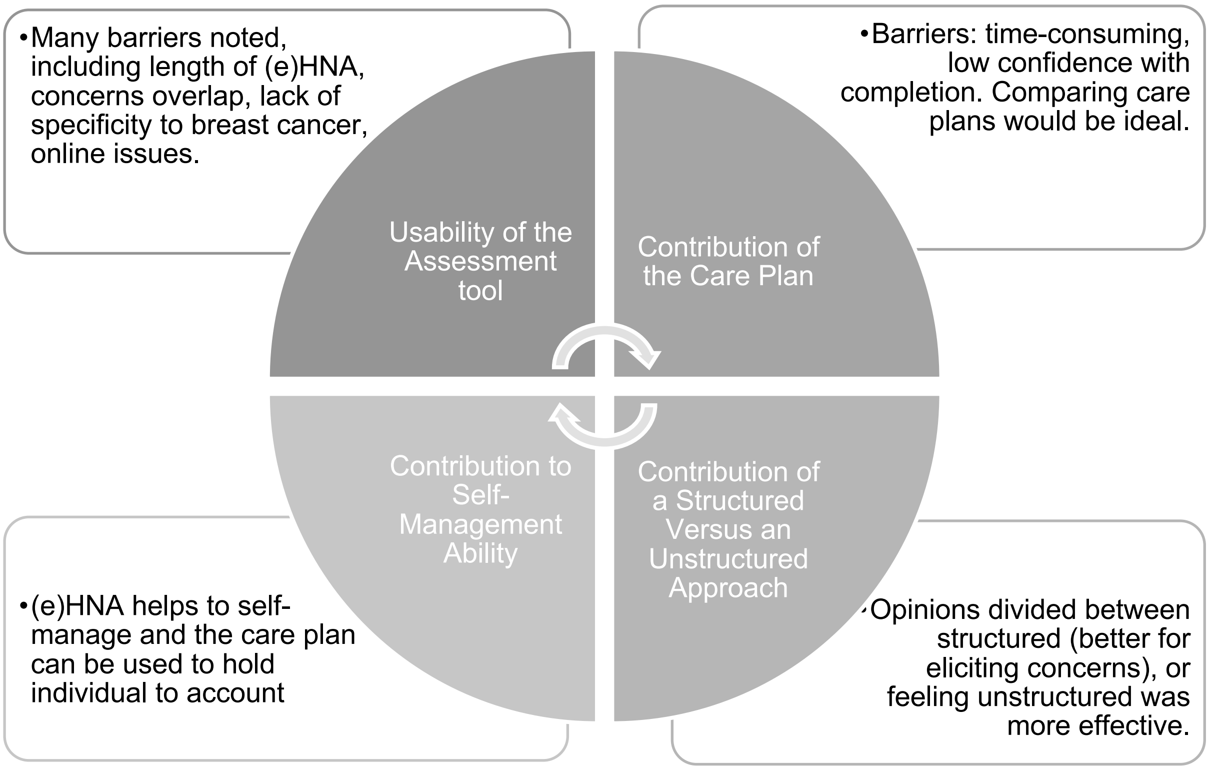
These examples suggest participants' acceptance of being given tasks to manage their needs, and their willingness to take ownership of these.

Overall, these categories highlight women's perspectives of the (e)HNA in terms of the contributions it provides in assessing and supporting their needs. The same categories are explored from the perspective of staff.

4.3.3 Class One: Perceived Contributions: Staff

As in Section 4.3.2, the same Class One categories are considered from a staff viewpoint, and the key points summarised in Figure 33.

Figure 33. Perceived Contributions: Staff: Key Points



- Many barriers noted, including length of (e)HNA, concerns overlap, lack of specificity to breast cancer, online issues.

- Barriers: time-consuming, low confidence with completion. Comparing care plans would be ideal.

- (e)HNA helps to self-manage and the care plan can be used to hold individual to account

- Opinions divided between structured (better for eliciting concerns), or feeling unstructured was more effective.

4.3.3.1 Usability of the Assessment Tool

Staff raised issues with the (e)HNA’s structure and usability, including a view that the follow-up conversation should be optional:

> *"Even if there was just like a little box at the bottom saying like would you like to discuss this with your nurse in charge or something... because then if someone does need that additional support, we’re not contacting someone who doesn’t want to be contacted and bringing it all up." (BCN 1, 0101S).*

BCN 1’s words imply that women may not always desire a follow-up discussion to address their concerns. However, interview data from women suggests that this conversation was often the most useful element of the (e)HNA process.

A further recommendation raised by staff referred to the lack of specificity of the (e)HNA to breast cancer, which was perceived as having greater impact if it was more tailored to different cancer types:

> *"It's never going to be right for every person and every tumour group because, again, even within breast, it probably needs to be a bit different for different people. They think it's the same tool across all cancers." (Lead BCN, 0108S).*

The use of the pronoun ‘they’ here implies an apparent divide in understanding between the breast team and those encouraging the (e)HNA’s implementation, or perhaps those involved in the original design of the assessment. Despite the barriers identified, staff felt the (e)HNA provided a positive structure for prioritising concerns:

> *"I always say it comes through in order of how high you’ve graded them, does that sound like a good way to go through this to you? Usually they’re quite happy with that." (SW 1, 0105S).*

This structure seemed especially beneficial in the online format of the (e)HNA, where concerns were ordered hierarchically by score. However, staff felt the online format also presented challenges for some women:

> *"Occasionally you’ll have some people say oh I don’t use the computer." (BCN 2, 0102S).*

> *"Sometimes the (e)HNA can be a bit exclusive to those if they are fearful of technology" (Programme manager, 0106S).*

> *"I think from our point of view the computer is better, but I think from the paper point of view the patients prefer it." (SW 1, 0105S).*

However, this view was not supported by women with cancer, who described the online format as simple to use. Therefore, staff's opinion that women preferred paper assessments may indicate that the sample of participants in this study may have had greater technological confidence than others staff had encountered.

4.3.3.2 Contribution of the Care Plan

Many staff concerns were raised around the challenges of completing a care plan. These included the increased workload involved and low confidence around how to complete one:

> *"A couple of the ones that I've done up to now I have literally just clicked the tab that says, "discussed concern," and I haven't really done much more about it because we did just discuss it and there was no action for me to do." (SW 1, 0105S).*

> *"Sometimes, it can be quite difficult if it's somebody who's got really high concerns all the way through." (SW 2, 0107S).*

> *"Sometimes I really struggle to know what you're supposed to put where and you know, and it says what actions have you*

> *done… I almost feel like you can’t ever completely resolve something.” (BCN 4, 0110S).*

These examples suggest possible low confidence in participants. Additionally, BCN 4’s (0110S) words demonstrate reluctance to document a concern as ‘resolved’. This hesitancy may suggest she feared formally documenting a concern was resolved, when she did not feel a complete resolution was possible to achieve. A task-oriented focus seemed evident from staff accounts of using the (e)HNA, which focused on actions taken to address concerns as a measure of its completion or success. The challenges staff described around undertaking care plans perhaps explain the perspectives of women, who suggested that minimal detail was included in some care plans.

Staff participants felt that future revisiting of the care plan would be beneficial, but this was depicted more as an ideal than an actual scenario:

> *“You need to build on an assessment… Very much it follows through the pathway. They shouldn't be done one here, one there. It's more you do an assessment, it then becomes a bit more of an elaborate assessment as you build your relationship and they start to get going with treatments.” (Lead BCN, 0108S).*

> *“You know what I haven’t looked at that, it’s a good point, no I haven’t looked at the one at the very beginning… one assumes things will have changed.” (ANP, 0111S).*

The suggestion that comparison was not carried out supports women’s comments, around not expecting to have the opportunity to revisit their assessments.

4.3.3.3 Contribution of a Structured Versus an Unstructured Approach

Many staff discussed the concept of unstructured assessment against the structured (e)HNA approach. Participant responses were divided between feeling the (e)HNA provided a more comprehensive approach to eliciting concerns, and a view that the tool contributed minimal beyond an unstructured conversation:

> *“They [women] can sometimes give you additional information that you weren’t privy to when you were talking to them, so it’s an extra kind of layer I suppose of finding out things about them." (ANP, 0111S).*

> *"I think you’ve got to have really, really good conversational skills to peel away, and get in your assessment of a patient if you’re not using a tool to peel away and understand the level of concern and make sure that absolutely every element has been covered, and you can’t do that in a conversation, you need a prompt.” (Project manager, 0106S).*

Staff discussed the in-depth communication techniques adopted to elicit needs in an unstructured conversation, such as intentional use of silence or non-verbal communication. These communication skills led staff to feel that the assessment process was undertaken informally as part of their daily role.

> *“You know it’s a good tool to make sure I’m not forgetting things, but it did feel like a solidifying of what I was already doing.” (BCN 5, 0112S).*

> *"I think nurses have always been doing it, but we've never used formal tools." (Lead BCN, 0108S).*

> *"The holistic needs assessment is more formal but I don't think it gets anymore information out of them that I can particularly get." (BCN 3, 0109S)*

Some staff also felt the (e)HNA detracted from conversations, by concentrating on issues which may not be genuine priorities:

> *“I think if they've done an assessment, then you're instantly honed to what they've ticked and scored, which means you possibly don't use your intuition in the same way because you're literally looking at scores on doors… Possibly you don't then pick up on something because it's down to them ticking the right box, or ticking the right box that they feel comfortable to share.” (Lead BCN, 0108S).*

> *“You’ve just let them open up about it and not… not put stuff in their head, not giving them ideas for things that aren’t a concern and have been a very long-standing thing.” (BCN 1, 0101S).*

The first example from the Lead BCN (0108S) may reinforce Laura’s example (see p148), in which her need for emotional support was not met by the (e)HNA. In this case, Laura’s emotional concerns (worry, fear or anxiety and uncertainty) featured low (based on score) in the list of seven concerns raised, which may have caused lower prioritisation of these. The second example, highlights the view that the (e)HNA may “put stuff in their head”, implying that concerns raised during the assessment may not be genuine issues, and may have come about as a result of the (e)HNA’s prompting.

4.3.3.4 Contribution to Self-Management Ability

In the final category, staff indicated that the (e)HNA was useful in directing individuals towards self-management. Therefore, many staff highlighted that they viewed the document as a tool they could use to give responsibility to women, by allocating tasks for them to complete:

> *“It should be a working document. Yes, they were assessed early in their pathway. "Well, did you do that? Didn't you do that? You're supposed to self-manage.” (Lead BCN, 0108S).*

> *"I think they’ve got it on a piece of paper as a kind of record of the conversation and it’s kind of back in their court isn’t it, of what they have to do." (BCN 5, 0112S).*

> ***Joan’s care plan (0109P):*** *Recommended actions for Joan’s declaration of feeling fatigued “discussed pacing herself and having regular rests, suggested attending ‘healthy living’ event for fatigue”.*

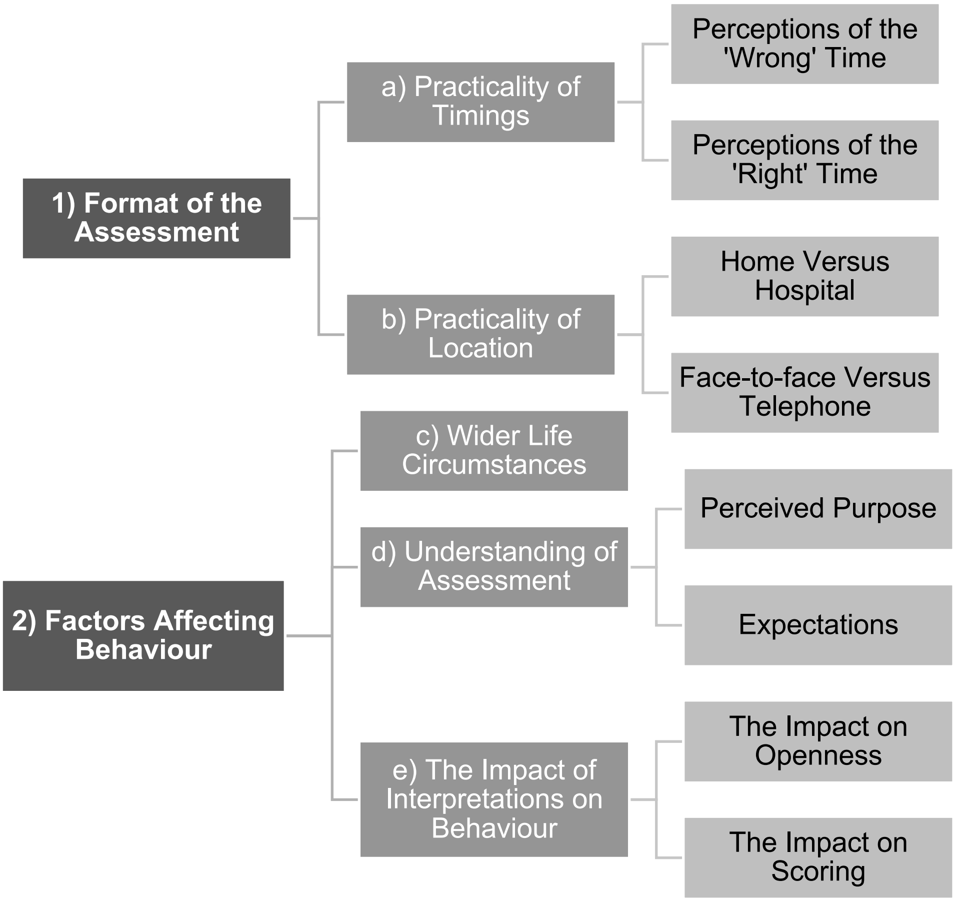
Many staff felt that the document strongly facilitated the process of encouraging self-management, by providing clear evidence of their recommendations and a means to check these were completed. Despite this, staff did not suggest that care plans were used to hold women to account for incomplete actions in reality.

This section summarised the perceived contributions of the (e)HNA in assessing and support women's needs from a staff perspective. However, the views of both staff and women highlighted an array of wider considerations which influence the (e)HNA's overall contribution. These factors are explored in Class Two.

4.3.4 Class Two: Wider Influencing Factors: Women with Cancer

As outlined in Class One, numerous factors appeared to affect women's perceptions of the (e)HNA's contribution in assessing and supporting their needs. Class Two considers wider influencing factors, and broadly covers three categories identified through Framework Analysis: 1) format of the assessment, 2) factors affecting behaviour and 3) organisational factors, each containing sub-categories. However, data in the third category incorporates staff perspectives only, due to the focus on organisational structures, pressures and culture, which were not reported in the data from women with cancer. This category (3) is therefore omitted from the discussion women's data. Figure 34 represents the subcategories of Category 1 and 2, which are discussed for women with cancer.

Figure 34. Class Two Categories- Women with cancer



4.3.4.1 Category 1: Format of the Assessment

The format of the assessment focuses on the time and location of (e)HNAs, which were deemed significant factors in the overall contribution of the assessment. Women expressed perceptions of correct and incorrect times to undertake (e)HNAs, and preferences for location (including in hospital or within their own homes). These factors also influenced the method of administration, in terms of whether the (e)HNA was undertaken face-to-face or on the telephone.

4.3.4.1.1 Sub-category a) Practicality of Timings

Perceptions of the ‘Wrong’ Time

Almost all women directly or indirectly commented on the timing of their (e)HNA, and how impactful the timing was. A predominant view emphasised that completing the assessment at diagnosis was unsuitable. This opinion was supported by indirect references, suggesting that the (e)HNA was irrelevant when completed at this time, as they had not yet experienced treatment side effects:

> *"When I looked at it, because I had only just been given the diagnosis, it was about side effects and things and I’d obviously not had any treatment then, so I didn’t think that it was particularly relevant." (Sarah, 0107P).*

> *"I wasn’t in the frame of mind to read everything that I had, I just wanted to get it over. I just wanted to have the op and have that done, and I wasn’t really interested in what there was around." (Ruth, 0104P).*

The heightened emotional response often experienced at diagnosis was recognised in Case Study 1’s typical approach to women’s care, where BCNs undertook a one-to-one appointment with women for emotional support immediately post-diagnosis (without completing an (e)HNA). Consequently, the quotations above question the value in conducting (e)HNAs at diagnosis, particularly if the emotional support conversation is already taking place without the need for an (e)HNA to prompt this.

Perceptions of the ‘Right’ Time

Despite views that diagnosis was an unsuitable time to undertake (e)HNAs, variation existed in what was perceived as the most useful time. Timings considered useful by women included the end of treatment, and in the gaps between appointments:

> *"In some ways I think maybe the holistic support would be a better tool at the end of the physical treatment, ’cause it’s like everything’s thrown at you and your head’s in a spin with everything, and then you get to the end of treatment and it’s like okay, now what?" (Tina, 0112P).*

> *“I think it's those times when you have a little bit of time to reflect and actually… it might be about when you've had that appointment, that follow-up appointment, that's a good time to do it because then you're looking forward to your next stage.” (Kate, 0103P).*

These examples suggest that whilst Case Study 1 aimed to offer (e)HNAs at set time points (diagnosis and end of treatment), some women desired assessments at a time when no other interventions were taking place (allowing space and time to wholly engage with this).

4.3.4.1.2 Sub-Category b) Practicality of Location

(e)HNA Questionnaire Completion: Home Versus Hospital

Variety also existed around preferences of face-to-face, home or telephone (e)HNAs, with all reported to have benefits and limitations.

Beginning with the questionnaire component of the assessment, benefits of the home-based approach included the absence of time pressures, and ability to reflect in private:

> *"To do it in your home environment is perhaps more conducive, you can do it over time, you're not feeling pushed or pressured to fill in something quickly." (Jane, 0101P).*

> *"Because to me it's about me only, I wouldn't want anybody else to be filling in that information about me." (Claire, 0111P).*

However, preferences for delivery methods also appeared connected with women's confidence in their own ability to complete the (e)HNA, as demonstrated by Harriett's words:

> *"It would've been quite useful possibly to just go through the first one with somebody to understand my feelings I suppose." (Harriett, 0110P).*

These comments were in response to an interview question about Harriett's thoughts on completing the (e)HNA at home. Harriett may have lacked confidence in expressing and processing her feelings, and may have desired help with this. Alternatively, her statement could indicate her need for support to understand which feelings to disclose on the (e)HNA, or how to score her concerns. Either way, Harriett's confidence appears to influence her opinion on (e)HNA delivery method, specifically that being in a face-to-face, hospital setting may have been beneficial.

(e)HNA Discussion: Face-to-Face Versus Telephone

The venue for discussion of concerns following the initial (e)HNA questionnaire was also deemed significant by participants. Face-to-face conversations were often viewed as more personal than telephone interactions:

> *“I think the one with the nurse felt more personal, because it was face-to-face and because I’d met her before. (Laura, 0105P).*

> *"If somebody is sat in front of you, you know you can read off how they’re feeling can’t you, it’s not just what they’re saying, you know it’s other things that you can pick up on really as to whether it’s a problem." (Sarah, 0107P).*

These examples suggest value in face-to-face methods, including non-verbal communication and participants’ increased comfortability when they had an existing relationship with staff. With regards to telephone discussions, views appeared less positive:

> *"I just guess I’m quite a private person and I wouldn’t often share feelings with somebody that I’d never met and I was just talking to them on the phone for the first time." (Marie, 0102P).*

Marie’s comments highlight the barriers presented from her inability to visualise the person she was speaking to about sensitive issues. Many examples in this category highlight factors beyond timing and location of (e)HNAs which may have influenced the way they assessments were perceived and experienced. These issues are explored in Category 2.

4.3.4.2 Category 2: Factors Affecting Behaviour

The category ‘factors affecting behaviour’ considers participants as individuals, and various factors which influenced their behaviour towards the (e)HNA. These included their life circumstances beyond their cancer diagnosis, how they understood the (e)HNA, and their perceptions of how staff viewed them. These circumstances may have influenced women’s behaviour towards the assessment, and how they perceived its contribution to their experiences of support. The sub-categories outlined in Figure 34 are explored in this section.

4.3.4.2.1 Sub-category c) Wider Life Circumstances

Several women referred to personal circumstances that appeared to guide their coping abilities or willingness to access support, for example caring responsibilities:

> *“I haven’t really got time for this, and that’s exactly how I felt. Because I hadn’t been feeling very good for a while. Stressed, tired.” (Laura, 0105P).*

> *“To be honest I haven’t done any of that… I feel that it’s gonna take me away from my husband when he needs my full attention, and if I get involved with too much and I’ve gotta go to a meeting or something, at the moment I can’t do that.” (Joan, 0109P).*

> *“I’m retired, I’ve got a house and a garden, I can afford to take a taxi if I need to… you know I don’t have a lot of the worries that for example someone with a young family will have” (Jane, 0101P).*

These examples demonstrate differing individual circumstances that may have affected women's desire for support, based on existing emotional burdens (or the absence of these). Financial concerns were raised by several participants as preventing a focus on other aspects of their health, such as their mental wellbeing:

> *"It's still just obviously the money side of things, you know, being able to cope. Because obviously being on my own, there's only one wage coming in. You know, a lot of people have got either a partner or husbands or whatever." (Paula, 0106P).*

> *"How you're feeling doesn't come into it 'cause that's not gonna pay the bills". (Marie, 0102P).*

Marie demonstrated that financial difficulties took such priority, she felt emotional concerns could not be put above this.

4.3.4.2.2 Sub-category d) Understanding of Assessment

Perceived Purpose

Women also reported varying levels of understanding and expectations of the (e)HNA, which may have influenced the value it held for them:

> *"I imagine I would've been referred to particular professionals who had sort of more experience in, I don't know, maybe emotional care, support or sleep issues, things like that." (Harriett, 0110P).*

> *“I did think why do they need to know all this business, they should know all this about me, they know what's wrong with me why do they want to know all this?” (Rose, 0108P).*

These examples suggest two different reactions to the (e)HNA’s introduction, and understanding its purpose. However, some participants showed no understanding of the (e)HNA’s purpose, and highlighted misconceptions or confusion from this lack of understanding:

> *“I’m quite a holistic person myself, and I’ve used alternative therapies before.” (Marie, 0102P).*

> *“Well, she just handed it to me and… she kind of dissed it a bit, do you know what I mean? To me this was the most important thing I was given now I realise, but when it was given to me… it didn’t give me that impression.” (Marie, 0102P).*

> *"I’m not a great believer in things like reflexology and things like that." (Claire, 0111P).*

Marie’s lack of understanding combined with staff members’ negative portrayal of the assessment led to the confusion that (e)HNAs related to alternative therapies, despite this view not being explicitly stated. Both Marie and Claire appeared to draw upon their prior knowledge of alternative therapies (medical therapies which are not orthodox medical treatments) (National Health Service (NHS), 2018) to make sense of the term ‘holistic’. In Marie’s case, this led to her non-completion of the (e)HNA, but she later went on to have a care plan generated from a telephone conversation, not initiated by the assessment.

Other participants indicated subtle rationales influencing their decisions to engage with the (e)HNA, such as the wish to help others, or feeling obliged to comply:

> *“It was being offered, and I should take it up because it was being offered, and I might need it, and maybe in the past there hadn’t been anything like that, and people had to struggle on, on their own." (Laura 0105P).*

> *"I guess if it comes and it says NHS on it, I kind of just do it, because you kind of I think when you’ve got cancer you kind of feel like the NHS has taken your life over, and they say jump you jump." (Tina, 0112P).*

> *“I just filled it in as a paper exercise is, like I was just doing it because I was asked to do it.” (Sarah, 0107P).*

Whilst all of these women appeared to feel obliged to complete their (e)HNAs, Laura’s sense of obligation appeared derived from feelings of duty based on the hardship other women faced when services were absent, so not accessing the support offered would appear ungrateful. Contrastingly, Tina and Sarah’s obligation seemed focused on compliance and a wish to follow instructions. Feeling compelled to undertake (e)HNAs may have also originated from the letter women were given (Document 1, Appendix P), which suggested that non-completion would prompt a telephone call from staff.

In one case, the sense of obligation appeared to extend further. Here, the participant indicated a desire for her (e)HNA answers to be relevant for the staff member conducting the assessment:

> *"I wasn't really sure who was going to be looking at it… you were filling it in but you weren't sure who was possibly going to access the information, not from a security point of view but who was going to look at it to make it relevant... who was going to come back to you?" (Sarah, 0107P).*

Sarah appears to be interpreting the role of staff in relation to the (e)HNA, suggesting her concerns may not be relevant to all professionals, or that she feels uncomfortable with particular staff viewing her answers. These considerations appear to influence her responses.

Expectations

Secondly, women's understanding of the (e)HNA process appeared linked to expectations of the (e)HNA's outcomes, for example what support would be available:

> *"I think I probably hold back, because I think I don't know where that's going to go to. That might be me asking for more than is allowed." (Laura, 0105P).*

> *"I kind of figured this wasn't really there for me because I wasn't a bad enough case." (Marie, 0102P).*

Marie's comment suggests that feeling she was not "bad enough" to access support may have influenced her disengagement with the (e)HNA. Her view around the seriousness of her diagnosis and usefulness of the (e)HNA may have been linked to the verbal introduction to the (e)HNA she received, or her associations with the (e)HNA's Macmillan Cancer Support branding.

4.3.4.2.3 Sub-category e) The Impact of Interpretations on Behaviour

The Impact on Openness

In some cases, women's expectations of the (e)HNA also appeared to limit their disclosure of concerns:

> *"I think the ones that I answered more were the more practical ones… I think I didn't want to address them really… A bit like a can of worms, isn't it? I sort of feel that if I start, I might not know where to stop." (Laura, 0105P)*

> *"You know you should be there, but at the same time you're thinking oh, I don't want to waste his time. This might not be important enough." (Laura, 0105P).*

Laura developed her own interpretation of what was acceptable to raise in the (e)HNA, how staff might perceive her, and the level of prominence staff would give her concerns among their many priorities. These views may have been influenced by Laura's personal experiences and self-confidence, alongside her interpretation of the healthcare environment where the high workload of staff was likely to have been visible.

Several participants also discussed that having an existing relationship with staff impacted on their willingness to disclose concerns:

> *"For me, being able to talk about stuff like this is all about you build a relationship, you trust somebody enough to tell them. So, in some ways it might be easier to do that online because you aren't actually saying stuff." (Kate, 0103P).*

> *"I think what I would've liked is some consistency and somebody, you could see the same person, 'cause you kind of, you build up like a relationship I guess don't you then." (Tina, 0112P).*

Kate's comment suggests that the (e)HNA was easier to do anonymously, and that declaring concerns face-to-face evoked difficult feelings. This apprehension may indicate fear of being judged over her concerns. Therefore, trust may be particularly important when individuals see their own concerns as difficult or embarrassing to explore.

Additionally, Rose highlighted negative feelings associated with the BCN in her (e)HNA consultation, which appeared connected to her decision to decline support:

> *"The thing where I said about I didn't really want to see a psychologist, it's like she sort of backed off, and I got the impression she felt well I'm trying to help you here, and you know you're not listening so that's it, that's how I felt." (Rose, 0108P).*

Although Rose did not disclose her reasons for declining the psychologist referral, she felt her rejection of the referral had been interpreted as failing to listen, and therefore that she had been judged negatively for this decision.

The Impact on Scoring

Considerations about disclosure of concerns also affected women’s allocation of scores in their (e)HNAs, which did not consistently reflect their level of concern. For example, one participant expressed consideration of how she might be perceived if she entered an ‘extreme’ score. This implies her focus was on how her (e)HNA (or she) will be perceived, rather than on addressing her needs:

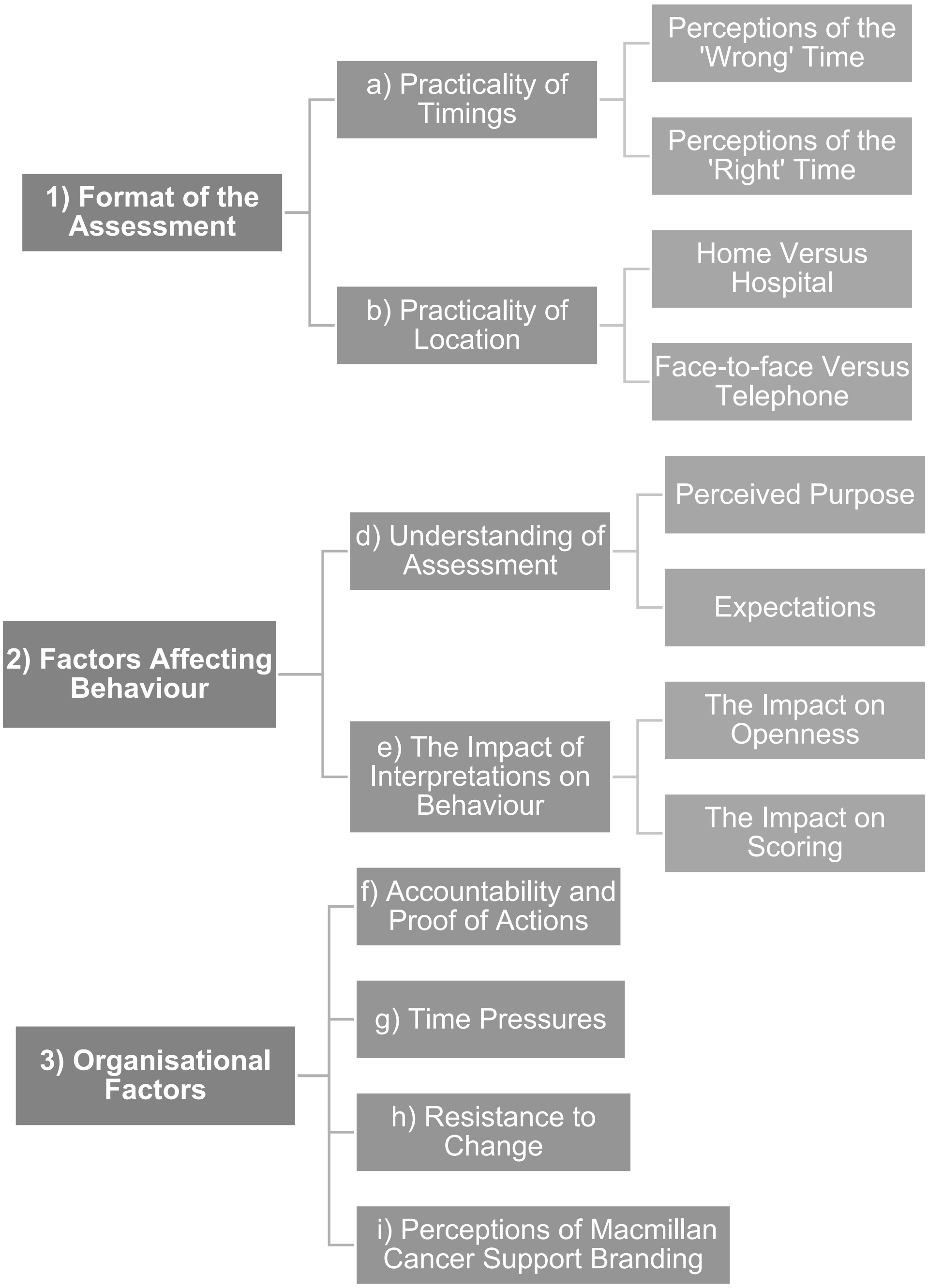
> *"You just go for the middle-of-the-road, you don’t want to be extreme either way." (Sarah, 0107P).*

The desire to provide inconspicuous (e)HNA results also indicates that Sarah deemed ‘extreme’ responses as undesirable to staff.

4.3.5 Class Two: Wider Influencing Factors: Staff

Following discussion of women’s perceptions in Class Two, this section now turns to staff views. The two previously discussed categories ‘format of the assessment’ and ‘factors affecting behaviour’ (sub-categories ‘a-e’) are presented, with the exception of sub-category ‘c’, ‘wider life circumstances’ (this was absent because data in this category related only to the experiences of women with cancer). A third category entitled ‘organisational factors’ (sub-categories ‘f-i’) is also discussed, as shown in Figure 35.

Figure 35. Class Two Categories - Staff



4.3.5.1 Category 1: Format of the Assessment

4.3.5.1.1 Sub-category a) Practicality of Timings

Perceptions of the ‘Wrong’ Time

Although routine practice in Case Study 1 was to undertake the (e)HNA at diagnosis, almost all staff echoed the women’s view that this timing was unsuitable:

> *"They’ve just been with the consultant and the nurse for like 30-45 minutes and had a lot of information given to them and I’m not sure if when they meet me they just hear, “Blah, blah, blah.” (SW 1, 0105S).*

> *“You’ve already given them lots of information and then you just give them another bit of information and sometimes they’re saturated and they just wanna get the hell out of here.” (ANP, 0111S).*

> *“It was very difficult to know when the right moment was to talk about it [the (e)HNA], because a lot of the time they were so floored by the fact that they’d had a cancer diagnosis that they didn’t wanna listen to anything else (BCN 4, 0110S).*

These examples highlight the concept of information overload at diagnosis, which also emerged in data from women’s interviews. Despite viewing this timing as inappropriate, staff appeared to accept the process, and continued to offer the (e)HNA at this time regardless of their reservations.

Perceptions of the ‘Right’ Time

Although diagnosis was an unpopular time to undertake assessments, views differed of what was a more suitable time:

> *"You need to be looking at it now, and you don’t wanna be forceful and say to the patient well actually it might help you if you have a look now, you know, but who’s gonna look after you after your operation?" (BCN 2, 0102S).*

> *"I don’t think there is a best time. I think the patient’s got to do it when they think it’s a necessity for them." (SW 2, 0107S).*

These examples present opposing opinions, where one participant believed that timing should be based on when the individual feels they require the (e)HNA (SW 2), and the other suggests use of a set time period in which the (e)HNA needed to be completed (BCN 2). Views such as those expressed by BCN 2 may provide further explanation as to why some women felt compelled to undertake their (e)HNAs, if this opinion was echoed in her (e)HNA instructions given to women. Additionally, the programme manager highlighted risks associated with incorrect timing, demonstrating the need to undertake these at an appropriate time for each individual:

> "It becomes a tick-box exercise, it can water down the content of the HNAs because people are trying to fit them in within a certain time period, and we probably get more declineds as a result of

> patients not being ready at that point in time." (Programme Manager, 0106S).

This highlights that whilst individuals may be asked to complete (e)HNAs at set times (whether this is motivated by targets or genuine belief that it would be useful at that time), there is a risk of women becoming disengaged if this does not meet their needs.

4.3.5.1.2 Sub-category b) Practicality of Location: Staff

(e)HNA Questionnaire Completion: Home Versus Hospital

The idea of completing the (e)HNA questionnaire at home was not widely discussed in staff interviews, and those who raised it appeared unsure of women's preferences. This was demonstrated by one BCN, who presented two contrasting standpoints:

> *"If a patient is at home and they're doing it off their own back, they might… I can't put all these things on there because they'll think I'm a nuisance, whereas if you're doing it as a face-to-face and it's just a general chit chat, they might be more open with you." (BCN 2, 0102S)*

> *"Doing it on their own at home is not necessarily a bad thing, because sometimes they will be a bit more honest when they're on their own, and it's a bit more impersonalised 'cause it's on the computer." (BCN 2, 0102S).*

These examples highlight the complexity of home-based (e)HNAs, as these may act as both a barrier and enabler to women's willingness to disclose concerns.

(e)HNA Discussion: Face-to-Face Versus Telephone

Staff referred frequently to (e)HNA follow-up discussions being undertaken over the telephone. Some staff felt that the absence of non-verbal communication was detrimental to the effectiveness of telephone (e)HNAs, yet many benefits to this approach were noted:

> *"It [the (e)HNA] talks about like lack of interest in sexual relationships and so on, somebody wouldn't come out and discuss that necessarily in a consultation… people bring it up more on the 'phone with me and I think it's again not being able to see somebody 'cause you can like detach yourself from it." (BCN 1, 0101S).*

> *"She's suicidal and stuff, that's quite difficult to deal with if you're just sat in a room with one person… I'm not trained for that so I think I would be like, what do I say? Whereas on the 'phone I think it's easier and also I can get someone else." (SW 1, 0105S).*

> *"They don't want to make another trip to see us… Practically, it's over the 'phone." (Lead BCN, 0108S).*

> *"I think the biggest barrier is that a lot of our patients live quite a long way from the Trust." (BCN 4, 0110S).*

SW 1’s quotation implies a lack of confidence in conducting face-to-face (e)HNAs, based on not having additional staff support available in these interactions. Additionally, several of the above comments suggest that staff viewed the practicalities of scheduling (e)HNAs as being important to women. However, these views were not reflected by women, who implied that face-to-face appointments were often more useful, and that gaps in between clinical appointments may be a better time to complete (e)HNAs. This contrast demonstrates the practicalities which staff felt were important (for example, reducing the number of hospital visits), but these did not appear to be as important among women.

This category has highlighted the practicalities of (e)HNA administration methods. However, several complexities emerged which staff felt may have influenced women’s (e)HNA engagement, completion, and perception of its value. These are discussed under Category 2.

4.3.5.2 Category 2: Factors Affecting Behaviour

4.3.5.2.1 Sub-category d) Understanding of Assessment

Perceived Purpose

Interview data suggested that staff themselves often received inadequate introductions to the (e)HNA, which led to negative perceptions (at least initially) and a lack of understanding of its purpose:

> *“So when I did it first it was quite brief, and I still thought this is another… gotta do something else.” (BCN 2, 0102S).*

> *“The way it was introduced, in that it was a bit of a pain to complete, you’ve gotta do it and that’s it, get over it.” (ANP, 0111S).*

This suggests that similar to women, staff also felt compelled to complete (e)HNAs, following instructions from more senior colleagues. Despite this, some staff took it upon themselves to do wider reading or research into the assessment, which appeared to improve opinions:

> *“Yeah, I think I could see that we… hadn't really given it a fair chance. It hadn't had any kind of planning of how it was going to work, it was just here… you need to start using it now, so there is no involvement, no working with the teams, no even vision of how it was going to help the patient. So there was a definite lack of knowledge, lack of involvement, lack of practicality, lack of just about everything initially.” (Project manager, 0106S).*

> *“I know a lot of people were very reluctant because they just saw it as extra work for us, I had a good look through it… and actually I thought it was really quite useful.” (BCN 4, 0110S).*

These examples suggest a possible relationship between staff conducting further independent research and them having a positive view of the (e)HNA. Greater ownership over the decision to undertake (e)HNAs (as opposed to being instructed to do so) may have influenced this response. Staff’s understanding of the (e)HNA may also affect choices around its administration, and consequently the verbal introduction given to women. For example, the quotation below demonstrates a scenario which implies that the (e)HNA is completed for staff:

> *“The receptionist hands them out, they just say to the patients when they come in, you know would you mind just filling this form out for the breast care nurses?” (BCN 4, 0110S).*

This example may explain why some women felt their (e)HNA was undertaken for the benefit of others.

Expectations

Staff expressed expectations about the types of concerns the (e)HNA prompted women to raise. For example, many staff held negative views of the (e)HNA’s tendency to prompt women to raise long-standing conditions, deemed irrelevant to their cancer:

> *“Are you concerned about a cough, yes I’ve had a cough for ten years so I’m going to score it, but it’s not actually something that’s in the back of their head or a priority or even a concern, but because the form has prompted them, they’ll then tick it as a ten.” (BCN 1, 0101S).*

This suggests that despite staff indicating that (e)HNAs were an opportunity to discuss an individual’s holistic needs, there was a common expectation and desire for the concerns raised to relate to cancer. One reason for this view may have been lack of confidence to address wider issues:

> *"My expertise are not in things that are not breast cancer related, so I can signpost, but I can only offer expertise in the area in which I am an expert in." (BCN 3, 0109S).*

> *"I don't think they always understand what it's about. Again, they'll sometimes tick things, well, they're things related to other problems." (Lead BCN, 0108S).*

> ***Rose's care plan (0108P) (1 of 2)****: Description of concern "Pre-existing - well controlled", plan of action "No action required" documented for five concerns.*

This highlights a potential gap between staff and women's perception about which concerns should be raised. A lack of confidence about concerns unrelated to cancer may be reflected in Rose's care plan, which documented the same phrase for five different concerns, stating the issue is 'well-controlled', despite Rose raising ongoing problems.

4.3.5.2.2 Sub-category e) Impact of Interpretations and Perceptions

The Impact on Openness

From a staff perspective, some participants felt that unstructured conversations may be better for encouraging women to be more open with divulging their concerns, compared to structured (e)HNAs. In some cases, staff felt that this related to how the individual believed staff viewed them (as a 'nuisance' for example):

> *"I think the ones who don't complete it are the elderly ones, the people who are a bit older. They don't like to be a nuisance and, you know, until you 'phone them and speak to them, 'no, everything's fine, no, that's alright." (SW 2, 0107S).*

Comments by staff also reinforced the views of women, suggesting greater willingness to disclose concerns when there was an existing relationship:

> *“I think it works better if you've got a relationship with someone, as in a therapeutic nurse/patient relationship. If they know you a bit, then that's when they'll start to divulge some of the things that are their real issues.” (Lead BCN, 0108S).*

> *“I think sometimes it’s an actual kind of conversation that they’ll tell you things because once you’ve had a while with them they kind of trust you and they open up to you about things.” (BCN 4, 0110S).*

These examples suggest trust as a key factor in encouraging women to divulge their concerns.

The Impact on Scoring

Almost all staff felt that (e)HNA scores were subjective, and that scores alone could not determine level of concern or actions taken in response to concerns:

> *"It’s kind of like pain isn’t it, so somebody could score 10/10 but they’re on their mobile phone and going out for a cigarette, so it just depends on your perception of the score." (BCN 1, 0101S).*

> *"Everyone's perception of how do you rate yourself, like, we could both be feeling the same way but I could call that an eight and you could call it a two." (SW 1, 0105S).*

> *"You know like online shopping things, you know you feedback and everything, it's just very easy just to click the same thing as you're going along." (ANP, 0111S).*

However, despite the view that scores were subjective, the policy in Case Study 1 was to assign either a registered or unregistered staff member to address (e)HNA concerns, depending on how these had been scored:

> *"Four and below, we can do. Anything that's five, and especially if it's medical, everything above five really should go back to either the breast care nurse, or the oncology team." (SW 2, 0107S).*

> *"You are supposed to in theory ignore anything scoring 4 or less. Well if somebody has identified it I don't feel I can't ignore it." (BCN 3, 0109S).*

Several care plans contained scores of above four, yet were undertaken by a SW with no suggestion this had been referred to a BCN. As an example, Laura's care plan listed no actions involving referral to a BCN:

> ***Laura's care plan (0105P):*** *All concerns scored 7-10, actions taken were "signposted to financial advice service", "signposted to support service" or "discussed concern" (no mention of referral to BCN).*

In scenarios such as these, the lead BCN felt that SWs were likely reassessing women, by evaluating the severity of their concerns in a discussion, as opposed to being entirely led by the documented scores:

> *“I would suggest that [support worker], when she then ’phones up to have a further discussion, there's a bit of a reassessment rather than oh right, so you've scored this number in that box and therefore this is where I'm going to signpost you to." (Lead BCN, 0108S).*

This highlights the perception that scores alone may not be sufficiently reliable to dictate actions taken, and that more case-by-case discretion is needed. The lead BCN also discussed the concepts of cut-off scores and pay banding, which may provide a partial rationale for the local decisions made:

> *"Yes, you can't pay someone at Band 4 to deal with some of the emotional stuff that a Band 6, 7 and 8 CNS works at. I think that's why, again, there's a cut-off. It's not that someone hasn't necessarily got the ability to deal with some of the bigger issues or higher scores, but there is a level of responsibility for banding and pay and stuff." (Lead BCN, 0108S).*

This example suggests that responding to concerns by cut-off scores relates more to responsibility level and pay, than individual staff skill level in addressing concerns.

Despite recognising the subjectivity of scoring, and sometimes using a level of discretion, the two SWs indicated that the score was a key factor influencing their approach to (e)HNAs actions:

> *"Or, they might have scored really high on that one, and just low scores on that one. You can say to them, you know, "What did you do to get that score down?" or, "What's happened to get that score up?" (SW 2, 0107S).*

> *"I always go to the ones that are higher scored first. They're the first port of conversation." (SW 1, 0105S).*

Scores were used to gauge women's priorities in a structured way. This was achieved through either considering scores in a hierarchy, or looking at scores that had increased or decreased between two different (e)HNAs undertaken. However, little evidence existed to suggest staff actually compared multiple (e)HNAs, which may imply this was an 'ideal' way to use scores.

Data in this category has provided greater understanding of the range of factors influencing staff's decision-making, and their perceptions of the (e)HNA's contribution to women. Category 3 highlights further factors related to the organisation itself, and its impact on (e)HNA implementation.

4.3.5.3 Category 3: Organisational Factors

The final category encompassed four sub-categories. The content primarily originates from staff data, based on women not discussing data related to accountability in healthcare roles or aspects of organisational culture. Therefore, only a small number of women's opinions are included in sub-category ‘i’, regarding perceptions of Macmillan Cancer Support branding.

4.3.5.3.1 Sub-category f) Accountability and Proof of Actions

As discussed previously, staff highlighted the role of the care plan in evidencing outcomes of the (e)HNA. Staff viewing this function positively, and felt it provided a report of the encounter, should they need to justify decisions made:

> *"I feel that if somebody came back to me and said I talked to you about this and nothing’s happened, I’ll look back on my nursing notes and say well I did suggest I’d do a clinical referral or whatever it might be… I suppose if they’ve got a care plan and it’s on there what they’ve gotta do, then they can’t come back to me and say you didn’t tell me that, when I did." (BCN 2, 0102S).*

> *“It's quite hard to say that you've done something if you haven't used a tool or you haven't got something to back you up.” (Lead BCN, 0108S).*

> ***Rose’s care plan (0108P) (2 of 2):*** *“Rose having concerns re medication discussed at EoT [End of Treatment] appt. Rose advised to take regular paracetamol for 1 week then to only take as necessary. Rose aware to contact CNS mid-September with response to Letrozole, aware if worsening side-effects to contact CNS for earlier review. Rose very reassured in knowledge can continue contact with CNS”*

These examples demonstrate staff’s expectations that they might be challenged, particularly in the absence of documentation to support their assertions. The excerpt from Rose’s care plan highlights a style of documenting which appears factual and targeted at an audience other than Rose herself (through use of medical acronyms and comments such as “Rose was very reassured”).

Staff were also conscious of what was documented in the care plan:

> *“She’s discussed her suicidal thoughts with me… there’s a little bit of a concern that you’re giving her a licence do something by saying we’ve spoken about it, we’ve acknowledged she’s got them.” (BCN 2, 0102S).*

> *"Because also if they have disclosed something sensitive and you’ve done something but you’ve not written them down, essentially you’ve not done anything, so it’s a good record of showing what you have done about it” (BCN 4, 0110S).*

These examples show contrasting perspectives about documenting concerns. For example, BCN 2 indicates concern that documenting feelings could give women permission to act upon extreme emotions. Alternatively, BCN 4 highlights the importance of documenting all sensitive discussions, as this could be the only proof that these occurred.

4.3.5.3.2 Sub-category g) Time Pressures

A second factor frequently raised by staff was the array of pressures on their time, which subsequently impacted (e)HNAs:

> *“The care plans that I have done from the (e)HNAs have taken hours and hours just for one person.” (BCN 1, 0101S).*

> *“It also depends on capacity as to whether every patient is offered one.” (Programme manager, 0103S).*

This suggests that whilst the organisation aimed to offer all individuals an (e)HNA, this was not always feasible. This may also be one explanation for why staff scheduled (e)HNAs at convenient times, such as prior to consultant appointments, so that the discussion would be time-limited.

With these time pressures in mind, many staff discussed how the introduction of SWs had improved the (e)HNA process, as they had taken on responsibility for the main workload:

> *“She was recruited to a particular post to deliver HNAs and that’s why it works. It was a designated post and you’re not asking anyone to add to what they’re already doing.” (Project manager, 0103S).*

> *“She’s played a huge part in making sure that they are completed… the service is much more successful.” (BCN 3, 0109S).*

> *“It’s made it so much better having [support worker]… just organising them from a practical point of view… she’s brilliant at signposting as well… and that helps a lot.” (BCN 5, 0112S).*

These comments emphasise the necessity of designated roles to prioritise, or 'champion' use of the (e)HNA, and also suggest that BCNs did not have capacity to prioritise it. The role of champions was also noted by the project manager, who outlined their impact on (e)HNA implementation and sustainability:

> *"If you compare with other cancer sites, the lead CNSs that are really engaged with HNA... then it works, but if you've got resistance from your leader, it filters through… They'll ask why certain months have certain dips… some of it's because it's so dependent on some key individuals." (Project manager, 0106S).*

This continued requirement to reinforce use of the (e)HNA underlines the previous point that this was a low priority for staff. Furthermore, the above quotation highlights the influence of leadership on the (e)HNA's implementation, and that this can filter through to other staff.

4.3.5.3.3 Sub-category h) Resistance to Change

As highlighted in Chapter One, targets for (e)HNA administration were adopted both locally and nationally. Staff, including those in management roles, recognised the issues involved in adhering to these targets:

> *"The targets themselves put a lot of pressure on the staff… they're run to capacity." (Project manager, 0106S).*

> *"I feel really strongly that they shouldn't be there, I totally understand that there needs to be some sort of metric... but we get disengagement from teams because it doesn't fit with their*

> *pathways… it can sometimes feel like a tick-box exercise to show that you're performing." (Programme manager, 0103S).*

> *"It's become more of an expected task and therefore it loses some of its realness about it." (Lead BCN, 0108S).*

These examples suggest that targets detract from the quality of (e)HNA conversations, through altering the outcomes to becoming a 'tick-box'. However, there was also acknowledgment that some form of objective was necessary:

> *"I kind of understand having a target because without a target it's very much left to the teams to... It gives something to aim for rather than, a good idea, let's implement it, and that fact that it's driven by the government now as opposed to the Trust or Macmillan or anybody else externally actually puts a bit of weight on it." (Project manager, 0106S).*

The reference to the (e)HNA being government-driven also links into previous discussions around champions, as staff appeared to require an aim or champion to drive delivery. This indicates that (e)HNAs were not self-sustaining in the absence of a driving force (and had therefore not yet become business as usual).

Conflicting issues are raised within this sub-category, indicating that use of targets may be detrimental to (e)HNA quality, and yet are an essential driving force behind successful implementation. Despite resistance to targets, there was an indication that some staff reluctance stemmed from the introduction of change itself:

> *"A lot of them [BCNs] are pre-retirement and they are very stuck in their ways. They're just sort of… I can do, I'm doing what I'm doing, and it works, and actually I'm too old in the tooth to learn something new." (Project manager, 0106S).*
>
> *"It's things like, "We don't need to do that, we've been doing this for years," and it's almost against me as if I'm the person bringing this thing in… I absolutely knew that everyone was anti-it and didn't want it, however, I also knew that it's not an optional thing." (SW 1, 0105S).*

SW 1 emphasises resistance which even extended to herself as the individual championing the (e)HNA. This implies that resistance to change may have existed within the team culture. Little explanation was provided by staff for this resistance, except two separate statements from one individual. These highlight the issue of confidence in the face of change, and viewing the (e)HNA's introduction as one of many temporary changes:

> *"Generally, we're not great with change you know, and yeah familiarity it's comfortable, and if you're confident and feel that you're competent to do that then that's why you prefer it." (ANP, 0111S).*

> *"Because they [(e)HNA tools] come and go and yeah if you've been in nursing a long time you see the wheel being reinvented constantly, so yeah maybe I have yeah an unconscious bias against tools." (ANP, 0111S).*

The (e)HNA was not a new concept to staff, and its continued reintroduction may have generated resentment towards it. The temporary nature of (e)HNA funding (such as for additional staff) may have also had an impact.

4.3.5.3.4 Sub-category i) Perceptions of Macmillan Cancer Support Branding

This final sub-category highlighting perceptions of Macmillan Cancer Support incorporates some views from women's data, to demonstrate a contrast with staff perceptions. One assertion from staff was the expectation from the public to associate the charity with death, or end-of-life care:

> *"I think, because we use the Macmillan tool, I think the general public still think of Macmillan in quite an old-fashioned way, in that they're for the end-of-life care as opposed to getting the support up front and giving them coping strategies." (BCN 2, 0102S).*

> *"There is still a bit of a historic thing about it being Macmillan…It's more to do with end-of-life hospice stuff." (Lead BCN, 0108S).*

In addition to this, several staff felt there was a negative culture towards the charity within the breast team:

> *"I think generally everyone is anti-Macmillan here anyway, so because the tool is a Macmillan tool that was straightaway, "We don't want to do it," and people don't like change and it's a bit different." (SW 1, 0105S).*

> *"Particularly in the breast team they've got very strong opinions about that and they don't like using the platform, they don't like to associate themselves with Macmillan and things." (Programme manager, 0103S).*

Staff appeared reluctant to discuss these views in their interviews but made comments that implied the charity had become less patient-focused. These perceptions influenced the way the (e)HNA or other support was introduced to women in some cases:

> *"I'm mindful of that Macmillan labelling… I say that this phone number on here it's for the breast care nurses, it's not Macmillan." (BCN 2, 0102S).*

BCN 2 also felt that women would not want their data saved on Macmillan Cancer Support's national database, and her quotations suggested her desire not to be associated with the charity. These views may have influenced the verbal introductions of the (e)HNA given to women.

Despite staff members' views, comments from the women in the study indicated positive views of Macmillan Cancer Support:

> *"I've always thought that Macmillan were fantastic." (Marie 0102P).*

> *"I mean the fact it's Macmillan supported is great you know." (Harriett, 0110P).*

> *"I phoned the Macmillan helpdesk, absolutely brilliant, they were my lifeline." (Tina, 0112P).*

Only one woman expressed a negative perception of the charity, which stemmed from a poor experience of an acquaintance, as opposed to her own experiences. Women's positive views largely related to their own experiences (or those of friends), and did not indicate an association with death and dying, as staff suggested.

4.3.6 Individual Case Example

The preceding sections have considered the complex factors which influenced the (e)HNA's contributions to assessing and supporting the needs of women. As a further illustration of these dynamics, Rose's (0108P) case presents a timeline of events throughout her cancer journey. This is described from her own perspective and a staff perspective.

The illustration in Figure 36 highlights the intricacy of Rose's life, and how numerous factors such as first impressions, previous experiences, interpretations and emotional state can cause the (e)HNA to fall short of expectations if these factors are not considered in its delivery.

Figure 36. Illustrative Example: Rose’s Case

Initial Diagnosis

Staff Perception

Rose received an initial diagnosis appointment, where she was provided with verbal and written information, an information pack to access the (e)HNA, and was assigned a BCN. Rose completed her (e)HNA and a subsequent discussion about her concerns over the telephone. She was sent her care plan in the post, which highlighted that she had raised primarily physical concerns unrelated to her cancer diagnosis, and the action plan stated these were mainly addressed.

Rose's Perception

Rose felt afraid when she received her diagnosis, not only over the cancer, but also fear of telling her children, and exacerbation of other anxieties, such as her husband’s recent stroke and finding a care home for her mother-in-law. When given the (e)HNA, Rose was reluctant to complete it due to a colleague's poor experiences of Macmillan Cancer Support, but she felt compelled to do so. She did not fully understand the (e)HNA's purpose, and filed away the care plan without reading it when she received it.

During Treatment

Staff Perception

Rose experienced some delays to treatment and reported side effects once this was underway. She made contact with the BCNs on three occasions to ask questions and was advised to read the written information she was provided with at diagnosis. Rose visited her GP due to side effects of her medication, she was advised that in future these discussions should be with her consultant. Additionally, Rose stated she wished to return to work, but was counselled this was not advisable at that time due to ongoing treatment.

Rose's Perception

Rose was worried about the impact her treatment would have on work, where she had a strong support network and felt desperate to return. Her side effects also meant she was unable to maintain her normally active lifestyle and subsequently gained weight, which impacted her mood and caused anxiety. Rose read all of the information she had received for support, and felt lucky she was not a severe enough case to attend support groups. Rose visited her GP about her side effects, but then felt guilty for this as her BCN stated this should not have occurred.

End of Treatment

Staff Perception

Rose was posted a repeat (e)HNA which she completed. She raised many concerns, including highly scored emotional issues. Rose had an end of treatment appointment to discuss her concerns with her BCN, in which she was tearful several times but made jokes throughout. Rose was offered a psychology referral which she declined. On the care plan, all documentation related to medication side effects and there was no mention of her emotional concerns. Rose phoned the BCN weeks later to inform her of improvements to her symptoms.

Rose's Perception

Rose felt negative about receiving a second (e)HNA, but she completed this honestly. During her end of treatment appointment, she declined the psychology referral as she felt able to manage, but thought the BCN viewed her as being difficult. Rose received her care plan and noticed the grammatical issues, it reminded her of the negative appointment. When she phoned the BCN about improvements in her side effects, she felt negative because the BCN said she was not listening in her appointment. Rose would not contact the BCNs again.

When presented with her two care plans during the research interview process, Rose felt that the (e)HNAs were a useful exercise. This was because the comparison displayed her progress, and provided a document she could refer back to. The two care plans were not compared with Rose by a BCN, and therefore her interview was the first time she was able to view these together.

Rose's case illustrates the complexity of factors influencing the (e)HNA's contribution, by demonstrating the layers of concern occurring in an individual's life beyond what may be presented to staff. These factors include not fully understanding the (e)HNA, her wider life circumstances, lack of rapport with her BCN, and the timing of her first assessment, all of which negatively affected her (e)HNA experience.

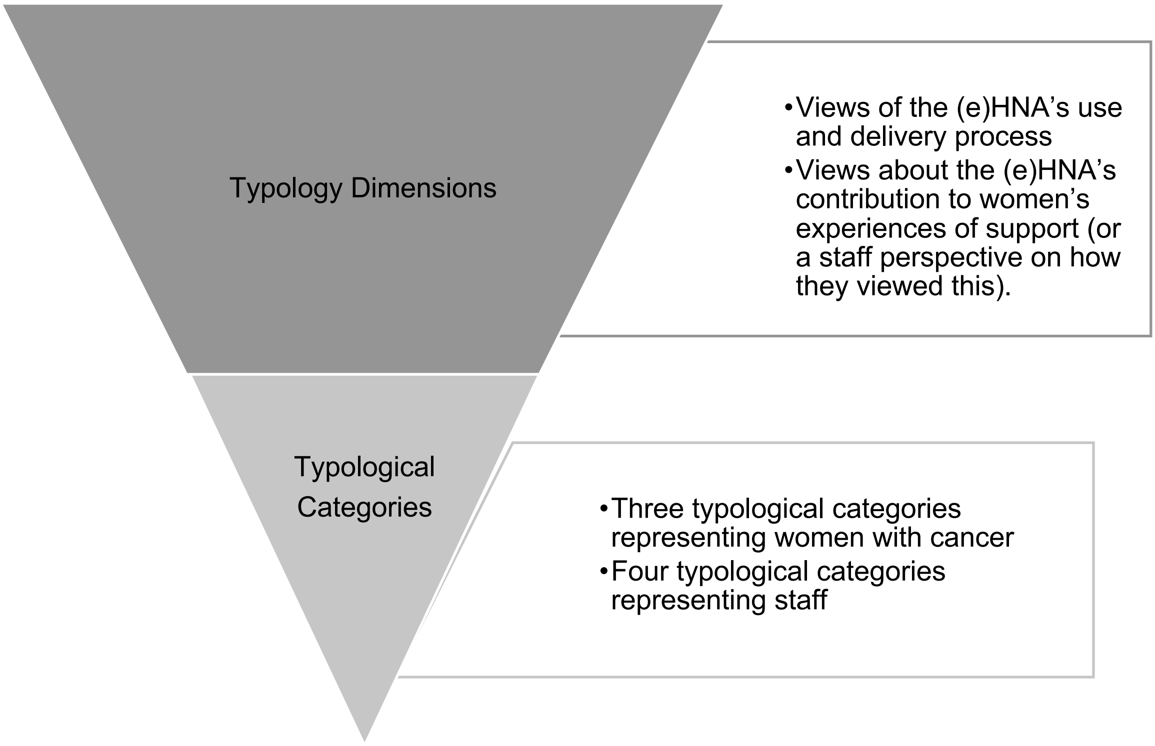
Following the detailed overview of classes and categories provided throughout this section, this chapter now moves on to the typologies that underpin the dataset. These allowed analysis to move from categorisation and classification, to refining data into an increasingly complex portrayal of the (e)HNA and its contribution to women's experiences of support.

4.3.7 Overarching Typologies

As highlighted in Section 4.3.1, Framework Analysis processes enabled the development of overarching typologies. These were based on two key dimensions: 'views of the (e)HNA's use and delivery process' and 'views about the (e)HNA's contribution to women's experiences of support (or a staff perspective on how they viewed this)'. In Case Study 1, these dimensions separate participants into three different categories for women, and four categories for staff.

Figure 37 demonstrates the construction of the typologies, and explains the typological categories within these.

Figure 37. Typology construction



4.3.7.1 Typological Categories – Women with Cancer

The tables throughout this section contain key information explaining why participants were grouped within a particular category. As a recapitulation from Section 4.3.1, the three typological categories representing women are displayed in Figure 38.

Figure 38. Recapitulation of Typological Categories: Case Study 1 Women with Cancer

1. "Positive in Principle"
   - The (e)HNA's use and delivery process is positive in principle, but there was little or no contribution from this to the overall experience.
2. "Paradoxical Experience"
   - The (e)HNA's use and delivery process is positive in principle, but had a negative contribution to the overall experience.
3. "Disconnection"
   - The process of (e)HNA was not engaged with, and had no contribution to the overall experience.

4.3.7.1.1 "Positive in Principle”

The initial typological category included seven out of 12 women in Case Study 1, who expressed a predominantly positive view of the (e)HNA ‘in principle’ but felt it had little or no contribution to assessing or supporting their needs. A summary of evidence displaying why each participant is in this category is outlined in Table 15:

Table 15. Typological Category 1 Evidence: “Positive in Principle”

Participant	Description of Views/Experience
Jane (0101P)	Jane liked the idea of entering a system of care, which she felt was taking place through her (e)HNA. Despite this, she raised no concerns when the assessment was undertaken and viewed it as irrelevant. Consequently, the (e)HNA’s value was based on the expectation that she would maintain access to support by repeating the (e)HNA, which kept her in the care system.

Marie (0102P)	When the (e)HNA was explained during her interview, Marie felt the concept was very useful and that she would have been better supported had she understood what it was at the time. In reality, Marie did not understand the (e)HNA when it was offered and therefore did not complete it. An unstructured conversation took place that was developed into a care plan, but this was not in response to an (e)HNA, and in her confusion Marie did not raise all of her concerns.
Kate (0103P)	Kate felt the (e)HNA made a positive contribution to her support needs, through providing a way to disclose concerns which she would not otherwise have been comfortable to discuss. However, Kate felt that the (e)HNA was less useful if not repeated, and this needed to be ongoing. She felt this would be more beneficial for others with more needs than herself.
Sarah (0107P)	Sarah did not feel the (e)HNA was particularly beneficial to her but liked the idea of it supporting others, and felt it would be useful if she repeated it. The contribution of the assessment for Sarah was minimal, as she felt it was irrelevant at the time, and did not fully engage with it.
Joan (0109P)	Joan liked the concept of the care plan, due to its ability to prompt memory in the future. When it was completed, Joan felt the (e)HNA was irrelevant, and its contribution to her support needs was minimal. This was due to her lack of understanding about what was involved, which made her reluctant to accept help.
Harriett (0110P)	Harriett felt that there was a positive contribution, namely having an opportunity to talk and be listened to. However, she did not fully understand the (e)HNA and thought it was compulsory. Harriett felt the assessment would have been more meaningful if she was supported with its completion, and if it had been offered at a more useful time.

Claire (0111P)	Claire believed strongly in the principle of the (e)HNA for people who required it. However, the contribution for Claire herself was minimal, due to her lack of understanding and feeling obliged to complete it.

In the examples above, each individual placed value on the (e)HNA in relation to its contribution ‘in principle’, as opposed to their actual experience of it. Their actual experiences appeared to fall short of the ideal for several reasons, including the timing, location, understanding, expectations, willingness to disclose concerns, and lack of repeat assessments.

For participants who discussed repeat assessments, they again related this to the (e)HNA’s potential to offer a positive contribution if it were repeated, rather than a contribution it had made in their experience. For example, Jane reflected a positive view of the support system she would enter following her (e)HNA, yet by the close of the study (seven months after initial recruitment), Jane had not been offered a second (e)HNA.

4.3.7.1.2 "Paradoxical Experience"

Similar to Typological Category 1, several other participants held views that the (e)HNA could provide a positive contribution ‘in principle’ in Typological Category 2. However, these women also felt the assessment had provided a negative aspect to their experiences of support, which may not have occurred had they not undertaken the (e)HNA.

Table 16. Typological Category 2 Evidence: “Paradoxical Experience”

Participant	Description of Views/Experience
Laura (0105P)	Laura felt that the care plan allowed reflection on her concerns and may be beneficial in future, if she referred back to it. However, the (e)HNA's contribution overall was minimal, as her lack of understanding meant she did not disclose all of her concerns. Laura also felt the (e)HNA presented additional burden to her experience, as she felt obliged to complete this, and was unsure what to disclose, how long her appointment was, how busy staff were, and had various other tasks and appointments weighing on her time.
Rose (0108P)	Rose felt her care plan could be useful one day, and found the (e)HNA's main contribution was the ability to compare care plans from the two different points in her journey. However, this action only occurred as part of her research interview. Alongside this, reading one care plan prompted negative memories of the appointment, where she had left feeling unhappy. Rose only completed her (e)HNAs because she felt they were compulsory.
Tina (0112P)	Tina felt the (e)HNA could prove useful if completed at the end of treatment. However, Tina described raised expectations from her (e)HNAs. Actions were discussed and documented that did not come to fruition, and then she felt worse for having disclosed them. She also felt the timing was unsuitable but that the (e)HNA's completion was compulsory.

These examples suggest three negative outcomes of the (e)HNA: increased burden, a negative reminder, and disappointment. Furthermore, all individuals within this typological category felt compelled to complete the (e)HNA for staff, which could add further pressure. Despite this, these participants retained some belief in the (e)HNA as useful 'in principle'.

4.3.7.1.3 “Disconnection”

The final typological category contained two participants, whose perception of the (e)HNA led to their complete lack of engagement. Consequently, they completed neither an assessment, nor had a conversation that was converted into a care plan.

Table 17. Typological Category 3 Evidence: “Disconnection”

Participant	Description of Views/Experience
Ruth (0104P)	The (e)HNA made no contribution to assessing and supporting Ruth’s needs. Unsuitable timing combined with her lack of understanding meant that she did not complete it.
Paula (0106P)	Paula felt she was given the (e)HNA alongside other substantial information, appointments and tasks to do, and she prioritised these. She perceived the (e)HNA as low priority and so did not complete it or read the information describing what it was. However, Paula later sought help independently, for concerns which could have been highlighted by the (e)HNA.

In the two cases above, both women showed a lack of understanding about the (e)HNA and felt no need to prioritise it. As these two participants did not complete their (e)HNAs or read the associated leaflets, their conclusions that this was low priority may have stemmed from the assessment’s verbal introduction from staff.

The typological categories representing women in the study presented a strong theme of the (e)HNA’s contribution ‘in principle’ (what people thought it ‘could’ contribute). The (e)HNA appeared more likely to be meaningful if certain key factors were present, but the absence of these could lead to no contribution, or a negative impact on experience. Examples of these key factors were timing, multiple assessments, location, the wider circumstances in an individual’s life, understanding, and perceptions of staff (such as viewing them as too busy to provide support).

4.3.7.2 Typological Categories- Staff

When considering a staff perspective, participants were grouped into four typological categories, recapitulated in Figure 39:

Figure 39. Recapitulation of Typological Categories: Case Study 1 Staff

1. "Paradoxical Expectations"
    - The (e)HNA's use and delivery process is positive 'in principle’, but they perceived that it contributed something negative to the overall experience.
2. "Comprehensively Negative Expectations"
    - The (e)HNA's use and delivery process is negative or has little benefit, and they perceived that it contributed something negative to the overall experience.
3. "Positive in Principle"
    - The (e)HNA's use and delivery process is positive in principle, but there was little or no contribution from this to the overall experience.
4. "Comprehensively Positive Expectations"
    - The (e)HNA's use and delivery process is positive, and they perceived that it contributed something positive to the overall experience.

4.3.7.2.1 “Paradoxical Expectations”

Echoing the views of women, some staff felt that the (e)HNA process was positive ‘in principle’, but had the potential to provide a negative contribution to the individual’s experience in reality.

Table 18. Typological Category 1 Evidence: “Paradoxical Expectations”

Participant	Description of Views/Experience
SW 1 (0105S)	SW 1 felt that repeated (e)HNAs could be useful for monitoring progress through comparison. However, she also felt its contribution was minimal beyond what was achievable through a conversation. She felt the (e)HNA could negatively affect women’s experiences by allowing concerns to be raised but not fully addressed, and staff focusing more on achieving targets than supporting people.
BCN 3 (0109S)	BCN 3 felt the (e)HNA could be useful if multiple assessments were undertaken, but similarly felt it contributed nothing beyond what could be elicited through a conversation. Its contribution could also be negative, for example, by making women feel as though they ‘should’ be ill, thus pressuring them to respond in a certain way.

In both experiences noted above, staff felt the process of undertaking multiple (e)HNAs could be useful because it offered a comparison, but this was not routinely undertaken in practice. Staff speculated on negative aspects of the (e)HNA process from the perspective of women, such as failure to address concerns and adding an additional burden through raised expectations. Staff felt this burden could also be present if the assessment was introduced too early, causing increased anxiety (through showing women a list of side effects), and feelings of pressure that they ‘should’ be ill and should be identifying concerns. Consequently, staff recognised that women may feel some obligation in their (e)HNAs (such as obligation to complete it or to raise concerns), a finding also highlighted by some women.

4.3.7.2.2 “Comprehensively Negative Expectations”

The second typological category involved similar views that the (e)HNA could contribute negatively to women’s experiences, but also that the delivery process itself was negative, or inconsequential. This was the most common typological category for staff, containing five out of the 12 participants in Case Study 1.

Table 19. Typological Category 2 Evidence: "Comprehensively Negative Expectations"

Participant	Description of Views/Experience
BCN 1 (0101S)	BCN 1 felt that the (e)HNA contributed nothing to women above and beyond a conversation. It could have a negative effect on their experience by bombarding them with additional tasks.
BCN 2 (0102S)	BCN 2 perceived that overall, an unstructured conversation without using the (e)HNA was more beneficial to women. She believed there were many barriers to using it from the perspective of women, (for example time-consuming).
MCISS staff member (0104S)	This staff member felt that use of a structured (e)HNA tool would detract from conversations. It could make individuals feel under pressure, or as though the staff member was being intrusive.
BCN 4 (0110S)	BCN 4 felt the (e)HNA had some benefits for individuals who were less likely to openly report their concerns in a conversation. However, benefits were outweighed by barriers, such as having additional hospital trips, when women may not wish to complete the (e)HNA.
BCN 5 (0112S)	BCN 5 felt the (e)HNA reinforced but contributed little to what BCNs were already doing in their roles. She also felt that there were many barriers (for example, technology, travelling in for additional appointments). She felt it could induce anxiety through listing potential concerns they might face later in their journey.

Two staff members above reported no perceived benefit to the (e)HNA process. Two indicated there were a small number of benefits, including the care plan acting as a reminder of tasks to undertake, but the negatives outweighed these. The perception of negative contributions related primarily to the (e)HNA placing pressure or burden on the woman. Additionally, responses also reflected some of the staff challenges encountered in Case Study 1, such as targets, internal pressures (for example shortage of staff), and feeling obliged to undertake (e)HNAs. Despite believing use of the (e)HNA was detrimental to the breast team and women, staff continued to undertake them. This could be due to their perceived obligation to complete these, or acceptance of the (e)HNA as part of their routine, without strong enough opinions to argue for change.

4.3.7.2.3 "Positive in Principle"

In the third category, some benefit from the (e)HNA delivery process was perceived, however these staff members also felt its contribution was insignificant to women's experiences of support.

Table 20. Typological Category 3 Evidence: "Positive in Principle"

Participant	Description of Views/Experience
Programme manager (0103S)	This staff member felt the care plan was positive to prompt women into action and assist with self-management. However, use of targets made the (e)HNA's contribution more focused on achievement of these, and reduced the potential benefits.
Lead BCN (0108S)	The Lead BCN felt the (e)HNA could assist individuals with cancer to self-manage. However, she felt targets led to (e)HNAs being less meaningful. She expressed that their overall contribution was small, due to the task-orientated focus and because assessments were often done in isolation, and not shared between professionals.
ANP (0111S)	This staff member felt the (e)HNA could potentially identify additional concerns if done correctly, but the contribution above and beyond a general conversation was minimal.

These staff felt that the targets assigned to (e)HNA completion (outlined in Chapter One) reduced the assessment's ability to have a positive contribution for women, because of the task-orientated approach these prompted (measuring success through completing, as opposed to how meaningful this was of this).

4.3.7.2.4 “Comprehensively Positive Expectations”

In the final typological category, only two staff felt the (e)HNA’s process and its contribution were positive for women.

Table 21. Typological Category 4 Evidence: “Comprehensively Positive Expectations”

Participant	Description of Views/Experience
Project manager (0106S)	Project manager reported that the (e)HNA allowed identification of more concerns than was possible through a conversation. They felt it gave permission for individuals to raise non-urgent concerns. The main disadvantages were from a staff perspective (for example, time pressures), as opposed to its contribution to women’s experiences.
SW 2 (0107S)	SW 2 felt positive contributions to an individual’s experience occurred through comparing care plans to monitor progress, and showing women actions were taken to address their concerns. Although some barriers were noted, these were specific issues with certain groups of individuals (for example use of computers with the elderly), as opposed to general views of the (e)HNA’s contribution overall.

Despite these views, the project manager was responsible for driving and implementing the (e)HNA from an operational perspective, and did not directly complete assessments with women. Consequently, her views may reflect what she saw as the benefits of (e)HNAs ‘in principle’, if delivered under the correct circumstances. Interestingly, SW 2 reported not thinking about targets in her role, which may be a factor in her more positive opinion of the (e)HNA’s contribution.

Following the discussion of individual typological categories, Spencer et al. (2013) highlight that grouping participants in this way can be especially valuable to show connections, which demonstrate how views are attached to specific groups or populations. Therefore, typological categories are a strong basis from which to explore deeper levels of explanation, through use of 'explanatory accounts' within the Framework Analysis approach (Spencer et al., 2013).

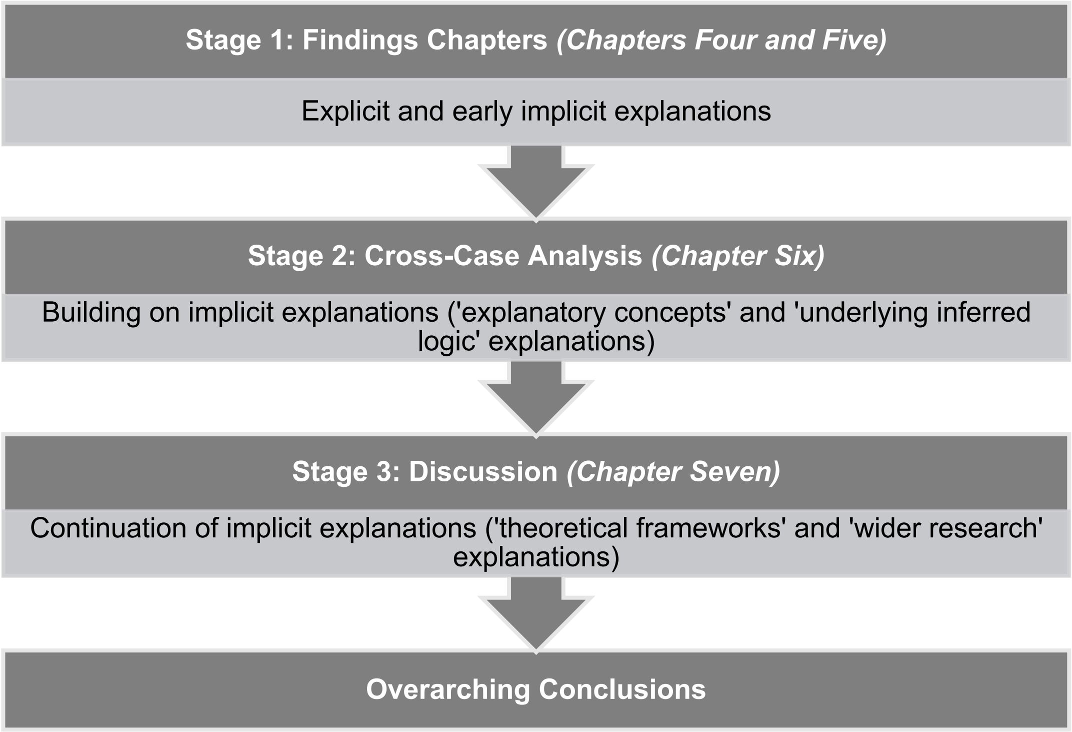
4.4 Findings: Explanatory Accounts

Framework Analysis continues beyond 'descriptive accounts' (the class-category framework and typological categories), into 'explanatory accounts'. The explanatory accounts process draws on connections within study data, using explicit and implicit explanations to provide greater depth of understanding (Spencer et al., 2013). Beginning with explicit explanations, these are derived from participants' own words, which are articulated to display their intentions, opinions or reasoning, rather than the researcher making assumptions about these (Spencer et al., 2013). Secondly, 'implicit explanations' build upon the explicit comments, considering inferences made by the researcher (elements not openly stated by participants) (Spencer et al., 2013). In order to identify implicit explanations, several techniques can be used, which are 'explanatory concepts', 'underlying inferred logic' and use of wider research or theoretical frameworks (Spencer et al., 2013) (defined in Figure 40). Within this thesis, implicit explanations are developed over Chapters Four-Seven, as displayed in Figure 41.

Figure 40. Explanatory Accounts Terminology (Spencer et al., 2013)

Term	Definition
Explanatory concept explanations	The development of analytic concepts (often a phrase or a single word) to explain a phenomenon, and to explain variations in behaviour or views.
Underlying inferred logic explanations	Inferred logic explanations can explore connections within the data, which may either use well-known patterns as explanations, or simply make sense as an explanation based on the information present.
Theoretical framework explanations	Explanations developed in line with a theoretical perspective and use of these to build on insights gained.
Wider literature explanations	Comparison of study findings with other research on similar phenomena, and testing identified explanations to see if they fit against the current study's findings.

Figure 41. Presentation of Explanatory Accounts Analysis



To consider each element of developing ‘implicit explanations’, this is divided into three Stages. Initially, Stage 1 (Chapters Four and Five), considers connections between the participants within the previously discussed typological categories (such as patterns of characteristics, personal circumstances or opinions). From these, explanations for these connections are created, using ‘explicit’ data, and some early ‘implicit’ explanations are considered. Subsequently, Stage 2 (Chapter Six), further develops these early implicit explanations, through use of ‘explanatory concepts’ and ‘underlying inferred logic’ techniques. Finally, Stage 3 (Chapter Seven) considers a theoretical framework and wider research to build upon these implicit explanations and enable final conclusions to be determined.

Beginning with Stage 1, explanatory accounts for women with cancer and staff are considered separately, by identifying the patterns or connections between participants in each typological category. This is achieved by focusing on patterns of views, characteristics and personal situations, alongside explicit data that supports these assertions. Early implicit explanations are interwoven throughout.

4.4.1 Explanatory Accounts: Women with cancer

4.4.1.1 Connections Between the Participants: Typological Category 1

Typological Category 1 is recapitulated in Figure 42, followed by the discussion of three main connections identified between its participants:

Figure 42. Women with Cancer: Typological Category 1

1. "Positive in Principle"

- The (e)HNA's use and delivery process is positive in principle, but there was little or no contribution from this to the overall experience.

1. **Low prioritisation of the (e)HNA**. All participants appeared to perceive the (e)HNA as a low priority. They suggested that when the (e)HNA was offered at diagnosis, it was prioritised below other information and decisions required at that time. Furthermore, perceptions of low prioritisation were indicated by the lack of initial engagement with the written (e)HNA material, or non-completion of this in Marie’s (0102P) case.

2. **Barriers to engagement with the support offered.** The rationales varied for these barriers in accessing support varied. For example, Joan (0109P) was concerned about the impact of accessing support upon her caring responsibilities for her

husband. Marie (0102P), felt restricted by both her financial situation (which made travel to support services challenging) and her family's medical needs that she needed to support. The impact of these factors upon engaging with support may be also demonstrated by data in Chapter Three, which showed that these women initiated no contact with the breast team to request support.

3. **Few concerns reported in (e)HNAs**. Many participants in this typological category reported few concerns or low-scored concerns. For example, Jane (0101P), Marie (0102P), Sarah (0107P) and Harriett (0110P) raised no more than two concerns in their (e)HNAs. This may suggest they felt their self-management abilities were sufficient to allow them to decline the support offered, or that they simply had few concerns. The only exception to this rule was Joan (0109P), who expressed a strong desire to avoid accessing support because of her caring responsibilities.

Early Explanations: In this category, the patterns identified showed that women held favourable opinions the (e)HNA in principle, but appeared reluctant to accept support offered (for various reasons). Perceptions of the assessment's contribution was therefore minimal. As previously discussed, lack of engagement with support may also relate to perceived low importance of the (e)HNA, or that these women's personal circumstances were simply not challenging enough to prioritise external support at that time.

4.4.1.2 Connections Between the Participants: Typological Category 2

Within Typological Category 2, four connections were identified between the participants.

Figure 43. Women with Cancer: Typological Category 2

2. "Paradoxical Experience"

- The (e)HNA's use and delivery process is positive in principle, but had a negative contribution to the overall experience.

1. **Obligation to complete the (e)HNA**. Many participants described feeling compelled to complete the assessment. For example, this was demonstrated by saying they felt the (e)HNA was part of the care process, or expressing that they ought to be compliant with staff requests.

2. **Strong perceptions of the NHS or hospitals**. Participants indicated specific views towards the NHS. For instance, some participants felt the NHS takes over people’s lives during treatment, or implied an association between hospitals and receiving bad news. All of these perceptions appeared to indicate a loss of control, in some form.

3. **Autonomy in seeking support**. Participants demonstrated some independence in initiating support. This was demonstrated by women identifying their own options and resources for support, without use of the (e)HNA.

4. **Higher scores and high numbers of concerns in (e)HNAs.** Women in this group raised higher numbers of concerns (or scored these highly), compared with other women. For example,

Laura (0105P), raised seven concerns with an average severity score of 8.7 out of ten, Rose (0108P), raised ten concerns in her first (e)HNA and 24 in her second (average scores 4.4 and 7.5), and Tina (0112P) raised 20 concerns in her first (e)HNA and 32 in her second (average scores 6.2 and 5.4).

Early Explanations: This category introduced a contradiction in perceptions, as participants felt favourably towards the (e)HNA in principle, but also felt it was detrimental to their experience. These women sought support through other avenues than the (e)HNA, so it may have been difficult to see purpose in undertaking an (e)HNA if they were able (and willing) to identify support themselves. The strong perceptions towards the NHS or hospital care may indicate perceived lack of control (for example, having to ‘jump’ when told to by the NHS, Tina, 0112P), which appeared to influence their engagement with the (e)HNA. Seeking their own support may have allowed these women to exercise control, which they did not appear to have in other aspects of their care. This may explain why the (e)HNA process was ineffective in these scenarios.

4.4.1.3 Connections Between the Participants: Typological Category 3

For the final typological category for women with cancer (Figure 44), two connections between the participants were highlighted.

Figure 44. Women with Cancer: Typological Category 3

3. "Disconnection"

- The process of (e)HNA was not engaged with, and had no contribution to the overall experience.

1. **Financial issues**. All participants were in full-time employment and expressed having financial challenges, which they sought support for. One woman initiated contact with the breast team to enquire about this, and the other contacted Macmillan Cancer Support for aid.

2. **No understanding of the (e)HNA**. The assessment was low-priority and not completed by these participants, based on the lack of understanding they reported about its purpose and benefits.

Early Explanations: Within this category, low prioritisation of the (e)HNA may have resulted from their financial difficulties. Many references were made to the requirement to attend work, generate income and the time pressures this presented, which were seen as a greater priority. Furthermore, they indicated requiring financial support and pursued this independently. This may demonstrate a lack of understanding of the (e)HNA, as they appeared unaware that their support needs may have been addressed through the (e)HNA process.

From the above connections between women, many issues discussed within the class-category framework are highlighted. For example, the impact of their level of need, understanding of the assessment, reason for completion, and its priority at the time it was offered. Broadly, perceptions of the (e)HNA's contribution appeared to vary between those individuals who had few supportive needs, those who reported high-level concerns and felt a subsequent absence of control, and those whose practical life circumstances took precedence, which led to disengagement.

Although it would be simplistic to suggest that all women with cancer are defined by these characteristics or opinions, these divisions suggest that different approaches to the (e)HNA might enhance its contribution if the central aspects of women’s lives were considered. For example, deferring an (e)HNA to a more relevant time for those with low-level concerns (or allowing them choice in determining this), or providing greater ownership of the assessment for women whose emotions and perceived level of control were complex.

A similar approach was adopted to identify connections between the staff typological categories.

4.4.2 Explanatory Accounts: Staff

4.4.2.1 Connections Between the Participants: Typological Category 1

Within the first typological category for staff (Figure 45), three connections were identified between the participants.

Figure 45. Staff: Typological Category 1

1. "Paradoxical Expectations"

- The (e)HNA's use and delivery process is positive 'in principle’, but they perceived that it contributed something negative to the overall experience.

1. **Resistance towards the (e)HNA**. The resistance expressed by these participants appeared to stem from perceptions that its contribution was minimal, when compared with an unstructured conversation.

2. **Lack of value in the local targets.** These staff perceived little value in the (e)HNA targets, which prompted a focus on achieving these, above conducting meaningful assessments. Much of the interview dialogue focused on ‘offering’ (e)HNAs as opposed to ‘completing’ (e)HNAs, which may also suggest that the priority was achieving required quantities of (e)HNAs, despite their recognition that these were often not meaningful.

3. **SW roles were important for the (e)HNA’s sustainability**. Participants indicated this view because they felt SWs had more time to conduct (e)HNAs.

Early Explanations: Staff evidently felt the reality of (e)HNA delivery processes hindered its value, due to time pressures and the need to achieve targets. Staff appeared to prefer unstructured conversations, which may suggest that the absence of targets enabled more natural conversations and assessments to take place.

4.4.2.2 Connections Between the Participants: Typological Category 2

Typological Category 2 (Figure 46) highlighted three connections between participants.

Figure 46. Staff: Typological Category 2

2. "Comprehensively Negative Expectations"

- The (e)HNA's use and delivery process is negative or has little benefit, and they perceived that it contributed something negative to the overall experience.

1. **Confidence issues with the (e)HNA.** All participants indicated greater confidence in conducting unstructured conversations using their communication skills than in (e)HNAs. Areas of low confidence highlighted were ending (e)HNA conversations in a timely manner, knowing what was acceptable to document on care plans, and the risks involved in giving women high expectations of what a structured (e)HNA could deliver.

2. **Prioritisation on evidencing their actions**. These staff indicated the importance of evidencing the actions they took, through comments suggesting undocumented actions ‘did not happen’, or by directly identifying evidence as a key benefit of the care plan.

3. **Sense of responsibility to the women**. Staff indicated feeling responsible towards the women in their care, through comments suggesting a desire to not disappoint them (by raising expectations unnecessarily) or a fear of initiating unwanted contact.

Early Explanations: Participants in this category indicated some low confidence and uncertainty about the best course of action to address (e)HNA concerns. Therefore, the flexibility of a conversation was more comfortable. Feedback suggested staff did not entirely believe in concept of the (e)HNA, as they appeared to think women would not want to discuss their concerns as part of a structured assessment.

4.4.2.3 Connections Between the Participants: Typological Category 3

Within Typological Category 3 (Figure 47), two connections applied to the participants.

Figure 47. Staff: Typological Category 3

3. "Positive in Principle"

- The (e)HNA's use and delivery process is positive in principle, but there was little or no contribution from this to the overall experience.

1. **Management roles**. All participants in this category were employed full-time in some form of leadership role (such as programme manager or lead BCN).

2. **(e)HNA was one part of a bigger picture.** Participants understood that (e)HNAs were one aspect of the wider support offered within the cancer journey. They referenced the ‘wider programmes’ which existed for women and how the (e)HNA aligned with these. There was evidence of bigger picture thinking, around targets and the view that these only measure quantity (not quality). It was stated that focusing on (e)HNA numbers alone did not demonstrate a full picture of support received, such as when an individual may have initiated numerous supportive telephone calls, but declined their (e)HNA.

Early Explanations: In this category, knowledge from a perspective beyond the healthcare frontline (from management) may have contributed to perceptions that the (e)HNA’s contribution was small. There was a recognition that (e)HNA processes prioritise quantity over quality.

4.4.2.4 Connections Between the Participants: Typological Category 4

For the final typological category (Figure 48), three connections were identified between the participants.

Figure 48. Staff: Typological Category 4

4. "Comprehensively Positive Expectations"

- The (e)HNA's use and delivery process is positive, and they perceived that it contributed something positive to the overall experience.

1. **Not pressurised by (e)HNA targets**. Staff in this category explicitly reported not feeling under pressure based on targets, despite the project manager being employed to support achievement of these.

2. **Less time in their job roles.** Although not new to their roles, these staff had been in post for fewer years in comparison to other staff involved in the study.

3. **The (e)HNA's contribution was superior to a general conversation.** Participants openly stated this view, as it enabled more depth of discussion and prompted concerns to be raised.

Early Explanations: The absence of target pressures these participants reported may have allowed greater focus on the (e)HNA's benefits, and may explain why their views were more positive than those in other categories. Additionally, these opinions differed significantly from those of BCNs, which may suggest that other factors were at play. For example, the SW and project manager's roles had a more central focus on (e)HNA delivery than BCN roles, which may have influenced these opinions.

Overall, staff perceptions of the (e)HNA's contribution may relate to their job role, the pressure they felt to achieve targets, and variable confidence they reported. Low confidence led to some staff preferring the (e)HNA to a conversation (as it offered a structure for meaningful conversations), or avoidance of the (e)HNA (due to uncertainties, for example, how to best address concerns), and therefore preferences for unstructured discussions. Furthermore, staff concerns about being held to account for target achievement may have negatively affected their view and delivery of the assessment, particularly if they perceived target achievement as the priority outcome. Therefore, each staff member's decisions about how they undertook the (e)HNA were likely derived from various factors, including personal confidence and background understanding of how the (e)HNA fits into the individual's cancer journey. These explanations are built upon during the cross-case analysis in Chapter Six, where 'explanatory accounts' are revisited.

4.5 Conclusion

This chapter has provided an overview of findings from Case Study 1 (Site 1). The structure presented data according to the Framework Analysis process, from the systematic development of descriptive accounts, to Stage 1 of explanatory accounts.

Overall, women in Case Study 1 felt the (e)HNA's contributions were primarily the care plan's ability to prompt memory and provide security. Staff perceived few benefits to the care plan beyond evidence of their actions and its contribution to encouraging self-management, and they experienced confidence issues with its completion. From an implementation perspective, timing and location had significant influence on views of the (e)HNA's value, but staff appeared reluctant to change existing practices, which they felt were unsuccessful. In many cases, women and staff felt compelled to complete or deliver the (e)HNA, which led to women's non-disclosure of concerns and staff resistance. Furthermore, 'champion' roles were necessary as a driving force in the (e)HNA's sustained implementation, due to the increased workload it presented. Overall, women appeared strongly influenced by staff in their approach to the (e)HNA. However, staff appeared motivated by target adherence (despite their acknowledgement that targets affected the quality of (e)HNAs) and preferred conversations without the tool. Whilst these findings cannot provide unequivocal conclusions about the ideal conditions needed for the (e)HNA to have a positive contribution, analysis has highlighted clear differences between women and staff in areas such as positivity towards the (e)HNA in principle, and the priority given to it. These differences exist not only between groups of staff members and women with cancer, but also within these two groups. These variations also suggest that standardised approaches to delivering (e)HNAs are not possible, and maximising its value requires consideration of the complex factors involved in making the assessment meaningful. A summary of findings from Case Study 2 is presented in Chapter Five, before cross-case comparison in Chapter Six.

Figure 49. Chapter Four Key Points

Chapter Four Summary: Key Points

- Case Study 1 data were illustrated using the Framework Analysis' class-category framework, focusing on women's and staff members' perceptions of the numerous contributions and influencing factors in valuable (e)HNAs. Explanations also adopted typological categories and components of Framework Analysis' explanatory accounts, which are further explored in Chapter Six.

- Women expressed the perception that the (e)HNA had minimal value in practice, but had the potential to offer a meaningful contribution to their experience of support in the right circumstances.

- Many staff and women felt compelled to complete (e)HNAs, and so engagement appeared target orientated for many staff, as opposed to focused on eliciting meaningful conversations.

- Implementation issues persisted, such as identifying the best time and location for assessments, challenges with staff workload, and resistance towards the (e)HNA which appeared embedded in staff culture.

- Staff indicated minimal freedom to change practices they felt were ineffective, such as (e)HNAs at diagnosis (or needs assessment using a formal tool generally).

Chapter Five: Case Study 2 Findings

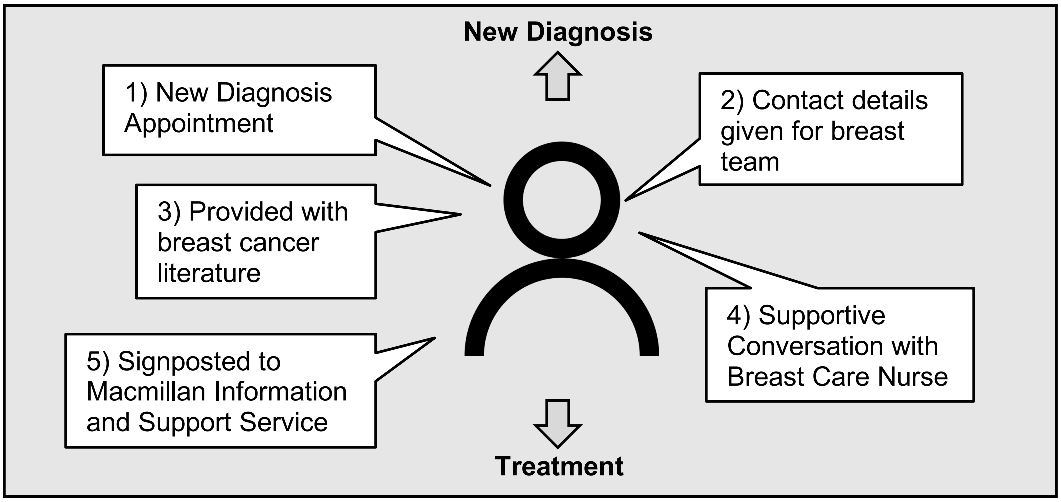
5.1 Introduction

This chapter explores data and findings from Case Study 2 (Site 2), adopting a similar approach to Chapter Four. Initially, Case Study 2's standard practices and participants are described. As with Chapter Four, findings are then presented using the structure of Framework Analysis' 'descriptive accounts' and 'explanatory accounts' processes. Within descriptive accounts, the class-category framework and overarching typologies are explored. Following this, early discussion of explanatory accounts occurs, using 'explicit' data, and early 'implicit' explanations, which are built upon throughout Chapters Six and Seven.

5.2 The Case

As discussed in Chapter Three, Case Study 2 was a large NHS Trust consisting of two hospitals involved in cancer care (including a day unit, various cancer inpatient wards and an outpatient area for breast cancer). Various treatments were delivered on site by the organisation, including chemotherapy, radiotherapy and surgery. In the Trust, women diagnosed with breast cancer were allocated a named breast care nurse (BCN). As with Case Study 1, the standard care process included their BCN's attendance at appointments with the consultant throughout the individual's journey, to provide support and relay information. However, women often met different members of the team during appointments, and not necessarily their named BCN. Women were also frequently signposted to their local Macmillan Information and Support Service.

Figure 50. ‘Routine Care’ in Case Study 2



5.2.1 Local (e)HNA Usage

In contrast to Case Study 1, staff recruited from Case Study 2 were mostly based in one place (either Hospital 1 or Hospital 2). As described in Chapter Three, differences were noted in (e)HNA delivery processes between Hospital 1 (the larger hospital where most treatments were undertaken) and Hospital 2 (a smaller site conducting diagnostic testing, some treatments and follow-up appointments). In line with the (e)HNA national targets, Case Study 2 aimed to offer the (e)HNA at the point of diagnosis, but this was later deemed unsuccessful (particularly in Hospital 1). Alternatively, they focused on ensuring the (e)HNA was offered to all women at some point in their journey. Delivery of this local target was primarily driven by the project managers, whose roles focused on (e)HNA implementation. The variations in (e)HNA delivery between the hospitals may have been influenced by contextual factors. For example, these were originally separate hospitals, which merged to become a joint organisation in 2018. Moreover, separate project managers were employed in each hospital to take responsibility for (e)HNA implementation.

Table 22 displays completion rates for (e)HNAs in Case Study 2 during 2019 (provided by the site's project managers). This table includes details about the point in the cancer journey where the (e)HNA was offered (pathway stage). However, these figures only represent data where a pathway stage was recorded, which was not done for all (e)HNAs in Case Study 2.

Table 22. Case Study 2 (e)HNA 'Expired or Declined' by Pathway Stage Figures 01/01/2019-31/12/2019

	Initial Diagnosis			During Treatment			End of Treatment		
	Total Offered	**Expired/ Declined**	**Total Completed**	**Total Offered**	**Expired/ Declined**	**Total Completed**	**Total Offered**	**Expired/ Declined**	**Total Completed**
H1	3	3 (100%)	0 (0%)	499	194 (39%)	305 (61%)	13	2 (15%)	11 (85%)
H2	191	152 (80%)	39 (20%)	116	23 (20%)	93 (80%)	129	17 (13%)	112 (87%)

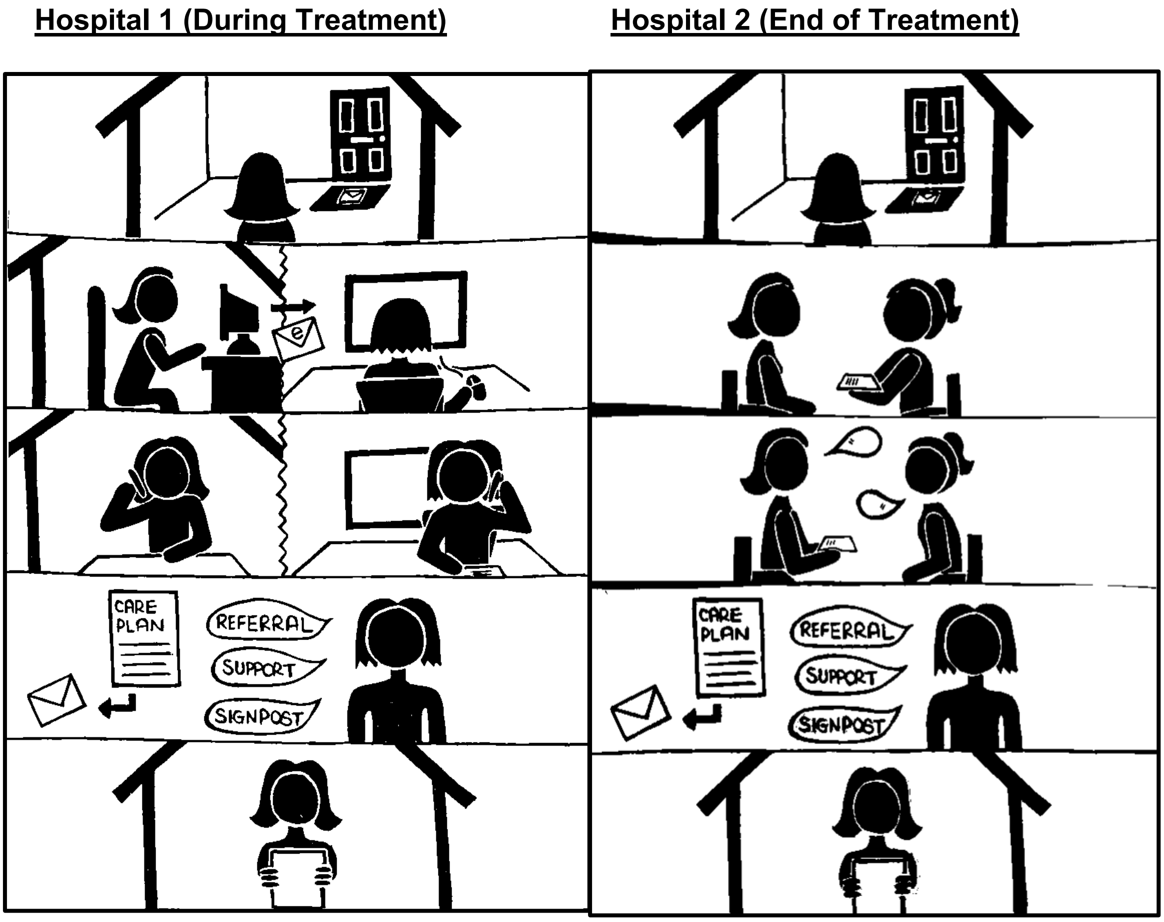
H1= Hospital 1 H2= Hospital 2

Table 22 shows that the percentage of (e)HNAs completed out of the total offered were similar between the two hospitals (n=316, 61% Hospital 1, n=244, 56%, Hospital 2). Expired or declined (e)HNAs were most frequently found when the assessment was offered at diagnosis (shown in Hospital 2 data).

5.2.1.1 (e)HNA Offers

Although Case Study 2 placed less emphasis on offering women (e)HNAs at a specific time, Figure 51 highlights the most commonly adopted approaches for completing these at each hospital (during treatment in Hospital 1, end of treatment in Hospital 2).

Figure 51. Image Representing ‘Gold Standard’ (e)HNA Delivery Process


Hospital 1 (During Treatment)

Hospital 2 (End of Treatment)

Image was drawn by and is the property of the researcher

In Hospital 1, the process of offering (e)HNAs included providing women with the same (e)HNA information pack discussed in Case Study 1 (a localised letter inviting them to complete the (e)HNA, a Macmillan Cancer Support card with details for online access, and a Macmillan Cancer Support (e)HNA leaflet). This was posted to women after they had undergone surgery. Women completed their (e)HNA online at home, and this was followed by a telephone call to discuss any concerns raised (or face-to-face appointments on some occasions). A care plan was then created and later posted to the individual. Women receiving radiotherapy (which took place in Hospital 1), were offered a further (e)HNA by radiotherapy staff. These two assessments were often offered to women close together, and staff reported that in many cases, women would only complete one of these. The radiotherapy staff and breast team appeared to communicate little about the proximity of their (e)HNAs.

Hospital 2’s standard (e)HNA delivery process involved undertaking these in scheduled, end of treatment appointments. No information pack was provided in these instances, and women received a clinic appointment through the post, before the (e)HNA was verbally introduced to them upon arrival. Subsequently, women were either left alone to complete the (e)HNA, or the staff member remained silent while it was completed. The discussion about any concerns identified then took place immediately afterwards, and a care plan was later created. (e)HNAs were also frequently offered at diagnosis in Hospital 2 (despite their low uptake, see Table 22), but were often unplanned, based on whether staff felt the woman required the assessment.

5.2.1.2 Addressing Concerns

As with Case Study 1, the process of addressing concerns was individualised for each woman, but this focused on ‘cut-off’ scores in Hospital 2 (of Case Study 2). However, whilst Case Study 1’s cut-off scores centred on whether a registered or unregistered staff member was involved in the (e)HNA discussion, the standard process in Hospital 2 utilised a cut-off score to determine how women were followed up. This meant that concerns scored at six or above determined whether discussions were offered face-to-face or over the telephone (with those above six triggering a face-to-face meeting). The origins of this decision were unclear, although one Support Worker (SW) indicated this was based on ‘six’ being the midpoint in the scoring system, with scores of five or below defined as ‘low-level’, and six or above as ‘high-level’. No reference to this system (or any use of cut-off scores) was reported in Hospital 1.

5.2.2 Participant Demographics

5.2.2.1 The Women

In Case Study 2, 12 women with breast cancer were recruited, ranging in age from 48-81 years, with a mean age of 60 years (further information is available in Appendix J). Most were of White, British (one White, Australian) ethnicity, despite letters of invitation being sent to individuals from various ethnic backgrounds. The women reflected a variety of circumstances, priorities and experiences that shaped their interview conversations. Further biographical information is provided in Table 23. Participants were provided with a unique study identifier, such as ‘0101S’ contingent on the number of the case (01 or 02), the order in which they were recruited (01-12) and whether they were ‘staff’ or ‘patients’ (‘S’ or ‘P’). Additionally, women were also allocated a pseudonym to present their data.

Table 23. Women with Cancer: Pseudonyms and Context

No.	Pseudonym/Age	Context
0201P	Anna, 76	Anna was undergoing radiotherapy at the time of her interview, and was retired. Anna lived with her husband, who she saw as her primary concern due to his poor health. Her research interview was conducted in hospital at her

		request, and the (e)HNA she completed was observed.
0202P	Eve, 81	Eve was retired and was experiencing a recurrence of a previous breast cancer diagnosis. She was the primary carer for her husband who had dementia, and felt worried when leaving him alone to attend appointments. Eve emphasised feeling lonely and had few opportunities to socialise. She mentioned enjoying the research interview because of this. The interview was conducted in her home. Her (e)HNA was observed in an appointment she attended for radiotherapy.
0203P	Jessica, 65	Jessica was married and retired. She outlined many emotional concerns that she believed were due to traumatic childhood experiences. She hid emotional concerns and early experiences from her family and friends, and did not seek emotional support until she declared this on her (e)HNA. Her interview was conducted in hospital following a radiotherapy appointment. An observation of her (e)HNA was conducted during a separate appointment.
0204P	Kathryn, 62	Kathryn was married and employed part-time. She had previously worked in a role undertaking mental health assessments, which she described as similar to (e)HNAs. This was Kathryn’s second diagnosis of breast cancer, and she accessed little support during her first diagnosis. Therefore, she was keen to take this opportunity to attend many supportive courses. She was interviewed in hospital at her request. There was no opportunity to undertake an observation.
0205P	Louise, 58	Louise was single and retired. She accessed many supportive services during her treatment, and was interviewed in hospital at her request, following a radiotherapy appointment. There was no opportunity for observation.
0206P	Olivia, 48	Olivia was married and employed part-time. She enjoyed being active, and frequently undertook activities such as running and yoga. She was interviewed at home and wanted to

		ask her husband's opinion about interview questions due to feeling unsure about what to say in some cases. There was no opportunity for observation.
0207P	Paula, 52	Paula was married and in part-time employment. She indicated difficulties in identifying people in her life to talk to for support. She enjoyed being active and was interviewed in her own home at her request. A separate end of treatment appointment was observed, where she completed and talked through a paper (e)HNA.
0208P	Victoria, 57	Victoria was married and retired. She lived with her husband but had two children who were geographically distant, and about whom she expressed concern. Victoria was interviewed at home, and a separate end of treatment appointment in which she completed an (e)HNA was observed.
0209P	Wendy, 68	Wendy was married and retired, living with her husband. She disclosed concerns about her husband's health (which she did not put on her (e)HNA), but also indicated that her two young grandchildren kept her busy, which left her little time to worry. She described herself as having a good social support network. Wendy was interviewed at home and a separate (e)HNA appointment was observed.
0210P	Lucy, 48	Lucy was married and owned her own business. At the time of her interview, she had recently undergone surgery. She did not know the rest of her treatment plan at that time, but described having a great social support network at home. Lucy was interviewed at home and no opportunities for observation were presented.
0211P	Georgina, 56	Georgina was divorced and worked full-time. She reported that this was her second diagnosis of breast cancer, and she felt as though she was much better supported this time. Georgina was interviewed at home, where she lived with her son. No opportunities were presented to undertake an observation.

0212P	Isabelle, 48	Isabelle was employed full-time and married, living with her husband and two children. Isabelle had relocated from a different country and missed her wider family. She enjoyed keeping active and her job as a teacher. Isabelle was interviewed in her own home at her request, and no opportunities for an observation were presented.

5.2.2.2 The Staff

As previously outlined, women were routinely allocated a BCN, but received support from the whole team. The site's SWs would often deal with tasks where BCN input was not necessary, or assist with duties that reduced pressures on the BCN's time.

Of the 12 staff participants recruited for Case Study 2, six were BCNs (n=6, 50%) and two were SWs (n=2, 16%). The project managers at each hospital were also recruited, alongside one radiotherapy nurse and one radiographer. The project management and SW roles had been in place for a similar length of time as those in Case Study 1, and consequently staff at Case Study 2 had comparable years of experience (2.4 years). BCNs' experience ranged from 2.5 years to ten years, but averaged 5.75 years. Most staff were employed full-time (n=7, 58%), and further demographic details are available in Appendix J. Table 24 provides a list of staff identifiers used throughout the presentation of findings.

Table 24. Staff Participant Identifiers Throughout Findings Chapters

No.	Age	Role	Referred to as
0201S[1]	49	Radiotherapy nurse	Radiotherapy nurse
0202S[1]	56	Project manager	Project manager 1
0203S[1]	50	SW	SW 1

0204S[1]	39	BCN	BCN 1
0205S[1]	26	Radiographer	Radiographer
0206S[1]	47	BCN	BCN 2
0207S[2]	56	BCN	BCN 3
0208S[2]	48	BCN	BCN 4
0209S[2]	62	Project manager	Project manager 2
0210S[1]	49	Lead BCN	Lead BCN
0211S[2]	34	BCN	BCN 5
0212S[2]	N/D	SW	SW 2

[1] Hospital 1 [2] Hospital 2 N/D (not declared)

Hospital references ‘1’ and ‘2’ only appear in Table 24, to show the context of where staff participants were based in their roles. This information is not referred to in the quotations used throughout this chapter.

5.2.3 Contextual Data

Prior to presenting Case Study 2 ’s findings, this section provides summary information about the observations undertaken and documents gathered. This includes participant behaviour in observations, how and when this occurred, a summary of the interaction, and documents collected (description of the document’s content). This was included to display the context in which interactions occurred. Firstly, Table 25 summarises the observations undertaken at Case Study 2.

Table 25. Case Study 2 Observation Context

Anna’s (0201P) Observation

Context: Clinic room face-to-face, following a radiotherapy treatment session.

Summary: Radiotherapy nurse conducted Anna's (e)HNA by providing an iPad to complete it on (while she waited), and subsequently discussed concerns.

Anna's (0201P) behaviour: Anna was initially tense, but relaxed following the radiotherapy nurse's communication techniques. She appeared to lack understanding of the (e)HNA, by checking what counted as a concern, and apologised for not 'ticking' many. Anna also verbally mentioned that 'isolation' and 'worry' were concerns for her, but she did not tick these on her assessment.

Radiotherapy nurse's (0201S) behaviour: Open body language (such as uncrossed arms and legs) was demonstrated throughout. She attempted to put Anna at ease using communication techniques. No response was provided when Anna appeared unsure what to write, and she only discussed the concerns that were 'ticked' as opposed to those raised verbally.

Eve's (0202P) Observation

Context: Clinic room face-to-face, immediately following a radiotherapy treatment session

Summary: A radiographer conducted Eve's (e)HNA by providing her with an iPad and leaving her alone to complete this for several minutes, before discussing concerns.

Eve's (0202P) behaviour: Eve appeared somewhat tense during the discussion, and showed a lack of understanding of the (e)HNA by not knowing what counted as a concern.

Radiographer's (0205S) behaviour: No introduction to the (e)HNA was provided, other than that staff would like Eve to complete it. The conversation was structured around the concerns raised, and the radiographer displayed closed body language (for example crossed arms and legs, facing away from the participant).

Jessica's (0203P) Observation

Context: Clinic environment, Jessica had visited the hospital especially for her (e)HNA appointment, mid-treatment.

Summary: BCN 2 had read Jessica's (e)HNA prior to the consultation, as this was completed at home. The conversation was initially structured around Jessica's concerns, but predominantly involved discussion of the childhood trauma disclosed.

Jessica's (0203) behaviour: Jessica displayed anxious body language, and expressed guilt at feeling her cancer was self-inflicted. She appeared more relaxed after disclosing her childhood trauma.

BCN 2's (0206S) behaviour: Jessica was invited to choose how she wanted to go through the (e)HNA, and open body language was used. BCN 2 asked open questions and was reassuring in her responses to Jessica's concerns.

Paula's (0207P) Observation

Context: Clinic environment, Paula visited the hospital especially for the (e)HNA appointment, at the end of treatment.

Summary: Paula attended her appointment with BCN 4, and was handed a paper (e)HNA. She was left to complete this independently, then the concerns raised were discussed.

Paula's (0207P) behaviour: Paula initially demonstrated anxious behaviour, which subsided quickly. She appeared to downplay her concerns through humour, and experienced one episode of tearfulness.

BCN 4's (0208S) behaviour: BCN 4 demonstrated closed body language throughout the appointment, and asked Paula to complete her (e)HNA in a seemingly apologetic manner. She went through concerns raised one-by-one, but discussed additional sensitive issues (such as sexual concerns) that had not been ticked on the (e)HNA and were not raised by Paula.

Victoria's (0208P) Observation

Context: Clinic environment, Victoria visited the hospital especially for the (e)HNA appointment at the end of treatment.

Summary: Victoria attended her appointment with BCN 4, and was given a paper (e)HNA. She was left to complete this independently, then the concerns raised were discussed.

Victoria's (0208P) behaviour: Victoria appeared at ease during the consultation, but made references to luck and guilt, due to feeling that her situation was better than that of others with cancer. She seemed to downplay many concerns she raised on the (e)HNA during the discussion.

BCN 4's (0208S) behaviour: BCN 4's body language was closed (crossed arms and legs), and she discussed all listed (e)HNA concerns individually. She encouraged Victoria not to downplay her issues, and the discussion encompassed other issues not listed on the (e)HNA (such as alcohol intake).

Wendy's (0209P) Observation

Context: Clinic environment, Wendy had visited the hospital especially for the (e)HNA appointment at the end of treatment.

Summary: Wendy was handed a paper (e)HNA in her appointment with BCN 4. She was left to complete this herself, but did not raise any concerns.

Wendy's (0209P) behaviour: Wendy appeared confident during the consultation, but expressed some lack of understanding of the (e)HNA. She apologised for not ticking anything on the assessment.

BCN 4's (0208S) behaviour: BCN 4 explained that Macmillan Cancer Support would not receive Wendy's personal information if she completed the (e)HNA. Wendy did not raise any concerns, so BCN 4 went on to provide generic health and wellbeing advice.

Alongside this, care plans were collected for the women. Table 26 displays details of the number of care plans, their content, and the role of the staff member who completed it.

Table 26. Case Study 2 Care Plan Context

Participant	No. of Care plans	No. of Concerns	Average Score of Concerns	Staff Role
Anna	1	1	10	Radiotherapy nurse
Eve	1	8	5.5	Radiographer
Jessica	1	20	7.6	BCN
Kathryn	2	0 Care plan 2) 21	- 6.6	SW BCN
Louise	2	Care plan 1) 10 Care plan 2) 2	3.2 11	SW SW
Olivia	2	Care plan 1) 21 Care plan 2) 11	7.2 6.5	SW BCN
Paula	2	Care plan 1) 12 Care plan 2) 14	7.3 3	SW BCN
Victoria	2	Care plan 1) 4 Care plan 2) 8	8.8 6.4	BCN BCN
Wendy	1	0	-	BCN
Lucy	1	9	6.1	SW
Georgina	2	Care plan 1) 2 Care plan 2) 10	5 6.5	Radiotherapy nurse BCN
Isabelle	1	11	5.9	SW

Finally, Hospital 1's processes highlighted the information pack posted to women often acted as their initial introduction to the (e)HNA. Table 27 summarises the contents of each document routinely provided.

Table 27. Case Study 2 Standard Documents Context

Document	Summary
Document 3: Macmillan Cancer Support HNA Booklet **(Not included as an appendix due to length of booklet)**	• 18-page booklet describing the (e)HNA as a concept and a process (described in Chapter Four on p135). Document available to view at: https://be.macmillan.org.uk/Downloads/CancerInformation/ResourcesForHSCP/InformationResources/MAC12957HNAE04LowresPDF20190115HS.pdf

Document 4: 'Extra Support' Card **(Appendix R)**	• Small card providing details of how to complete the online (e)HNA.
Document 5: Letter 1 **(Appendix S)**	• States the (e)HNA is being offered as a means of accessing extra support, and provides examples of service/support referrals. • Provides option to access (e)HNA without an internet connection. • Provides explanation of how to complete the electronic version, including visual representations of the webpage. • Emphasises that respondents are not obliged to complete the (e)HNA and that not doing so will not affect their care. • States that contact will be made once the (e)HNA is completed, to discuss concerns. • States they can contact the team in future to request an (e)HNA during, or after treatment.

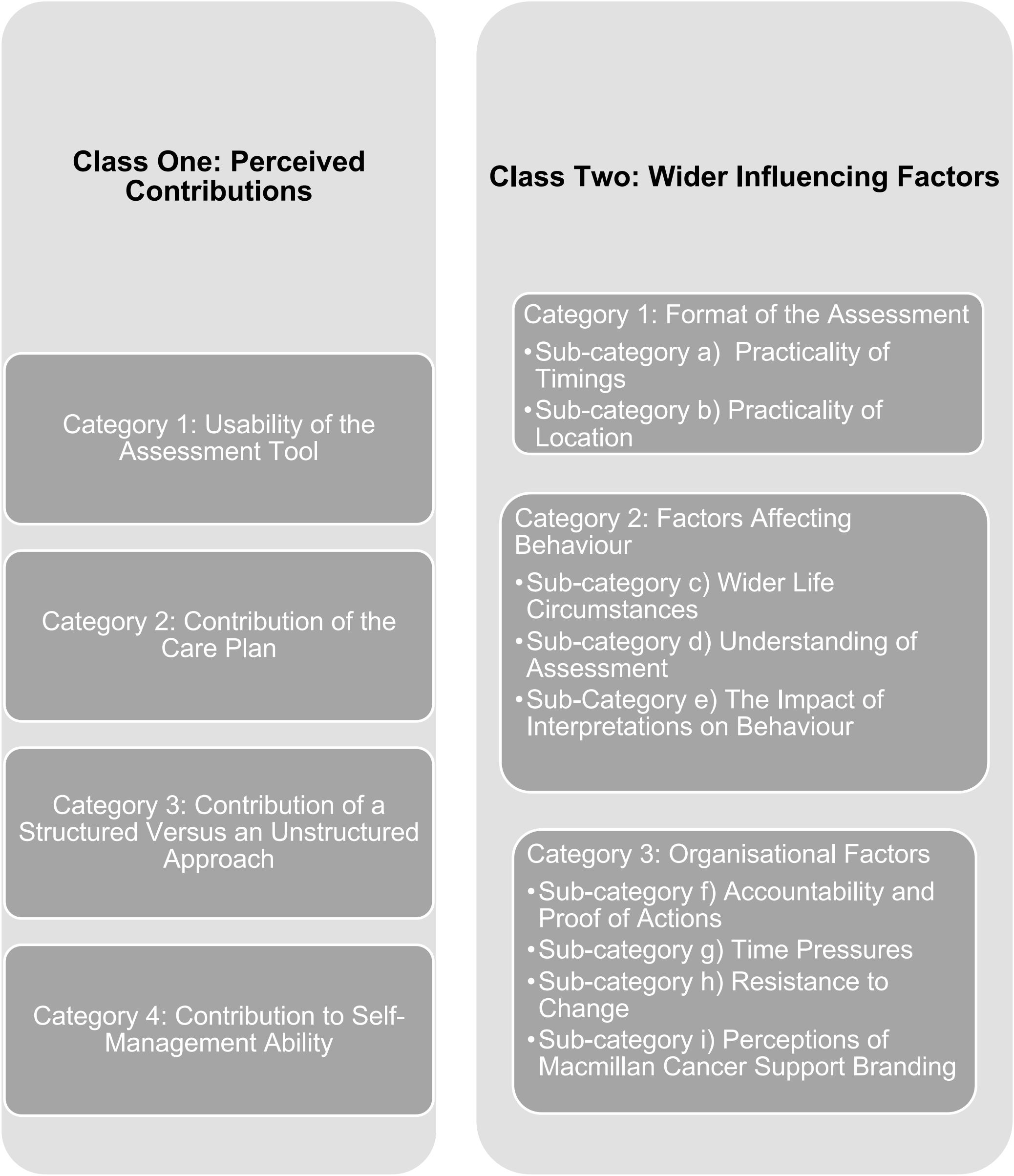
This discussion of Case Study 2's background information sets the scene for this chapter's discussion of findings. As in Chapter Four, Framework Analysis processes are followed to present these findings, beginning with an initial summary of 'descriptive accounts' results, before exploring these in more detail. Following this, 'explanatory accounts' analysis is discussed.

5.3 Findings: Descriptive Accounts

5.3.1 Overview of Findings

Within descriptive accounts, the study's overarching class-category framework is revisited from Chapter Four, succeeded by discussion of key, overarching typologies to represent participants and their views. Within this section, the descriptive accounts findings are summarised, before detailed discussion of each element.

Figure 52. Overarching Classes and Categories



Following creation of the class-category framework, the process of developing typologies was undertaken (multidimensional groupings, which allow the social world to be divided) (Spencer et al., 2013). Typologies are created from identifying key dimensions in the data (Spencer et al., 2013), and two key dimensions were identified for both cases, (explained in-depth in Chapter Four):

1. Views of the (e)HNA's use and delivery process
2. Views about the (e)HNA's contribution to women's experiences of support, (or a staff perspective on how they viewed this).

These dimensions enabled identification of connections between the participants, allowing them to be divided into 'typological categories' based on their views and characteristics. In Case Study 2, four categories were identified for women and three categories for staff.

Figure 53. Typological Categories: Women with Cancer

1. "Predominantly Positive Experience"

- The (e)HNA's use and delivery process is mostly positive, but the contributions to the overall experience were both positive and negative.

2. "Comprehensively Positive Experience"

- The (e)HNA's use and delivery process is positive, and its contribution to the overall experience was mostly positive.

3. "Positive in Principle"

- The (e)HNA's use and delivery process is positive in principle, but there was little or no contribution from this, to the overall experience.

4. "Paradoxical Experience"

- The (e)HNA's use and delivery process is positive in principle, but had a negative contribution to the overall experience.

Figure 54. Typological Categories: Staff

1. "Predominantly Positive Expectations"
    - The (e)HNA's use and delivery process is positive, and they perceive that it has a positive contribution to the overall experience, but has the potential to also introduce something negative.
2. "Comprehensively Positive Expectations"
    - The (e)HNA's use and delivery process is positive, and they perceive that it contributed something positive to the overall experience.
3. "Delivery Limitations"
    - The (e)HNA's use and delivery process requires improvements, but has a positive contribution to the overall experience

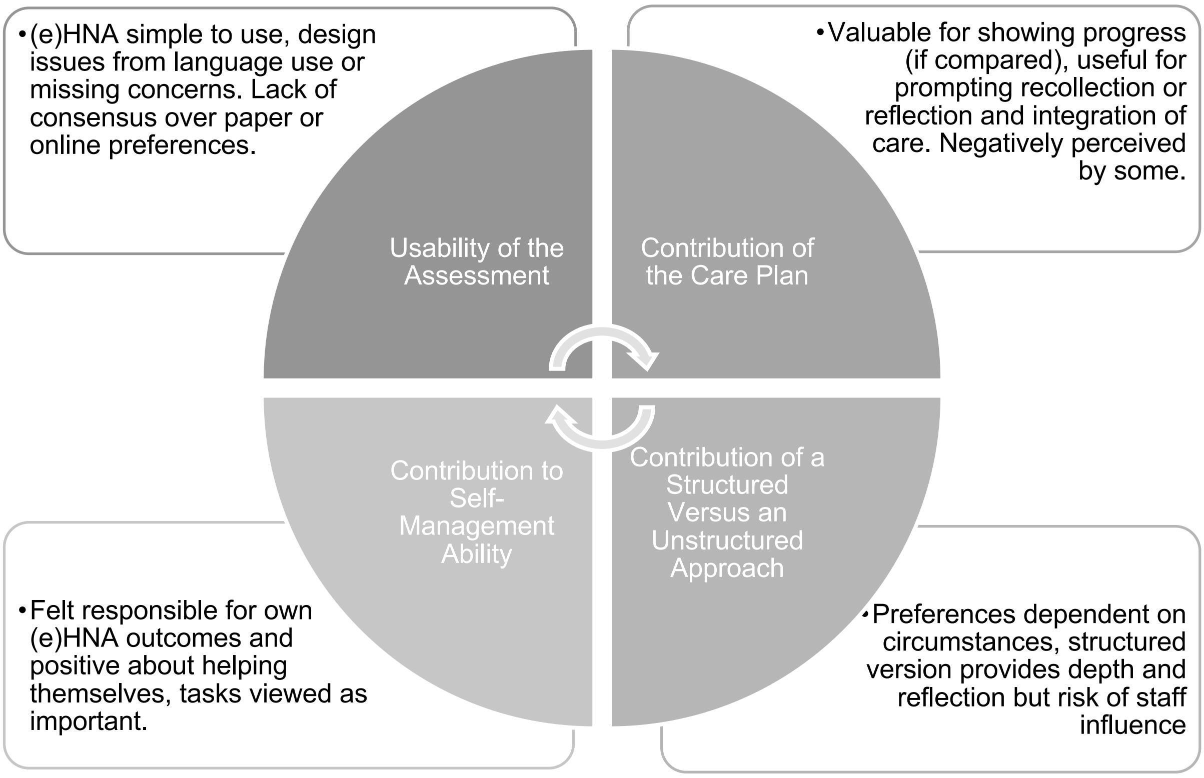
The two elements of descriptive accounts analysis (class-category framework and typologies) are discussed in more depth in the next section. First, the class-category framework presents participant data to support the findings, followed by exploration of the typological categories.

As in Chapter Four, the opinions of women and staff are addressed separately in this discussion of findings.

5.3.2 Class One: Perceived Contributions: Women with Cancer

Class One presents perceptions of the (e)HNA’s contribution, initially from the perspective of women. Key points are summarised in Figure 55.

Figure 55. Perceived Contributions: Women with Cancer: Key Points



5.3.2.1 Usability of the Assessment

Several women discussed convenience and simplicity of the (e)HNA questionnaire itself, and others alternatively highlighted design/structural issues. For example, design limitations included the inability to respond flexibly:

> *"I guess with all of these things you know, it's good to have somewhere where you can put free text, you don't necessarily fit into the sort of specific categories that were available" (Louise, 0205P).*

This comment suggests that Louise felt the (e)HNA's structure was rigid, and that there may be missing concerns or unclear terminology, which meant that her concerns did not automatically “fit” the (e)HNA’s model.

Data in this category also highlight that paper and online versions of the (e)HNA were experienced differently. For example, one individual expressed a preference for the paper version:

> *I’m not so good at doing things on a computer, I would actually personally I’d prefer to do it on paper" (Paula, 0207P).*

During the observation of Paula’s (e)HNA appointment, the paper form was offered due to internet connectivity issues, and she preferred this. However, another participant preferred the electronic version:

> *"Well it was easier to be online to be honest… it’s much easier, and it’s straight away so I can just do it at my leisure and didn’t have to worry about people looking over and things like that, so that made it easier, and I suppose just in the modern world, once you’ve sent it off it’s gone.” (Isabelle, 0212P).*

Isabelle’s view was not exclusive to the convenience of completing the (e)HNA online, but also the ease and speed of submission. Views such as Isabelle’s may have been influenced by the (e)HNA’s initial offer letter (Document 5) (Appendix S), which recommended online completion, and gave clear instructions on how to do this. Although the letter offers the option of attending hospital for an (e)HNA, the letter’s emphasis is on the electronic version, which may therefore inadvertently encourage use of this method.

A further participant completed both electronic and paper (e)HNAs in separate consultations, and concluded that the paper version held more meaning:

> *"It might be skewed because there were different platforms, so the paper one seemed to mean more to me, but that's probably 'cause the session did, and I was a bit confused about the first one, so that might not be fair." (Victoria, 0208P).*

However, Victoria's comments may refer to factors other than the format of the (e)HNA. Firstly, the less meaningful (e)HNA (online version) was completed immediately before an appointment with the consultant, so Victoria felt distracted. Secondly, no distractions were present for the second assessment, which may have made it more valuable. Having undertaken an (e)HNA previously may have also led to familiarity, which could have improved Victoria's engagement in the second encounter.

Completing the (e)HNA online was viewed as providing admission to a system of care which women could re-access as needed. Consequently, some participants felt their progress was being monitored, which was positive:

> *"It's kind of nice to know that you're still in the system with them, so just because I didn't particularly tick anything, I still think it's yeah, I think it's a good thing to have definitely." (Wendy, 0209P).*

5.3.2.2 Contribution of the Care Plan

Many women felt that the care plan prompted them to recall issues and reflect on their concerns. They believed it provided opportunities to assess progress between two time points, which was beneficial in principle:

> *“I think it would be worth keeping them, because then you can refer back to them… this is right at the beginning you felt like this, and then you know three months or a year later, actually this has cropped up again." (Isabelle, 0212P).*

> *"It would have been interesting to see the three points of reference, to see where your emotions were in that journey." (Paula, 0207P).*

> *“At the very beginning if somebody had said we’re gonna do this with you now, and there will be another one in so many weeks, and we will look at the two and assess your journey between the two, that would’ve been better for me.” (Victoria, 0208P).*

Victoria’s comment suggests that the (e)HNA’s relevance would have been clearer if she had been informed at the outset that care plans would be compared.

The care plan appeared to represent different functions for different participants. One participant described how it had been shared with her general practitioner (GP), which demonstrated integration of care, and enabled her to see that the (e)HNA process was successful:

> *"I know that they had the care plan there and they could see things were there when I enquired about the medication and so on, so I felt like they, you know that assessment process had gone through because the doctor had seen it." (Isabelle, 0212P).*

Participant views in this category reflect the variety of expectations and perceived purposes of the (e)HNA. These include whether the purpose was to promote supportive actions from staff, enter a care system, or encourage communication with other professionals. An additional advantage of the care plan was its role as a prompt, either to encourage recollection of discussions, or to remind individuals to undertake specific actions:

> *"I've got so much on my mind that I forget a lot, I mean I've been so busy looking after my husband that I don't remember a lot… yes I suppose it would be better if it was written down." (Eve, 0202P).*

However, some participants saw no benefit to receiving a care plan. For example, Jessica's experience was negative, and highlighted that receiving the care plan would prompt feelings of disappointment:

> *"That plan wouldn't have come to fruition, so inevitably I would've felt worse about it, you know you sort of think well they've give me this plan, it leads you to expect that you're going to get support and help, and then you don't." (Jessica, 0203P).*

> ***Jessica's care plan (0203P):*** *Description of concern: "Jessica didn't really have any questions about her diagnosis or prognosis, the consultation went into another direction. Jessica divulged that she has had psychological issues since childhood*

> *caused by abuse witnessed and experienced.” Plan of Action: “Referral to psychologist”.*

The other factors highlighted in Jessica’s example (such as disappointment and unfulfilled expectations) are explored as an illustrative example later in this chapter

5.3.2.3 Contribution of a Structured Versus an Unstructured Approach

The third category highlights the use of a structured (e)HNA tool compared to unstructured, supportive conversations. Overall, participants indicated preferences for the structured (e)HNA, because of the greater depth and reflection it facilitated. However, advantages to both approaches were noted by women, displaying the differences between a general conversation and an (e)HNA, but viewing them both as useful:

> *“I can only say different, not better or worse… at that stage I don’t think it was to the depth that this [the (e)HNA] enables, but that wasn’t detrimental to me.” (Louise, 0205P).*

> *"Just conversations are little gems, but the holistic one gives you more information about more than you know is out there, more than you think you can be asked… I think that holistic one makes you think more about more things… you concentrate on yourself and it makes you ask yourself how you’re feeling." (Victoria, 0208P).*

These comments suggest the unique contributions of both unstructured conversation and structured (e)HNAs, and that each has particular benefits (for example, the (e)HNA's ability to prompt reflection on feelings). Other participants discussed benefits of a structured (e)HNA, or suggested an overall preference for this type of assessment:

> *"The formal one is probably better… If you don't want to go into depth you can say I'll just get over it or you won't mention it, whereas you have a list of set criteria there that makes you, I mean again you can ignore it if you want to, but you have your prompts... to make you think about it and actually put a number on it and it makes you actually stop and think a little bit about things." (Paula, 0207P).*

> *"So, I felt that I could move on from some of the things after reflecting on them during that time, and thought actually you know mentally I've processed some of that information, I can move myself forward." (Isabelle, 0212P).*

These examples emphasise the value of the (e)HNA in encouraging participants to reflect on their concerns, making it more difficult to avoid particular issues. In a similar way, some participants felt that structured (e)HNAs were preferable because they removed the influence of staff on the concerns raised:

> *"Well you could put yes or no or whatever on the iPad, whereas when you're talking to someone, well I don't know, you don't feel as though you can" (Anna, 0201P).*

> *"I think maybe the assessment [(e)HNA] because you're doing it yourself in your own time, 'cause if you're doing it with someone*

> *else and they’re just having a chat, I suppose they’re gonna put what they think, they’re gonna translate it the way they think you have said it I think." (Lucy, 0210P).*

Anna and Lucy’s views highlight that the value of the (e)HNA was the opportunity it provided to raise concerns in private. However, Anna completed her (e)HNA in the presence of a staff member, which may suggest that this privacy was given by not having to verbalise her concerns.

5.3.2.4 Contribution to Self-Management Ability

Participants highlighted that the (e)HNA facilitated understanding of their own responsibility to self-manage, and taking ownership of their concerns:

> *“I will pursue it, I think complementary therapies I think that’s a very good idea … also she was going to find some information regarding [support service], and I think that would be important for me to follow-up.” (Paula, 0207P).*

Paula’s comment suggests that despite the care plan indicating that staff had responsibility for some tasks, Paula felt it was her role to ensure her parts were completed. Olivia also indicated a desire to manage her own health; something she viewed positively:

> *“I came away feeling quite positive from the conversations I’ve had with the nurses, and I suppose you know things like changing my diet slightly and setting yourself small objectives,*

> *you know they're the sort of things that I've, it gave me something to focus on and to deal with myself." (Olivia, 0206P).*

> ***Olivia's care plan (0206P):*** *"Questions about diagnosis: Description: General concerns raised about effects of treatment including tiredness, feeling of "loss" and numbness about her diagnoses and treatment. Feels flat in mood, questioning why she is better off than other survivors. Plan of Action: Discussed the above and talked about moving forward, reassured that these feelings are normal and that everybody's experience is different. Olivia has changed working hours which has helped."*

These comments suggest Olivia's desire to do something to support herself, and may signify an aspiration for greater control or autonomy over her own health behaviours. The excerpt from the care plan reflects a style of documentation which appears encouraging. The participant's feelings are justified as being 'normal' by the staff member, and the positive steps she has taken (such as the change of working hours), are acknowledged.

Many participants seemed prepared to take ownership of the actions recommended in their care plans, which highlighted the importance they placed on these, and their willingness to accept the support offered. This is illustrated by Victoria, who describes needing to initiate requests for support and engage in new behaviours, as a result of the (e)HNA's recommendations:

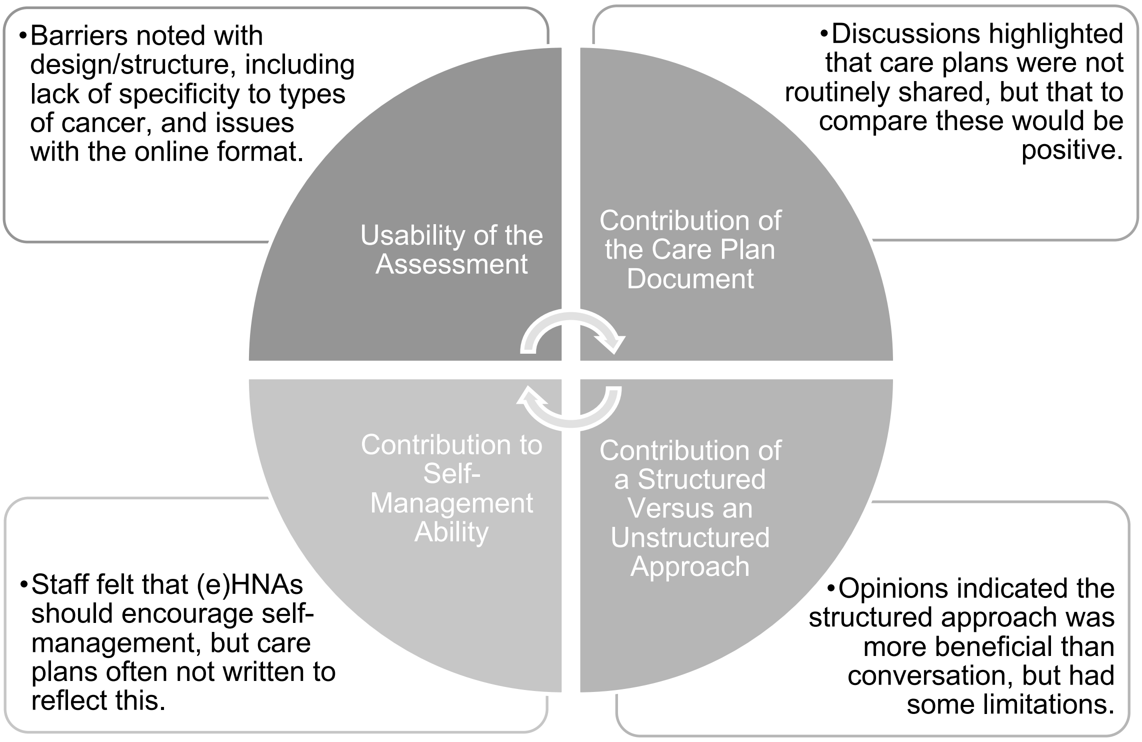
> *"I felt it was kind of in my court to say that is a real concern of mine, I need some help with that… last night and the night before I actually tried to relax, do mindfulness techniques, and do you know I had two better nights' sleep… I feel great that this has*

> *been offered and we'll get in touch with you about potentially having some therapy for sleep disorder, so that's wonderful." (Victoria, 0208P).*

5.3.3 Class One: Perceived Contributions: Staff

The same four categories in Class One are considered from a staff perspective in this section, with the significant points summarised in Figure 56.

Figure 56. Perceived Contributions: Staff: Key Points



5.3.3.1 Usability of the Assessment

In the first category, staff indicated that the (e)HNA's online format presented challenges for both themselves and women:

> *"Well a lot of them [other staff] didn't like doing stuff online for a start, anything to do with computers (BCN 1, 0204S).*

> *"I gave them a paper one, cause I'm phobic of anything to do with technology, I'm horrendous." (BCN 2, 0206S).*

Whilst these examples show that in some circumstances, the BCN's feelings about using technology influenced the format of (e)HNAs she offered, women's preferences were also considered:

> *"If there was a person that wasn't technologically minded, they would struggle, and even presenting them with the laptop you can see the fear in their face." (BCN 3, 0207S).*

However, some staff indicated preferences for the electronic format. For instance, BCN 4 described overlooking highly rated concerns during a consultation using the paper (e)HNA, because unlike the online version, this did not present the concerns in order of priority:

> *"When I do it electronically which is something I need to notice next time is that, I get them in priority, whereas this on paper it doesn't and I didn't scan to see what her priorities cause otherwise I should've gone straight to the nine." (BCN 4, 0208S).*

Other considerations raised about the usability of the (e)HNA related to its design, such as some concerns being deemed not applicable to breast cancer. Staff felt a more cancer type-specific assessment was needed, or space to provide elaboration on responses given:

> *“I think some of the stuff in the tools is too vast… If I was doing the tool’s assessment for breast care… I would zone in primarily on what’s going to affect them before surgery, what’s going to affect them after surgery, what’s going to affect them before chemo… because that is then tailor made for that.” (SW 2, 0212S).*

> *"I don’t know whether it would be better placed to have a comment box really, like a not applicable or add a comment to sort of give them a chance to explain.” (SW 1, 0203S).*

These examples highlight the need for further development of the (e)HNA’s design to increase its relevance to women with breast cancer.

5.3.3.2 Contribution of the Care Plan

Comments from staff suggested that comparison of the care plan between different time points was beneficial, but this often did not occur in practice. The straightforward structure of the document facilitated comparison:

> *"I think it’s a good way of showing ’cause nothing's better than if the patient’s scored it, and now they’re scoring it this, it’s showing them some progress for them I think." (BCN 4, 0208S).*

> *"Other advantages as well is that you've got it to refer to, so if they were a patient that wanted more than one because of their concerns, you can always refer to the one previously because the format is set out the same." (BCN 5, 0211S).*

In contrast, reading previous care plans was seen to potentially obscure judgement and lead the conversation in a less appropriate direction, due to focusing on historic information:

> *"It might cloud your judgement or might cloud what you are going to ask the patient, you can afterwards go back and go gosh they asked me exactly the same questions." (SW 2, 0212S).*

Staff also indicated many care plans were not routinely shared:

> *"I don't think the doctor would read it anyway if I'm honest with you, they're gonna see it as the nurse's care plan." (BCN 4, 0208S).*

> *"'Cause I'm old and I'm terrible at things like that, it wouldn't enter my head, I would deal with the concern, but I wouldn't then think that the other person needed to see it." (BCN 2, 0206S).*

The views expressed in these comments were supported by some women participants, who read their care plans for the first time during their study interview and did not recall receiving a copy. This may suggest staff's views about who was the care plan's target audience, in that care plans were seen as a means of reporting and evidencing their own work, rather than something to be shared with women. These issues are further explored in Class Two.

5.3.3.3 Contribution of a Structured Versus an Unstructured Approach

When comparing approaches to assessing needs, one staff member indicated preferring unstructured conversations over structured (e)HNAs. This was based on the view that the tool may ‘force’ the conversation:

> *"It seems, if I’m giving you a paper, fill this paper in, it’s more formal, when I’m just chatting to you, you’re more relaxed... the conversation flows, so you’re not forcing any issues." (BCN 3, 0207S).*

However, most staff felt the (e)HNA was advantageous to women, providing options that were otherwise absent in a supportive conversation (such as identifying extra concerns). In some circumstances, staff acknowledged having a negative view of the (e)HNA initially, which changed when its benefits became apparent:

> *“I probably didn’t like the HNA at first. I just felt like… we do that anyway and it’s just more paperwork, but when I actually started doing them… I think there are a lot more psychological issues that people have that they don’t let on to unless probed, sometimes and that’s picked up from the HNAs. (Radiotherapy nurse, 0201S).*

> *"Just ticking the boxes saying I want information about complementary therapies, well-being events, things like that just instigated me to give her those [leaflets], whereas I probably wouldn’t have given them her before." (BCN 1, 0204S).*

Alongside this, staff felt the (e)HNA allowed women to focus on aspects of their lives not conventionally deemed priorities when attending appointments:

> *“I’ve got 5-10 minutes, I need to tell them that I’m feeling sick, I’ve been really drowsy… but then that means that they don’t talk about I’m afraid who’s going to look after my wife… using a tool, whichever tool it is, might help them to just organise the thoughts in their brain a little bit easier for them." (Project manager 1, 0202S).*

> *"Sometimes it does give patients that opportunity, well actually who’s going to look after my pets when I go for breast surgery, and then it makes them think gosh you know that is a concern." (BCN 5, 0211S).*

Overall, staff indicated that the (e)HNA’s structured approach provided contributions beyond an unstructured conversation, through its ability to identify and assess needs.

5.3.3.4 Contribution to Self-Management Ability

In the final category, staff suggested that the care plan placed a responsibility upon women to act upon (e)HNA recommendations. Several staff members expressed a desire to encourage self-management:

> *"I let them take responsibility to do that, because I put information on to them and I feel like if they really want that then*

> *they’re the ones that have got to do it." (Radiotherapy nurse, 0201S).*

> *"That’s very important in my role, ’cause what we’re trying to do is we’re trying to give patients the tools to manage their condition themselves and be independent." (BCN 3, 0207S).*

However, despite the aim of the care plan being to support self-management, this was not how it was always used in practice:

> *“The ones I’ve seen are probably more staff actions… if this is again a care plan to support a patient to self-manage, actually there probably should be a bit of both.” (Project manager 1, 0202S).*

> ***Isabelle’s care plan (0212P):*** *Plan of action: “Talked about travel insurance, will send Isabelle details of travel insurance companies”. Plan of action: “Talked about support for the children, horses help healing therapy leaflet sent in post.” Plan of action: “Informed Isabelle about benefits advice and Macmillan grant. Application form put in the post.”*

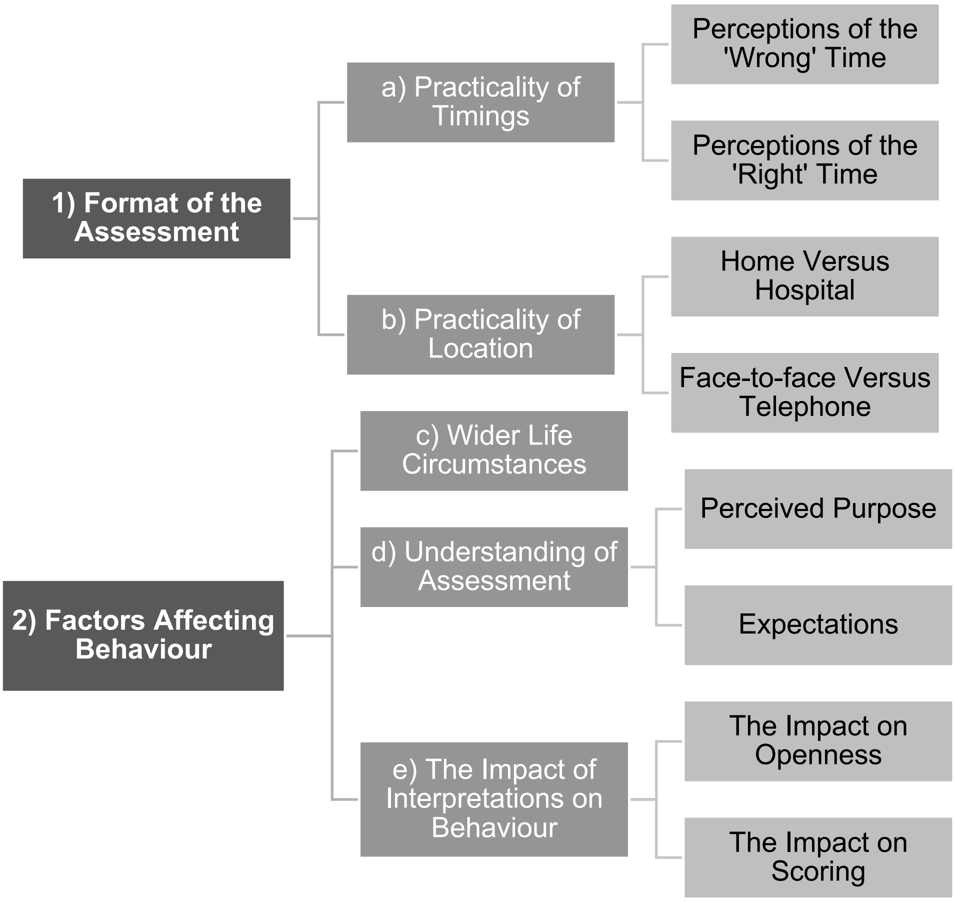
This example shows that despite some recommended actions being linked to tasks for Isabelle (such as completing the benefits application form), the emphasis was on staff members’ role in these tasks, as opposed to Isabelle’s (the focus was on posting the application, rather than completing it). Additionally, staff who felt the care plan should give women responsibility were unaware of whether their recommendations were actually followed.

This section has provided a summary of the (e)HNA's contributions from the perspective of women and staff. The key issues identified suggest wider factors may influence how meaningful the (e)HNA was, which are discussed in the sections on Class Two.

5.3.4 Class Two: Wider Influencing Factors: Women with Cancer

For women's opinions, Class Two is structured by presenting two main categories, as shown in Figure 57. This structure echoes the one used in Chapter Four.

Figure 57. Class Two Categories - Women with Cancer



5.3.4.1 Category 1: Format of the assessment

The first discussion of ‘wider influencing factors’ focuses on the (e)HNA’s format, which was divided into sub-categories.

5.3.4.1.1 Sub-category a) Practicality of Timings

Perceptions of the ‘Wrong’ Time

The timing of (e)HNAs was referred to by all the women, yet perceptions of what constituted the right and the wrong time varied. If completed at diagnosis, the timing was seen as suboptimal and led to lack of engagement:

> *"I don’t know, maybe I wasn’t taking it seriously, maybe I had it too early probably." (Lucy, 0210P).*

> ***Kathryn’s care plan (0204P) (1 of 2):*** *19 Concerns raised, no discussion or plans of action “Kathryn is having further surgery so decided she would prefer to do the (e)HNA after surgery”.*

The example from Kathryn’s care plan suggests the timing was unsuitable, as despite raising many concerns, she did not wish to explore these and complete the (e)HNA process until she had recovered from surgery.

Whilst no other Case Study 2 participants completed the (e)HNA at diagnosis, data from other women supports the view that completing the (e)HNA would not have been beneficial at this point:

> *“I don’t think earlier would’ve helped cause I think you’d just…it all happens very quickly, well for me my treatment happened very quickly, it was just boom, boom, boom, surgery, recover (Paula, 0207P).*

> *“Possibly a bit too much because you’re just processing so much information at that time.” (Isabelle, 0212P).*

Further support for these views may be inferred from Case Study 2’s (e)HNA completion figures (Section 5.2.1), which show that more (e)HNAs were declined or ‘expired’ when offered at diagnosis than at subsequent points.

Perceptions of the ‘Right’ Time

Suggestions were made by women for more appropriate times to undertake (e)HNAs, for example between treatments:

> *“I think it’s between the appointments… if there’s a bigger gap that you probably need more of the holistic assessment or just that support there I think, because you don’t have a point of reference, you’re not seeing anybody in between.” (Isabelle, 0212P).*

> *“I think the end of treatment’s good but yeah maybe… perhaps another one just a catch up if you like and see how things are and see if anything’s changed (Wendy, 0209P).*

Isabelle’s view reflects similar to those expressed in Case Study 1, suggesting that (e)HNAs may be more meaningful when completed in the ‘gaps’, as opposed to alongside other existing appointments. The following example highlights the complications involved in adding the (e)HNA to an existing appointment:

> *“I think I was focused on my next job was to go and see the consultant… and she’s going to assess me and she’ll look at my scar, but that was more important to me, so maybe the timing of the two, I think left to it on my own, I would have taken in more really, I think I was distracted.” (Victoria, 0208P).*

This implies that although the timing meant her (e)HNA had less priority, Victoria’s saw value in undertaking the (e)HNA, as she indicated her desire to fully engage with it without distractions.

5.3.4.1.2 Sub-category b) Practicality of Location

(e)HNA Questionnaire Completion: Home Versus Hospital

A further factor influencing the (e)HNA’s perceived value concerned where it was undertaken. The online format provided opportunities for individuals to complete it in the privacy of their homes, which was advantageous, as previously discussed.

> *“You fill this in and the lady who was there was sitting there with me and I think there was a student in as well… so yes I think at home probably it’s a bit more relaxed.” (Georgina, 0211P).*

> *"You're also in this surreal position that doesn't let you think things through, you're quite reliant on people asking you, 'cause all the time you're thinking yes it's relevant to me, is it relevant to the breast care issue, and so that was it was almost like writing a blank, it was like a blank cheque that I could fill in about everything that was important to me." (Jessica, 0203P).*

A contrasting viewpoint was that undertaking (e)HNAs at home may cause distress. Should this happen, the home environment offered no immediate access to support from staff:

> *"I can see negatives on that too if you're left to do it on your own and there's a lot of emotional things… at least if you do it with someone there you've got someone to support you, as you saw I got very upset, but it was, I felt okay, it was okay to be upset with people there." (Paula, 0207P).*

> *"Maybe just doing it at home on your own is… you've not got anybody supporting you through it." (Kathryn, 0204P).*

In addition, uncertainty about how to complete the (e)HNA in the absence of support led to feelings of embarrassment with one participant who completed it at home:

> *"But ticking those boxes prompted them to call me the next day saying are you okay, so I thought that was really nice but I felt a bit silly that I'd filled it in wrong." (Lucy, 0210P).*

(e)HNA Discussion: Face-to-Face Versus Telephone

The final sub-category in this class relates to the mode of contact adopted by staff, once an (e)HNA was submitted. For instance, several participants indicated preferences for completing the (e)HNA at home, followed by a telephone call to reduce the number of inconvenient hospital visits:

> *"Unless you had a separate appointment to go in and do that but then that's a bit of a pain driving up there again isn't it, but yeah I think that's probably easier to just do it at home." (Lucy, 0210P).*

> *"We were down at the hospital anyway, because we're having to you know, come quite a way, we'd have had to come especially just for them." (Anna, 0201P).*

There may be a number of reasons for Lucy and Anna's reluctance to add additional journeys for the (e)HNA, including low prioritisation of the assessment, feeling they had few support needs, or that an additional journey (alongside their regular trips for treatment) was burdensome. Lucy and Anna's care plans highlighted few concerns and needs, whereas Paula and Kathryn (who suggested risks with completing the (e)HNA at home) reported greater emotional concerns. This may suggest that preferences are influenced by perceptions of the need for support.

Completing the (e)HNA at home with a subsequent telephone call to discuss concerns may also have been preferable because it required less confidence than discussing sensitive concerns face-to-face:

> *“Well if you talk about that you know, your intimacy, I don’t think I would have been feeling quite as confident…I don’t think I would’ve been really thinking about that because I was in a public space, so I don’t think I would’ve reflected on that quite as truly as I did when I was just on my own.” (Isabelle, 0212P).*

Conversely, some individuals preferred face-to-face communication, feeling telephone contact may make it less comfortable to disclose their concerns:

> *"I might have felt a bit inhibited...well I guess it’s difficult to be honest and maybe doing it as a face-to-face discussion, you might open up a bit more." (Louise, 0205P).*

The factors raised in this category suggest that (e)HNA preferences may vary according to practical considerations (for example convenience and level of need). It may also be the case that readiness to disclose concerns is influenced by the presence or absence of staff. These considerations are discussed in Category 2.

5.3.4.2 Category 2: Factors Affecting Behaviour

Category 2 encompasses three sub-categories, previously described in Figure 57 (p256).

5.3.4.2.1 Sub-category c) Wider Life Circumstances

Beginning with wider life circumstances, these impacted upon women’s acceptance of support offered by the (e)HNA in some cases. The following examples reflect scenarios where additional support was not required because participants' work, financial and social support situations were stable:

> *"I've just retired, I'd never been ill, so we are financially okay at the moment, we've got lots of things to look forward to, the kids are always home, I was just in a fortunate position that I don't feel a lot of it I needed at that time because of my situation." (Victoria, 0208P).*

> *"I mean I read through it all, and there was certainly the physical side of things yeah, the emotional side of things, any other support that you thought you needed financial, all that, none of which really I felt applied to me." (Wendy, 0209P).*

However, wider circumstances acted as a barrier to accepting support in other cases:

> *"I was concerned about leaving my husband to come for radiotherapy… but that was a worry in a way, 'cause if I was delayed either by traffic or at the hospital, then I was sort of on edge all the while really until I got back home, to make sure he was alright." (Eve, 0202P).*

Eve's situation may have acted as a barrier to accessing support, which was reflected by a participant in Case Study 1 who reported similar caring responsibilities. However, considerations raised by relationships and responsibilities within the family unit (such as becoming a carer if a spouse becomes unwell) may explain why these women felt unable to prioritise their own needs above those of their family members.

In addition to a person’s life situation, other factors influenced engagement with, the perceived usefulness of, and outcome of (e)HNAs. These are discussed under the next two sub-categories.

5.3.4.2.2 Sub-category d) Understanding of Assessment

Perceived Purpose

Explanations of women’s understanding of the (e)HNA appeared to cover several different ideas. The following examples present three different interpretations of the (e)HNA and its purpose:

> *“Just to be able to access, I mean there’s a list of things…the team can potentially do for you.” (Jessica, 0203P).*

> *"To give you ideas of how, of what’s out there to help you, and maybe be part of a process where you can offer your experiences to support other people as well as probably helping yourself, and like for research." (Kathryn, 0204P).*

> *"Is it to do with the complementary therapies and that sort of thing or not?" (Georgina, 0211P).*

Jessica appears to feel that concerns within the (e)HNA had specific actions attached to them. Kathryn’s view suggests a focus on understanding the landscape of support available, and the hospital’s use of data from the (e)HNA to help others and support research. Georgina appears to view the term ‘holistic’ in the alternative interpretation it holds, relating to complementary therapies. Also, her use of a question shows her lack of confidence in this understanding.

Alongside varying interpretations of its purpose, some participants indicated that their engagement with the (e)HNA occurred as a result of feelings of obligation, or because completion would benefit others with cancer:

> *"It was alright but I felt guilty 'cause everything was 'no'… I don't know, I just thought well, I thought perhaps I was wasting her time 'cause I just kept saying 'no'." (Anna, 0201P)*

> *"I felt that if they're trying to collect information and be able to look forward for other people… because I didn't tick anything, I didn't think I was being particularly helpful." (Wendy, 0209P)*

Many participants who described feeling under pressure to respond to the (e)HNA in a specific way suggested this was based on a desire to help others, as well as a possible desire to please staff. This view also appeared to prompt feelings of guilt in cases where an individual reported no concerns, as they felt this was somehow unhelpful.

Expectations

A second aspect of understanding (e)HNAs was related to participants' initial expectations. In some cases, this led to them feeling either dissatisfied, or pleasantly surprised as a result of being offered more support than was expected:

> *“I don’t think I fully understood… I thought maybe it was a tick-box exercise, maybe…but I didn’t know for instance that I would get…there will be treatment or a therapy potentially for sleep disorder…I’ve not been sleeping well for a long time.” (Victoria, 0208P).*

> *“I was drawn in by the fact that it says holistic needs, great…I expected something else from it, not…I felt like well you’re ok really, you don’t need any help...I would’ve liked oh there’s this course there’s that…I feel like people are looking at me well there’s something wrong with her.” (Kathryn, 0204P).*

Victoria’s experience of the (e)HNA was that it contributed more than she expected. Conversely, unfulfilled expectations had a negative impact on Kathryn, who felt judged because she had discussed feelings that indicated there was something ‘wrong’ with her.

5.3.4.2.3 Sub-category e) The Impact of Interpretations on Behaviour

The Impact on Openness

The previous category highlighted a reluctance to openly express concerns because a staff member was present. Similarly, several participants empathised with staff based on feeling the (e)HNA was an emotional burden for staff, or that it placed them under additional time pressures:

> *"I know these people try their very, very best and I wouldn’t want them to be under any hardships or I might have been a bit soft…*

> *kinder in some of the responses or maybe not as truthful… I think there would be more expectations on me to feel that in the view of what other people think, so even though they may not be saying anything… would impact on how I would respond to those questions, because it's a human." (Isabelle, 0212P).*

> *"I'd got this time and I'm always sort of conscious of taking up you know any of the professional's time… I feel as though they've got more important things to be doing, which is only right". (Georgina, 0211P).*

> *"No the only barriers to opening up was, was it appropriate, you know you're all busy, I don't want to take up the specialist nurses' time." (Victoria, 0208P).*

> ***Observation of Victoria's (e)HNA (0208P):*** *Victoria made various comments to downplay her emotional concerns, which the BCN attempted to prevent by encouraging her to discuss them. She went on to complement the care she received.*

These comments suggest that in some cases, women felt hesitant to fully disclose their concerns. Victoria's reluctance to add to staff workload was also evident during the observation of her (e)HNA, when she held back her concerns and changed the focus to complementing staff for the care she received.

Finally, the quality of the relationship between staff and women appeared to influence their willingness to disclose and discuss concerns:

> *"I didn't feel that rapport with her, so you know… I didn't feel like I could speak perhaps to her if I you know if I had have had the anything I wanted to discuss, I didn't feel that was the right environment." (Georgina, 0211P).*

> *"Sometimes talking to a stranger it's quite a leveller, but also on the flip side I can also see if you've built up a relationship with someone… you perhaps open up more." (Paula, 0207P).*

The same factors influencing willingness to disclose, also occasionally affected the scores women allocated to their concerns on the (e)HNA.

The Impact on Scoring

Responses from women in the study highlighted scenarios where their scoring of concerns on the (e)HNA did not reflect their genuine feelings. For example, doubts about who would have access to their information may have influenced their (e)HNA scoring:

> *"You're thinking that somebody's going to read this, so maybe you know, you maybe think oh well actually I feel like this, but I won't put that I'll put something else, I'll put that I feel a bit better than I'm actually saying." (Kathryn, 0204P).*

Kathryn's comment suggests hesitancy in providing true scores based on the fact staff would read the assessment, which may suggest that she associated scoring with particular consequences, or that high scores might be viewed negatively be staff. Furthermore, higher scores were thought more likely to elicit action from staff:

> *"I wanted to be truthful for it to be of any use, but I didn't want to be completely truthful in case it led anywhere, there were things that I felt, but I didn't want to discuss them, so maybe in some instances I would've scored down cause I wasn't prepared to investigate things further." (Victoria, 0208P).*

Victoria's comments are realised in observational data, in which staff used the scores assigned to concerns as a means to structure and prioritise discussions (addressing the highest scored concerns first).

> ***Observation of Victoria's (e)HNA (0208P)****: Referred to list of concerns and highlighted she mentioned emotional issues and rated them as 8/10, linked them altogether by listing them and saying, "can you tell me a bit more about this?"*

Women also referenced the subjective nature of scores, and how to best apply them. For example, one reference was made to scoring 'ten out of ten' based on the individual's uncertainty:

> *"I suppose I just put 10 because I didn't know what else to put." (Anna, 0201P)*

Olivia highlighted that she and her husband might rate differently, further indicating the subjectivity of scores:

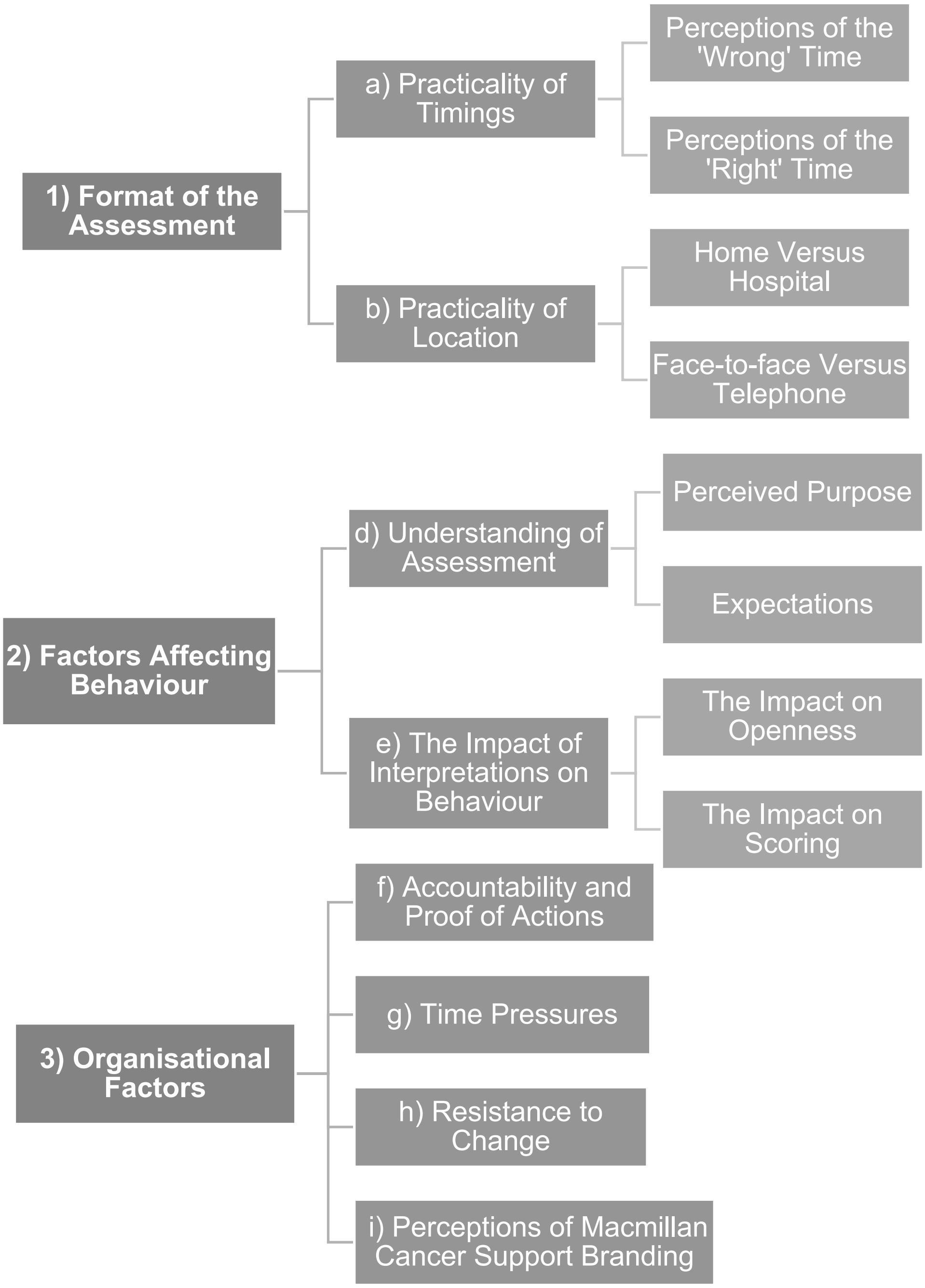
> *"You know well I do feel that but you know I sort of rate it and then John would say well is it really that high, you know…so I guess how I'm feeling was very much different to how I was portraying it to the family if that makes sense." (Olivia, 0206P).*

Olivia felt she may have appeared less concerned to her family than her (e)HNA responses indicated. This suggests that concerns may be presented differently in varying contexts, and that family members' perspectives might also influence (e)HNA responses, if they are present during its completion.

5.3.5 Class Two: Wider Influencing Factors: Staff

The same structure for Class Two is used to present findings from staff data (Categories 'a-e'), with the addition of Category 3 (organisational factors, Sub-categories 'f-i'), shown in Figure 58. As in Case Study 1, Sub-category 'c' (wider life circumstances) is absent, because this primarily reflected data from women participants, not staff.

Figure 58. Class Two Categories - Staff



5.3.5.1 Category 1: Format of the Assessment

5.3.5.1.1 Sub-category a) Practicality of Timings

Perceptions of the ‘Wrong’ Time

Alongside women, staff participants also viewed diagnosis as an unsuitable time to complete the (e)HNA, for several reasons:

> *“The thing we’ve found with that is that it’s too overwhelming, the information they’re given at that diagnosis, they cannot compute all the information… let alone what their needs are at that point.” (BCN 3, 0207S).*

> *"There are so many things that a patient has to take in at the point of diagnosis, it takes a while for that to sink in, and for the reality for them to come to terms if they ever do, but for their needs to surface, so at the point of diagnosis is definitely not the right time we felt." (Project manager 2, 0209S).*

As highlighted in women’s interviews, the volume of information given at diagnosis made it difficult to engage fully with the (e)HNA. Staff also felt that offering the (e)HNA at diagnosis led to many concerns being scored highly. Consequently, they worried that inviting women to raise concerns (which would likely be high), would lead to disappointment due to them not being able to solve these:

> *"I feel that if you do it too soon you’re almost asking them to ask you the question that you can’t answer, so it’s kind of like you’re letting them down." (BCN 1, 0204S).*

> *"We gave them at diagnosis which was way too quick because everybody was scoring ten out of everything, which was of use, 'cause it showed what distress somebody was in, but equally… it felt like we'd opened too much of a lid off Pandora's box." (BCN 2, 0206S).*

BCN 2's comments highlight that whilst an early assessment could cause disappointment, the highly rated concerns gave staff an indication of women's overall emotional distress levels, which in some way helped gauge their support needs. However, these comments may also suggest a desire to avoid discussions of these complex concerns to some extent. Comparing completion of the (e)HNA at diagnosis to 'opening Pandora's box' implies that negative emotions will be released that cannot be controlled, and attaches negative connotations to this.

Perceptions of the 'Right' Time

In the light of the limitations of offering (e)HNAs at diagnosis, Case Study 2 staff (in both hospitals) took the initiative to change practice, to move the assessment to time points they deemed more beneficial:

> *"I tend to send them out post-operatively, because I was finding when I was sending them out prior to that, most patients were coming back scoring very highly because they had questions about their diagnosis… for us I think it works better post-operatively, and that's where we're doing them, but that doesn't mean it's not open to change." (SW 1, 0203S).*

> *“We found it failed, it just didn’t work because they weren’t in the right mindset, even be exploring that themselves, so then we tried it at post-op.” (BCN 3, 0207S).*

These comments suggest that staff felt empowered to change practice based on their experiences. Also, changing practice due to high scores may imply this outcome was undesirable enough to motivate the change.

Staff reflected no consensus about the correct time to conduct (e)HNAs, yet none suggested the gaps between appointments or treatments as a possible alternative (as women suggested). Staff proposals for the best time to undertake (e)HNAs varied, but included the end of treatment, during treatment, or lack of a set interval:

> *“I think we need to, our offer it just needs to be there open all the time, so that when it is the right time for that individual, they are able to fill it in.” (Project manager 1, 0202S).*

These comments may reflect an ideal scenario, rather than one that was possible in practice, as giving an open invitation to complete the (e)HNA may be challenging for staff to incorporate into their schedule (discussed in Category 3 below).

5.3.5.1.2 Sub-category b) Practicality of Location

(e)HNA Questionnaire Completion: Home Versus Hospital

A further significant factor in undertaking (e)HNAs was determining the best place for these to be conducted. Completion at home seemed to be considered the superior option for eliciting meaningful results:

> *"I think they prefer doing that than doing it at home to be honest, but whether when we're sat there with them puts them on their guard, I don't know." (Radiotherapy nurse, 0201S).*

> *"I do think automatically you know if I'm in a uniform it's that boundary that automatically is created when you sit with somebody with a uniform on, I just think let them do it in their own time, in their own home, because then it will be true." (Project manager 1, 0202S).*

This home assessment was viewed as advantageous for several reasons, such as not completing the (e)HNA in the presence of staff, which may influence responses given.

However, completion of assessments at home appeared challenging for women who lacked confidence in the (e)HNA process, as suggested by their need to double-check with staff about which concerns were appropriate to raise:

> ***<u>Observation of Wendy's (e)HNA (0209S)</u>***: *Stated that she would not 'tick' hot flushes because they were not related to cancer, so she did not see them as relevant.*

> ***Observation of Anna’s (e)HNA (0201S):*** *Talked through concerns while doing (e)HNA, appeared to be checking for ‘what counts’, for example “I’ve had a sore throat for ages but it’s not really bothering me” and highlighted feeling isolated but did not ‘tick’ this.*

The act of verbally clarifying these uncertainties suggests that women were checking with staff whether a minor concern should be recorded. They also appeared unsure of how severe or longstanding a concern ‘should’ be, before it needed to be declared on the (e)HNA.

(e)HNA Discussion: Face-to-Face Versus Telephone

Staff’s views of where the (e)HNA’s follow-up conversation should take place predominantly reflected the anticipated burden of undertaking additional hospital trips for a face-to-face (e)HNA:

> *“I think actually you don’t need to bring them in… you can avoid a visit, a lot of people don’t like coming here anyway because of the car parking, especially if they live quite out of the way.” (BCN 1, 0204S).*

> *“For some people, coming into the hospital to keep coming for appointments, they don’t want to, it’s another thing that they’ve got to do… the other thing is I think talking to somebody one-to-one you can identify a problem, the severity of it a little bit easier than you can on the phone I think.” (Project manager 2, 0209S).*

However, another example highlights the possibility that whilst additional trips may be inconvenient, the alternative telephone assessment also presents challenges, namely obtaining an accurate picture of concerns:

> *"Somebody could be saying to you no I'm fine, their concern is 1, but you're looking at them thinking you're not, you can just tell but you can't do that over a telephone, so I do think the telephone conversations for HNAs could be quite difficult and maybe we're not meeting all of the patient's concerns by doing that." (BCN 5, 0211S).*

These comments suggest that telephone (e)HNA discussions may present barriers to assessing needs. The recorded concerns appeared largely dependent on how confident the individual felt to disclose them.

5.3.5.2 Category 2: Factors Affecting Behaviour

As with women's data, Category 2 covers staff's understanding of the (e)HNA, and factors which they felt influenced women's behaviours towards it (for example, disclosure or non-disclosure of concerns).

5.3.5.2.1 Sub-category d) Understanding of Assessment

Perceived Purpose

Staff reported similar understanding of the (e)HNA to what was reported by staff in Case Study 1. The Initial training received when the (e)HNA was introduced was deemed insufficient:

> *“We were never given like a proper introduction to this is why we do it and this is how you do it kind of thing… I don’t feel like we’ve had proper training, on like how we can like deal with things that people bring up." (Radiographer, 0205S).*

> *"It was very much you have got to do this, so that was very much how it was put, this is something you have got to do, so there was no choice there really." (BCN 3, 0207S).*

Feeling compelled to undertake (e)HNAs was not reported by all participants, but those who expressed it seemed to change their opinion once they understood the (e)HNA’s benefits:

> *“But then you’re looking at it and what you can see is it makes people look at their needs” (BCN 3, 0207S).*

> *"Good I think, once I sort of you know, had a look, did a bit of research of what it actually was." (SW 1, 0203S).*

This change of opinion suggested that staff were open to implementing the innovation despite initial resistance. One staff member also considered the impact of negative staff perceptions on how the assessment was presented to women. They felt this could impact women’s engagement with the (e)HNA:

> *"Are they expiring because we’re not properly offering it and we’re not giving somebody the information about what this is and how it can benefit them?" (Project manager 1, 0202S).*

Expectations

Staff also divulged their opinions about how concerns ‘should’ be addressed:

> *"I suppose in our head as a nurse we feel that we should, but whether they expect it or not I don’t know actually." (BCN 4, 0208S).*

> *"I mean everybody has bad days, but I find it hard sometimes, I do find it hard sometimes because I just feel I’ve not done enough, because I can’t do anything I can’t solve it." (Radiotherapy nurse, 0201S).*

> *"Sometimes we just cherry pick a few and then double-check that they’re happy I’ve done enough." (BCN 1, 0204S).*

These examples suggest the responsibility some staff felt to do ‘enough’ in supporting women’s concerns. BCN 4 appears to feel pressurised to act, despite being unsure about what the person completing the (e)HNA expects. BCN 1’s example suggests that staff determine the (e)HNA’s ‘success’ by women feeling that ‘enough’ support was provided to address their concerns. They indicated that support did not always need to be in the form of action, as sometimes listening was sufficient for women:

> *“HNA is more about listening to them, sometimes that's all it needs, it’s not always possible to solve them.” (Radiotherapy nurse, 0201S).*

This corroborates an earlier example from Isabelle (p246), who suggested that the act of reflection allowed her to process her concerns, and no concrete action was required.

5.3.5.2.2 Sub-category e) The Impact of Interpretations on Behaviour

The Impact on Openness

Staff implied that some women chose not to disclose their concerns, and discussions required some interpretation of other signs to accurately assess needs:

> *“You’re picking up on the cues of what they’re maybe trying to drop in on that conversation… they’ve not physically ticked anything, or said my concern is 10.” (BCN 5, 0211S).*

> *"Sometimes if they say something to you you’ve got to probe a little bit… I suppose it’s clarifying what they’re actually saying… I think that’s what I find frustrating about the job, that you see them that once, you go through with them, and then you don’t see them again." (Radiotherapy nurse, 0201S).*

The communication techniques adopted to elicit genuine information about an individual’s feelings included ‘probing’ and acting on cues. Radiotherapy nurse’s example indicates these communication techniques may be more successful or easier to apply, if staff had an existing relationship with the woman.

Staff felt a further barrier to disclosure related to the nature of concerns, particularly if these were sensitive:

> *"Nobody will tick it on that paper because they don't want you to think that they're having sexual problems… they sometimes perceive... what they should be saying, and how they should be reacting, so they won't actually be over honest." (BCN 3, 0207S).*

> *"They're embarrassed to talk about it, but sometimes it's about they're not sure who to raise it with, who they can talk to about it, and I suppose by me asking them it's giving like permission." (BCN 4, 0208S).*

Here, BCN 4 attempted to overcome the barriers to disclosure by directly asking a question about personal issues, which gives women permission to disclose these. This method of eliciting concerns demonstrates a powerful combination of using the (e)HNA as a prompt and adopting communication skills to build upon the information gathered.

The Impact on Scoring

Staff felt that women's interpretations of the (e)HNA's rating scale affected how they scored concerns:

> *"It's a bit like pain isn't it, some people will say oh it's pain it's okay, somebody else will say actually the pain was horrendous, so I think some of it's down to that person's ability to cope with different things and what they may score as a ten, somebody else might score as a five." (Lead BCN, 0210S).*

> *"I think scores are an indicator but I don’t think you can take it as absolutely this is ten out of ten I must address this most importantly, but I think human nature if we see a ten and I think I’ve only got an hour with the lady I’ll perhaps go for the ones that are scored out of ten.” (BCN 2, 0206S).*

The first example indicates that based on the individuality of women’s perceptions, scoring of concerns may only be useful for prioritising concerns within one woman’s (e)HNA, as opposed to prioritising severity of concerns between different participants. The second example highlights that whilst scores are subjective, insufficient time to address all concerns led to scores being used to determine which concerns to discuss first.

Finally, Case Study 2 (Hospital 2) identified ‘cut-off’ points for scoring and specific actions. For instance, scores of more than six triggered a face-to-face appointment instead of a telephone call:

> *"Any patient that scores six and above is offered an opportunity to come back into clinic and then there are nurses on site, so if anything is above a certain, say eight, then I will ask a nurse to come and step in and address their concern." (SW 2, 0212S).*

> *"For telephone calls if it was five or below you could do a telephone conversation, if it was scoring five or more then we need to invite them in for a one-to-one." (BCN 5, 0211S).*

Whilst staff did not elaborate on the rationale for these cut-offs, these demonstrated an opinion that face-to-face appointments had greater benefits or effectiveness for those with higher-scored concerns.

5.3.5.3 Category 3: Organisational Factors

The final category in Class Two considers organisational factors, and contains four sub-categories.

5.3.5.3.1 Sub-category f) Accountability or Proof of Actions

Staff discussed the pressure they felt to evidence actions taken within the (e)HNA process. They felt the care plan document itself functioned as a source of evidence in some cases:

> *"It doesn’t look like anything does it, it doesn’t exist on paper, it’s what we automatically do, it’s kind of like what we train to do." (BCN 1, 0204S).*

> *"I think the other thing is, it’s our evidence that actually we have had that discussion, so I think, I know this sounds awful but actually it’s our proof that we have had that conversation." (Lead BCN, 0210S).*

> ***Kathryn’s care plan (0204P):*** *Questions about diagnosis: “She said that she has previously been for counselling with [service] but did not find this helped, and she is on the waiting list for the mindfulness course… She had an appointment with her oncologist and has had a lot of her concerns and questions*

> *answered then. I therefore discussed the health & wellbeing events, Hope course, active recovery programme and gave her the moving forward file, which she appreciated.”.*

Staff appeared to feel that evidence was required for actions taken, and that an unstructured assessment (without an (e)HNA tool) did not facilitate ‘evidence’ of actions. This shows the importance placed on documentation for the team’s accountability. Furthermore, the excerpt from Kathryn’s care plan highlights a factual reporting style of writing, documenting that all appropriate actions were taken (for example highlighting that Kathryn’s concerns were answered by the oncologist and that she appreciated receiving information). These comments would have minimal use or value to Kathryn herself. However, if the document was audited by staff or management, expressions such as “which she appreciated” may provide validation of actions taken by staff.

Staff’s focus on providing evidence appeared to affect how they wrote care plans in some cases. For example, some staff felt the need to document additional information in the clinical notes, or use cautious wording that reflects uncertainty about who might read the care plan:

> *"I will write something in the care plan but I think I need to back it up with a bit more information on the clinical notes… Sometimes there’s some stuff that you don’t wanna put on the care plan that you’ve discussed with the patient that didn’t fit in, or if I’ve got concerns about them I’m not necessarily gonna put that on the care plan." (BCN 4, 0208S).*

> *"I used to put a lot, but now I just kind of highlight mainly, because I don’t know where that information is going and who*

> *else, other healthcare professionals have got access to it, their GP might have access to it, they might not want them to know the intimate details of the conversation that they've had." (BCN 1, 0204S).*

These examples highlight variations in what staff felt comfortable to document in care plans, particularly if the documentation was available to other healthcare professionals and women. This may indicate that whilst staff provide thorough reports of events in clinical documentation, they were keen to adopt sensitive language to protect the woman and their privacy (by limiting content available for others to read). Conversely, this may relate to fear of how women might react to what is documented about them. For example, if an individual attempted to present an image of composure, it might be distressing if documentation stated they were upset.

5.3.5.3.2 Sub-category (g) Time Pressures

An additional organisational factor influencing the contribution of (e)HNAs related to time pressures on staff. This also appeared to affect their ability to follow-up completed (e)HNAs in some cases:

> *"If that patient's taken two hours then does it really matter, no it doesn't, but on a nurse, yeah it does… two hours is a lot for her, whereas for me to sit and just let somebody cry it's not that much of a bigger deal on my time" (SW 2, 0212S).*

SW 2's comments emphasise the importance of offering time for women to discuss their concerns. Additionally, the quotation shows that SWs had more time to give to these discussions than BCNs. Many staff recognised the value of the SW role in releasing time to focus on (e)HNAs:

> *"I feel like we're only brought in for the big gun stuff." (BCN 2, 0206S).*

> *"We found that the specialities with SWs have thrived, the patients have thrived." (Project manager 2, 0209S).*

The first of these examples reinforces perceptions that the (e)HNA was a lesser priority than other elements of the BCN role. However, the scheduling of (e)HNA appointments for SWs did not take account of additional factors, such as the emotional burden on staff:

> *"You could only do so many because it was exhausting, if you can do four in one day that's pretty remarkable, if those four were straightforward, I've got no concerns... great you can do probably 12, but if you've got one that has highlighted all the concerns… they're extremely draining." (SW 2, 0212S).*

This shows the potentially negative impact of undertaking large numbers of assessments. The use of selected individuals to offer the majority of (e)HNAs and to act as a form of 'champion' was also viewed as involving risk:

> *"If you've got a service where there is only one CNS or a couple of CNSs and one goes off that may have been your champion sort of person, it falls down, any staffing vacancies, and there have been challenges certainly in the breast team as well as in other teams." (Project manager 1, 0202S).*

These comments show the influence of key individuals on implementation. Therefore, despite the necessity of ‘champions’, there was a need to engage whole teams to mitigate risk and facilitate sustainability.

5.3.5.3.3 Sub-category h) Resistance to Change

Staff resistance to change was more notable in the early stages of (e)HNA implementation, but persisted in some cases. Both of the site’s project managers reported issues from this perspective:

> *"I think others are afraid of change and haven’t had the opportunity yet to really get in there and understand and work with me, and I think others just don’t want change, thank you very much I’m quite happy doing what I want, so there’s the cultures to deal with as well which are challenges." (Project manager 1, 0202S).*

> *"I got a lot of resistance, although and I think it’s because of they didn’t understand wholly what it was, perhaps they felt threatened that they weren’t doing their job properly and that’s not the idea of it at all… there were lots of problems." (Project manager 2, 0209S).*

These examples suggest possible reasons for resistance, including lack of understanding, feeling they would be perceived as not doing their job correctly, or time pressures. However, BCNs’ perceptions of the reasons for initial resistance appeared more related to team or individual opinions:

> *"I'm quite stroppy, so when it was all you must do it this way, I was like nobody's telling me to must do it this way, I'll do it my way… But again if we didn't have a target would we ever have got around to doing it? No, it's a bit like it goes against the grain when hospitals are fined because they do something wrong, yes that's ridiculous, but equally would they have learnt from things if they weren't fined?" (BCN 2, 0206S).*

> *"It's very difficult to kind of go let's do something new, when they're always kind of like, almost sort of didn't like somebody younger and new coming in is trying to change things, it was like no, no, no, this is how we do things and that's that." (BCN 1, 0204S).*

> *"I think it's the team I work in and the people that lead it, whereas you might get other areas where they work with nurses that didn't really want to do it." (SW 1, 0203S).*

BCN 2's example highlights general resistance towards being compelled to implement something new. However, she also described understanding the requirement for targets (such as the national (e)HNA targets). BCN 1's comment also suggests the reluctance of colleagues to implement interventions. The reference to her age implies she may have felt unable to influence change, because she believed other staff saw her as inexperienced.

Several examples from interview data suggest that national targets may have had a negative impact on the (e)HNA process:

> *"I think across the board, very tunnel vision that we've got to achieve these targets, how do we achieve that... it's a bit of a harder battle to get them interested in the touchy feely stuff, and I guess but also proving the benefit of that touchy feely stuff is a challenge… I really hate it, you know we tick the box but miss the point." (Project manager 1, 0202S).*

> *"I think our roles were very primarily brought in to drive it, which in part we have succeeded and at least every patient is offered an HNA at diagnosis, which is a good thing, that only one per cent take it up is not a good thing, it means we're failing." (SW 2, 0212S).*

Concerns highlighted here reinforce the points previously made about the impact of targets upon when (e)HNAs are offered. The reference to the (e)HNA as 'touchy-feely', and as attracting little interest from senior stakeholders, further implies that it was viewed as low priority.

5.3.5.3.4 Sub-category i) Perceptions of Macmillan Cancer Support Branding

Some staff saw Macmillan Cancer Support as representing a connection with death and dying. Consequently, they felt women would also perceive the charity in this way:

> *"I think a lot of it is hard without using the word Macmillan, because so many people still see it as oh you've sent me a Macmillan thing I'm dying when actually they're not." (BCN 1, 0204S).*

Staff perceptions that women viewed the charity unfavourably did not solely relate to its association with death and dying. This was highlighted by radiotherapy nurse’s comment, which suggested some women felt the charity did not support their needs:

> *“Some people are anti-Macmillan because they didn't help with such-and-such, I find it surprising.” (Radiotherapy nurse, 0201S).*

In some cases, staff’s experiences of how women perceived the charity may have influenced how they approached their (e)HNA discussions, for instance feeling obliged to reassure women that Macmillan Cancer Support would not have access to personal information.

> *“They’ve had bad experiences and they’ve not gone into it so I’ve sort of left it, so they wouldn’t have anything that’s got Macmillan on it… and it’s that sharing of information if you didn’t want to share information, so that’s stopped them doing it.” (BCN 4, 0208S).*

> ***Observation of Wendy’s (e)HNA (0209P):*** *“What I normally ask you to do is a concerns checklist, I can write you a care plan afterwards, so Macmillan don’t get any of your name and address but they do get some of the concerns, we’re mainly doing it today to focus your conversation.”*

The comments made during the observation of Wendy’s (e)HNA suggest that the BCN is expecting her to have concerns about sharing personal information with Macmillan Cancer Support, and she attempts to minimise this view.

Overall, staff themselves did not report negative views about Macmillan Cancer Support, and their views were neither supported nor challenged by the comments from women participants in this study, who did not discuss the charity.

The sections above show the multitude of factors which divided into the ‘contributions’ and ‘wider influencing factors’ that determined the (e)HNA’s role in assessing and supporting women’s needs.

5.3.6 Individual Case Example

In this section, Jessica’s (0203P) case is presented to illustrate the factors that may have influenced her perceptions of the (e)HNA’s value. Figure 59 features a timeline of events throughout Jessica’s cancer experience.

Figure 59. Illustrative Example of Jessica’s Case

Initial Diagnosis

Staff Perception
Jessica attended the initial diagnosis appointment, where she was provided with verbal and written information about her cancer. At this point, she was also assigned a BCN and given emotional support.

Jessica's Perception
Jessica reported feeling scared at the point of diagnosis and had difficulty processing this. She was worried about telling her children, and experienced guilt from feeling that being overweight caused the cancer. Jessica had lived through a traumatic childhood experience, which caused ongoing anxiety and affected her ability to cope. However, she appreciated the supported provided by her BCN at diagnosis.

During Treatment

Staff Perception
An (e)HNA was set up for Jessica after her surgery, which she completed at home. This highlighted that she had many concerns, including highly-scored emotional issues. Jessica had a face-to-face appointment to discuss her (e)HNA concerns and disclosed her traumatic childhood experience. Her care plan outlined that a psychology referral was made to address these issues. Later, Jessica was telephoned to cancel the psychology referral, as her concerns were unrelated to cancer, and she was offered a referral to a counselling service.

Jessica's Perception
Jessca felt her (e)HNA was an opportunity to access support for her childhood trauma. When completing this, she reflected and completed it honestly. During the discusson, she disclosed her trauma and her previous poor experiences with counselling services. She was appreciative of the opportunity to see a psychologist. Following the phone call retracting the offer of a psychology referral, Jessica felt extremely let down and as though she was ‘too bad’ a case to receive support. She felt the (e)HNA had raised her expectations and disappointed her.

End of Treatment

Staff Perception
At the point at which data collection for the study closed, the BCN had highlighted her plans to send Jessica a repeat (e)HNA at the end of her treatment, as per the standard process locally.

Jessica's Perception
Jessica never received her care plan from the first (e)HNA, but felt there was no action plan, and so to have received this would have further disappointed her. Jessica stated that if she received one, she would not complete an (e)HNA again because this would be a pointless activity.

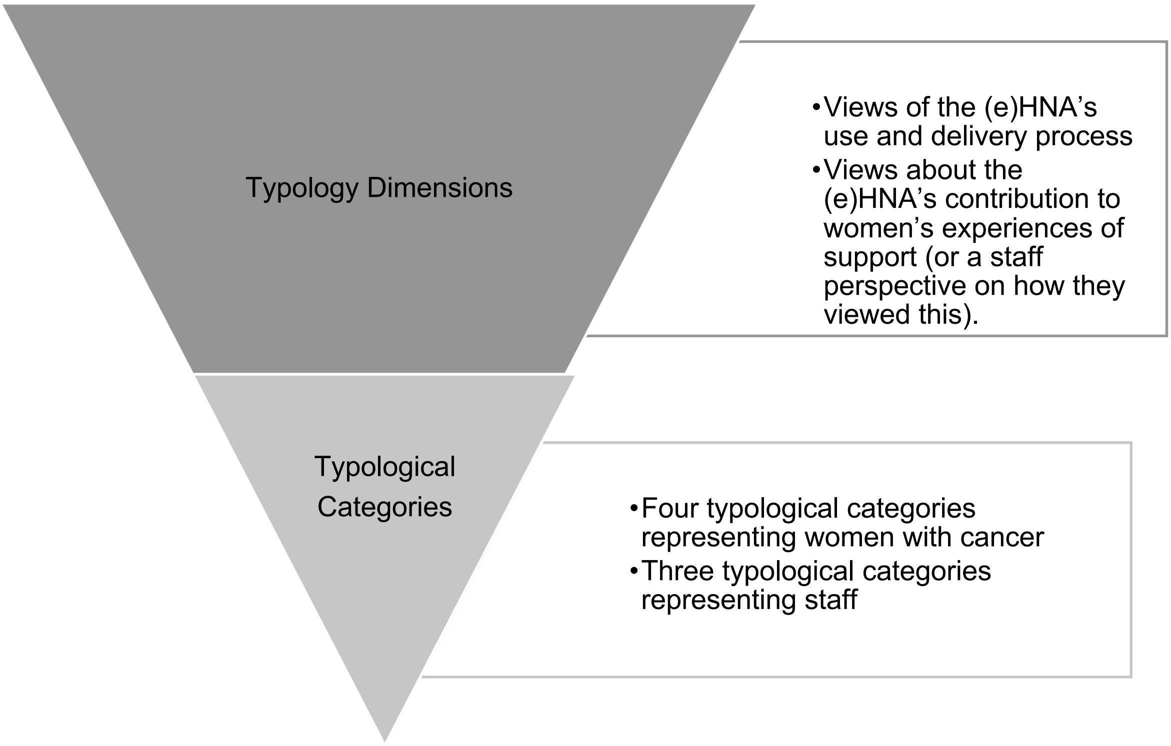
Jessica’s experiences are an example of where the (e)HNA processes contributed to a potentially harmful outcome, based on her expectations being raised and not met, and how this made her feel. Although this case may not be representative of all women’s experiences, it illustrates potential issues with the (e)HNA, if the system of care around the assessment is not set up to fully support women with anything it might reveal. In Jessica’s case, this was the need for a type of support that was not available. Here, the (e)HNA appeared to separate cancer-related concerns from the rest of Jessica’s life, thus providing a paradox to the concept of ‘holism’, which aims to focus on all elements of an individual’s life.

Following discussion of the class-category framework, overarching typologies (discussed in the overview of findings in Section 5.3.1) are revisited in more depth.

5.3.7 Overarching Typologies

As a further element of Framework Analysis’ ‘descriptive accounts’ processes, the overarching typologies developed for Case Study 2 grouped participants’ perceptions of the (e)HNA into typological categories. These were highlighted in four different categories for women, and three for staff, shown in Figure 60.

Figure 60. Typology Construction



5.3.7.1 Typology Categories - Women with Cancer

To revisit the groupings presented at the outset of this chapter, Figure 61 presents a summary of typological categories representing women participants, which shows similarities to those highlighted in Case Study 1. Key information explaining why participants are grouped within a specific category is provided in the evidence tables throughout this section.

Figure 61. Recapitulation of Typological Categories: Case Study 2 Women with Cancer

1. "Predominantly Positive Experience"
    - The (e)HNA's use and delivery process is mostly positive, but the contributions to the overall experience were both positive and negative.
2. "Comprehensively Positive Experience"
    - The (e)HNA's use and delivery process is positive, and its contribution to the overall experience was mostly positive.
3. "Positive in Principle"
    - The (e)HNA's use and delivery process is positive in principle, but there was little or no contribution from this to the overall experience.
4. "Paradoxical Experience"
    - The (e)HNA's use and delivery process is positive in principle, but had a negative contribution to the overall experience.

5.3.7.1.1 "Predominantly Positive Experience"

The initial typological category represents the experiences of three women, who reflected the view that the process of delivering the (e)HNA was positive, but contributions to their experiences of support could be positive and negative.

Table 28. Typological Category 1 Evidence: "Predominantly Positive Experience"

Participant	Description of Views/Experience
Anna (0201P)	Anna felt there were merits to both structured (with an (e)HNA) and unstructured conversations. However, she felt the (e)HNA facilitated greater openness in divulging concerns and gave her the opportunity to reflect.

	However, Anna did not feel that she had many worries, and so felt guilty for taking up staff time.
Georgina (0211P)	Georgina was pleased that the (e)HNA allowed her to offload and to think about considerations beyond diagnosis and treatment. The care plan was useful in preventing her from forgetting the discussion. However, she was conscious of taking up staff time and felt no rapport with her BCN. Georgina felt it would have been useful to compare her care plans and reflect on progress, but this opportunity was not presented.
Isabelle (0212P)	Isabelle was pleased with the opportunity to complete the (e)HNA alone, as it enabled reflection without being influenced by others. Having more than one assessment would also be a useful opportunity to compare these and see progress. The (e)HNA supported integration of care, as her GP had referred to it during an appointment. However, Isabelle feared causing hardship to staff with the answers she gave, so did not consistently disclose her concerns. She also felt reluctance to disclose these if the (e)HNA was done with staff present.

These experiences reflect predominantly positive views of the (e)HNA. However, the conversation following the (e)HNA led to feelings of guilt in some cases, or desire to hide their true feelings. Reasons for this included wasting staff time when they had few concerns, or placing too much emotional burden on staff by expressing their true feelings.

5.3.7.1.2 “Comprehensively Positive Experience”

The second typological category included views of four women, suggesting that the (e)HNA process was positive, and provided a largely positive contribution to their overall experience.

Table 29. Typological Category 2 Evidence: "Comprehensively Positive Experience”

Participant	Description of Views/Experience
Louise (0205P)	Louise preferred use of the structured (e)HNA, which allowed her to reflect, and provided more depth than a conversation. She had clear expectations of the assessment and thought it was positive that she could compare care plans from before and after surgery. To Louise, the (e)HNA’s contribution was positive, as it exceeded her expectations by offering non-medical support. She referred back to the care plan, which enabled reflection and prompted her to complete actions.
Olivia (0206P)	Olivia had clear expectations of the (e)HNA process. She completed two, after being informed they would not be compared because staff wanted a true reflection of her feelings without being influenced by previous assessments. She took completion of the (e)HNA very seriously, as she felt a personal need to deal with concerns she was avoiding. She found the care plan provided useful pointers for improving her life. However, she had not seen copies of the care plans prior to her interview and felt these would have been useful to receive.
Paula (0207P)	Paula preferred the (e)HNA to an unstructured conversation, on the basis that it enabled reflection, which was further facilitated by scoring concerns. She experienced minor issues with completion but felt that the care plan was a good prompt and memory aid.
Victoria (0208P)	Victoria felt the (e)HNA encouraged more reflection than an unstructured conversation. The assessment exceeded her expectations by offering a range of supportive interventions, which she had not thought herself worthy of. She expressed a desire to fully engage with the assessment to make it useful, but did not feel prepared to face some personal issues through further exploration. Receiving the care plan would have been useful for Victoria as a memory aid, but she did not receive one. Of the two (e)HNAs completed, the initial one contributed little, due to Victoria being distracted at the time and not fully understanding its purpose. Victoria felt the second (e)HNA was much more meaningful.

These participants perceived the (e)HNA as significant, with each of them outlining the opportunity it presented to reflect and engage with the process. Two participants (Victoria and Louise) explicitly stated that their expectations were exceeded by the assessment, and its subsequent offers of support. Although minor process limitations were identified (such as not receiving a copy of the care plan), the (e)HNA provided a positive contribution to assessing and supporting their needs.

5.3.7.1.3 “Positive in Principle”

The third typological category contained three women with cancer. Their perception was that the (e)HNA process was positive ‘in principle’, but practical considerations meant that its contribution - whilst not negative - was small or non-existent.

Table 30. Typological Category 3 Evidence: "Positive in Principle”

Participant	Description of Views/Experience
Eve (0202P)	Eve found it difficult to concentrate on the (e)HNA because she was caring for her husband. She therefore felt that a conversation where she was directly asked questions would have been easier to engage with than reading them. However, she liked the care plan, which could act as a memory aid.
Wendy (0209P)	Wendy had a clear understanding of the (e)HNA, despite not ticking anything (because of her perception that the list of concerns was not relevant to her), yet it was still useful for her to know she had entered into a system of care. However, she felt that the (e)HNA’s timing was wrong, and that it would have been better before the end of treatment. She felt she was being unhelpful because she did not tick any concerns, and apologised during the observation.

Lucy (0210P)	Lucy felt the (e)HNA was useful to allow reflection on how she felt without being influenced by staff. However, the timing of its completion meant she could not take this seriously (as she was preoccupied with her upcoming treatments). She felt she completed it without understanding what would happen, but felt pleased she could tick something off her to do list. Lucy expected to complete this again at some point during her journey.

In two of the cases above (Eve and Lucy), factors beyond the assessment itself appear to affect views about the (e)HNA's contribution. The interviews indicated that women felt unable to prioritise or fully engage with its completion due to competing priorities (caring responsibilities and poor timing). In Wendy's case, this appeared related to timing, as she that felt by the time her (e)HNA was completed, she no longer had concerns, and the assessment was therefore irrelevant.

5.3.7.1.4 "Paradoxical Experience"

The final typological category for women included two participants, and whilst positive views of the (e)HNA 'in principle' were reflected, actual experiences of it introduced something negative into their experiences of support.

Table 31. Typological Category 4 Evidence: "Paradoxical Experience"

Participant	Description of Views/Experience
Jessica (0203P)	Jessica was excited to complete the (e)HNA, which she felt was an opportunity to disclose concerns she had kept private and have these addressed. She spent a great deal of time reflecting on its completion, which was possible because of the online, at home format.

	Jessica’s expectations were not met by the (e)HNA, and she felt disappointed when she could not access support for her complex psychological concerns. She described feeling worse for having completed the (e)HNA, based on a view that staff thought her concerns were too extreme to support. This was further emphasised by the care plan, which listed actions that did not occur.
Kathryn (0204P)	Kathryn felt the (e)HNA was a great way to use data collectively to help others. She had accurate expectations that it would allow her to raise concerns, at which point she would be signposted to supportive services and courses. Kathryn’s (e)HNA discussion led to negative feelings and a view that the staff thought she did not require help. She felt it was a waste of time and found courses to access herself. Kathryn did not receive her care plan, and when reading it at her interview, commented that she would have liked to receive it, but that it contained many meaningless acronyms.

Both individuals expressed a positive view of the (e)HNA process, adopting language such as ‘great’ and being ‘excited’ to express their views. However, the reality fell short of their expectations, leading to disappointment in both cases. They felt that it was their personal situations in particular that led to this failure to provide support. This was shown by Jessica’s view that staff felt her case was too extreme to support, and Kathryn’s belief that staff felt she did not require support. Consequently, the (e)HNA not only failed to address their concerns, but also led to negative feelings introduced solely as a result of the (e)HNA process.

The views of women in these categories indicate positive perceptions of the (e)HNA (or the (e)HNA in principle), but individual considerations restricted its overall contribution to their experiences of support.

5.3.7.2 Typological Categories - Staff

From a staff perspective, three categories were identified, shown in Figure 62.

Figure 62. Recapitulation of Typological Categories: Case Study 2 Staff

1. "Predominantly Positive Expectations"
   - The (e)HNA's use and delivery process is positive, and they perceive that it has a positive contribution to the overall experience, but has the potential to also introduce something negative.

2. "Comprehensively Positive Expectations"
   - The (e)HNA's use and delivery process is positive, and they perceive that it contributed something positive to the overall experience.

"Delivery Limitations"
- The (e)HNA's use and delivery process requires improvements, but has a positive contribution to the overall experience

5.3.7.2.1 “Predominantly Positive Expectations”

Staff in the first typological category felt that the process of undertaking (e)HNAs was positive, as was its contribution to women’s overall experience. However, there was also a view that it had the potential to introduce negative feelings, if expectations were not met.

Table 32. Typological Category 1 Evidence: "Predominantly Positive Expectations”

Participant	Description of Views/Experience
Radiotherapy nurse (0201S)	This staff member felt the (e)HNA was valuable to allow offloading. She found she was able to identify more concerns with the (e)HNA than through a conversation

	alone, as the assessment prompted women to raise their concerns and gave them responsibility to self-manage. However, practical barriers were outlined (for example computer issues). She had concerns about disappointing women by not being able to resolve all the issues raised.
BCN 1 (0204S)	BCN 1 felt the (e)HNA prompted her to take action to address concerns which she would not normally take. She felt it provided direction to a conversation, allowing questions to be pre-empted. However, some practical barriers were noted (for example use of computers, extra hospital trips). She also felt that conducting the (e)HNA at a time when concerns could not be addressed could lead to disappointment.

In the experience of these staff members, the (e)HNA had many benefits. However, the concern that the (e)HNA may cause disappointment suggests its potential to raise expectations that staff were unable to meet, some of which may relate to practical considerations (such as timing of the offer). BCN 1 felt that prompting women to ask questions which could not be answered at the time (for example, treatment-related questions before treatment decisions were made), could lead to dissatisfaction.

5.3.7.2.2 “Comprehensively Positive Expectations”

The three staff in Typological Category 2 reflected positive views of the (e)HNA’s delivery process, and mostly positive views of its contribution to women’s experiences of support. It also reflected a small number of practical barriers, such as the (e)HNA’s time-consuming nature and the requirement for additional hospital trips.

Table 33. Typological Category 2 Evidence: "Comprehensively Positive Expectations"

Participant	Description of Views/Experience
BCN 2 (0206S)	This staff member felt the (e)HNA was a good tool overall once she understood it, especially for staff who did not ordinarily adopt a holistic approach. She also felt that it provided opportunities for women to be honest and gave them permission to raise concerns.
Project Manager 2 (0209S)	The project manager felt the (e)HNA enabled women to raise important concerns which may not have been prioritised in a routine appointment. Furthermore, she explained that she did not value (e)HNA national target achievement as being more important than having conversations which were meaningful to women. Some minor practical barriers were noted, such as the (e)HNA being time-consuming and requiring an extra hospital trip for women.
BCN 5 (0211S)	BCN 5 suggested that the (e)HNA provided permission to raise concerns, and prompted individuals to raise concerns they may not previously have thought to raise. She felt it encouraged them to take ownership by providing a schedule for self-management. However, she felt women may be reluctant to raise non-clinical issues with a BCN, but believed that having the opportunity to signpost them was positive, and that she could lighten their burden.

Whilst the staff in this category acknowledged the practical barriers associated with (e)HNA delivery, these did not appear to impact the positive view of its contribution and the delivery process itself. Staff also appeared able to look beyond the national targets set, with BCN 2 outlining initial resistance to these targets but subsequent acceptance and understanding of them. Similarly, project manager 2 took an individualised approach based on acknowledgement of the need to give women opportunities to raise anything important to them, whilst recognising their possible reluctance to do so.

5.3.7.2.3 “Delivery Limitations”

Seven out of the 12 staff were situated in the final category, which highlighted room for improvement in the (e)HNA process. However, they felt it still provided a positive contribution to women’s overall experience of support within their cancer journey.

Table 34. Typological Category 3 Evidence: "Delivery Limitations”

Participant	Description of Views/Experience
Project manager 1 (0202S)	This staff member felt the (e)HNA made the BCN’s role easier, and helped women organise their thoughts and prioritise their concerns, so these were not forgotten. However, she reported feeling the (e)HNA’s introductory ‘offer’ was not always high-quality, suggesting that assessments which ‘expired’ may not have been fully understood by women. Also, she was unsure how valuable the care plan was to women.
SW 1 (0203S)	SW 1 reported an overall good impression of the (e)HNA once she understood what it was, but felt it would be useful to standardise the process so all staff took the same approach. Furthermore, she felt that more scope to describe concerns would be useful, in addition to ticking boxes in the assessment.
Radiographer (0205S)	This staff member felt the (e)HNA helped identify concerns not routinely raised within a discussion. However, she did not feel as though sufficient training was provided to provide high-quality assessments. Additionally, practical barriers (such as the time taken to complete the (e)HNA, and women’s difficulty understanding what should be ticked) were noted.

BCN 3 (0207S)	BCN 3 indicated that (e)HNAs provided structure and focused the conversation, supporting women to self-manage and reflect. However, practical barriers existed (for example, delays with psychology appointments after referrals). Also, concerns were expressed about staff not reading completed care plans if they were shared.
BCN 4 (0208S)	BCN 4 emphasised that the (e)HNA provided a structure to prioritise concerns. She felt it gave respondents permission to raise personal concerns. The scoring system provided a good way to demonstrate progress. However, she also felt that the assessment offer may be flawed because many women allowed their (e)HNA to expire. She felt that care plans should be shared but often were not.
Lead BCN (0210S)	The lead BCN highlighted the (e)HNA's value above and beyond a conversation, if women were able to complete it in private. She felt it facilitated honesty and allowed them to highlight issues they might ordinarily be too embarrassed to raise. The ability to revisit discussions through the care plan was viewed as beneficial, but did not occur often. Furthermore, elements of the implementation process were dictated by national targets (for example timing) which was unhelpful.
SW 2 (0212S)	SW 2 favoured the (e)HNA's flexibility to cater to all types of individuals (through factors such as altering the timing, format and type of appointment). However, some practical barriers were noted, for example that the (e)HNA was time-consuming and emotionally draining to undertake.

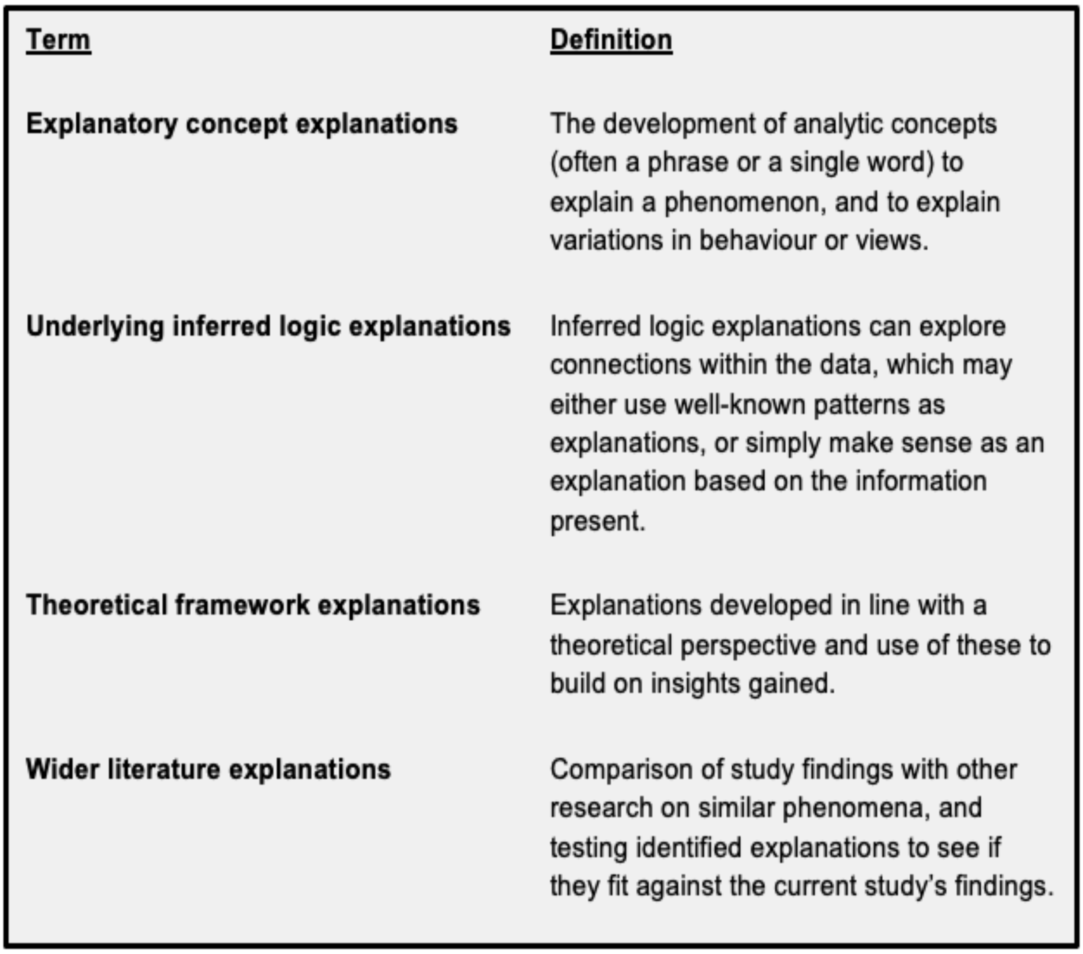
As set out above, the (e)HNA was perceived as requiring improvement by staff, as a result of shortcomings in how it had been implemented, as opposed to issues with the (e)HNA model itself. These shortcomings included issues with how the (e)HNA was initially offered to women, how it was undertaken, and the influence this had on women's engagement, which could originate from various factors. For example, insufficient sharing of care plans or staff training needs could affect the introduction and outcomes of (e)HNAs (through women misunderstanding the assessment or not receiving their care plan). Additionally, the emotional impact of conducting consecutive (e)HNA consultations had a negative impact on staff wellbeing. Staff appeared able to reflect on the shortcomings in their implementation methods, which led to them making changes to processes, such as ceasing to offer (e)HNAs at diagnosis. However, the lead BCN acknowledged challenges involved in applying changes when national targets dictated certain processes. She feared that in some cases, these targets overrode individual decision-making.

Following presentation of these typological categories, a further level of explanation is added through discussion of 'explanatory accounts'.

5.4 Findings: Explanatory Accounts

As in Chapter Four, Framework Analysis' 'explanatory accounts' process draws on connections between within study data to create in-depth explanations (Spencer et al., 2013). This process is undertaken by identifying 'explicit' explanations (derived from participants' own views or behaviours expressed), and 'implicit' explanations (inferences made by the researcher) (Spencer et al., 2013). As with Chapter Four, several techniques are used to identify implicit explanations from the data (recapitulated in Figure 63).

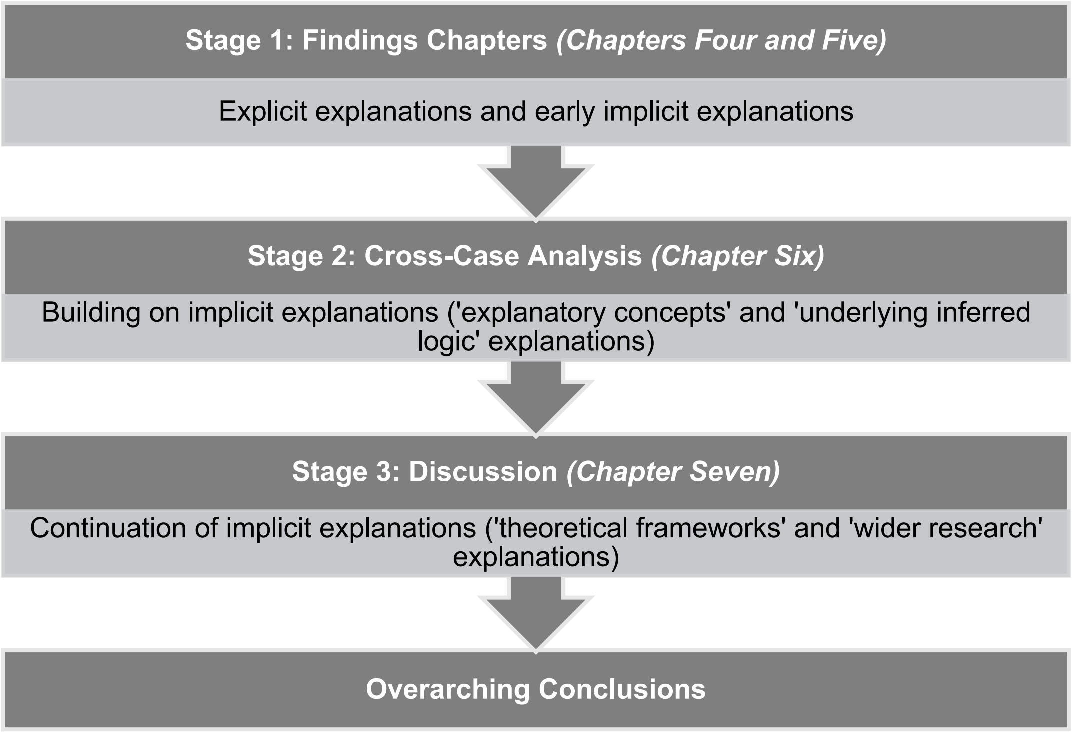
Figure 63. Explanatory Accounts Terminology (Spencer et al., 2013)



Term	Definition
Explanatory concept explanations	The development of analytic concepts (often a phrase or a single word) to explain a phenomenon, and to explain variations in behaviour or views.
Underlying inferred logic explanations	Inferred logic explanations can explore connections within the data, which may either use well-known patterns as explanations, or simply make sense as an explanation based on the information present.
Theoretical framework explanations	Explanations developed in line with a theoretical perspective and use of these to build on insights gained.
Wider literature explanations	Comparison of study findings with other research on similar phenomena, and testing identified explanations to see if they fit against the current study's findings.

Within this thesis, the presentation of implicit explanations continues over Chapters Four-Seven, and is divided into Three stages (shown in Figure 64). Echoing Chapter Four, Stage 1 involves identifying patterns of opinions and characteristics between the participants, within the previously discussed typological categories. These patterns are explained using explicit data, and some early implicit explanations. The early implicit explanations are built upon in Chapters Six and Seven, as previously described in Chapter Four.

Figure 64. Presentation of Explanatory Accounts Analysis



Chapter Four’s structure is adopted for the discussion of Stage 1 explanatory accounts analysis, for Case Study 2 data. This focuses on patterns of views, characteristics and personal circumstances between participants in each typological category, alongside explicit and early implicit explanations to support these.

5.4.1 Explanatory Accounts - Women with Cancer

5.4.1.1 Connections Between the Participants: Typological Category 1

In Typological Category 1 (Figure 65), three main connections were identified between the participants:

Figure 65. Women with Cancer: Typological Category 1

1. "Predominantly Positive Experience"

- The (e)HNA's use and delivery process is mostly positive, but the contributions to the overall experience were both positive and negative.

1. **Consciousness of the perceptions of staff.** Women reported awareness of how staff might perceive them, or indicated pressure to respond in a certain way in their (e)HNAs based on these perceptions. Evidence to support this includes women's direct expressions of preferences for undertaking (e)HNAs at home, to have privacy and space to reflect.

2. **Family concerns.** All participants expressed concerns about their families, which appeared at least partially responsible for their emotional concerns or anxieties. For example, one participant reported worries over her husband's health (Anna, 0201P), one about her children's risk of developing cancer (Georgina, 0211P), and one reported being extremely geographically separated from her family, which caused emotional distress (Isabelle, 0112P).

3. **Awareness of the burden they placed upon staff**. Participants recognised the burden they added to staff's workload. This was reflected in perceptions that they were wasting staff's time, or that offloading emotional concerns would be onerous for staff. This was also implied in one observation (Anna, 0201P), where the individual apologised for ticking few concerns on the assessment. This implies a perception that staff time was better spent on those with greater concerns, or on different tasks.

Early Explanations: Feeling under pressure appeared to be a key feature among participants in this category, which was apparent through the focus on staff perceptions and women feeling as though they were burdensome. Moreover, comments about preferring to do their assessments at home may have indicated a wish to avoid this pressure. Furthermore, wider life circumstances (relating to their families) may provide some explanation of why the (e)HNA produced negative as well as positive contributions to their overall experience. For instance, the assessment may have prompted reflection on their anxieties, at a difficult time.

5.4.1.2 Connections Between the Participants: Typological Category 2

For the second typological category (Figure 66), six connections were identified between the participants:

Figure 66. Women with Cancer: Typological Category 2

2. "Comprehensively Positive Experience"

- The (e)HNA's use and delivery process is positive, and its contribution to the overall experience was mostly positive.

1. **Reasonable understanding of the (e)HNA**. Participants understood that the (e)HNA considered the ‘whole person’ and enabled reflection on side-effects and wellbeing after treatment. For one individual (Victoria, 0208P), this understanding was present in her second (e)HNA but not the first, and she reported feeling the second held greater meaning.

2. **Expressed a tendency towards self-management.** Participants implied this through a desire to address concerns independently wherever possible, yet they accepted referrals for support with emotional concerns where this was offered.

3. **Completion of two (e)HNAs.** The fact that all participants had completed two (e)HNAs was evident from data gathered in the study.

4. **Completion of treatment.** All participants had reached the end of treatment prior to their study interview.

5. **Initiated contacts with the breast team.** These participants all initiated contact with the breast team (for some form of advice or support), separate to the (e)HNA (shown in Chapter Three, p93).

6. **Raised more (e)HNA concerns**. Compared to other categories, these participants raised more concerns that were mainly high-level, which they reported had improved by their second (e)HNA.

Early Explanations: The positive views of these individuals suggest that a sound understanding of the (e)HNA may influence its perceived value. Furthermore, those who completed the (e)HNA twice appeared to hold a better understanding of the assessment, which may be due to repeating the process. Additionally, all had a tendency towards self-management, shown through their expressed desire to manage their concerns independently wherever possible. This desire to support themselves was further emphasised by their willingness to initiate contact with the hospital separate to the (e)HNA. The fact that participants in this category reported overall positive experiences of the (e)HNA in comparison to others, may suggest that the (e)HNA's contribution is greater for individuals inclined towards self-management.

5.4.1.3 Connections Between the Participants: Typological Category 3

Within Typological Category 3 (Figure 67), two main connections were identified between the participants:

Figure 67. Women with Cancer: Typological Category 3

3. "Positive in Principle"

- The (e)HNA's use and delivery process is positive in principle, but there was little or no contribution from this to the overall experience.

1. **Lack of understanding of the (e)HNA.** This was demonstrated through interview comments which suggested lack of clarity around how to complete an (e)HNA. Two participants also requested clarification about whether their concerns 'counted' during observations (Wendy, 0209P and Lucy, 0210P).

2. **Description of low-level concerns**. Participants in this category described their concerns as insignificant, with one elaborating that her disclosure of concerns was solely due to the (e)HNA prompting this (Lucy, 0210P). One participant's low-level concerns were also demonstrated during an (e)HNA observation (Wendy, 0209P), where she explained that her only concern (hot flushes) was unrelated to her cancer diagnosis.

Early Explanations: These participants expressed low-level concerns and apparent indifference towards the (e)HNA's contribution, which was perhaps because they did not feel they had significant support needs.

The absence of understanding around the (e)HNA may have also affected how they completed it. For example, despite some participants raising concerns (and rating some highly) in their (e)HNAs, participants' interview responses suggested these issues were minor, or no longer relevant.

5.4.1.4 Connections Between the Participants: Typological Category 4

The final typological category for women (Figure 68) displayed three connections between the participants:

Figure 68. Women with Cancer: Typological Category 4

4. "Paradoxical Experience"

- The (e)HNA's use and delivery process is positive in principle, but had a negative contribution to the overall experience.

1. **Clear expectations of (e)HNA outcomes**. Participants explicitly stated expectations that the (e)HNA process involved receiving support or signposting to supportive resources.

2. **Worry about how emotional concerns would be perceived.** Participants articulated these worries, resulting in them modifying the scores given to concerns. This may have explained why both individuals (Jessica, 0203P and Kathryn, 0204P) had preferences for completing the (e)HNA at home, which allowed for anonymity and avoided staff presence influencing their responses.

3. **High-level concerns**. Both participants assigned high scores to their concerns (Jessica's (0203P) average score for her (e)HNA

concerns was 7.6 out of ten, and Kathryn's (0204P) 6.6 out of ten). Both participants reported feeling that their psychological concerns had not been addressed. For example, Jessica's care plan highlights a referral to a psychologist, which was later retracted on the basis that her concerns were unrelated to cancer.

Early Explanations: The connections above indicate that participants experienced significant emotional concerns in other aspects of their lives (prior to diagnosis), and were concerned about how they may be viewed by others. Jessica and Kathryn reflected high expectations of the (e)HNA, and were therefore disappointed when the concerns they raised were not addressed, leading to negative feelings.

In summary, women in Case Study 2 reflected similar perceptions of the (e)HNA's value to those in Case Study 1, where the central aspects of their lives appeared to influence the assessment's contribution to their experiences of support. However, a stronger thread among women in this case study appeared to be the connection between greater understanding of the assessment and feeling it was more valuable. The value of greater understanding was more apparent in women who had completed two (e)HNAs, suggesting that repetition improved their knowledge.

5.4.2 Explanatory Accounts - Staff

5.4.2.1 Connections Between the Participants: Typological Category 1

The first typological category for staff participants (Figure 69), highlighted three patterns between the participants:

Figure 69. Staff: Typological Category 1

1. "Predominantly Positive Expectations"

- The (e)HNA's use and delivery process is positive, and they perceive that it has a positive contribution to the overall experience, but has the potential to also introduce something negative.

1. **The association of Macmillan Cancer Support with death and dying**. Staff in this category reported that women associated the charity with death and dying. They also highlighted their perception that women would prefer Macmillan Cancer Support did not store or use the information provided in their (e)HNA.

2. **Negative view of the (e)HNA, which improved.** The initially negative views described by participants reportedly improved, once their understanding of the assessment's benefits increased.

3. **Responsibility towards women**. Participants demonstrated feelings of responsibility towards women, by their feelings of not having done 'enough' to address concerns. This sense of responsibility was also expressed through concerns about breaking trust if they divulged sensitive aspects of their conversation on their care plan.

Early Explanations: Participants appeared cautious about the (e)HNA, fearing it could introduce something negative to women's experiences. However, staff communicated a greater sense of responsibility to help these individuals than was expressed by staff participants in other categories. Moreover, they felt women would have high expectations of the (e)HNA, which may provide an insight into their perceptions of their own roles, such as feeling nurses should 'solve' all concerns. These factors demonstrated staff's lack of clarity about what women expected, and lack of confidence in what the (e)HNA could contribute in supporting concerns.

5.4.2.2 Connections Between the Participants: Typological Category 2

Two connections were identified between the participants in Typological Category 2 (Figure 70):

Figure 70. Staff: Typological Category 2

2. "Comprehensively Positive Expectations"

- The (e)HNA's use and delivery process is positive, and they perceived that it contributed something positive to the overall experience.

1. **'Championed' the (e)HNA.** All staff participants either acted as an (e)HNA champion or were strongly motivated by one. For example, one participant was employed to champion the (e)HNA (project manager 2, 0209S), and another would take over responsibility for conducting the (e)HNAs of other, less confident staff to ensure support was received (BCN 2, 0206S). The final

participant (BCN 5, 0211S) described finding the motivation to undertake (e)HNAs from a colleague who passionately encouraged its use.

2. **Positive impact of the SW role.** Participants stated that the SW role enabled BCNs to prioritise their workload, and enabled the breast team to thrive.

Early Explanations: The participants most positive about the (e)HNA's contribution were in this typological category. They advocated use of the (e)HNA either through being employed to implement it, or championing (e)HNA based on their sense of genuine belief in the assessment's value. The perceived effects of SW roles may be partially responsible for the more positive views, as they facilitated a less pressurised environment for the BCNs to prioritise other work. Regardless of whether the (e)HNA was part of their role, these participants appeared to see the value in it. This view reflected a particular orientation towards the (e)HNA, as they had either decided to apply for a (e)HNA-focused job role, chosen to support other staff, or felt genuinely motivated to undertake assessments, as opposed to feeling obliged to do so.

5.4.2.3 Connections Between the Participants: Typological Category 3

Consideration of Typological Category 3 (Figure 71), highlighted two connections between the participants:

Figure 71. Staff: Typological Category 3

3. "Delivery Limitations"

- The (e)HNA's use and delivery process requires improvements, but has a positive contribution to the overall experience

1. **Received a poor introduction.** Participants in this category reported that their introduction to the (e)HNA left them feeling compelled to complete it, and they did not understand the assessment initially. Several staff explicitly described attempting to overcome this by undertaking their own background research, whilst others reported ongoing training needs.

2. **Need for flexibility as a prerequisite for success of the (e)HNA.** Staff in this category indicated that flexibility in the (e)HNA's delivery was essential for success. This was highlighted in comments they made about the best time, location and format (paper or online) to deliver (e)HNAs. Several participants felt that lack of flexibility often led to 'expired' or declined (e)HNAs.

Early Explanations: This final typological category included staff who appeared to show a lack of understanding and confidence in using (e)HNAs as a result of poor training in its use. However, these participants did not appear restricted by this, and sought their own information regarding its purpose in several cases. Their references to the need for flexibility and an individualised approach suggest the need to act beyond the rigidity of national targets and established processes. These views highlight the requirement for improvements in the mode of delivery of (e)HNAs, and suggest that staff saw its potential benefits if delivered in the right way for each individual.

Overall, staff in Case Study 2 presented a connection around the role of choice and positivity towards the (e)HNA. For instance, many participants expressed views of the assessment that were initially negative, but subsequently improved. Therefore, ‘championing’ the (e)HNA (or the effect of a champion on others) appeared much more effective when the motivation was genuine and intrinsic, and not simply a response to external pressures (such as targets). This positivity, combined with the freedom to make changes to unsuccessful practices (such as the timing of (e)HNAs), may have contributed to the more positive attitudes found in Case Study 2. Some patterns of low confidence emerged, both because of uncertainty about the (e)HNA’s contribution, and the belief that it could have negative effects in some circumstances. Positive views of the (e)HNA were consistent between participants in management roles and other staff, compared to the more opposing views between these groups found in Case Study 1.

5.5 Conclusion

This chapter has outlined key findings from Case Study 2 (Site 2). This involved reflecting Framework Analysis processes, including initial discussion of ‘descriptive accounts’ analysis (the data supporting each class and category, followed by presentation of typologies and typological categories). The initial stage of ‘explanatory accounts’ was then set out to provide further analysis and interpretation. As with Case Study 1 data, this systematic approach to analysis highlighted many differences between participants, and has shown the range of complex variables which influenced perceptions of the (e)HNA’s value.

In Case Study 2, women expressed primarily positive views about the (e)HNA and care plan (at least in principle), as these were felt to provide opportunities to reflect and process their concerns. In some cases, women felt obligated to complete (e)HNAs, but this was often related to a sense of duty towards others with cancer, as opposed to staff. However, women seemed strongly influenced by staff's perceptions of them when undertaking their (e)HNAs. From a Case Study 2 staff perspective, benefits were reported regarding the assessment's capacity to elicit more concerns and structure a conversation. They saw value in the care plan's ability to evidence their actions and encourage self-management. From an implementation viewpoint, timing and location both affected perceptions of the assessment's value, and staff appeared to feel some level of freedom to change practices that had been deemed unsuccessful. Furthermore, some staff reported low confidence and resistance to the (e)HNA's implementation and targets, which often subsided once its value was understood. Despite a small number of negative experiences, staff responses suggested that (e)HNAs were conducted in more depth at Case Study 2, when compared with Case Study 1. This was evident in how women approached their (e)HNAs and how staff dealt with women's concerns, which reflected a stronger focus on addressing their emotional needs and ensuring the encounter was valuable.

Following the separate presentation of findings for Case Studies 1 and 2, Chapter Six considers further conclusions and a comparison between the cases, developed through Stage 2 of the 'explanatory accounts' analysis process.

Figure 72. Chapter Five Key Points

Chapter Five Summary: Key Points

- Case Study 2 data were presented using Framework Analysis' class-category framework. This focused on women and staff members' perceptions of the various contributions, and wider influences for meaningful (e)HNAs.

- Explanations were also explored using typological categories and components of Framework Analysis 'explanatory accounts', for continuation in Chapter Six's cross-case analysis.

- Both women and staff expressed predominantly positive views of the assessment, but engagement still occurred due to feelings of obligation in some cases, and some (e)HNAs left women disappointed.

- Case Study 2 participants provided evidence of having completed (e)HNAs in a more in-depth way than in Case Study 1, and the data overall indicates a stronger focus on emotional concerns in Case Study 2.

- Implementation issues persisted following the (e)HNA's introduction, including identifying the best time and venue for assessments, and the challenge of managing staff workload. However, staff reflected some sense of freedom to change ineffective practices, such as removing the use of (e)HNAs at diagnosis

Chapter Six: Cross-Case Synthesis

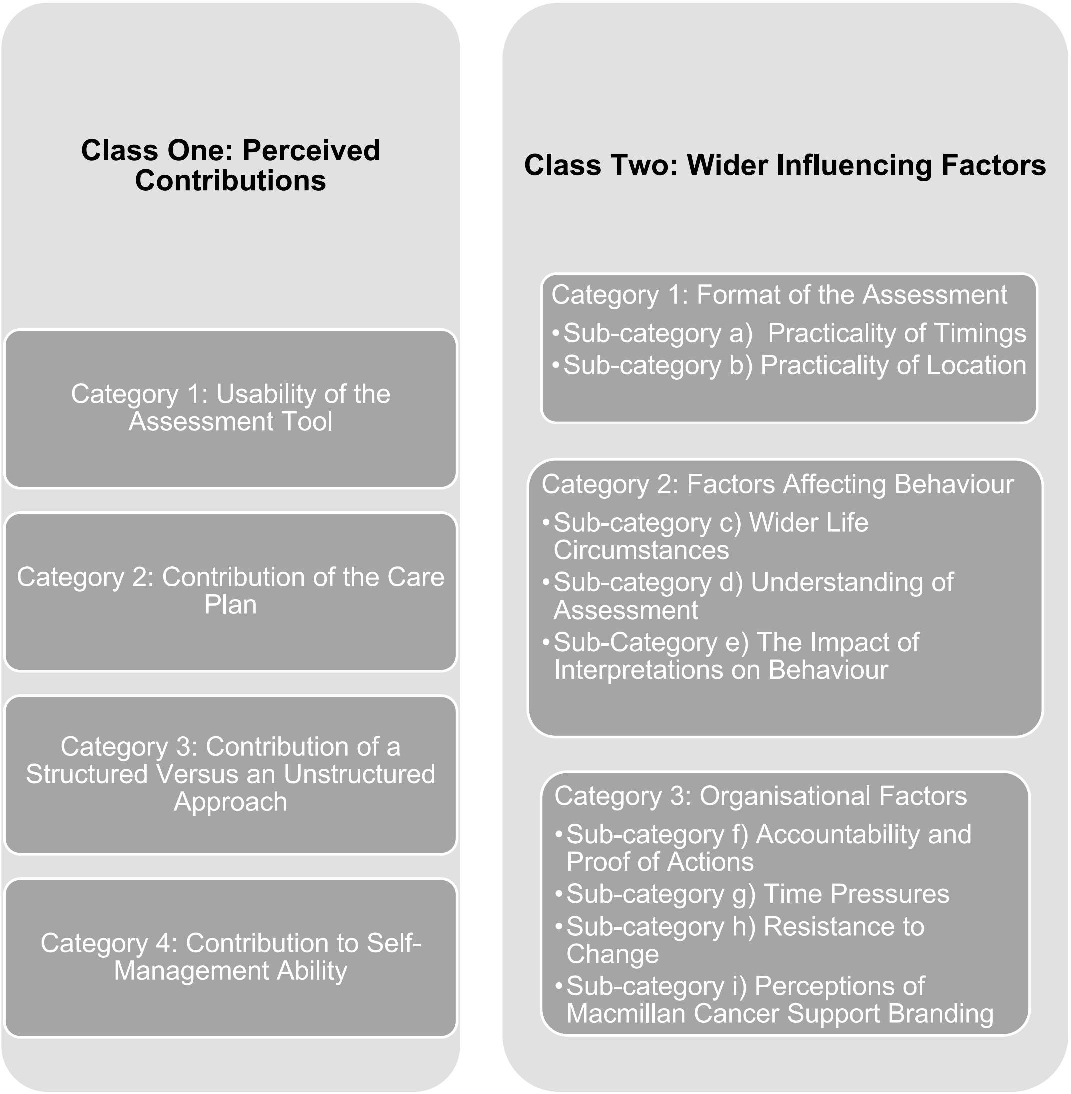
6.1 Introduction

In Chapters Four and Five, a detailed overview of findings was presented to summarise each case. Alternatively, this chapter focuses on the comparison and conclusions drawn between cases. Interview and observational data are compared using the class-category framework created through Framework Analysis (set out in Chapters Four and Five), and a separate care plan analysis is explored. Following this, in-depth integration of findings occurs between cases, including merging of the typological categories and clearer, overarching conclusions for discussion in Chapter Seven.

6.2 Cross-Case Analysis Process

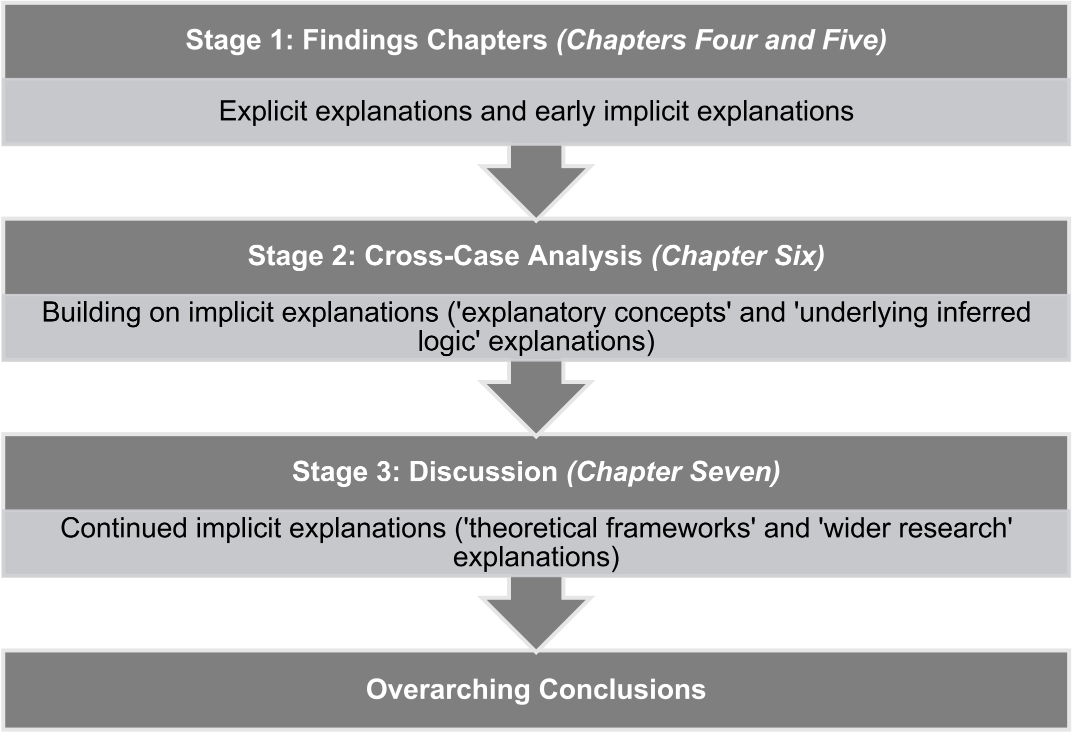
In Chapter Three, Stake's (1995) approach to case studies was described, including the use of techniques to facilitate comparison between cases. For example, 'thematic worksheets' (summaries of findings from each case, organised by common themes) can enable comparison, and support overarching conclusions to be drawn (Stake, 2006). Within this chapter, variations of Stake's (2006) worksheet are adopted (displayed as tables), to show similarities and differences between the cases. Each table represents a sub-category of the class-category framework, where data is already grouped by topic (recapitulated in Figure 73).

Figure 73. Recapitulation of the Class-Category Framework



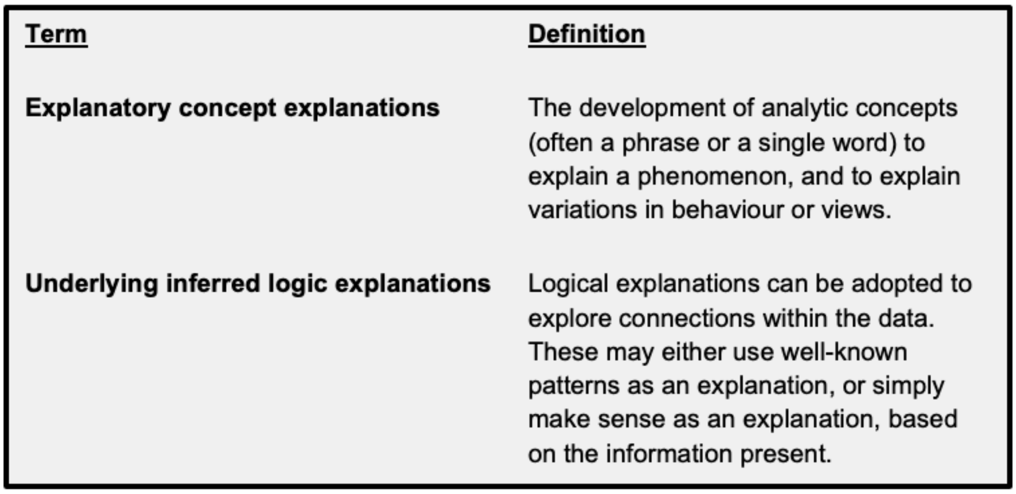
Alongside presentation of these worksheets to compare data between cases, Framework Analysis' 'explanatory accounts' processes are revisited. As part of this, Chapters Four and Five described the three-stage process of exploring 'implicit explanations', which is reiterated in Figure 74.

Figure 74. Presentation of Explanatory Accounts Analysis



Stage 1 of ‘explanatory accounts’ was explored within Chapters Four and Five, by identifying connections between participants in each typological category, using explicit and early implicit explanations. Subsequently, this chapter focuses on building upon these early implicit explanations, using techniques known as ‘explanatory concepts’ and ‘underlying inferred logic explanations’ (defined in Figure 75).

Figure 75. Explanatory Accounts Terminology (Spencer et al., 2013)



Term	Definition
Explanatory concept explanations	The development of analytic concepts (often a phrase or a single word) to explain a phenomenon, and to explain variations in behaviour or views.
Underlying inferred logic explanations	Logical explanations can be adopted to explore connections within the data. These may either use well-known patterns as an explanation, or simply make sense as an explanation, based on the information present.

The above techniques expand upon implicit explanations, and support the identification of overarching study conclusions. Therefore, in Sections 6.3 and 6.4, each sub-category within the class-category framework is discussed through presentation of a table (comparing data between cases), and description of identified ‘explanatory concepts’ and ‘underlying inferred logic explanations’ relating to that sub-category.

6.3 Cross-Case Synthesis: Perceived Contributions (Class One and Sub-Categories)

6.3.1 Usability of the Assessment

Table 35. Comparison - Usability of the Assessment

	Case Study 1 Key Points	**Case Study 2 Key Points**
Women	• The online version of the (e)HNA was viewed positively by many women. • Participants desired a way to elaborate on concerns, suggesting possible issues in the (e)HNA's design.	• Many women felt the (e)HNA was simple to use, but space to elaborate on concerns would be useful. • Women's preferences for format (online, paper) related to wider factors, such as digital skills, location and timing.
Staff	• Staff reported issues with the (e)HNA (overlapping concerns, connectivity issues, non-specificity to breast cancer). • Staff felt women disliked the online format and did not always desire follow-up discussions, but this version was useful for structuring discussions.	• The structure provided by the online (e)HNA was viewed positively by staff, but they felt women would dislike this. • Staff felt that not all concerns were applicable to breast cancer.
Cross-Case Comparison	This sub-category highlighted that the (e)HNA's design was perceived as being somewhat incomplete for those using it. From women's perspective, this was shown through their desire to elaborate on concerns, and for staff this related to the overlapping content and non-specificity to breast cancer. Furthermore, women and staff viewed the online format differently, as most women found this acceptable, but staff were aware of groups of women who found this more difficult.	

Explanatory Concept: Desired value

The concept of ‘desired value’ may further explain views and behaviours of women in the study, as they appeared to desire (e)HNA conversations which were meaningful. For example, completion of the (e)HNA left some participants feeling they wanted to say more than was possible using the questionnaire’s structure. This desire may have existed for several reasons, including feeling that their concerns lay outside the scope of the (e)HNA, or that the terminology used did not fully describe their concerns. These views existed despite the more flexible discussions of concerns which followed a submitted (e)HNA. Therefore, this may indicate that the (e)HNA’s rigidity influenced follow-up discussions. For instance, having been introduced to the (e)HNA in a structured format through the assessment, women may have approached the follow-up conversation in a similarly less flexible way, by expecting that their discussion of concerns was restricted to what they ticked on the assessment.

Inferred Logic Explanations: Suitability of the online assessment

Participants reported varying preferences for the assessment’s format (online or paper versions), which appeared dependent on multiple individual factors. These included confidence in using a computer and the reliability of technology (connectivity issues). Staff acknowledged that the restricted nature of the online version (which did not allow elaboration on responses) was more acceptable to some groups of women than others.

6.3.2 Contribution of the Care Plan

Table 36. Comparison - Contribution of the Care Plan

	Case Study 1 Key Points	Case Study 2 Key Points
Women	• The care plan provided a 'safety net' for women to stay connected to support, a memory aid to undertake tasks, and they felt it would be useful to compare two care plans. However, care plans could be an unwelcome reminder if the interaction raised their expectations.	• Women felt the idea of comparing care plans was useful, and provided a way for them to stay connected to support. • Care plans were a useful memory aid and supported integration of care (with general practitioners) in one case. • Care plans could be negative if they failed to address concerns.
Staff	• Staff perceived little benefit to the care plan, except recording their actions and giving responsibility to women. • Staff felt care plans should be compared throughout the journey (in principle). • Writing care plans was seen as challenging, and there were uncertainties about what was acceptable to write.	• Care plans were not routinely shared, but the idea of comparing these over time was seen as beneficial. • Staff felt care plans were useful as evidence for the actions they took.
Cross-Case Comparison	Women appeared to place more value on the care plan than staff. However, women's views largely related to the idea of the care plan, rather than the actual care plan they received. Despite staff in both case studies acknowledging the care plan's importance for evidencing their actions, they were more positive towards the document in Case Study 2. Many staff (both cases) also discussed practices they viewed as ideal, rather than the reality (for example sharing care plans or comparing them). These variations may suggest challenges with turning the ideal delivery of (e)HNAs into a reality, possibly due to workload pressures, or low prioritisation of this.	

Explanatory Concept: Safety and security

The concept of ‘safety and security’ may partially explain the diverse behaviours and views of both women and staff participants. It is possible that care plans provided encouragement and security to women by demonstrating their progress, allowing them to maintain a connection to support, and providing a failsafe to ensure recommended tasks were not forgotten. However, the care plan (or the idea of this) seemed meaningful as a form of support whether specific supportive referrals were made or not. If the care plan was perceived negatively, this occurred when it was not conducive to support and security. For example, negative perceptions existed when the care plan reminded participants of a consultation where they felt unsupported by staff, or where actions staff had committed to were not completed (therefore rendering the assessment meaningless).

For staff, the same concept of safety and security appeared significant, with the care plan providing a means through which they could be held to account for their actions. This may have led to the style of documentation being more factual, based on the assumption that the care plan may be audited by the organisation, or reflecting how secure staff felt to document sensitive concerns (such as suicidal thoughts). Additionally, the care plan was also viewed as a way to give responsibility to women to act upon recommended tasks, and their compliance could be monitored if desired.

Inferred Logic Explanations: Low prioritisation of the (e)HNA

As the care plan seemed to represent a way of evidencing actions for staff, was not consistently shared (particularly in Case Study 2), and was often written in a matter-of-fact style, this may suggest low prioritisation of the (e)HNA as a supportive intervention. Staff's workload pressures and priorities may have therefore prevented detailed completion of care plans. If evidencing actions was a priority, the style of documentation may be targeted more at staff who may audit the document, rather than the women themselves.

6.3.3 Contribution of a Structured Versus an Unstructured Assessment

Table 37. Comparison – Contribution of a Structured Versus an Unstructured Assessment

	Case Study 1 Key Points	Case Study 2 Key Points
Women	• Women did not consistently understand that the (e)HNA questionnaire and subsequent discussion were connected. • Women's desire for flexibility in methods of assessing concerns (such as in private, or with a member of staff), suggested the need for both the questionnaire and discussion. • Several women had negative views of the (e)HNA.	• Women perceived benefits to both structured and unstructured methods of assessment. • Women felt the (e)HNA allowed more reflection (which sometimes resolved concerns by allowing these to be thought through and moved past). • Completing the (e)HNA at home was useful to avoid staff influencing responses.
Staff	• Few benefits to structured (e)HNAs were noted by staff. • Many felt they assessed concerns in their role, and preferred an unstructured approach.	• All but one staff member felt the (e)HNA contributed something extra to an unstructured conversation (for example, prompting women to raise concerns, providing structure to address these).

	- Some staff felt the (e)HNA could negatively influence the conversation's focus.	- Many had initially negative views of the (e)HNA, which improved once they could see the benefits.
Cross-Case Comparison	Although opinions were divided, a more positive view of the structured (e)HNA was evident in Case Study 2 (women and staff). However, both questionnaire and discussion components of the (e)HNA process were deemed important by most participants, as they had different contributions to providing assessment and support. Furthermore, resistance to the structured (e)HNA appeared stronger in Case Study 1, and there was an undertone of defensiveness in staff comments, for example, how they 'do it anyway'. Resistance from staff in Case Study 2 subsided when the (e)HNA's value was identified.	

Explanatory Concept: Intentions

The concept of 'intentions' was identified from women's behaviours and views in relation to structured (e)HNAs, compared with unstructured conversations. Women felt that the (e)HNA was sometimes simpler to fill in alone without staff present, and this prompted them to raise concerns they were not otherwise comfortable to discuss. For women who wished to avoid revealing their emotional issues, it seemed preferable to have an unstructured conversation rather than an (e)HNA, (which prompted disclosure of concerns). Women's preferences therefore varied according to what they wished to discuss, or whether they intended to avoid discussion of private issues altogether.

Explanatory Concept: Vulnerability

Staff in Case Study 1 expressed resistance to the structured (e)HNA process, and a level of defensiveness was notable in their responses. This related to their belief that they were already undertaking an unstructured version of the (e)HNA in their daily roles. Consequently, the (e)HNA was seen as a threat to their role (by undermining their skills), which was less notable in Case Study 2. These disparities between cases also seemed to be reflected in women's views, as those in Case Study 1 did not express the same degree of reflection and depth in their (e)HNAs as those in Case Study 2.

Inferred Logic Explanations: 'Extra workload'

Considering that staff believed they were routinely undertaking unstructured (e)HNAs, and were documenting this activity in women's clinical notes, the structured approach may have been viewed as an unnecessary addition to their workload (having to complete a care plan alongside the clinical notes), or a duplication of work.

6.3.4 Contribution to Self-Management Ability

Table 38. Comparison – Contribution to Self-Management Ability

	Case Study 1 Key Points	**Case Study 2 Key Points**
Women	• Women appeared to accept responsibility to undertake tasks allocated to them in (e)HNAs.	• Women appeared to accept responsibility to undertake actions from their (e)HNAs. • They expressed a desire to do 'something' to support themselves, including working towards 'small goals'.
Staff	• Staff allocated responsibility to women to act upon recommendations made in their (e)HNAs (and could use these to hold them to account), which was facilitated by the care plan.	• Action plans identified through the (e)HNA were used to give responsibility to women, but staff were unsure if action plans were actually followed by women.

Cross-Case Comparison	Most staff and women agreed that the idea of allocating tasks to women enabled them to self-manage. Staff seemed to view the care plan document as enabling them to hold women responsible for undertaking recommended actions (more prevalent in Case Study 1). However, this did not occur in reality, and most staff were unsure of whether tasks were actioned or not. This may suggest a greater focus on delegating responsibility than ensuring action plans were followed.

Explanatory Concept: Control

In relation to the explanatory concept of ‘control’, women appeared to desire an active role in their (e)HNAs (such as the desire to be given small tasks they could work towards themselves). Additionally, completing small tasks seemed to give women some control over improving their wellbeing, and many women placed importance on the recommendations made to them.

Explanatory Concept: Delegation

Many staff appeared to perceive the allocation of tasks in the (e)HNA as a means to delegate responsibility to women. This view was more prevalent in Case Study 1, where staff described that the care plan enabled a concrete way to hold women responsible for completing tasks, if they chose to follow this up. However, the fact that staff rarely checked to see if actions had been undertaken suggests that the focus was more on delegation, as opposed to ensuring recommendations were followed-up. This delegation may suggest that despite completing (e)HNAs, achieving meaningful outcomes may not always be staff’s priority. For example, the (e)HNA process suggests that concerns should be ‘addressed’. Therefore, delegating this responsibility to women may be seen as a way of addressing them, in the same way that referrals are passed on to other healthcare professionals. Although these concepts were less prevalent in Case Study 2's data, the task-orientated emphasis (focusing on the completion of tasks as a measure of success) (Collins Dictionary, 2021) was still evident through the style of care plan documentation in some cases. For example, staff covered various angles by explaining how each concern was resolved, and stating that the woman was happy with the outcome.

Inferred Logic Explanations: Reduction in workload

The act of delegation or shifting responsibility onto women or other services to ensure tasks were undertaken, may demonstrate staff's desire to reduce their workload. If they felt obliged to 'address' concerns, shifting responsibility to someone else showed that they had acted. This may have influenced how concerns were addressed in some cases.

6.4 Cross-Case Synthesis: Wider Influencing Factors (Class Two and Sub-Categories)

6.4.1 Practicality of Timings

Table 39. Comparison – Practicality of Timings

	Case Study 1 Key Points	Case Study 2 Key Points
Women	• Women felt diagnosis was an unsuitable time to do (e)HNAs, and that gaps between treatment or appointments would be better times, as they allowed space for engagement.	• Most women did not complete the (e)HNA at diagnosis, but speculated that this would be a suboptimal time to do this.

		- Women saw in between treatments or appointments as a better time.
Staff	- Staff felt diagnosis was an unsuitable time to do (e)HNAs. - There was no consensus on what the best time was.	- Staff felt diagnosis was an inappropriate time to offer (e)HNAs, and the team had changed timings based on this view. - There was no consensus about when the right time was.
Cross-Case Comparison	All participants (staff and women) agreed that diagnosis was an unsuitable time to complete the (e)HNA. However, there was a difference in the response to this between the cases. Staff in Case Study 1 continued to offer the (e)HNA at diagnosis, whereas staff in Case Study 2 changed their practice in response to their experience.	

Explanatory Concept: State of mind

'State of mind' was identified as an explanatory concept to represent women's views, relating to their perceived ability to cope, and their willingness to genuinely engage with the (e)HNA. Women's state of mind appeared to influence their preferences around (e)HNA delivery, for example, preferring these while waiting for results and in gaps between appointments (rather than adjacent to other appointments). On the one hand, this preference may have arisen because women felt they were experiencing more concerns at these times (for example, increased anxiety due to waiting), or that they could reflect on their concerns more thoroughly when they were not otherwise distracted. These possibilities suggest that women saw value in undertaking (e)HNAs, based on their apparent wish to fully engage with and gain support from them. Therefore, the (e)HNA's contribution may have been perceived as more positive if completed at more valuable time points.

Explanatory Concept: Desire for direction

From a staff perspective, ‘desire for direction’ was identified as an explanatory concept. Staff had views of what the ‘wrong’ time to offer the (e)HNA was, but they were unsure about the right time. Accordingly, other means were used to decide these timings, including recommendations in local/national targets, or practical considerations such as reducing hospital trips by conducting (e)HNAs adjacent to an existing appointment (despite women preferring separate interactions). Although all staff participants indicated that diagnosis was the wrong time to complete (e)HNAs, Case Study 2 staff appeared more ready to change this. This may have been a result of management support for frontline staff to decide best use of the assessment, or the more positive view of the (e)HNA at Case Study 2 may have made it easier to refine the process.

Inferred Logic Explanations: Variability in timings

Differences in timing preferences may have occurred among women due to differences in their background, priorities, and level of concern at the time (for example, if women felt they had few support needs, an extra hospital trip may have been perceived as burdensome).

6.4.2 Practicality of Location

Table 40. Comparison - Practicality of Location

	Case Study 1 Key Points	Case Study 2 Key Points

Women	- There was no consistency in preferences for face-to-face or home (e)HNAs. - Views of telephone assessments were less positive, or neutral.	- There were no consistent preferences for location, but many women outlined benefits to the home format, and potential barriers to disclosing concerns over the telephone. - Factors such as confidence to complete (e)HNAs alone appeared to influence preferences.
Staff	- Staff held no consistent preferences for where to conduct (e)HNAs. - Many benefits to telephone methods were noted (for example, avoiding embarrassing issues and extra journeys).	- Staff viewed home-based (e)HNAs positively. - They acknowledged barriers in the telephone format (for example, causing non-disclosure), yet also recognised the burden of adding hospital trips.
Cross-Case Comparison	No participant groups had consistent preferences for location of (e)HNAs, however the telephone format was viewed less positively by women overall. The benefits of home assessment were more clearly noted among Case Study 2 staff, whereas Case Study 1 staff appeared to view telephone (e)HNAs as more beneficial.	

Explanatory Concepts: Self-assurance

The explanatory concept of ‘self-assurance’ was useful in understanding behaviours. For example, desiring or avoiding the presence of staff when completing (e)HNAs, or understanding why certain factors were related to the disclosure of concerns. Although no consistency was found in preferences for (e)HNA locations, value was seen in the privacy provided by conducting assessments at home. Women's preferences also changed depending on their needs. For example, those who felt they had sensitive issues seemed to prefer a telephone option, and those with higher numbers of emotional concerns appeared to feel the home environment left them vulnerable, without immediate access to support.

Explanatory Concept: Desire for direction

There was minimal consensus in staff perspectives about the best venue for undertaking (e)HNAs. If staff were uncertain about women's preferences, decisions about location appeared determined by practicalities (such as the simplicity of telephone discussions, which were reportedly shorter than face-to-face conversations, would avoid additional journeys, and could be scheduled into a support worker's (SW) free time).

Inferred Logic Explanations: Individual differences

As with timings, location preferences could be explained by individual differences and circumstances between participants. Staff members' thoughts about the practical aspects of where to deliver (e)HNAs appeared to focus on workload reduction, which was evidently a priority for many of them. SWs for example, could be more flexible around location, as they had more time for (e)HNAs than staff in other roles typically did.

6.4.3 Understanding of Assessment

Table 41. Comparison - Understanding of Assessment

	Case Study 1 Key Points	Case Study 2 Key Points
Women	• Some women were unsure of the (e)HNA's purpose, which led to non-completion in some cases. • Verbal introductions to the (e)HNA contributed to women's expectations or assumptions, and many felt compelled to complete it.	• Some women felt compelled to complete (e)HNAs. • Expectations of the (e)HNA's outcome varied, but some had a good understanding of its purpose.
Staff	• Staff felt women lacked understanding of the (e)HNA, because they raised concerns irrelevant to cancer. • Some staff lacked confidence to address non-cancer related concerns. • Staff received brief training for the (e)HNA and perceived this negatively. • Some felt compelled to complete the (e)HNA, but the few who conducted further reading became more supportive of this.	• Staff reported initially negative opinions of the (e)HNA (due to lack of understanding and poor introductions), but these improved as a result of reflection and use. • There were mixed views on how concerns should be addressed. • Staff felt women were unsure about which concerns to raise in (e)HNAs, as many concerns were unrelated to cancer.
Cross-Case Comparison	Some women described feeling compelled to complete (e)HNAs, a view more commonly noted in Case Study 1. Expectations or understanding of the (e)HNA's purpose varied among participants in both cases, however Case Study 2 women expressed greater understanding. All staff reported initially negative views of the (e)HNA and feeling compelled to complete it, but this lessened in those who did further research into understanding it (more commonly seen in Case Study 2). Staff had different views of what type of concerns should be raised, compared with women.	

Explanatory Concept: Making sense

The concept of 'making sense' is used to describe women's individual interpretations of the (e)HNA. These may be determined by personal beliefs and circumstances which led to assumptions (for example, previously encountering the word holistic in relation to alternative therapies, and assuming the (e)HNA was connected to this). Women also highlighted gaps in their understanding of how to complete the (e)HNA ‘correctly’, showing a desire to undertake the assessment in the way staff intended. This was supported by data from three observations in Case Study 2, where women appeared to check what counted as a concern and apologised for having raised a few of them. In the absence of direction from staff, women created their own interpretations of the right way to complete the (e)HNA, which often came from their expectations (such as thinking they should raise concerns, rather than leaving sections blank).

The same explanatory concept applied to staff data, where the lack of understanding apparent during their introduction to the (e)HNA influenced their feelings towards it. For example, feelings of resistance seemed to result if staff interpreted the (e)HNA as a duplication of their work, or a threat to their jobs (found more commonly in Case Study 1). A more positive interpretation appeared to develop if staff researched and more fully understood the (e)HNA, which may suggest that this negativity stemmed from the brief introduction to the assessment they received.

Inferred Logic Explanations: Impacts of poor understanding

Perceptions of the (e)HNA were more negative when women did not understand the tool’s value. For instance, if the way it was introduced to the women implied that it was compulsory, this could influence their perceptions of its value. Furthermore, the greater understanding of the (e)HNA noted among Case Study 2 women may have resulted from more of them undertaking a second (e)HNA. If understanding of the (e)HNA increased when a second one was completed, this may suggest that the initial introduction to it was inadequate, and therefore clarity only increased after completion of two.

6.4.4 The Impact of Interpretations on Behaviour

Table 42. Comparison - The Impact of Interpretations on Behaviour

	Case Study 1 Key Points	**Case Study 2 Key Points**
Women	• Reasons for non-disclosure of concerns existed (such as fear (e)HNA outcomes, for example, being drawn away from caring responsibilities). • Women perceived what was acceptable or expected of them from staff in relation to the (e)HNA. • It was sometimes easier to do (e)HNAs with a 'stranger' online, but a relationship was beneficial for openness.	• Staff presence affected women's openness in some cases (for example, withholding concerns due to understanding staff's workload pressures) • Having a pre-existing relationship with staff could be both positive and negative when disclosing concerns.
Staff	• Staff felt women could withhold concerns on (e)HNAs due to the presence of staff. • An existing relationship with the woman was seen as beneficial. • There was recognition that (e)HNA scores helped to gauge priorities but were subjective.	• Staff felt women withheld some concerns, and an existing relationship facilitated openness. • Staff viewed scores as useful to prioritise concerns, but were subjective and therefore should not be considered as the sole determinant of recommendations made.
Cross-Case Comparison	Participants from both cases acknowledged that the presence of staff may affect disclosure of concerns in (e)HNAs. The staff-patient relationship was deemed important by most participants, but some women indicated a preference to discuss concerns	

with a person they did not know. Scores were subjective, but were useful in the prioritisation of concerns providing the (e)HNA had been completed honestly.

Explanatory Concept: Priorities

Women's perceptions about disclosure of concerns in the (e)HNA appeared influenced by their 'priorities', including their own familial caring responsibilities, how they felt they might be perceived (or judged) by staff, or their sense of empathy with staff. This suggests that women felt their priorities were different to those of staff, and that they might be viewed negatively for disclosing concerns (adding to their workload, or their concern being perceived as low priority). Many women indicated feeling vulnerable about disclosing concerns, which they responded to in different ways (either increased openness when a relationship existed with staff, or preferences to disclose concerns anonymously). These views also seemed to affect the way women allocated scores to concerns, for example by choosing mid-point numbers so as to not appear too extreme. Scores appeared more useful for prioritising the severity of one individual's concerns, than for comparing one person's scores to another's.

The factors influencing disclosure of concerns were also recognised by staff. (e)HNAs provided a structure for prioritising concerns, but the value of this depended on how open women were, and how they formulated their responses. For example, during one observation (Case Study 2), the breast care nurse (BCN) attempted to structure a consultation around the concerns which the (e)HNA had placed into priority order. However, the woman revealed significant underlying issues (from previous traumatic experiences), and she viewed the various concerns raised as side effects or behaviours which stemmed from this (for example overeating behaviours and emotional concerns).

Therefore, the concerns highlighted by the (e)HNA were in a sense only a snapshot, and were exacerbated by a greater underlying issue. Once this became apparent, the staff member did not use the (e)HNA to structure the conversation. The differences in (e)HNA 'cut-off scores' for addressing concerns may also reflect what each case study perceived as important factors to support women. In Case Study 1, cut-off scores determined which staff member attended to the concerns (SW or BCN), and in Case Study 2, they influenced the type of consultation (face-to-face or telephone).

Inferred Logic Explanations: Subjectivity of answers

When considering interpretations and scoring, it is foreseeable that participants viewed the scoring system differently to reflect the severity of their concerns (based on the individuality of perceptions). Women's variations also differed from those of staff, who often interpreted concerns in a different way, based on their own understanding of severity in making clinical judgements.

6.4.5 Accountability and Proof of Actions

Table 43. Comparison - Accountability and Proof of Actions

	Case Study 1 Key Points	**Case Study 2 Key Points**
Staff	• The care plan was viewed as useful for proving actions taken (evidence and defence if challenged). • Staff sometimes felt uncomfortable sharing information with other staff, or	• Staff felt assessments did not 'exist', without documentation. • They felt they could not comment openly on care plans, as women could read what they had written.

	the woman completing the (e)HNA.	• There was a desire to protect ‘intimate details’ of conversations from other staff.
Cross-Case Comparison	• There was consensus that the care plan had value as a source of evidence, but reluctance to share it was apparent in both case studies.	

Explanatory Concept: Safety and security

As described in Section 6.3.2, staff used the care plan to demonstrate that they had responded to women’s needs, and rarely shared care plans. This prioritisation of proving actions and acting ‘correctly’ was also apparent in two observations (Case Study 2). In these, addressing concerns appeared to be guided by only the concerns raised on the assessment, despite the women either verbally indicating they had additional concerns, or stating that the ones they had ticked were not genuine issues. Therefore, staff may have felt obliged to address the concerns which had been formally declared, even if this was of little benefit to the woman. There also seemed to be differences in who staff felt accountable to, whether this was an employer (Case Study 1), or the women themselves (Case Study 2).

Inferred Logic Explanations: Type of documentation

If staff saw the purpose of care plans as a way to show they had acted appropriately in response to women’s concerns, this may explain why these were sometimes written in a similar format to clinical documentation (factual and containing medical terminology). The wording of care plans is explored in Section 6.5.

6.4.6 Time Pressures

Table 44. Comparison- Time Pressures

	Case Study 1 Key Points	**Case Study 2 Key Points**
Staff	• Lack of time affected staff's ability to achieve targets. • Targets were perceived as burdensome but also necessary in hospitals. • SW roles were essential for achieving targets, as they were 'championing' roles.	• Time pressures affected staff's ability to follow up (e)HNAs. • Targets often affected the quality of these but were recognised as necessary. • 'Championing' roles such as SWs were deemed key in achieving targets.
Cross-Case Comparison	The views from both cases about pressures, targets and 'championing' roles were consistent. However, references to these were more common in Case Study 1.	

Explanatory Concept: Resignation

The concept of resignation was adopted to encompass staff behaviours and views. It reflects staff's acknowledgement that time pressures combined with targets negatively impacted their ability to undertake (e)HNAs. However, targets were accepted as necessary to drive implementation. This suggests that the issue may be the targets' focus, rather than their existence (for example focusing on quantifying (e)HNAs rather than the quality). In some cases, staff responses indicated that targets were viewed as more important than high-quality (e)HNAs (primarily Case Study 1). Furthermore, the continued need to drive the (e)HNA's use implied that many staff viewed it as a low priority, which needed encouragement due to their lack of enthusiasm.

Inferred Logic Explanations: Time pressures affected quality

The focus of local/national targets recommending that each individual was offered an (e)HNA (therefore creating the need to conduct significant quantities of these), inevitably increases time pressures on staff. Therefore, the need to produce high quantities of (e)HNAs appeared to hinder their quality.

6.4.7 Resistance to Change

Table 45. Comparison - Resistance to Change

	Case Study 1 Key Points	**Case Study 2 Key Points**
Staff	• Many staff expressed resistance to the (e)HNA, for reasons such as lack of confidence, feeling they were already undertaking assessments, and lack of sustainability from seeing similar assessments come and go.	• Resistance was mainly in the early stages of (e)HNA implementation (due to factors including feeling they were already undertaking assessments, lack of understanding, feeling compelled to conduct (e)HNAs). • This resistance largely resolved.
Cross-Case Comparison	Reasons for resistance among staff were similar across cases, but this persisted longer in Case Study 1 than Case Study 2.	

Explanatory Concept: Investment

‘Investment’ was used to represent staff members’ resistance to the (e)HNA, which was more persistent in Case Study 1 than Case Study 2. Although some key reasons for this were common to both cases (such as feeling they were doing (e)HNAs anyway, inadequate training), there appeared to be a focus on sustainability in Case Study 1, where staff had seen similar interventions come and go, and they felt a lack of genuine investment in the latest version.

Inferred Logic Explanations: Cultural variations

The fact that over time, resistance largely resolved in Case Study 2, this suggests a difference in culture between the cases. There may be a number of reasons for this, including staff's apparent greater involvement in decision-making regarding (e)HNAs in Case Study 2, and a more collaborative approach adopted by the management team, which may have enabled better engagement.

6.4.8 Perceptions of Macmillan Cancer Support Branding

Table 46. Comparison - Perceptions of Macmillan Cancer Support Branding

	Case Study 1 Key Points	Case Study 2 Key Points
Women	• Comments from women indicated primarily positive views of the charity.	• Women did not discuss opinions of Macmillan Cancer Support.
Staff	• Staff felt women associated Macmillan Cancer Support with death and dying. • The team had negative views of the charity.	• Staff felt women saw the charity as centred on death and dying, and that women may not wish to share their data with Macmillan Cancer Support.

		- Staff themselves did not appear to have negative views of the charity.
Cross-Case Comparison	Staff perceptions of what women thought did not reflect women’s own views of Macmillan Cancer Support. There also appeared to be a culture within Case Study 1 that impacted staff resistance towards Macmillan Cancer Support and (e)HNAs. This was not present in Case Study 2.	

Explanatory Concept: Symbolism

Staff felt that public perceptions of Macmillan Cancer Support were an association with death and dying. However, staff in Case Study 1 also reflected a poor opinion of the charity, whereas staff at Case Study 2 were complimentary of the charity and its work. Staff members’ views were sometimes carried over into their encounters with women, based on how they expected women to view the (e)HNA. For example, during two observations (Case Study 2) women were informed that Macmillan Cancer Support would not receive their personal information. This may have been made clear because staff wanted to distance themselves from what the charity symbolised, and did not want to cause fear within women (if they made an association with death and dying, or disliked the charity).

Inferred Logic Explanations: Varied opinions

Considering each woman’s experience of their cancer journey, their expectations and the support they received, it is unsurprising that their views of Macmillan Cancer Support may be variable. Therefore, staff were likely to have encountered various women’s views towards the charity, which may have shaped their opinions if some of these were negative.

6.5 Cross-Case Synthesis: Care Plans

The central research question for the thesis focuses on how the (e)HNA contributes to the assessment and support of women's holistic needs. However, when considering the matrices of data created through Framework Analysis processes, many interview comments highlighted traits of (e)HNA care plans which appeared to influence their contribution in supporting women needs. Although some of these examples are highlighted through the above discussion of the class-category framework, this was given a separate focus within this chapter. In the Framework Analysis 'explanatory accounts' process, Spencer et al., (2013) permit the occasional use of quantitative data to facilitate the identification of explanations. Therefore, this section presents a list of perceived strengths, weaknesses and important features of care plans. Each feature was raised by at least two participants (a combination of staff and women) in their interviews. From this list, each care plan collected for the study was analysed to quantify how many contained these strengths and weaknesses. This process aimed to describe what participants felt were important features, but also to provide some level of explanation as to why care plans may have been viewed as useful or unhelpful by participants, based on their quality. Furthermore, consideration was also given to which groups of staff completed care plans most often, and the number of recommended actions.

Within Case Study 1, 14 care plans were analysed, and 19 from Case Study 2. Of these, n=10 (72%) care plans in Case Study 1 were completed by a SW (n=4 28% by a BCN), compared to only n=7 (38%) in Case Study 2 (n=12, 62% were completed by a BCN, radiographer or radiotherapy nurse). Overall, in Case Study 1, SWs created more care plans with actions for staff to undertake than for women (n=6 (43%) staff actions, and n=3 (21%) women's actions), whereas BCNs assigned more tasks to the women (n=6, 43%), but no care plans included actions for staff to undertake. The absence of staff actions on BCNs' care plans may relate to previous discussions, such as a desire to reduce their workload, or the focus on encouraging women's self-management in care plans. There was no consistency in task allocation based on staffing roles in Case Study 2.

Within the care plans, similar positive and negative features were reported in participants' interviews across both cases, shown in Sections 6.5.1 and 6.5.2.

6.5.1 Perceived Strengths of Care Plans

Within interviews, nine strengths of either the care plan document or the care planning process (such as the benefits of completing it even if the woman had few concerns) were identified as important by participants. Of these nine characteristics, seven related to the care plan document (numbers 1-7 below), and two for the care planning process.

1. Allocating small goals for women to undertake was useful.
2. Reassuring, supportive comments were useful.
3. Women liked care plans to be personalised, such as using their name.
4. It was important to women that descriptions of concerns were articulated well but were not excessively lengthy.
5. Clearly documented answers to questions asked, or recommended actions were useful.
6. Diverse support options were useful (multiple recommendations to suit their needs).

7. Open offers of support were appreciated (contact details and permission to request further support when needed).
8. Reviewing their progress over time was useful, so using a previous care plan to go through a new one was beneficial.
9. The care plan enabled women to feel they were entering a ‘safety net’ of care, so completing a care plan was useful even if they had very few needs or recommended actions.

The care plans collected for the study were then reviewed to ascertain the frequency of how often these features appeared (Table 48).

Table 47. Number of Care Plans containing Strengths

Strengths	Case Study 1	Case Study 2
Allocation of tasks to women	9	8
Supportive comments	4	3
Personalisation	11	11
Descriptive (but not excessively so)	1	3
Clearly documented responses to questions/ actions	3	5
Diverse options of support	0	2
Open offer of support	0	1

Overall, the strengths most frequently identified in the care plans were allocation of tasks to women, the use of supportive comments, personalisation of care plans by using the woman’s name, and clearly documented responses to questions.

6.5.2 Perceived Weaknesses of Care Plans

Eight features were deemed undesirable to appear in care plans, listed below. Two of these connect to the process of care planning as opposed to the document itself (such as when the care plans were not received by women), which are numbers 7-8. As with the identified strengths, Table 49 highlights the six undesirable care plan features (numbers 1-6 below), and how many of the study's care plans reflected these traits.

1. Acronyms and medical terminology were unhelpful, and may suggest that healthcare professionals were the target audience of the care plan.
2. It was undesirable when the care plan's intended structure was not adhered to (such as discussion of multiple concerns under a single heading, or recommended actions written in the 'description' box).
3. It was undesirable for highly personal or sensitive information to be written on a care plan.
4. Lack of detail in the care plan was unhelpful if answers and recommendations were summarised very briefly.
5. Duplicated information was unhelpful (paragraphs or phrases repeated across a number of concerns).
6. Spelling or grammar issues were undesirable.
7. When staff documented actions they would undertake, and this did not happen, this was unfavourable and sometimes caused disappointment.
8. Many women who wished to receive their care plans did not receive them.

Table 48. Number of Care Plans containing Weaknesses

Weaknesses	**Case Study 1**	**Case Study 2**
Acronym/Medical Terminology Used	6	4

Structural Issues	3	4
Inappropriate content disclosed	1	2
Lack of detail	2	1
Duplicated information	2	2
Spelling or grammar issues	1	4

The most common limitations within care plans were acronym/medical jargon use, structural issues (where content was documented under incorrect headings on the care plan) and spelling/grammar issues. Use of acronyms/jargon was more common in Case Study 1 (n=6, 43% of care plans) than in Case Study 2's (n=4, 21% of care plans). This may support previous findings about how little value was placed on the (e)HNA's contribution to women in Case Study 1, and staff's tendency to focus on target adherence and accountability.

Despite the different opinions expressed by Case Study 1 and Case Study 2 staff, there were many similarities in the strengths and weaknesses of care plans between cases. Case Study 2 appeared to have higher numbers of these features in some cases, but these differences were likely to occur because more care plans were analysed (19 as opposed to 14 in Case Study 1). There were noticeably more limitations in the care plans across both cases than positives, and no one care plan included all seven strengths. A breakdown of this care plan analysis is presented in Appendix T.

6.6 Integration of Findings

6.6.1 Comparison Between Care Plans and Key Findings

For some women in the study, they received their care plan in the post, and others read the document for the first time during their research interview. The limitations identified above may help to explain why the (e)HNA (particularly the care plan aspect) was thought to make little contribution to women's experiences of support, why it sometimes acted as a reminder of the negative impact of a consultation, or why some participants felt it existed to 'tick a box' by ensuring each concern had some comment against it (even if it was the same phrase each time). Furthermore, lack of detail and a written style that was not appropriate for a lay audience may have led women to value the care plan less, and explain why some simply filed it away when they received it.

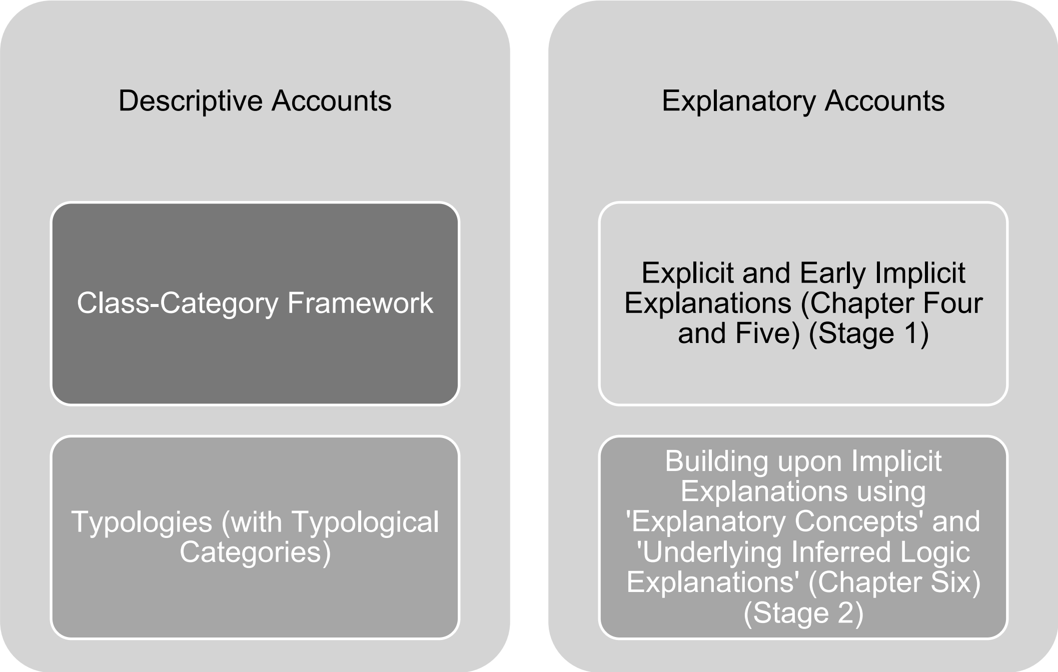
Whilst almost all care plans contained one of the weaknesses highlighted above, positive qualities (such as supportive comments and clearly documented actions) may explain the level of importance some women gave the document and the tasks assigned to them (particularly in Case Study 2). However, detailed comparison between the two cases is difficult, because although Case Study 2 adopted some positive styles of documentation not found in Case Study 1 (such as providing a wide range of options for support and an open offer of support whenever required), more women from Case Study 2 reported having never received their care plan. If Case Study 2 staff primarily intended care plans to be a means of evidencing their own practice (rather than sharing these with women), this may help to explain why six care plans contained no recommended actions at all, and were structurally inconsistent with the care plan's template. A greater percentage of care plans in Case Study 1 contained supportive comments (n=4, 29% versus n=3, 16% in Case Study 2), which is interesting considering that staff at Case Study 1 appeared to value the (e)HNA less than Case Study 2, but clearly expected women to read them.

Following care plan comparison across cases, integration of findings revisits the ‘typological categories’ (groupings of participants identified through Framework Analysis) (Spencer, et al., 2013) discussed in Chapters Four and Five.

6.6.2 Integration of Explanatory Accounts: Stage 1 and Stage 2

So far, this chapter has begun to combine the findings from each case across several aspects of Framework Analysis, in areas of ‘descriptive accounts’ and ‘explanatory accounts’. As a recapitulation of these processes, Figure 76 highlights the primary outputs from ‘descriptive accounts’ (creation of a class-category framework and typologies), and how explanations are developed through ‘explanatory accounts’ (explicit and implicit explanations).

Figure 76. Recapitulation of Framework Analysis processes (Spencer et al., 2013)



In Chapters Four and Five, ‘typological categories’ were used for Stage 1 of ‘explanatory accounts’ analysis. Within this chapter, Stage 2 of explanatory accounts includes several elements. Firstly, Sections 6.3 and 6.4 used ‘explanatory concepts’ and ‘underlying inferred logic’ to determine explanations in each component of the class-category framework. Secondly, the next section provides further integration of findings by combining each case’s typological categories. Thirdly, overall insights from this chapter are then used to create a summary of factors which influence the (e)HNA’s contribution to women’s experiences of support, and a staff perspective on this.

In summary, the elements of this chapter a) display the similarities and differences between cases around key subjects (within the class-category framework, and care plan analysis) b) provide an overall picture of shared views, characteristics and behaviours which exist between groups of participants (typological categories), and c) use these insights to develop a summary of overarching conclusions.

6.6.2.1 Integration of Typological Categories

Beginning with women, participants in both case studies fit into a total of five typological categories, shown in Figure 77.

Figure 77. Women with Cancer - Typological Categories Cross-Case

1. "Positive in Principle" (10 women)

- The (e)HNA's use and delivery process is positive 'in principle', but there was little or no contribution from this to the overall experience.

2. "Paradoxical Experience" (5 women)

- The (e)HNA's use and delivery process is positive 'in principle', but had a negative contribution to the overall experience.

3. "Comprehensively Positive Experience" (4 women)

- The (e)HNA's use and delivery process is positive, and its contribution to the overall experience was mostly positive.

4. "Predominantly Positive Experience" (3 women)

- The (e)HNA's use and delivery process is mostly positive, but the contributions to the overall experience were both positive and negative.

5. "Disconnection" (2 women)

- The process of (e)HNA was not engaged with, and had no contribution to the overall experience.

Despite the overall more negative view of the (e)HNA reported by women in Case Study 1, the typological categories identified were similar across both case studies. The category that contained the most women was those who saw the (e)HNA’s potential, but felt it had little to no impact on their experience of support (n=10, (42%), seven from Case Study 1 and three from Case Study 2). The second largest category was those who saw the (e)HNA’s potential but had a negative experience (n=5, 21%, three from Case Study 1 and two from Case Study 2). The third and fourth categories were made up of entirely Case Study 2 participants, who reported either mostly or comprehensively positive experiences of the (e)HNA. The final category contained only participants from Case Study 1, who did not engage with the (e)HNA.

Overall, despite the negative experiences of some women, all participants who completed their (e)HNA (n=22, 92%) felt that the (e)HNA’s delivery processes were positive ‘in principle’, even if the reality did not always live up to an ideal portrayal of this.

From a staff perspective, more variations were noted in the typological categories between Case Study 1 and Case Study 2, resulting in a total of six categories, as only one overlapped between the two case studies (Figure 78).

Figure 78. Staff - Typological Categories Cross-Case

1. "Delivery Limitations" (7 staff)
   - The (e)HNA's use and delivery process requires improvements, but has a positive contribution to the overall experience
2. "Comprehensively Positive Expectations" (5 staff)
   - The (e)HNA's use and delivery process is positive, and they perceived that it contributed something positive to the overall experience.
3. "Comprehensively Negative Expectations" (5 staff)
   - The (e)HNA's use and delivery process is negative or has little benefit, and they perceived that it contributed something negative to the overall experience.
4. "Positive in Principle" (3 staff)
   - The (e)HNA's use and delivery process is positive in principle, but there was little or no contribution from this to the overall experience.
5. "Paradoxical Expectations" (2 staff)
   - The (e)HNA's use and delivery process is positive 'in principle’, but they perceived that it contributed something negative to the overall experience.
6. "Predominantly Positive Expectations" (2 staff)
   - The (e)HNA's use and delivery process is positive, and they perceive that it has a positive contribution to the overall experience, but has the potential to also introduce something negative.

Firstly, the category containing the most staff was those who felt the (e)HNA’s delivery process required improvement, despite their perceptions that it contributed something positive to women’s experiences of support (n=7, 29%, all from Case Study 2). Secondly, both ‘comprehensively positive expectations’ (n=5, 21%, two from Case Study 1 and three from Case Study 2) and ‘comprehensively negative expectations’ (n=5, 21%, all from Case Study 1) contained equal numbers of participants. Categories four and five contained only Case Study 1 staff, who felt the (e)HNA was positive in principle, but that it contributed little, or something negative to women’s experiences.

Considering these categories overall, over half of Case Study 1’s staff (n=7, 58%) felt that the (e)HNA contributed something negative to women’s experiences of support, compared with only n=2 (17%) participants in Case Study 2. In both cases, very few staff indicated positive perceptions of the (e)HNA’s delivery processes, with n=12 (50%) viewing this as requiring improvement or negative, and a further n=5 (21%) feeling these processes were positive ‘in principle’, as opposed to the reality they presented.

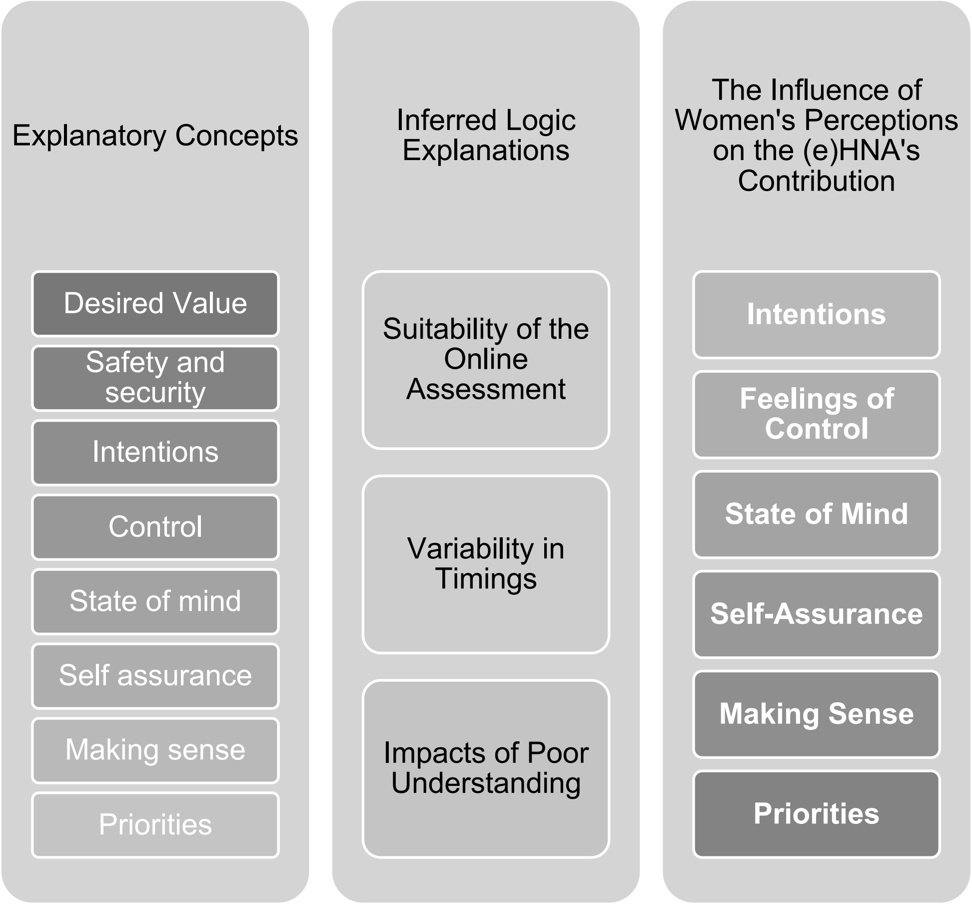
6.6.2.2 Integration of Overarching Findings

Following the integration of typological categories, this is combined with Stage 2 of the ‘explanatory accounts’ process, to generate a summary of key factors which influence the (e)HNA’s contribution to women’s experiences of support.

Key headings derived from ‘explanatory concepts’ and ‘underlying inferred logic’ explanations are displayed in Figure 79, which have been amalgamated to identify six key phrases/words for women, and seven for staff.

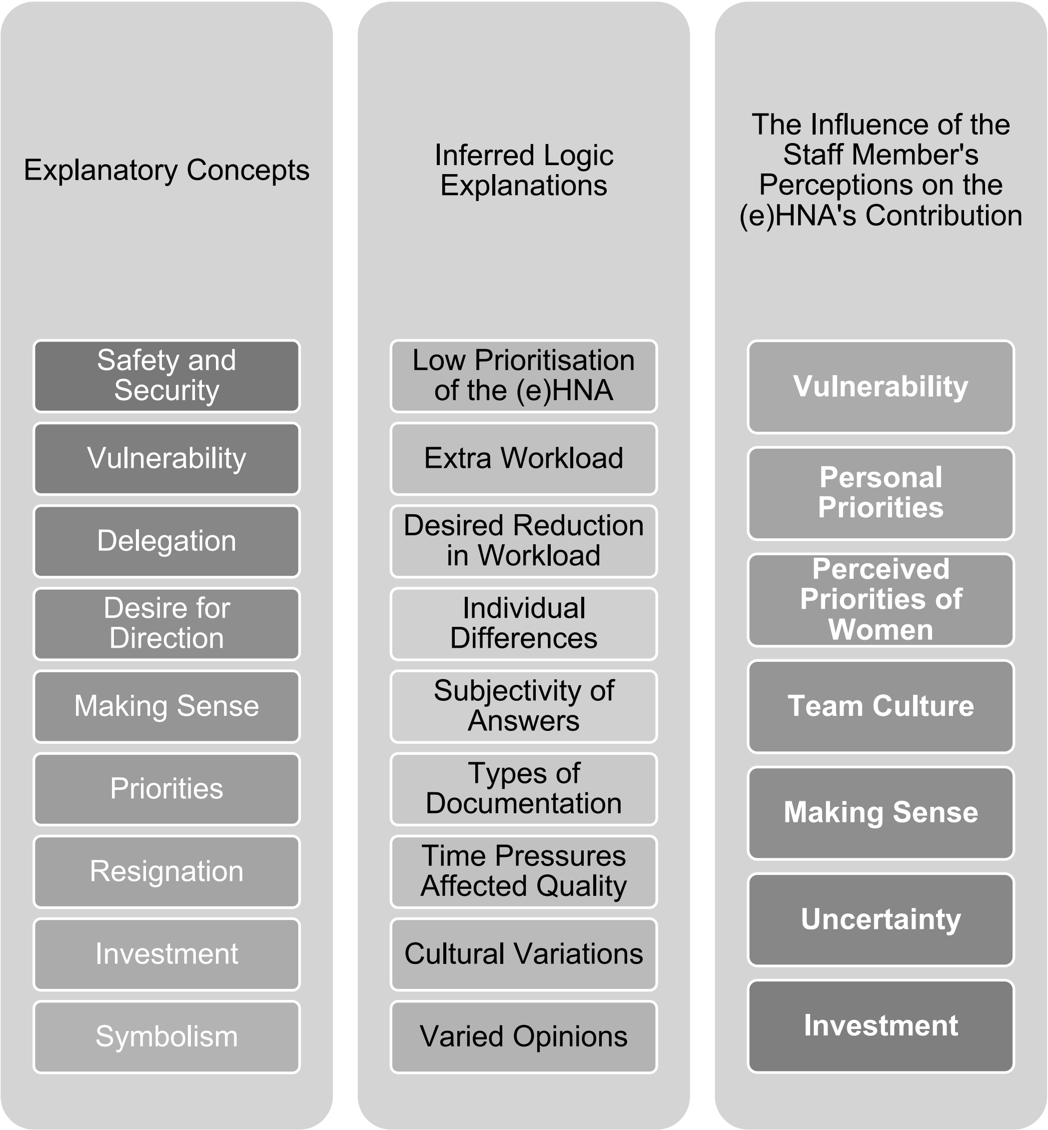
Beginning with women, these expressions represent six factors influencing their perceptions of the (e)HNA’s contribution to their overall experiences of support. As an example of how this was achieved, the previously discussed explanatory concepts relating to women's preferences (such as suitability of the online assessment and variability in timings) were combined under the heading 'priorities'.

Figure 79. The Influence of Women's Perceptions on the (e)HNA's Contribution



The process of identifying key words/phrase was also undertaken to represent staff perspectives on how they perceived and delivered the (e)HNA, and what they felt it contributed to women's experiences of support (Figure 80). As an example of how these seven words/phrases were identified, explanatory concepts such as 'desire for direction' (with when and where to offer (e)HNAs) were amalgamated under 'uncertainty'.

Figure 80. The Influence of the Staff Member’s Perceptions on the (e)HNA's Contribution



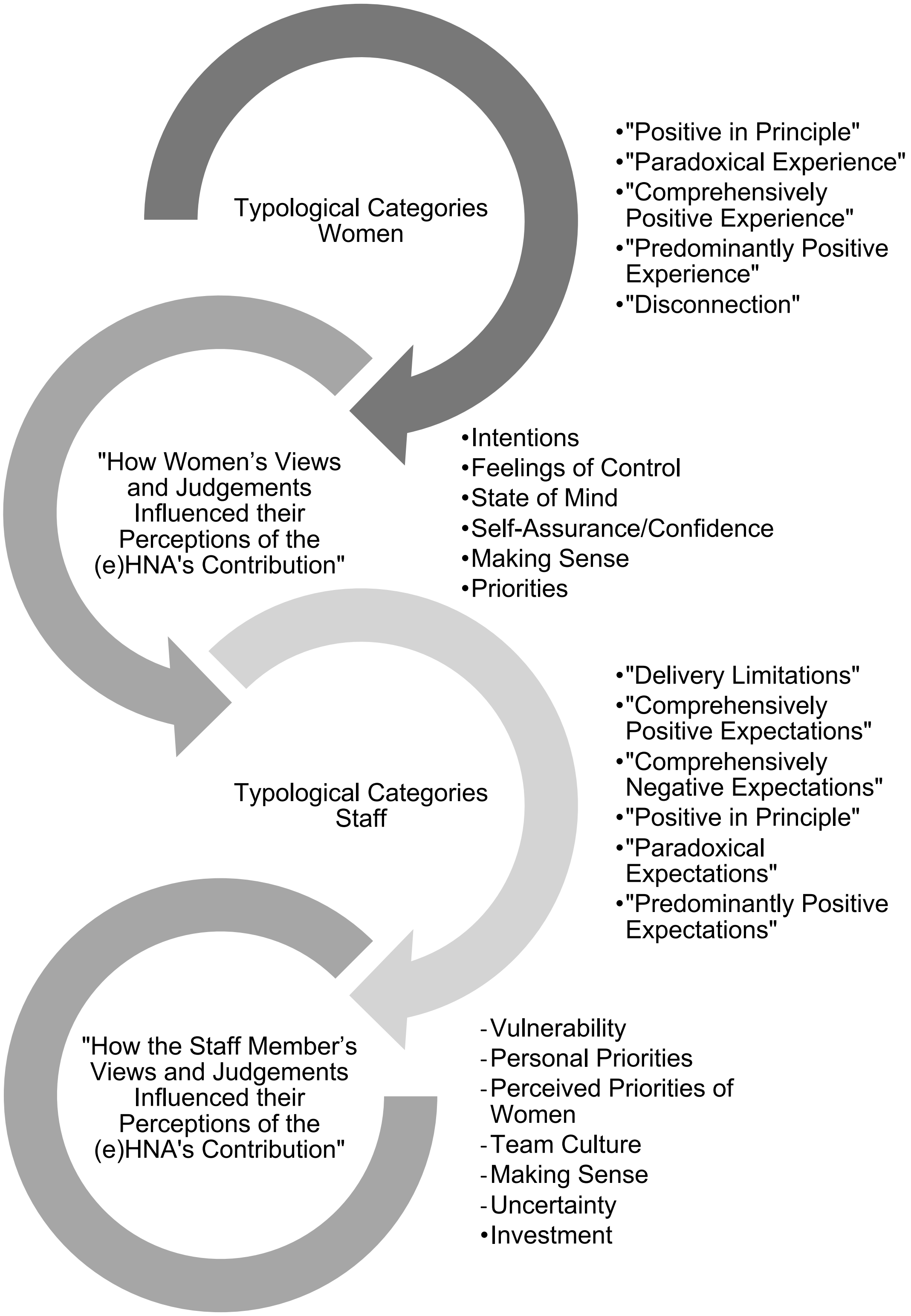
Explanatory Concepts	Inferred Logic Explanations	The Influence of the Staff Member's Perceptions on the (e)HNA's Contribution
Safety and Security	Low Prioritisation of the (e)HNA	**Vulnerability**
Vulnerability	Extra Workload	**Personal Priorities**
Delegation	Desired Reduction in Workload	**Perceived Priorities of Women**
Desire for Direction	Individual Differences	**Team Culture**
Making Sense	Subjectivity of Answers	**Making Sense**
Priorities	Types of Documentation	**Uncertainty**
Resignation	Time Pressures Affected Quality	**Investment**
Investment	Cultural Variations	
Symbolism	Varied Opinions	

When considering these lists of key influences upon women’s and staff’s perceptions of the (e)HNA’s contribution, alongside the combined typological categories, this is captured in Figure 81. This figure displays the spectrum of participant views (through the typological categories), followed by the possible factors influencing these. For example, women’s typological categories showed positive views towards the (e)HNA’s delivery (in reality or in principle), with a contribution to their experiences of support which ranged from positive through to negative.

The second section of the figure then consider the key factors which may have influenced this view, such as their understanding of the (e)HNA, state of mind at the time it was undertaken, and where it featured within their priorities.

The views and categories of women and staff interlink within the figure, due to the overlap in these influencing factors. For example, if a woman's priority in an (e)HNA appointment was to add no additional burden on staff's workload, this may influence the way they complete the (e)HNA (such as giving low scores to concerns), which then influences staff's approach to addressing concerns (such as decisions to conduct a telephone follow-up discussion, rather than face-to-face).

Figure 81. Explanatory Accounts Insights



6.6.2.2.1 "How Women’s Views and Judgements Influenced their Perceptions of the (e)HNA's Contribution"

The typological categories identified for women highlighted that the (e)HNA’s contribution to their experiences of support was on a spectrum, from beneficial to potentially harmful. Where the woman’s experience was on this continuum appeared dependent on the following factors:

- **Intentions**: Women’s intentions towards how they approached the (e)HNA appeared to affect its contribution. Preferred methods of discussion (structured tool or unstructured conversation) varied according to whether women wished to discuss some concerns, disclose all concerns and genuinely engage with the assessment, or avoid disclosing personal issues.

- **Feelings of control**: Women indicated varying degrees of perceived or desired control through their responses. Some preferred to help themselves, and others stated their desire to place themselves in the hands of healthcare professionals. This may be due to other challenging factors in their lives which took precedence (such as familial caring responsibilities), which made it beneficial to have less responsibility for their care.

- **State of mind:** Women’s state of mind at the point of (e)HNA completion appeared to influence its contribution. State of mind could affect the time at which they desired the (e)HNA (this was challenging at the overwhelming time of diagnosis, or when upcoming, higher priority appointments were distracting them during an (e)HNA). This was also displayed by women's indication that the (e)HNA appeared more valuable when reflection had taken place during its completion. A further influence was whether women felt they were experiencing concerns at that time (or wished to raise these), and how severe these were. This relates to the care plan being viewed as a form of encouragement and security to stay connected to support, as this was more frequently reported by women who desired support and reassurance, than with those reporting few supportive needs.

- **Self-assurance/confidence**: Confidence was a further factor affecting (e)HNA encounters. Many women reported being unsure about how to complete the (e)HNA, and it was sometimes deemed beneficial to have a staff member present to assist them with its completion. Conversely, if low confidence meant they were reluctant to raise concerns in the presence of staff (or felt their responses would be influenced by staff), this could lead to preferences to complete the (e)HNA at home.

- **Making sense**: The completeness of understanding was an important factor in the (e)HNA's contribution to women's experiences, and varied with how women interpreted the assessment. Women's initial perceptions of the (e)HNA appeared crucial to 'how' they engaged with it. For example, in some cases, women misinterpreted the (e)HNA's terminology (such as the definition of 'holistic') or felt obliged to complete it. This seemed to influence their engagement and the extent to which they valued the assessment. Furthermore, if women were unsure about what the (e)HNA was leading to, this could lead to disappointment or withholding information. For example, this could include the expectation of greater benefits than were delivered, or fearing that accepting support would mean committing to sessions they were unable to attend. Many women who completed two (e)HNAs appeared to find the second one more meaningful and have a better understanding of the process. This suggests that the tool may not be properly understood until after its initial completion or following a detailed explanation. Additionally, women who did not fully understand the (e)HNA may have either not read their information leaflets (or did not obtain a clear understanding from these) or may have received the (e)HNA at a time when they could not fully process the information.

- **Priorities**: Disclosure of concerns and genuine engagement with the (e)HNA also appeared to be influenced by priorities. For example, these priorities included fearing they would be judged for disclosing emotional concerns, fear of leaving their partner home alone whilst they attended support sessions, or being a burden to busy staff. These factors could all affect the disclosure of concerns and the scores allocated to these. This could also relate to (e)HNA timings, because if their priority at diagnosis was to leave the hospital as quickly as possible, or to be on time for an adjoining appointment, the aim may be to complete the (e)HNA quickly, rather than giving it the level of attention it required.

6.6.2.2.2 "How the Staff Member’s Views and Judgements Influenced their Perceptions of the (e)HNA's Contribution"

As was the case with women, the typological categories for staff highlighted a range of views of the (e)HNA, from positive through to neutral or negative. Where staff members' views lay was also based on several factors:

- **Vulnerability:** Some staff indicated feelings of hostility towards the (e)HNA, because they felt it was a task routinely undertaken without the need for a tool. Therefore, the (e)HNA could be seen as a threat or as undermining their role. The care plan was viewed as providing security and as a means of evidencing their actions, should these be called into question.

- **Personal priorities:** Staff views varied depending on how high the (e)HNA was in their priorities, and many staff indicated that it was a low priority given the overall size of their workload. They appeared to almost delegate tasks to women to reduce their workload, by transferring responsibility for completing the recommended actions. Additionally, these factors dictated whether achieving externally set targets (because they were compulsory) or having a meaningful conversation (which they believed was facilitated by the (e)HNA) was the highest priority. The style of the (e)HNA's elicitation of concerns was seen by some staff as more rigorous than general conversation, and as more time-consuming for staff to undertake. It could increase workload by stimulating discussions of non-cancer related concerns (which would not otherwise have been raised), and by requiring completion of a care plan (especially if this was seen to duplicate other clinical documentation).

- **Perceived priorities of women:** Staff perceptions of women's priorities also affected their approach to the (e)HNA. They took these into account by organising appointments based on practical issues they felt would be important to women, such as reducing numbers of hospital trips, or acknowledging that they might feel more able to disclose concerns at home.

- **Team culture**: The organisation's culture present within each breast team also appeared to influence the (e)HNA's delivery and perceptions of it. This included the positivity or negativity of colleagues, alongside the attitudes of senior staff (such as Case Study 1, where the team appeared resistant towards Macmillan Cancer Support, and so the (e)HNA).

- **Making sense:** Staff members' own understanding of the (e)HNA also influenced their perceptions of what it contributed to women's experiences of support. This was both in the sense of how well they understood it, and the balance of the benefits and burdens of implementing it. Poorer understanding of the (e)HNA seemed related to more negative views and resistance to it. These views may have resulted from how the (e)HNA was introduced to them, as those who conducted their own background research into understanding it often felt its contribution was positive.

- **Uncertainty:** The effects of uncertainty were highlighted in staff members' need for direction about the timing and location of the delivery of (e)HNAs. Many staff identified scenarios where timing was unsuccessful (for example, at diagnosis), but were unsure of a better time and therefore made decisions based on other factors (such as completing it at the time points set by targets).

- **Investment**: The level of genuine buy-in to the (e)HNA appeared to influence staff's perceptions and delivery of it (whether the (e)HNA was undertaken because of a sense of obligation, or was undertaken as a result of authentic belief). These opinions also appeared to influence how women perceived the tool.

6.7 Conclusion

In this chapter, a cross-case comparison and synthesis was conducted, and a deeper exploration of the ‘explanatory accounts’ aspect of Framework Analysis. This added depth of understanding and more detailed conclusions to the findings. The (e)HNA’s contribution to assessing and supporting women’s needs was shown to be influenced by a wide range of factors, related to women’s and staff’s interpretations of the assessment. Chapter Seven continues the explanatory process by considering two final factors of ‘explanatory accounts’, the relevance of the wider literature and theoretical frameworks

Figure 82. Chapter Six Key Points

Chapter Summary: Key Points

- The cross-case comparison identified key similarities and differences between case studies, with team cultural considerations and persisting negative opinions of the (e)HNA more prevalent in Case Study 1. This was evident in their attitudes towards the assessment, and their seemingly target-focused approaches to delivery.

- Although some of these attributes were still present, Case Study 2 expressed more freedom to change ineffective practices and a stronger belief in the value of the (e)HNA.

- Care plan analysis revealed similar documentation styles between cases, which contained both strengths and weaknesses, suggesting an overall writing style which did not indicate women were the intended readers of the care plan in some cases.

- Framework Analysis' 'descriptive accounts' and 'explanatory accounts' were used to identify key influences on the (e)HNA's contribution, such as women's perceptions (intentions, feelings of control, state of mind, confidence, understanding and priorities) and staff perceptions (vulnerability, personal/women's priorities, team

Chapter Seven: Discussion

7.1 Introduction

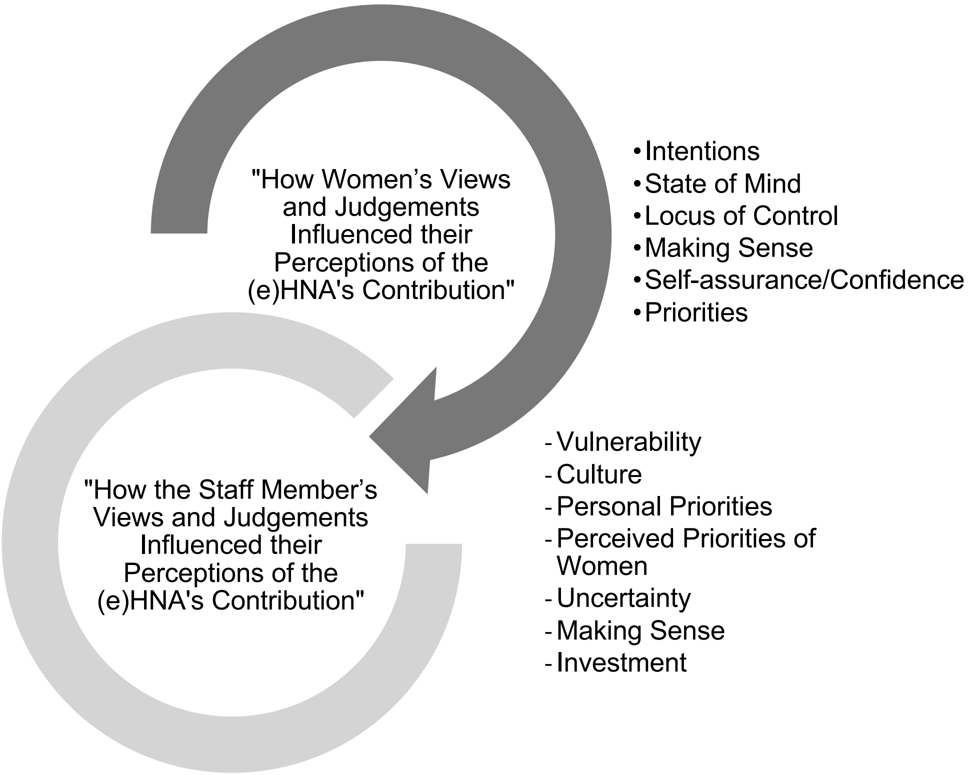
Following Chapter Six's cross-case comparison and synthesis, this chapter presents the thesis' discussion. This chapter also incorporates the final level of Framework Analysis' 'explanatory accounts', which builds upon explanations using theoretical frameworks and wider literature. Firstly, overarching findings are summarised from Chapters Four-Six. Secondly, the constructivist paradigm (explored in Chapter Three) is revisited, followed by a discussion of Normalisation Process Theory (NPT) and broader evidence. This provides further depth of interpretation to the key study findings, and enables the expansion of final study conclusions, set out in Chapter Eight.

7.2 Statement of Findings

As described in Chapter Six, the (e)HNA's contribution to women's experiences of support ranged from beneficial to potentially detrimental, suggesting the aim of the assessment (to provide support) and reality (minimal or negative impact) were paradoxical in some cases. Where the woman's experience featured on this continuum appeared to be dependent on numerous factors, including their intentions towards the (e)HNA encounter, their state of mind, perceived feelings of control (based on how much support they felt was necessary or desirable), self-confidence, and their openness to disclosing concerns. Women's experiences also appeared connected to their priorities at the point of (e)HNA completion, and how they understood the assessment's purpose.

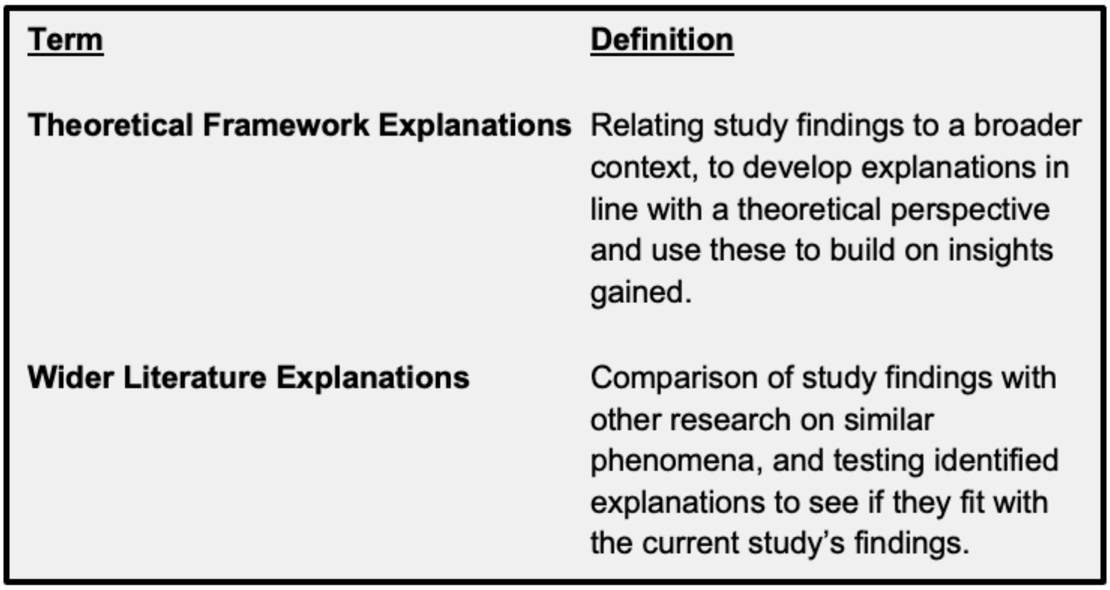
From a staff perspective, the experience and delivery of the (e)HNA was also dependent on multifactorial influences. These included feelings of vulnerability or defensiveness (reflecting the view that the (e)HNA was duplicating work or undermining their role), a desire to evidence their actions through the care plan, and their view of where the (e)HNA featured in a hierarchy of workload priorities. Staff also speculated about women's priorities (but remained uncertain about these), which affected their approach to (e)HNA provision. Finally, staff's understanding of the (e)HNA also influenced their delivery of it, with poorer understanding often linked to negative views and resistance. These key influences on the (e)HNA's contribution to women's experiences of support are recapitulated in Figure 83.

Figure 83. Recapitulation of Chapter Six's Explanatory Accounts



As described in previous chapters, Framework Analysis' 'explanatory accounts' analysis was approached by developing 'implicit explanations' (inferences made by the researcher) (Spencer et al., 2013), which was divided into three stages across Chapters Four-Seven. Stage 1 of this process was undertaken in Chapters Four and Five (explicit and early implicit explanations), Stage 2 was explored in Chapter Six (building upon implicit explanations using various techniques), and Stage 3 occurs in this chapter. Consequently, Stage 3 involves drawing together explanations from the study data, using knowledge from ‘theoretical frameworks’ and the ‘wider literature’, to refine implicit explanations, defined in Figure 84.

Figure 84. Explanatory Accounts Definitions (Spencer et al., 2013)



Term	**Definition**
Theoretical Framework Explanations	Relating study findings to a broader context, to develop explanations in line with a theoretical perspective and use these to build on insights gained.
Wider Literature Explanations	Comparison of study findings with other research on similar phenomena, and testing identified explanations to see if they fit with the current study’s findings.

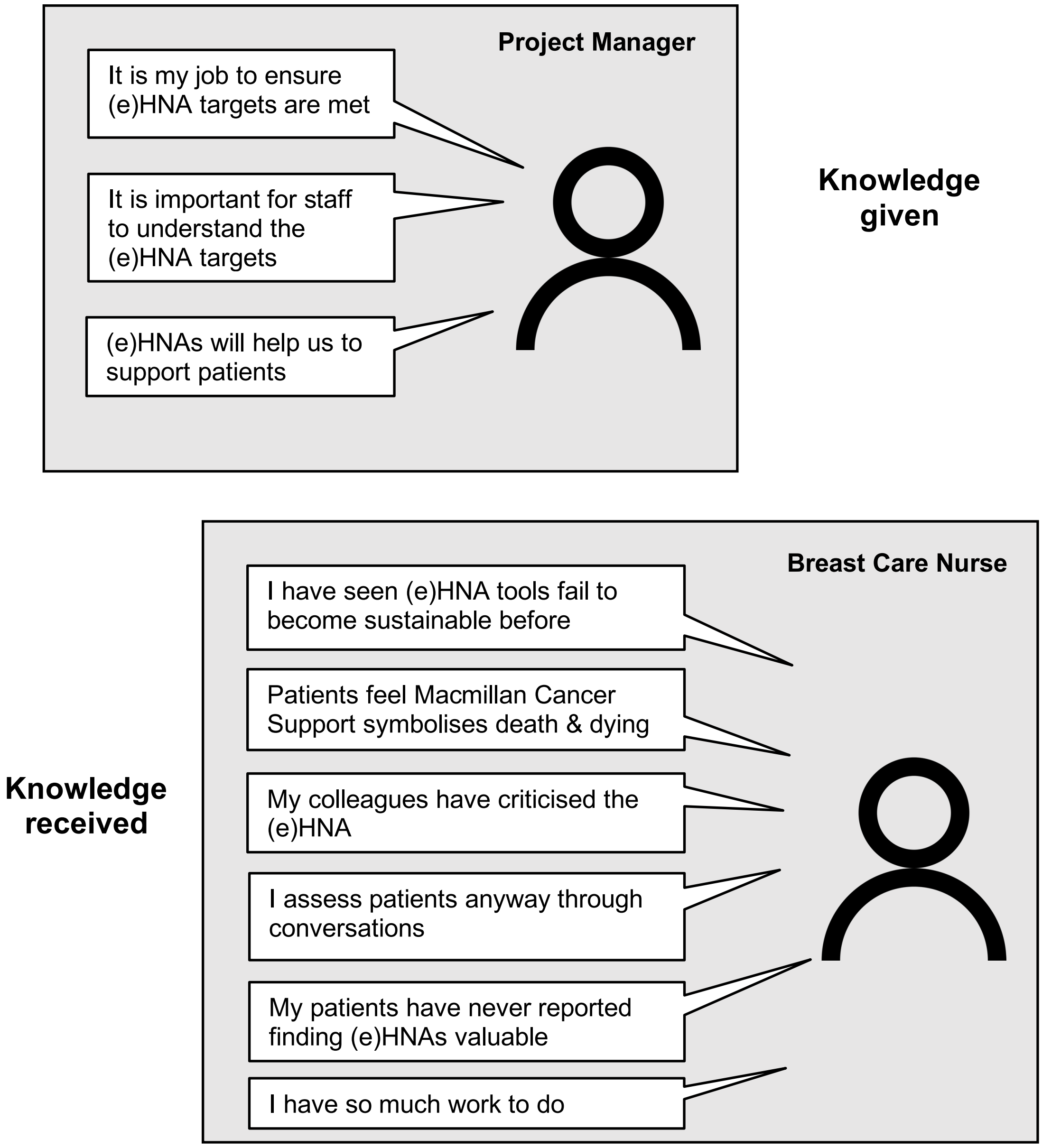
Prior to building upon and refining the study’s overarching explanations and conclusions, the concept of constructivism is revisited to provide a lens through which key study findings can be viewed, and to provide a foundation for the discussion.

7.3 Interpretation through Constructivism

As described in Chapter Three, this study was approached using elements of the interpretivist-constructivist paradigm. This section sets out key findings relating to the (e)HNA's contribution to women's experiences of support, taking into account the multitude of individual contexts and interpretations that influence their construction of knowledge. This chapter also presents a focus on NPT, as a theoretical framework that centres on participants' behaviours surrounding the (e)HNA's implementation. However, NPT also aligns with constructivism, through considering individual thought processes, and how the construction of knowledge and understanding influences learning, and determines subsequent behaviour (Thomas, 2014).

Although much constructivist research focuses on learning theories, the approach has also been applied to 'knowledge translation' in healthcare contexts (Thomas, 2014). Knowledge translation refers to the exchange, combination and ethical application of knowledge, to improve health or care services (World Health Organisation, 2021). Constructivism views knowledge exchange between groups (such as various healthcare staff, or between staff and patients), as mutually constructed social contexts, with understandings formed by those who produce, utilise and share knowledge (as opposed to simply passing knowledge on) (Thomas, 2014). Those receiving the new knowledge then apply meaning to it based on their previous experiences and relevant understandings (Thomas, 2014). The principles of constructivist knowledge translation may be applicable to the findings identified in Chapters Four to Seven, relating to the requirement participants had to develop an understanding of the (e)HNA, either as a recipient of the assessment, or being key to its introduction and delivery. Therefore, the ways in which the (e)HNA was introduced to participants are highlighted through elements of a constructivist viewpoint. This displays how study participants may have applied meaning to the (e)HNA in these encounters. Figure 85 gives an example of how the (e)HNA may be initially introduced (in this instance, a breast care nurse (BCN) is introduced to the (e)HNA by the project manager).

Figure 85. Constructivist Knowledge Translation



In this scenario, the project manager’s interpretations and opinions of the assessment would not be directly mirrored by the BCN, who would use their previous experiences to construct their own understanding and opinions of the (e)HNA. Various factors may shape these opinions, such as former involvement in unsuccessful (e)HNAs, receiving positive or negative feedback about it from colleagues, or perceptions of the Macmillan Cancer Support brand. Furthermore, the project manager’s priority for the (e)HNA may be to achieve the national targets associated with it (this being a key element of their role), and the importance of targets may feature in the verbal introduction provided to the BCN. When combined with the BCN’s prior knowledge that meeting targets is crucial to the funding hospitals receive, this may then become their own priority for (e)HNA delivery. However, these views may differ from those of a BCN who had never seen an (e)HNA in practice and had little knowledge of targets. However, this individual may still be influenced by the views of other staff, or their existing knowledge about using questionnaires or holistic care.

From the perspective of women participants, opinions and understanding could be similarly socially constructed from their own knowledge and experiences. For example, understanding of the (e)HNA’s purpose may draw on prior knowledge of the term ‘holistic’, linking the intervention to alternative therapies. If the (e)HNA was introduced in a similar way to other hospital surveys, it may be seen as a form of service improvement, for example. In Chapters Four and Five, data were used to highlight the wider life circumstances affecting women’s ability to make sense of the (e)HNA, and to show how previous experiences of care (or those of family) shaped decisions to engage with (e)HNAs or disclose concerns. These influencing factors include expectations of what support is available (affected by drawing on experience of a previous breast cancer diagnosis, or interpretations of the information provided).

With this in mind, women and staff's opinions and behaviours in response to receiving or delivering the (e)HNA, appeared influenced by the way they interpreted and organised knowledge. This is explored further through NPT's theoretical perspective to the implementation of innovation.

7.4 Normalisation Process Theory

Use of theoretical frameworks can support the development of research findings, by providing structure and a means to further understand phenomena (Maxwell, 2013; Polit & Beck, 2012). Theory can be applied to research in multiple ways, including producing new theory from data, or using it as a guide to interpret data (Collins & Stockton, 2018). The current study adopted an inductive approach (gathering data before theory is introduced at a later stage) (Goddard & Melville, 2004), by utilising theory to provide further depth of interpretation to existing data.

The NPT framework was selected due to its widespread use in healthcare research, and its ability to explain social processes occurring through the implementation of innovation (May & Finch, 2009). The framework aims to comprehend and explain the social processes which facilitate or hinder the integration of innovations into healthcare settings, such as individual and collective practices undertaken to embed interventions (May & Finch, 2009). Strengths of this model include its ability to accurately show important aspects of implementation processes, its successful adoption in a large number of intervention studies to explain outcomes, and its flexible use across a range of settings (May et al., 2018). Furthermore, the model is congruent with a constructivist approach to research, through its focus on the individual nature of how reality is understood (De Brún et al., 2016). NPT consists of four overarching constructs with sub-components, as shown in Table 50.

Table 49. Core Constructs Framework in NPT (May et al., 2015).

Core Constructs	**Components of Core Construct**			
Coherence	Differentiation	Communal Specification	Individual Specification	Internalisation
Cognitive Participation	Initiation	Enrolment	Legitimation	Activation
Collective Action	Interactional Workability	Relational Integration	Skill Set Workability	Contextual Integration
Reflexive Monitoring	Systematisation	Communal Appraisal	Individual Appraisal	Reconfiguration

7.4.1 Coherence

Exploring each construct individually, ‘coherence’ encompasses how people make sense of challenges with implementing a particular practice (May et al., 2015). Firstly, this process includes ‘differentiation’, through understanding how new practices differ from existing ones (for example dissimilarities between new and existing (e)HNA tools). Developing understanding focuses on both individual (individual specification) and shared views (communal specification) of the intervention’s purpose, aims and expected outcomes. ‘Internalisation’ relates to the research undertaken to identify value in the new practice (for example, further research into the (e)HNA led to greater understanding of its value) (May et al., 2015).

Staff often differentiated the (e)HNA from usual practice in a negative way, believing it duplicated existing work and was too time-consuming. However, many aspects of ‘coherence’ appeared to be lacking, including agreement about the (e)HNA’s purpose and value, and genuine understanding of how to undertake assessments. The absence of these features may therefore have influenced staff's delivery of the (e)HNA, such as how they introduced and explained this to women, and how valuable they depicted the assessment to be. Using NPT as a theoretical lens highlights that key considerations in the implementation process were absent, and exposes variations and cultural influences within the breast teams.

7.4.2 Cognitive Participation

The second construct 'cognitive participation' includes developing a community around an intervention; involving key individuals to drive its delivery forward (initiation), and establishing collective buy-in from teams (enrolment). 'Legitimation' involves a genuine belief that involvement in the intervention's delivery is essential and appropriate to that individual. Finally, NPT describes the collective defining of actions, required to achieve sustainability from the intervention (activation) (May et al., 2015).

When considering this construct in relation to study findings, this suggests that buy-in and continued, self-sustaining support for the (e)HNA were often deficient. The 'cognitive participation' of staff appeared dependent on the champions to drive it forwards, but this did not appear to facilitate sincere engagement.

7.4.3 Collective Action

The 'collective action' construct denotes the operational tasks occurring to enact the new practices, including interactions between people. Additionally, this construct includes 'relational integration', which refers to the generation of confidence in the new processes (for example confidence in the (e)HNA's ability to elicit concerns, or the ability of those in support worker (SW) roles to conduct comprehensive assessments). However, there was no evidence in the data to suggest that (e)HNAs conducted by a SW were any less meaningful than those in registered healthcare professional roles. Similarly, 'skill set workability' focuses on allocation of work to the correct individuals, based on need and ability to undertake it. The last sub-component is resource allocation, required to allow integration of the intervention to occur (May et al., 2015) (for example, additional staff required to conduct supplementary clinical appointments for (e)HNAs).

In this study, the aspect of 'collective action' that participants most frequently achieved was the actual performance of the intervention tasks, but collective approaches (such as mutual trust and equal allocation of workload) were not adopted. Use of NPT highlights staff willingness to perform the (e)HNA itself, but shows that a lack of trust and resource allocation inadequacies appeared to affect how it was delivered.

7.4.4 Reflexive Monitoring

The final component of NPT centres on work undertaken to understand how the introduced change affects individuals and others. The first element of 'reflexive monitoring' is 'systematisation', where information is collected formally and informally, to establish the usefulness of the new intervention. This monitoring then leads to 'communal appraisal', where staff work together to establish the new practice's value and effectiveness. Alongside this collective process, appraisal of value also occurs at an individual level, and the ultimate 'reconfiguration' step incorporates the process of changing practices according to these appraisals (May et al., 2015).

‘Reflexive monitoring’ appeared to be lacking from the processes of (e)HNA implementation reported by staff. Few individual staff felt the (e)HNA was meaningful in reality (particularly in Case Study 1) and little discussion of the assessment’s value was apparent among participants, with the exception of practical considerations such as timing. The absence of these reflective activities may have influenced the view that the (e)HNA provided paradoxical support, through the lack of appraisal of its value or feeling unable to change ineffective practices.

When considering the current study’s findings in relation to NPT’s individual constructs, the NPT online toolkit (May et al., 2015) can be used to generate a visual representation of implementation issues in each construct. This toolkit uses 16 questions (based on the sub-components of the four constructs) and a sliding-scale measurement of negative to positive (May et al., 2015). The toolkit aims to encourage critical reflection on implementation issues, and produces a graph-based summary for each construct (May et al., 2015). The authors emphasise that response patterns on the outside edges of the graphs indicate positivity, whereas those collected around the centre may indicate:

> “Participants cannot make sense, or have not signed up to the innovation. Perhaps they cannot enact it in a way that works for them, or cannot assess its effects and their value.” (May et al., 2015).

Using the NPT toolkit for the current study’s findings highlighted that implementation of the (e)HNA produced predominantly negative results

(Appendix U). For example, when considering the ‘reflexive monitoring’ construct, key elements appeared absent from the case studies. These included participants accessing information about the effects of the intervention, and individually or collectively assessing its value as worthwhile. These issues were more pronounced in Case Study 1, where the communal view of the (e)HNA appeared to be influenced by the breast team’s negative culture in relation to it, and participants also indicated an inability to modify working practices based on their views. However, mapping the overarching study findings on to the NPT toolkit highlighted largely negative responses in almost all 16 aspects of the framework (particularly from Case Study 1 opinions), with the exception of several operational elements (such as actual performance of the (e)HNA, and the existence of key individuals to drive the intervention).

In this study, the (e)HNA’s implementation appeared somewhat superficial, and stuck in the early stages of implementation. Participants indicated many gaps in understanding, buy-in, and reflection on its value, despite it having been in place for several years. Although NPT was valuable for interpreting study findings, it has been criticised for not considering wider organisational contexts influencing the implementation of innovation (Clarke et al., 2013). Factors such as negative cultures and organisational restrictions (for example, Case Study 1’s negative culture towards the (e)HNA, and Case Study 2 employing two project managers who delivered the (e)HNA in different ways) may have further influenced implementation success. Furthermore, NPT has also been criticised for its limited acknowledgement of temporal considerations in implementation, and for not addressing the issue of how long implementation should take (Alharbi et al., 2014). In the current study, ongoing debates about when to conduct the (e)HNA (including changing the timing in Case Study 2, and the view that the timing was unsuccessful in Case Study 1) suggested that the process of embedding the assessment remained a work in progress, and that staff regarded implementation as mixed at best. Additionally, NPT has historically been criticised for its focus on the agency of healthcare professionals, and not including the perspectives of those receiving the intervention (Segrott, 2017). Interestingly, when answering the questions in the NPT toolkit to indicate women’s overall views from the perspective of the (e)HNA’s delivery process, this yielded similar results to those obtained for staff. A lack of buy-in and reflective understanding of the assessment’s value was found, suggesting that staff views were mirrored by those receiving the intervention.

Following consideration of key study findings through the lens of NPT, the wider literature is introduced to situate these findings within a broader evidence base.

7.5 Discussion

7.5.1 Discussion: How Women’s Views and Judgements Influenced their Perceptions of the (e)HNA's Contribution

As described in the statement of findings (Section 7.2), women’s experiences of the (e)HNA appeared determined by various factors which were personal to them as individuals. These included their intentions towards completion of the assessment, state of mind, feelings of control, confidence and understanding, all of which influenced their subsequent behaviour and engagement with the (e)HNA.

7.5.1.1 Engagement and Openness with the (e)HNA

Many women in the study did not disclose all of their concerns on the (e)HNA. Focusing initially on the act of non-disclosure (rather than reasons for this), some women simply did not raise concerns, or reduced the likelihood of concerns being identified by avoiding the (e)HNA (for example, by asking to discuss concerns in an unstructured conversation, or over the telephone).

The choice to not disclose concerns raises the issue of women's intentions in an (e)HNA consultation. Limited evidence appears to discuss intentions in clinical encounters, but one study highlighted patients' non-disclosure of psychological concerns, and they described that this non-disclosure was their intention even prior to entering the consultation (Penalba et al., 2019). With this in mind, women in the current study described methods which facilitated withholding concerns, such as telephone discussions. Wider research emphasises the importance of non-verbal communication in clinical encounters (Henry, 2012; Riess & Kraft-Todd, 2014), and telephone communication may restrict rapport development due to the absence of these non-verbal cues (Irvine, 2013). Participants in Irvine's (2013) study also indicated increased difficulty with interpretations over the telephone, by seeking clarification that responses were adequate (Irvine, 2013; Kaminsky et al., 2017). Video consultations however, allowed the same visual cues and interaction quality as face-to-face contact (Barsom et al., 2020; Seuren et al., 2020). Participants in the current study appeared to acknowledge and use the limitations in telephone communication as a means of achieving their aim (such as non-disclosure, or avoidance of concerns), which does not appear to have been explored in wider literature. Alternatively, some women felt less anxious about discussing sensitive issues on the telephone, which was easier when they were unable to see the person they were talking to.

Alongside the act of not disclosing concerns in (e)HNAs, wider literature can also be used to explore the reasons for this. In the current study, these reasons for non-disclosure included avoiding judgement from staff over embarrassing concerns, lack of a relationship with staff, not wishing to burden staff, desiring to make the (e)HNA relevant to the staff reading it, wishing for privacy, or needing to prioritise others (if they were a carer). These considerations suggest that the (e)HNA failed to assess and offer support in some circumstances, as women felt the need to withhold their concerns.

These issues are reflected in the wider literature, relating initially to where lack of trust or the absence of an existing relationship affected disclosure of concerns in some way. For example, one study reported that insufficient trust towards unknown staff members affected disclosure of issues which were deemed embarrassing (Julliard et al., 2008). Additionally, a further study found that patient questionnaire responses (positive or negative), appeared dependent on their relationship with staff, and their expectations (Abdelhamid, 2017; Burt et al., 2017). The effects of having no relationship with staff on patients' disclosure may also highlight their fear of judgement from staff. For example, some patients reported non-disclosure of health-related information due to fear being judged, not wishing to hear facts about potentially harmful behaviours, embarrassment, and wanting to avoid being seen as 'difficult' (Levy et al., 2018). Therefore, this research supports the findings of the current study, which suggests that patients are conscious of how they are perceived by staff, which may influence their disclosure of concerns. Furthermore, considering findings from the current study in the light of Levy et al's (2018) findings, it may be that women who reported withholding their concerns (for reasons such as not feeling ready to discuss them), did so to avoid hearing advice they were 'not ready' to act upon.

Additionally, women's knowledge of staff's roles appeared to affect disclosure on the (e)HNA (such as feeling they were too busy, or lack of understanding about the (e)HNA's relevance to their roles), which was also apparent in wider literature. For example, two studies highlighted patients' views of not wanting to disturb busy staff, and many felt that their concerns were a low priority to staff, which led to avoidance of reporting these (McCabe, 2004; McColl et al., 1996). This explanation is also supported by the (e)HNA literature in Chapter Two's scoping review, which emphasised that participants may withhold their concerns if they see themselves as burdensome (Biddle et al., 2016; Briggs et al., 2019; Taylor et al., 2012). Alongside not disturbing staff, several (e)HNA scoping review studies reported patients' desire to adjust their behaviours based on how they viewed the role of the staff member completing the assessment (such as not disclosing concerns if they felt they were irrelevant to that staff member) (Briggs et al., 2019; O'Donnell et al., 2013). The current study has added understanding around why perceptions of staff's roles could alter women's responses, and highlighted the paradoxical nature of women's (e)HNA experiences in comparison to the assessment's aims (to provide support). For example, some women appeared to feel compelled to complete (e)HNAs or raise concerns even if they had none, because they perceived this benefitted staff in performing their roles (or was desirable to them).

7.5.1.2 Preferences

Alongside women's interpretations which shaped their engagement with the (e)HNA, participants also expressed different preferences for the assessment's practicalities, such as its timing, location, and their desire to obtain (and stay connected to) support through the tool. Firstly, participants felt that diagnosis was an overwhelming and unsuitable time at which to complete (e)HNAs. This is supported by wider research, which highlights the emotional impact of a new cancer diagnosis. In this scenario, patients may not absorb information due to shock, and additional stress may be caused by busy outpatient departments (Ardern-Jones et al., 2005; McCaughan & McKenna, 2007). The experiences of outpatient departments outlined by McCaughan and McKenna (2007) may explain why some women in the current study wished to complete their assessments at home, as they may have felt overwhelmed by the hospital environment.

Secondly, many participants in the study saw the online format of the (e)HNA as acceptable (it enabled completion at home). However, this is challenged in wider research, where preferences for face-to-face communication were found in patients accessing support groups (Boyes et al., 2018), and in older age groups (Huber et al., 2018). Chapter Two's scoping review also identified variable preferences, including the view that home-based (e)HNAs were unfeasible, and that paper assessments were preferable (Ipsos Mori, 2015; Rogers et al., 2018). Issues identified with digital tools include lack of confidence, time needed to learn and adjust, and technical issues (Escriva Boulley et al., 2018). The differences between findings from the current study and wider literature may be partly due to this study's small sample (which may not represent all views). However, this variation may also suggest that circumstances influence preferences. For example, women in this study expressed a desire for space to reflect on their concerns, which was facilitated by the online/home (e)HNA method. Alternatively, the participants in Boyes et al's (2018) study may have preferred face-to-face methods, due to the more social nature of support groups.

Thirdly, women showed preferences for taking ownership of decision-making, including whether they pursued recommendations from their care plans (such as referrals to services). However, the care plan document itself appeared helpful in the absence of specific actions or referrals, because it provided a failsafe method of staying connected to support, and an opportunity to talk/be listened to. This is also reflected in the wider literature, where support is described as a flexible concept, incorporating physical, informational support, or providing the opportunity to talk without the need for physical actions (Coffman, 2008; Hirschman & Bourjolly, 2005).

Moreover, these preferences (such as whether to act on recommendations, or to complete the (e)HNA) also influenced women's behaviour, and appeared connected to their feelings of being in control. Perceptions of control and their impact on behaviour is referred to in the wider literature. For example, locus of control can be internal (the view that positive outcomes result from one's own actions) or external (the view that positive outcomes are unconnected to one's own behaviour) (Crisson & Keefe, 1987). This literature suggests that individual characteristics and locus of control may determine views and behaviours, including variable preferences between delegating decision-making to healthcare professionals, or desiring ownership of this (Burt et al., 2014; Cullati et al., 2011; Schneider et al., 2006). In the current study, individual perceptions of control may have influenced decisions about whether to engage with or decline the (e)HNA, based on their desire to seek support independently or be 'in the hands' of staff. This may have also influenced readiness to complete staff recommendations. Moreover, feelings of control have been discussed in research surrounding the 'hospital-patient role' (feeling obliged to submit to the hospital's requests without complaint, and believing that non-conformity could be detrimental to their care) (Lorber, 1975). A study by Frosch et al. (2012) found that participants attempted to regain control through covertly undertaking research into treatment options (to avoid asking questions), and bringing along family members to have another person 'on their team' (Frosch et al., 2012). With this in mind, participants in the current study may have been attempting to maintain control through not pursuing recommendations made to them by staff.

The desire to maintain control and the idea of the ‘hospital-patient role’ relate to further findings in the current study, where many women completed the (e)HNA because they felt obliged to, and appeared to want to please staff, desired someone to be on ‘their team’ and made references to being a ‘nuisance’ patient. These views are consistent with literature relating to power dynamics (how unequal power affects the relationship between two people, such as one being in a position of authority over the other) (McDonald et al., 2012). For example, power dynamics may manifest by showing a lack of respect for a patient’s knowledge, and patients not being involved in completing documentation which represented their experiences (Griscti et al., 2017). When these undesirable power dynamics existed, this has been found to influence patients’ behaviours, such as acting according to what they believed the organisation desired to avoid negative consequences (for example repercussions if behaviour was difficult, or receiving better care if they were a ‘good patient’) (Griscti et al., 2017; Taylor, 1979). Therefore, women in the current study may have completed their (e)HNAs (despite not always seeing the value in these), in order to comply with what they felt staff desired, or to be viewed as a ‘good patient’, rather than a ‘nuisance’.

7.5.1.3 Understanding

Key findings from the current study also focused on women’s understanding of the (e)HNA and how they made sense of it, such as whether it was optional or what expected outcomes would be. Many participants demonstrated a lack of understanding of the (e)HNA’s purpose, and examples of medical jargon were present in care plans, which may have exacerbated this issue. This is consistent with wider literature, which considers patients’ lack of understanding of literature given to them, for reasons such as limited health literacy or unclear information leaflets provided (Graham & Brookey, 2008; Protheroe et al., 2015). Graham and Brookey (2008) highlight the need to avoid medical jargon and to be aware of 'red flags' which indicate low literacy skills, such as requests for information to be read aloud. Although many of this study's participants did not report or display literacy difficulties, health literacy issues may provide some explanation as to why project managers at each case reported high numbers of 'expired' (e)HNAs. Furthermore, Chapter Two's scoping review also identified misunderstandings about the (e)HNA's scoring system (Hughes et al., 2011) and incorrect assumptions about the assessment purpose and outcomes (Snowden et al., 2012), although these were not reported in depth. The current study has expanded on these findings by providing reasons for misunderstandings, such as inadequate (e)HNA introductions (or introductions which misrepresented its purpose, such as saying it needed to be completed 'for staff'). Within the current study, assumptions and misunderstanding led to experiences which were potentially harmful to participants (through feeling distressed, disappointed or overwhelmed) in some cases.

7.5.2 Discussion: How the Staff Member's Views and Judgements Influenced their Perceptions of the (e)HNA's Contribution

7.5.2.1 The (e)HNA's Introduction

Staff members' views of delivering the (e)HNA were dependent on various influences. Many reported feeling unsettled by the (e)HNA's introduction, perceiving it as unsustainable because of inadequate resources, because they feared increasing their workload, or because they had seen similar interventions fail in the past. This is supported by wider literature, including findings from the scoping review that staff believed the (e)HNA was unsustainable (Williamson et al., 2020). When considering key requirements for the sustainability of innovations, these have been found related to positive perceptions of the benefits, consistent goal achievement, and routinisation, which means that the intervention is no longer viewed as an extra piece of work (Fleiszer et al., 2015). NPT's 'cognitive participation' construct provides a useful way to consider these findings, highlighting that ongoing engagement from staff is necessary once an intervention has been introduced, to promote sustainability (May et al., 2015). Many of the findings from the current study seemed to show that the drive to establish the (e)HNA within a service did not sufficiently take account of the need to foster ongoing engagement and sustainability.

7.5.2.2 Obligations and Culture

As a further consideration, many staff in the current study reported feeling obliged to complete the (e)HNA, which was enforced from those in positions of authority (a 'top-down' approach). However, some Case Study 2 staff appeared able to exercise independent judgement about making changes. The wider literature suggests that introducing change can be perceived as threatening and disruptive to stability (Appelbaum & Wohl, 2000; Oreg, 2003). A limitation of the 'top-down' approach is its unfamiliarity with the frontline, and unrealistic procedures and targets may follow as a result (Sabatier, 1986). However, alternative 'bottom-up' (driven by patients or frontline staff) methods have also been criticised for lacking clear organisational goals, or leading to different stakeholders setting goals that contradict each other (Sabatier, 1986). The research literature suggests that both approaches are needed to create a culture of successful implementation (Sabatier, 1986; Smeds et al., 2003).

Findings from the current study suggest a cultural, hierarchical structure that junior staff felt made it difficult for them to initiate change (for example, views that change should be management-driven, or initiated by senior rather than junior nurses). Furthermore, some participants indicated that dominant team opinions existed, such as resistance to staff championing the (e)HNA. In the wider literature, responses and resistance to local/national targets is seen in the context of organisational culture, which reflects three, primary levels (‘visible manifestations’, ‘shared ways of thinking’, ‘deeper shared assumptions’) (Mannion & Davies, 2018; Schein, 1985). Shared norms and values have been widely researched in the context of organisational culture, which manifest as dominant behaviours within a group (Maguire et al., 1996). Moreover, pressures to conform to cultures can be further influenced by a leader who functions as a source of guidance on group standards, thus shaping goals and values (Hogg, 2010). Furthermore, findings from this study can be viewed in light of this organisational culture research, alongside the ‘reflexive monitoring’ construct in NPT (which highlights the individual/communal appraisal process which occurs to establish value in new practices) (May et al., 2015). For example, staff in this study (particularly in Case Study 1) indicated that their assessment of the (e)HNA’s value was influenced by cultural considerations and conformity to the values of the team (for example, Case Study 1 staff indicating an underlying team resistance towards Macmillan Cancer Support and the (e)HNA). However, this collective view was sometimes contradicted by their own individual comments, such as indicating that they felt that the assessment was meaningful.

Alongside the feelings of obligation to complete (e)HNAs, staff also articulated ethical obligations they felt towards the women. These responsibilities were perceived based on the risk that (e)HNAs could lead to disappointment. For example, disappointment may occur if concerns could not be addressed, or if expectations of support were high and women felt not ‘enough’ had been done. This view is supported by wider literature, as patients’ expectations sometimes exceed what nurses themselves believe their responsibilities to be, leading to resentment or poor experiences of care (Boodhoo, 2015; Peter et al., 2004; Young et al., 2018). Failing to meet expectations may also lead staff to feel as though they have failed in their moral obligation to patients (Peter et al., 2004; Sandgren et al., 2007). The nursing profession is governed by a set of moral principles dictating attitudes and behaviours, present through the Nursing and Midwifery Council's (NMC) code of conduct (NMC, 2018). However, despite the NMC's focus on a 'no blame' approach, blame culture continues to exist within healthcare settings (Chesterton et al., 2020). Cultures of blame are widely documented in the healthcare literature, including the view that a misconstrued sense of accountability can lead to defensiveness, and restrict the ability to deliver improvements (Dekker & Hugh, 2014).

Considering blame cultures more broadly, staff in the current study felt they could be held to account through the standards of (e)HNA targets, but other sources of blame were also present. For example, staff expressed concerns about what was 'safe' to document on care plans, and agreed that these documents could provide evidence of their actions (suggesting the desire to avoid blame if questioned). The wider research literature highlights the notion of documenting activity as a form of self-protection to evidence actions (Junttila et al., 2005; Tiusanen et al., 2010), and the invisibility of an undocumented nursing encounter (Tiusanen et al., 2010).

Additionally, staff can be judged against their ability to meet targets, which are often feared because they can be seen as a route through which to initiate blame (Armstrong et al., 2018). Considering these findings in light of the current study, blame cultures and staff's feelings that targets were not measuring meaningful aspects of care may have contributed to the resistance expressed in some cases. However, in wider literature, performance indicators and targets have been deemed necessary for the functioning of any complex system, to provide an element of control (Bird et al., 2005). Furthermore, it has been emphasised that the process of setting targets should address the challenge of measuring heterogeneous data, which often leads to the choice of target being determined by the most important outcome (Birnberg et al., 2002). With the (e)HNA specifically, such variety of needs make quality difficult to measure, so targets appear based on quantity completed. However, a recent study of intentional rounding in nursing (nurses carrying out frequent, scheduled checks of patients' essential care needs using standardised documentation) highlighted a primary focus on data collection and staff protecting themselves by gathering evidence (Sims et al., 2020). Furthermore, research highlights the danger of measuring aspects of care which are simple to quantify, rather than the aspects which ensure it is compassionate and meaningful (Chochinov, 2007; Sims et al., 2020). These behaviours removed the focus of care from compassion, quality and individualisation, to achieving required goals (Sims et al., 2020). As such, the (e)HNA targets' focus on quantity over quality may explain why some staff viewed these negatively, or felt they detracted from the (e)HNA experience.

7.5.2.3 Quality

Alongside blame cultures and the need staff felt to evidence actions, the quality of (e)HNA care plans and their meaningfulness to women also varied. Many care plans adopted a factual, clinical style (such as medical acronyms and jargon), and it frequently appeared as though either a meaningful conversation had occurred without a care plan (separately from the (e)HNA), or a care plan was produced without the meaningful conversation (driven by obligation to complete it). Consistent with this, findings from the scoping review noted that the (e)HNA encouraged a task-orientated approach among staff (Thayssen et al., 2017). Moreover, similar styles of documentation were identified in another study, which concluded that despite the importance of the 'patient's voice' in documentation, more prominence was placed on providing factual information about interventions and hospital processes (for example discharge information or episodes of care) (Laitinen et al., 2010). In addition, wider research has differentiated between the concept of ‘care planning’ (the act of planning and agreeing actions to be undertaken) and completing a ‘care plan’ (a document which records and reports the outcome of this planning) (Burt et al., 2014). Table 51 demonstrates how Burt et al’s (2014) research categorised approaches to care planning.

Table 50. Care Plan and Care Planning (Burt et al., 2014)

		Care Planning?	
		Yes	**No**
Care Plan?	**Yes**	**A:** ‘Gold standard’ (care plan is produced as a result of in-depth care planning)	**B:** Potential target-driven outcome (care plan is produced without actually undertaking a care planning process)
	No	**C:** Current typical care (within Burt et al’s (2014) study) (care planning discussion occurred but no care plan was created)	**D:** Poor care (No care plan was created and no care planning conversation occurred)

The analysis of care plans in Chapter Six identified that these varied in terms of quality, which was measured against what the women desired to see in their care plans. Previous research has developed methods of assessing the quality of nursing documentation using data extraction tools. This was highlighted in a systematic review that identified 77 studies assessing documentation quality, by measuring features such as thoroughness, accuracy, chronology of event reporting and emphasis on clear, factual information (Wang et al., 2011). However, a further study focused alternatively on whether patient-centred care approaches were present in nursing documentation, by adopting a framework that separated quality into measurable components (Broderick & Coffey, 2012). These included measures of whether staff were compassionate in their documentation, by providing evidence of having listened to patients and considered their needs (Broderick & Coffey, 2012). With this in mind, the apparent lack of quality assessment in the (e)HNA processes may partially explain why the value of care plans to women was variable, or paradoxically appeared to lead to negative experiences of care in some cases.

7.5.2.4 Role Perceptions

Staff opinions also appeared to influence whether recommended actions on the care plan should be for staff or for women to undertake, and what type of actions should be documented (including practical instructions or commending the individual's progress and providing small goals). How care plans were completed appeared related to staff's views of needing use the (e)HNA process to encourage women to self-manage, as well as feeling the desire to help or support them. This is consistent with wider research, where nurses' perceptions of the lines between encouraging self-management and maintaining professional accountability to deliver high quality care can become blurred, leading to a reduction in the autonomy given to patients (Wilkinson et al., 2016). Furthermore, the Clinical Nurse Specialist (CNS) role has been found to lead to patient dependency, due to the supportive nature of the role encroaching on aspects of self-management (Cook et al., 2019). A variety of opinions from nursing staff about self-management have been reflected in the research literature, with some nurses reflecting a medically-orientated approach (for example, by focusing on adherence to treatment regimens or monitoring symptoms), and others preferring a biopsychosocial approach (based on factors such as acceptance, coping with diagnosis, and the nurses' role in supporting this process) (Been-Dahmen et al., 2015).

7.5.2.5 Uncertainties

Uncertainties about how to document and deliver quality in care plans were not the only challenges for staff in producing meaningful (e)HNAs. This study also highlighted staff's uncertainty about when, where and how to offer (e)HNAs to women. Staff often used their perceptions of women's priorities or practical considerations (such as numbers of hospital trips) to make decisions, even if these deviated from their instructions in some cases (for example, Case Study 2 removing new diagnosis (e)HNAs based on seeing these as unsuccessful). Chapter Two's scoping review supports these findings, suggesting that views about the right time to do (e)HNAs vary considerably among staff (Ipsos Mori, 2015; Kotronoulas et al., 2017; Sterba et al., 2017; Thewes et al., 2016). The notion of using practical considerations to make choices is supported by the wider research on 'heuristics' (techniques used to assist with decision-making) (Cranley et al., 2009). These techniques include representativeness (making decisions based on previous experiences, such as the likelihood a specific choice will be the patient's preference) and availability (using a vivid memory of an experience to dictate how similar situations are approached in future) (Cioffi & Markham, 1997). In the current study, these principles may have been used by staff to guide choices about when and where to offer (e)HNAs, such as experiences of particularly memorable feedback from women (for example, regularly encountering their association between Macmillan Cancer Support and dying). There is also a connection with NPT's 'coherence' construct, where internal thought processes determine the value placed on the new intervention and influence its delivery (May et al., 2015). Staff in the current study appeared to conclude that their priorities were the practical aspects of (e)HNA delivery (such as reduced hospital trips) and made decisions accordingly.

However, staff's assumptions about women's preferences did not consistently align with the preferences women reported themselves, despite staff using these assumptions to make decisions. For example, telephone (e)HNAs avoided an additional hospital trip (seen as a priority by staff), but they also did not facilitate the depth of discussion desired by some participants. This is highlighted in wider literature, where nurses have reported views about which aspects of care are most important to patients, which differ from patients' own views (Young et al., 1996). In the current study, differences of opinion between women and staff were also noted in relation to Macmillan Cancer Support branding, where staff incorrectly perceived that women associated the charity with death and dying – a subject that often elicits anxiety in those with cancer and the general public (Mosher & Danoff-Burg, 2007). Consequently, staff preferred to avoid associating themselves with the brand. Similar issues can be found in the wider literature on marketing, where 'brand resistance' occurs when there is a perceived difference in values, or there are social risks of stigma associated with the brand (Cambefort & Roux, 2019). In relation to Macmillan Cancer Support, staff members' desire to disassociate themselves from the charity appeared to stem from a difference in values and priorities (primarily in Case Study 1), and a wish to prevent women from the misinterpreting the severity of their diagnosis.

7.5.2.6 Knowledge and Training

As a final consideration, staff implementing the (e)HNA reported insufficient training and knowledge about the assessment. This, alongside other factors (such as targets and feeling compelled to complete (e)HNAs), led to a lack of buy-in. However, some staff took it upon themselves to conduct their own background research into the (e)HNA to bridge knowledge gaps, demonstrating motivation to deliver the assessment to a high standard. Inadequate knowledge and training to conduct (e)HNAs is a finding which is consistent with the (e)HNA literature identified through the scoping review (Biddle et al., 2016; Mitchell, 2017). It is also supported by wider research literature, where insufficient training and confidence led to nurses delivering health promotion interventions unsuccessfully (Burke & Fair, 2003) or cancer-specific advice (Wallace et al., 2015). The concept of 'coherence' in NPT is again relevant, highlighting the need for staff to understand their responsibilities and tasks, and to believe in the value of the intervention for it to work well (May et al., 2015). As such, study participants who attempted to increase their own knowledge through additional research into the (e)HNA appeared to report more positive views about the assessment. This highlights the importance of depth of understanding for the successful integration of the intervention.

In this study, some staff behaviours also suggested low confidence, including not responding to women's cues which indicated a need for emotional support in some cases. The wider literature on discussing emotionally challenging topics highlights the potential for support-seeking cues to be disregarded (Jansen et al., 2010). This is consistent with scoping review findings, which highlighted doctors' dismissal of psychological concerns raised in (e)HNA consultations (Lambert et al., 2018; Mitchell et al., 2012). Jansen et al. (2010) termed these actions 'distancing behaviours', because they discourage the discussion of the patient's concerns (for example, by changing subject or giving inappropriate responses). Furthermore, distancing behaviours have been found to limit disclosure of concerns, and occur due to staff feeling they have inadequate time, or low confidence (Jansen et al., 2010). In contrast, 'facilitating factors' (such as summarising discussions and picking up cues), appear to contribute to more thorough assessments (Jansen et al., 2010).

7.6 Conclusion

This chapter’s use of wider literature and a theoretical framework has situated conclusions from the previous three findings chapters in a broader context. This exploration has enabled further refinement and interpretation of study findings, and builds upon the principles of Chapter Six’s cross-case analysis. Additional insights from NPT and the wider literature highlight aspects of the (e)HNA’s implementation process that appeared insufficient, and suggested a paradox between the aims and the reality of the (e)HNA's value in supporting women. Although individual perceptions remain key to these issues, the discussion also focused on cultural considerations, such as top-down or bottom-up management styles, hierarchical leadership structures, and the organisational priorities, which influenced the (e)HNA’s contribution to the support of women with breast cancer. The final conclusions of the thesis are presented in Chapter Eight, alongside recommendations for applying new knowledge in clinical practice settings where the (e)HNA is delivered.

Figure 86. Chapter Seven Key Points

Chapter Seven Summary: Key Points

- Use of NPT as a theoretical framework provides a way to understand the (e)HNA's delivery and limitations of its integration. This includes the assessment's implementation appearing superficial and still a 'work in progress', despite having been in place for several years. This also highlighted the lack of reflective processes undertaken by staff, which affected how they delivered the (e)HNA, and how women subsequently perceived it.

- The discussion of key findings about the influence of women's perceptions on the (e)HNA's contribution included exploration of engagement and openness in the completion of assessments, as well as individual understanding of, and preferences about its delivery. These findings supported and challenged what previous literature highlighted, including possible reasons why participants may have preferred home/online (e)HNAs, or why they desired to tailor (e)HNA answers to benefit staff.

- In the discussion of staff perspectives, key findings were explored within wider literature, including organisational culture, role perceptions, assessment quality and implementation, and uncertainties surrounding the assessment process. This provided a clear overview of the importance of organisational considerations, such as targets, implementation processes, staff's competing priorities, and team dynamics which influenced the (e)HNA's value in producing meaningful assessments.

Chapter Eight: Conclusions and Recommendations

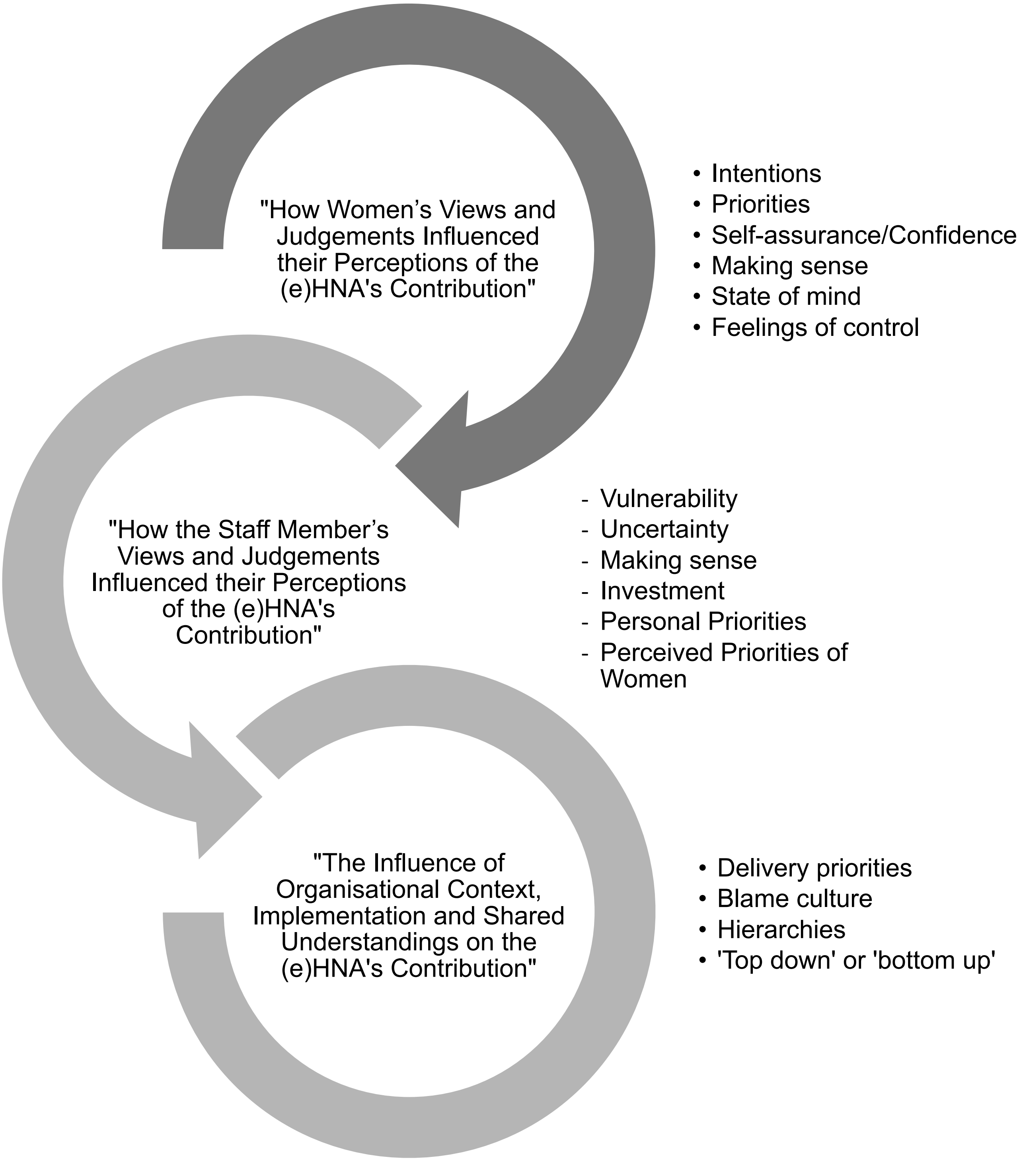
8.1 Introduction

The final chapter of the thesis presents the study's overarching conclusions, in response to the research question 'how does the (e)HNA contribute to the assessment and support of the holistic needs of women living with or beyond breast cancer?' To present these conclusions, key findings are described in an initial summary, which highlights a trio of key influences on the (e)HNA's contribution to women's experiences of support through their cancer journey. Subsequently, the chapter describes a series of recommendations, to apply to clinical practice settings where (e)HNAs are delivered.

8.2 Summary of Findings

Detailed summaries of findings were presented in Chapters Six and Seven, which showed that the (e)HNA's contribution was subject to a number of interlinking factors. However, when combining the in-depth Framework Analysis processes from Chapters Four-Six, with Chapter Seven's additional insights from wider literature and theory, this highlighted a trio of influences on how meaningful the (e)HNA was to women's experiences of support. Figure 81 in Chapter Six (p363) highlighted the impact of both women and staff's views and judgements on how they perceived the (e)HNA. This is built upon through the addition of 'the influence of organisational context, implementation and shared understandings' as a third, central influence on the (e)HNA's contribution, shown in Figure 87.

Figure 87. Trio of Influences on the (e)HNA’s Contribution



- Intentions
- Priorities
- Self-assurance/Confidence
- Making sense
- State of mind
- Feelings of control

- Vulnerability
- Uncertainty
- Making sense
- Investment
- Personal Priorities
- Perceived Priorities of Women

- Delivery priorities
- Blame culture
- Hierarchies
- 'Top down' or 'bottom up'

8.2.1 How Women and Staff’s Views and Judgements Influenced their Perceptions of the (e)HNA’s Contribution

As described in previous chapters, the connections between participants in the typological categories highlighted that the (e)HNA’s contribution as perceived by women, ranged from beneficial to potentially harmful, introducing a paradox between the aims of the (e)HNA as a supportive tool, and the reality of its use. Where the woman’s experience appeared on this spectrum appeared to be dependent on a range of factors, shown in Figure 87 above.

This section provides a summary of elements which appeared to influence women’s perceptions. Firstly, some women reflected **‘intentions’** towards how they engaged with the (e)HNA, which ranged from intentions to avoid discussion of their concerns, through to full disclosure of their worries to seek emotional support. Secondly, intentions connected to women’s **‘priorities’**, including whether their priority at diagnosis was to leave the hospital quickly, or to be punctual for appointments that followed their (e)HNA. Their priorities appeared to affect perceptions of how meaningful the (e)HNA was. Women’s prioritisation of the (e)HNA appeared to be a question of finding a balance between engaging with support offered by the assessment, the risk of leaving family members at home if they had caring responsibilities, or the risk of being judged by staff for disclosing concerns that were thought to be embarrassing or of little importance.

Women were also affected by what they perceived staff members’ views were. This appeared linked to their **‘self-assurance/confidence’** in completing the assessment. Some women reported low confidence or requested clarification about the correct way to complete (e)HNAs.

This seemed to highlight their desire to complete it in the ‘correct’ way, from the staff perspective (or to make it useful for staff). Moreover, women’s interpretation of why they were completing the assessment, appeared to be a significant influence on its contribution. **‘Making sense’** or misunderstanding of the (e)HNA sometimes led to high expectations of its what it was able to deliver, which may have caused the feelings of disappointment. Furthermore, not understanding its purpose led to others feeling obligated to comply with completion. Terminology such as 'holistic' was ambiguous to several participants, and presented further challenges in understanding the assessment's purpose and how they engaged with it.

Finally, women’s **‘state of mind’** and views about **‘feelings of control’** seemed to influence the (e)HNA’s contribution to their experiences of support. This was dependent on how much support women felt they required, whether they felt emotionally able to process the assessment (if offered at a difficult time), and how able they felt to self-manage their concerns. Furthermore, if women thought they could manage on their own, they may not have been as forthcoming about their concerns during the (e)HNA. However, even when women felt they did not require support from the (e)HNA at the time they completed it, undertaking the assessment and receiving a care plan enabled some participants to feel as though they had a safety net to stay connected to support. This was also useful if the (e)HNA was repeated.

Staff members’ views of the (e)HNA also appeared dependent on multiple influences, with some reporting feelings of **‘vulnerability’**, or defensiveness about the (e)HNA potentially undermining their role. Despite this, many staff felt that the care plan provided evidence of the support given, or was a record of their actions that could be used as evidence of good practice. However, many staff demonstrated **‘uncertainty’** around the ‘right’ way to conduct an (e)HNA discussion, as their interpretations of this differed widely. Similarly, staff members' '**making sense'** of the (e)HNA varied, including how they weighed up the potential benefits and burdens of its implementation, and how this affected their **'investment'** or buy-in to using the (e)HNA. Some staff suggested women completed (e)HNAs incorrectly, because they raised concerns irrelevant to cancer. Generally, poorer understanding of the (e)HNA appeared related to negative opinions and resistance to its implementation, and many staff indicated a desire for more clarity or training needs in conducting meaningful (e)HNAs. Additionally, their positive and negative views often translated into how the women themselves perceived the assessments.

The **'personal priorities'** of staff were also important in their approach to (e)HNA delivery. Assessments often appeared to be low priority tasks, and they reported that some aspects of the (e)HNA received greater priority than others. For example, some staff prioritised the outcome of delivering an (e)HNA discussion that was meaningful for women (more pronounced in Case Study 2), and others prioritised achieving their local targets, particularly in Case Study 1. Some staff also considered '**perceived priorities of women'** in their (e)HNA delivery approach, by altering timing and venue of assessments, based on what they expected women to find important, such as reducing the frequency of hospital visits. Despite this, many staff remained uncertain about what women's preferences actually were.

8.2.2 The Influence of Organisational Context, Implementation and Shared Understandings on the (e)HNA's Contribution

Considering the (e)HNA's implementation beyond decisions made by individual staff, it is clear that practice and preference variations existed between case studies. Particularly in Case Study 1, a focus on achieving local targets and preferences for telephone (e)HNAs were reflected across the breast team. Additionally, a strong influence on (e)HNA delivery from leadership teams was apparent, as staff in both case studies perceived a responsibility to evidence their actions, which was particularly evident in Case Study 1. The need to provide evidence was reflected in defensiveness in staff members' views and behaviours, which suggested that they expected to be challenged about their practice. Consequently, this appeared to affect (e)HNA delivery, by increasing the focus on providing evidence and meeting targets rather than meaningful (e)HNAs. Hierarchies within the staff structure also seemed to influence how participants delivered the (e)HNA, demonstrated by support workers (SW) making judgements about which aspects of care required a registered nurse. However, there was no significant difference in the data to suggest that one staff role performed increasingly meaningful (e)HNAs over another. Some staff also perceived that the influence exerted by those in leadership positions translated into the (e)HNA implementation approach taken by the team. This appeared to differ in terms of whether it was management-driven ('top-down') (Case Study 1), or whether decisions were made from a combination of management, frontline staff and patient-driven approaches ('bottom-up') (Case Study 2). This contrast was reflected in Case Study 2, specifically through the example of frontline staff feeling able to change their practices depending on how successful they felt the (e)HNA delivery methods were, as opposed to these decisions being made solely by those in leadership roles (as was indicated in Case Study 1). The generally more positive attitudes noted in Case Study 2 suggested that the combination of top-down and bottom-up approaches to implementation may have been more successful.

Overall, the organisational cultures (shared beliefs, attitudes and customs which both restrict and stabilise the behaviours of a group)

(Schein, 2004) present within each case affected how individual staff appeared to approach their assessments, and how women subsequently perceived these (such as leadership style, and staff perceptions of their ability to initiate change). Predominantly in Case Study 1, staff members' motivations to undertake (e)HNAs seemed driven by feelings of obligation, alongside pressures to achieve targets. Some core features of the successful implementation of innovation (including staff's knowledge, buy-in and reflective practice) appeared absent in both organisations (highlighted in the discussion of Normalisation Process Theory in Chapter Seven). Therefore, delivery of the (e)HNA appeared superficial in these case studies, and Case Study 1 in particular seemed to focus on ensuring (e)HNAs were completed, rather than supporting reflection and understanding of the process that women appeared to find valuable.

Overall, many women's and staff members' opinions of the (e)HNA highlighted limitations in the support it provided, which was wholly ineffective in some cases. Despite this, many participants (particularly women) indicated that the (e)HNA had the 'potential' to make a positive contribution to their experiences of support. The focus on the (e)HNA's 'potential' suggests a need for culture change in their delivery, moving away from task-orientated approaches, and staff introductions which focused on their obligation to achieve targets. Whilst some participants indicated that the (e)HNA tool itself appeared to be an important aspect of the assessment process (based on its ability to encourage reflection on concerns, or assist staff with prioritising concerns), it did not appear to be useful in supporting women's needs unless it was completed under the 'right' set of circumstances for that individual.

8.3 The Study’s Contribution to Gaps in the (e)HNA Literature

In Chapter Two’s scoping review, several evidence gaps were highlighted in relation to the (e)HNA. For example, previous studies evaluating the (e)HNA reported staff members’ negative perceptions of it, but little evidence to explain these views. Furthermore, implementation issues existed, such as how, when and where to offer (e)HNAs, and some staff lacked confidence in making decisions about these factors. The scoping review findings also highlighted non-disclosure of concerns in (e)HNAs as an issue, but further exploration was required to understand the reasons why women might withhold their concerns, and what impact this might have on the value of their (e)HNAs. Additionally, the scoping review also showed that there was a lack of research exploring the (e)HNA’s contributions from the patient’s perspective. Instead, much literature focused on the outcome of the assessments, often by quantifying referrals to other services, or by determining if the assessment had accurately captured patients’ concerns compared to other tools.

This thesis has provided greater depth of understanding of participants’ experiences, around the key issues which affect the (e)HNA’s delivery and its contribution. The study has captured that although (e)HNAs may successfully elicit women’s concerns and meet local targets, the process of delivering these assessments is more complex.

Firstly, an in-depth understanding of the reasons for negative perceptions of the (e)HNA was uncovered. This included staff’s feelings of obligation embedded within their organisational hierarchies, through to considerations of how (e)HNAs conducted at the ‘wrong’ time, could change an opportunity to receive support into a burden, pressure, or something entirely paradoxical. Secondly, the study provided a better understanding of the low confidence issues affecting staff, which stemmed from their lack of training, inexperience in addressing non-cancer related concerns, and the challenges of finding the ‘right’ way to deliver an (e)HNA when women’s preferences were so diverse. Thirdly, resistance to change is a widely researched phenomenon, but this study allowed an understanding of it in the context of (e)HNA delivery. Organisational culture, the repeated unsuccessful introduction of different (e)HNA tools, and the importance of staff’s understanding of the assessment, were influential on how it was delivered. Furthermore, women’s experiences of the support provided from the (e)HNA were dependent on how they engaged with it. This study has shown engagement to be influenced by other priority factors in women’s lives, personal characteristics (such as feelings of control), readiness to explore their feelings, understanding of the (e)HNA, and perceptions of where disclosure of concerns might lead. Overall, exploring the in-depth experiences of women showed the potential of the (e)HNA to offer a positive contribution to their experiences of support, but also showed that the delivery processes were not yet conducive to providing this. No literature within the scoping review considered both women’s and staff members’ perspectives on the (e)HNA. Exploration of both viewpoints together facilitated greater understanding of how the opinions and delivery methods adopted by staff translated into opinions and meaningful outcomes for women.

8.4 Application to Clinical Practice

The summary of findings shows that a shift in how the (e)HNA is presented and delivered to both staff and women, may lead to increasingly valuable assessments. Only a small proportion of health research is translated into clinical practice settings. An increased focus has therefore been placed on using evidence-based findings to improve the quality of healthcare (Tabak et al., 2012). Therefore, findings from the current study are considered in their application to healthcare settings, through a series of practice recommendations. This focuses on five core components of the (e)HNA delivery process: the introductions given, practicalities, use of targets, the care planning conversation, and the care plan document. These recommendations are aimed at leadership teams and frontline staff, and focus on improving elements of the (e)HNA process that this study has shown were crucial to developing more meaningful assessments.

The recommendations that follow are applicable to both management and frontline staff involved in the (e)HNA's direct delivery. A critical approach was taken to their development, incorporating deliberation from the study's Patient and Public Involvement and Engagement Group (PPIE) (described in Chapter Three). This considered each recommendation in terms of wording, and suggestions they identified. The recommendations are based on five key areas of focus:

- How the (e)HNA is introduced to women
- Practical considerations
- Targets and resistance
- The care planning conversations
- The care plan document

8.4.1 How the (e)HNA is Introduced to Women

1. Introductions should focus on reframing the (e)HNA to emphasise the benefits to individuals with cancer, and should include an outline of the assessment's purpose and set out reasonable expectations, to remove any inference that the

assessment is beneficial for staff to achieve their targets. Clear information should set the scene, including how long appointments last, what happens next (for example verbal discussion of concerns, action planning), and information about the care plan and its function.

2. Leadership teams should encourage ‘bottom-up’ approaches to implementation, alongside existing ‘top-down approaches’. This allows staff a degree of flexibility to be involved in decisions about how the (e)HNA is offered to their patients, and maximises staff engagement with the process.

3. Staff should be reflective when using the (e)HNA, and have awareness of their unconscious biases (such as the assumption that patients will dislike Macmillan Cancer Support), to minimise the risk of these influencing consultations. For example, by reflecting on language used, or any assumptions made.

4. Staff should adjust their expectations of acceptable ways to deal with concerns and not expect to ‘fix’ everything. Some individuals emphasised that reflecting through the (e)HNA allowed them to process and move on from concerns raised, without the requirement for specific actions. Therefore, asking the individual about their goals for the (e)HNA discussion may help to determine a course of action for them.

5. The scope of the (e)HNA should be identified and agreed within an assessment encounter. Both staff and women referred to not knowing ‘what counts’ as a concern, and highlighted that many concerns raised were not relevant to

their cancer. Therefore, a clear picture of the (e)HNA's scope should be provided, to focus on aspects of their life exacerbated by their cancer diagnosis (for example, if they have a pre-existing cough which worsened during treatment). This explanation should be included in the (e)HNA's introduction, or adjusted if deemed appropriate for specific patients.

8.4.2 Practical Considerations

1. Staff should consider use of video (e)HNAs, especially during the current COVID-19 pandemic, but also as a longer-term solution. These may provide more effective communication than telephone methods (ability to interpret non-verbal communication), whilst simultaneously reducing additional hospital trips.

2. 'Cut-offs' in how (e)HNA concerns are dealt with should consider an overall picture of support needs, alongside scores. Some people completing the (e)HNA have concerns which require support, but may not score their concern 'high enough'. Therefore, assessments should look beyond scoring (which may not reflect the true seriousness of concerns, or urgency of need) to determine actions taken. For example, body language, or discussion of concerns which might imply concerns are more severe than scoring suggests.

3. Staff should consider patterns of concerns raised by individuals in their (e)HNAs. Many concerns within the assessment are linked, so focusing only on the highest-scored concerns may cause issues to be missed. For

example, if 30 concerns were raised in an (e)HNA, and the five highest-scored were emotional concerns, staff time pressures may mean that these become the sole focus of the discussion. However, considering the assessment as a whole may draw attention to key areas requiring support, through identifying patterns (for example, ‘anxiety’, ‘difficulty sleeping’ and ‘uncertainty’ are entirely separate concerns, but may all result from worry about upcoming treatment). Therefore, considering patterns of concerns could facilitate a more comprehensive and productive discussion.

8.4.3 Targets and Resistance

1. Leadership teams should ensure frontline staff are informed about the ‘bigger picture’ of (e)HNA implementation nationally (as being part of the national ‘personalised care’ agenda, for example), to broaden their views of how this factors into the individual’s cancer journey. This may improve engagement and help to develop a greater understanding of the (e)HNA, as part of a national programme of work.

2. Local targets could be broadened to focus on ensuring individuals are offered support, as opposed to solely measuring this through the quantity of (e)HNA offers. For example, one individual could decline their (e)HNA, but make twelve phone calls to their breast care nurse (BCN), leading to service referrals for benefits advice and psychological support.

3. Audit tools could be developed to capture a range of support provision and have an increased focus on quality. For example, care plan audit tools could be designed, to identify

positive and negative traits of care plans (such as those described on p349-351) and highlight areas of training needs. Further examples of measures to support this could include patient experience surveys, quantification of support calls made to the breast team, and audits to consider patterns of (e)HNA activity, such as high numbers of declined assessments, and following up with patients to ascertain whether their care plan recommendations were useful.

4. Successful (e)HNA implementation requires a culture change, moving away from the focus on target achievement, and towards valuable outcomes for people with cancer. This may be facilitated by use of language which describes the personalised nature of the tool without the ambiguity, such as 'personalised care and support planning' (aligned with the national personalised care agenda). Additionally, the introduction staff receive to the (e)HNA should move away from the focus on quantity alone, and promote those delivering it to have a thorough understanding of its complexity and nature as a tool to support meaningful conversations.

8.4.4 The Care Planning Conversation

1. The (e)HNA and subsequent discussion should be offered in multiple formats. This allows completion of the assessment at home whenever desired, based on the benefits of privacy, fewer time pressures, and the ability to reflect on concerns without staff present.

2. Creating a safe space is important. However, meeting the same staff member for consultations is not always possible, so adopting communication skills to establish trust before an

assessment may facilitate disclosure of concerns.

3. Draw attention to the ‘sensitive’ concerns. People are worried about being judged, raising embarrassing concerns, or concerns they think others would perceive as unimportant. Referring to this kind of concern directly provides extra permission to discuss these.

4. Decisions to involve different professionals in an (e)HNA should depend on practicalities (such as available time) or specialist needs (such as requiring high-level emotional support or psychology input), as opposed to scores in assessments, as the staff member's role did not appear to influence how meaningful assessments were.

5. As the (e)HNA tool alone was not sufficient to support women's needs in the absence of a valuable conversation and the 'right' set of circumstances, staff training in delivering the care planning conversation should focus on the significance of this process being meaningful. This could be maximised through ensuring their clear understanding of the (e)HNA's purpose and value for women, generating confidence to make decisions about the appropriate course of action, understanding how to have an effective (e)HNA conversation, and what/what not to include in a care plan, based on the traits women found most useful.

8.4.5 The Care Plan Document

1. Repeating the (e)HNA and revisiting care plans were viewed as important to patients. This was experienced as supportive,

and reflecting on progress was a powerful way to reassure and empower people.

2. Individuals should be given some ownership over completion of the care plan. Furthermore, making it clear that the aim is to support them may balance power dynamics, and reduce misconceptions about the (e)HNA's purpose (for example that non-compliance with the (e)HNA would be detrimental to care).

3. Although some elements of (e)HNA's delivery appeared to call for greater staff autonomy, certain components also required less autonomy and more structure. For example, guidance on how care plans should be completed, and what should and should not be disclosed in these.

4. Key elements should be considered when writing care plans, to show patients that an individualised and supportive approach has been taken to meet their support needs. Table 51 highlights a range of features and corresponding explanations which participants in the current study highlighted as important care plan attributes (adapted from Chapter Six). Use of these may therefore be valuable in improving the quality of care plans.

Table 51. Care Plan Quality Improvement

Feature	Explanation
Display listening	People may open up about their deepest concerns and experience a range of emotions. It is important to show these have been listened to, by documenting any answers to questions asked (which also provides a prompt to remember responses, if the information is not retained at the time).

Offering solutions	Where possible, offering solutions can be important in showing support, and giving the individual ownership in self-managing their concerns. As such, it is valuable to provide the individual with tasks they can do for themselves, no matter how small these might seem.
Supportive	The care plan is not just about description of the discussion and actions. The style of writing should incorporate a supportive presence, which highlights the individual's positive progress to support their own health and wellbeing. The author of the care plan should consider the individual as the main audience for the care plan, rather than only a means of evidencing good practice.
Mindful of fears	It is important to consider the diverse emotions individuals are experiencing during their cancer journey. Any information which can lessen their anxieties or their apprehension during long waits can be meaningful.
Showing dedication	Although addressing a full list of concerns can be time-consuming, it is important to show the individual that staff are dedicated to supporting them. Addressing concerns should also be driven by the needs of the individual, and how much support they feel they require (rather than by (e)HNA scores alone).
Giving time	Showing the individual that staff are prepared to invest their time in them does not only apply to the (e)HNA discussion itself. This can also be translated into the care plan, and the effort taken to write this.
Enabling self-management	Awareness of how individuals' personal circumstances affect their ability to follow recommendations is important. Therefore, recommendations should be practical and achievable. For example, identifying services that are geographically nearby, accessible online, and ensuring contact details are available for patients to ask questions if necessary.
Unrestricted support	At the point of an (e)HNA discussion, individuals may not feel they require support, may forget to raise concerns, or may not wish to disclose them in that environment. Therefore, the care plan should indicate an open offer of support, which they can access if/when they require it.

Consideration of needs, priorities and values	Individuals appreciated the personalisation of care based on what mattered to them, and how they were feeling. This might include acknowledgement of their inability to access a service at this time due to other responsibilities (and so it is helpful to repeat the offer in a subsequent consultation), or acknowledgement of their preference for one-to-one support rather than group supportive sessions.

Considered together, these recommendations serve to translate the key findings of this study into a strategy to improve the quality of (e)HNAs, with a view to increasing their value to women.

8.5 Study Limitations

Although this study has contributed new insights about use of the (e)HNA, a number of limitations were identified.

Overall, the sample of study participants was an effective one. It enabled in-depth exploration of people's experiences, which led to the development of strong, key themes that contribute to an expanding evidence base on (e)HNAs. This study's methods could be used to conduct further research into experiences of the (e)HNA, and provide additional data on implementation pathways for this important intervention. However, this was a qualitative study conducted with a purposive sample of women, meaning that it was not possible to reflect the views of everyone who completed (e)HNAs at the study sites. Different experiences of care may have been identified in a larger sample. Additionally, the study was undertaken in two organisations, covering three breast teams. Therefore, despite emergent issues related to organisational culture and challenges identified, different organisations may have approached the (e)HNA's implementation differently and had variable experiences. Furthermore, the study was conducted with women who had breast cancer and were of a white, British ethnicity (except one participant). Consequently, the contribution of the (e)HNA may be different for people with other cancers, or those from different ethnicities or cultural backgrounds.

As discussed in Chapter Three, several factors made it challenging to undertake observations in the study. Consequently, less (e)HNA consultations were observed than were initially planned (for example, it was only possible to conduct one period of observation in Case Study 1). The contribution of participants' (e)HNAs were also challenging to monitor. For instance, if an individual received a psychologist referral, recommendations to attend support groups, and information leaflets based on their (e)HNA, these interventions have an impact over time, so their contribution can only be properly evaluated longitudinally.

Finally, Chapter Three's discussion of reflexivity highlighted the requirement to acknowledge the researcher's influence on interpretation of the study data. Whilst every attempt was made to maintain a neutral position, the study was approached from the perspective of existing knowledge of the subject matter, which may have carried over into data collection and analysis. Alongside this, informal discussions with staff prior to their recruitment highlighted more extreme views (primarily negative) about the (e)HNA, which were less apparent in research interviews. My presence as the researcher may have influenced the nature of the content raised, and the openness with which questions were answered. Despite this possibility, the research data provided a wide range of perspectives, including numerous reflections on the shortcomings of the (e)HNA. Therefore, it is likely that the views expressed in interviews did not censor key viewpoints, and provided access to a wide range of experiences, positive and negative.

8.6 Recommendations for Future Research

The summaries of findings and limitations set out above highlight further gaps in the research evidence that require exploration. These include:

- Detailed exploration of the organisational cultures impinging on the (e)HNA, in a diverse range of environments (for example community settings where the (e)HNA is delivered).

- Greater in-depth analysis of the different communication styles and behaviours used by staff (such as ‘distancing’, discussed in Chapter Seven) and their influence on (e)HNA outcomes.

- A focus on care plan outcomes and where these lead (for example who the care plan is shared with, if it is read, and if it is acted upon as part of a cycle of care).

- Increased understanding of how a wider cross-section of healthcare professionals view the care plan (for example staff working in community or general practice settings, or nursing staff in other hospital environments, such as inpatient).

- Observation of telephone/video (e)HNA’s to identify the characteristics of these, and to determine whether telephone assessments can provide effective (e)HNAs.

- Consideration of the differences in (e)HNA discussion quality when led by different types and levels of staff, and whether key learning can be used to produce any overarching guidelines.

- Longitudinal consideration of individuals completing the (e)HNA to consider outcomes over time (in the case of interventions whose impact is only apparent over time).

8.7 Conclusion

This study has captured the complex factors which exist within (e)HNA practice. From a staff perspective, this understanding extended from their personal interpretation and priorities, through to the influence of their organisational culture and its approach to implementation. From the perspective of women, a recurrent theme was the concept of the (e)HNA ‘in principle’. For example, women perceived the assessment would have been more useful if it was undertaken at a more appropriate time, it was completed in privacy, or they had known the staff member prior to the (e)HNA appointment. What this highlighted was that despite issues with implementation and wider factors influencing its success, women felt that the (e)HNA had ‘potential’ to provide a meaningful contribution to assessing and supporting their needs. However, it appeared that the (e)HNA had not yet moved beyond being meaningful ‘in principle’ into meaningful ‘in practice’ for most individuals. Therefore, the (e)HNA tool itself did not appear to support women's needs, without the inclusion of an effective structure which enabled the provision of support. This structure included consideration of timing, venue, how the assessment was introduced, the value of the subsequent care planning conversation, the quality of the care plan and wider factors affecting each woman's perceptions.

Dissemination of recommendations to key stakeholders may help to reframe the emphasis of the (e)HNA. Specifically, this requires a culture change to maximise the delivery of meaningful assessments, as opposed to assessments which paradoxically led to negative experiences for women, based on prioritisation of targets or organisational goals. A transition appears necessary to move away from task-orientated (e)HNAs, to reflective (e)HNAs, which consider many of the wider factors applicable to the behaviour and knowledge of individuals. These factors include their understanding of (e)HNAs, willingness to disclose concerns, assumptions about the assessment process, and elements in their lives dictating their decisions which we cannot readily see.

For some individuals, the (e)HNA was an opportunity to talk, be listened to, and to access support, with the aim of making long-awaited changes to their lives. In order to provide this essential care, it is paramount that the (e)HNA facilitates the holistic, meaningful conversations it sets out to do, and that ‘holistic’ is not separated from the ‘needs assessment’.

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Appendix A- Contextual information about HNA tools

Sheffield Profile for Assessment and Referral to Care (SPARC)

The SPARC tool was initially developed in 2004 (Ahmedzai et al., 2005) by the University of Sheffield, in response to concerns that those with a palliative cancer diagnosis were not receiving access to adequate support (Hughes et al., 2015). As such, the tool has a palliative care focus and is therefore primarily used to assess individuals who are no longer undergoing treatment with the aim of curing their cancer (Richardson et al., 2005).

Quality of Life Assessment & Social Difficulties Inventory

A further assessment included in the eHNA is the Quality of Life Assessment, which appears to be made up from two assessment tools. These are the EQ-5D-5L instrument- which focuses on health-related quality of life and is not specific to cancer- (EuroQol Research Foundation, 2019), and the EORTC QLC-C30 which is a cancer specific quality of life measurement tool which has been widely validated and adopted (EORTC Quality of Life Group, 1995). However, the Quality of Life Assessment is one of the least adopted assessments within the eHNA platform (see Table 1), and informal conversations with Macmillan Cancer Support discussed above highlighted that inclusion of this questionnaire within the eHNA was based on NHS England requesting pilot testing of the EORTC QLC-C30 (MCS/NCSI Professional, 2019). The rationale for inclusion of the Social Difficulties Inventory (SDI) (Wright et al., 2011) appears to have been included for similar reason, and is the least frequently adopted assessment within the eHNA platform (reports indicated that this is potentially being removed from use in the near future) (Macmillan Cancer Support/NCSI Professional, 2019). This assessment was developed in 2011 in order to target the numerous social concerns which may affect an individual following their cancer diagnosis, such as day-to-day activities and financial issues (Wright et al., 2011).

London HNA

Despite the DT&PL being abandoned as the primary focus of the eHNA, a similar assessment with an added rating scale remains present within the eHNA in the form of the London HNA (O'Donnell et al., 2013). According to informal conversations, this is due to London-based members of the NCSI voicing an overall preference for inclusion of their adapted version of the DT&PL (The London HNA) within the eHNA, to which its continued presence can be attributed (Macmillan Cancer Support/NCSI Professional, 2019).

Finally, the personal communication with Macmillan Cancer Support also highlighted that the head and neck version of the Concerns Checklist was based on the work of Rogers et al. (2009), from work completed around the Head and Neck HNA tool called the 'Patients Concerns Inventory' (Macmillan Cancer Support/NCSI Professional, 2019; Rogers et al., 2009). The Head and Neck Concerns Checklist simply offers a small number of additional concerns prevalent in those treated for head and neck cancer (Macmillan Cancer Support/NCSI Professional, 2019).

Appendix B- Process for completing the Concerns Checklist

1. The assessment can be set up for completion at home (through accessing a weblink and entering a unique pass code), or in a hospital setting (using a tablet device set up on the eHNA website which can similarly be accessed using a unique pass code, or on a paper version).

2. When an assessment is set up, the staff member is also required to identify a time period for completion up to a maximum of 12 weeks. If not completed during the specified time period, the assessment is saved on the system as ‘expired’ and is no longer accessible.

3. When the individual with cancer begins their assessment, they are initially required to read a consent disclaimer and agree to this before proceeding to the assessment itself.

4. A series of screens are then presented listing a number of concerns, for example ‘caring responsibilities’, ‘work and education’, ‘money or finance’, and the individual is then required to click on any concern which is an issue for them. At this point, an additional box will appear asking them to rate the concern between 0-10 for severity before moving onto the next screen.

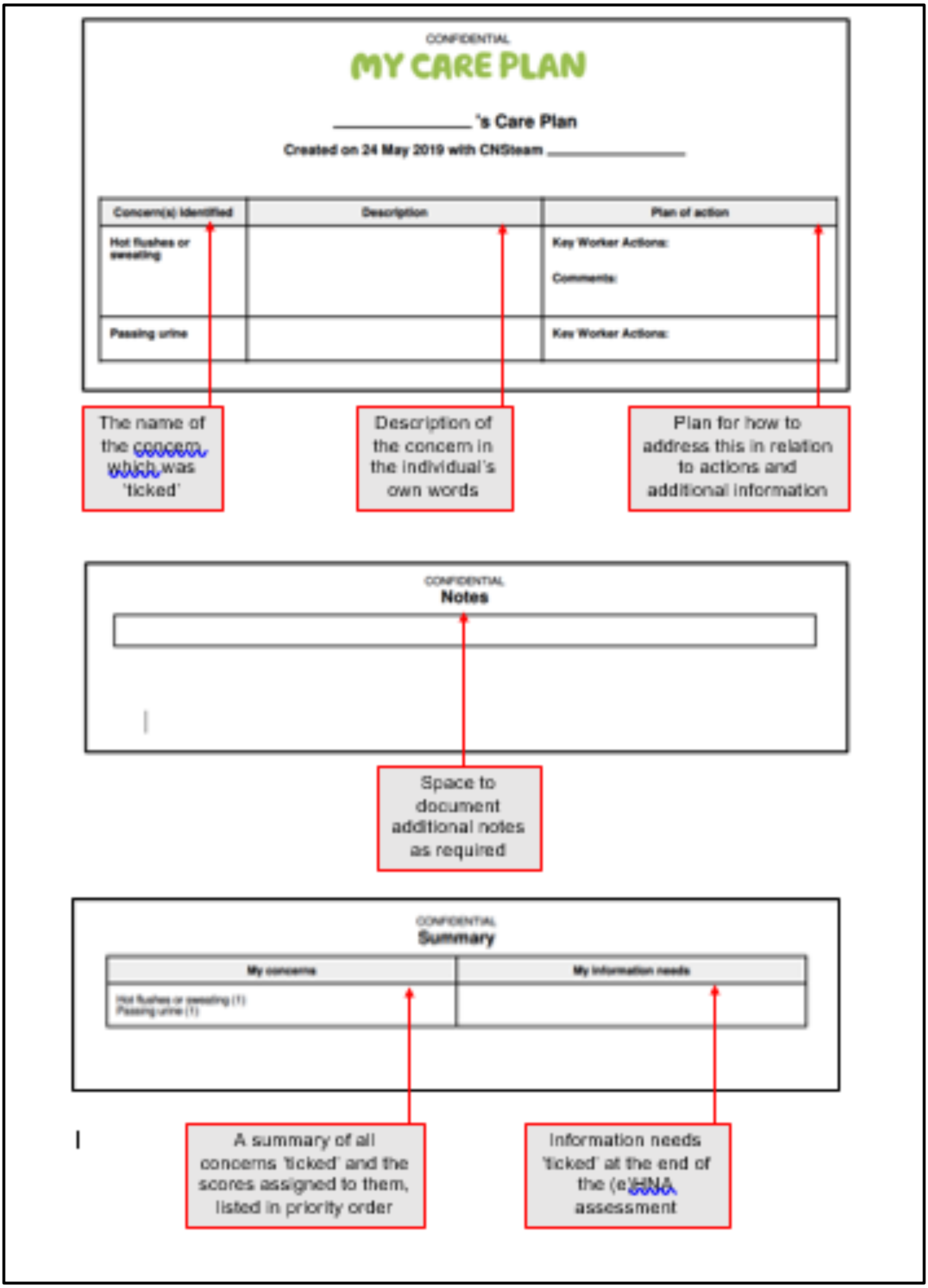
5. Towards the end of the assessment, an initial screen outlines ‘information needs’, such as ‘diet and exercise’ and ‘complementary therapies’ which can be ticked if the individual would like to receive further information.

6. A final component is whether the individual has questions about their diagnosis or treatment which is a further optional box to tick, before subsequently submitting the assessment.

7. Following this, the healthcare professional will then enter the online platform and complete a Care Plan, which includes the staff member entering a description of each concern (what the individual stated the specific issue was), followed by an action plan and any additional comments related to these actions. The structure of this Care Plan is demonstrated in Appendix C.

8. As a final step, the healthcare professional is required to choose options for how the Care Plan will be shared, for example whether this has been shared with or was declined by the individual, or was shared with the GP.

Appendix C- Example Care Plan



CONFIDENTIAL

MY CARE PLAN

_______________ 's Care Plan

Created on 24 May 2019 with CNSteam _______________

Concern(s) identified	Description	Plan of action
Hot flushes or sweating		Key Worker Actions: Comments:
Passing urine		Key Worker Actions:

The name of the concern which was 'ticked'

Description of the concern in the individual's own words

Plan for how to address this in relation to actions and additional information

CONFIDENTIAL

Notes

Space to document additional notes as required

CONFIDENTIAL

Summary

My concerns	My information needs
Hot flushes or sweating (1) Passing urine (1)	

A summary of all concerns 'ticked' and the scores assigned to them, listed in priority order

Information needs 'ticked' at the end of the (e)HNA assessment

Appendix D- PICo

Types of Participants

Participants in studies included in both stages of the review encompassed any adults (aged 18+). The systematic reviews referred to in the above 'Existing Reviews' section highlight the importance of the healthcare professional in undertaking assessments, but also a clear gap which is the perspective of the individual with cancer. As such, studies conducted with healthcare professionals and/or individuals with cancer were included. No restrictions were placed on the types of individuals within the included studies, other than having a cancer diagnosis (current or previous). The following healthcare professional groups were deemed suitable to be included in the review, based on their involvement in HNA processes:

Nurses or nursing support staff (registered or unregistered), doctors, psychologists, social workers, all Allied Health Professionals (Art therapists, drama therapists, music therapists, chiropodists, dieticians, occupational therapists, operating department practitioners, orthoptists, osteopaths, paramedics, physiotherapists, prosthetists, radiographers and speech and language therapists), local council workers (social care related roles), counsellors.

Concept

The key concept or phenomenon of interest was HNA tools in use since 2010. This time period was chosen, as despite initial recognition of the ongoing issues and needs of individuals with cancer appearing in policy from 2007, it was 2010 when the National Cancer Survivorship Initiative (NCSI) identified their vision and need for significant changes, which subsequently triggered the creation of guidelines and wider exploration of these issues (NCSI2013).

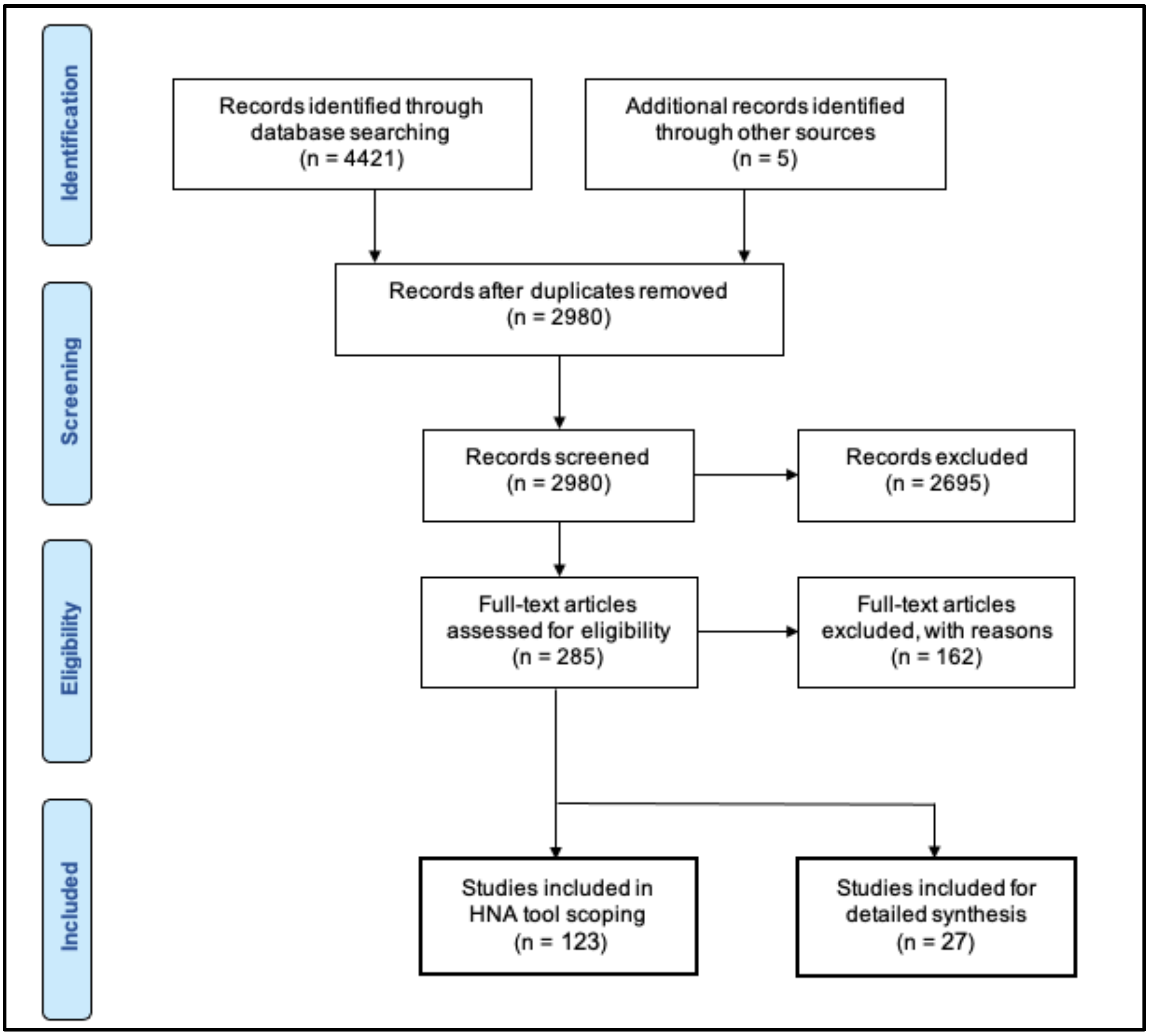
No limits were placed on whether the identified HNA tools were general or specific to one cancer type, with the only criterion being that the tool was in use for adult cancer patients (not solely for carers), and covered four of the identified domains of holistic needs as outlined in the 'situating the review' section above.

Context

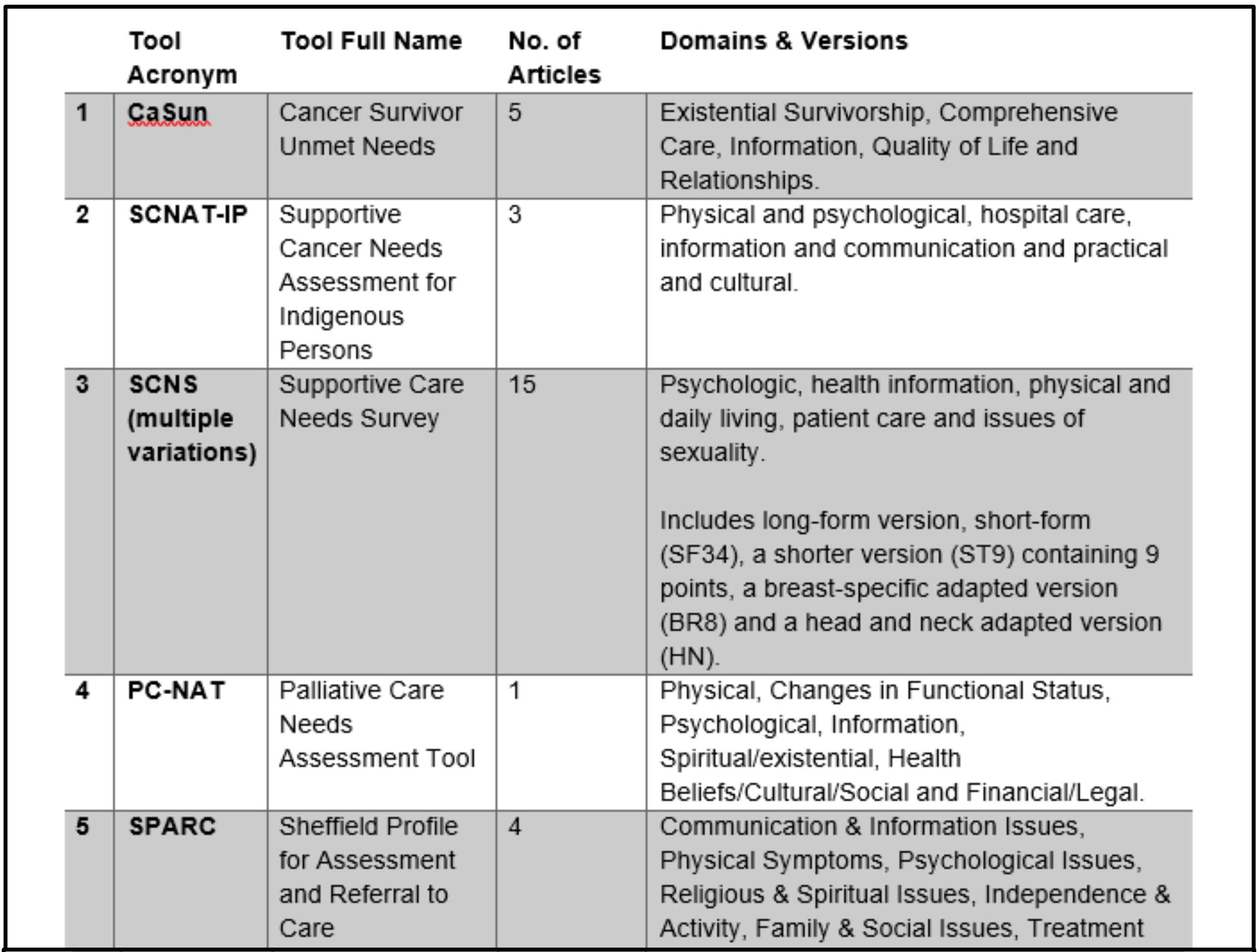
The criteria for included studies were designed to identify HNAs which occurred in any of the following contexts or settings:

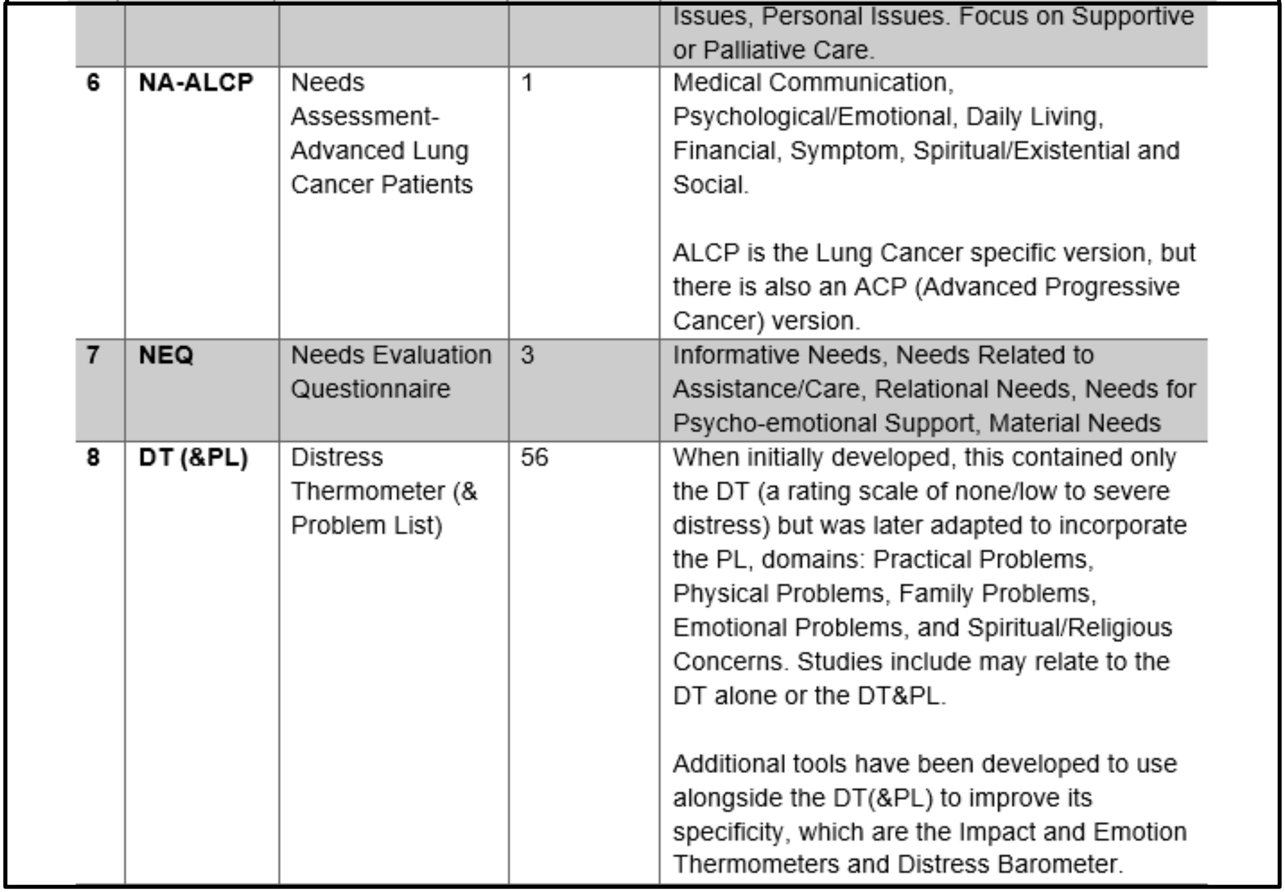
- Hospitals
- Primary care (such as general practitioner (GP) practices)
- Community organisations
- The individual's own home
- Telephone discussions
- Council or social care setting

Appendix E- PRISMA Diagram



Appendix F- HNA tools identified through scoping review





	Tool Acronym	Tool Full Name	No. of Articles	Domains & Versions
1	**CaSun**	Cancer Survivor Unmet Needs	5	Existential Survivorship, Comprehensive Care, Information, Quality of Life and Relationships.
2	**SCNAT-IP**	Supportive Cancer Needs Assessment for Indigenous Persons	3	Physical and psychological, hospital care, information and communication and practical and cultural.
3	**SCNS (multiple variations)**	Supportive Care Needs Survey	15	Psychologic, health information, physical and daily living, patient care and issues of sexuality. Includes long-form version, short-form (SF34), a shorter version (ST9) containing 9 points, a breast-specific adapted version (BR8) and a head and neck adapted version (HN).
4	**PC-NAT**	Palliative Care Needs Assessment Tool	1	Physical, Changes in Functional Status, Psychological, Information, Spiritual/existential, Health Beliefs/Cultural/Social and Financial/Legal.
5	**SPARC**	Sheffield Profile for Assessment and Referral to Care	4	Communication & Information Issues, Physical Symptoms, Psychological Issues, Religious & Spiritual Issues, Independence & Activity, Family & Social Issues, Treatment Issues, Personal Issues. Focus on Supportive or Palliative Care.
6	**NA-ALCP**	Needs Assessment-Advanced Lung Cancer Patients	1	Medical Communication, Psychological/Emotional, Daily Living, Financial, Symptom, Spiritual/Existential and Social. ALCP is the Lung Cancer specific version, but there is also an ACP (Advanced Progressive Cancer) version.
7	**NEQ**	Needs Evaluation Questionnaire	3	Informative Needs, Needs Related to Assistance/Care, Relational Needs, Needs for Psycho-emotional Support, Material Needs
8	**DT (&PL)**	Distress Thermometer (& Problem List)	56	When initially developed, this contained only the DT (a rating scale of none/low to severe distress) but was later adapted to incorporate the PL, domains: Practical Problems, Physical Problems, Family Problems, Emotional Problems, and Spiritual/Religious Concerns. Studies include may relate to the DT alone or the DT&PL. Additional tools have been developed to use alongside the DT(&PL) to improve its specificity, which are the Impact and Emotion Thermometers and Distress Barometer.

9	**PCI (multiple variations)**	Patient Concerns Inventory	7	Patient Concerns Inventory (including brain version and H&N version) Several versions have been developed, including two head and neck tools (after diagnosis and post-treatment), and breast cancer and neuro-oncology cancer specific versions.
10	**Pearlman-Mayo**	N/A	1	Physical Effects, Social Issues, Emotional Aspects, Spiritual Issues, Other Issues (including who to call and when), Health Information Needs
11	**CNAT**	Cancer Needs Assessment Tool	1	Physical Symptoms, Psychological Problems, Religious/Spiritual Concerns, Information, Family/Social Support, Finance/Job-Related Needs, Health Care Staff, Hospital Facilities/Services.
12	**CaNDI**	Cancer Needs Distress Inventory	1	Has 2 subscales for depression and anxiety, other domains: Emotion, Social, Health-Care, Practical and Physical
13	**3LNQ**	3 Levels of Need Questionnaire	1	Problem Intensity Items, Problem Burden Items, Felt Need Items, (Levels of Need) Additional Items (broadly covers Sexual Issues, Physical Issues, Psychological Issues, Social Issues, Healthcare). Developed for Palliative Care.
14	**SUNS**	Survivor Unmet Needs Survey	4	Emotional health, access and continuity of care, relationships, financial concerns, information needs. Also has short form version.
15	**S&CC**	Symptom and Concerns Checklist	1	Physical Symptoms, Cognitive/Psychological, Other Concerns (broadly covers practical, social and sexual concerns and experience of healthcare).
16	**SATp**	Self-Assessment Tool for Patients	1	Physical, Emotional, Social and Practical Concerns
17	**NAT**	Needs Assessment Tool	3	Considers some of the key domains as a prompt for conversation (not direct questions), domains of: Physical Symptoms, Practical, Psychological/Existential, Financial/Legal, Health Beliefs, Social & Cultural and Information. Has a Progressive Disease Cancer (PD-C) version.
18	**PCNA-EAV**	Palliative Care Needs Assessment-English/Arabic Versions	1	Physical/Functional, Social, Psychological/Emotional, Information, Communication, Helpful Resources, Financial, Religious/Spiritual and Priority of Need.
19	**Pepsi-Cola Aide Memoire**	N/A	1	Physical, Emotional, Personal, Social Support, Information Communication, Control and Autonomy, Out of Hours, Living with your Illness, After Care.

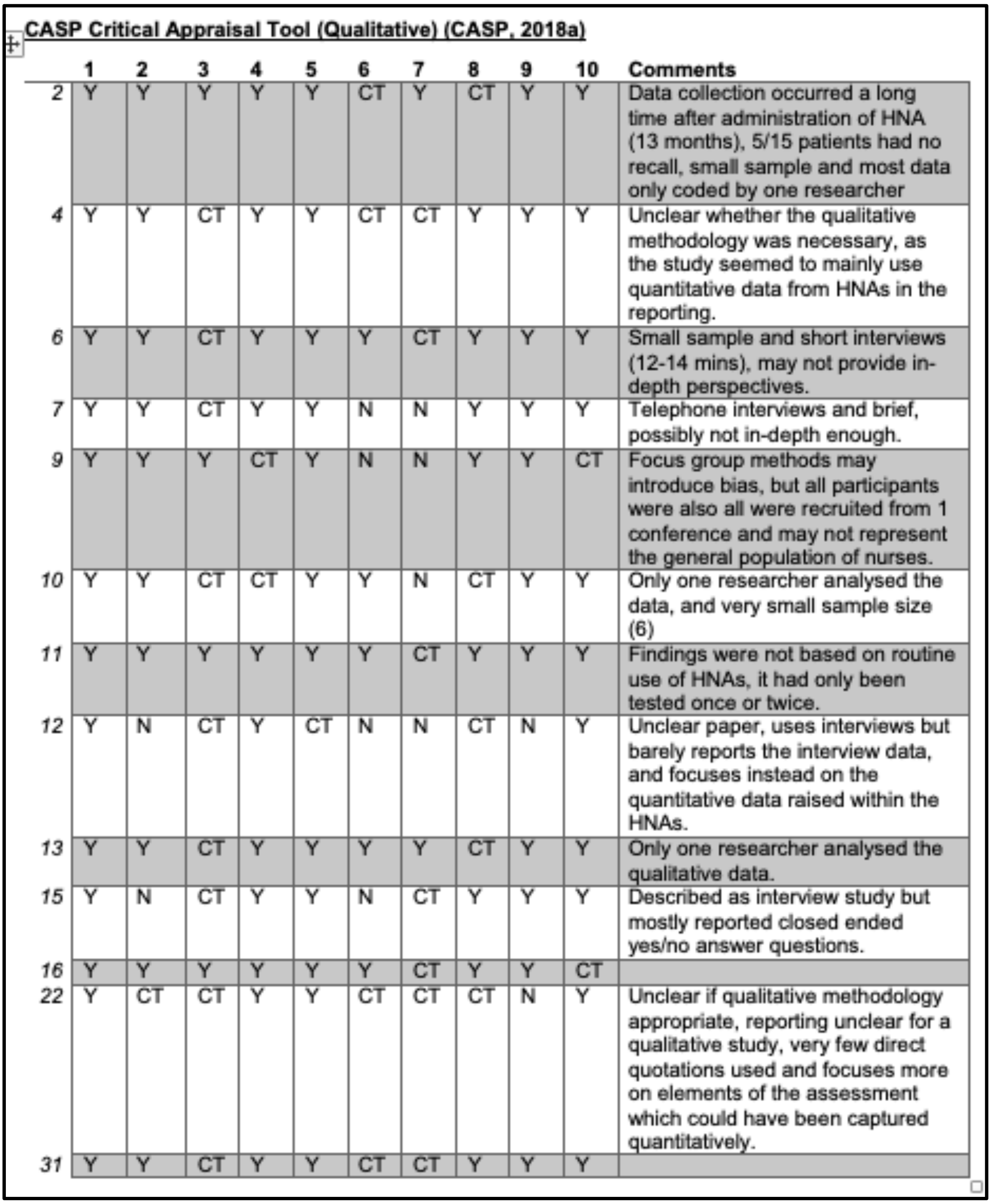
20	**CARES**	Cancer Rehabilitation Evaluation System	3	Physical, Medical Interaction, Psychosocial, Sexual, Marital, Miscellaneous (including Treatment and Finances). Also has Short Form version.
21	**PO BADO-SF**	Psycho-oncological Basic Documentation Short Form	2	Briefly covers Physical, Psychological, Social and Practical concerns. Also available in Long Form version.
22	**SNST**	Supportive Needs Screening Tool	1	Physical, Information, Psychological, Spiritual, Social and Other Suggestions.
23	**SNAP**	Survivorship Needs Assessment Planning	1	Focuses on Head and Neck Cancer. Physical, Psychological, Social and Practical.
24	**NFBrSI-24**	Functional Assessment of Cancer Therapy-Brain Symptom Index	1	Physical Wellbeing, Social/Family Wellbeing, Emotional Wellbeing, Functional Wellbeing, Additional Concerns (Functional Assessment of Cancer Therapy-Brain), Likert scale. There are many versions of this, including general. (Functional Assessment of Cancer Therapy- Lung) NFBrSI-24 is the Brain Version, and this is also available as a generic assessment called FACT (Functional Assessment of Cancer Therapy) and many other tumour site specific versions (including breast, bladder, colorectal, Cervix etc).
25	**CESC**	Spanish Questionnaire of Cancer Survivor Unmet Needs (Spanish)	1	Physical, Emotional, Social, and Practical.
26	**FADE**	Functional Analysis of Disease Effects	1	Basic questionnaire (containing 8 questions) Physical, Emotional, Social and Practical issues covered- the domains are ‘Personal Changes’ and ‘Functional Changes’.
27	**PDQ-BC**	Psychosocial Distress Questionnaire-Breast Cancer	1	Psychological Risk Factors, Anxiety and Depressive Symptoms, Social Problems, Physical Problems, Body Image, Financial Problems and Sexual Problems.
28	**SPEED**	Screen for Palliative and End-of-Life Care Needs in the Emergency Department	1	Social, Therapeutic, Physical, Psychological, Spiritual.
29	**NS-C**	Need Scale for Cancer (Korean)	1	Physical Symptoms, Diet and Exercise, Support; Relationship with Health Professionals, Treatment and Prognosis and Keeping Mind under Control.
30	**PNAP**	Palliative Needs Assessment in Palliative Care	1	Physical Symptoms, Social Area, Respect and Support from Health Professionals, Meaning of Life and Reconciliation, Autonomy, Chance to Share Emotions, and Religious Needs.

31	**SASN**	Self-Assessed Support Needs	1	Diagnosis, Treatment, Support, Femininity and Body Image, Family and Friends, Information and Aftercare.
32	**JAMES SCS**	James Supportive Care Screening	1	Emotional Concerns, Physical Symptoms, Social/Practical Problems, Spiritual Problems, Cognitive Concerns and Healthcare Decision-Making/Communication Issues.
33	**DS**	Distress Screener	1	Emotional, Physical, Functional and Social Wellbeing Domains. Adopts a Likert Scale that allows the individual to decide if they would like to: 'Talk with a Member of the Team, have the team, Provide Written Information, or Nothing Needed at this time' for each concern.
34	**eHNA**	Electronic Holistic Needs Assessment	3	Incorporates several tools into an electronic version (as discussed in Chapter 1), but users primarily adopt the Concerns Checklist option. Domains for Concerns Checklist (below) apply.
35	**CC**	Concerns Checklist	2	Physical, Practical, Emotional, Family or Relationship Concerns, Spiritual Concerns, Information or Support.

Appendix G- Critical Appraisal of Scoping Review Studies

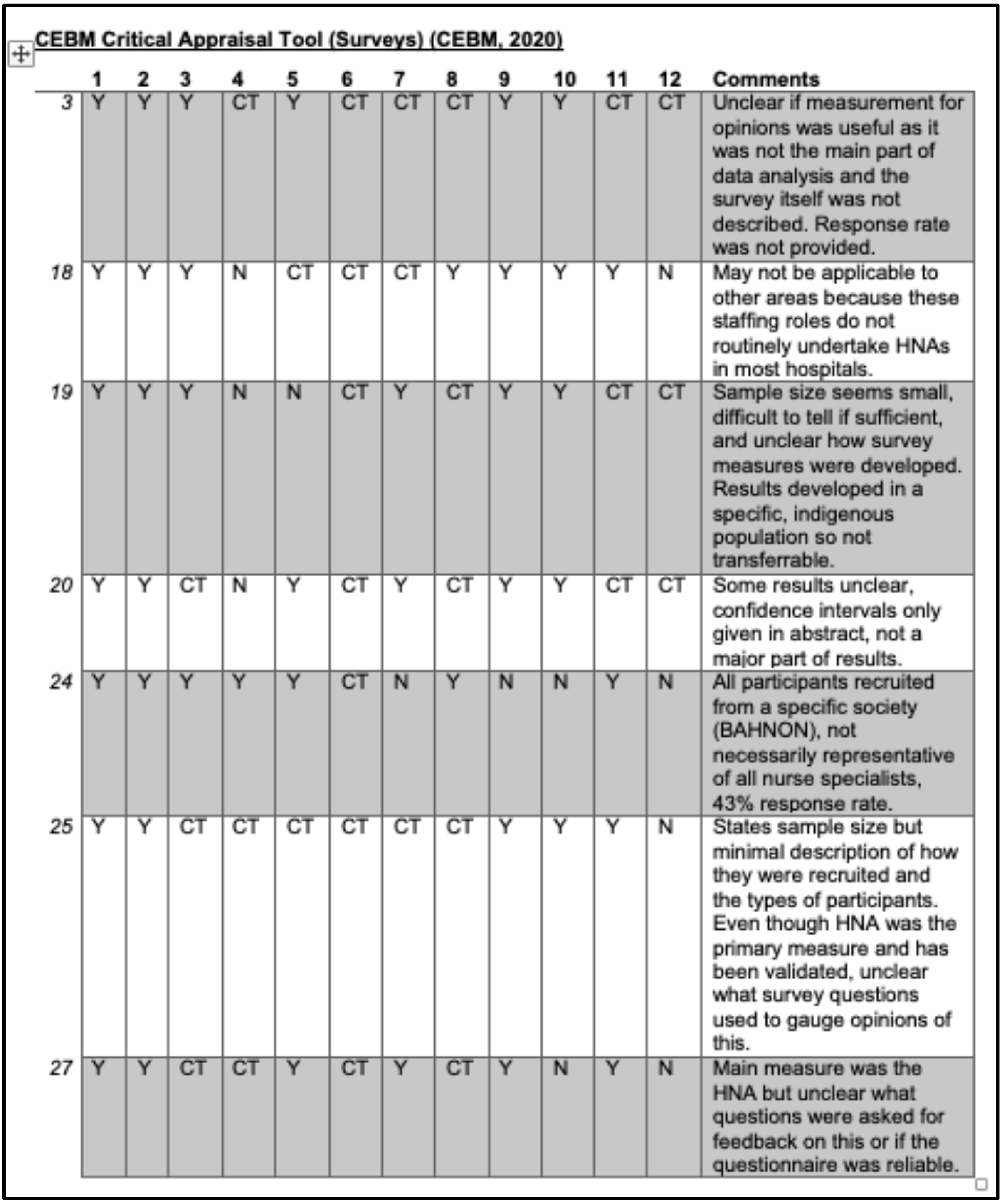
The first column of each table denotes the corresponding research study number from Table 1 of the thesis (Chapter Two).

Y- Yes N- No CT- Can't Tell



CASP Critical Appraisal Tool (Qualitative) (CASP, 2018a)

	1	2	3	4	5	6	7	8	9	10	Comments
2	Y	Y	Y	Y	Y	CT	Y	CT	Y	Y	Data collection occurred a long time after administration of HNA (13 months), 5/15 patients had no recall, small sample and most data only coded by one researcher
4	Y	Y	CT	Y	Y	CT	CT	Y	Y	Y	Unclear whether the qualitative methodology was necessary, as the study seemed to mainly use quantitative data from HNAs in the reporting.
6	Y	Y	CT	Y	Y	Y	CT	Y	Y	Y	Small sample and short interviews (12-14 mins), may not provide in-depth perspectives.
7	Y	Y	CT	Y	Y	N	N	Y	Y	Y	Telephone interviews and brief, possibly not in-depth enough.
9	Y	Y	Y	CT	Y	N	N	Y	Y	CT	Focus group methods may introduce bias, but all participants were also all were recruited from 1 conference and may not represent the general population of nurses.
10	Y	Y	CT	CT	Y	Y	N	CT	Y	Y	Only one researcher analysed the data, and very small sample size (6)
11	Y	Y	Y	Y	Y	Y	CT	Y	Y	Y	Findings were not based on routine use of HNAs, it had only been tested once or twice.
12	Y	N	CT	Y	CT	N	N	CT	N	Y	Unclear paper, uses interviews but barely reports the interview data, and focuses instead on the quantitative data raised within the HNAs.
13	Y	Y	CT	Y	Y	Y	Y	CT	Y	Y	Only one researcher analysed the qualitative data.
15	Y	N	CT	Y	Y	N	CT	Y	Y	Y	Described as interview study but mostly reported closed ended yes/no answer questions.
16	Y	Y	Y	Y	Y	Y	CT	Y	Y	CT	
22	Y	CT	CT	Y	Y	CT	CT	CT	N	Y	Unclear if qualitative methodology appropriate, reporting unclear for a qualitative study, very few direct quotations used and focuses more on elements of the assessment which could have been captured quantitatively.
31	Y	Y	CT	Y	Y	CT	CT	Y	Y	Y	



CEBM Critical Appraisal Tool (Surveys) (CEBM, 2020)

	1	2	3	4	5	6	7	8	9	10	11	12	Comments
3	Y	Y	Y	CT	Y	CT	CT	CT	Y	Y	CT	CT	Unclear if measurement for opinions was useful as it was not the main part of data analysis and the survey itself was not described. Response rate was not provided.
18	Y	Y	Y	N	CT	CT	CT	Y	Y	Y	Y	N	May not be applicable to other areas because these staffing roles do not routinely undertake HNAs in most hospitals.
19	Y	Y	Y	N	N	CT	Y	CT	Y	Y	CT	CT	Sample size seems small, difficult to tell if sufficient, and unclear how survey measures were developed. Results developed in a specific, indigenous population so not transferrable.
20	Y	Y	CT	N	Y	CT	Y	CT	Y	Y	CT	CT	Some results unclear, confidence intervals only given in abstract, not a major part of results.
24	Y	Y	Y	Y	Y	CT	N	Y	N	N	Y	N	All participants recruited from a specific society (BAHNON), not necessarily representative of all nurse specialists, 43% response rate.
25	Y	Y	CT	CT	CT	CT	CT	CT	Y	Y	Y	N	States sample size but minimal description of how they were recruited and the types of participants. Even though HNA was the primary measure and has been validated, unclear what survey questions used to gauge opinions of this.
27	Y	Y	CT	CT	Y	CT	Y	CT	Y	N	Y	N	Main measure was the HNA but unclear what questions were asked for feedback on this or if the questionnaire was reliable.

CASP Critical Appraisal Tool (RCT) (CASP, 2018b)

	1	2	3	4	5	6	7	8	9	10	11	Comments
21	Y	Y	CT	CT	Y	Y	Y	Y	N	N	CT	40% of participants lost to follow-up and did not meet required sample size, all had generally low-level distress, mainly older male participants.

Mixed-Methods Appraisal Tool (MMAT) (Pluye et al., 2011)

	Screening		1				4				5			Comments
23	Y	Y	CT	Y	Y	N	Y	N	Y	Y	Y	Y	N	Feasibility study only, 10 participants, 6 patients for interview and 1 member of staff, analysis only done by 1 researcher, convenience sample, did not avoid bias.

(Domains included: Screening Questions, 1, 4, 5, as domains 2 & 3 not applicable to this type of quantitative research)

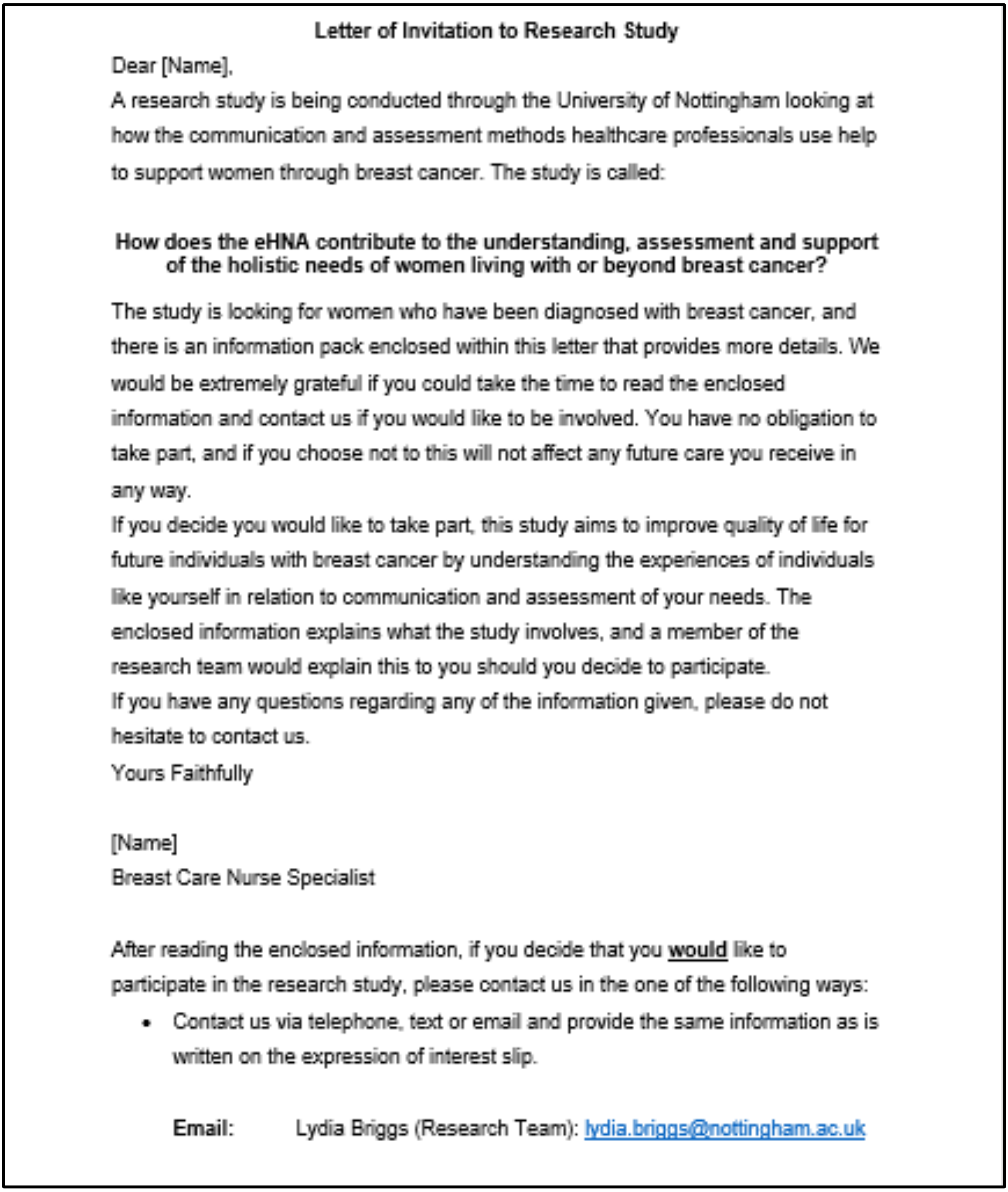
Audit Studies

	Comments
1	Large scale evaluation, large sample, mixed-methods, commissioned by Macmillan Cancer Support
14	Audit study that was used to compare HNA outcomes, small sample and does not explore why more concerns were elicited by an HNA than a general conversation.
26	Audit, so even though it used to understand when concerns were missed etc, this was done retrospectively based on what was documented. Tool did not show increased referrals for support but minimal context for why this might be.

Abstracts only

	Comments
5	Unable to quality assess
8	Unable to quality assess

Appendix H- Letter of Invitation



Letter of Invitation to Research Study

Dear [Name],

A research study is being conducted through the University of Nottingham looking at how the communication and assessment methods healthcare professionals use help to support women through breast cancer. The study is called:

How does the eHNA contribute to the understanding, assessment and support of the holistic needs of women living with or beyond breast cancer?

The study is looking for women who have been diagnosed with breast cancer, and there is an information pack enclosed within this letter that provides more details. We would be extremely grateful if you could take the time to read the enclosed information and contact us if you would like to be involved. You have no obligation to take part, and if you choose not to this will not affect any future care you receive in any way.

If you decide you would like to take part, this study aims to improve quality of life for future individuals with breast cancer by understanding the experiences of individuals like yourself in relation to communication and assessment of your needs. The enclosed information explains what the study involves, and a member of the research team would explain this to you should you decide to participate.

If you have any questions regarding any of the information given, please do not hesitate to contact us.

Yours Faithfully

[Name]
Breast Care Nurse Specialist

After reading the enclosed information, if you decide that you **would** like to participate in the research study, please contact us in the one of the following ways:

- Contact us via telephone, text or email and provide the same information as is written on the expression of interest slip.

Email: Lydia Briggs (Research Team): lydia.briggs@nottingham.ac.uk

Telephone: Lydia Briggs (Research Team): 077XXXXXXX

- Return the expression of interest slip below to this address:

Dr Holly Blake
School of Health Sciences
University of Nottingham
B Floor, Queen's Medical Centre
Nottingham
NG7 2HA

Research Study Title:

How does the eHNA contribute to the understanding, assessment and support of the holistic needs of women living with or beyond breast cancer?

I have read the study information sent to me and I am interested in taking part in the above research study. I am happy to be contacted a member of the research team to discuss this.

Name: ____

Contact Number: ____

Email Address: ____

Address:

____

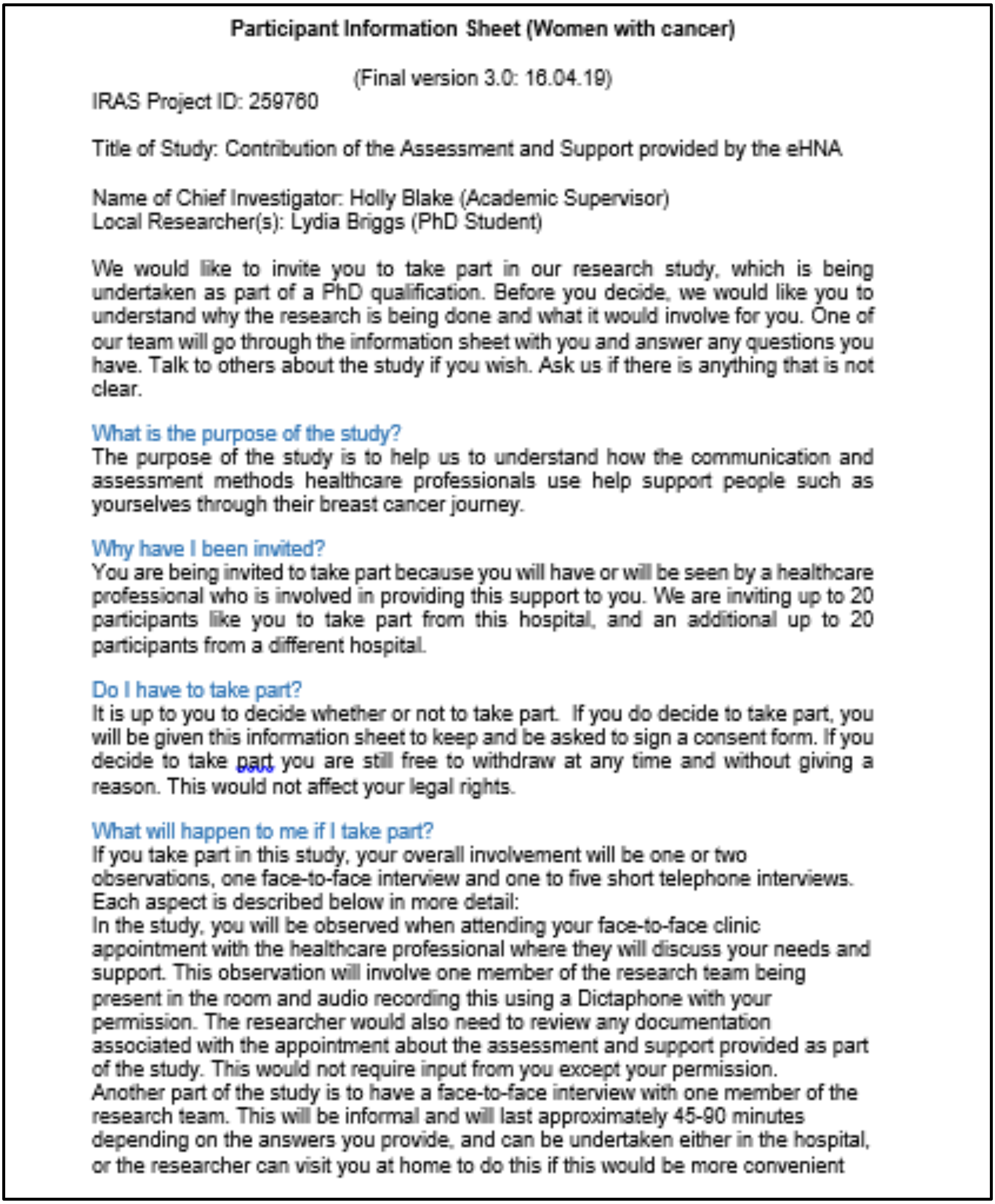
____

______

The best way to contact me is:

Email ☐ Telephone ☐ Post ☐

Appendix I- Participant Information Sheets



Participant Information Sheet (Women with cancer)

(Final version 3.0: 16.04.19)

IRAS Project ID: 259760

Title of Study: Contribution of the Assessment and Support provided by the eHNA

Name of Chief Investigator: Holly Blake (Academic Supervisor)
Local Researcher(s): Lydia Briggs (PhD Student)

We would like to invite you to take part in our research study, which is being undertaken as part of a PhD qualification. Before you decide, we would like you to understand why the research is being done and what it would involve for you. One of our team will go through the information sheet with you and answer any questions you have. Talk to others about the study if you wish. Ask us if there is anything that is not clear.

What is the purpose of the study?

The purpose of the study is to help us to understand how the communication and assessment methods healthcare professionals use help support people such as yourselves through their breast cancer journey.

Why have I been invited?

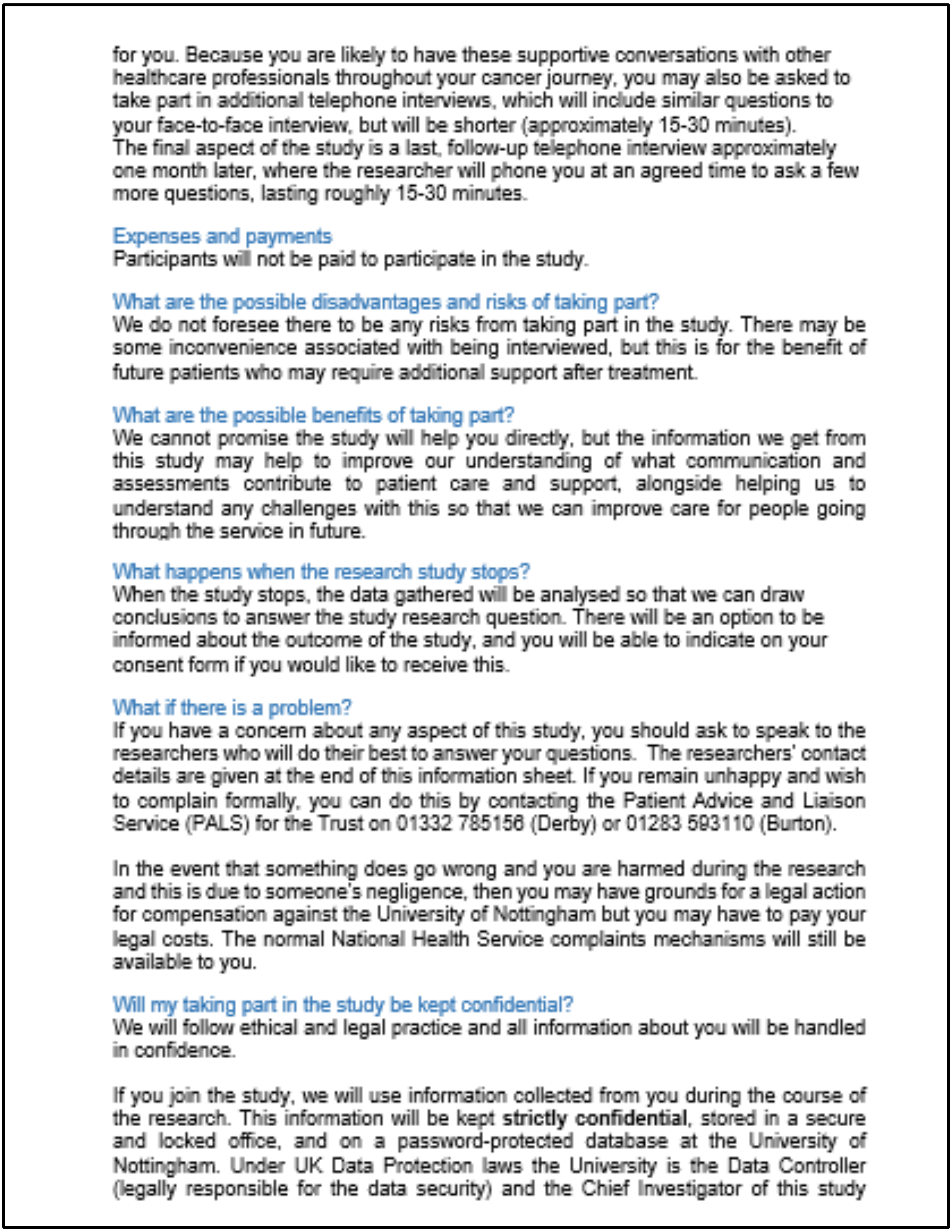
You are being invited to take part because you will have or will be seen by a healthcare professional who is involved in providing this support to you. We are inviting up to 20 participants like you to take part from this hospital, and an additional up to 20 participants from a different hospital.

Do I have to take part?

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

What will happen to me if I take part?

If you take part in this study, your overall involvement will be one or two observations, one face-to-face interview and one to five short telephone interviews. Each aspect is described below in more detail:
In the study, you will be observed when attending your face-to-face clinic appointment with the healthcare professional where they will discuss your needs and support. This observation will involve one member of the research team being present in the room and audio recording this using a Dictaphone with your permission. The researcher would also need to review any documentation associated with the appointment about the assessment and support provided as part of the study. This would not require input from you except your permission.
Another part of the study is to have a face-to-face interview with one member of the research team. This will be informal and will last approximately 45-90 minutes depending on the answers you provide, and can be undertaken either in the hospital, or the researcher can visit you at home to do this if this would be more convenient



for you. Because you are likely to have these supportive conversations with other healthcare professionals throughout your cancer journey, you may also be asked to take part in additional telephone interviews, which will include similar questions to your face-to-face interview, but will be shorter (approximately 15-30 minutes).
The final aspect of the study is a last, follow-up telephone interview approximately one month later, where the researcher will phone you at an agreed time to ask a few more questions, lasting roughly 15-30 minutes.

Expenses and payments

Participants will not be paid to participate in the study.

What are the possible disadvantages and risks of taking part?

We do not foresee there to be any risks from taking part in the study. There may be some inconvenience associated with being interviewed, but this is for the benefit of future patients who may require additional support after treatment.

What are the possible benefits of taking part?

We cannot promise the study will help you directly, but the information we get from this study may help to improve our understanding of what communication and assessments contribute to patient care and support, alongside helping us to understand any challenges with this so that we can improve care for people going through the service in future.

What happens when the research study stops?

When the study stops, the data gathered will be analysed so that we can draw conclusions to answer the study research question. There will be an option to be informed about the outcome of the study, and you will be able to indicate on your consent form if you would like to receive this.

What if there is a problem?

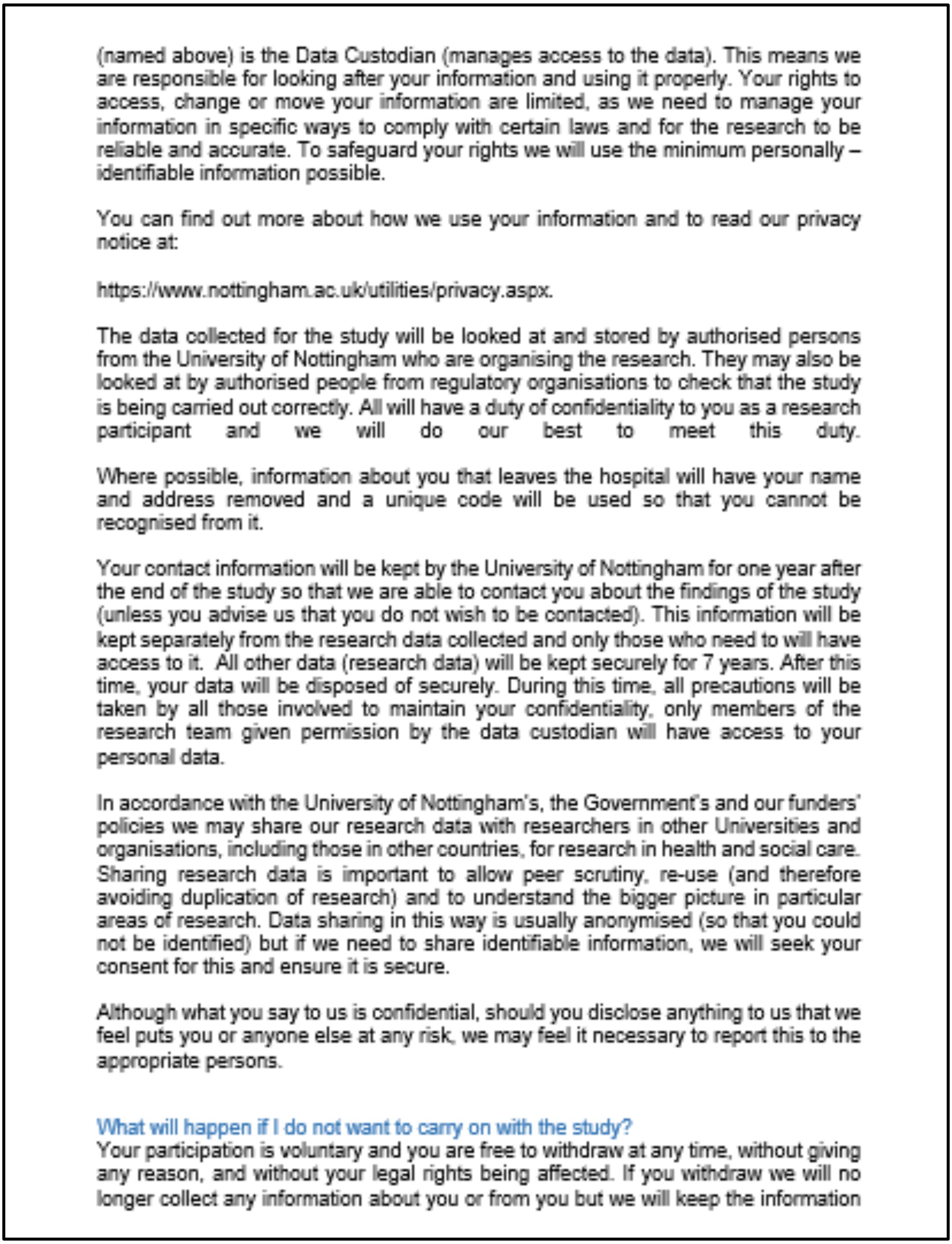
If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. The researchers' contact details are given at the end of this information sheet. If you remain unhappy and wish to complain formally, you can do this by contacting the Patient Advice and Liaison Service (PALS) for the Trust on 01332 785156 (Derby) or 01283 593110 (Burton).

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

Will my taking part in the study be kept confidential?

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

If you join the study, we will use information collected from you during the course of the research. This information will be kept **strictly confidential**, stored in a secure and locked office, and on a password-protected database at the University of Nottingham. Under UK Data Protection laws the University is the Data Controller (legally responsible for the data security) and the Chief Investigator of this study



(named above) is the Data Custodian (manages access to the data). This means we are responsible for looking after your information and using it properly. Your rights to access, change or move your information are limited, as we need to manage your information in specific ways to comply with certain laws and for the research to be reliable and accurate. To safeguard your rights we will use the minimum personally – identifiable information possible.

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

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

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

Where possible, information about you that leaves the hospital will have your name and address removed and a unique code will be used so that you cannot be recognised from it.

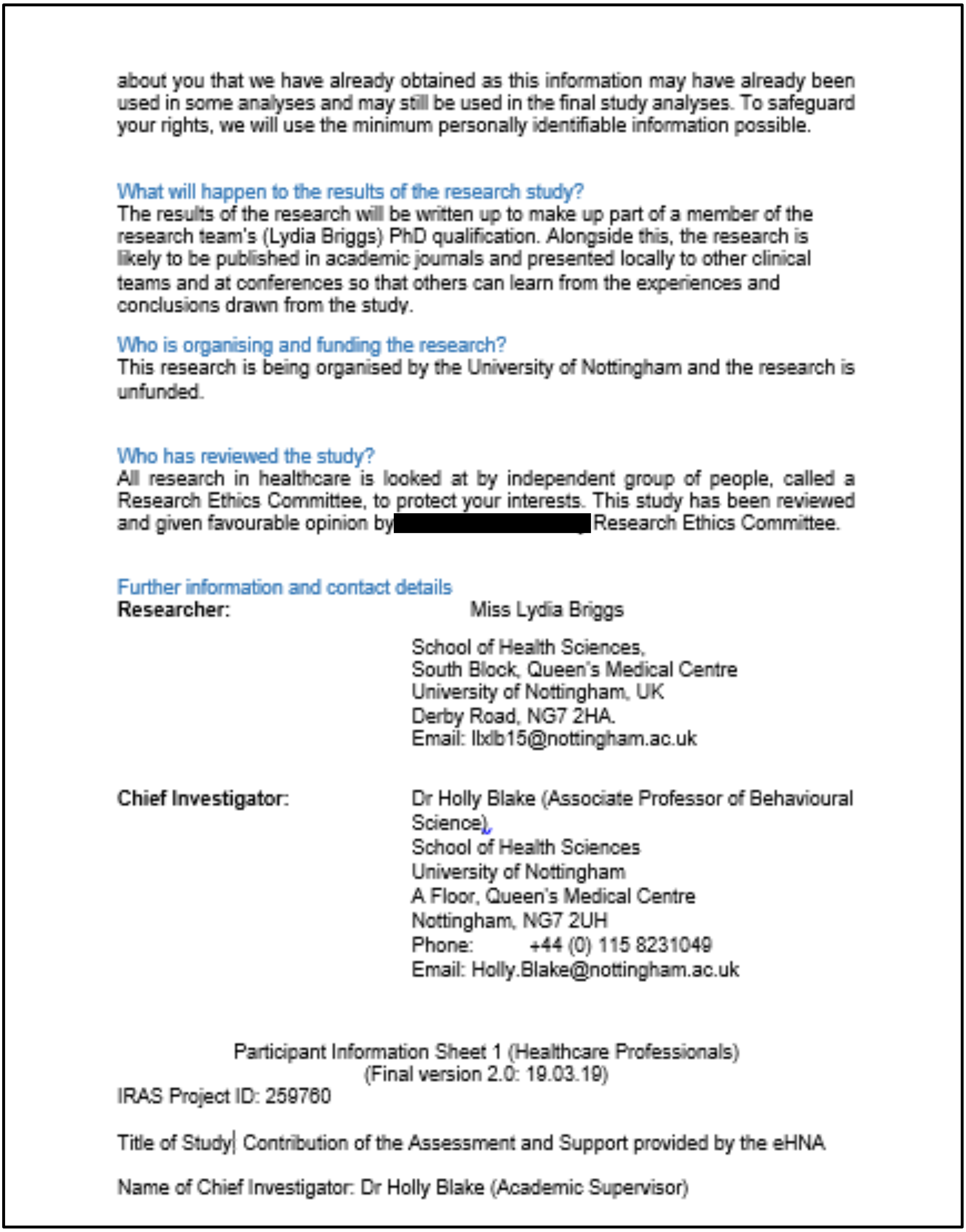
Your contact information will be kept by the University of Nottingham for one year after the end of the study so that we are able to contact you about the findings of the study (unless you advise us that you do not wish to be contacted). This information will be kept separately from the research data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

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

Although what you say to us is confidential, should you disclose anything to us that we feel puts you or anyone else at any risk, we may feel it necessary to report this to the appropriate persons.

What will happen if I do not want to carry on with the study?

Your participation is voluntary and you are free to withdraw at any time, without giving any reason, and without your legal rights being affected. If you withdraw we will no longer collect any information about you or from you but we will keep the information



about you that we have already obtained as this information may have already been used in some analyses and may still be used in the final study analyses. To safeguard your rights, we will use the minimum personally identifiable information possible.

What will happen to the results of the research study?

The results of the research will be written up to make up part of a member of the research team's (Lydia Briggs) PhD qualification. Alongside this, the research is likely to be published in academic journals and presented locally to other clinical teams and at conferences so that others can learn from the experiences and conclusions drawn from the study.

Who is organising and funding the research?

This research is being organised by the University of Nottingham and the research is unfunded.

Who has reviewed the study?

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

Further information and contact details

Researcher: Miss Lydia Briggs

School of Health Sciences,
South Block, Queen's Medical Centre
University of Nottingham, UK
Derby Road, NG7 2HA.
Email: llxlb15@nottingham.ac.uk

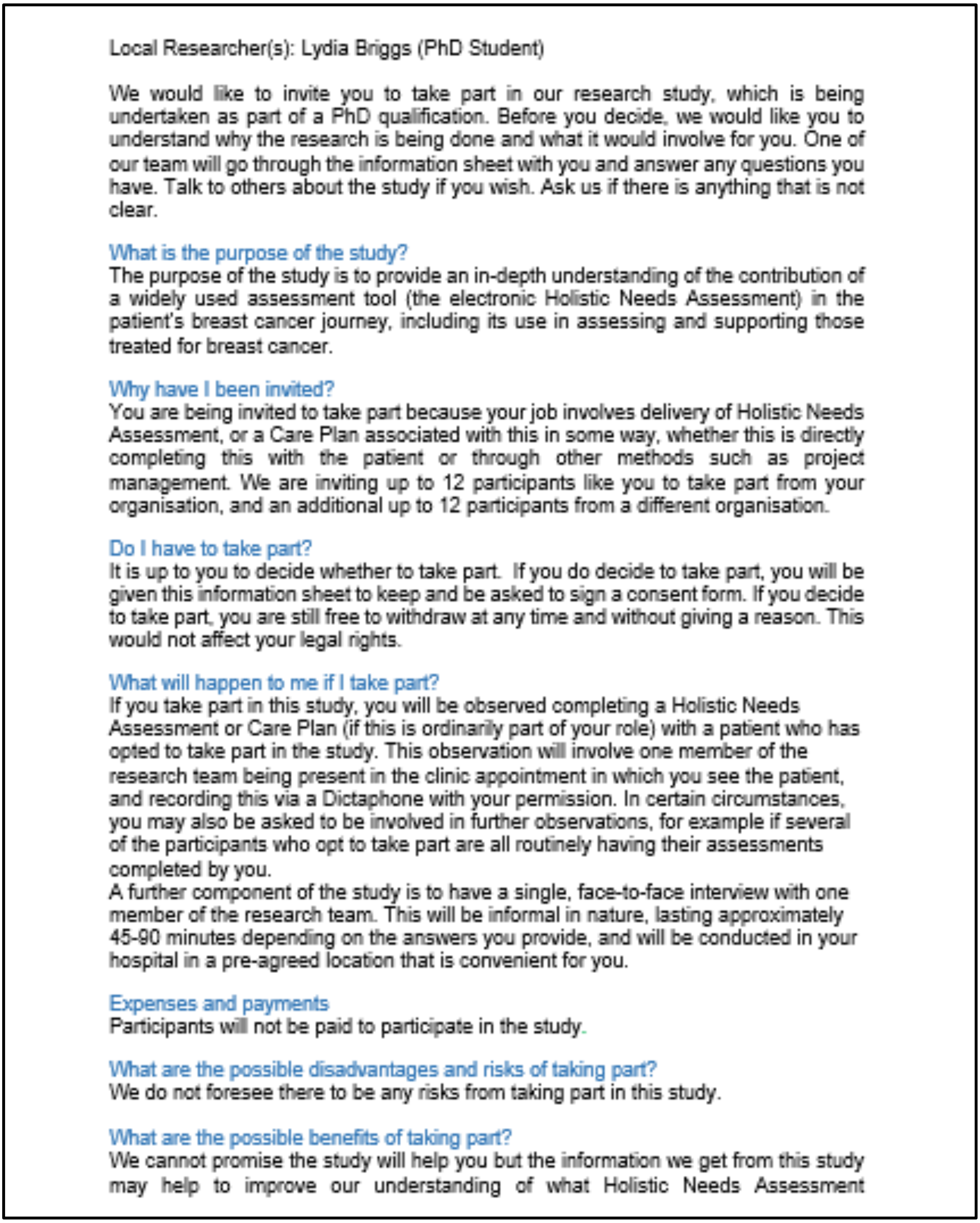
Chief Investigator: Dr Holly Blake (Associate Professor of Behavioural Science),
School of Health Sciences
University of Nottingham
A Floor, Queen's Medical Centre
Nottingham, NG7 2UH
Phone: +44 (0) 115 8231049
Email: Holly.Blake@nottingham.ac.uk

Participant Information Sheet 1 (Healthcare Professionals)
(Final version 2.0: 19.03.19)

IRAS Project ID: 259760

Title of Study: Contribution of the Assessment and Support provided by the eHNA

Name of Chief Investigator: Dr Holly Blake (Academic Supervisor)



Local Researcher(s): Lydia Briggs (PhD Student)

We would like to invite you to take part in our research study, which is being undertaken as part of a PhD qualification. Before you decide, we would like you to understand why the research is being done and what it would involve for you. One of our team will go through the information sheet with you and answer any questions you have. Talk to others about the study if you wish. Ask us if there is anything that is not clear.

What is the purpose of the study?

The purpose of the study is to provide an in-depth understanding of the contribution of a widely used assessment tool (the electronic Holistic Needs Assessment) in the patient's breast cancer journey, including its use in assessing and supporting those treated for breast cancer.

Why have I been invited?

You are being invited to take part because your job involves delivery of Holistic Needs Assessment, or a Care Plan associated with this in some way, whether this is directly completing this with the patient or through other methods such as project management. We are inviting up to 12 participants like you to take part from your organisation, and an additional up to 12 participants from a different organisation.

Do I have to take part?

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

What will happen to me if I take part?

If you take part in this study, you will be observed completing a Holistic Needs Assessment or Care Plan (if this is ordinarily part of your role) with a patient who has opted to take part in the study. This observation will involve one member of the research team being present in the clinic appointment in which you see the patient, and recording this via a Dictaphone with your permission. In certain circumstances, you may also be asked to be involved in further observations, for example if several of the participants who opt to take part are all routinely having their assessments completed by you.
A further component of the study is to have a single, face-to-face interview with one member of the research team. This will be informal in nature, lasting approximately 45-90 minutes depending on the answers you provide, and will be conducted in your hospital in a pre-agreed location that is convenient for you.

Expenses and payments

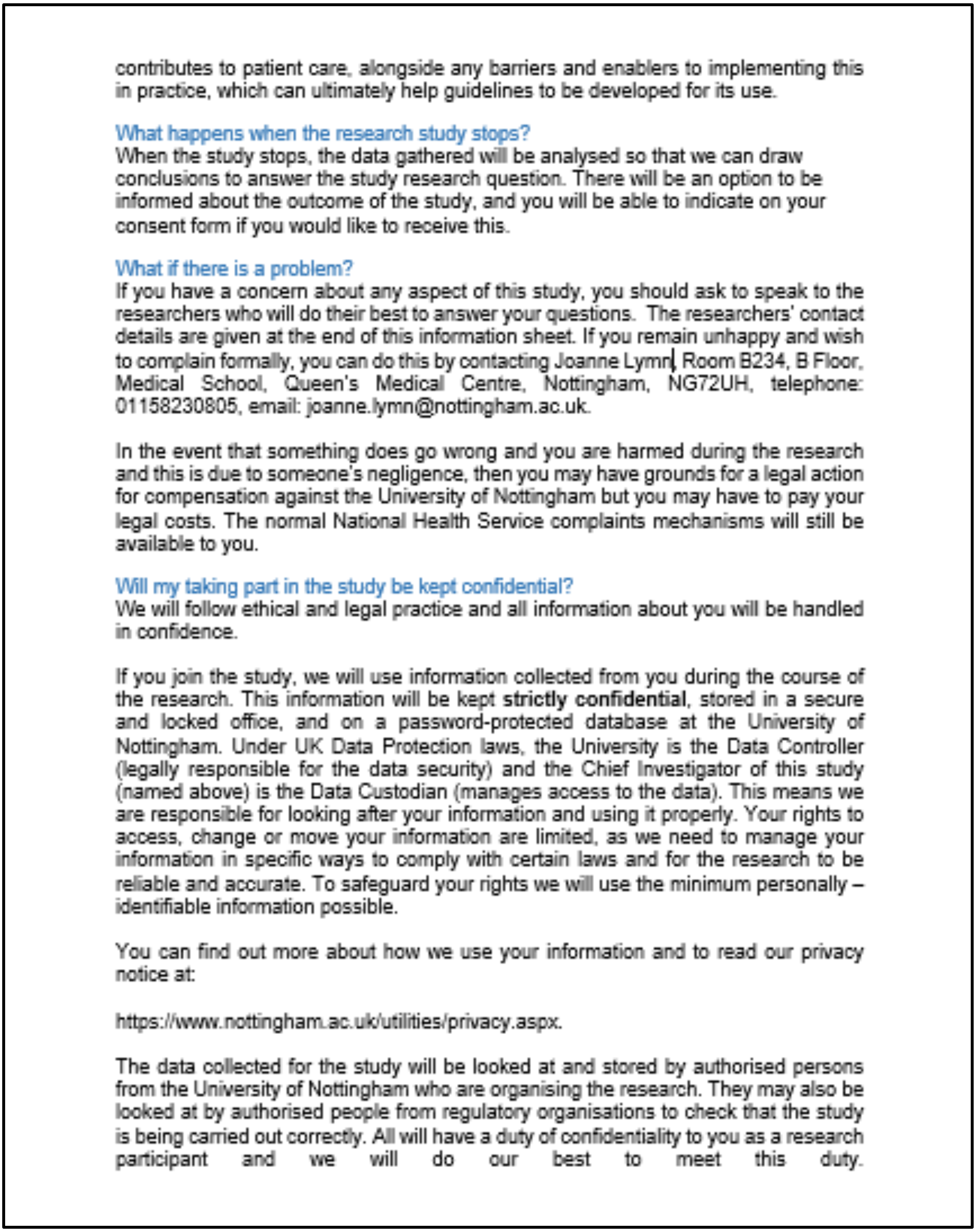
Participants will not be paid to participate in the study.

What are the possible disadvantages and risks of taking part?

We do not foresee there to be any risks from taking part in this study.

What are the possible benefits of taking part?

We cannot promise the study will help you but the information we get from this study may help to improve our understanding of what Holistic Needs Assessment



contributes to patient care, alongside any barriers and enablers to implementing this in practice, which can ultimately help guidelines to be developed for its use.

What happens when the research study stops?

When the study stops, the data gathered will be analysed so that we can draw conclusions to answer the study research question. There will be an option to be informed about the outcome of the study, and you will be able to indicate on your consent form if you would like to receive this.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. The researchers' contact details are given at the end of this information sheet. If you remain unhappy and wish to complain formally, you can do this by contacting Joanne Lymn, Room B234, B Floor, Medical School, Queen's Medical Centre, Nottingham, NG72UH, telephone: 01158230805, email: joanne.lymn@nottingham.ac.uk.

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

Will my taking part in the study be kept confidential?

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

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

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

Where possible information about you which leaves the hospital will have your name and address removed and a unique code will be used so that you cannot be recognised from it.

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

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

Although what you say to us is confidential, should you disclose anything to us that we feel puts you or anyone else at any risk, we may feel it necessary to report this to the appropriate persons.

What will happen if I do not want to carry on with the study?

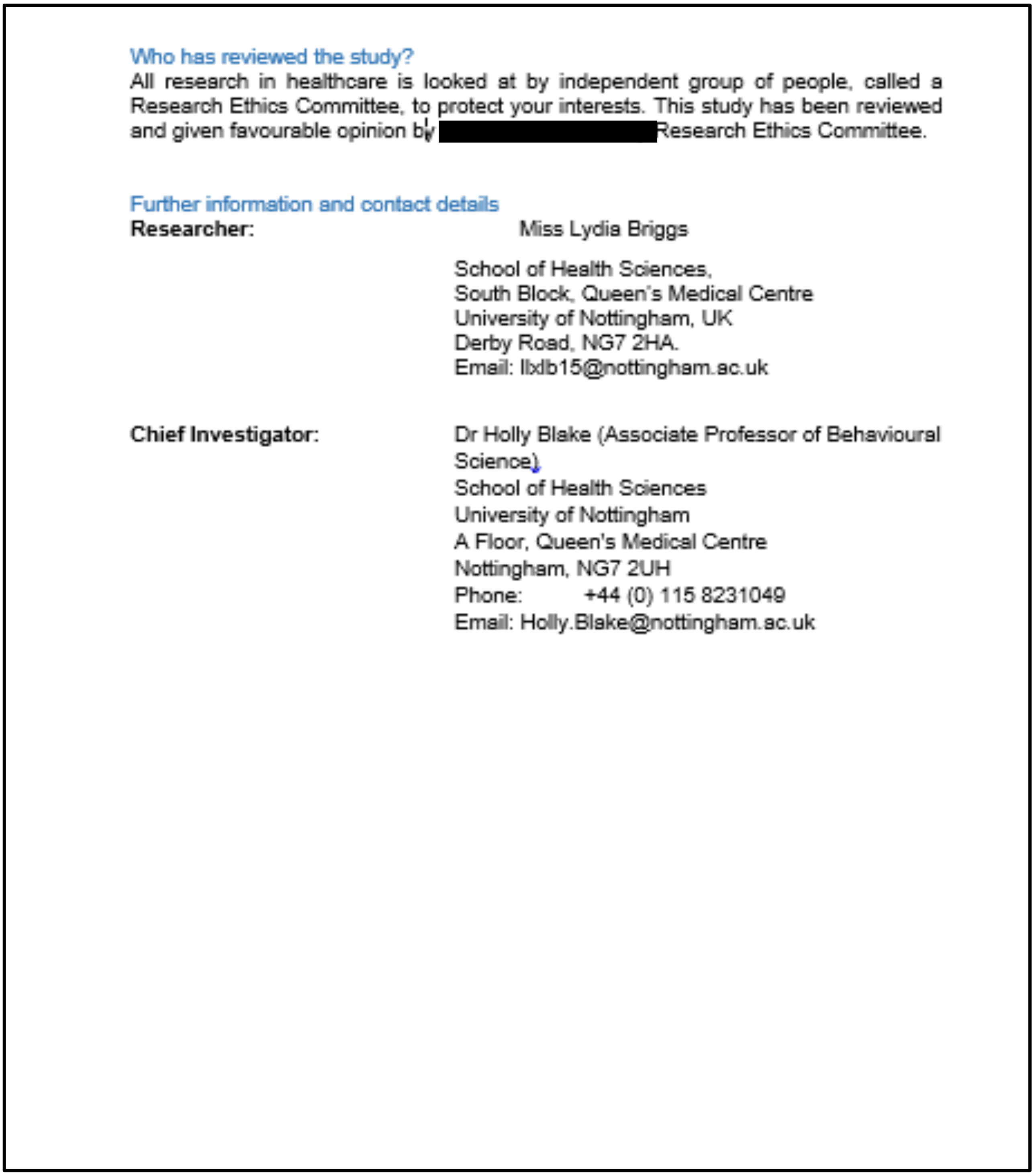
Your participation is voluntary and you are free to withdraw at any time, without giving any reason, and without your legal rights being affected. If you withdraw we will no longer collect any information about you or from you but we will keep the information about you that we have already obtained as this information may have already been used in some analyses and may still be used in the final study analyses. To safeguard your rights, we will use the minimum personally identifiable information possible.

What will happen to the results of the research study?

The results of the research will be written up to make up part of a member of the research team's (Lydia Briggs) PhD qualification. Alongside this, the research is likely to be published in academic journals and presented locally to other clinical teams and at conferences so that others can learn from the experiences and conclusions drawn from the study.

Who is organising and funding the research?

This research is being organised by the University of Nottingham and the research is unfunded.



Who has reviewed the study?

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

Further information and contact details

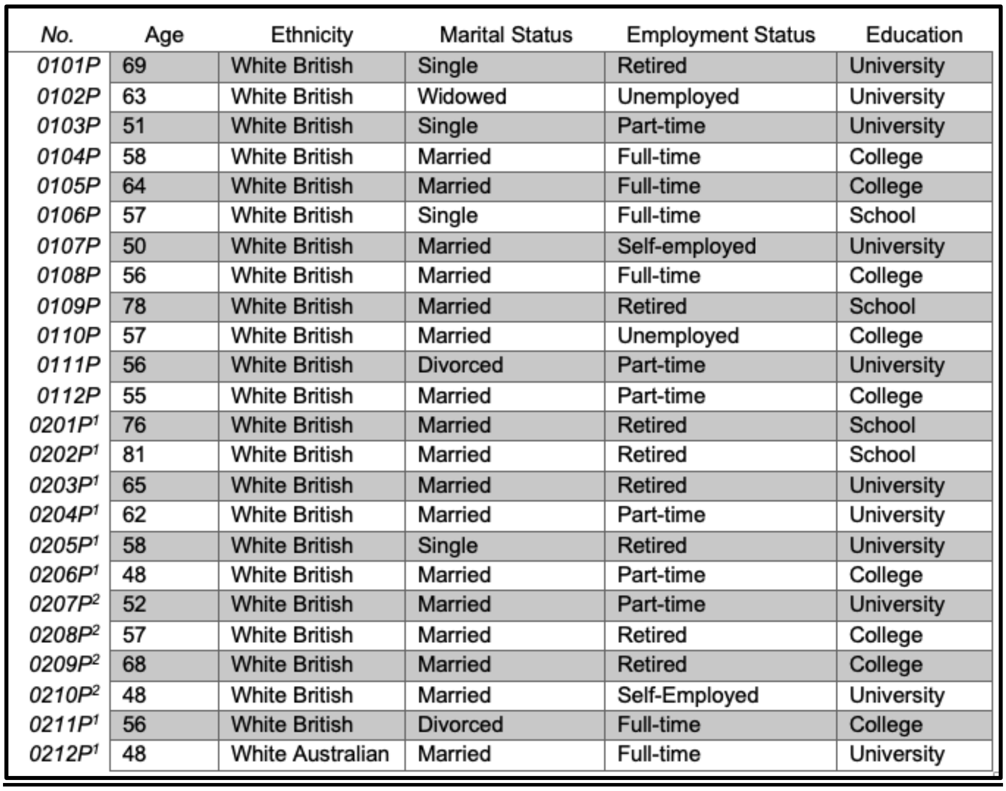
Researcher: Miss Lydia Briggs

School of Health Sciences,
South Block, Queen's Medical Centre
University of Nottingham, UK
Derby Road, NG7 2HA.
Email: llxlb15@nottingham.ac.uk

Chief Investigator: Dr Holly Blake (Associate Professor of Behavioural Science)
School of Health Sciences
University of Nottingham
A Floor, Queen's Medical Centre
Nottingham, NG7 2UH
Phone: +44 (0) 115 8231049
Email: Holly.Blake@nottingham.ac.uk

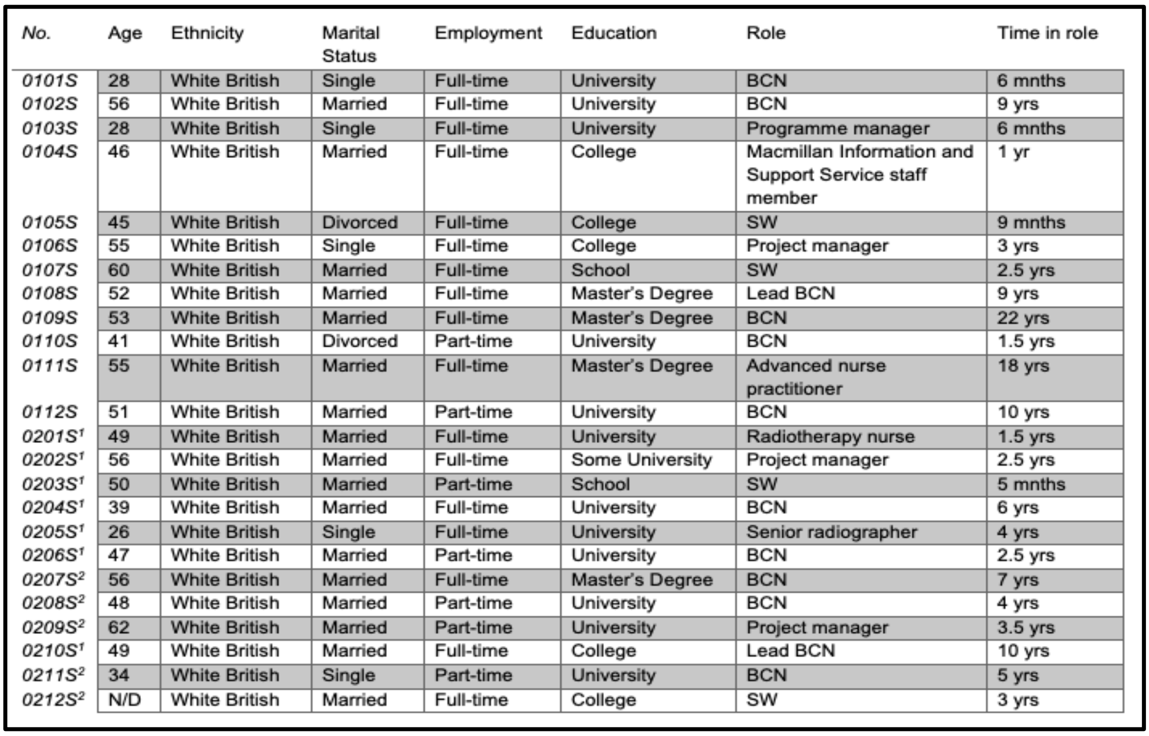
Appendix J- Participant demographic details

Women with cancer



No.	Age	Ethnicity	Marital Status	Employment Status	Education
0101P	69	White British	Single	Retired	University
0102P	63	White British	Widowed	Unemployed	University
0103P	51	White British	Single	Part-time	University
0104P	58	White British	Married	Full-time	College
0105P	64	White British	Married	Full-time	College
0106P	57	White British	Single	Full-time	School
0107P	50	White British	Married	Self-employed	University
0108P	56	White British	Married	Full-time	College
0109P	78	White British	Married	Retired	School
0110P	57	White British	Married	Unemployed	College
0111P	56	White British	Divorced	Part-time	University
0112P	55	White British	Married	Part-time	College
0201P[1]	76	White British	Married	Retired	School
0202P[1]	81	White British	Married	Retired	School
0203P[1]	65	White British	Married	Retired	University
0204P[1]	62	White British	Married	Part-time	University
0205P[1]	58	White British	Single	Retired	University
0206P[1]	48	White British	Married	Part-time	College
0207P[2]	52	White British	Married	Part-time	University
0208P[2]	57	White British	Married	Retired	College
0209P[2]	68	White British	Married	Retired	College
0210P[2]	48	White British	Married	Self-Employed	University
0211P[1]	56	White British	Divorced	Full-time	College
0212P[1]	48	White Australian	Married	Full-time	University

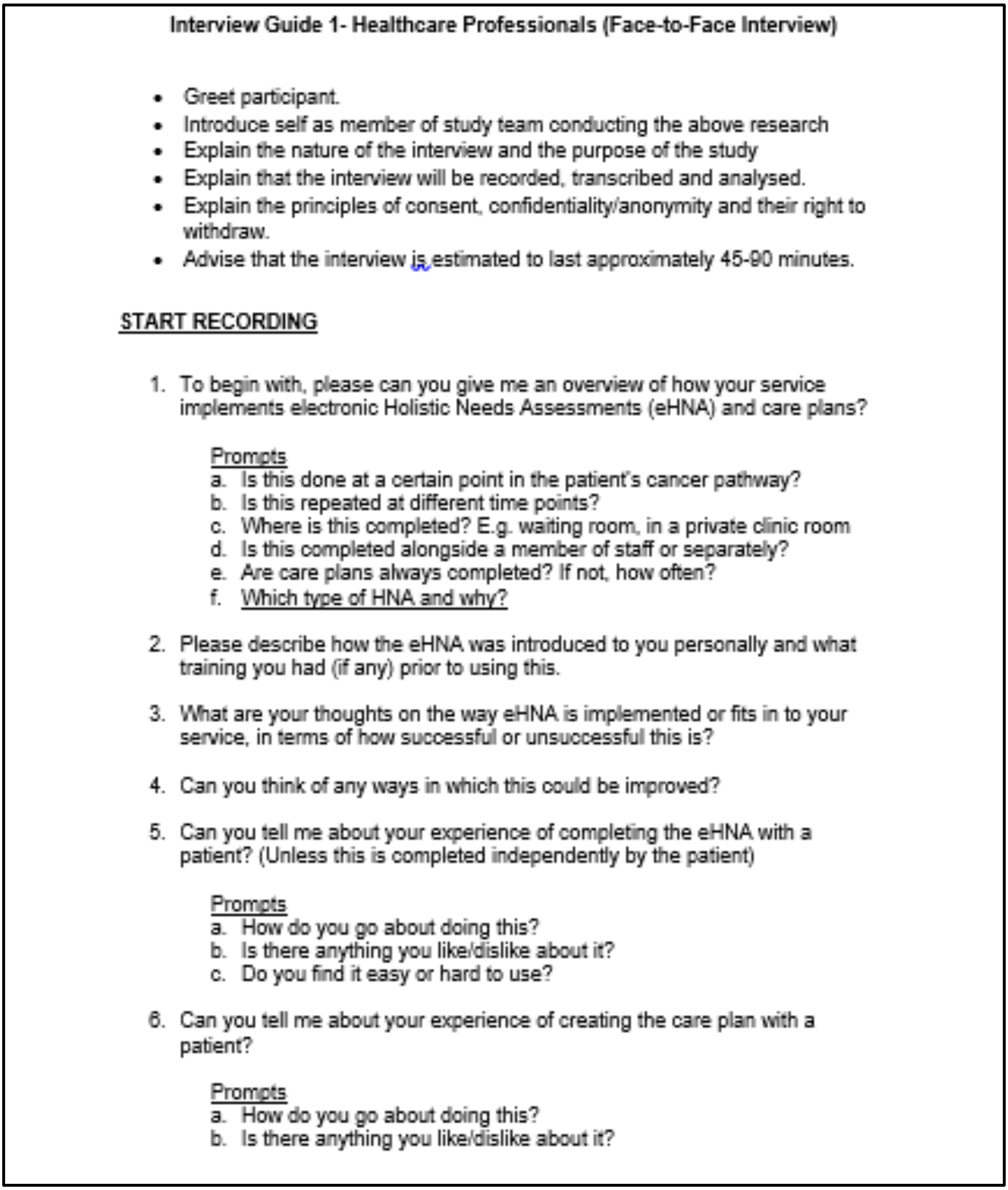
Staff



No.	Age	Ethnicity	Marital Status	Employment	Education	Role	Time in role
0101S	28	White British	Single	Full-time	University	BCN	6 mnths
0102S	56	White British	Married	Full-time	University	BCN	9 yrs
0103S	28	White British	Single	Full-time	University	Programme manager	6 mnths
0104S	46	White British	Married	Full-time	College	Macmillan Information and Support Service staff member	1 yr
0105S	45	White British	Divorced	Full-time	College	SW	9 mnths
0106S	55	White British	Single	Full-time	College	Project manager	3 yrs
0107S	60	White British	Married	Full-time	School	SW	2.5 yrs
0108S	52	White British	Married	Full-time	Master's Degree	Lead BCN	9 yrs
0109S	53	White British	Married	Full-time	Master's Degree	BCN	22 yrs
0110S	41	White British	Divorced	Part-time	University	BCN	1.5 yrs
0111S	55	White British	Married	Full-time	Master's Degree	Advanced nurse practitioner	18 yrs
0112S	51	White British	Married	Part-time	University	BCN	10 yrs
0201S[1]	49	White British	Married	Full-time	University	Radiotherapy nurse	1.5 yrs
0202S[1]	56	White British	Married	Full-time	Some University	Project manager	2.5 yrs
0203S[1]	50	White British	Married	Part-time	School	SW	5 mnths
0204S[1]	39	White British	Married	Full-time	University	BCN	6 yrs
0205S[1]	26	White British	Single	Full-time	University	Senior radiographer	4 yrs
0206S[1]	47	White British	Married	Part-time	University	BCN	2.5 yrs
0207S[2]	56	White British	Married	Full-time	Master's Degree	BCN	7 yrs
0208S[2]	48	White British	Married	Part-time	University	BCN	4 yrs
0209S[2]	62	White British	Married	Part-time	University	Project manager	3.5 yrs
0210S[1]	49	White British	Married	Full-time	College	Lead BCN	10 yrs
0211S[2]	34	White British	Single	Part-time	University	BCN	5 yrs
0212S[2]	N/D	White British	Married	Full-time	College	SW	3 yrs

N/D- Not disclosed

Appendix K- Interview Topic Guides 1-3



Interview Guide 1- Healthcare Professionals (Face-to-Face Interview)

- Greet participant.
- Introduce self as member of study team conducting the above research
- Explain the nature of the interview and the purpose of the study
- Explain that the interview will be recorded, transcribed and analysed.
- Explain the principles of consent, confidentiality/anonymity and their right to withdraw.
- Advise that the interview is estimated to last approximately 45-90 minutes.

START RECORDING

1. To begin with, please can you give me an overview of how your service implements electronic Holistic Needs Assessments (eHNA) and care plans?

   Prompts
   a. Is this done at a certain point in the patient's cancer pathway?
   b. Is this repeated at different time points?
   c. Where is this completed? E.g. waiting room, in a private clinic room
   d. Is this completed alongside a member of staff or separately?
   e. Are care plans always completed? If not, how often?
   f. Which type of HNA and why?

2. Please describe how the eHNA was introduced to you personally and what training you had (if any) prior to using this.

3. What are your thoughts on the way eHNA is implemented or fits in to your service, in terms of how successful or unsuccessful this is?

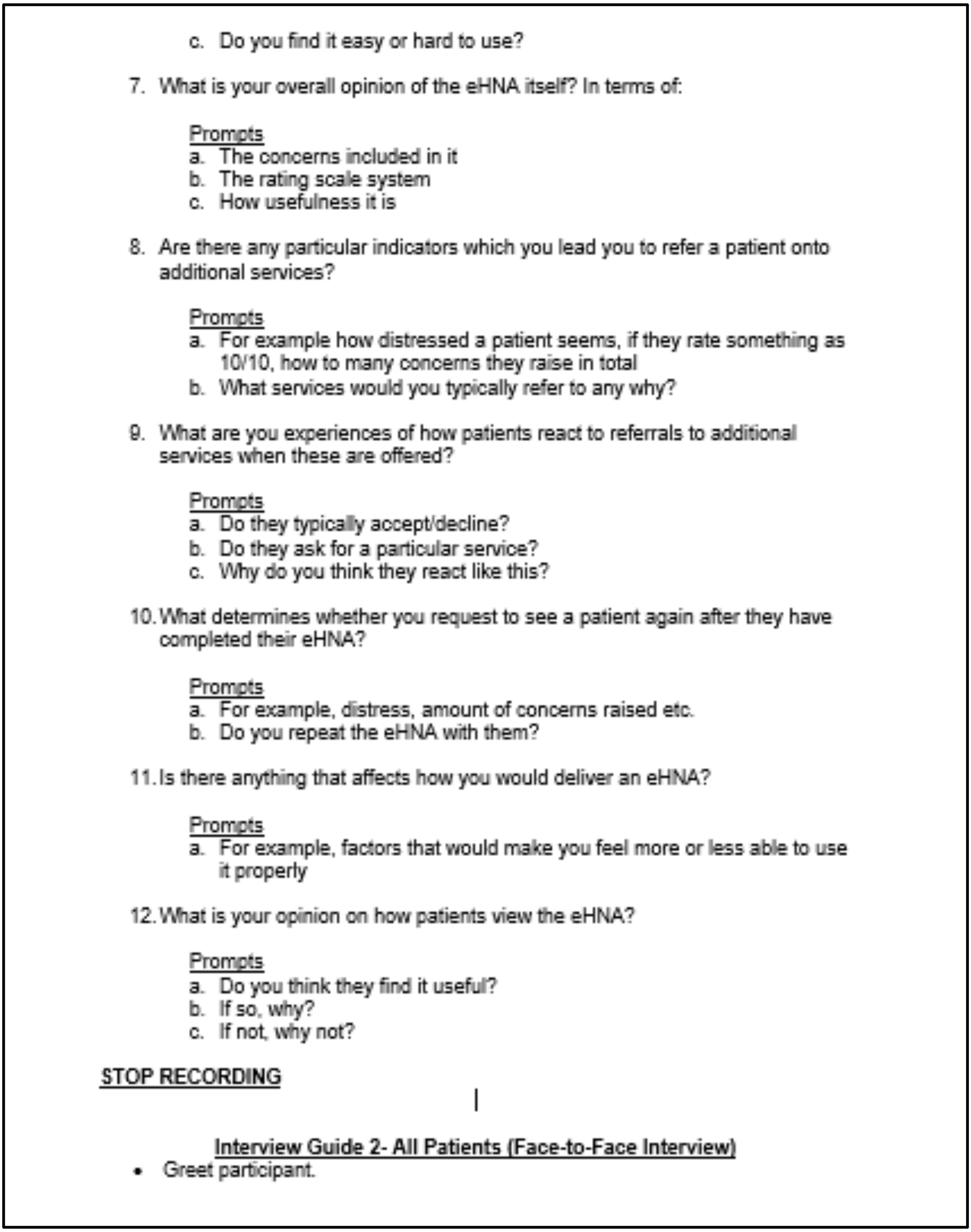
4. Can you think of any ways in which this could be improved?

5. Can you tell me about your experience of completing the eHNA with a patient? (Unless this is completed independently by the patient)

   Prompts
   a. How do you go about doing this?
   b. Is there anything you like/dislike about it?
   c. Do you find it easy or hard to use?

6. Can you tell me about your experience of creating the care plan with a patient?

   Prompts
   a. How do you go about doing this?
   b. Is there anything you like/dislike about it?



   c. Do you find it easy or hard to use?

7. What is your overall opinion of the eHNA itself? In terms of:

   Prompts
   a. The concerns included in it
   b. The rating scale system
   c. How usefulness it is

8. Are there any particular indicators which you lead you to refer a patient onto additional services?

   Prompts
   a. For example how distressed a patient seems, if they rate something as 10/10, how to many concerns they raise in total
   b. What services would you typically refer to any why?

9. What are you experiences of how patients react to referrals to additional services when these are offered?

   Prompts
   a. Do they typically accept/decline?
   b. Do they ask for a particular service?
   c. Why do you think they react like this?

10. What determines whether you request to see a patient again after they have completed their eHNA?

    Prompts
    a. For example, distress, amount of concerns raised etc.
    b. Do you repeat the eHNA with them?

11. Is there anything that affects how you would deliver an eHNA?

    Prompts
    a. For example, factors that would make you feel more or less able to use it properly

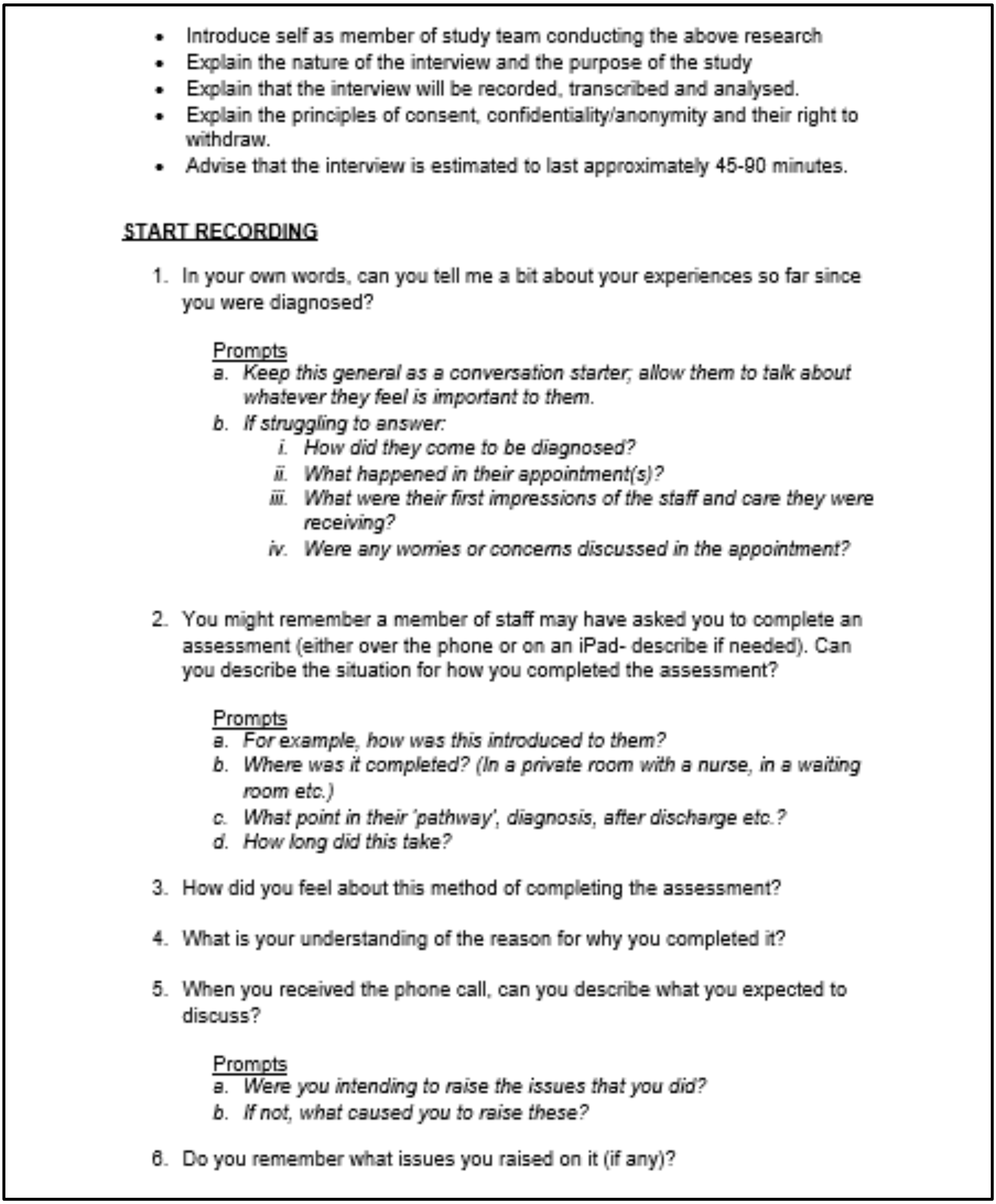
12. What is your opinion on how patients view the eHNA?

    Prompts
    a. Do you think they find it useful?
    b. If so, why?
    c. If not, why not?

STOP RECORDING

Interview Guide 2- All Patients (Face-to-Face Interview)

- Greet participant.



- Introduce self as member of study team conducting the above research
- Explain the nature of the interview and the purpose of the study
- Explain that the interview will be recorded, transcribed and analysed.
- Explain the principles of consent, confidentiality/anonymity and their right to withdraw.
- Advise that the interview is estimated to last approximately 45-90 minutes.

START RECORDING

1. In your own words, can you tell me a bit about your experiences so far since you were diagnosed?

   Prompts

   a. *Keep this general as a conversation starter; allow them to talk about whatever they feel is important to them.*
   b. *If struggling to answer:*
      i. *How did they come to be diagnosed?*
      ii. *What happened in their appointment(s)?*
      iii. *What were their first impressions of the staff and care they were receiving?*
      iv. *Were any worries or concerns discussed in the appointment?*

2. You might remember a member of staff may have asked you to complete an assessment (either over the phone or on an iPad- describe if needed). Can you describe the situation for how you completed the assessment?

   Prompts

   a. *For example, how was this introduced to them?*
   b. *Where was it completed? (In a private room with a nurse, in a waiting room etc.)*
   c. *What point in their 'pathway', diagnosis, after discharge etc.?*
   d. *How long did this take?*

3. How did you feel about this method of completing the assessment?

4. What is your understanding of the reason for why you completed it?

5. When you received the phone call, can you describe what you expected to discuss?

   Prompts

   a. *Were you intending to raise the issues that you did?*
   b. *If not, what caused you to raise these?*

6. Do you remember what issues you raised on it (if any)?

Prompts

  a. *If so, would you be happy to tell me what these were?*
  b. *How did you feel while you were discussing these?*

7. Do you feel that you disclosed all of the issues you had at the time?

   Prompts

   a. *If not, why was this? For example, forgetting or not wanting to disclose an issue.*
   b. *Did you think of things you wish you had raised after completing the assessment?*

8. What is your opinion on how helpful or not helpful the assessment was? How about the care plan?

   Prompts

   a. *Did you like the electronic version?*
   b. *How did you find completing it at home (if applicable)?*
   c. *What did you like and dislike?*
   d. *Compare it to any holistic conversations had*

9. Can you describe the conversation you had with the nurse around the concerns you had?

   Prompts

   a. *For example, were these discussed or were you given leaflets?*

10. When you and the nurse agreed some actions to address the issues you raised (if applicable), how did you feel about these?

    Prompts

    a. *What are your expectations after this appointment?*
    b. *Had you been given information or referrals at a different point?*

11. Can you think of any ways in which this could be improved?

    Prompts

    a. *Whether this is the appointment itself, your understanding of it, how the issues were discussed or the actual concerns listed on the assessment etc.*

STOP RECORDING

Check the patient is not feeling distressed, give list of useful contacts for support if needed or refer to Breast Care Nurse.

Interview Guide 3- Patients (Subsequent Telephone Interviews)

- Greet participant.
- Re-introduce self and re-check verbal consent (consent form will already have been signed).
- Explain the nature of the interview.
- Explain that the interview will be recorded, transcribed and analysed.
- Advise that the interview is estimated to last approximately 15-30 minutes.

START RECORDING

12. In your own words, can you describe the situation for how you completed the assessment this time (having already completed it once or multiple times)?

    Prompts
    a. *For example, in a private room with a nurse, in a waiting room etc.*
    b. *What point in their 'pathway', diagnosis, after discharge etc.?*
    c. *How long did this take?*

13. How did you feel about this method of completing it?

    Prompts
    a. *Did you prefer this method to the method use for other assessments you completed (if there was a difference)?*

14. Has your understanding of what the electronic Holistic Needs Assessment is changed at all? If so, how?

15. Do you remember what issues you raised on it?

    Prompts
    a. *If so, would you be happy to tell me what these were?*
    b. *How did you feel while you were discussing these?*

16. Do you feel that you disclosed all of the issues you had at the time?

    Prompts
    a. *If not, why was this? For example, forgetting or not wanting to disclose an issue.*

17. What is your opinion on how useful or not useful the assessment was?

18. Has this changed from the opinion you had when you completed the assessment at other time points? If so, how?

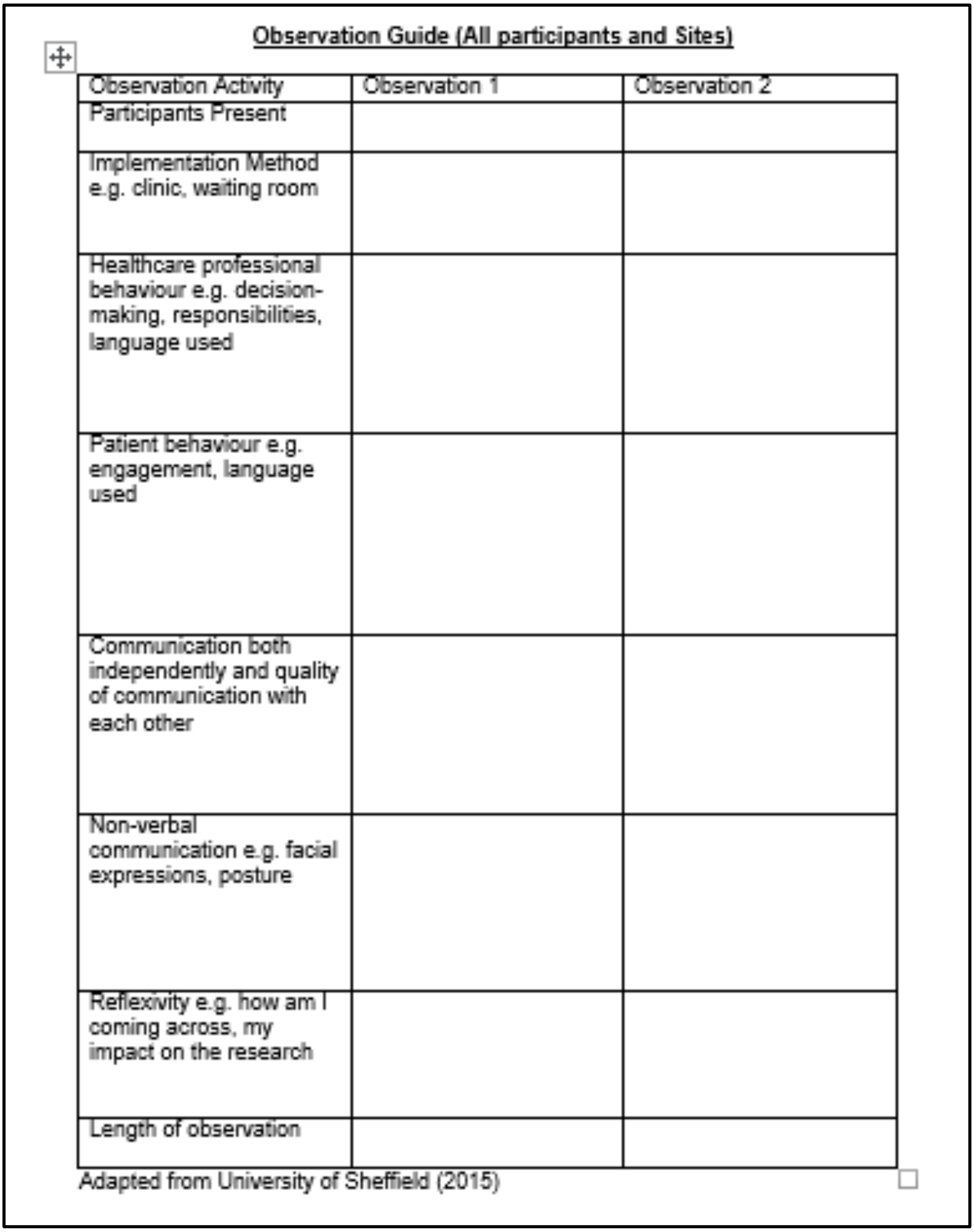
19. Were there any key differences between this assessment and previous assessments that made a difference to you?

Prompts

a. *The timing of the assessment?*
b. *The staff member completing it?*
c. *Your expectations?*
d. *Privacy or how much time the healthcare professional had?*
e. *You had more issues to raise?*

STOP RECORDING

Appendix L- Observation Guide



Observation Guide (All participants and Sites)

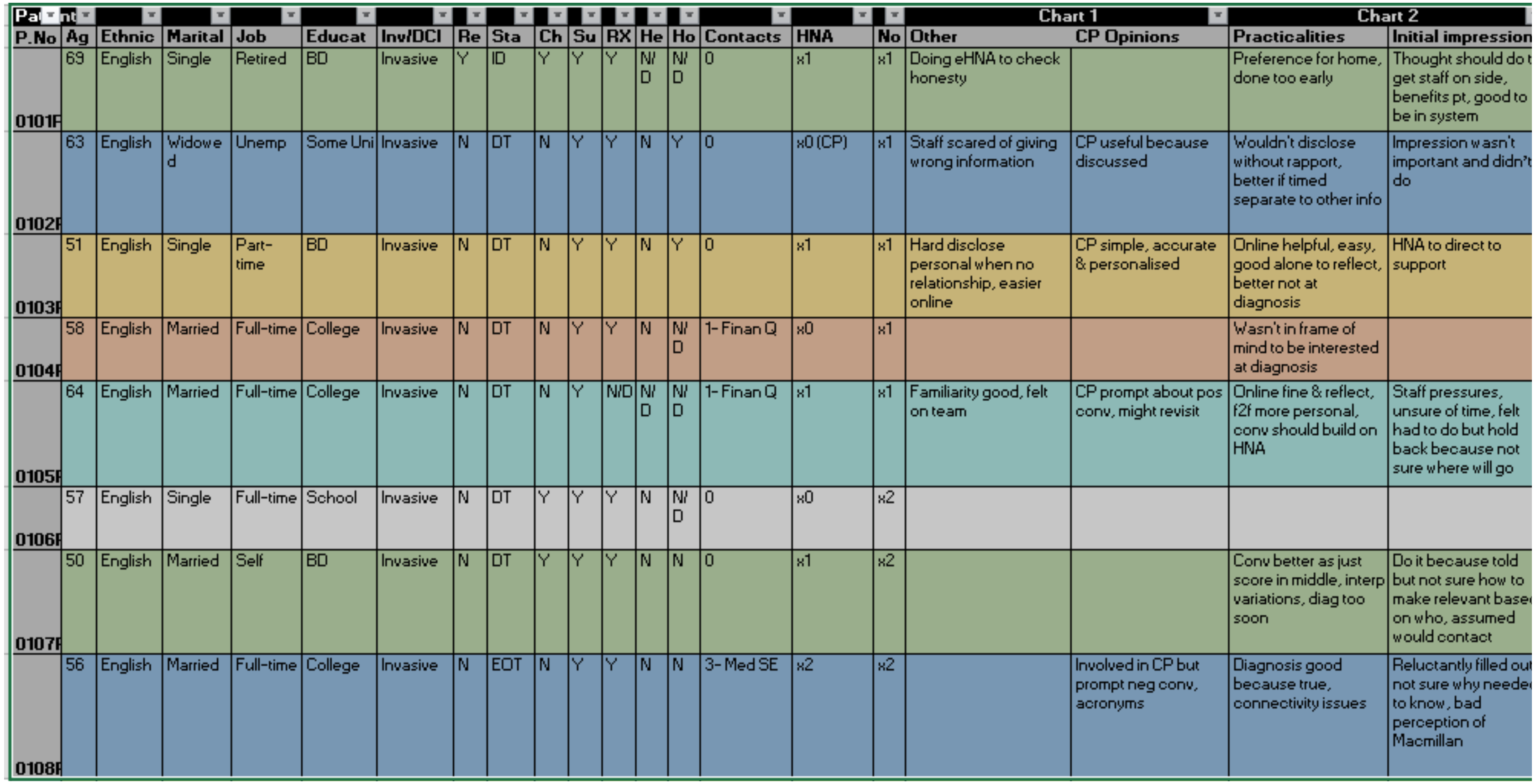
Observation Activity	Observation 1	Observation 2
Participants Present		
Implementation Method e.g. clinic, waiting room		
Healthcare professional behaviour e.g. decision-making, responsibilities, language used		
Patient behaviour e.g. engagement, language used		
Communication both independently and quality of communication with each other		
Non-verbal communication e.g. facial expressions, posture		
Reflexivity e.g. how am I coming across, my impact on the research		
Length of observation		

Adapted from University of Sheffield (2015)

Appendix M- Matrix Excerpt

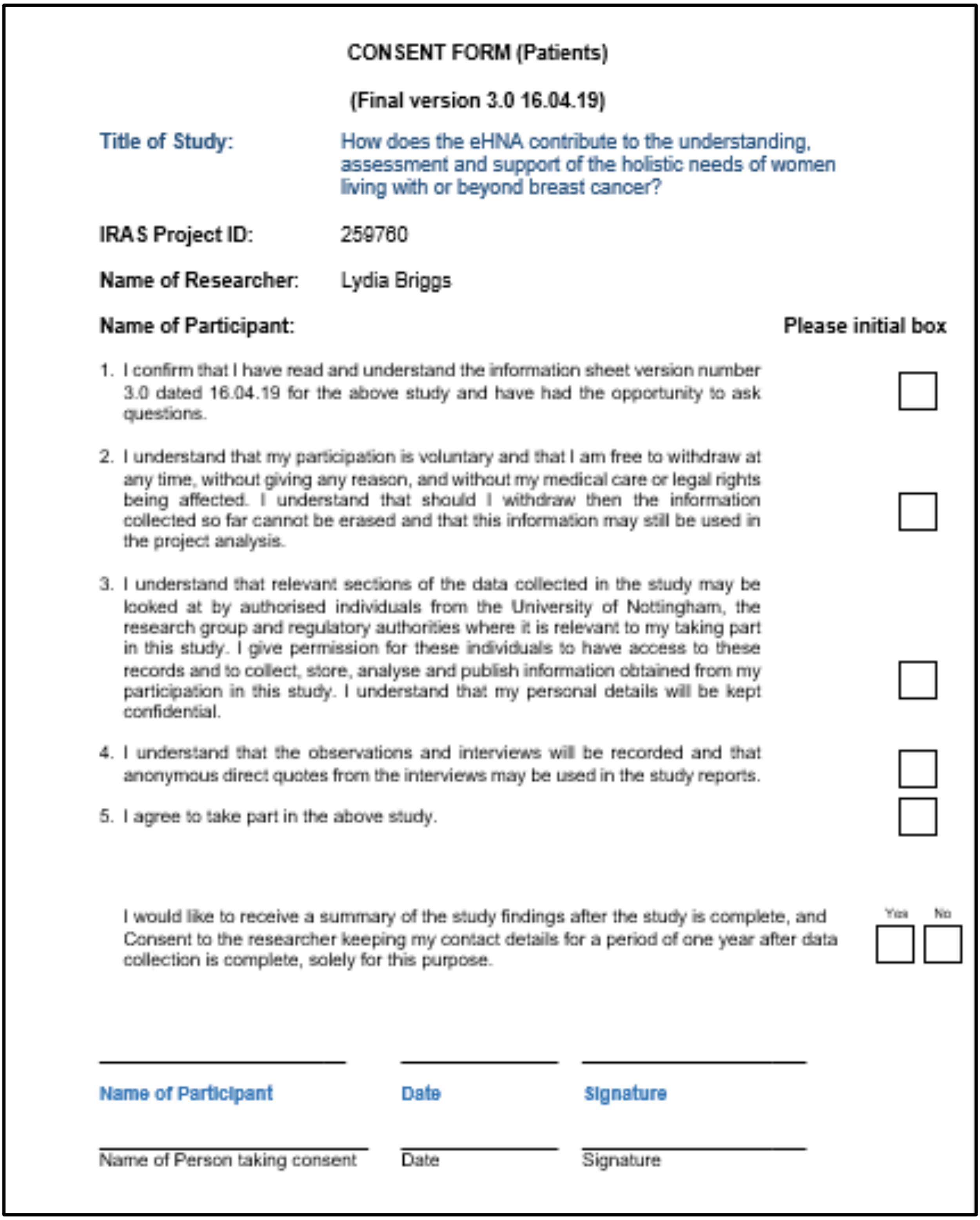
HNA Delivery Methods									
ID	Online format 2.3	Elements/Dimensions	Categories	Location 2.4	Elements/Dimensions	Categories	Timing 2.5	Elements/Dimensions	Categories
0101P	1- "We do so much on a computer today… I didn't feel one way or another; I didn't feel it was more comfortable than sitting with an iPad in an office somewhere." 2- At least if eHNA done now it stores it in the system maybe further down the line, but on the other hand if you do it now, "at least somewhere you're in the system, and one thing I know is when you feel tired and cross and lack energy in the middle of treatments, you know, you don't really want to get on to a new thing" better if you have a familiar system from day one.	No preference for home assessment or iPad in office eHNA stores it for later use Good thing to be registered in system for later use	Location of assessment Revisiting data	1- Preference for doing at home, can do in your own time without feeling pressured to fill in quickly.	Preference for home as no pressure	Location of assessment	1- May have additional issues halfway through treatment, does not currently require it but may do 6 months down the line. 2- Unsure whether needs will change when has a treatment plan in front of her. 3- "I think at the moment the issues aren't there to be resolved because it's too early."	HNA not required presently but might be later Needs might change after treatment plan Issues aren't there now as too early	Needs change over time Suitability of HNA timing
0102P				1- "I just guess I'm quite a private person and I wouldn't often share feelings with somebody that I'd never met and I was just talking to them on the phone for the first time."	Private person wouldn't share feelings over the phone Wouldn't share feelings if no relationship	Honesty	1- Doing HNA at a different time when it was not extra to all other information would have been good.	HNA better if not on top of all other information	Suitability of HNA timing

Appendix N- Central Chart Excerpt



Pa nt																	Chart 1		Chart 2	
P.No	Ag	Ethnic	Marital	Job	Educat	Inv/DCI	Re	Sta	Ch	Su	RX	He	Ho	Contacts	HNA	No	Other	CP Opinions	Practicalities	Initial impression
0101F	69	English	Single	Retired	BD	Invasive	Y	ID	Y	Y	Y	N/D	N/D	0	x1	x1	Doing eHNA to check honesty		Preference for home, done too early	Thought should do t get staff on side, benefits pt, good to be in system
0102F	63	English	Widowed	Unemp	Some Uni	Invasive	N	DT	N	Y	Y	N	Y	0	x0 (CP)	x1	Staff scared of giving wrong information	CP useful because discussed	Wouldn't disclose without rapport, better if timed separate to other info	Impression wasn't important and didn't do
0103F	51	English	Single	Part-time	BD	Invasive	N	DT	N	Y	Y	N	Y	0	x1	x1	Hard disclose personal when no relationship, easier online	CP simple, accurate & personalised	Online helpful, easy, good alone to reflect, better not at diagnosis	HNA to direct to support
0104F	58	English	Married	Full-time	College	Invasive	N	DT	N	Y	Y	N	N/D	1- Finan Q	x0	x1			Wasn't in frame of mind to be interested at diagnosis	
0105F	64	English	Married	Full-time	College	Invasive	N	DT	N	Y	N/D	N/D	N/D	1- Finan Q	x1	x1	Familiarity good, felt on team	CP prompt about pos conv, might revisit	Online fine & reflect, f2f more personal, conv should build on HNA	Staff pressures, unsure of time, felt had to do but hold back because not sure where will go
0106F	57	English	Single	Full-time	School	Invasive	N	DT	Y	Y	Y	N	N/D	0	x0	x2				
0107F	50	English	Married	Self	BD	Invasive	N	DT	Y	Y	Y	N	N	0	x1	x2			Conv better as just score in middle, interp variations, diag too soon	Do it because told but not sure how to make relevant base on who, assumed would contact
0108F	56	English	Married	Full-time	College	Invasive	N	EOT	N	Y	Y	N	N	3- Med SE	x2	x2		Involved in CP but prompt neg conv, acronyms	Diagnosis good because true, connectivity issues	Reluctantly filled out not sure why neede to know, bad perception of Macmillan

Appendix O- Consent Forms



CONSENT FORM (Patients)

(Final version 3.0 16.04.19)

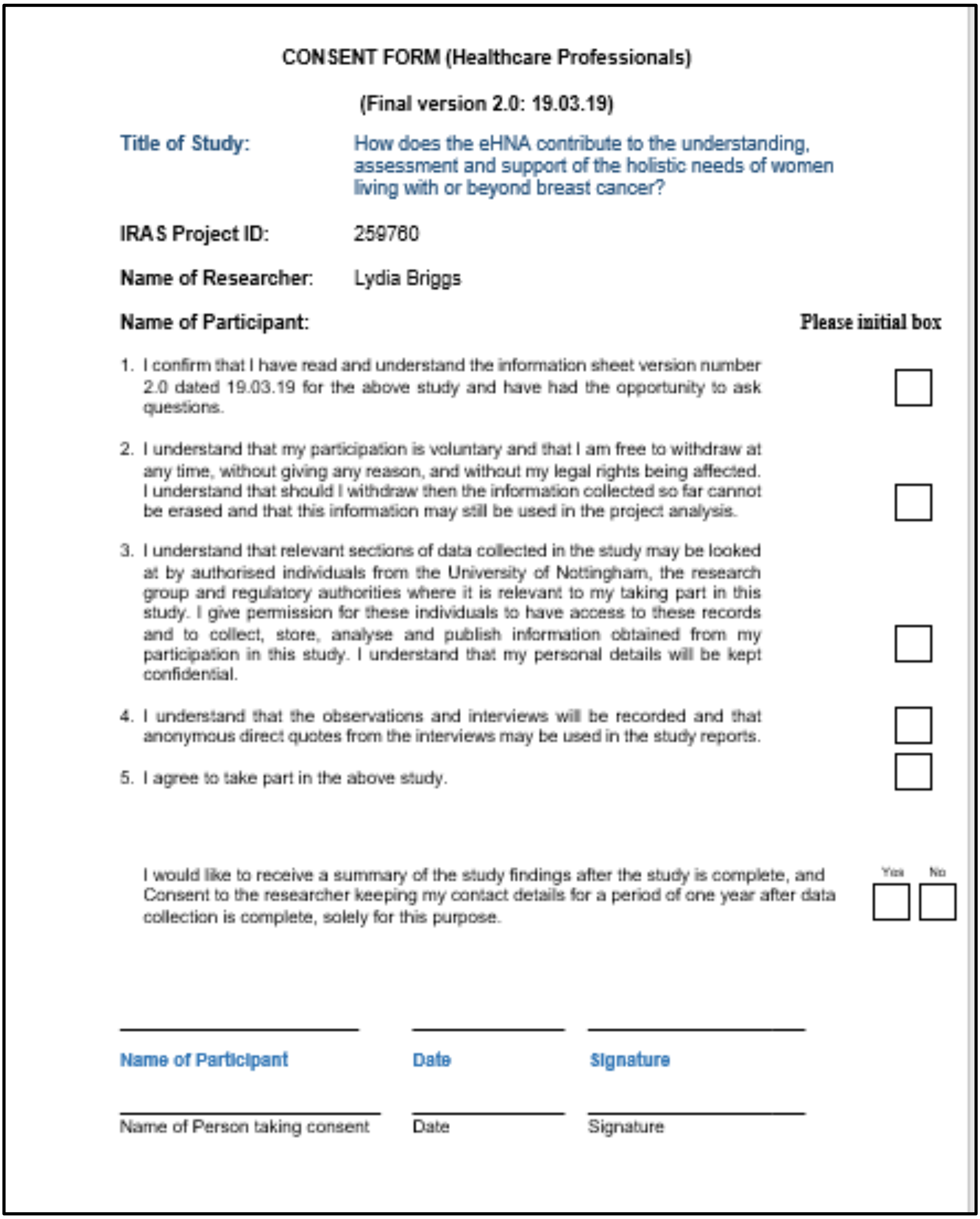
Title of Study:	How does the eHNA contribute to the understanding, assessment and support of the holistic needs of women living with or beyond breast cancer?
IRAS Project ID:	259760
Name of Researcher:	Lydia Briggs

Name of Participant: **Please initial box**

1. I confirm that I have read and understand the information sheet version number 3.0 dated 16.04.19 for the above study and have had the opportunity to ask questions. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, and without my medical care or legal rights being affected. I understand that should I withdraw then the information collected so far cannot be erased and that this information may still be used in the project analysis. ☐
3. I understand that relevant sections of the data collected in the study may be looked at by authorised individuals from the University of Nottingham, the research group and regulatory authorities where it is relevant to my taking part in this study. I give permission for these individuals to have access to these records and to collect, store, analyse and publish information obtained from my participation in this study. I understand that my personal details will be kept confidential. ☐
4. I understand that the observations and interviews will be recorded and that anonymous direct quotes from the interviews may be used in the study reports. ☐
5. I agree to take part in the above study. ☐

I would like to receive a summary of the study findings after the study is complete, and Consent to the researcher keeping my contact details for a period of one year after data collection is complete, solely for this purpose. Yes ☐ No ☐

____________________	____________	________________
Name of Participant	**Date**	**Signature**
____________________	____________	________________
Name of Person taking consent	Date	Signature



CONSENT FORM (Healthcare Professionals)

(Final version 2.0: 19.03.19)

Title of Study: How does the eHNA contribute to the understanding, assessment and support of the holistic needs of women living with or beyond breast cancer?

IRAS Project ID: 259760

Name of Researcher: Lydia Briggs

Name of Participant:

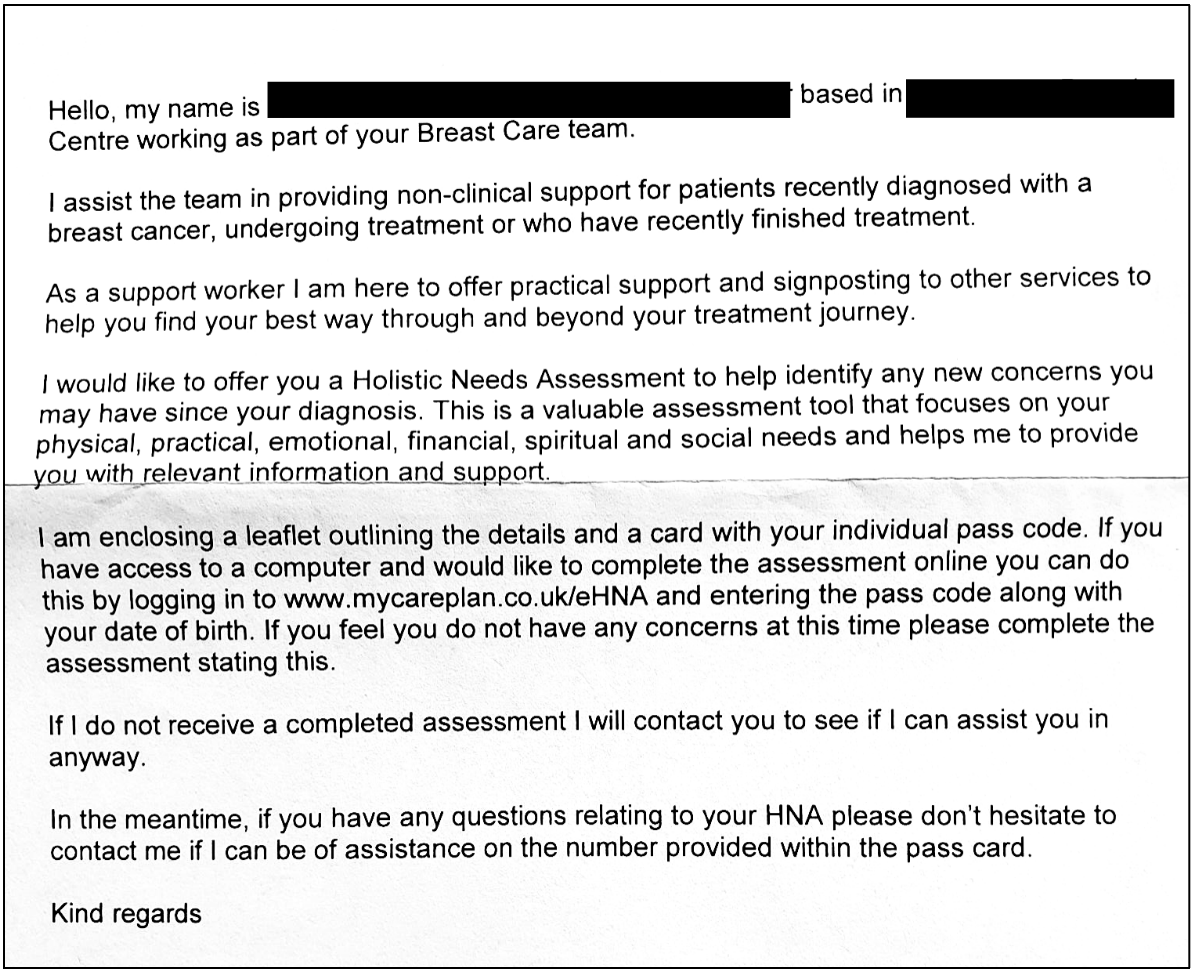
Please initial box

1. I confirm that I have read and understand the information sheet version number 2.0 dated 19.03.19 for the above study and have had the opportunity to ask questions. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, and without my legal rights being affected. I understand that should I withdraw then the information collected so far cannot be erased and that this information may still be used in the project analysis. ☐
3. I understand that relevant sections of data collected in the study may be looked at by authorised individuals from the University of Nottingham, the research group and regulatory authorities where it is relevant to my taking part in this study. I give permission for these individuals to have access to these records and to collect, store, analyse and publish information obtained from my participation in this study. I understand that my personal details will be kept confidential. ☐
4. I understand that the observations and interviews will be recorded and that anonymous direct quotes from the interviews may be used in the study reports. ☐
5. I agree to take part in the above study. ☐

I would like to receive a summary of the study findings after the study is complete, and Consent to the researcher keeping my contact details for a period of one year after data collection is complete, solely for this purpose. Yes ☐ No ☐

Name of Participant	**Date**	**Signature**
Name of Person taking consent	Date	Signature

Appendix P- Document 1 (Case Study 1’s letter of invitation to complete an (e)HNA for all patients)



Hello, my name is [redacted] based in [redacted] Centre working as part of your Breast Care team.

I assist the team in providing non-clinical support for patients recently diagnosed with a breast cancer, undergoing treatment or who have recently finished treatment.

As a support worker I am here to offer practical support and signposting to other services to help you find your best way through and beyond your treatment journey.

I would like to offer you a Holistic Needs Assessment to help identify any new concerns you may have since your diagnosis. This is a valuable assessment tool that focuses on your physical, practical, emotional, financial, spiritual and social needs and helps me to provide you with relevant information and support.

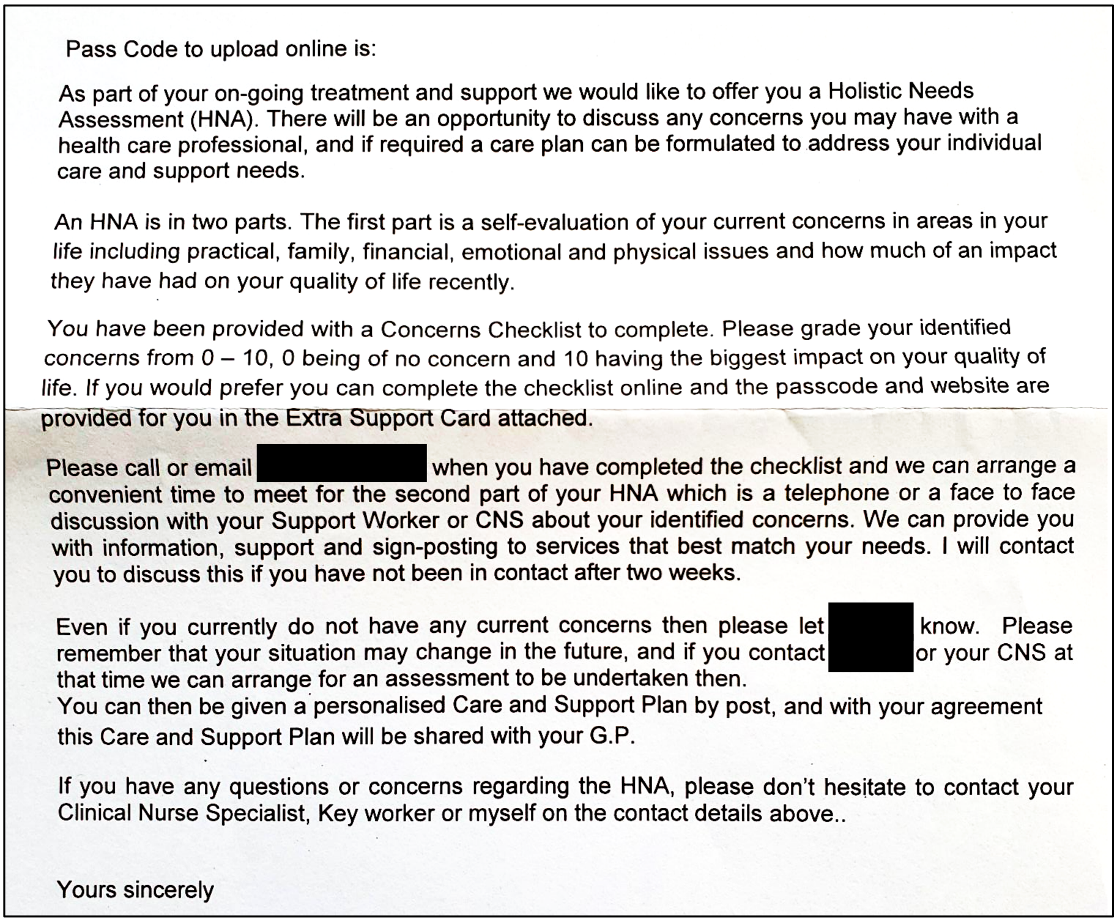
I am enclosing a leaflet outlining the details and a card with your individual pass code. If you have access to a computer and would like to complete the assessment online you can do this by logging in to www.mycareplan.co.uk/eHNA and entering the pass code along with your date of birth. If you feel you do not have any concerns at this time please complete the assessment stating this.

If I do not receive a completed assessment I will contact you to see if I can assist you in anyway.

In the meantime, if you have any questions relating to your HNA please don't hesitate to contact me if I can be of assistance on the number provided within the pass card.

Kind regards

Appendix Q- Document 2 (Case Study 1’s letter of invitation to complete an (e)HNA if having chemotherapy)



Pass Code to upload online is:

As part of your on-going treatment and support we would like to offer you a Holistic Needs Assessment (HNA). There will be an opportunity to discuss any concerns you may have with a health care professional, and if required a care plan can be formulated to address your individual care and support needs.

An HNA is in two parts. The first part is a self-evaluation of your current concerns in areas in your life including practical, family, financial, emotional and physical issues and how much of an impact they have had on your quality of life recently.

You have been provided with a Concerns Checklist to complete. Please grade your identified concerns from 0 – 10, 0 being of no concern and 10 having the biggest impact on your quality of life. If you would prefer you can complete the checklist online and the passcode and website are provided for you in the Extra Support Card attached.

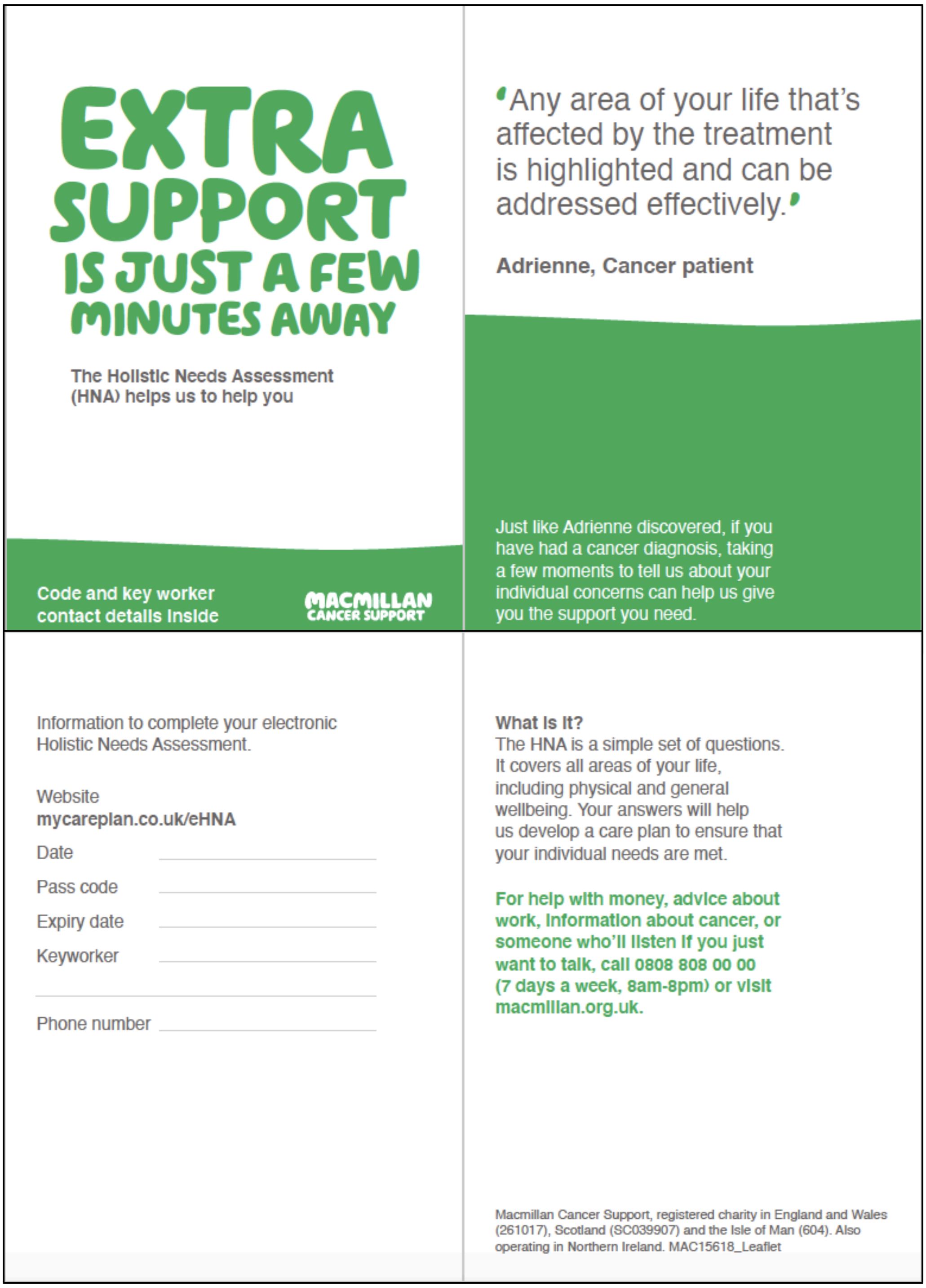
Please call or email [redacted] when you have completed the checklist and we can arrange a convenient time to meet for the second part of your HNA which is a telephone or a face to face discussion with your Support Worker or CNS about your identified concerns. We can provide you with information, support and sign-posting to services that best match your needs. I will contact you to discuss this if you have not been in contact after two weeks.

Even if you currently do not have any current concerns then please let [redacted] know. Please remember that your situation may change in the future, and if you contact [redacted] or your CNS at that time we can arrange for an assessment to be undertaken then.
You can then be given a personalised Care and Support Plan by post, and with your agreement this Care and Support Plan will be shared with your G.P.

If you have any questions or concerns regarding the HNA, please don’t hesitate to contact your Clinical Nurse Specialist, Key worker or myself on the contact details above..

Yours sincerely

Appendix R- Document 4 (Macmillan 'Extra Support' Card



EXTRA SUPPORT IS JUST A FEW MINUTES AWAY

The Holistic Needs Assessment (HNA) helps us to help you

Code and key worker contact details inside

MACMILLAN CANCER SUPPORT

'Any area of your life that's affected by the treatment is highlighted and can be addressed effectively.'

Adrienne, Cancer patient

Just like Adrienne discovered, if you have had a cancer diagnosis, taking a few moments to tell us about your individual concerns can help us give you the support you need.

Information to complete your electronic Holistic Needs Assessment.

Website
mycareplan.co.uk/eHNA

Date ____________________

Pass code ____________________

Expiry date ____________________

Keyworker ____________________

Phone number ____________________

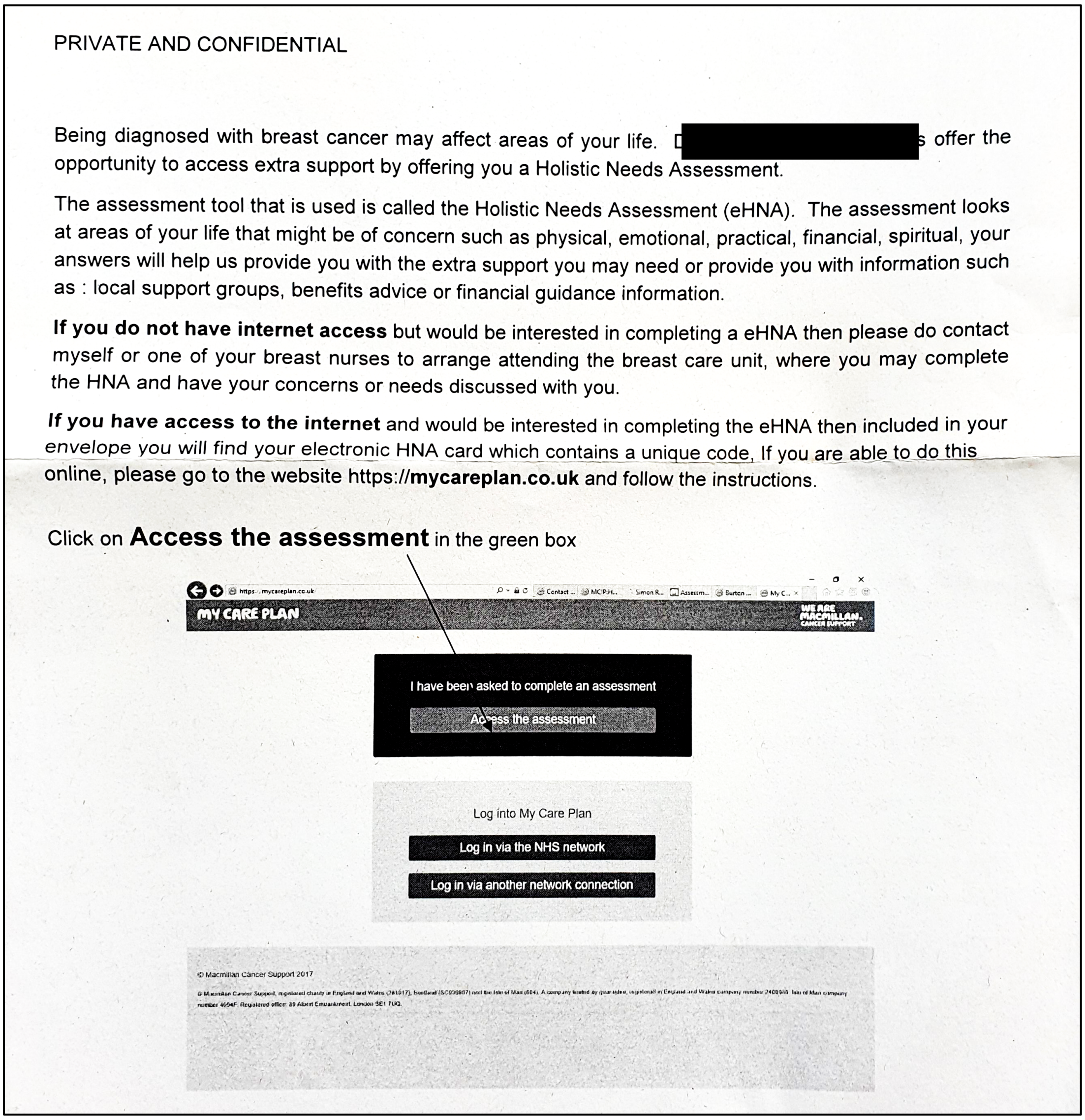
What is it?
The HNA is a simple set of questions. It covers all areas of your life, including physical and general wellbeing. Your answers will help us develop a care plan to ensure that your individual needs are met.

For help with money, advice about work, information about cancer, or someone who'll listen if you just want to talk, call 0808 808 00 00 (7 days a week, 8am-8pm) or visit macmillan.org.uk.

Macmillan Cancer Support, registered charity in England and Wales (261017), Scotland (SC039907) and the Isle of Man (604). Also operating in Northern Ireland. MAC15618_Leaflet

Macmillan Cancer Support (2018) eHNA Leaflet. Available at: https://be.macmillan.org.uk/be/p-25089-ehna-leaflet.aspx [Accessed 19th March 2021].

Appendix S- Document 5 (Case Study 2 's letter of invitation to complete an (e)HNA for all patients)



PRIVATE AND CONFIDENTIAL

Being diagnosed with breast cancer may affect areas of your life. [redacted] offer the opportunity to access extra support by offering you a Holistic Needs Assessment.

The assessment tool that is used is called the Holistic Needs Assessment (eHNA). The assessment looks at areas of your life that might be of concern such as physical, emotional, practical, financial, spiritual, your answers will help us provide you with the extra support you may need or provide you with information such as : local support groups, benefits advice or financial guidance information.

If you do not have internet access but would be interested in completing a eHNA then please do contact myself or one of your breast nurses to arrange attending the breast care unit, where you may complete the HNA and have your concerns or needs discussed with you.

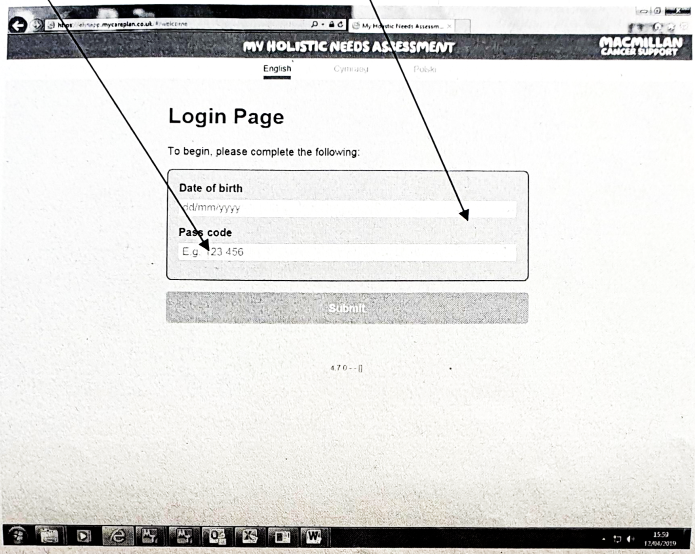
If you have access to the internet and would be interested in completing the eHNA then included in your envelope you will find your electronic HNA card which contains a unique code, If you are able to do this online, please go to the website https://**mycareplan.co.uk** and follow the instructions.

Click on **Access the assessment** in the green box

The next page will be a login Page (as below)

You must enter your **date of birth** for example as 01/01/1901

And **enter your pass code** (which is found on the card included in the pack)



Login Page

To begin, please complete the following:

Date of birth
dd/mm/yyyy

Pass code
E.g. 123 456

I will contact you once you have completed the online HNA, where you will be offered the opportunity to attend the breast unit to discuss your concerns and or needs, or if you wish a telephone discussion.

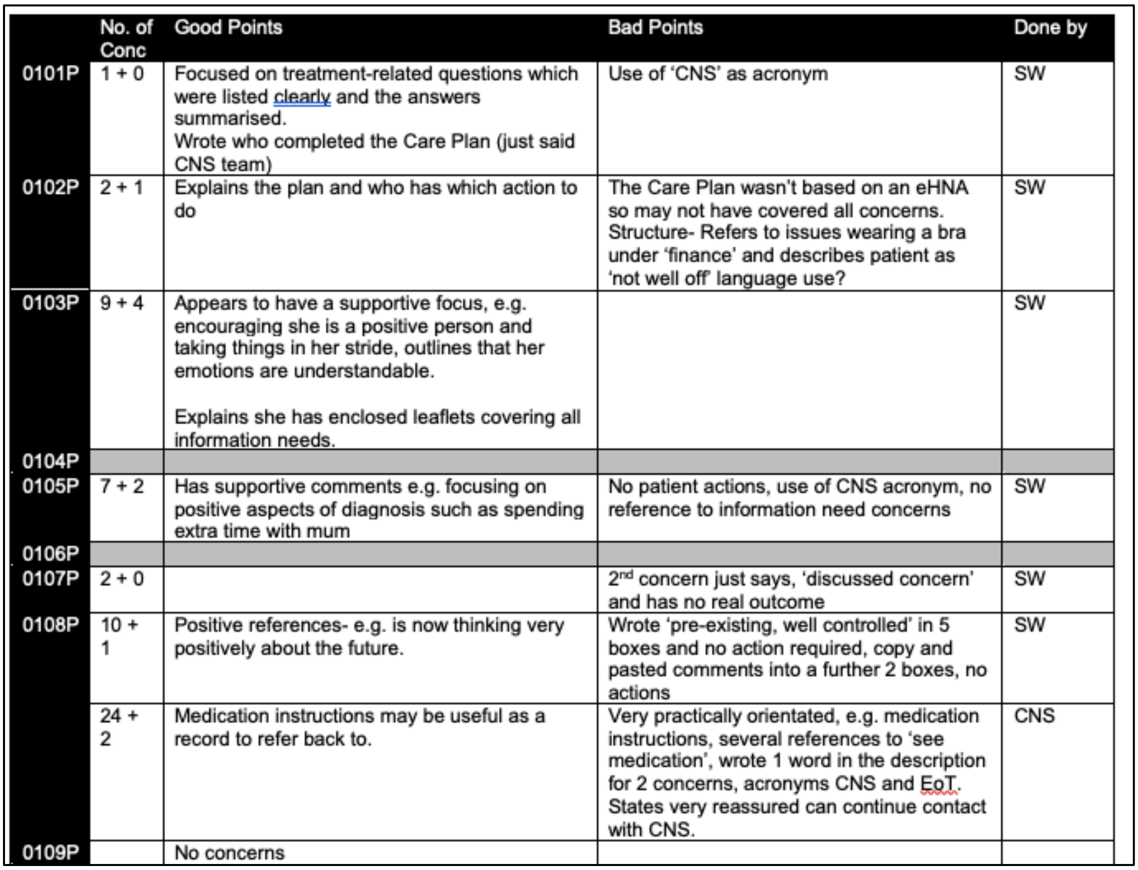
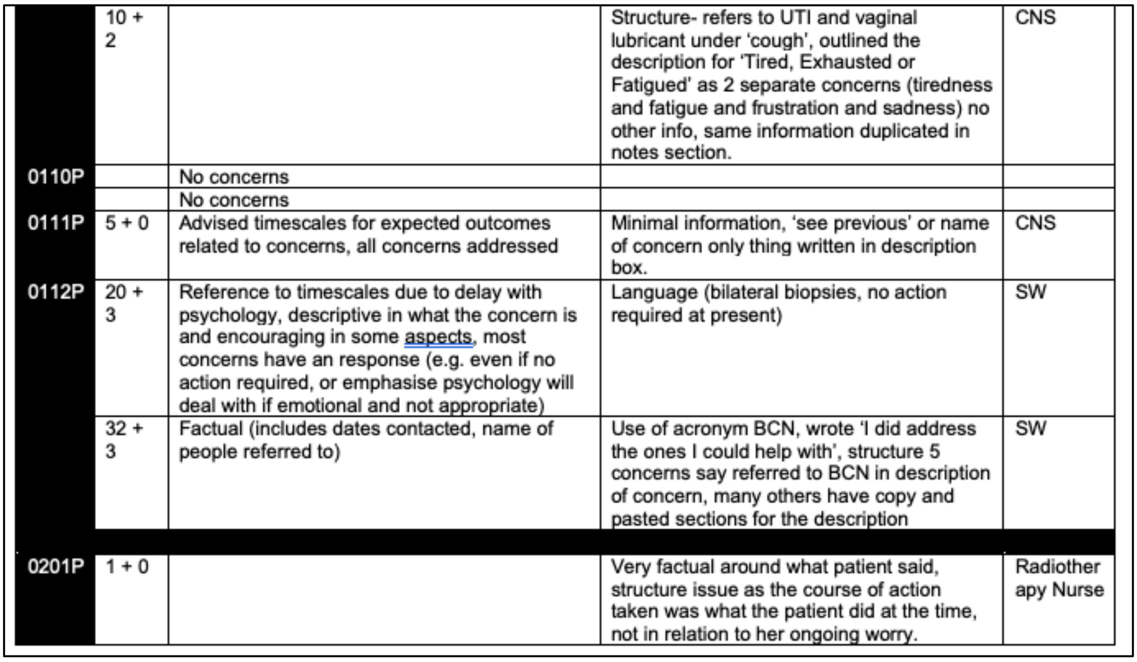
You are not obliged to complete the assessment and if you decide you do not wish to proceed at the moment please do contact myself or one of the breast care nurses. This **will not have any impact on how we treat you**, and if you have any concerns now or in the future please do remember to contact the breast care team for support and advice.

You may wish however at any point during or after your cancer treatment to request an HNA by contacting myself or one of the breast care nurses to arrange.

If you have any questions please do not hesitate to give the breast care team including myself to discuss.

Kind regards

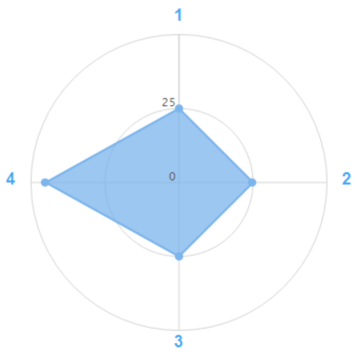
Appendix T- Care Plan Analysis

	No. of Conc	Good Points	Bad Points	Done by
0101P	1 + 0	Focused on treatment-related questions which were listed clearly and the answers summarised. Wrote who completed the Care Plan (just said CNS team)	Use of 'CNS' as acronym	SW
0102P	2 + 1	Explains the plan and who has which action to do	The Care Plan wasn't based on an eHNA so may not have covered all concerns. Structure- Refers to issues wearing a bra under 'finance' and describes patient as 'not well off' language use?	SW
0103P	9 + 4	Appears to have a supportive focus, e.g. encouraging she is a positive person and taking things in her stride, outlines that her emotions are understandable. Explains she has enclosed leaflets covering all information needs.		SW
0104P				
0105P	7 + 2	Has supportive comments e.g. focusing on positive aspects of diagnosis such as spending extra time with mum	No patient actions, use of CNS acronym, no reference to information need concerns	SW
0106P				
0107P	2 + 0		2nd concern just says, 'discussed concern' and has no real outcome	SW
0108P	10 + 1	Positive references- e.g. is now thinking very positively about the future.	Wrote 'pre-existing, well controlled' in 5 boxes and no action required, copy and pasted comments into a further 2 boxes, no actions	SW
	24 + 2	Medication instructions may be useful as a record to refer back to.	Very practically orientated, e.g. medication instructions, several references to 'see medication', wrote 1 word in the description for 2 concerns, acronyms CNS and EoT. States very reassured can continue contact with CNS.	CNS
0109P		No concerns		
	10 + 2		Structure- refers to UTI and vaginal lubricant under 'cough', outlined the description for 'Tired, Exhausted or Fatigued' as 2 separate concerns (tiredness and fatigue and frustration and sadness) no other info, same information duplicated in notes section.	CNS
0110P		No concerns		
		No concerns		
0111P	5 + 0	Advised timescales for expected outcomes related to concerns, all concerns addressed	Minimal information, 'see previous' or name of concern only thing written in description box.	CNS
0112P	20 + 3	Reference to timescales due to delay with psychology, descriptive in what the concern is and encouraging in some aspects, most concerns have an response (e.g. even if no action required, or emphasise psychology will deal with if emotional and not appropriate)	Language (bilateral biopsies, no action required at present)	SW
	32 + 3	Factual (includes dates contacted, name of people referred to)	Use of acronym BCN, wrote 'I did address the ones I could help with', structure 5 concerns say referred to BCN in description of concern, many others have copy and pasted sections for the description	SW
0201P	1 + 0		Very factual around what patient said, structure issue as the course of action taken was what the patient did at the time, not in relation to her ongoing worry.	Radiotherapy Nurse

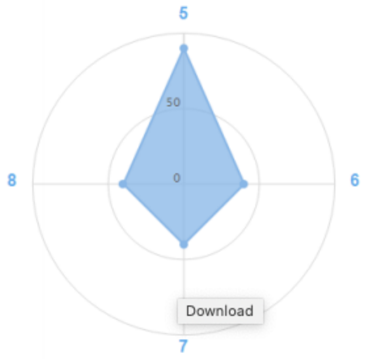
0202P	8 + 0	Clear recommendations.	Confusing wording- says patient finds situation stressful because no support but then in action box says declined support,	Radiographer
0203P	20 + 4	Wrote in notes section that the things they didn't get time to cover could be discussed at any point if she made contact.	Very sensitive information written on care plan (and patient said would hide), spelling mistakes, many say 'not discussed' (so why mention at all?), actions repetitive (all refer to psychology.	CNS
0204P		No concerns		
	21 + 4	Offered various options for support	Structure- only comments written under qs about diagnosis concern, in the description said all addressed but then covered many issues in comments and all referrals offered/actions taken	CNS
0205P	10 + 1	Provided dates for expected outcomes related to worries	Some copy and pasted sections for descriptions and actions	SW
	1 + 0	Documented answers to her questions which may serve as a prompt	Written very formally (sounds like written about her rather than for her), use of BCN acronym, some grammatical errors	SW
0206P	21 + 7		Only 1 concern addressed structurally- questions about treatment but also mentions others in this such as flat mood, very limited advice and no recommendations, just mentioned something pt has already done to help.	SW
	11 + 3	Made some useful recommendations for patient and focus on making small objectives.	Lots of references to 'covered already' or 'not discussed' in descriptions, makes it seem rushed. Minimal description, quite bullet pointed	BCN
0207P	14 + 0	Reassurance and encouragement 'how well she has done to lose weight', descriptive, described supportive conversations as well as actions.		BCN
	12 + 3		Only 1 concern mentioned on Care Plan 'breathing difficulties' discontinued HNA due to clinical review requirement, spelling mistakes, acronym 'HNA', mentions will reschedule but did not appear to happen.	SW
0208P	4 + 0		Defensive language, when asked if wanted help said she wanted to bury it (even though accepted psych referral?), minimal detail	BCN
	8 + 0	Supportive comments such as justifying how she feels, used the patient's own words in some of the descriptions, provided more detail around wider support and booklets given in notes section.	Spelling mistakes.	BCN
0209P		No concerns		
0210P	9 + 4	Documented that written information would be sent in post.	Structure- wrote answers in notes section rather than using usual format of choosing a specific concern to elaborate on, wrote BCN would contact re questions but no idea if followed up and structure unhelpful. Also highlighted that patient hadn't understood assessment- ?embarrassing	SW
0211P	2		No description provided for concerns in this column, listed underneath actions instead (structure) and no actual actions provided, minimal information given.	Radiotherapy Nurse
	10 + 5	Supportive comments to normalise feelings and reassure, e.g. lumps and bumps quite normal now	Medical jargon 'oral medication', 'analgesia'	BCN
0212P	11 + 3	Some concerns described in detail demonstrating has listened to patient, informed about information leaflets sent and some reassuring comments	Medical jargon 'oncotype', 'adjuvant', 'RT'	SW

Appendix U- Normalisation Process Theory Toolkit Results (May et al., 2015)



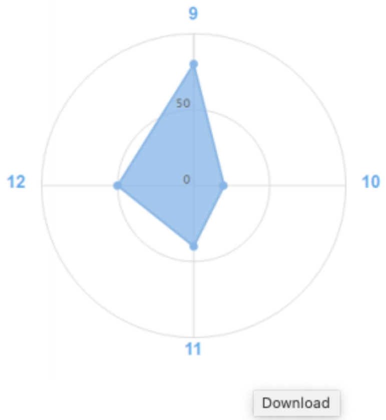
Sense-making

1. Participants distinguish the intervention from current ways of working.
2. Participants collectively agree about the purpose of the intervention.
3. Participants individually understand what the intervention requires of them.
4. Participants construct potential value of the intervention for their work.



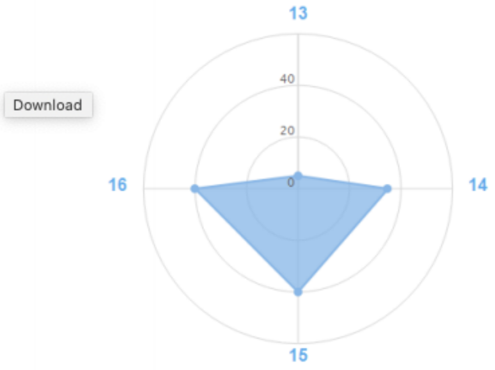
Participation

5. Key individuals drive the intervention forward.
6. Participants agree that the intervention should be part of their work.
7. Participants buy in to the intervention.
8. Participants continue to support the intervention.



Action

9. Participants perform the tasks required by the intervention.
10. Participants maintain their trust in each otherâ€™s work and expertise through the intervention.
11. The work of the intervention is appropriately allocated to participants.
12. The intervention is adequately supported by its host organization.



Monitoring

13. Participants access information about the effects of the intervention.
14. Participants collectively assess the intervention as worthwhile.
15. Participants individually assess the intervention as worthwhile.
16. Participants modify their work in response to their appraisal of the intervention.