# *When You Don't Know, You Don't Know.*

# Haematopoietic Stem Cell Transplantation Recipients' Experiences of Long-Term Follow-Up Care in England: A Multi-Method Study

**Blossom Bell**

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Population Health Sciences Institute

Newcastle University

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# Abstract

Understanding and meeting the informational needs of haematopoietic stem cell transplantation (HSCT) recipients is essential for developing person-centred long-term follow-up (LTFU) care. This thesis explores the lived experiences of HSCT recipients in England as they navigate LTFU care, focusing on the psychological, informational, and structural factors that shape engagement and well-being. Using a phenomenological, multi-method approach, it comprises three studies: a systematic review and qualitative evidence synthesis, a qualitative analysis of online written accounts from seventeen HSCT recipients in England, and in-depth interviews with fourteen recipients exploring their informational needs during LTFU.

Findings reveal that recipients frequently encounter insufficient information about potential long-term complications and LTFU practices, resulting in persistent uncertainty. Insights from written accounts and interviews show that *Future Uncertainty* is central to LTFU care for HSCT recipients in England. This uncertainty manifests in two key ways: service navigation uncertainty, relating to how recipients access and move through care systems, and health uncertainty, concerning ongoing risks, late effects, and self-management. While recipients express a strong desire to be prepared for future health events, this is often undermined by the timing, clarity, and objectivity of information provided by transplant clinics. Many become proactive in seeking information, often turning to online resources and peer support, which can be both empowering and anxiety-inducing.

Unclear transitions, evolving health risks, and gaps in information contribute to psychological strain, reinforcing the overarching theme of Future Uncertainty in LTFU care. Addressing these challenges requires clear communication, tailored and timely information, written care plans, and strong clinical relationships. Supporting health literacy, clarifying care roles, and guiding recipients to reliable information sources can empower recipients to manage their care with confidence. This thesis highlights the importance of acknowledging the lived experience of uncertainty, encapsulated by one HSCT recipient as: "*When you don't know, you don't know.*"

## Acknowledgements

I express my profound gratitude to my supervisors, Dr. Kate Swainston and Dr. Rachel Stocker. This PhD would not have been achievable without your support, guidance, and counsel.

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Finally, to my husband, thank you for your unwavering support and for being my source of strength throughout this journey. I could not have completed this PhD without you.


## Dedications

I dedicate this thesis to the memory of my father, Captain Stewart David Bell, Master Mariner, and brother-in-law Jonathan Mark Audain, D.Litt. (Honoris causa). Thank you both for the encouragement in starting this project, especially Jonathan, for just "getting it", understanding the enormity of any research journey and expressing your words of support when I needed it the most. *Never forgotten. Always missed.*

To my husband, for always believing in me.
To my mother, for your incredible strength all those years ago.
To my eldest brother, for giving me some of your stem cells.
To my siblings and "add-ons", for the joy and support you and your families bring.
To my closest friends, for just being you.
Last, but not least, to all haematopoietic stem cell transplant recipients, who alone truly comprehend the journey.

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# List of Abbreviations

Allo-HSCT: Allogeneic Haematopoietic Stem Cell Transplant

ASBMT: American Society for Blood and Marrow Transplantation

Auto-HSCT: Autologous Haematopoietic Stem Cell Transplant

BSBMTCT: British Society of Blood and Marrow Transplantation and Cellular Therapy

CIBMTR: Centre for International Blood and Marrow Transplant Research

EBMT: European Society for Blood and Marrow Transplantation

FACT: Foundation for the Accreditation of Cellular Therapy

GP: General Practitioner

GvHD: Graft-versus-Host Disease

HLA: Human Leukocyte Antigen

HSC: Haematopoietic Stem Cells

HSCT: Haematopoietic Stem Cell Transplant

IU: Illness Uncertainty Theory

IUT: Intolerance of Uncertainty Theory

JACIE: Joint Accreditation Committee of the International Society for Cell and Gene Therapy and the EBMT

LTFU: Long-term Follow-up

NHS: National Health Service

NHSE: National Health Service England

QOL: Quality of Life

ROI: Republic of Ireland

SCT: Social Cognitive Theory

UK: United Kingdom

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# Publications and Oral Presentations

## Peer-reviewed publications

Bell, B., & Swainston, K. (2024). The lived experience of long-term follow-up clinical care for haematopoietic stem cell recipients in England: a qualitative exploration. *Journal of cancer survivorship: research and practice*, *18*(5), 1590–1599. https://doi.org/10.1007/s11764-023-01399-w

Bell, B., Thursby, S., Limbrick, H., & Swainston, K. (2024). A Systematic Review and Metasynthesis of Hematopoietic Stem Cell Transplant (HSCT) Patient's Experiences of Long-Term Monitoring Clinics from the Patient's Perspective. *Journal of Patient Experience*, *11*. https://doi.org/10.1177/23743735241229378

## Oral Presentations

Bell, B., & Swainston, K. (2024, April). The informational needs of post haematopoietic stem cell transplant patients in England: A qualitative exploration [Oral presentation O169]. In Patient Advocacy - Oral Session (O164–O169), 50th Annual Meeting of the European Society for Blood and Marrow Transplantation. Bone Marrow Transplantation, 59(Suppl 1), 772–777. https://doi.org/10.1038/s41409-024-02358-4

# Chapter 1. Introduction

## 1.1 Chapter Introduction

Haematopoietic stem cell transplantation (HSCT) is a potentially curative therapy for a range of malignant and non-malignant haematological (blood) diseases, but it does not mark the end of the healthcare journey. Due to significant risks of late effects and ongoing health complications, recipients require lifelong long-term follow-up (LTFU) care. This thesis aims to understand how HSCT recipients experience LTFU care in England, with a particular focus on the psychological, informational, and structural factors that shape engagement, adaptation, and well-being.

This introductory chapter provides an overview of the background of this thesis (Chapter 2), the research purpose, research questions, and objectives, as well as the significance and limitations of this programme of work. This chapter concludes with a summary of the thesis structure.

## 1.2 Setting the Scene

HSCT is a complex and rigorous procedure that offers the possibility of cure for a range of haematological diseases. It involves replacing malfunctioning stem cells with healthy counterparts, enabling the recovery of normal haematopoietic (blood-forming) function (Aiuti et al., 2024; Maziarz, 2021; see Section 2.2.1). However, survivorship does not mark the end of the care trajectory. HSCT recipients remain at an increased risk of treatment-related mortality and morbidity from infections, relapse, graft-versus-host disease (GvHD), subsequent cancer, and organ dysfunction (Bhatia et al., 2021, 2022; Styczyński et al., 2020; see Section 2.3).

In recognition of these risks, accreditation standards for HSCT centres mandate the implementation of LTFU guidelines (FACT-JACIE, 2021; see Section 2.2.3). LTFU care models vary, with some centres in the United Kingdom (UK) adopting hybrid care models with primary/secondary providers (Dignan et al., 2021; see Section 2.5.1). Multidisciplinary team approaches are recommended (Majhail et al., 2012; Rotz et al., 2024), but access to such teams is inconsistent, leading to disparities in care and support (Dignan et al., 2021: Hamblin et al., 2017; see Section 2.5.4).

As the population of HSCT survivors grows, and with known variation in centre practices, attention has shifted to the management and infrastructure of LTFU care. There is now a policy emphasis on person-centred and personalised stratified follow-up (PSFU) pathways for cancer

survivors (NHS, 2019, 2020a). While PSFU is being implemented for cancer survivors in England, its application to HSCT recipients remains uncertain. Nevertheless, the trend towards self-managed pathways is likely to affect this population in the future (NHS, 2022; see Section 2.6.1).

To deliver person-centred care, it is essential to understand patient experiences (Havana et al., 2023; see Section 2.7). While the HSCT pathway has been discussed among professionals, there is a lack of research exploring recipients' lived experiences of LTFU care in England (see Section 4.2). This thesis addresses this gap through a hermeneutic phenomenological, multi-method sequential study (see Section 3.3 and 3.5), aiming to illuminate the realities of LTFU care from the recipient perspective.

A key conceptual lens for this thesis is the Candidacy Framework (Dixon-Woods et al., 2006) (see Section 2.4.2). The Candidacy Framework conceptualises access to healthcare as a negotiated and dynamic process, shaped by individual, relational, and structural factors. It is particularly relevant for understanding how HSCT recipients interpret their eligibility for support, navigate ambiguous transitions, and respond to fragmented systems in LTFU care (see Sections 2.4 and 2.5). This framework is adapted in this thesis to reflect the conditional, interpretive, and emotionally charged nature of post-transplant healthcare navigation, and is developed further in later chapters.

This thesis aims to bridge the gap in knowledge and understanding that is essential to delivering patient-centred care. Viewpoints about LTFU services derived from lived experiences can be used collectively to highlight deficiencies or areas of concern (Brett et al., 2014; see Section 5.4 and 6.4). Understanding recipients' lived experience of LTFU can also identify specific health needs in order to deliver a more tailored approach. This, in turn may facilitate recipients' ability in managing their future health and well-being (Brett et al., 2014), which is one of the NHS's aims as set out in the ten-year plan (NHS, 2019).

## 1.3 Research Orientation

### *1.3.1 Purpose Statement*

The purpose of this programme of work is to understand and illuminate HSCT recipients' lived experience of LTFU care in England. Through the triangulation of written accounts (see Chapter 5) and in-depth qualitative interviews (see Chapter 6), the research identifies the essence of recipients' experiences and their specific healthcare informational needs. The findings are

intended to inform healthcare professionals, policy makers, and service providers, in supporting the development of more person-centred, responsive LTFU care for HSCT recipients in England.

### *1.3.2 Research Question*

The overarching research question is: How do haematopoietic stem cell transplantation (HSCT) recipients experience long-term follow-up (LTFU) care in England?

This research question was chosen to reflect the qualitative, interpretive nature of the study and to foreground the lived experiences of recipients within the English healthcare context (see Chapter 3 for methodological approach). Sub-questions developed over time, as knowledge gained from the insights of recipients' experiences of LTFU care broadened:

1. How do HSCT recipients, in general, experience LTFU care?
   This sub-question explores the broader, international literature and general experiences of HSCT recipients, regardless of country or healthcare system.

2. How do HSCT recipients experience LTFU care specifically within the healthcare system in England?
   This sub-question focuses on the lived experiences of recipients navigating LTFU care in England, considering the unique organisational, policy, and service delivery context.

3. What are the informational needs of HSCT recipients as they enter and move through the LTFU pathway, and how do these needs shape their engagement with care?
   This sub-question explores the nature, timing, and purpose of recipients' informational needs, and how these influence their ability to manage their health and well-being.

### *1.3.3 Research Objectives*

In line with the research questions, the following objectives were identified:

1. To systematically review, and qualitative evidence synthesise, the existing literature on HSCT recipients' experiences of LTFU care generally, identifying common themes and knowledge gaps.

2. To explore and interpret the lived experiences of HSCT recipients attending LTFU care in England, with attention to psychological, informational, and structural factors.

3. To identify and analyse the specific informational needs of HSCT recipients as they transition into, and navigate, LTFU care.

4. To generate evidence-based recommendations for clinical practice and service design that support person-centred, responsive LTFU care for HSCT recipients in England.

5. To highlight areas for future research and clinical development in the field of HSCT survivorship and LTFU care.

### *1.3.4 Research Novelty*

This thesis is the first to provide a comprehensive, multi-method qualitative account of HSCT recipients' experiences of long-term follow-up (LTFU) care across multiple National Health Service (NHS) providers in England (see Chapters 4–6). Guided by health psychology and hermeneutic phenomenology (see Chapter 3), the research integrates systematic review, written accounts, and in-depth interviews, with data triangulation enhancing the credibility of the findings (see Section 3.7).

The study adapts and extends the Candidacy Framework (Dixon-Woods et al., 2006) to reflect how recipients negotiate access and recognition within complex care pathways (see Sections 7.3 and 7.4). It also introduces the constructs of 'ambiguous outpatient' and the 'relevance ambiguity' to describe the unique forms of uncertainty and anxiety experienced by recipients. These contributions provide a robust evidence base for improving person-centred LTFU care and guiding future research and clinical practice.

### *1.3.5 Research Limitations*

This study focuses on the experiences of HSCT recipients in England, excluding other UK regions. This decision reflects the distinct structure and governance of the NHS in England. Narrowing the scope enables this thesis to capture the specific policies and frameworks relevant to recipients within England, contributing to a more nuanced understanding of their experiences.

### 1.4 Chapter Summary and Thesis Structure

This chapter sets the scene for this thesis by providing an initial overview of HSCT physiology and the healthcare pathway, which are explored in greater depth in Chapter 2. It outlines the research aim, questions, objectives, and the significance of this programme of work, and concludes with a summary of the thesis structure. The structure is introduced here, and each of the elements is developed further in the chapters that follow.

- **Chapter 2: Haematopoietic Stem Cell Transplantation (HSCT) and Long-term Follow-up (LTFU) Care in Context**
  Details the physiology of HSCT, the healthcare pathway, and the policy/clinical context for long-term follow-up (LTFU) care. (Supports Objective 2).

- **Chapter 3: Methodology: Philosophical Foundations and Hermeneutic Phenomenological Design**
  Outlines the philosophical assumptions, theoretical framework, and hermeneutic phenomenological research design. (Supports all objectives by establishing the approach).

- **Chapter 4: Systematic Review with Qualitative Evidence Synthesis of HSCT Recipients' Experiences of LTFU Care (Study 1)**
  Presents a qualitative evidence synthesis of the broader literature on HSCT recipients experiences of LTFU care (Addresses Objective 1).

- **Chapter 5: Written Accounts Study of HSCT Recipients' Experiences of LTFU Care in England (Study 2)**
  Reports findings from a qualitative study of written accounts by HSCT recipients in England, focusing on LTFU clinic experiences (Addresses Objective 2 and informs Objective 4).

- **Chapter 6: In-Depth Interview Study of Informational Needs Among HSCT Recipients Navigating LTFU Care in England (Study 3)**
  Explores recipients' informational needs during transitions into and along the LTFU pathway through qualitative interviews. (Addresses Objective 3 and supports Objective 2).

- **Chapter 7: Synthesis of Findings and Theoretical Interpretation**

  Integrates findings from Chapters 5 and 6, using the Candidacy Framework to interpret access and engagement in LTFU care, and to inform recommendations. (Addresses Objective 4 and highlights areas for Objective 5).

- **Chapter 8: Discussion, Recommendations, and Conclusion**

  Discusses findings in relation to existing literature, highlights contributions, addresses strengths and limitations, and offers recommendations. (Addresses Objectives 4 and 5).

- **Chapter 9: Reflexive Narrative: The View from Within**

  Provides a reflexive account of the research journey, shaped by the author's dual role as HSCT recipient and academic. It explores how subjectivity, emotional engagement, and ethical responsibility informed the study. (Supports all objectives by enhancing transparency and critical reflection).

# Chapter 2. Haematopoietic Stem Cell Transplantation (HSCT) and Long-Term Follow-Up (LTFU) Care in Context

## 2.1 Chapter Introduction

Long-term follow-up (LTFU) is widely recognised as the cornerstone of care after haematopoietic stem cell transplantation (HSCT), as introduced in Chapter 1. This chapter examines the clinical, policy, and psychosocial factors that shape LTFU for HSCT recipients, with a particular focus on how biological, psychological, and social dimensions interact to influence patient experiences and outcomes. This chapter adopts a health psychology perspective to highlight the complexities and challenges faced by recipients. In doing so, this chapter establishes the conceptual basis for enhancing patient-centred care, an area where persistent gaps in knowledge, policy, and practice remain.

Accordingly, the chapter first outlines the clinical and policy context for HSCT and LTFU. It then explores the physical, psychological, and social outcomes following transplantation, and introduces key health psychology theories and models relevant to recipient experiences. Further sections investigate the challenges associated with LTFU, including models of care delivery and inequalities in access. The chapter concludes by identifying current gaps in knowledge and establishing the rationale for the research presented in this thesis.

## 2.2 Clinical and Policy Context

### *2.2.1 Overview of Haematopoietic Stem Cells and Transplantation*

Haematopoietic stem cells (HSCs) are pluripotent cells that initiate and maintain blood cell formation (haemopoiesis) (Hoffbrand & Moss, 2016). HSCs primarily reside in the bone marrow but are also present in peripheral blood and umbilical cord blood. HSCs can both self-renew, thereby creating a subsequent cell that maintains primary cell function, and, through cell division and differentiation, form any type of blood cell (Lee & Hong, 2020). HSCs initially differentiate to form either a myeloid or lymphoid progenitor cell, which then commits to further divisions and differentiations along the respective cell lineage (see Figure 2.1). Cells divide and differentiate to produce more progenitor and precursor cells, becoming increasingly restricted in lineage potential before maturing into a specific blood cell type (refer to Bujko et al., 2019 for further details). Cells of the myeloid lineage will mature into either erythrocytes (red blood cells which carry oxygen and carbon dioxide), platelets (promote blood clotting), monocytes (destroy germs and bacteria), basophils (defend from allergens), neutrophils (fight infection and heal injuries), or eosinophils (defend from parasites and allergens). Cells of the

lymphoid lineage will mature into either B lymphocytes (detect germs), T lymphocytes (fight germs and protect from disease), or natural killer cells (destroy infected and disease cells) (Hoffbrand & Moss, 2016). This self-renewal and differentiation process is continuous, maintaining adequate concentrations of blood cells in circulation for normal immune and haematopoietic function (Aiuti et al., 2024). It is these two functional properties that provide the scientific basis for HSCT.

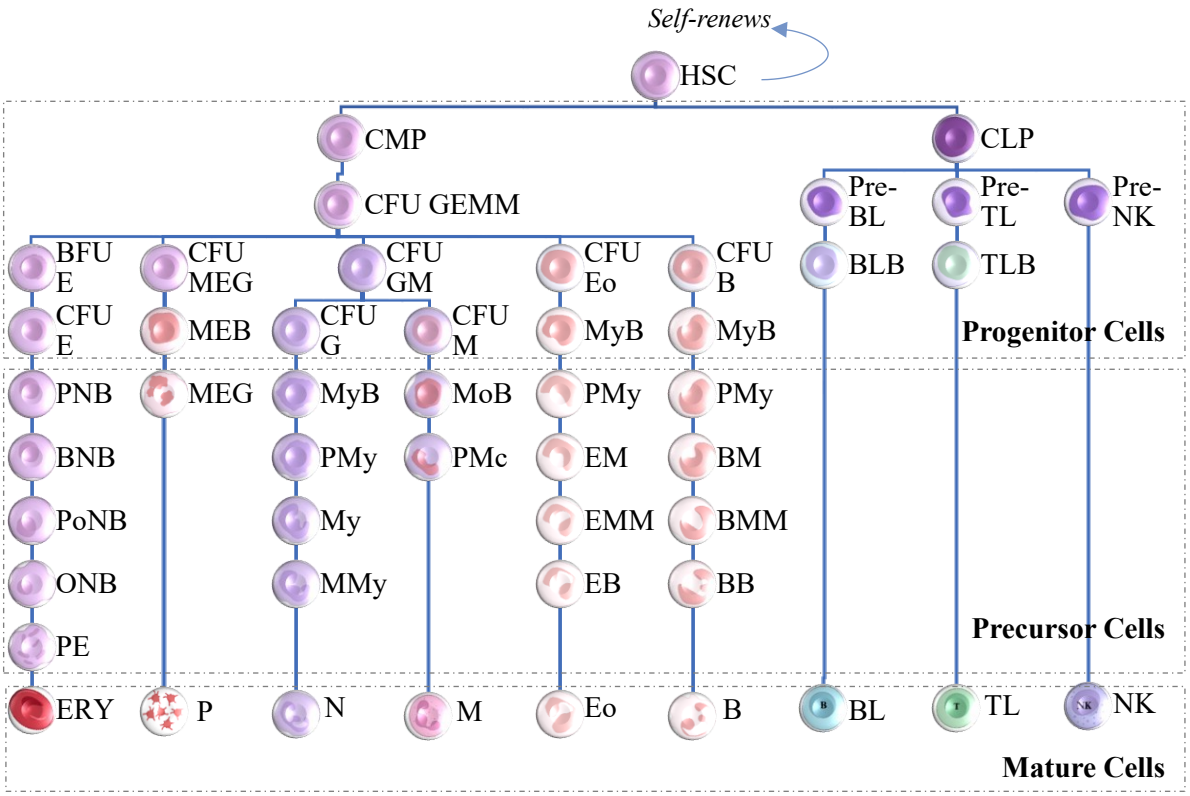


**Figure 2.1 Haematopoietic Stem Cell Differentiation Overview.**
B, basophil; BB, basophil band; BFU, burst-forming unit; BL, B Lymphocyte; BLB; B lymphoblast; BM, basophilic myelocyte; BMM; basophilic metamyelocyte; BNB, basophilic normoblast; CFU, colony-forming unit; CLP, common lymphoid progenitor; CMP, common myeloid progenitor; E, erythroid; EB, eosinophilic band; EM, eosinophilic myelocyte; EMM, eosinophilic metamyelocyte; Eo, eosinophil; ERY, erythrocyte (red blood cell); G, granulocyte; GEMM, granulocyte, erythroid, monocyte and megakaryocyte; GM, granulocyte monocyte; HSC, haematopoietic stem cell; M, monocyte; MEB, megakaryoblast; MEG, megakaryocyte; MoB, monoblast; MMy, metamyelocyte; My; myelocyte; MyB; myeloblast; N, Neutrophil; NK, natural killer cells; ONB, orthchromic normoblast; P, Platelets; PE, polychronmatic erythrocyte; PNB; Pronormoblast; PMc, Promonocyte; PMy, promyelocyte; PoNB, polychromatic normoblast; TL, T Lymphocyte; TLB, T lymphoblast; (diagram adapted from Hoffbrand & Moss, 2016, p3)

HSCT is a complex medical procedure that replaces a patient's defective haematopoietic system with new HSCs to initiate and maintain haematopoietic recovery (Hatzimichael & Tuthill, 2010). This internationally recognised procedure is widely used to treat several malignant and non-malignant haematological diseases (Maziarz, 2021). Diseases such as leukaemia and immune-deficiency diseases can cause defective, abnormal, or immature cells to proliferate, impairing haemopoiesis (Majhail et al., 2015). For example, in Acute Myeloid Leukaemia myeloblast cells fail to mature in the bone marrow, resulting in dysfunctional "blast" cells entering the bloodstream (Hoffbrand & Moss, 2016). In Acute Lymphoblastic Leukaemia, excessive and impaired function of lymphoblast cells accumulate in the bone marrow, preventing normal blood cell formation (Hoffbrand & Moss, 2016). Haemopoiesis can also be disrupted by therapeutic treatments such as chemotherapy and radiotherapy, which eradicate malignant cells but simultaneously destroy healthy HSCs (Maedler-Kron et al., 2016). When such haematopoietic defects arise, HSCT offers a curative treatment through a multiphase procedure in which HSCs are collected and intravenously reinfused to restore bone marrow function (Maziarz, 2021). HSCs' ability to self-renew and differentiate is crucial for haematopoietic recovery, and because patients undergo conditioning therapy prior to reinfusion to eliminate underlying disease, the HSC pool is subsequently reduced (Aiuti et al., 2024).

The source of HSCs used for transplantation distinguishes the two main types of HSCT: autologous (Auto-HSCT) which uses the patient's own HSCs, and allogeneic (Allo-HSCT) which uses donor HSCs. Allogeneic HSCT includes several subtypes, as full or partial human leukocyte antigen (HLA) match between the donor and recipient is required (Leis et al., 2021). HLAs are cell markers that help the immune system distinguish which cells belong to the host, and which are foreign (see Choo, 2007). The matching of HLAs allows recipients' immune systems to recognise donor stem cells as their own, thereby reducing the risk of stem cell rejection (Leis et al., 2021). In the donor selection process, transplant centres first seek an HLA-identical sibling (HLA-Matched Related Donor). If unavailable, they search registries for an unrelated HLA-compatible (HLA-Matched Unrelated Donor) or partially compatible donor (HLA-Mismatched Unrelated Donor). If no match is found, umbilical cord blood or a haploidentical donor (HLA half-matched Related Donor) may be considered (Galgano et al., 2023). The type of HSCT undertaken is determined by the underlying indication and patient eligibility (see Section 2.2.2).

**The HSCT Procedure**

Once a decision has been reached to proceed with HSCT, a patient will transit through four key procedural phases (see Figure 2.2). The initial phase is harvesting HSCs for transplantation from either the patient's or a donor's peripheral blood or bone marrow, and in Allo-HSCT, umbilical cord blood may also be used. For bone marrow harvesting, marrow is removed from the pelvic bone under general anaesthetic, and HSCs are separated in the laboratory. For peripheral blood harvesting, blood is processed through a machine that isolates HSCs before returning the remaining blood to the patient or donor. Due to low levels of HSCs in the peripheral blood, haematopoietic cytokines are administered beforehand to increase production and mobilise HSCs into the bloodstream (Leis et al., 2021). Once an adequate number of HSCs have been collected, they are mixed with a cryoprotective agent and frozen until transplantation, which occurs after conditioning treatment.

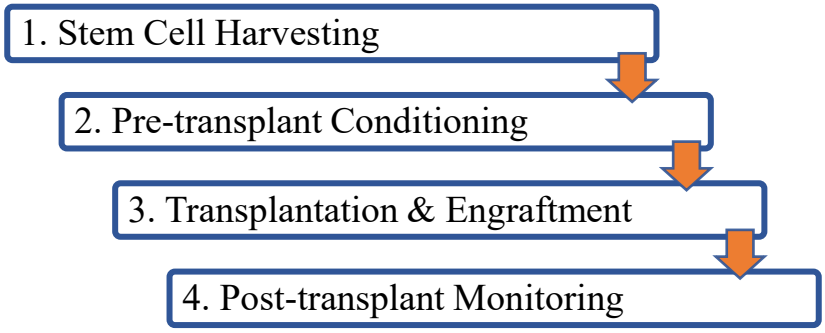


**Figure 2.2 Haematopoietic Stem Cell Transplantation Procedural Phases**

Prior to HSC infusion, patients undergo a pre-transplant conditioning regimen of chemotherapy, radiotherapy, and/or immunotherapy. Chemotherapy destroys rapidly dividing haematopoietic cells by preventing differentiation or causing cell death (apoptosis), while radiotherapy uses ionising radiation and immunotherapy uses antibodies to target and eliminate malignant cells (Zulu & Kenyon, 2023). The aim of conditioning is to eradicate bone marrow function to make space for engraftment, reduce risk of relapse, and if present, to eradicate malignancy. In Allo-HSCT, conditioning also suppresses the immune system to prevent donor HSC rejection (Bubalo, 2021). Conditioning intensity ranges from myeloablative (full eradication) to nonmyeloablative (partial eradication), depending on whether complete or partial destruction of the haematopoietic system is required (Bacigalupo et al., 2009). Myeloablative conditioning causes pancytopenia, resulting in low levels of mature red blood cells (anaemia), white blood cells (neutropenia), and platelets (thrombocytopenia). While this approach fully eliminates the haematopoietic system, reduced-intensity regimens are available to minimise the morbidity and

mortality risks associated with HSCT (see Section 2.3). If only partial eradication is needed, a nonmyeloablative regime is used, which causes low levels of blood cells or platelets (cytopenia) and suppresses the immune system sufficiently to allow for HSC engraftment after infusion.

After conditioning, patients receive the harvested HSCs intravenously under close observation in isolated conditions ("Day Zero"). Engraftment follows, as HSCT migrate to bone marrow niches and begin to proliferate, aiming to restore effective haemopoiesis (Runaas et al., 2021). During this period, patients' blood concentration levels remain low resulting in no effective immune system and high susceptibility to infections, often requiring blood transfusions for anaemia and thrombocytopenia (Brixey & Primack, 2021). Side effects such as fatigue, pain, nausea, and reduced appetite are common but usually improve with engraftment, which typically occurs within 1-3 weeks from infusion (van der Linden et al., 2023). Successful engraftment is indicated by a sustained neutrophil count above 500 x $10^6$/L for three consecutive days (Hutt, 2023). Once neutrophil recovery reduces infection risk, patients are discharged to outpatient follow-up.

After leaving inpatient care, recipients initially enter short-term acute care before transitioning into long-term follow-up care (LTFU). Acute care focuses on immediate risks and complications, such as engraftment failure, relapse, or, in Allo-HSCT settings, acute graft-versus-host disease (aGvHD) (Wallhult et al., 2023). Monitoring requirements during this phase vary depending on the type of HSCT, individual circumstances, and the presence of complications, though established recommendations exist. The European Blood and Marrow Transplant Society (EMBT) recommend short-term monitoring for at least the first 100 days for both auto- and Allo-HSCT, with guidance differing by transplant type (Suárez-Lledó & Rovira, 2024). For Auto-HSCT, appointment frequency is determined by the recipient's overall health, with clinical evaluation and treatment as needed. In contrast, Allo-HSCT recipients follow a more intensive schedule: weekly evaluations during the first month, every other week until the second month, and then every two weeks until the third month. Appointment intervals then gradually extend from six months to annually, after which recipients transition to LTFU care. This phase primarily monitors for longer-term risks and implements preventative measures to address potential late complications affecting mortality and morbidity (Kenyon et al., 2023; see Section 2.3).

### *2.2.2 Incidence, Service Provisions, and Commissioning*

It is estimated that more than 1.5 million HSCTs were performed worldwide between 1957 and 2019 (Niederwieser et al., 2022). In Europe and neighbouring countries, over 940,000 HSCTs have taken place since 1990 (Passweg et al., 2024). HSCT activity in 2019 increased by 2.2% compared to the previous year, with 48,512 HSCTs were performed, comprising of 41% Allo-HSCT and 59% Auto-HSCT (Passweg et al., 2021). A similar trend was observed in the UK and Republic of Ireland (ROI), where the number of first-time HSCTs rose by 2.8% in 2019 (n = 4,148), according to the British Society of Blood and Marrow Transplantation and Cellular Therapy (BSBMTCT, n.d.). In total, 48,032 first time HSCTs, comprising 40.2% Allo-HSCT and 59.8% Auto-HSCT, were performed in UK and ROI between 2010 to 2022. As shown in Figure 2.3, there has generally been a steady year-on-year increase of Auto-HSCT in the UK and ROI, while the number of Allo-HSCTs plateaued after a period of growth from 2010 to 2014. In 2020, HSCT activity dropped sharply due to the global SARS-CoV-2 pandemic (Passweg et al., 2022). Since then, annual activity for Auto-HSCT has recovered and surpassed pre-pandemic levels, but the recovery for Allo-HSCT has been slower. This pattern contrasts with post-pandemic activity trends across Europe, where both Allo- and Auto-HSCT rates have declined for reasons that remain unclear (Passweg et al., 2024).

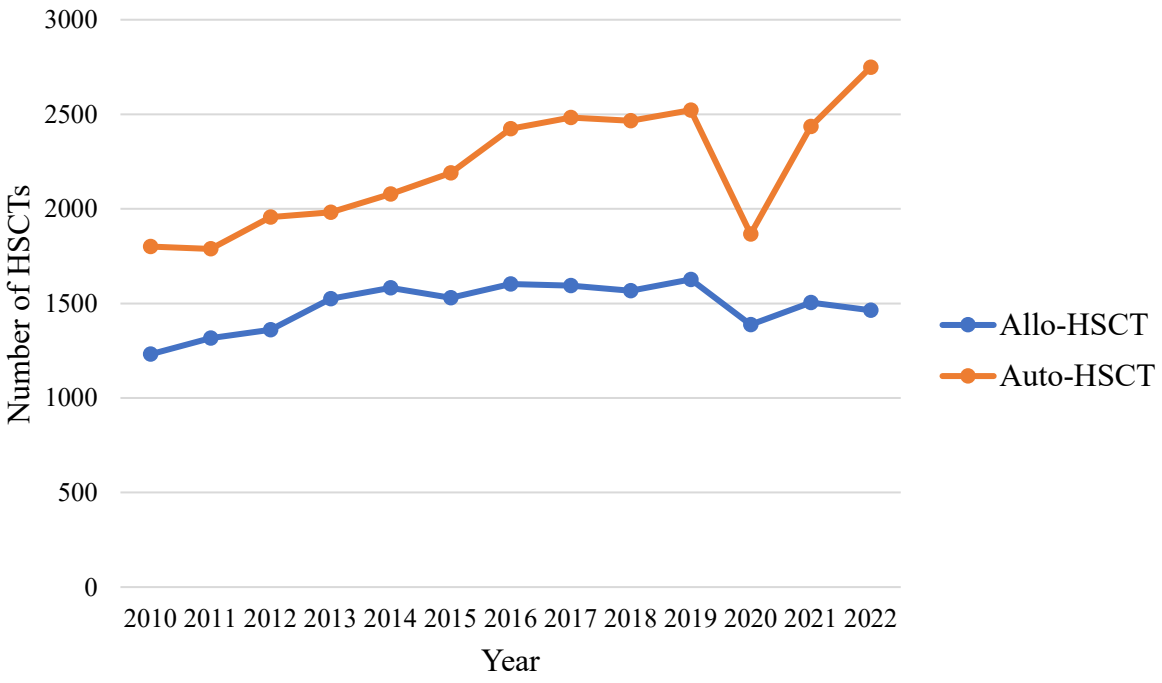


**Figure 2.3 Annual HSCT Activity in the UK and ROI between 2010 to 2022.**

Despite the fluctuations, the number of HSCT centres in the UK and ROI continues to grow. At present, there are fifty HSCT centres across the UK and ROI, three of which have applied for accreditation for the first time since 2022 (EBMT, n.d.). Accreditation is awarded in accordance with the international accreditation standards jointly developed by the Foundation for the Accreditation of Cellular Therapy (FACT) and the Joint Accreditation Committee of the International Society for Cell and Gene Therapy and the EBMT (JACIE), collectively known as the FACT-JACIE standards. These standards provide a comprehensive framework for quality and safety in HSCT and cellular therapies, covering all stages from cell collection to administration. Accreditation demonstrates that HSCT centres are meeting established standard of excellence and have implemented an effective quality management system (Charley et al., 2023). In England, there are 39 accredited centres located across 26 cities, as shown in Figure 2.4 each accredited for different types of HSCT. This accreditation is crucial for HSCT commissioning in England.

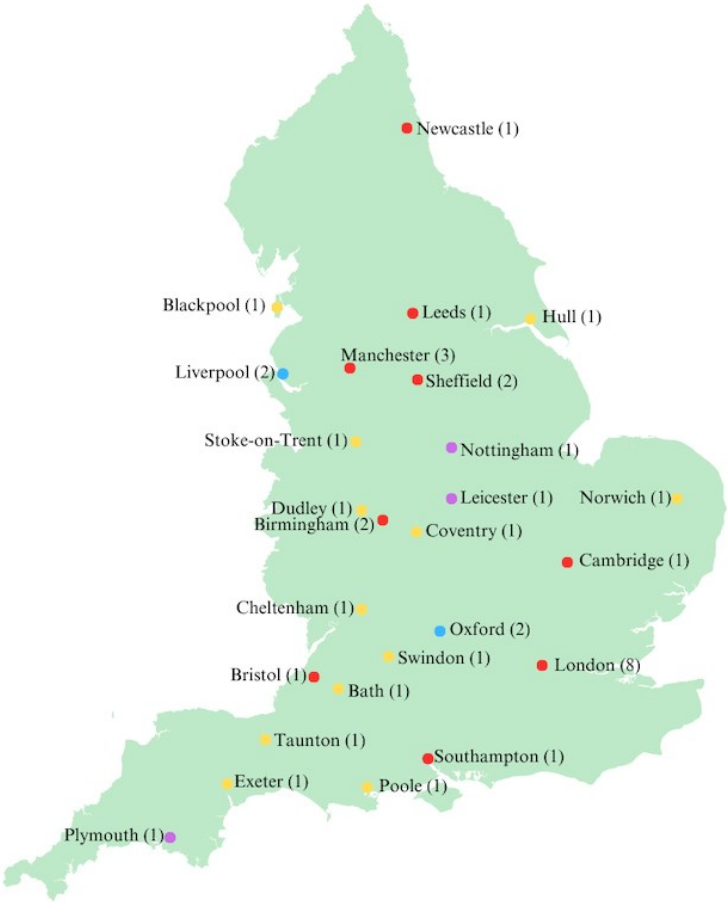


**Figure 2.4 HSCT in England: Centre Location and Type.**
(n) is the number of transplant centres in each city. Colour of circle indicate transplant type available; red, adult and paediatric auto- and Allo-HSCT; blue, adult auto- and Allo-HSCT and paediatric Auto-HSCT only; purple, adult auto- and Allo-HSCT; yellow, adult Auto-HSCT only. Data adapted from the JACIE list of accredited centres and accreditation renewal pending reports published via the EBMT (n.d.) website.

The commissioning of HSCTs in England is complex due to the NHS structure. NHS England (NHSE) oversees the system, which includes multiple regional and local organisations (NHSE, 2024). Integrated Care Systems bring together NHS organisations, local authorities, and other partners to plan and deliver health care services for their local population. Within each Integrated Care Systems, the Integrated Care Board is responsible for commissioning health services within its geographical area (Health and Care Act, 2022). However, not all Integrated Care Boards have hospitals that operate HSCT centres, and those that do may only be accredited for specific types of HSCT. For example, the integrated care board in Cornwall does not have a hospital offering HSCT services (NHS Cornwall and Isles of Scilly, 2024), while NHS Devon (2024) lacks an accredited paediatric HSCT centre but does have two hospitals accredited for adult HSCT.

To address commissioning challenges that arise from geographical restrictions, NHS England funds all transplant-related costs from 30 days before the procedure until 100 days post-transplantation (NHSE, n.d.-a; NHSE Specialised Services, 2021). After the initial 100-day post-transplant period, the recipient's primary healthcare provider assumes responsibility for ongoing care costs, which may fall outside the recipient's residential integrated care board if the transplant was performed in a different region. While commissioning of HSCT is increasingly being delegated to integrated care boards, NHS England currently retains direct commissioning for these highly specialised services and continues to provide assurance and oversight.

NHS England will only consider the commissioning of HSCT for diseases listed in the BSBMTCT table of indications (NHSE Specialised Services, 2021). The indication tables offer clinical guidance for both adults (BSBMTCT, 2022a) and paediatric patients (BSBMTCT, 2022b), categorising indications as either standard of care, clinical option, developmental, or generally not recommended based on clinical evidence. For indications listed as standard or clinical option, NHS England automatically accepts all first-time HSCTs. For developmental or not recommended indications, commissioning is considered on an individual basis through an individual funding request application (NHSE Specialised Services, 2021). As shown in Figure 2.5, malignant and non-malignant blood disorders accounted for 92.8% of all first-time HSCTs (n = 4212) in the UK and ROI during 2022, with Myeloma (41.5%), Non-Hodgkin's Lymphoma (15.6%), and Acute Myeloid Leukaemia (12.7%) being the most common. Autoimmune diseases, such as Multiple Sclerosis, accounted for 5.2% of all HSCT, while solid tumours, such as Ewing's sarcoma, accounted for 2.8%.

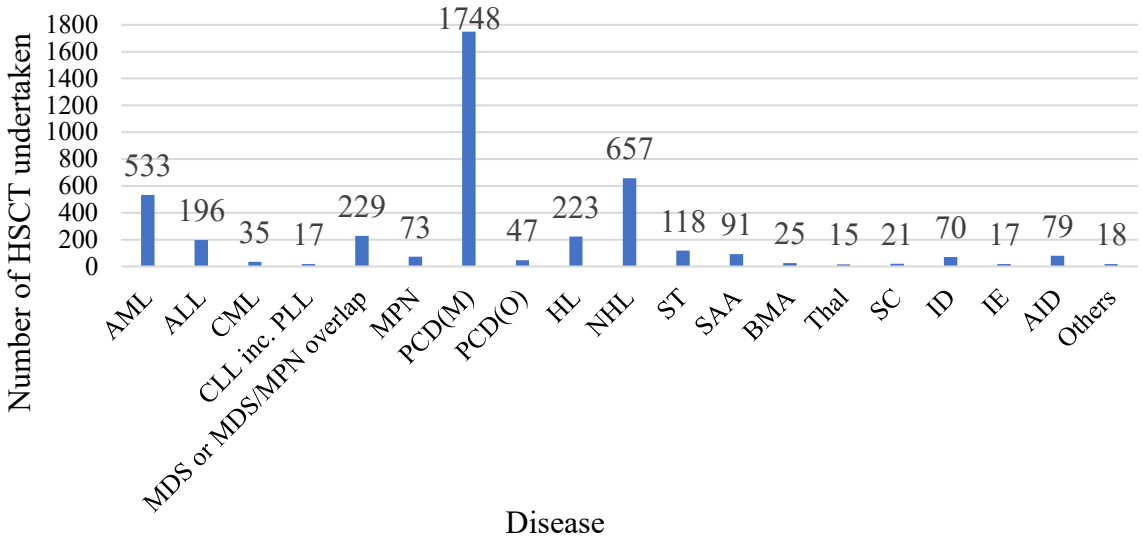


**Figure 2.5 First-time HSCTs per indication undertaken in the UK and ROI in 2022.**
AML, Acute Myeloid Leukaemia; ALL, Acute Lymphoblastic Leukaemia; CML, Chronic Myeloid Leukaemia; CLL, Chronic Lymphocytic Leukaemia; PLL, Prolymphocytic Leukaemia; MDS, Myelodysplastic Syndromes; MPN, Myeloproliferative Neoplasms; PCD(M), Plasma Cell Disorders Myeloma; PCD(O), Plasma Cell Disorders Others; HL, Hodgkin Lymphoma; NHL, Non Hodgkin Lymphoma; ST, Solid Tumours; SAA, Severe Aplastic Anaemia; BMA, Bone Marrow Aplasia; Thal, Thalassaemia; SC, Sickle Cell; ID, Immune Deficiencies; IE, Inborn Errors; AID, Auto-Immune Disease. Data adapted from the BSBMTCT (n.d.) Annual Activity reports.

Eligibility for HSCT depends not only on the underlying condition but also on the disease stage, which influences the type of HSCT recommended. The BSBMTCT indication tables specify the appropriate HSCT type based on disease stage for each condition. For example, Myelodysplastic Syndromes (MDS) are a group of malignant blood disorders characterised by bone marrow failure to produce healthy blood cells. MDS is sub-categorised by risk level, such as low, intermediate-1, intermediate-2, and high. Auto-HSCT is generally not recommended for any MDS sub-group. An Allo-HSCT, either from a related or unrelated donor, is considered the standard of care for patients with intermediate-2 and high risk MDS, while it is classified as a clinical option for those with low or intermediate-1 risk (BSBMTCT, 2022a).

As shown in Figure 2.6, the majority of Auto-HSCT undertaken in the UK and ROI between 2012 and 2022 were used to treat plasma cell disorders such as Myeloma, Lymphoma, solid tumours and auto-immune disorders. Allo-HSCT were primarily used to treat leukaemia, BM failure disorders such as myelodysplastic syndromes, bone marrow aplasia (e.g., anaemia, thalassaemia), immune deficiencies, and in-born errors.

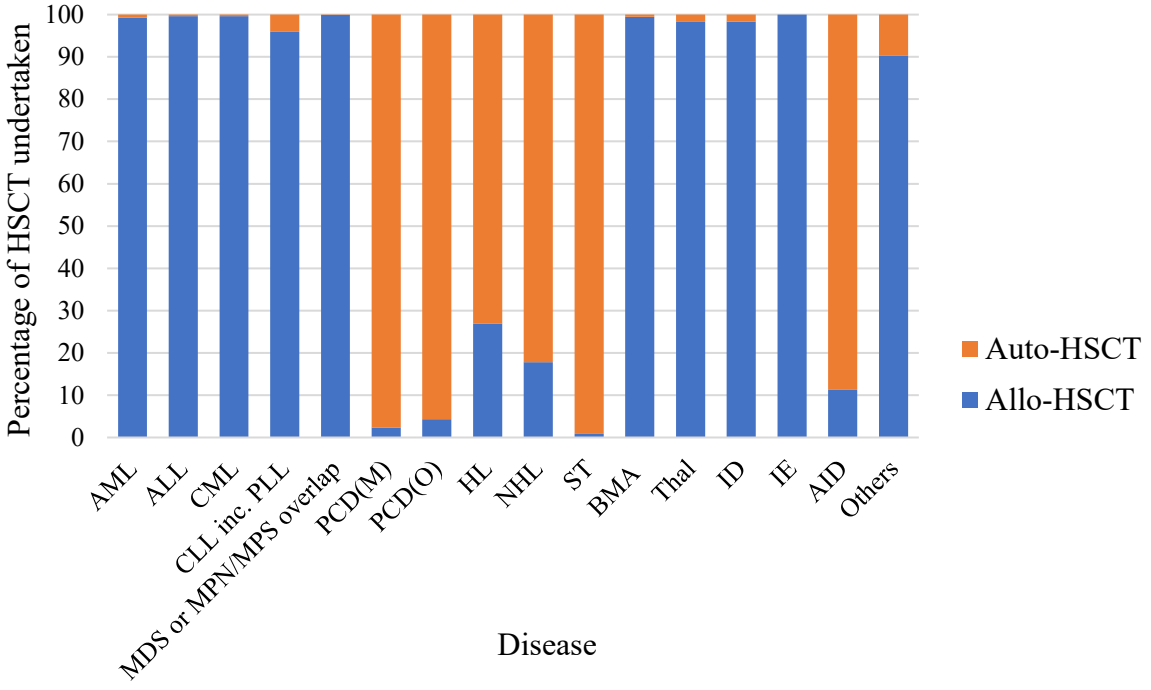


**Figure 2.6 HSCTs per indication and type undertaken in the UK and ROI 2012-2022.**
AML, Acute Myeloid Leukaemia; ALL, Acute Lymphoblastic Leukaemia; CML, Chronic Myeloid Leukaemia; CLL, Chronic Lymphocytic Leukaemia; PLL, Prolymphocytic Leukaemia; MDS, Myelodysplastic Syndromes; MPN, Myeloproliferative Neoplasms; PCD(M), Plasma Cell Disorders Myeloma; PCD(O), Plasma Cell Disorders Others; HL, Hodgkin Lymphoma; NHL, Non Hodgkin Lymphoma; ST, Solid Tumours; BMA, Bone Marrow Aplasia; Thal, Thalassaemia; SC, Sickle Cell; ID, Immune Deficiencies; IE, Inborn Errors; AID, Auto-Immune Disease. Data adapted from the BSBMTCT (n.d.) Annual Activity reports.

The decision to proceed with HSCT is complex and extends beyond the underlying disease indication. While clinical eligibility is often guided but the BSBMTCT indication tables, which categorise conditions based on evidence of benefit, the final decision is influenced by a range of patient-specific factors. These include overall physical health, functional status, coexisting medical conditions, disease stage or risk, and psychosocial circumstances (Kennedy & Muffly, 2021). Given the significant risks associated with HSCT, such as treatment-related morbidity and mortality, clinicians must carefully weigh the potential benefits against the risks (Majhail et al., 2015; Tay et al., 2019). The decision-making process is inherently interdisciplinary, involving transplant clinicians, nurses, psychologists, and social workers, and is made in collaboration with the patient. There is no specific guidance on determining patients' suitability for HSCT; the decision to proceed remains with the treating clinician and patient based on the available evidence as to whether proceeding with HSCT is a valuable and sensible decision (Kennedy & Muffly, 2021). This personalised approach ensures that the risks and benefits are carefully balanced for each patient.

### *2.2.3 Long-Term Follow-Up Policy and Guidelines*

Long-term follow-up (LTFU) for HSCT recipients is now recognised as a vital aspect of post-transplant care. This reflects growing awareness of late complications and the importance of optimising long-term outcomes (see Section 2.3). The development of LTFU policies has been shaped by international standards, national accreditation requirements, and evolving clinical evidence.

Since May 2018, transplant centres seeking accreditation under the FACT-JACIE standards must have formal LTFU guidelines covering treatment and care planning (FACT-JACIE, 2018a). These guidelines must, at a minimum, ensure monitoring of endocrine, reproductive, cardiovascular, renal, and respiratory functions, alongside screening for osteoporosis and secondary cancer risks. Reference sources such as the international consensus guidelines by Majhail et al. (2012) are recommended and widely adopted. While FACT-JACIE encourages the establishment of dedicated LTFU clinics, this is not mandatory if the required monitoring standards are met (FACT-JACIE, 2018b). Centres may opt for shared care arrangements with primary care providers, balancing specialist oversight with local accessibility and cost-efficiency. Regardless of the model, transplant centres remain responsible for ensuring compliance with LTFU standards.

Across the UK, LTFU care models vary significantly. Some centres operate dedicated LTFU clinics, while others integrate follow-up into acute post-transplant or general haematology outpatient services. Shared care models involving local primary and secondary care providers are also common. Transition to shared care typically occurs over time, but by ten years post-transplant, only half of patients continue to receive monitoring, highlighting historical gaps in LTFU requirements (Dignan et al., 2021). A multidisciplinary approach is consistently recommended, involving clinicians, specialist nurses, social workers, psychologists, nutritionists, and physical therapists, supported by consulting specialists in fields such as pulmonology, endocrinology, and gynaecology (Tichelli et al., 2021a). However, access to these teams and services varies, resulting in inequalities and unmet needs (see Section 2.5).

The importance of detecting and preventing late complications gained traction in the early part of this century. In 2006, the EBMT, Centre for International Blood and Marrow Transplant Research (CIBMTR), and the American Society for Blood and Marrow Transplantation (ASBMT) published a set of recommended screening and preventative practices for long-term survivors post-HSCT (Rizzo et al., 2006). At the time, primary care providers often discharged

recipients instead of referring them to the care of specialised HSCT teams. As a result, the aim of the recommendations was to provide general healthcare providers with an overview of the potential late complications, and offer suggested care practices to optimise HSCT outcomes through early screening and preventative practices. Due to limited evidence, the guidelines relied on research identifying specific complications rather than evidence from randomised or other controlled trials. As such, not all recommendations were applicable to every HSCT recipient, and application of the recommendations required clinical judgement.

Majhail et al. (2012) updated the 2006 recommendations, which have since become the cornerstone of LTFU guidance globally. The updated guidelines provide a systematic approach to monitoring autologous and allogeneic HSCT recipients who have survived at least six months post-transplant. Consistent with the original 2006 publication, the 2012 recommendations address a broad spectrum of potential late complications, recognising that not all preventative and screening measures are appropriate for every recipient. The application of these recommendations should be guided by medical judgement, as the guidance itself prioritises screening and preventative measures according to organ or tissue type, potential late complications, and associated risk factors. For example, secondary cancers may include solid tumours, haematological malignancies, and post-transplant lymphoproliferative disorders, with risk factors such as GvHD, total body irradiation (TBI), and chemotherapy exposure. Recommended tests include cancer screening and full blood counts, while preventative strategies encompass education on secondary cancer risks, encouragement of self-examination, and counselling to avoid high-risk behaviours. The recent publication of updated guidance (Rotz et al., 2024) reflects the advancing knowledge and understanding of these long-term complications and their associated risk factors.

Transplant centres are encouraged to provide recipients with a survivorship care plan to support care transition, serve as a screening aide-mémoire, and educate recipients about the potential late effects associated with HSCT (Majhail et al., 2012; Tichelli et al., 2021b). These plans aim to promote patient engagement in long-term care, enhance adherence to follow-up protocols, and improve overall quality of life (Kenyon et al., 2023). As there is no specific survivorship care plan tailored for HSCT recipients, centres are advised to consider adapting plans developed for cancer survivors more broadly (Majhail et al., 2012). Typically, such plans include information on cancer type, treatments received, potential long-term consequences, and recommendations for screening and preventive care (McCabe et al., 2013). The American

Society of Clinical Oncology (ASCO, n.d.) recommends that survivorship care plans clearly define the roles and responsibilities of care providers to optimise the efficiency of LTFU.

However, the revised 2024 screening and preventative care recommendations have withdrawn the endorsement of survivorship care plans for HSCT recipients. Despite evidence suggesting psychological benefits for recipients (Majhail et al., 2019), the updated guidance stresses that survivorship care plans should not be viewed as substitutes for a fully integrated and personalised long-term care approach (Rotz et al., 2024). The EBMT, which contributed to these recommendations, now advocates for individualised LTFU plans that include treatment summaries and personalised risk factors (Suárez-Lledó & Rovira, 2024). The guidance does not specify how, or if, this information should be presented to recipients. As a result, current recommendations lack clarity regarding the role and implementation of survivorship care plans, leaving their application and content at the discretion of individual transplant centres.

Recent NHS initiatives, such as the Personalised Stratified Follow-Up (PSFU) pathways, signal a shift towards more tailored and empowering care models (NHS, 2019). The aim of PSFU is to adapt care to meet individual patient needs, enabling patients to make informed choices about their health, support self-management, and improve long-term health and well-being (NHS, 2020a). The introduction of PSFU also seeks to reduce unnecessary hospital appointments for cancer survivors, thereby freeing up resources for those with more complex needs and increasing appointment capacity for new referrals (NHS, 2016). There are essentially two approaches to follow-up: self-managed (patient-activated) pathways and scheduled clinic follow-up pathways (NHS, 2020a). In the self-managed pathway, remote monitoring supports patients in managing their own needs. Patients continue to receive the necessary monitoring tests but are not invited for face-to-face discussions unless abnormal results are detected, and if any health concerns arise, they can quickly re-enter specialist services. In contrast, the scheduled appointment pathway involves regular, routinely scheduled face-to-face or telephone appointments. Clinicians and patients jointly decide on the most appropriate pathway, with self-managed options considered only for those with non-complex cases, low risk of disease recurrence, and the ability and preparedness to manage their own care. Although PSFU is not formally recognised as being applied to HSCT recipients, currently implemented LTFU models closely resemble the underlying core principles of PSFU.

These principles are reinforced by evidence from other cancer patient cohorts that highlights the tangible benefits of PSFU in practice. Peer-reviewed studies have shown that PSFU reduces

unnecessary outpatient appointments, empowers patients to take an active role in their care, and supports earlier identification of complications (Davies et al., 2021; Foster et al., 2020). Implementation of PSFU has also led to workforce development, such as the introduction of cancer support workers who play a key role in delivering personalised care interventions and supporting patients throughout their follow-up (NHS, 2020b). These advances in follow-up care are particularly relevant in the context of HSCT, where recipients often face a complex and evolving spectrum of health challenges long after their initial treatment. As survivorship increases, so too does the need for robust, patient-centred follow-up models that can address the unique and persistent risks associated with HSCT (FACT-JACIE, 2021; Majhail et al., 2012; Rotz et al., 2024). The integration of PSFU into post-transplant care not only streamlines service delivery but also ensures that recipients are better equipped to monitor their own health, recognise early warning signs, and access timely interventions. This proactive approach is essential given the potential for late effects and health complications that can arise months or even years after transplantation.

## 2.3 Post-Transplant Complications

### *2.3.1 Overall Survival and Late Mortality*

Reflecting the impact of advances in HSCT practice and supportive care, HSCT recipients who remain disease-free for two years post-transplant experience encouraging long-term survival outcomes. For those who have undergone an Allo-HSCT, the conditional probability of overall survival after two years disease-free stands at 90%-93% at five years, 85%-87% at ten years, and 80%-83% at fifteen years (Atsuta et al., 2016; Bhatia et al., 2007; Majhail et al., 2020; Wong et al., 2020). Auto-HSCT recipients also demonstrate favourable survival, with rates of 74.8% at five years, 57.1% at ten years, and 53.4% at 15 years (Ashton et al., 2014; Bhatia et al., 2022). These survival trends have been shaped by sustained improvements in clinical practice and supportive care over the last three decades. Specifically, developments such as the adoption of less harmful conditioning protocols (Gratwohl et al., 2002), enhanced HLA typing techniques (Mayor et al., 2019), increased donor availability (Passweg et al., 2017), and more effective patient management (Penack et al., 2020), have all contributed to improved outcomes (Bhatia et al., 2021, 2022; McDonald et al., 2020). Nevertheless, despite these promising survival statistics, HSCT recipients continue to face ongoing risk of late mortality, emphasising the necessity for vigilant LTFU and timely intervention.

Despite achieving two years disease-free survival, HSCT recipients continue to experience higher mortality rates compared to the general population (Kliman et al., 2020). Studies indicate

that recipients of Allo- and Auto-HSCT have an 8.8- and 2.1-fold increased risk of mortality, respectively (Bhatia et al., 2021, 2022: Martin et al., 2010). The most frequently reported leading cause of late death among all HSCT recipients is relapse, while other significant causes include infection, malignant neoplasms, cardiovascular disease, pulmonary disease, and, in the case of Allo-HSCT, chronic graft-versus-host disease (Ashton et al., 2014; Atsuta et al., 2016; Bhatia et al., 2005, 2007, 2021, 2022; Grønvoid et al., 2024; Martin et al., 2010; Wingard et al., 2011; Wu et al., 2023). While transplant centres have reported a reduction in all-cause mortality rates for Auto-HSCT recipients over the last decade, no such reduction has been observed for Allo-HSCT recipients at five or more years post-transplant (Styczyński et al., 2020). Allo-HSCT recipients remain at risk of non-relapse mortality for up to fifteen years post-transplant, with mortality rates continuing to exceed those of the general population for at least thirty years, resulting in only a partial restoration of life expectancy (Bhatia et al., 2021, 2022; Martin et al., 2010; Styczyński et al., 2020; Tanaka et al., 2016). This persistent risk of late mortality is closely linked to the wide range of health complications that can arise following HSCT.

### *2.3.2 Physical, Psychological, and Psychosocial Late Effects*

HSCT recipients experience a complex range of late effects that span physical, psychological, and psychosocial domains, as illustrated in Figure 2.7. These outcomes are deeply interconnected: physical complications such as chronic pain or fatigue can exacerbate psychological distress, while anxiety or depression may, in turn, intensify physical symptoms and hinder social reintegration (Bevans et la., 2017; Sun et al., 2011; Vetsch et al., 2017). Aside from risk of late mortality, recipients of HSCT are at significant risk of developing a wide range of disease- or treatment-related health complications (Majhail et al., 2012; Rotz et al., 2024). A ‘late effect’ is any health complication that arises from the underlying disease or its therapeutic interventions months or years following diagnosis or treatment (FACT-JACIE, 2021), manifesting as physical, psychological, and/or psychosocial impairments (Diesh-Furlanetto et al., 2021; Kenyon et al., 2023; Savani et al., 2011).

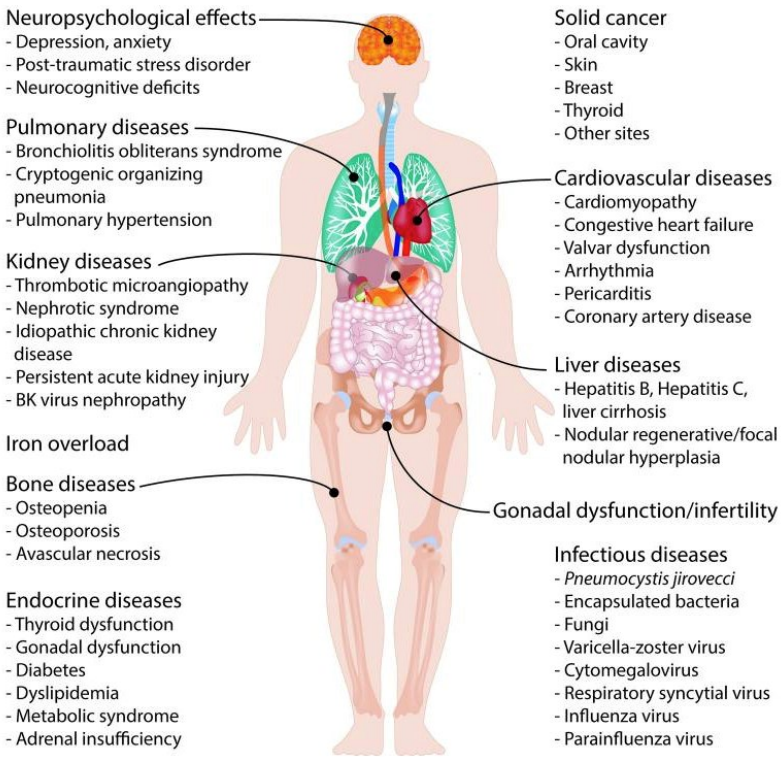


**Figure 2.7 Potential Physical and Psychological Impairments post-HSCT**
Reproduced from Inamoto & Lee, 2017 with permission.

The potential physical late effects associated with HSCT are extensive and well-documented in the literature. Pulmonary complications, such as bronchiolitis, can significantly reduce recipients' quality of life and increase long-term morbidity (Inamoto & Lee, 2017; Martin et al., 2010; Styczyński et al., 2020). Cardiovascular diseases, such as heart failure, arrhythmias, and vascular complications, are also prevalent and tend to increase in incidence over time, influenced by factors including conditioning regimens and chronic inflammation (Martin et al., 2010; Styczyński et al., 2020). Renal impairment, frequently attributed to treatment medications and graft-versus-host disease (GvHD), while liver dysfunction, is particularly associated with chronic GvHD and iron overload (Kenyon et al., 2023; Savani et al., 2011; Styczyński et al., 2020). Bone health is frequently compromised, with osteoporosis and avascular necrosis linked to steroid use and GvHD and persistent immune dysfunction leaves recipients at risk of common and opportunistic infections for years post-transplant (Kenyon et al., 2023; Savani et al., 2011; Styczyński et al., 2020). Gonadal dysfunction and infertility are common, especially after myeloablative conditioning or total body irradiation, and there is a significantly increased risk of developing secondary solid cancers, including skin, oral, and gastrointestinal malignancies, in long-term recipients (Kenyon et al., 2023). Among these complications, GvHD warrants particular attention, given its prevalence and wide-ranging impact across multiple organ systems.

GvHD is particularly notable in this context, as it is widely recognised as the most frequently reported and clinically significant late effect following HSCT (Giaccone et al., 2022). GvHD occurs when transplanted stem cells (the graft) recognise the recipient's (host) healthy tissues as foreign and initiate an immune response against them (Murray et al., 2023). This reaction can inflict harm on the host's tissues and organs, particularly affecting the skin, liver, intestines, eyes, mouth, hair, nails, joints, muscles, lungs, kidneys and genitals (Murray et al., 2023; Wolff et al., 2024). GvHD may manifest within the initial months post-transplant (acute) or at a later stage (chronic), the latter occurring in approximately 50% of all Allo-HSCT recipients and as early as three months post Allo-HSCT (Arai et al., 2015). Incidences of chronic GvHD have continued to increase over the last few decades due to increasing age at transplantation, more frequent use of unrelated and/or mismatched donors and reduced-intensity conditioning regimes (Arai et al., 2015; Sobkowiak-Sobierajska et al., 2022). Furthermore, the presence of chronic GvHD is a predictor of adverse psychological implications in HSCT recipients post-HSCT (Jacobs et al., 2019; Lee et al., 2018; Majhail & Rizzo, 2013).

Psychological implications associated with HSCT are predominantly depression and anxiety. Research exploring depression and anxiety following HSCT is heterogeneous in the findings (Mosher et al., 2009). Whilst moderate to high levels of depression and anxiety are more commonly reported within the first-year post-transplant (El-Jawajri et al., 2016), research suggests a gradual decline in symptom burden as time from HSCT increases (Mosher et al., 2009; Sun et al., 2011). However, for some recipients, the prevalence of depression and anxiety may persist even several years post-HSCT (Jim et al., 2016; Kuba et al., 2017), this includes high prevalence rates in adult recipients of paediatric HSCT (Di Giuseppe et al., 2020). Depression during HSCT and the acute post-transplant phase is closely related to developing post-traumatic stress disorder post-HSCT (Fenech et al., 2021). While pre-transplant depression and anxiety are predictive factors for health-related quality of life post-HSCT (Ames et al., 2024), depression post-transplant can also be persistent in recipients exhibiting low levels pre-transplant depression (Artherholt et al., 2014). As previously stated, chronic GvHD is a predictor of depression and anxiety in recipients post-HSCT, other predictors include age and chronic pain, and in cases of Allo-HSCT, female sex (Jim et al., 2016).

In addition to depression and anxiety, fear of cancer recurrence (FCR) is increasingly recognised as a significant psychological concern among HSCT recipients. FCR refers to the persistent worry or concern that cancer may return or progress and has been identified as a

prevalent and distressing experience in this population. Studies indicate that HSCT survivors frequently report moderate to high levels of FCR, which can persist for years post-transplant and is associated with poorer psychological adjustment and reduced quality of life (Brice et al., 2020; Sarker et al., 2014). For example, a systematic review by Simard et al. (2013) found that FCR is one of the most reported unmet needs among adult cancer survivors, including those who have undergone HSCT. More broadly, FCR is now recognised as a universal issue across cancer types, with high levels linked to increased psychological distress, impaired functioning, and greater healthcare utilisation (Fodor et al., 2023; Kim et al., 2025). As such, addressing FCR is considered a critical component of comprehensive survivorship care for both HSCT recipients and the wider cancer survivor community.

The relationship between LTFU, screening practices, and fear of cancer recurrence (FCR) is complex. While some recipients find regular monitoring reassuring, others report that it exacerbates anxiety and hypervigilance (Austin-Ketch & Paplham, 2015; Bergerot et al., 2022; Brice et al., 2020; Reed et al., 2021). Despite the prevalence and impact of FCR, access to psychological support remains limited in many transplant centres, highlighting a critical gap in survivorship care (Hashmi et al., 2018; Dignan et al., 2021; Salooja et al., 2016). As a result, many recipients must navigate these fears with limited professional guidance, which can further intensify the psychological and social challenges experienced after HSCT.

Psychological outcomes such as depression, anxiety, and FCR can have a profound impact on other post-HSCT psychosocial outcomes. These psychological factors often disrupt a range of psychosocial domains, including interpersonal relationships, occupational functioning, and overall quality of life. A recent scoping review found that recipients often have elevated rates of sexual dysfunction, exhaustion, sleep disturbances, pain, cognitive impairment, emotional anguish, financial burden, and non-compliance with medication and healthcare recommendations, even years post-HSCT (Bevans et al., 2017). FCR has been shown to intensify emotional distress and contribute to avoidance behaviours, hypervigilance, and increased healthcare utilisation, further complicating psychosocial recovery (Fodor et al., 2023; Kim et al., 2025). These findings highlight how psychological factors, whether stemming from depression, anxiety, or FCR can exacerbate other difficulties, such as fatigue, sleep disruption, sexual dysfunction, and engaging in high-risk behaviours. Consequently, returning to pre-transplant health and previous activities can vary for recipients, including returning to education or employment (Anthony Nolan, 2017; Bhatt et al., 2024; Kirchhoff et al., 2010; Kiserud et al., 2016; Tichelli et al., 2017; Winterling et al., 2014). A proportion of HSCT recipients do not

return to work full-time, and those that do frequently report experiencing work-related limitations compared to their pre-transplant capabilities (Kirchhoff et al., 2010). Fatigue, reduced immunity, cognitive impairment, and psychological distress, including FCR, have all been identified as barriers to recipients returning to work, either full-time or partially (Persoon et al., 2019).

The late effects experienced by HSCT recipients are rarely confined to a single domain. Physical late effects such as GvHD, fatigue, endocrine dysfunction, and secondary malignancies can directly impair daily function and quality of life. These physical challenges frequently interact with psychological outcomes, most notably depression, anxiety, and FCR, which are themselves prevalent and persistent among HSCT recipients (Brice et al., 2020; Sarker et al., 2014). The psychological burden can, in turn, exacerbate psychosocial difficulties, including social isolation, strained relationships, financial hardship, and challenges in returning to work or education. Recent literature highlights that these domains are interconnected: for example, chronic pain or fatigue may limit social participation and employment, while psychological distress can amplify perceptions of physical symptoms and hinder engagement with healthcare or support services (Cheon et al., 2021). Survivors often describe the cumulative toll of managing multiple appointments, ongoing side effects, and uncertainty about long-term health, which can lead to disengagement from care and diminished self-management (Hwang et al., 2012). Consequently, the burden of late effects is not merely the sum of individual challenges but reflects a dynamic interaction, where physical, psychological, and psychosocial domains mutually reinforce and intensify one another. This highlights the importance of integrated, patient-centred approaches that address the full spectrum of recipients' needs across physical, psychological, and psychosocial domains.

These interrelated challenges are not exclusive to HSCT recipients. Similar patterns of psychological and psychosocial challenges have been observed in recipients of other solid organ transplants, including kidney, liver, heart, and lung transplants. Research highlights that depression, anxiety, and post-traumatic stress disorder are common across transplant populations, with these conditions linked to poorer health outcomes and increased mortality (Nassar et al., 2025). For instance, persistent depression post-kidney transplant is associated with higher mortality (Dew et al., 2018), while depressive symptoms in heart transplant recipients can double the risk of death (Duerinckx et al., 2021). Liver and lung transplant recipients also face significant psychological burdens, with new-onset depression post-transplant raising particular concern, due to its prevalence and association with reduced

adherence, increased hospitalisation, and higher mortality (Dew et al., 2012a; DiMartini et al., 2018). Health psychology research emphasises the importance of psychological assessment and intervention throughout the transplant process, as these approaches are critical for supporting emotional adjustment, improving adherence, and enhancing long-term outcomes (Nassar et al., 2025). A narrative review further highlights that psychosocial factors, such as mental health, social support, and coping, play a vital role in transplant success by influencing outcomes like treatment adherence, emotional adjustment, and long-term survival (Dew et al., 2012b). This reinforces the need for ongoing psychological screening and support to manage uncertainty, promote adherence, and maintain quality of life.

Given this multifactorial landscape, predicting the nature, severity, or number of late effects recipients may experience following HSCT remains a significant challenge. Studies report that within the first five years post-HSCT, 79% of patients experience at least one physical chronic health condition, and 59% experience two or more (Armenian et al., 2011; Sun et al., 2011). The risk and complexity of late effects tend to increase over time, particularly among recipients under 40 years of age treated with Auto-HSCT and after paediatric Allo-HSCT (Holmqvist et al., 2024; Wilhelmsson et al., 2015). While the occurrence of late effects is difficult to predict, several risk factors have been identified in the literature, including younger age at transplant, being female, total body irradiation, chronic GvHD, and certain underlying diagnoses such as lymphoblastic leukaemia (Cheon et al., 2021; Rotz et al., 2024). These factors not only increase the risk of physical complications but are also associated with heightened psychological and psychosocial vulnerability (Richardson et al., 2016; Timko Olson et al., 2024). Consequently, there is broad consensus that HSCT recipients require ongoing, multidisciplinary monitoring and support to reduce morbidity and mortality and to facilitate recovery (Majhail et al., 2012; Rotz et al., 2024).

### *2.3.3 Impact of Late Effect on Engagement with Long-Term Follow-Up Care*

LTFU care is a critical aspect of survivorship for HSCT recipients, as it is within this context that the impact of late effects on ongoing engagement with healthcare becomes most apparent (Diesch-Furlanetto et al., 2021; El-Jawahri et al., 2017; Kenyon et al., 2023). The presence and severity of late effects such as chronic pain, fatigue, GvHD, and psychological distress can influence HSCT recipients' willingness and ability to participate in recommended follow-up regimens and self-management activities (Bevans et al., 2017; Diesch-Furlanetto et al., 2021; Jim et al., 2016; Kenyon et al., 2023; Persoon et al., 2019; Sun et al., 2021). This relationship is further supported by broader cancer survivorship research, which demonstrates that persistent

symptoms and psychological distress are associated with reduced engagement and adherence (Davies et al., 2021; Foster et al., 2020). For HSCT recipients, the experience of persistent or unpredictable late effects can serve as a powerful motivator to remain engaged with healthcare providers, attend regular appointments, and adhere to monitoring protocols (Diesch-Furlanetto et al., 2021; El-Jawahri et al., 2017; Holmqvist et al., 2024; Syrjala et al., 2012). Conversely, the cumulative burden of late effects, particularly when accompanied by uncertainty or a lack of perceived benefit, can also lead to disengagement, reduced self-management, or avoidance of follow-up care (Diesch-Furlanetto et al., 2021; Jim et al., 2016; Nakajima & Kamibeppu, 2022; Vetsch et al., 2017). This interplay between physical symptoms and psychological responses highlights the need to distinguish between the tangible burden of late effects such as pain or fatigue, and the subjective perceptions recipients form about their health and future risks. These findings suggest that understanding the nuanced ways in which late effects shape engagement is essential for tailoring LTFU strategies to individual needs.

Studies have demonstrated that recipients' perceptions of their ongoing risk of relapse or late complications, as well as their beliefs about the value and efficacy of continued monitoring, play a central role in shaping engagement behaviours (Christalle et al., 2019; Diesch-Furlanetto et al., 2021; Kenyon et al., 2023; Sun et al., 2021). Those who perceive themselves as vulnerable to late effects, or who recognise substantial benefit in ongoing surveillance, are more likely to remain actively involved in their care (Diesch-Furlanetto et al., 2021; Holmqvist et al., 2024; Kenyon et al., 2023). In contrast, individuals who view their risk as low, or who encounter barriers such as logistical difficulties, psychological distress, or insufficient information, may be less inclined to participate fully in LTFU (Bevans et al., 2017; Persoon et al., 2019; Vetsch et al., 2017). These perceptions are dynamic and can be shaped by previous experiences, the quality of communication with healthcare professionals, and the availability of psychosocial support (Diesch-Furlanetto et al., 2021; El-Jawahri et al., 2017; Nakajima & Kamibeppu, 2022). Recognising and responding to these evolving perceptions is therefore key to sustaining meaningful engagement.

Understanding how late effects and individual perceptions interact to influence engagement is essential for developing effective, person-centred interventions in LTFU care (Alharbi et al., 2014; Nkhoma et al., 2022). This perspective highlights the importance of not only addressing the physical and psychological sequelae of transplantation, but also supporting survivors in navigating the complexities of long-term care, shaping adaptive beliefs, and reducing barriers to sustained engagement. These insights have direct implications for the design of cancer

survivorship programmes (Bandini et al., 2024), suggesting that tailored communication and psychosocial support may be as critical as clinical monitoring in maintaining long-term engagement.

## 2.4 Health Psychology Perspective on Long-Term Follow-Up Care

### *2.4.1 The Relevance of Health Psychology to Long-Term Follow-up Care*

Exploring HSCT recipients' experiences of LTFU care through a health psychology lens is essential as the impact of transplantation extends far beyond physical recovery. Building on the multidimensional challenges outlined in section 2.3.2, health psychology provides a framework for understanding how these domains interact and influence recipients' engagement with LTFU care. While biomedical models traditionally focus on physical complications such as GvHD, fatigue, and endocrine dysfunction, they often fail to account for the persistent psychological burden and social disruption that many recipients experience years after transplantation (Hwang et al., 2012). In contrast, health psychology offers a biopsychosocial framework that not only recognises this interplay but also addresses how psychological well-being and social context shape health outcomes and behaviours. This approach is particularly relevant given the prevalence of depression, anxiety, and fear of cancer recurrence among HSCT recipients (Brice et al., 2020). These psychological outcomes are closely linked with physical symptoms (e.g., chronic pain, fatigue), influence healthcare behaviours (e.g., medication adherence, appointment attendance), and shape broader psychosocial outcomes such as return to work, social reintegration, and quality of life.

Psychological factors such as beliefs about illness, perceived control, and coping style have been shown to influence not only mental health but also physical recovery in patients with chronic illnesses and following cancer treatment (Kumar & Sharma, 2024; Roick et al., 2024). Thus, applying a health psychology lens enables services to move beyond a narrow clinical focus and respond to the full spectrum of recipients' LTFU needs. By examining constructs such as illness perceptions, coping strategies, self-efficacy, and emotional responses, health psychology provides a deeper understanding of how survivors interpret their health status, manage uncertainty, and engage with LTFU care. For example, intolerance of uncertainty and illness-related anxiety can lead to avoidance behaviours and disengagement from care, while strong self-efficacy and social support are associated with better adjustment and proactive health behaviours (Poudel et al., 2025). Moreover, health psychology aligns with contemporary healthcare priorities, including the NHS Long Term Plan's emphasis on person-centred, psychologically informed care (NHS, 2025). It supports the identification of unmet needs, the

development of tailored interventions, and the integration of patient-reported outcomes into service design.

### *2.4.2 Core Theories and Models in Health Psychology*

The decision to underpin this thesis with health psychology is rooted in the discipline's unique capacity to bridge the biological, psychological, and social dimensions of patient experience (Ogden, 2019). Health psychology offers a comprehensive framework for understanding how individuals interpret, respond to, and manage the challenges of LTFU care after HSCT. This approach is particularly valuable given the complex and enduring nature of survivorship, where patients must navigate uncertainty, adapt to shifting health statuses, and engage with healthcare systems over extended periods. By drawing on health psychology, the thesis can foreground the lived experiences of recipients, capturing not only the clinical aspects of care but also the cognitive, emotional, and behavioural processes that shape adaptation and well-being. This perspective is supported by a growing body of research demonstrating that psychological factors such as illness perceptions, coping strategies, and self-efficacy are closely linked to outcomes in HSCT populations, as well as among broader groups of cancer survivors and solid organ transplant recipients (El-Jawahri et al., 2017; Foster et al., 2015; Germain et al., 2020). The integration of health psychology thus enables a more holistic and patient-centred analysis, aligning with calls in the literature for survivorship research to move beyond biomedical models and address the full spectrum of patient needs.

Within this broad framework, the thesis focuses on a select group of theories and models that have demonstrated relevance to the experiences of HSCT recipients in LTFU. Two theories are prioritised due to their strong conceptual alignment with the uncertainty experienced by this population: Intolerance of Uncertainty Theory (Freeston et al., 1994) and Illness Uncertainty Theory (Mishel, 1988). Intolerance of Uncertainty Theory posits that individuals who struggle to tolerate ambiguity or unpredictability are more prone to anxiety and maladaptive coping behaviours, which is particularly relevant to HSCT recipients who often live with ongoing ambiguity regarding relapse, late effects, and long-term health outcomes (Grønvold et al., 2024; Wu et al., 2023). Illness Uncertainty Theory, meanwhile, describes how patients interpret and respond to ambiguous illness-related events, suggesting that uncertainty arises when individuals cannot assign meaning to illness experiences due to lack of information, complexity, or unpredictability. This is an experience common among HSCT recipients, who often face unclear prognoses and fluctuating recovery pathways (Bhatia et al., 2021,2022; Styczyński et al., 2020). These theoretical perspectives are supported by empirical studies showing that difficulty

tolerating uncertainty is associated with heightened anxiety, maladaptive coping, and poorer adjustment in HSCT cohorts (Germain et al., 2020; Newcomb et al., 2024), with similar findings reported in studies of cancer survivors (Maheu et al., 2021; Shen et al., 2024) and solid organ transplant recipients (Guo et al., 2023).

Building on these perspectives, additional psychological theories offer further insight into how HSCT recipients adapt to the demands of LTFU care. The Transactional Model of Stress and Coping (Lazarus & Folkman, 1984) conceptualises stress as a dynamic interaction between individuals and their environment, emphasising the role of cognitive appraisal and coping strategies in managing health-related challenges. Self-Determination Theory (SDT) (Ryan & Deci, 2017) highlights the importance of autonomy, competence, and relatedness in supporting motivation and well-being, suggesting that recipients' engagement with follow-up care is shaped by their sense of agency, capability, and connection with healthcare professionals. Despite their conceptual relevance, neither theory has been applied in studies of HSCT recipients. Elements of the Transactional Model have been explored in related contexts, such as among HSCT caregivers and in stress management interventions for recipients (Amonoo et al., 2023; Lawrence et al., 2023), but applications of the models to HSCT recipients themselves remains absent. Similarly, although SDT has been widely applied in health psychology and chronic illness management (Eassey et al., 2020; Sheeran et al., 2020), no studies have employed it directly to exploring HSCT recipients' motivation or engagement post-transplantation.

In line with this psychological orientation, the thesis draws on health behaviour theories to elucidate the factors influencing engagement and participation among HSCT recipients in LTFU, specifically the Health Belief Model (Rosenstock, 1974) and Social Cognitive Theory (Bandura, 2001). The Health Belief Model posits that individuals' engagement in health-promoting behaviours is shaped by their perceptions of susceptibility to illness, the severity of potential outcomes, the benefits of acting, and the barriers that may prevent them from doing so. This is particularly pertinent for HSCT recipients, whose adherence to follow-up regimens and engagement with self-management are influenced by how they perceive their ongoing risk of relapse or late effects, as well as the perceived value and challenges of continued monitoring and care (Christalle et al., 2019; Diesch-Furlanetto et al., 2021; Kenyon et al., 2023; Sun et al., 2021). Social Cognitive Theory, meanwhile, emphasises the role of personal agency, observational learning, and self-efficacy, which is defined as the belief in one's ability to successfully perform a behaviour. For HSCT recipients, self-efficacy and outcome expectations

are especially relevant, as survivors must often navigate complex care routines, monitor for late effects, and make informed decisions about their health (Bevans et al., 2017; Persoon et al., 2019; Vetsch et al., 2017). These theoretical perspectives are supported by empirical studies showing that constructs such as perceived susceptibility, self-efficacy, and outcome expectations predict adherence and engagement in follow-up care across survivorship contexts (Diesch-Furlanetto et al., 2021; Kenyon et al., 2023; Sun et al., 2021; Syrjala et al., 2012).

Cognitive Dissonance Theory (Festinger, 1957), a core psychological theory with broad applications in health behaviour, offers further insight into the motivational processes underlying engagement. The theory posits that individuals experience psychological discomfort when their behaviours conflict with their beliefs or values, prompting efforts to restore consistency. In the context of HSCT survivorship, this discomfort may arise when recipients neglect follow-up care despite recognising its importance, thereby motivating re-engagement to reduce dissonance. Dissonance-based interventions have been shown to effectively promote health behaviour change across diverse populations (Freijy & Kothe, 2013), particularly when individuals are made aware of discrepancies between their actions and health-related beliefs.

The Candidacy Framework (Dixon-Woods et al., 2006) is a sociological framework that describes healthcare engagement as a negotiated process across seven stages, in which individuals assess their eligibility and navigate various barriers (see Section 7.4). Koehn et al. (2024) expanded the model by adding the embodied relational self to reflect how chronic illness shapes identity and care-seeking. Sinnott et al. (2024) found the framework relevant to primary care, especially in understanding how patients negotiate eligibility, while Tookey et al. (2018) showed that general practitioners (GPs) interactions influenced patients' help-seeking for cancer symptoms. Although not directly applied to LTFU care, studies in survivorship reflect candidacy principles. Chan et al. (2021) identified barriers like poor coordination and facilitators such as patient engagement and flexible services to care. Mead et al. (2020) highlighted survivor priorities including preparation and empowerment, which align with candidacy concepts. These studies suggest candidacy offers a useful lens for understanding access and engagement for HSCT recipients navigating LTFU care. This framework helps illuminate how individuals perceive their eligibility for ongoing support, negotiate complex care pathways, and respond to structural and interpersonal challenges.

These theoretical frameworks will underpin the analysis in subsequent chapters, shaping how the thesis explores and interprets the experiences of HSCT recipients in LTFU care. The next

section will illustrate how these concepts inform practical understanding and application within this context.

### *2.4.3 Applying Health Psychology to Long-term Follow-Up Practices*

A health psychology lens provides practical insights into how HSCT recipients navigate long-term follow-up care, building on the theoretical foundations already discussed. Rather than restating psychological constructs, this section focuses on how recipients' beliefs, coping strategies, and levels of self-efficacy shape their engagement with follow-up services. For example, recipients who view follow-up as an opportunity for empowerment and reassurance are more likely to attend appointments, follow recommendations, and actively manage late effects (Syrjala et al., 2004; Visintini et al., 2022). In contrast, those who experience ongoing uncertainty or anxiety about relapse may avoid care (Richardson et al., 2023). These patterns highlight the need for interventions that address illness perceptions and intolerance of uncertainty (Germain et al., 2020; Newcomb et al., 2024). Practical strategies such as tailored education, peer support, and self-management programmes have shown effectiveness in improving psychological adjustment and clinical outcomes for HSCT survivors (El-Jawahri et al., 2017; Syrjala et al., 2012). These approaches work best when they are responsive to individual needs and integrated into routine follow-up pathways, helping survivors develop adaptive coping mechanisms and confidence in managing their health.

The health psychology perspective differs from biomedical and sociological approaches by recognising the interaction between psychological, social, and physical domains in follow-up care. Biomedical models focus on monitoring for late effects and recurrence, but often overlook how psychological distress, such as fear of cancer recurrence or low self-efficacy, can worsen physical symptoms and reduce engagement with care (Brice et al., 2020; Cheon et al., 2021). Health psychology frameworks also draw attention to inequalities in access to information and support, identifying groups at higher risk of unmet needs, such as younger recipients, females, and those with complex medical histories (Richardson et al., 2016; Timko Olson et al., 2024). In practice, this means follow-up services should include patient-reported outcomes, co-design interventions with survivors, and ensure fair access to psychosocial support (NHS, 2025; Rotz et al., 2024; Stanton et al., 2015). By focusing on lived experience and prioritising person-centred care, health psychology enables services to move beyond surveillance and towards meaningful recovery, improved quality of life, and reduced morbidity for HSCT recipients.

## 2.5 Models and Challenges in Long-term Follow-Up Care

As previously discussed, the interaction between physical, psychological, and psychosocial outcomes is central to the long-term experiences of HSCT recipients. This interplay shapes not only the challenges survivors face but also their needs and expectations of follow-up care. In this section, the focus shifts from the theoretical and clinical context to the lived realities of recipients, exploring how these multidimensional effects manifest in everyday life. Drawing on recent research and patient accounts, the following section examines models of long-term follow-up care, patient-reported needs, health behaviours, and the impact of inequalities in access to support.

### *2.5.1 Long-Term Follow-Up Care Models*

Given the complex and interconnected nature of physical, psychological, and psychosocial late effects, models of LTFU care must address a wide spectrum of HSCT recipients' needs. This very complexity contributes to the ongoing debate over optimal LTFU models for HSCT recipients, highlighting both the challenges of survivorship and the limitations of current research. While FACT-JACIE standards advocate for dedicated specialised LTFU clinics, the evidence base supporting their effectiveness is limited. Studies such as Dignan et al. (2021) and Tichelli et al. (2021a) highlight that dedicated LTFU clinics are beneficial for continuity of care and access to expert knowledge. However, these benefits are undermined by resource constraints, limited skilled workforce, patient demographics, and financial implications. Hashmi et al. (2017) found that even in centres with dedicated clinics, patients may still experience fragmented care due to poor integration with primary and community services. Shared care models, while theoretically offering a cost-effectiveness and local accessibility, are frequently hampered by ambiguous roles and communication breakdowns, leading to gaps in monitoring and support (Tichelli et al., 2021a). Critically, the heterogeneity of patient populations, transplant types, and health system contexts makes it difficult to generalise findings or establish best practice. The ongoing evolution of LTFU models, as described by Hashmi et al. (2015, 2017) and Rotz et al. (2024), may reflect adaptability, but it also signals a lack of consensus and standardisation, with potential consequences impacting quality of care.

The pivotal role of specialist nurses and multidisciplinary teams in supporting HSCT recipients is increasingly recognised in the survivorship literature. Nurses frequently act as the main facilitators of care, bridging communication between professionals and providing both clinical and psychosocial support throughout the follow-up period (Baskin et al., 2023; Corcoran et al., 2015; McCaughan et al., 2021). As the population of HSCT survivors continues to grow,

concerns regarding the sustainability of current models have led to calls for dual or shared-care approaches involving both transplant centres and primary care providers (Dignan et al., 2021; Greenfield et al., 2009; Tichelli et al., 2021a). However, barriers such as limited resources, lack of awareness of guidelines, and communication gaps between services persist, challenging the effective delivery of long-term follow-up (Eikeland et al., 2022; Liemburg et al., 2022; Mani et al., 2020). These workforce and system-level challenges are reflected in the diversity of LTFU models currently adopted across UK transplant centres.

The LTFU model adopted by UK HSCT centres varies. In a 2019 survey of 25 transplant centres in the UK (21 of which were in England), Dignan et al. (2021) found that 13 centres had established dedicated LTFU clinics specifically for Allo-HSCT recipients, while five centres had LTFU clinics for both Allo- and Auto-HSCT recipients. Three additional centres integrated LTFU monitoring with acute post-transplant clinics, and one centre managed long-term complications in general haematology outpatients settings. Only one centre reported having no formal LTFU care arrangement, and two centres did not disclose their follow-up model. Of the 25 centres surveyed, eleven had implemented a shared care approach involving collaboration between the transplant centre and the recipients' local primary and secondary care providers. The timing of shared care initiation varied: in four centres, it began between +100 days to one year post-transplant; in another four, it commenced from one year post-transplant; and in two centres, it started at five years post-transplant. Notably, by ten years post-transplant, only half of the recipients across these centres continued to receive monitoring, with the remainder having been discharged. This is perhaps unsurprising, as accreditation standards requiring transplant centres to retain monitoring responsibilities were only introduced in 2018 (FACT-JACIE, 2018a). Prior to this, there was no minimum requirement for ongoing monitoring.

### *2.5.2 Patient-Reported Needs*

Studies consistently report high levels of unmet needs among HSCT survivors, particularly in information provision and psychological support. Previous research has highlighted that HSCT recipients experience unmet medical, psychological, and social needs post-transplantation, including a desire for more information on treatment, social, financial, and lifestyle topics, even when such information has previously been provided (Austin-Ketch & Paplham, 2015; Hahn et al., 2017; Hawkins et al., 2008; Pulewka et al., 2021; Yanling et al., 2023). The Anthony Nolan (2019) survey's finding that only 54% of those needing psychological support received it, is an illustration of widespread organisational deficiencies. These findings suggest that despite

growing awareness of survivorship challenges, existing support systems remain fragmented and reactive, leaving many patients without the guidance and continuity of care they require.

Hawkins et al. (2008) and Vetsch et al. (2017) suggest that patients often feel abandoned or "in limbo" after acute care, with unclear pathways for accessing ongoing support. This is compounded by the lack of standardisation in information provision as patients frequently report receiving inconsistent or conflicting advice, and many are unaware of available resources. In short, recommendations and guidance lack clarity in their approach to late-effects literature and education programmes, with content often left at the discretion of transplant centres. International studies corroborate these concerns, highlighting the challenge of translating guidelines into practice across diverse settings (Foster et al., 2020; Syrjala et al., 2012). Recent research from North America, Europe, and Asia confirms that HSCT survivors frequently report persistent psychological distress, anxiety, and depression, which are often exacerbated by unmet informational and emotional needs (Pulewka et al., 2021; Yanling et al., 2023). For example, a systematic review found that both patients and their informal caregivers experience high levels of anxiety and depression before and after transplantation, with qualitative studies identifying the empowering effect of clear information and the emotional burden of uncertainty as central themes (Yang et al., 2023). Cancer survivors, including HSCT recipients, also report that uncertainty about the future can undermine their sense of control and well-being (Foster et al., 2020; Syrjala et al., 2012).

Poor communication between transplant centres, primary care, and other healthcare services has been shown to adversely affect patient outcomes and contribute to feelings of abandonment and discontinuity of care (Vermeir et al., 2015). Recipients' information needs are highly individual and may change over time; while some seek comprehensive details about late effects and self-management, others prefer only essential information to avoid unnecessary anxiety (Ormandy, 2011). It is also common for information about late effects to be provided reactively and only when complications arise, rather than proactively as part of routine survivorship education, which can leave recipients unprepared for the challenges they may face (Bompoint et al., 2023; Murray et al., 2023).

Patients consistently highlight the importance of clear, tailored information about late effects, self-management, and available support services, noting that inadequate or poorly timed information can hinder adaptation and increase anxiety (Nakajima & Kamibeppu, 2022; Vetsch et al., 2017). Furthermore, studies show that positive psychological well-being is closely linked

to better patient-reported outcomes, such as quality of life; however, many survivors report low levels of positive affect and persistent distress (El-Jawahri et al., 2017; Yang et al., 2023). El-Jawahri et al. (2024) found that allogeneic HSCT survivors report persistently low levels of positive psychological well-being, such as gratitude and optimism, alongside high rates of anxiety and distress. The study also noted that tailored psychosocial interventions remain scarce, and that a shortage of trained personnel is a major barrier to accessible support for this population. The trial demonstrated that positive psychology interventions that are simple and designed to cultivate well-being are both feasible and acceptable for HSCT survivors and may help buffer psychological distress and improve quality of life. Collectively, these findings highlight that patient-reported needs encompass not only access to medical care, but also psychosocial support, relevant and actionable information, and interventions that strengthen psychological resilience and empowerment.

Critically, the literature points to a need for system-level interventions, such as routine, standardised needs assessments, integrated care pathways, and proactive psychological support. To ensure that patient-reported needs are identified and addressed, rather than left to chance or individual clinician initiative (Foster et al., 2020; Pulewka et al., 2021). Without such measures, the gap between policy aspirations and the lived experience of HSCT survivors is likely to persist. The evidence suggests that addressing these needs requires not only improvements in clinical practice but also a cultural shift towards genuinely person-centred care, where survivors' voices are actively sought and responded to. As the population of HSCT survivors continues to grow, the imperative to close the gap between policy and practice becomes ever more urgent, demanding coordinated action from clinicians, service providers, and policymakers alike.

### *2.5.3 Health Behaviours and Self-Management*

The promotion of health behaviours and self-management is widely endorsed, though the evidence for effective interventions in HSCT LTFU is mixed and often context dependent. Transplant centres are encouraged to increase recipients' awareness of potential late effects through literature and education, with the aim of encouraging participation in their own long-term care (Kenyon et al., 2023). Attitudes towards illness and treatment are important factors in shaping patient outcomes, adherence to follow-up care, and improving quality of life. Patients who have lower levels of informational requirements and encounter fewer information obstacles tend to experience higher quality of life and lower levels of anxiety and depression (Christalle et al., 2019). In contrast, individuals who report low overall health after surviving a

disease sometimes struggle with coping and adapting to their condition, which leads to a higher number of unmet needs (Nakajima & Kamibeppu, 2022; Vetsch et al., 2017). These findings reinforces the importance of not only providing information but also ensuring that it is accessible, relevant, and tailored to individual needs, particularly as patients transition into LTFU and are expected to take a more active role in managing their health.

While patient education and empowerment are associated with better adherence and quality of life (Kenyon et al., 2023; Nakajima & Kamibeppu, 2022), studies also show that information alone is insufficient to drive sustained behaviour change. For example, Vetsch et al. (2017) found that even well-informed recipients may struggle with self-management due to psychological distress, fatigue, or lack of social support. There is a risk that an overemphasis on self-management may inadvertently shift responsibility onto patients without adequate support, exacerbating inequalities for those with lower health literacy or fewer resources (Foster et al., 2020). Furthermore, the timing and mode of information delivery are critical, as noted by Giaccone et al. (2020) and Kenyon et al. (2023), information about potential secondary cancer risk should be provided at the initial consent for transplant consultation, and this is an ideal time to highlight positive health behaviour changes, if applicable. Early, tailored discussions about late effects and health behaviours are more likely to be effective, but such approaches are rarely standardised. The literature also highlights a lack of clarity regarding the content and delivery of educational interventions, with most studies relying on small samples or single-centre designs (Bahtia, 2014; Diesch-Furlanetto et al., 2021). Despite recommendations to provide information about potential long-term complications, no guidance is offered as to the content of such information. There is a pressing need for rigorous, context-sensitive research to identify which interventions work, for whom, and under what circumstances.

One area of emerging interest in this regard is the concept of “teachable moments” following HSCT, where the experience of transplantation and survivorship may motivate recipients to adopt healthier behaviours (Bishop et al., 2010; Demark-Wahnefried et al., 2005; Rabin et al., 2009). However, evidence suggests that neither the transplant experience nor FCR alone is sufficient to drive sustained behaviour change, and structured interventions may be required to support recipients in making positive lifestyle adjustments (Fisher et al., 2016; Kirsch et al., 2014; McBride et al., 2008; Williams et al., 2013). Importantly, the effectiveness of such interventions and the ability of recipients to benefit from them can be significantly influenced by broader structural factors, including equitable access to care, resources, and support.

### *2.5.4 Inequalities and Access*

Inequalities in access to LTFU care are a persistent and under-addressed issue, with critical implications for recipient outcomes. Dignan et al. (2021) highlight significant variation in access to multidisciplinary teams and specialist services, with geography, age, ethnicity, and socioeconomic status all playing a role. Internationally, studies have shown that minority ethnic groups and those from lower socioeconomic backgrounds are less likely to receive comprehensive LTFU, contributing to disparities in morbidity and mortality (Majhail et al., 2012; Richardson et al., 2016). The NHS Long Term Plan (2019) explicitly acknowledges these inequalities, but progress towards equitable access remains slow, hampered by resource constraints and organisational inefficiencies. Moreover, the literature suggests that digital health innovations, while promising, may exacerbate rather than reduce inequalities if not carefully implemented (Absolom et al., 2021). There is also a lack of research examining how these factors combine and interact, as most studies examine single dimensions of inequality in isolation, overlooking the complex ways in which multiple disadvantages may interact. Addressing these disparities requires not only policy commitment but also targeted investment and ongoing evaluation to ensure that all recipients, regardless of background, can access the care and support they need.

The literature frequently recommends a multidisciplinary approach for LTFU due to the complex nature of post-HSCT care and long-term complications (Suárez-Lledó & Rovira, 2024; Tichelli et al., 2021a). A core team of clinicians and nurses with specialised knowledge of HSCT, GvHD, and long-term complications, along with social workers, psychologists, nutritionists, and physical therapists, should form the ideal composition of the multidisciplinary team (MDT) (The core team should receive support from a network of consulting services specialising in long-term care in fields like pulmonary, endocrinology, and gynaecology (Tichelli et al., 2021a). However, access to a multidisciplinary team for HSCT recipients varies significantly across UK centres. Dignan et al. (2021) reported that out of twenty-five HSCT centres, only 12% of centres provide access to a MDT for recipients older than 25 years, and just 20% for those aged 25 or younger. The composition of these teams also differed, with younger recipients more likely to have access to psychologists and social workers. Furthermore, while most centres had access to certain specialists, such as endocrinologists, clinical psychologists, dieticians, respiratory physicians, ophthalmologists, dermatologists, and financial advisors, others relied on community resources or lacked access to key services like symptom management and fertility support. This variation means that some recipients may not

receive the comprehensive care and support they need during recovery, highlighting persistent inequalities in LTFU provision.

## 2.6 Policy to Practice of Person-Centred Long-Term Follow-Up Care

### *2.6.1 Policy Shifts and Patient-Reported Measures*

The 2019 NHS Long Term Plan marked a pivotal moment in the evolution of cancer care in England, laying a foundation for improved early diagnosis, faster access to treatment, and enhanced survival outcomes (NHS, 2019). It acknowledged the importance of personalised care and reducing health inequalities, but its approach to LTFU remained largely biomedical and system driven. LTFU care was often framed as a continuation of clinical monitoring rather than a holistic, patient-centred process. While the plan referenced the need for better psychological support and quality of life considerations, these elements were not deeply embedded in its implementation strategies. The emphasis remained on efficiency, throughput, and measurable clinical outcomes, with limited structural support for integrating psychosocial care into routine practice. This left a gap between policy ambition and the lived experiences of cancer survivors, particularly those with complex or long-term needs (Watson et al., 2021). The plan's success depended heavily on local interpretation (Alderwick & Dixon, 2019), which led to variability in how person-centred principles were applied across regions and services.

In contrast, the 2025 NHS "Fit for the Future" plan represents a more explicit and structured commitment to person-centred, psychologically informed care (Department of Health and Social Care, 2025). It reframes prevention to include comprehensive post-treatment clinical, psychological, and social support that promotes a shift from NHS-led models to community-first, digitally enabled, and co-designed care pathways. This evolution reflects a growing recognition that survivorship is not merely the absence of disease but the presence of well-being, resilience, and autonomy (Strasser, 2021). The plan calls for care that is not only clinically effective but also psychologically supportive, flexible, and responsive to the lived realities of each patient. It places greater emphasis on patient involvement, self-managed care pathways, and tailored support for individuals (NHS, 2025). However, realising this vision requires more than policy ambition as it requires practical investment in workforce development, digital infrastructure, and cultural change within clinical teams (Khan, 2025).

This policy shift, building on the foundations of the 2019 NHS Long Term Plan, aligns with international evidence that person-centred care improves patient satisfaction, engagement, and outcomes (Santana et al., 2018). Reflecting this momentum, there is a growing focus on utilising

Patient-Reported Outcome Measures (PROMs) in LTFU services (Kenyon et al., 2023), which is helping to raise awareness of the need for a more person-centred approach to post-HSCT long term care. A person-centred approach ensures care is respectful of patients' preferences, values and needs, delivering support that is tailored, integrated, and empowering (Santana et al., 2018; The Health Foundation, 2015). It facilitates access to personal health information, enhances patients' knowledge, promotes engagement, and prioritises outcomes significant to the patient, such as quality of life (Simpson et al., 2022; The Health Foundation, 2015).

A key mechanism for operationalising person-centred care is the use of patient-reported outcome measures (PROMs) and patient-reported experience measures (PREMs), which are short, self-completed questionnaires that assess health status or quality of life before and after treatment (Office for Health Improvement and Disparities, 2020). These measures are increasingly used to inform service design, support value-based healthcare, and ensure alignment with patient priorities. Despite endorsement in the NHS Long Term Plan (2019), their integration into routine post-cancer care remains inconsistent, even though evidence shows PROMs can improve symptom management, satisfaction, and survival in oncology (Basch et al., 2016). In HSCT follow-up, their use is still limited due to barriers such as infrastructure gaps, lack of clinician training, and limited buy-in (Absolom et al. 2021). Moreover, PROMs risk becoming a "tick-box" exercise unless embedded in meaningful clinical LTFU conversations (Kenyon et al., 2023). The literature also emphasises the need to expand PROMs to capture the full spectrum of patient experience, including psychosocial, emotional, and existential concerns and not just physical symptoms (Lines et al., 2015). This broader scope is essential for delivering truly person-centred care, which respects patients' preferences, values, and needs.

Despite increased awareness and policy support, many HSCT centres still lack sufficient resources to deliver comprehensive person-centred care, particularly in addressing psychosocial outcomes (NHS, 2022). For example, routine psychosocial screening by transplant centres in the UK is rare (Horne et al., 2014) and only forms part of standard operating procedures in eight (32%) centres (Dignan et al., 2021), which was a similar finding five years prior (Hamblin et al., 2017). This challenge is not unique to HSCT recipients, as limited access to psychological support is a well-documented issue across the wider patient populations. A systematic review by Hemming et al. (2024) found that psychosocial support remains inconsistently available in the UK, especially for those with rare cancers or in rural areas. Similarly, Lowther-Payne et al. (2023) identified persistent barriers to accessing psychological support, including financial

constraints and lack of integrated services, highlighting ongoing systemic gaps in psychological care across oncology and transplant services. Therefore, unless HSCT centres are equipped to serve recipients' needs, and as stated by the UK Stem Cell Forum (NHS, 2022), the ambition of the NHS for everyone to receive personalised care and support post-cancer treatment is unlikely to be achieved.

### *2.6.2 Bridging Policy, Theory, and Lived Experience*

Despite significant advances in policy and clinical guidelines for LTFU after HSCT, there remains a persistent gap between the ambitions of person-centred care and the realities experienced by recipients. Recent policy initiatives, such as the NHS Long Term Plan (2019; 2025) and the evolution of FACT-JACIE (2021) standards, have emphasised the importance of personalised, psychologically informed survivorship care. However, evidence from both HSCT and broader cancer survivorship research consistently highlights that these aspirations are not fully realised in practice, with many recipients reporting unmet needs, fragmented care, and ongoing psychosocial challenges (Austin-Ketch & Paplham, 2015; Hemming et al., 2024). While accreditation standards and national guidelines provide a robust framework for LTFU, their implementation is often inconsistent, leading to variability in service provision and access to multidisciplinary support. Studies in the UK and internationally have shown that inequalities persist, particularly for minority ethnic groups, younger recipients, and those from lower socioeconomic backgrounds (Majhail et al., 2012; Richardson et al., 2016). These disparities are compounded by resource constraints, workforce shortages, and organisational inefficiencies (Dignan et al., 2021; Hawkins et al., 2008), resulting in many recipients feeling in a state of uncertainty after acute care, uncertain about how to access ongoing support.

Quantitative outcome measures, such as survival rates and incidence of late effects, provide valuable insights into the clinical impact of HSCT. However, they do not capture the full complexity of survivorship, which encompasses psychological, social, and existential dimensions (Bevans et al., 2017; El-Jawahri et al., 2017). Qualitative research has demonstrated that recipients' perspectives are essential for understanding the barriers and facilitators to effective LTFU, as well as the nuanced ways in which policy and practice intersect with everyday life (Nakajima & Kamibeppu, 2022; Vetsch et al., 2017). For example, studies have found that clear, tailored information and psychosocial support are critical for adaptation and quality of life, yet many survivors report persistent distress and low levels of positive affect, even years post-transplant (El-Jawahri et al., 2024; Yang et al., 2023).

There is a growing recognition in the wider cancer and transplant literature that qualitative inquiry is needed to uncover the lived realities of survivors, particularly those facing complex or long-term needs (Fatma et al., 2021; Foster et al., 2020). Such approaches allow for the exploration of individual experiences, coping strategies, and the impact of health system structures on engagement with care. In HSCT populations, qualitative studies have revealed that survivors often encounter fragmented care pathways, ambiguous roles among providers, and a lack of standardised information, all of which contribute to feelings of abandonment and uncertainty (Hashmi et al., 2017; Pulewka et al., 2021). By foregrounding recipients' voices, research can identify actionable priorities for service improvement and inform the development of interventions that are responsive to real-world challenges.

### 2.7 Person-Centred Approaches and the Contribution of this Thesis

The rationale for exploring HSCT recipients' experiences of LTFU care is closely aligned with the broader shift towards person-centred, psychologically informed healthcare. Research demonstrates that person-centred approaches improve patient satisfaction, engagement, and outcomes, particularly when care is tailored to individual preferences, values, and needs (Santana et al., 2018). The use of patient-reported outcome measures (PROMs) and qualitative research methods is increasingly recognised as essential for capturing the full spectrum of survivorship, including psychosocial, emotional, and existential concerns (Basch et al., 2016; Lines et al., 2015). In the context of HSCT, this means moving beyond surveillance and clinical monitoring to embrace a holistic understanding of recovery, resilience, and well-being. Addressing the gap between policy ambition and lived experience, this thesis explores HSCT recipients' perspectives on LTFU care. Through qualitative inquiry, it aims to illuminate the barriers and facilitators to effective LTFU, identify unmet needs, and generate practical insights for the design and delivery of person-centred survivorship services. In doing so, it contributes to the ongoing evolution of HSCT care, ensuring that the voices of recipients are central to future policy and practice.

### 2.8 Chapter Summary

This chapter set out to examine the clinical, policy, and psychosocial context of LTFU after HSCT, with the aim of understanding how these factors shape recipient experiences and outcomes. The discussion demonstrated that LTFU is not simply a matter of clinical surveillance, but involves addressing a wide range of physical, psychological, and social challenges, as well as navigating diverse models of care and persistent inequalities in access. Key arguments highlighted the importance of person-centred approaches, such as personalised

stratified follow-up (PSFU), and identified significant gaps in current knowledge and practice, particularly regarding the lived experiences of recipients and the variability in service provision.

Situating LTFU within a broader health psychology and policy context, this chapter contributes to the overall thesis by establishing the rationale for a more person-centred, empirically informed approach to survivorship care. The following chapter outlines the methodological approach underpinning this thesis, detailing the interpretive paradigm, hermeneutic phenomenological framework, and multi-method research design of this thesis.

# Chapter 3. Methodology: Philosophical Foundations and Hermeneutic Phenomenological Design

## 3.1 Chapter Introduction

The previous chapter showed that HSCT initiates a lifelong journey, with LTFU care addressing recipients' broad physical, psychological, and social needs. As LTFU becomes more person-centred, understanding the lived experiences of HSCT recipients is essential for developing effective and tailored supportive care. This chapter sets out the methodological framework used to explore HSCT recipients' experiences of LTFU care.

The chapter provides a transparent account of the research design, beginning with the philosophical assumptions and theoretical framework, and the rationale for adopting a hermeneutic phenomenological methodology. Researcher positionality and reflexivity are discussed, followed by an overview of the research strategy, ethical considerations, and measures to ensure trustworthiness and rigour.

Clarifying these methodological foundations demonstrates how the chosen approach supports the central research objectives and coherence of the thesis. The chapter also reflects on the strengths and limitations of the methodology, including researcher subjectivity, data collection during the COVID-19 pandemic, and the challenges of qualitative inquiry in health research. This groundwork lays the foundation for the empirical chapters that follow, where the specific methods and findings of each study phase are presented in detail.

## 3.2 Philosophical Orientation

All research is underpinned by philosophical assumptions concerning the nature of existence and knowledge that determine the research *paradigm*. A research paradigm, in essence, demonstrates how the researcher views the world, which subsequently reveals a theoretical framework that guides the research approach (Clarke, 2016; Clark et al., 2021). The two main philosophical assumptions that distinguish research paradigms are ontology, "the science of *being*" (Lowe, 2005, p. 84) and epistemology, "the theory of *knowledge*" (Hamlyn, 2005, p. 260). In relation to social science research, ontology relates to *what* exists that can be known within the world of social phenomena (Grix, 2019) and is concerned with how researchers view and define social reality, namely the social world that research aims to study (Blaikie & Priest, 2019). Epistemology relates to *how* knowledge of this social reality can be known by the observer (Corbetta, 2003); that is, how researchers view *how* knowledge comes into existence

and whether such existence is independent of consciousness or influenced by it (Crotty, 1998). Accordingly, how researchers view and define their ontological and epistemological positions determines their research paradigm.

Broadly speaking, research paradigms fall on a continuum from positivism to interpretivism. Positivists view social reality as existing independently of human consciousness (ontological realism) and hold that *meaning* exists within an object of the world prior to and independently of any consciousness of it (epistemological objectivism). From a positivist's perspective, there is only one verifiable social reality that can be explained and understood through observation and measurements of objective properties (Grix, 2019). Positivists traditionally obtain law-like natural generalities that explain the social world through quantitative methods, such as experiments, surveys or observational studies. At the other end of the spectrum, interpretivists view social reality as constructed in the human mind by and between individuals and therefore multiple subjective realities exist (ontological relativism). Interpretivists hold that *meaning* is created through the interactions of consciousness and the social world (epistemological constructionism) (Crotty, 1998). Interpretivists view knowledge of the social world as something that relies on human construction and interpretation, which possesses no tangible properties that can be measured or observed (Grix, 2019). They seek to create knowledge of social reality through interactions by using case studies, grounded theory or phenomenology methodology via the collection of qualitative data (Creswell & Poth, 2018).

Whilst research paradigms can be seen as implicit in nature, defining and explicitly expressing one's research paradigm is becoming more widespread (Denscombe, 2002). The researcher holds an ontological relativists and epistemological constructionist view; therefore, the theoretical perspective adopted is *interpretivism*. This research paradigm aligns with the aim of the study: to understand HSCT recipients' experiences of LTFU care. Experiences such as feelings, thoughts and perceptions are subjective and therefore not independent of human understanding or interpretation. As such, individuals create their own version of reality and no one singular true reality exists. There is no objective *truth* of HSCT recipients' experiences waiting to be discovered. The knowledge, and therefore the meaningful reality, of HSCT recipients' experiences sought in this thesis only comes into existence through the researcher's engagement and interpretation. However, as knowledge is not believed to exist independently of the researcher's interpretation, the researcher is not detached from the meaningful reality being researched, and is therefore aware that personal opinions, attitudes and values may inevitably influence the meanings constructed within this thesis (see Section 3.4).

Explicitly expressing one's research paradigm strengthens the research's credibility and minimises the uncertainty associated with interpreting the results (Denscombe, 2002). Paradigms are also defined as a collective set of views and agreements that scientists have regarding how problems should be comprehended and resolved (Kuhn, 1962/2012). Therefore, understanding and applying philosophical assumptions in line with an appropriate paradigm strengthens the academic legitimacy of the research. Expressing one's paradigm contributes to the rigour and trustworthiness of the research, as it enables readers to comprehend and assess the fundamental assumptions in relation to research design, methodology, and procedures (Creswell & Poth, 2018). It also aids the reader in contextualising the findings within the appropriate conceptual and philosophical framework, signifying that interpretations are made with an understanding of the underlying assumptions (Grix, 2019).

## 3.3 Methodological Approach: Phenomenology

Within the interpretive research paradigm, there are several methodological approaches to research enquiry: narrative, phenomenology, grounded theory, ethnographic and case study research (Creswell & Poth, 2018). The approach adopted depends on the research focus, and on identifying which approach addresses the research needs. Broadly speaking, as the focus of this thesis was to understand HSCT recipients' experiences of LTFU care, rather than developing a theory explaining LTFU practice (grounded theory), understanding shared patterns of behaviour within the HSCT community (ethnographic), or conducting in-depth analysis of individual cases within a given LTFU setting (case study) (Creswell & Poth, 2018), both narrative and phenomenological approaches were considered. Given that the aim of this thesis was not to understand the detailed narrative accounts of HSCT recipients' experiences of LTFU in isolation (Squire et al., 2014), but rather the *essence* (i.e. nature or meaning) of the experience from several HSCT recipients (van Manen, 2016), a phenomenological approach was taken.

### *3.3.1 Phenomenology and its Philosophical Underpinnings*

Phenomenology, in its broadest sense, means the "study of phenomena" (Zahavi, 2019, p. 9). In principle, phenomenology focuses on exactly how a phenomenon (which can be any object) is experienced (Zahavi, 2019). Phenomenology emerged due to dissatisfaction with the natural sciences' failure to account for human experiences and the relationship between consciousness and the existence of objects (Moustakas, 1994). In phenomenology, it is acknowledged that human experiences are the essence of consciousness, influenced by both the objective world and the subjective self (Pinkard & Baur, 1998). However, the subjective entity of consciousness differs among philosophers, which underpins certain approaches to phenomenology,

predominantly Husserl's transcendental (descriptive) phenomenology and Heidegger's hermeneutic (interpretive) phenomenology (Peoples, 2021).

The philosopher Edmund Husserl (1859-1938), in his quest to develop phenomenology as a science, identified the essence of consciousness as an intentional act between the subject and object (Howell, 2013). To ask someone about their experiences of a phenomenon, their consciousness is directed to that phenomenon, the phenomenon is then intricately related to the consciousness of it (Creswell & Poth, 2018). That is, to think is to think about something. Objects, according to Husserl, acquire meaning through consciousness, as meaning arises when a person becomes aware of or experiences the object. This meaning is influenced by interactions with the ever-changing world, and is further expanded through reflection (Zahavi, 2019). Therefore, to reach the essence of an experience, one must look at the "original, pre-reflective, pre-theoretical attitude" (van Manen, 2016, p. 7), before it becomes a conscious object. According to Husserl, to go "back to the things themselves" (Crotty, 1998, p. 78), as initially presented in consciousness, all pre-conceived understanding of the phenomenon should be suspended, a process known as bracketing or epoché (Howell, 2013). Husserl believed that by suspending any pre-existing knowledge or understanding of a phenomenon, the "natural attitude of the everyday life" can be reached (Gill, 2014, p. 120), and therefore the descriptive essence of the phenomenon as lived can be known.

In contrast to Husserl's focus on consciousness and bracketing, the philosopher Martin Heidegger (1889-1976) argued that meaning of objects is not just meaning within consciousness, but rather that meaning is created through actions in daily life (Zimmermann, 2015). Heidegger argued that being *within* the world cannot be separated from being *in* the world. It is this state of being *in* the world that Heidegger (1978/1962) refers to as Dasein, which means "*to exist"* or *"to be there*" (Inwood, 2013, p. 22). According to Heidegger (1978/1962), the *being* of a phenomenon is already an entity, which can only be understood through interpretation. Through interpretation, any pre-conceived biases and understanding (fore-sight) are revised until new understandings emerge. This is a circular process of reading, reflecting and interpreting between parts and the whole of collated data to discover meaning, referred to as the hermeneutic circle (Gadamer, 1975/2004). It is only through this circular interpretative process that the essence and expression of an experience can be known. The interpretative process is self-reflexive, where researchers evaluate their subjective influence on the research process (Olmos-Vega et al., 2022). Therefore, to obtain the essence of a phenomenon, pre-existing knowledge and understanding should be acknowledged prior to any

research. Hans-Georg Gadamer (1900-2002) expanded on Heidegger's concept of the hermeneutic circle, specifically identifying the limits of definitive interpretation. Gadamer argued that one's perspective contributes to interpretation, as interpretation cannot occur without an initial view to interpret from (Peoples, 2021). Therefore, new perspectives continually evolve with each interpretation, creating new understanding.

Though Heidegger's hermeneutic phenomenology emerged as an alternative approach to phenomenological understanding, it does not devalue the significance of Husserl's transcendental phenomenology in identifying the fundamental essence of experience, nor does it intend to supersede the method. The philosophical approaches both aim to reveal the human experience as it is lived and rooted in the foundations of transforming philosophical phenomenology to a scientific methodology (Howell, 2013). Where they differ is based on epistemological and ontological considerations, as transcendental phenomenology focuses on what can be *known* about the world (epistemology), while hermeneutic phenomenology focuses on what it *means* to be in the world (ontology) (Farrell, 2020). The choice of phenomenological approach depends on the nature of the experience the researcher seeks to explore.

### *3.3.2 Determining a Hermeneutic Phenomenology Approach*

As the primary aim of this thesis was to understand the experiences of HSCT recipients attending LTFU care, a hermeneutic phenomenological approach was taken. This approach allowed the researcher to collect the experiences of individuals to understand the "universal essence" of the experience (Creswell & Poth, 2018, p. 75). A phenomenological approach is also well suited to health education, as it is effective in exploring challenging problems within the healthcare sector (Neubauer et al., 2019). Learning from the experiences of those who use health care services helps to understand the challenges faced in achieving a person-centred care service, as well as helping service providers feel prepared for delivering such care (Auld et al., 2024). To achieve this, the researcher aimed to go beyond the descriptive essence of HSCT recipients' experience of LTFU care and focus on understanding the meaning of the experience. Hence, a hermeneutic phenomenological approach to this thesis, as opposed to a transcendental one, was taken.

This approach was also determined by the researcher's personal views regarding perception and beliefs. The researcher disagrees with Husserl's view that objects are inherently assigned meaning and that, by suspending all pre-conceived knowledge, one can gain the essence of a phenomenon. Instead, it is believed that meaning and knowledge are constructed and shaped

by personal history, social status, and societal interactions, all of which influence how meaning is interpreted and how individuals make sense of their *being.* This view holds that no single true interpretation exists, but rather several useful interpretations (Crotty, 1998). This aligns with Heidegger's belief that the hermeneutic circle is a process of understanding, and in adopting this view, the researcher acknowledges the significance of their own pre-conceived knowledge.

### 3.4 Researcher's Foresight and Reflexivity Positionality

As stated by van Manen (1997/2016), phenomenology 'is always a project of someone: a real person, who, in the context of particular individual, social, and historical life circumstances, sets out to make sense of a certain aspect of human existence' (p. 31). This resonates with the present thesis, which was shaped by the researcher's personal experience as a HSCT recipient. Over three decades ago, the researcher lay in a hospital bed, surrounded by clinicians in protective gear, awaiting a life-saving stem cell infusion. At the time, they could not have foreseen that surviving the treatment would entail a lifelong commitment to annual health reviews to monitor for late effects. With the exception of a six-year gap between paediatric and adult services, the researcher has attended annual follow-up appointments under various care models for the past sixteen years. The experiences formed the presupposition for this thesis.

The researcher retains a preconceived understanding of the world of LTFU care from a recipient's perspective. This understanding is grounded in personal experience of "growing up" with LTFU monitoring, as well as engaging with HSCT recipients through previous academic research conducted at undergraduate and masters levels. The researcher believes that the *actual* experience of attending LTFU is significant in some way to HSCT recipients' ability to manage their future health and well-being, a foresight that shaped the research. This foresight, while present, was initially tentative and evolved throughout the study. Therefore, it is through this foresight that the researcher approaches the pre-reflexive assumptions of the study, as pre-reflexive assumption are the foundations on which all self-reflexive interpretation takes place (May & Perry, 2011).

To critically engage with this positionality, the researcher employed *reflexive journaling*, a structured method that supports ongoing self-reflection and interpretive rigour. A reflexive journal was initiated at the start of this thesis and maintained throughout, serving as a critical space for documenting interpretations, questioning assumptions, and engaging with the philosophical and methodological dimensions of the study (see Appendix 1 for an example). This practice enabled the documentation of evolving thoughts, emotions, assumptions, and

decisions, offering a space to critically examine how personal values and experiences shape the thesis design and analysis (Olmos-Vega et al.,2023). Alongside reflexive journaling, analytic memoing was used during the familiarisation and coding stages of data analysis. These memos focused on the content of individual accounts and the emerging patterns across the dataset (see Appendix 2 for examples). It is important to distinguish between these two practices. Reflexive journaling centres on the researcher's subjectivity, positionality, and influence on the research process, serving as a tool for critical self-awareness and transparency (Dado et al., 2023; Edwards, 2023). In contrast, analytic memoing focuses on tracking insights, coding decisions, and thematic development within the data, supporting conceptual clarity and analytical depth (Bingham, 2023; Birks et al., 2008). Used in tandem, memoing deepened engagement with the data, while journaling provided a structured space for documenting the researcher's evolving assumptions and interpretive stance.

Reflexivity was treated as a continuous, iterative process, with journaling capturing "personal, interpersonal, methodological, and contextual" developments (Olmos-Vega et al., 2021, p.1). As Edwards (2023) notes, journaling facilitates the tracking of subjectivity, revealing how interpretations deepen through engagement with data. This approach aligns with the cyclical nature of qualitative inquiry, where doing, reflecting, and learning are interwoven. Reflexive journaling is particularly compatible with hermeneutic phenomenology, which acknowledges that understanding is shaped by prior knowledge and cannot be separated from the researcher's being-in-the-world. Rather than eliminating bias, it embraces subjectivity as a resource for interpretation (Alvesson & Sköldberg, 2017).

### 3.5 Research Strategy: Qualitative Multi-Method Sequential Design

The research strategy was qualitatively driven and underpinned by an interpretivist research paradigm. Interpretivists hold that the separation between 'fact' and 'value' is not absolute and therefore do not prescribe the methods of enquiry typically used in empirical investigation (e.g. quantitative methods). Instead, they employ qualitative methods, which align with a phenomenological approach, to obtain text-based data (e.g. open-ended questions, observations, interviews) that help interpret the meaning, context, and subjective experiences of individuals or groups (Creswell & Poth, 2018; Grix, 2019).

Given the paucity of research in how HSCT recipients experience LTFU care, a three-phase multi-method sequential design was chosen (Creswell & Plano Clark, 2007). This approach, illustrated in Figure 3.1, comprised: (1) a systematic review with qualitative evidence synthesis,

(2) written accounts from HSCT recipients, and (3) semi-structured interviews with HSCT recipients. Enabled by a sequential, data-driven strategy, each study built on the results of the previous one, allowing the researcher to be guided by the data (Hesse-Biber et al., 2015). The findings from Studies 2 and 3 were subsequently integrated and synthesised, as presented in Chapter 7, to enhance the credibility and depth of interpretation.

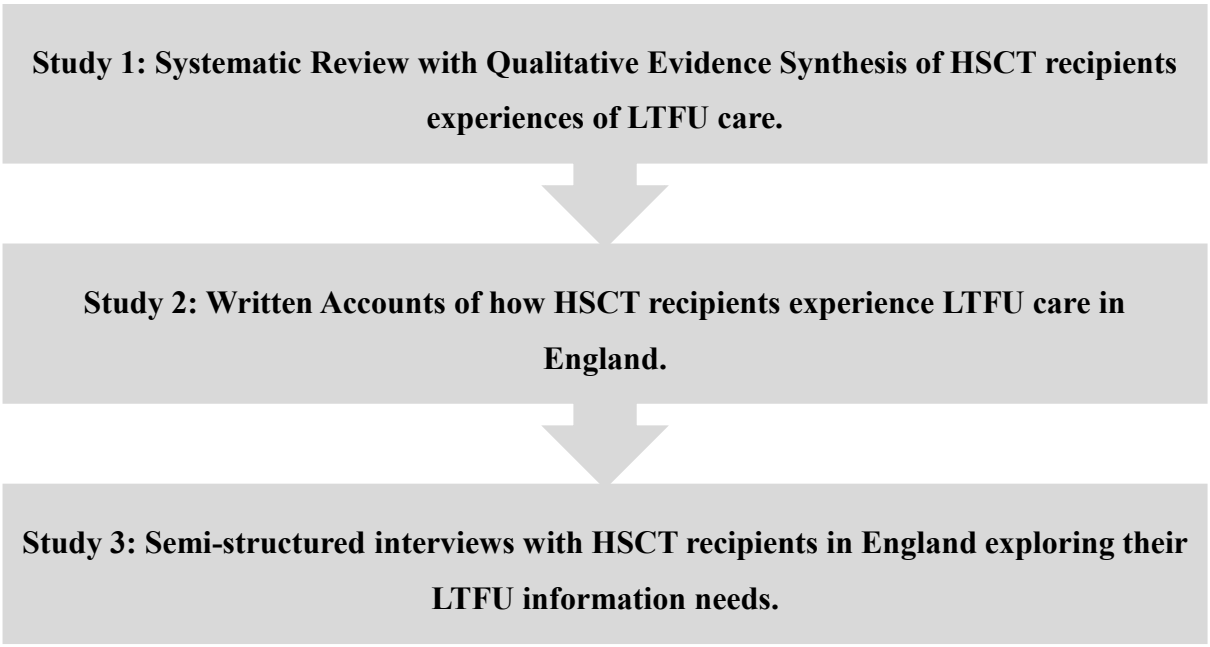


**Figure 3.1 Breakdown of Key Studies within the Multi-Method Sequential Design**

The first study was a systematic review with qualitative evidence synthesis of HSCT recipients' experiences of attending LTFU care in general (see Chapter 4). The purpose of this review was to ascertain what was currently known in the literature regarding how recipients experience LTFU care. In doing so, it identified gaps in the knowledge relating to recipients' experiences in England, which subsequently informed the design and focus of Study Two.

Study Two was conducted as a qualitative investigation comprising online written accounts that explored how recipients in England experience LTFU care (see Chapter 5). Each written account was analysed using reflexive thematic analysis, and themes of experience were generated through an active process of interpretation and engagement with the data. One key theme identified was the lack of information provided to recipients regarding late effects and the post-transplant long-term monitoring process. Recognising the need for a deeper understanding of this finding, a third phase of data collection was initiated.

In response, Study Three involved interviewing HSCT recipients to examine their informational needs as they transitioned from acute post-transplant care into LTFU care and beyond (see Chapter 6). Data were again analysed using reflexive thematic analysis, with the aim of further exploring the informational needs highlighted in the previous studies and providing a more comprehensive account of recipients' experiences. In both empirical studies, data sufficiency was determined through the principle of analytic sufficiency, rather than aiming for saturation. This involved ongoing reflexive assessment of the richness, diversity, and stability of the data, ensuring that further data collection was unlikely to yield substantially new insights (see Sections 5.3.3 and 6.3.3 for details).

The findings from Studies Two and Three were subsequently triangulated to identify converging themes across different data sources, enhancing the credibility and depth of interpretation. These findings were then synthesised to construct a comprehensive understanding of HSCT recipients' experiences of LTFU care in England. These findings are then further interpreted and contextualised in Chapter 8, which offers discussion, recommendations, and conclusions in relation to the main research question: How do haematopoietic stem cell transplant recipients experience long-term follow-up in England?

### 3.6 Ethical Considerations

The primary principle of all research is that it does no harm. As stated by the Department of Health (DoH, 2005), the safeguarding of the "dignity, rights, safety, and well-being of participants must be the primary consideration in any research study" (p. 7), which supersedes scientific or any other considerations or interests. Such safeguarding measures are achieved through research ethical considerations, both prior to and during data collection (Wiles, 2013). Several ethical considerations and procedures were undertaken in accordance with university policies and procedures. During the period between Studies 2 and 3, this thesis was transferred from Teesside University to Newcastle University following the first supervisor's change of employment.

In September/October 2020, the global COVID-19 pandemic was entering its seventh month. As a nation, the UK had already experienced unprecedented lockdown and social distancing measures, and the threat of a second lockdown loomed (Institute for Government Analysis, 2022). HSCT recipients were classed as clinically vulnerable due to compromised immune systems, and the pandemic posed an additional threat to their health. The researcher questioned whether it was ethically appropriate to undertake research with this population during such a

difficult time. However, the implications of conducting the research were minimal, given that the risks associated with participation were low and participation was voluntary.

Central to all ethical research practices is informed consent (Wiles, 2013). As studies 2 and 3 involved collecting data about and from human participants, informed consent was obtained from all participants prior to the commencement of data collection. Prior to consenting, all participants were provided with a participant information sheet (PIS) (Appendix 3 for Study 2, and Appendix 4 for Study 3) to ensure they were fully informed of the research purpose, method and potential use of the findings. The participant information sheet emphasised that participation was voluntary, and that participants had the right to withdraw without reason up until a specified date. The procedure for withdrawing consent was also provided. Participants were informed that any information about them would be handled confidentially, anonymity would be respected, and a pseudonym would be allocated. They were asked to confirm that they had read and understood the information sheet, acknowledged that participation was voluntary, and provided their consent to proceed (see Appendix 5 for Study 2 and Appendix 6 for Study 3).

While no risk was associated with participation in either Study 2 or 3 for the researcher or participants, it was acknowledged that participation might raise clinical questions that the researcher could not answer. Additionally, as participants were asked to recall experiences from a potentially difficult period in their lives, it was recognised that this could be upsetting for some. This concern was addressed in the information sheet, and participants were provided with a debrief sheet (Appendix 7 for Study 2, and Appendix 8 for Study 3) following participation. The debrief listed organisations that could offer further guidance or support and invited participants to contact the researcher and/or supervisor should they have any further questions.

Ethical approval was applied for and granted for both Study Two and Study Three by the respective research ethic boards. Ethical approval for Study Two was obtained from Teesside University Research Ethics Committee in June 2021 (see Appendix 9). One minor amendment was made after approval: the withdrawal date was extended to allow for more time for participant recruitment. This amendment was accepted by the ethics committee in September 2021 (see Appendix 10). Ethical approval for Study Three was granted by Newcastle University Faculty of Medical Science Research Ethics Committee in April 2023 (see Appendix 11). Two subsequent amendments were made. The first amendment request, submitted in July 2023,

introduced an incentive in the form of a £20 Amazon voucher due to the low participation uptake.

It was debated whether offering and informing participants of an incentive prior to consent negatively influences the voluntary nature of informed consent (Resnik, 2015; Wiles, 2013). However, the National Research and Ethics Advisors' Panel (NEREAP, 2024) states that incentives are not deemed coercive when the associated risks and obligations are those that a competent adult might legitimately accept without compensation. Given that three participants were recruited prior to the incorporation of the incentive and that the associated risk of participating was low, it was deemed reasonable to conclude that an incentive was ethically acceptable. This amendment was approved by the Newcastle University Ethics and Integrity Committee in July 2023 (see Appendix 12). Notably, the three participants who completed the study prior to the inclusion of the incentive were issued a voucher retrospectively. A second amendment, to further extend the project and withdrawal dates, was made and subsequently approved in October 2023 to allow for additional participant recruitment (see Appendix 13).

In addition to safeguarding participants, ethical research practice must also consider the safety and well-being of the researcher. This is particularly important in qualitative studies involving sensitive topics or emotionally charged narratives, where researchers may be exposed to distressing accounts (Dickson-Swift et al., 2008). In this thesis, the researcher's dual role as both investigator and HSCT recipient presented unique challenges, including potential emotional triggers and the need to manage personal boundaries. To mitigate these risks, a self-care plan was developed and implemented, which included regular supervision meetings, reflexive journaling, and access to institutional support services if required. These measures align with recommendations in the literature that advocate for proactive strategies to support researcher well-being in emotionally demanding qualitative research (Kumar & Cavallaro, 2018; Nicholls et al., 2022). In addition, ethical approval processes at both Teesside and Newcastle Universities explicitly considered researcher welfare. At Teesside, the application required a formal declaration prioritising the safety and well-being of both participants and researchers, with supervisor oversight. At Newcastle, the risk assessment confirmed no potential risks to the researcher, as all data collection was conducted online, removing hazards such as lone working or home visits.

Ethical research practice also requires careful attention to data management, including how data is collected, stored, protected, shared, and preserved. A data management plan was developed

during the project approval stage and updated, when necessary, throughout the research (see Appendix 14). The plan outlined procedures for secure data storage, anonymisation of participant information, controlled access, and long-term archiving. All personal data were encrypted and stored on the university's secure Microsoft OneDrive, with access restricted to the research team. These practices align with ethical standards in qualitative research, which emphasise responsible data handling as a core component of participant protection and research integrity (Taquette & Souza, 2022).

### 3.7 Trustworthiness

There is no uniform approach to assess the quality of qualitative research (Leung, 2015; Rolfe, 2006), unlike the widely accepted quality assessment criteria of validity (internal and external), reliability, and objectivity in quantitative research (Howitt & Cramer, 2020). Validity, in its most basic definition, refers to whether research substantiates its assertions. Internal validity refers to the degree in confidence that research has been conducted without bias. External validity refers to the generalisability of research findings being applied to other contexts (Andrade, 2018). The reliability of research refers to consistency and accuracy of measures used, and the objectivity refers to research being free from subjective bias (Howitt & Cramer, 2020).

The debate among scholars is whether the terms of validity and reliability are appropriate to evaluate qualitative research (Long & Johnson, 2000; Rolfe, 2006). It is argued that the terms, in their broadest context, can be applied to interpretative research (Long & Johnson, 2000). However, alternative frameworks for ensuring research quality are considered more appropriate, given the philosophical stances and purposes of qualitative and quantitative research are fundamentally different (Sandelowski, 1993). One such framework, established by Lincoln & Guba (1985), is trustworthiness, which pertains to the creditability (vs. internal validity), transferability (vs. external validity), dependability (vs. reliability) and confirmability (vs. objectivity) of qualitative research (Stahl & King, 2020). Strategies that were implemented within this study to enhance quality and trustworthiness of this study are provided in Table 3.1.

| Trustworthiness Element | Implemented Strategy |
|---|---|
| Creditability<br>*The trust and confidence one can have in the research findings* | **Reflexivity**: A reflexive journal maintained throughout the research process (see Section 3.4), and Chapter 9 further enhances creditability by providing a transplant account of how the researcher's dual perspective as HSCT recipient and researcher informed methodological choices, interpretation, and ethical considerations.<br>**Representativeness**: Rich verbatim descriptions of participants' accounts were included to support research findings (See Sections 5.4, 6.4, 7.2 and 7.3).<br>**Data triangulation**: Two methods of data collection consisting of written accounts and interviews provided a more comprehensive set data findings of patients' experiences (see Chapter 7).<br>**Publication**: Studies 1 and 2 peer-reviewed and published (see Appendices 15 and 25) . |
| Transferability<br>*The generalisability of research* | **Auditability**: A comprehensive account of the research process, encompassing the outline, the formulation of methodologies, and the presentation of findings (see Sections 3.3 and 3.5).<br>**Settings:** Recruitment of participants was not limited to one demographic location; therefore, findings are transferable to all LTFU clinics located within England. |
| Dependability<br>*Findings, and interpretation supported by the data* | **Decision Trail**: Detailed and transparent description of the research process outline and documented throughout (see Section 3.5). Reflexive diary documented challenges and assisted in maintaining study aims.<br>**Peer debriefing**: Themes discussed with research supervisors who had qualitative research expertise. Interpretations and assumptions could be challenged, discussed and consensus reached (see Sections 5.3.5 and 6.3.5). |
| Confirmability<br>*Mitigating subjective biases* | **Foresight**: Acknowledging subjective biases throughout the research process through reflexive journaling and question pre-existing understanding by continuously reading, reflecting and interpreting of the data to discover meaning (see Section 3.4 and Chapter 9). |

**Table 3.1 Strategies implemented to enhance research quality and trustworthiness**

As discussed in Section 3.4, a reflexivity journal was maintained throughout this programme of work. This aligns with best practices in qualitative health research, where reflexivity is essential for ethical and rigorous inquiry by increasing transparency and awareness of researcher influence (Braun & Clarke, 2022; Olmos Vega et al., 2023). As Sibbald et al. (2025) highlight, reflexivity moves beyond identity disclosure to engage with power dynamics, positionality, and interpretation. This was particularly relevant given the researcher's dual role as both HSCT recipient and investigator, requiring careful attention to avoid over identification or bias. To ensure the credibility of the research, several strategies were implemented in line with established qualitative research guidance (Braun & Clarke, 2022; Lincoln & Guba, 1985; Nowell et al., 2017). The reflexive journal provided a continuous record of evolving assumptions, emotional responses, and methodological decisions, allowing the researcher to critically examine and manage personal bias (Braun & Clarke, 2022). Analytic memoing during coding further distinguished the researcher's perspectives from those of participants (Nowell et al., 2017). Regular peer debriefing with supervisors and colleagues enabled interpretations and assumptions to be challenged and refined, ensuring that findings remained grounded in participant data (Braun & Clarke, 2022).

Triangulation was also central to credibility. Two distinct qualitative methods, written accounts and semi-structured interviews, were used to collect data. This data triangulation allowed for comparison and cross validation of themes across different data sources (Carter et al., 2014; Meydan & Akkaş, 2024; Tsindos, 2025). For example, themes identified in written accounts were checked against those emerging from interviews, and both were interpreted considering the broader literature. Triangulation enhanced credibility by revealing both convergence and divergence in findings, ensuring that the research findings were not dependent on a single method or dataset, but instead reflected a comprehensive and robust understanding of the phenomenon (Carter et al., 2014). Regarding transferability, the thesis provided thick, contextual descriptions of research settings, participant demographics, and care models, as recommended by Lincoln & Guba (1985) and Creswell & Poth (2018). Recruitment was not limited to a single demographic or location, but included participants from across England and from a range of long term follow up care models. This level of detail enables readers to judge the applicability of the findings to other contexts and supports the transfer of insights to similar settings (Braun & Clarke, 2022; Vasileiou et al., 2018).

Dependability was addressed through a transparent decision trail and detailed documentation of methodological choices, supporting an audit trail that allows others to trace the research

process (Braun & Clarke, 2022; Nowell et al., 2017). The reflexive diary recorded challenges, adaptations, and the rationale behind key decisions. Peer debriefing further contributed to dependability by providing opportunities for external review and consensus building on interpretations and thematic development (Nowell et al., 2017). The research also strengthened confirmability by maintaining an audit trail of analytic decisions and by explicitly acknowledging and managing subjectivity through reflexive journaling (Lincoln & Guba, 1985; Olmos Vega et al., 2023). The interpretive process was guided by Gadamer's hermeneutic principles, which emphasise engaging with pre-understandings in dialogue with participant narratives (Bartley & Brooks, 2022). This fusion of horizons deepened the understanding of lived experiences while maintaining transparency about the researcher's influence. All findings were grounded in participant data, with direct quotes and clear links to the original accounts, ensuring that interpretations were shaped by the data rather than personal assumptions (Braun & Clarke, 2022).

### 3.8 Chapter Summary

This chapter outlined the methodological approach underpinning this thesis, rooted in an interpretive research paradigm and a hermeneutic phenomenological framework to explore HSCT recipients' experiences of LTFU care. This chapter detailed a qualitative, multi-method sequential design, comprising a systematic review with qualitative evidence synthesis (Study 1, see Chapter 4), written accounts (Study 2, see Chapter 5), and interviews (Study 3, see Chapter 6), with each phase building on the last to provide a comprehensive exploration of the research question.

Key methodological strengths include the integration of multiple qualitative methods and a strong emphasis on reflexivity and triangulation to enhance credibility and rigour. Ethical considerations were addressed throughout, including informed consent, safeguarding of participants and the researcher, and robust data management procedures. The chapter also acknowledged limitations, such as the challenges of conducting qualitative research during the COVID-19 pandemic and the potential influence of researcher subjectivity.

Establishing a transparent and rigorous methodological foundation in this chapter demonstrates how the chosen approach supports the central research objectives and ensures coherence across the thesis. The next three chapters each present a distinct empirical study, beginning with a systematic review with qualitative evidence synthesis, and together provide the empirical basis for addressing how HSCT recipients' experience  LTFU care in England.

# Chapter 4. Systematic Review with Qualitative Evidence Synthesis of HSCT Recipients' Experiences of LTFU Care

## 4.1 Chapter Introduction

This chapter builds on the foundations laid in Chapters 2 and 3, which established the lifelong nature of HSCT care and introduced the interpretive, hermeneutic phenomenological methodology underpinning this thesis. The focus now shifts to a systematic review with qualitative evidence synthesis (QES)[1] to explore existing literature regarding HSCT recipients' experiences of LTFU care. QES offers a rigorous approach to integrating diverse perspectives from the literature, thereby advancing knowledge in this area (Booth et al., 2019; Snyder, 2019).

The review is registered with PROSPERO (see Section 4.3) and follows best-practice guidance, including transparent search strategies, critical appraisal, and confidence assessment using the GRADE Working Group's CERQual approach (see Section 4.3.7). Consequently, this chapter provides a comprehensive account that extends beyond the version published in the Journal of Patient Experience (see Appendix 15).[2] The chapter proceeds by outlining the study's background and context, detailing the review methodology, presenting the synthesised findings, and discussing their implications for future research and practice. In doing so, it establishes the foundation for the subsequent empirical chapters.

## 4.2 Background

As established in Chapter 2, the growing population of HSCT survivors, alongside persistent risks of transplant-related mortality and morbidity, has driven a shift in focus from acute post-transplant care to the long-term management and healthcare infrastructure of LTFU care. This shift reflects an increasing recognition of the need for a more person-centred, holistic approach to LTFU care that is responsive to the individual needs, preferences, and lived experiences of HSCT recipients (Bevans et al., 2017; Kenyon et al., 2023). Person-centred LTFU encompasses not only clinical monitoring, but also tailored information, psychosocial support, and health

[1] In this thesis, the term "systematic review with qualitative evidence synthesis (QES)" reflects both the structured review process and the qualitative methodological approach. The study followed a registered PROSPERO protocol, applied a comprehensive search strategy, and used the PRISMA 2020 framework. This terminology aligns with the phrasing used in the peer-reviewed publication, which referred to the study as a systematic review with meta-synthesis, in line with editorial input received during the review process.

[2] Only three of the four themes presented in this chapter were submitted for publication due to the word count restriction. The selection of themes was based on the Grading of Recommendations Assessment, Development, and Evaluation (GRADE) working group's Confidence in the Evidence from Reviews of Qualitative Research (CERQual) approach.

education to empower recipients in managing their recovery and well-being (Suárez-Lledó & Rovira, 2024).

However, despite policy advances and accreditation standards, the structure and delivery of LTFU services across transplant centres in England remain inconsistent, with significant variations in care models, multidisciplinary access, and psychological support provisions (Dignan et al., 2021). As highlighted in Chapter 2, these inconsistencies contribute to persistent inequalities and unmet needs, particularly regarding emotional and informational support (Hahn et al., 2017; NHS, 2022). While patient involvement is increasingly recognised as central to the development of responsive and effective healthcare systems (Havana et al., 2023; Schroeder et al., 2022), the lived realities of HSCT recipients navigating complex care pathways are not always reflected in current service models. Patient experiences offer crucial insights into the burdens of illness, survivorship, and unmet needs, and have been shown to positively influence clinical effectiveness and service quality (Doyle et al., 2013; Rand et al., 2019). Although there is a growing emphasis on personalised care, psychological screening and survivorship planning remain underdeveloped. As outlined in Chapter 2, no comprehensive synthesis of qualitative studies has explored HSCT recipients' experiences of LTFU care, leaving a gap in the literature and limiting the development of truly person-centred models.

Recent literature further highlights several ongoing debates and gaps that shape the context for this study. These include the pivotal role of specialist nurses and multidisciplinary teams in delivering LTFU care (Baskin et al., 2023; Corcoran et al., 2015; McCaughan et al., 2021), the challenges of communication and information provision (Bompoint et al., 2023; Murray et al., 2023; Vermeir et al., 2015), and persistent inequalities in access to psychological support (Dignan et al., 2021; Hashmi et al., 2018; Salooja et al., 2016). The complex relationship between follow-up practices and fear of cancer recurrence (FCR) is particularly important; while regular monitoring can provide reassurance for some HSCT recipients, for others it may heighten anxiety and hypervigilance, especially in the absence of adequate psychological support (Austin-Ketch & Paplham, 2015; Bergerot et al., 2022; Brice et al., 2020; Reed et al., 2021). In addition, there is increasing recognition that health behaviour change, and self-management are influenced not only by individual motivation but also by broader structural factors, such as equitable access to resources and support (Bishop et al., 2010; Fisher et al., 2016; Kirsch et al., 2014; Rabin et al., 2009; Williams et al., 2013). Situating this study within these key debates, the research aims to generate insights that are directly relevant to current policy and practice challenges in LTFU care for HSCT recipients.

To address the literature gap, a systematic review with qualitative evidence synthesis (QES) has emerged as a rigorous and systematic approach to analysing published qualitative research, enabling the identification, interpretation, and integration of findings from diverse studies. Unlike traditional systematic reviews, which focus on quantitative data, systematic reviews with QES are particularly suited to exploring complex phenomena such as healthcare experiences, where context and meaning are paramount (Downe et al., 2019). While debates persist regarding the epistemological challenges of synthesising qualitative evidence, in particular the need to preserve contextual depth and interpretive nuance (Dixon-Woods et al., 2006), QES is increasingly recognised as a valuable tool for informing policy, practices, and future research (Booth et al., 2019; Noyes et al., 2019; Thomas & Harden, 2008), and has gained traction in healthcare research, particularly in exploring patient experiences and perceptions across clinical illness and survivorship contexts (MacDonald et al., 2020; Seers, 2015; Stern et al., 2014). It enables researchers to assess the current state of knowledge, identify gaps, and clarify the contribution of new studies to the broader academic and clinical discourse (Nyanchoka et al., 2019).

Informed by this approach, and as detailed in Chapter 3, this study adopts an interpretivist, hermeneutic phenomenological framework, positing the QES as the first phase in a multi-method exploration of HSCT recipients' experiences of LTFU care in England. By synthesising qualitative evidence, this study aims to address a gap in the literature, generate new insights into the lived realities of HSCT recipients, and contribute to the development of more equitable, person-centred models of care.

### 4.3 Method

This qualitative evidence synthesis was conducted in accordance with methodological guidance of Butler et al. (2016) and Thomas & Harden (2008) and was prospectively registered with PROSPERO (registration number CRD4202132860, see Appendix 16). PROSPERO is an international database of prospectively registered systematic reviews in health and social care, managed by the Centre for Reviews and Dissemination at the University of York and funded by the National Institute for Health and Care Research (NIHR, n.d.). Its purpose is to promote transparency, reduce reporting bias, and prevent duplication and research waste by making review plans publicly accessible prior to execution. Registering a protocol in PROSPERO ensures that the review's objectives, eligibility criteria, and planned methods are clearly defined in advance, thereby supporting reproducibility and accountability in research.

The initial protocol for this review was submitted to PROSPERO on 18 January 2021 and officially registered on 21 January 2021. A minor revision was made in May 2021 due to a change in appointed second supervisor and expected end date. To reflect the completion and journal publication of the review, a final update of the protocol was published in July 2024 (see Appendix 17). The original systematic literature search was conducted in February 2021, followed by a thematic synthesis of three papers. To ensure the review remained current and suitable for publication, the search was repeated in January 2023 using the same protocols and methodology, with the only modification being an expanded search window to include newly published materials.[3] This second search identified one additional study, which, although it did not introduce new findings, served to reinforce the themes identified in the original synthesis.

### *4.3.1 Search Strategy and Conceptual Framework*

The review was designed as a systematic review with qualitative evidence synthesis of HSCT recipients' experiences of LTFU care, with exploratory attention to the possible relationship between LTFU attendance and fear of cancer recurrence (FCR). To support the qualitative nature of the review, the PICo framework (Population, Interest, and Context) was consistently applied throughout the search strategy and inclusion criteria. The Population was defined as HSCT recipients; the Interest focused on dimensions of LTFU care; and the Context included emotional and perceptual aspects such as fear, threat, impact, and perception, which were used to capture elements associated with FCR.

A systematic search of eight databases was conducted using a combination of keywords derived from the review question. Once the keywords were identified, a list of all synonyms was compiled to form search terms based on the PICo framework, a mnemonic designed for qualitative literature searches (Aromataris et al., 2024) (see Table 4.1). PICo was selected instead of an alternative SPIDER framework, which comprises Sample, Phenomenon of Interest, Design, Evaluation, and Research type, to avoid the potential omission of relevant studies. SPIDER has been noted for lower sensitivity in certain contexts (Methley et al., 2014). The eight databases searched were: PsychINFO, Medline, The Allied and Complementary Medicine Database, CINAHL, Psychology and Behavioural Science Collection, Scopus, Embase, and ProQuest Nursing and Allied Health Source. The selection of these databases was strategically guided by the interdisciplinary nature of the review questions, which encompassed health sciences, psychology, behavioural research, and allied health. Together, these databases

[3] The need for a second search and the delay between the original search and submission for publication consideration was due to the unexpected and sudden bereavement of an immediate family member.

supported a comprehensive and methodologically rigorous search strategy, maximising the likelihood of identifying all relevant studies across multiple disciplines and reducing the risk of publication bias. The year parameter was set for articles published from January 2006 to December 2022, in line with the first published recommended screening and preventive practice for HSCT survivors (Rizzo et al., 2006).

| PICo | Population | Interest | Context |
|---|---|---|---|
| Search Terms | 'stem cell transplant*' OR SCT OR HSCT OR 'bone marrow transplant*' OR BMT | 'late effect*' OR late-effect* OR secondary OR 'follow up' OR follow-up OR 'long term' OR long-term OR post-transplant* OR 'post transplant*' OR monitor* OR surviv* | View* OR experience* OR opinion* OR attitude* OR perce* OR belie* OR feel* OR understand* OR threat* OR impact OR influence* OR consequence* OR repercuss* |

**Table 4.1 PICo Search Terms**

Although the PROSPERO registration form follows the Population, Intervention, Comparison, and Outcome (PICO) framework, this review employed PICo to better align with its qualitative focus. Any perceived inconsistency between the registration and the review's design stems from limitations in the PROSPERO template, which does not explicitly accommodate qualitative frameworks. Clarification of scope was informed by peer review feedback received during journal submission for Study 1. Reviewers noted that FCR was not consistently addressed across the included studies and was therefore not sufficiently supported as a central focus, and consequently was constructed as a subordinate theme. Furthermore, feedback prompted a revision of the manuscript title and the adoption of the term "meta-synthesis" for publication. For the purposes of this study, the original design title has been retained to reflect the intended scope and structure. These refinements are reflected in the thesis write-up, as FCR was initially included as a focus and informed the search strategy through its inclusion under the Context element of the PICo framework. Furthermore, this refinement reflects the academic development through critical engagement with peer review feedback, and clarifies how the PICo elements were operationalised and why they may appear inconsistent with the PROSPERO registration format.

### *4.3.2 Inclusion Criteria*

As this systematic review with QES focuses on HSCT recipients' experiences of LTFU care, only studies written in English that examined adult HSCT recipients, who received a stem cell transplant at least 100 days prior to the study and explored experiences specific to LTFU and/or

monitoring impact were included. Limiting the review to English-language studies was a pragmatic decision based on resource constraints, including translation capacity, and although this may introduce language bias, it ensures accurate interpretation and synthesis of qualitative data (Cumpston et al., 2024). The 100-day post-transplant threshold aligns with clinical definitions of the transition from acute to long-term care, ensuring that the studies reflected experiences relevant to LTFU care rather than immediate post-transplant recovery (Majhail et al., 2012; Rotz et al., 2024). The criterion for experiences specific to LTFU and/or monitoring impact ensured that included studies directly addressed the core research question of how recipients experience LTFU care, rather than broader or unrelated aspects of their transplant journey.

Another key inclusion criterion was the use of any qualitative methodological approach, including studies employing mixed-methods designs that incorporated a qualitative component. The rationale for this decision was twofold. Firstly, qualitative research is uniquely positioned to capture the depth and complexity of lived experiences, making it particularly well-suited for exploring the nuanced and subjective perspectives of HSCT recipients regarding LTFU care (Yadav, 2022). Secondly, the inclusion of mixed-methods studies was a strategic choice aimed at broadening the scope and comprehensiveness of the review. Mixed-methods research often includes rich qualitative data, such as interviews, focus groups, or open-ended survey responses, that can be extracted and analysed independently of the quantitative components. Extending the review to mixed-methods studies enable a wider range of relevant literature to be incorporated, thereby enhancing the diversity of perspectives and contextual richness of the findings (Booth et al., 2019).

In addition to meeting the inclusion criteria, studies were excluded based on several specific factors. First, any study that did not present data directly from patients' responses was excluded, as the focus of the review was on capturing patients' own perspectives. Second, studies that concentrated solely on recipients' experiences of the transplant procedure itself, or that focused exclusively on late-effects symptoms, were not considered relevant. Finally, research that explored the experiences of perspectives of healthcare providers, rather than patients, was also excluded. These criteria ensured that the selected studies aligned closely with the objective of understanding recipients' lived experiences in a comprehensive and meaningful way.

### *4.3.3 Search Results*

To ensure transparency and reproducibility of the review process, the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) 2020 guidelines were followed. The PRISMA flow diagram (see Figure 4.1), illustrates the number of records identified, screened, assessed for eligibility, and included in the final synthesis. As recommended by Butler et al. (2016), PRISMA flowchart has been used as a pictorial representation of the search process, even though such diagrams are traditionally applied in meta-analysis. The PRISMA 2020 checklist (see Appendix 18) is also included to provide a comprehensive overview of the review process and ensure alignment with best practice standards (Page et al., 2021).

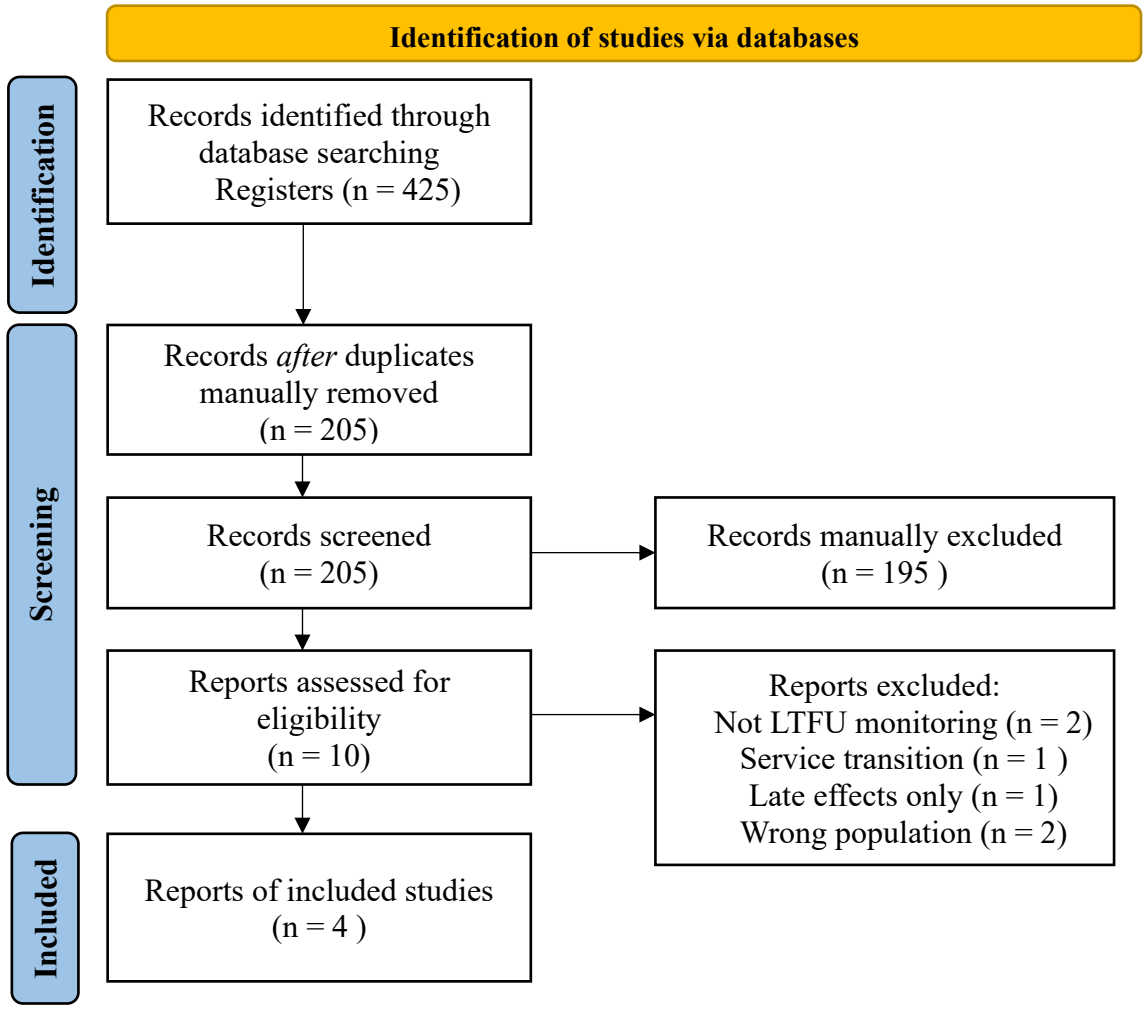


**Figure 4.1 PRISMA 2020 flow diagram (adapted)**

The initial search yielded 425 records. After removing duplicates, 205 unique records remained. The titles and abstracts of 205 papers were screened independently by two reviewers, the primary researcher and first supervisor, using Rayyan, a web-based software tool designed to

assist researchers in conducting systematic review, particularly during the screening and selection of studies (Ouzzani et al., 2016). Developed by the Qatar Computing Research Institute (QCRI), Rayyan helps streamline the review process by allowing users to import references from databases, collaboratively screen titles and abstracts, apply inclusion and exclusion criteria, and filter studies. The number of papers was divided in half; 103 papers were screened by primary researcher and 102 papers by the first supervisor, while the second supervisor was available to resolve any discrepancies, though not required.

Following the screening of the 205 papers, ten were selected for full-text review based on their alignment with the inclusion criteria or the need for further assessment due to insufficient detail at the abstract level. This stage was conducted collaboratively by the primary researcher and first supervisor. Upon completion, six articles were excluded for reasons such as lack of relevance to LTFU care, a focus solely on service transitions or late effects, or inclusion of an inappropriate population (see Appendix 19). Any discrepancies during this stage were resolved through discussion with the second supervisor. Only one minor discrepancy occurred, in relation to the relevance of the study to LTFU care, where the time frame from transplantation was difficult to determine. This multi-reviewer approach aligns with best practice recommendations for qualitative evidence synthesis and supports the credibility and trustworthiness of the findings (Noyes et al., 2018).

### *4.3.4 Eligible Studies*

This qualitative evidence synthesis included four studies that explored HSCT recipients' experiences of LTFU care (see Table 4.2). The studies were selected based on their methodological alignment with the review question and their relevance to the phenomenon of interest. Each study offered rich, contextually-grounded insights into the lived experiences of HSCT recipients, contributing to a diverse and comprehensive evidence base. The studies were conducted in the United States of America (USA) (Hwang et al., 2012), Singapore (Sharin et al., 2020), Germany (Parisek et al., 2021), and the UK (de Vere Hunt et al., 2021), which enabled the identification of both commonalities and context-specific challenges in LTFU care. This diversity enhances the transferability of findings and supports the synthesis in addressing systemic influences on patient experiences, a recognised strength in qualitative research (Flemming et al., 2019; Thomas & Harden, 2008)

| Author(s) / Country | Population | Aim | Method | Themes identified by primary study authors |
|---|---|---|---|---|
| De Vere Hunt et al. (2021). United Kingdom | 8 Allo-HSCT patients (M = 6 / F = 2 ). Age range 46-68 yrs. Mean time since transplant 3 yrs (range 0.25-15 yrs). | Exploration of patient perspective of their HRQOL and experience of service provisions | Qualitative thematic analysis of one-to-one semi-structured interviews. | Themes related to patient experience of the healthcare service provision; Personal care and close relationship with BMT nurses; Efficiency versus long waiting times - 'on the case straight away'; Information provision - *'went into it with a bit of a rosy view'*; The role of support groups |
| Hwang et al. (2012). USA | 22 Allo-HSCT patients (M = 11 / F = 11). Age range 22-69 yrs. Mean time since transplant was 5.2 yrs (range 2.4-8 yrs). | To explore the attitudes of long-term survivors of HSCT about their healthcare use and information needs | Thematic analysis using grounded theory approach. Three focus groups and 12 structured interviews conducted | Late effects; healthcare issues; health education and outreach; personal factors; social factors |
| Parisek et al. (2021). Germany | 32 Allo-HSCT patients (M = 16 / F = 16) and 18 partners. Age range was 25-68 yrs. Mean time since transplant was 2.7 yrs (range 1.2 - 5 yrs). | To explore in-depth HSCT survivors' experiences and needs post-transplant. Partners included to provide further information. | Framework method of analysis of semi-structured telephone interviews. | Diversity of long-term treatment side-effects as a major challenge in Allo-HSCT survivorship care; Time post discharge as a dynamic process with individual peaks of burden; Transparent communication and support with patient empowerment; Continuity in the care system and help with claiming social benefits as cornerstones of optimal survivorship care |
| Sharin et al. (2020). Singapore | 8 patients (1 auto & 7 Allo-HSCT) (M = 3 / F = 5). Age range 27-67 yrs. Mean time since transplant was 8.13 yrs (range 4-20 yrs). | To explore the experiences of HSCT survivors attending a long-term follow-up clinic | Qualitative thematic analysis of one-to-one semi-structured interviews. | Comprehending the experiences; acknowledging the meaningfulness of the experience; managing threats to a new life after transplant |

**Table 4.2 Systematic Review Summary of Included Studies.**
M, Male; F, Female; Allo, allogeneic HSCT; Auto, autologous HSCT; yrs, year

Across the four studies, seventy HSCT recipients were included, comprising sixty-nine allogeneic and one autologous HSCT recipient. The gender distribution was relatively balanced (34 females and 36 males), with participants aged between 22 and 69 years. The mean time since transplant ranged from 2.7 to 8.13 years, with an overall span of 0.25 to 20 years. Each study employed a qualitative methodology appropriate to its aims, including thematic analysis, grounded theory, and framework analysis. Interviews and focus groups were used to elicit nuanced patient experiences, consistent with best practice in qualitative synthesis (Booth et al., 2019; Noyes et al., 2018). The inclusion of studies from different healthcare systems also allowed for comparative insights into service provision and survivorship care models.

The studies varied in focus, with some addressing general survivorship experiences and others exploring health-related quality of life (HRQOL), service provision, and psychosocial needs. This heterogeneity was managed through thematic synthesis, enabling the abstraction of higher-order themes that transcend individual study contexts (Barnett-Page & Thomas, 2009; Noblit & Hare, 1988). The inclusion of mixed-methods studies with a qualitative component was a deliberate strategy to broaden the scope of the synthesis and capture a wider range of patient perspectives. However, none of the studies that met the inclusion criteria employed a mixed-methods design. This approach is supported by methodological literature, which emphasises the value of integrating qualitative data from diverse study designs to enhance the richness and depth of findings (MacDonald et al., 2020). Collectively, the eligible studies provided a robust and diverse evidence base for exploring recipients' experiences of LTFU care

### *4.3.5 Critical Appraisal*

To ensure the methodological integrity and relevance of the eligible studies of this review, a critical appraisal was conducted using the Critical Appraisal Skills Programme (CASP) tool for qualitative research (CASP, 2018). The CASP framework offers a structured and reflexive approach to evaluating qualitative studies, focusing on domains such as clarity of research aims, appropriateness of methodology, rigour of data collection and analysis, ethical considerations, and the value of the findings. The appraisal was carried out independently by the primary researcher and an academic peer, with any discrepancies resolved through discussion. This dual-review process aligns with best practice recommendations for qualitative evidence synthesis and supports the credibility and trustworthiness of the findings (Noyes et al., 2018). All four studies met the criteria for inclusion, achieving full scores across the CASP domains. Each study demonstrated methodological rigour, transparency, and relevance to the review question. Table 4.3 summarises each study's assessment against the ten CASP screening questions.

| Author/ Year | Critical Appraisal Skills Tool Screening Questions | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| | 1. Was there a clear statement of the aims of the research? | 2. Is qualitative methodology appropriate? | 3. Was the research design appropriate to address the aims of the research? | 4. Was the recruitment strategy appropriate to the aims of the research? | 5. Was the data collected in a way that addressed the research issue? | 6. Has the relationship between the researcher and participant been adequately considered? | 7. Have ethical issues been taken into consideratio n? | 8. Was the data analysis sufficiently rigorous? | 9. Is there a clear statement of findings? | 10. How valuable is the research? |
| de Vere Hunt *et al*. (2021) | Yes - statement provided on p. 2 | Yes - as explored subjective experiences | Discussion given to the application of qualitative method | Full details provided / recruited from GvHD clinic | Full details provided / in person interviews | Specific researcher and clinical roles identified | Statement of ethical board approval provided on p. 2 | Discussion of TA analysis provided | Findings are explicit, and thoroughly discussed | Valuable – to clinical practice and healthcare coordination |
| Hwang *et al*. (2012) | Yes - statement provided on p. 344 | Yes - as explored subjective attitudes and needs | Identified surveys/RCT insufficient to meet aim. | Full details provided / Recruited from SCT registry | Full details provided / Choice of focus group or interview | Moderators with no prior relationship employed | Statement of ethical board approval provided on p. 345 | Clear and detailed explanation of TA provided | Findings are explicit, and thoroughly discussed | Valuable – to clinical practice and tailored care plans |
| Parisek *et al*. (2021) | Yes - statement provided on p. 3 | Yes - as explored subjective experiences and needs | Discussed insufficient studies exploring HSCT exp. | Full details provided / Recruited from LTFU clinic | Full details provided / choice of in person or telephone interviews | Yes, and the Interview guide formed by team and the literature | Statement of ethical board approval provided on p. 3 | Detailed discussion of framework analysis provided | Findings are explicit, and thoroughly discussed | Valuable – statement of clinical implications provided. |
| Sharin *et al*. (2020) | Yes - statement provided on p. 4276 | Yes - as explored subjective experiences and needs | Theoretical underpinning /justification of method provided | Full details provided / Recruited from LTFU clinic | Full details provided / in person interviews | Researchers not part of the LTFU team | Statement of ethical board approval provided on p. 4277 | Discussion of TA analysis provided | Findings are explicit, and thoroughly discussed | Valuable – nurses' key role in managing QOL & GvHD |

**Table 4.3 CASP Assessment of Included Studies.**

RCT, Randomised Control Trials; SCT, Stem Cell Transplant; TA, Thematic Analysis; Exp, experiences; GvHD, graft-verse-host disease; QOL, Quality of Life

While the CASP tool is widely used in qualitative research, its application in evidence synthesis requires a reflexive and context-sensitive approach. Braun and Clarke (2022) emphasise that appraisal tools should not be applied in a rigid or automatic manner but rather used to support critical engagement with the research process. In this synthesis, the CASP assessments were not used to rank or exclude studies based on numerical scoring alone but to ensure that each study demonstrated sufficient transparency, coherence, and relevance to the phenomenon of interest. This approach reflects a growing consensus in qualitative research that appraisal should be integrated into the interpretive process rather than treated as a separate evaluative step (Carroll et al., 2011; Flemming et al., 2019). This interpretive process refers to the reflective and context-sensitive engagement with each study's methodological and conceptual contributions, rather than applying appraisal criteria as a rigid checklist. Incorporating appraisal into the broader synthesis framework ensures that the findings are grounded in robust and credible evidence, while also acknowledging the interpretive nature of qualitative inquiry.

#### *4.3.6 Data Extraction and Analysis*

To ensure the robustness and credibility of the thematic synthesis, all eligible studies were read multiple times to facilitate deep familiarisation with the data and to enhance the accuracy of coding and theme development. This iterative reading process is a recognised strategy in qualitative research to ensure that nuanced meanings and patterns are not overlooked (Braun & Clarke, 2006). During each reading, findings that specifically related to participants' experiences of LTFU care were highlighted and abstracted into a structured data extraction form (see Appendix 20 for an example). To enhance the trustworthiness of the extracted data and reduce interpretive bias, the completed extraction form was peer-reviewed by a fellow postgraduate student and healthcare professional. This dual-review approach aligns with best practices in qualitative evidence synthesis, where peer validation is recommended to ensure interpretive consistency and to identify any potentially overlooked findings (Barnett-Page & Thomas, 2009). The peer review process also supports methodological transparency and strengthens the credibility of the synthesis by incorporating diverse professional perspectives (McCashin & Murphy, 2023). In addition, the use of a structured extraction form facilitated consistency across studies and supported the systematic organisation of first- and second-order constructs, which is essential for developing meaningful analytical themes (Tong et al., 2012).

The data extraction and analysis followed the thematic synthesis approach outlined by Thomas and Harden (2008), which is widely used in qualitative evidence synthesis for its transparency and adaptability (Gough et al., 2012). The eligible studies were uploaded into MAXQDA

(MAXimum Qualitative Data Analysis), a computer-assisted qualitative data analysis software tool designed to support systematic coding, theme development, and data organisation across qualitative datasets (Kuckartz & Rädiker, 2019). All text labelled as 'results' or 'findings' was examined line by line for meaning and content by the primary researcher and a fellow postgraduate student. Free codes were generated without hierarchical structure and included both direct participants quotes (first-order constructs) and the original authors' interpretation (second-order constructs). This open coding process was iterative and interpretive, allowing for the identification of recurring patterns and concepts across studies. To ensure that all relevant experiences of LTFU care were captured, the studies were revisited multiple times and discussed at length between reviewers. This collaborative approach reflects the importance of reflexivity and dialogue in qualitative analysis, as recommended by Braun and Clarke (2022), and supports the development of a coherent and credible synthesis.

Following the generation of free codes, related codes were grouped into descriptive themes that captured the underlying meaning of participants' experiences. These descriptive themes were then synthesised into higher-level analytical themes that extended beyond the findings of the primary studies to offer new insights into the participants' experiences of LTFU care (third-order construct). This process of abstraction is central to thematic synthesis and allows for the development of concepts that are transferable across contexts (Noblit & Hare, 1988; Thomas & Harden, 2008). Any interpretive disagreements were discussed and resolved with the second thesis supervisor. This was only required once during the process and concerned the interpretation of a participant's quote regarding whether the care described was provided by nurses or consultants. The resolution of this disagreement through supervisory dialogue reflects the importance of triangulation and collaborative interpretation in qualitative research (Nowell et al., 2017). Overall, the analytical process was designed to ensure methodological rigour, transparency, and depth, thereby enhancing the credibility and relevance of the review findings.

### *4.3.7 Assessing Qualitative Findings Confidence*

To determine the overall confidence in the findings of this synthesis, the Grading of Recommendations Assessment, Development and Evaluation - Confidence in the Evidence from Reviews of Qualitative Research (GRADE-CERQual) approach was applied (Colvin et al., 2018; Glenton et al., 2018; Lewin, Bohren, et al., 2018; Lewin, Booth, et al., 2018; Munthe-Kaas et al., 2018; Noyes et al., 2018). This approach was developed to support and strengthen the use of qualitative evidence in decision-making by providing a transparent and systematic method for assessing how much confidence can be placed in individual review findings (Lewin,

Booth, et al., 2018). GRADE-CERQual evaluates four key components: methodological limitations, coherence, adequacy of data, and relevance. These components are considered in relation to each review finding, and an overall assessment is made regarding the level of confidence, which can be rated as very low, low, moderate or high. These rating reflect the likelihood that a review finding is a reasonable representation of the phenomenon of interest (Lewin, Booth, et al., 2018).

In this study, the first and second reviewers independently assessed each of the four synthesised themes using the GRADE-CERQual framework. Each component was discussed in turn, and agreement was reached on the overall confidence rating for each theme. High confidence was determined for theme one, *"[It's] important to maintain good relationship with the nurses and doctors"* and theme two, *"There's always the thing about the logistics"*. These findings were supported by data from all four included studies and demonstrated minimal concerns across all four CERQual components. Theme three, *"Small print after the event and the broad brushstrokes beforehand"*, and theme four; *"Once you have cancer, you're always thinking do I have it again?"* were assessed as having moderate confidence. These ratings reflected minor concerns regarding relevance and coherence in one of the contributing studies. Table 4.4 provides a summary of the CERQual assessments for each theme. The application of GRADE-CERQual in this synthesis enhances the transparency and credibility of the findings and supports their use in informing future research and practice related to LTFU care for HSCT recipients.

| Objective: To explore and synthesise the qualitative evidence pertaining to HSCT recipients' experiences of LTFU care. | | | |
|---|---|---|---|
| Summary of review findings | Studies | CERQual confidence | Explanation of CERQual assessment |
| ***1. "[It's] important to maintain good relationship with the nurses and doctors"***: Patients establishing relationships with clinical personnel was seen as a crucial element to receiving personal and attentive care, as well as maintaining health | Hwang *et al*. (2012)<br>Parisek *et al*. (2021)<br>Sharin *et al*. (2020)<br>de Vere Hunt *et al*. (2021) | High Confidence | Four studies with no or very minor concerns about coherence, relevance, adequacy, and methodological limitations. |
| ***2. "There's always the thing about the logistics"***: Patients identified several logistical problems with attending monitoring clinic appointments, such as, delays, length, frequency, and financial consequences. | Hwang *et al*. (2012)<br>Parisek *et al*. (2021)<br>Sharin *et al*. (2020)<br>de Vere Hunt *et al*. (2021) | High Confidence | Four studies with no or very minor concerns about coherence, relevance, adequacy, and methodological limitations. |
| ***3. "Small print after the event and the broad brushstrokes beforehand"***: The understanding of long-term monitoring being a critical and burdensome part of the care trajectory was only realised by some patients' post-transplant. | Hwang *et al*. (2012)<br>Parisek *et al*. (2021)<br>de Vere Hunt *et al*. (2021) | Moderate Confidence | Two studies with no or very minor concerns about coherence, relevance, adequacy, and methodological limitations. One study with no or very minor concerns about, adequacy, methodological limitations and coherence but a minor concern with relevance |
| ***4. "Once you have cancer, you're always thinking do I have it again?"***: Patients reported a fear of recurrence and uncertainty of the future, feelings of which were associated with monitoring practice. | Hwang *et al*. (2012)<br>Parisek *et al*. (2021)<br>Sharin *et al*. (2020) | Moderate Confidence | Two studies with no or very minor concerns about coherence, relevance, adequacy, and methodological limitations. One study with no or very minor concerns about, relevance, adequacy, and methodological limitations but a minor concern with coherence. |

**Table 4.4 CERQual Summary of Qualitative Findings**

### 4.4 Findings

The synthesis of study findings identified four themes regarding recipients' experiences of LTFU care (see Figure 4.2). These themes reflect the diverse, although interconnected, ways in which recipients experience LTFU care. They encompass relational, logistical, informational, and emotional dimensions, as captured in the following four themes: "[It's] important to maintain a good relationship with the nurses and doctors"; "There's always the thing about the logistics"; "Small print after the event and the broad brushstrokes beforehand"; and "Once you have cancer, you're always thinking do I have it again?"


**Figure 4.2 Synthesis of findings - Recipients' Experiences of LTFU Care**

#### *4.4.1 "[It's] important to maintain a good relationship with the nurses and doctors"*

Maintaining close relationships with clinical personnel was central to recipients' experiences of LTFU care. This was seen as a key element in receiving personal and attentive care, as well as in supporting ongoing health. Direct contact with staff who were familiar with recipients' medical histories was both comforting and contributed to clinical efficiency, in contrast to having to repeatedly relay their history to new staff. The need to strengthen these relationships became more pronounced over time. Recipients trusted the guidance of clinical personnel and valued them as a source of information, especially liaison nurses in outpatient care.

> *You see… how important to maintain a good relationship with others who care for you, even the nurses and doctors.* (Sharin et al., 2020)

> *Having those individual contacts rather than, you know, just ring up and you'll get a team cos it happens every time. You know, cos otherwise... every time, you know, you're explaining your problem and your history over and over again, whereas... the individuals get to know you and remember your history.* (de Vere Hunt et al., 2021)

> *I really have to praise it - this wonderful system of building a bridge between hospital care and care at home. There is someone who takes the time to tell us what to look out for at home.* (de Vere Hunt et al., 2021)

While the importance of patient-provider relationships was widely recognised, participants frequently distinguished between nurse-patient and doctor-patient relationships. Establishing close relationships and having direct contact with clinical liaison nurses was associated with ongoing clinical support and reassurance. Nurses were seen as the primary facilitators of efficient patient care and as key communicators among healthcare professionals.

> *You always have the feeling that you can call the team of liaison nurses if you need to.* (Parisek et al., 2021)

> *I've had ready access to XXX, the post-transplant nurse co-ordinator, and she's been very good; seems very knowledgeable and very encouraging... I think that it's probably the availability of XXX on the end of the phone that… you can have a friendly voice that knows you, so I think a personal relationship is important. And the fact that she has access to all of the other colleagues that she can then go and speak to and get back to me. So, she has been really helpful as an access to information.* (de Vere Hunt et al., 2021)

In contrast, relationships with clinical doctors were typically associated with receiving health information during scheduled appointments, rather than facilitating health needs between visits. This contributed to patients' confidence that their health was being monitored, encouraged proactive engagement with their care, and provided comfort.

> *I had a fabulous oncologist, and I had her sit down and explain everything—the side effects, the AML [acute myelogenous leukaemia]—just explain it to me where I can understand it.* (Hwang et al., 2012)

> *I've had situations where one of the consultants has called me several times after the clinic appointment once he's had a look at my bloods and things… in fact one of them phone me only this morning to make sure that an adjustment to made to the meds yesterday was going ok.* (de Vere Hunt et al., 2021)

However, building relationships with clinicians was sometimes hindered by not seeing the same clinician at each visit. Additionally, when clinicians were not specialists, many patients felt that they were less informed or less able to address their needs.

> *Every time I build a relationship with a doctor they leave soon after. It is really annoying. Because you always talk a bit about yourself. First, the doctor is a stranger to you, then, during the second visit, you start to get to know them, and again during the third visit, and when you want to meet them for the fourth time they are gone.* (Parisek et al., 2021)

> *I feel very comfortable [with the cancer specialists] like they really do care about you. [O]ne year I got real sick, and I ended up going to a [non-cancer specialist]. And they made me feel like they weren't solving the problem.* (Hwang et al., 2012)

Overall, recipients' experiences highlighted that maintaining close relationships with clinical personnel was central to receiving attentive and efficient care. While recipients appreciated the care provided by both nurses and clinicians, the opportunity for physical attendance also contributed to their experiences. See Appendix 21 for first-order construct (patients' experience) and the original authors' interpretation of the findings (second order construct) that informed this theme.

#### *4.4.2 "There's always the thing about the logistics"*

Patients' experiences of LTFU care were shaped by a range of logistical factors. While some recipients expressed satisfaction with the organisation and structure of clinics, others identified several practical problems. In one study, patients described long waiting periods at clinical appointments or with associated services such as haematology and pharmacy. However, sympathy for busy staff and the urgent needs of other patients often mitigated their frustration.

*I've been impressed basically in terms of, you know, efficiency... it all seems to be, you know, well organised, efficient, or reasonably efficient when I go, you know, you're never seen exactly on time but, you know, you do get seen... people do spend time with you… from my point of view it seems to work quite well; very well, not just quite well; very well.* (de Vere Hunt et al., 2021)

*Occasionally, it doesn't happen very often now, but there are occasions where it is a long wait… But then I know that when I was poorly I had the attention of my consultant… there was no rush if you know what I mean, so I appreciate that there would be someone somewhere in with somebody who's very poorly and is taking a long time more, which I understand.* (de Vere Hunt et al., 2021)

Other recipients reported struggling with the length and frequency of appointments, which often required them to commit to a full day at the hospital. This resulted in prolonged absences from work and made it difficult to plan other meaningful activities.

*I see my [eye doctor and a doctor for] GvHD... [Appointments] pile up during the day…I'm here from 8:00 in the morning until 4:00 in the afternoon... [Y]ou just get tired of waiting and sitting.* (Hwang et al., 2012)

*Got to wait quite a long time, and then even after seeing the doctor got to wait for pharmacy… It's really waste XXX all day because it's the middles of the part of the day is in the hospital, so it's really you can't do anything that day.* (de Vere Hunt et al., 2021)

The frequency of appointments also had financial implications for some patients, leading them to question the necessity of certain visits. Despite these concerns, many accepted the costs as part of maintaining their health.

*Having to go to the doctor so many times… my out-of-pocket spending is just so much.* (Hwang et al., 2012)

*All these appointments are not cheap. It is very expensive. If having more appointments as the days goes by, it means the expenses will be more for us. Sometimes I even ask them whether it is important for these appointments. I understand all these, I need to spend.* (Sharin et al., 2020)

Despite delays and financial issues, some patients reported that clinics organised as multidisciplinary service responded quickly to their concerns, especially regarding GvHD. Quick referrals and appointment access provided reassurance and streamlined the process.

> *The once that I asked to see a dermatologist, I was able to see her that same day, so that was reassuring.* (de Vere Hunt et al., 2021)

However, communication issues between monitoring clinics and other medical departments, including general practitioners' (GPs) and accident and emergency care (A&E), were also reported. Patients perceived that other departments and charitable organisations often lacked the medical knowledge and experience needed to address the long-term consequences of HSCT, which sometimes intensified feelings of abandonment.

> *Involving the patient's GP [=is important]. They should set aside an hour or two between the GP and the specialist. The GP is the extended arm [=of the specialist]. Aren't they? This would not cost a lot… that they know exactly what they are doing.* (Parisek et al., 2021)

> *I'll call cancer care and I'll Google the cancer patient resources. There is help, but only for people in treatment. It's like they've forgotten the people after they've survived.* (Hwang et al., 2012)

In summary, recipients' experience of LTFU care were associated with several logistical issues. While these challenges could be frustrating, there was also a level of acceptance that the inconvenience was part of the process, especially when the reasons for ongoing monitoring were understood. See Appendix 22. for the first-order constructs (patients' experiences) and the original authors' interpretations of the findings (second-order constructs) that informed this theme.

#### *4.4.3 "Small print after the event and the broad brushstrokes before-hand"*

Despite being informed about the complex nature of HSCT transplantation and its potential complications, some recipients felt unprepared for the extent and intensity of the late effects. For some, the realisation of the impact of late effects only emerged during recovery, after transplantation had taken place.

*I have to admit, I did not expect the treatment complications.* (Parisek et al., 2021)

*Was a totally new experience to acknowledge or to learn to acknowledge that you are not cured but that the process of healing was continuing and that the time after the transplant was a very important time.* (Parisek et al., 2021)

Recipients' awareness and understanding of long-term complications were closely linked to the information they received, which varied across studies. Some participants felt that they had received sufficient information and had opportunities to discuss any questions. Others noted that information provision focused more on the transplant and its immediate impact, with less emphasis on long-term consequences. For some, additional information was provided after transplant, and this delayed approach was appreciated.

*So, the information I was given, the leaflet or booklet like GvHD, was very good and I read carefully, and if I don't understand or have a question, so I ask the doctor and things like that. So, didn't really much problem I had. (*de Vere Hunt et al., 2021)

*I think that it was certainly mentioned but not stressed, and I think that I probably had sufficient information. I think once I had had the transplant then interestingly, I was given the book… So, in some ways I feel a bit as though I was given the small print after the event and the broad brushstrokes before-hand.* (de Vere Hunt et al., 2021)

Information needs and preferences were highly individual. Some patients wanted to know more about the spectrum of potential late effects, including the implications of long-term treatment. Others preferred only essential information, feeling that knowing all possible risks to future health would cause unnecessary worry. For others, receiving more information would have helped reduce anxiety associated with uncertainty about what to expect.

*[I would] like information about … life expectancy–I guess taking–like my medications, how many years can I take it without doing damage to my body. (Hwang et al., 2012)*

*It's a very personal thing [=information needs and preferences]. Everybody is different. Clearly there are things I need to know. But there are also things when I think, just leave them. I don't want to know. Yes, I would worry too much.* (Parisek et al., 2021)

*[S]ometimes, the less you know, the less you worry.* (Hwang et al., 2012)

*I think we could have been given more information just as to what to expect… In actual fact, it wasn't as bad as I thought it was going to be...They told me everything that was going to happen to me when the stem cells went in, and they were right about that, but that little bit afterwards I think I could have maybe done with a little bit more information just to ... to sort of like put my mind at rest as to know what to expect because it was an unknown quantity.* (de Vere Hunt et al., 2021)

Other recipients reported feeling overwhelmed by the volume of information, which sometimes affected their ability to adhere to the advice. There was a general need for explanations about why certain recommendations were made, particularly regarding health behaviours, rather than simply being told what monitoring or surveillance was required.

*You get so much information that you cannot really understand what has just happened. The first information came like a landslide.* (Parisek et al., 2021)

*Maybe not just what you shouldn't do, but also an explanation why [certain things should be done] would be good.* (Parisek et al., 2021)

Variation in recipients' awareness and understanding of potential long-term complications shaped their experiences of LTFU care, particularly regarding screening practices. See Appendix 23 for the first-order constructs (patients' experiences) and the original authors' interpretations of the findings (second-order constructs) that informed this theme.

#### *4.4.4 "Once you have cancer, you're always thinking do I have it again?"*

Concerns about late complications and the possibility of cancer recurrence were a persistent feature of recipients' experiences of LTFU care. Participants described a heightened need to maintain control over their health, which led to increased vigilance around attending follow-up appointments and participating in recommended screening practices.

*After your transplant, when it's time to go for follow-up you go. It's important not to forget your appointment…When the doctor says six months, I say okay.* (Sharin et al., 2020)

For some recipients, regular screening provided reassurance and a sense of safety, helping them to feel that their health was being actively monitored. However, for others, the fear of recurrence was not alleviated by screening; instead, it fuelled a sense that no amount of monitoring was ever truly enough. This ongoing anxiety meant then even when following medical advice, some recipients continued to worry about the possibility of relapse of new complications.

> *If you did less [screening], you'll always have that in your head, '[Do] I have something?' Once you have cancer you're always thinking ...do I have it again.* (Hwang et al., 2012)

Interactions with healthcare professionals during screening could also be a source of distress. The way clinicians communicated test results, especially when speaking in technical terms or thinking out loud, sometimes led recipients to interpret uncertainty or further investigations as signs of bad news, intensifying their anxiety.

> *The ultrasound image showed up something on my thyroid. And then they [the treating clinician] say to you: 'Well, we'll definitely have to investigate that….' And my reaction was: danger, danger, danger!* (Parisek et al., 2021)

For many, the threat of cancer recurrence became an ever-present aspect of life after transplantation. This fear was not always at the forefront, but it lingered in the background, shaping how recipients thought about their health and future. The unpredictability of late complications and the uncertainty about long-term outcomes contributed to a sense of pessimism for some, who felt that relapse was inevitable and struggled to move beyond the shadow of their diagnosis.

> *I am quite pessimistic. I feel like a relapse is inevitable. It is just a matter of time… It haunts me.* (Sharin et al., 2020)

Awareness of potential long-term complications often heightened recipients' engagement with monitoring and self-care, but it could also reinforce the cycle of worry and hypervigilance. For some, this meant that the process of follow-up care was not only about physical health, but also about managing ongoing psychological challenges. See Appendix 24 for the first-order constructs (patients' experiences) and the original authors' interpretations of the findings (second-order constructs) that informed this theme.

### 4.5 Discussion

This qualitative evidence synthesis provides the first known systematic review of qualitative studies exploring the experiences of HSCT patients attending LTFU care. The findings highlight that relationships with healthcare professionals and the logistical arrangements of care play a central role in shaping recipients' experiences. Some recipients reported a lack of awareness or full understanding of the potential long-term implications of HSCT, which left them feeling unprepared for the monitoring process. While attending LTFU clinics and participating in screening activities was reassuring for some, others found it problematic due to concerns, worry or fear of cancer recurrence (FCR).

A central theme was the perception that clinical liaison nurses act as primary facilitators of care and as the main communicators between healthcare professionals. Establishing close relationships with clinical personnel was essential for maintaining clinical support. Participants appreciated and were reassured by having direct contact with nurse specialists, whom they could approach with any concerns or questions about their health. This efficient and attentive care suggests that participants rely on nurses for clinical support, reinforcing the perceived importance of the patient-nurse relationship. This perception is supported by the literature, which recognises nurses as central to providing and maintaining quality of care post-cancer treatment (Corcoran et al., 2015; McCaughan et al., 2021). Within cancer care and survivorship, nurses often manage multiple care services and are seen as treatment managers as well as healthcare providers (Baskin et al., 2023).

It remains unclear from this review whether participants' reliance on liaison nurses diminishes as time from transplant increases. This reliance may be influenced by the clinical management structure rather than solely by the relationship itself. For example, clinicians in LTFU clinics reportedly spend less than one-third of their time on HSCT-related tasks (Nivision-Smith et al., 2018), despite clinics being predominately clinician-led (Dignan et al., 2021). Nevertheless, the need to maintain relationships with LTFU clinical personnel suggests that participants may view clinics as primary care providers, a finding that reflects the shifting boundaries between specialists and primary care described in the literature (Dignan et al., 2021; Tichelli et al., 2021a).

Primary care providers, such as general practitioners (GPs), are the *front door* to NHS services and the initial point of contact for individuals seeking medical advice or services (NHS, n.d.-b). If participants perceive LTFU clinics as their primary care providers, this may become

problematic as the number of HSCT survivors increases (Majhail et al., 2013). HSCT centre accreditation standards require centres to retain responsibility for recipients LTFU care (FACT-JACIE, 2021), meaning recipients are never fully discharged from transplant centre clinical care. As the number of LTFU service users grow, so too may the burden on transplant clinics to deliver personalised care. Whilst clinics currently offer personal and attentive care to HSCT recipients, this may not be sustainable in the future. The implementation of dual LTFU approaches with primary care providers may be a strategy to reduce clinical burden, as highlighted in recent studies (Dignan et al., 2021; Tichelli et al., 2021a).

Several HSCT centres offer a dual approach to LTFU care, sharing responsibility between the transplant centre and primary care providers (Dignan et al., 2021). Clinicians report this as advantageous, as it allows them to focus on the needs of recipients currently undergoing transplant or within the acute phase of recovery (Greenfield et al., 2009). However, from the participants' perspective, healthcare services outside of the transplant centre often lack sufficient knowledge and expertise to manage their needs, making transplant clinical personnel the preferred provider of LTFU care. GPs themselves report barriers to delivering LTFU care post-HSCT, including insufficient resources, time, and awareness of screening and prevention guidance (Mani et al., 2020). Whilst primary care providers express a general willingness to provide LTFU cancer care (Eikeland et al., 2022; Liemburg et al., 2022), research suggests reluctance to monitor HSCT-related medical and cancer screening requirements (Mani et al., 2020). This reluctance, combined with participants' perceptions of primary care providers' ability, suggests an educational need exists as evidenced by previous research (Eikeland et al., 2022; Mani et al., 2020).

Transplant centres adopting a dual approach to LTFU care may encounter challenges due to insufficient communication between clinics, GPs, and accident and emergency (A&E) departments, as reported by participants. These communication barriers can prevent participants' needs from being met or may intensify feelings of abandonment. This observation aligns with wider literature, which demonstrates that poor communication in healthcare is associated with adverse outcomes, including patient dissatisfaction and discontinuity of care (Vermeir et al., 2015). Given that the primary studies included in this review originated from different countries with varying healthcare systems, it remains unclear whether these communication barriers are universal or localised. Further research conducted within a single national context (such as England), would help clarify whether these issues are inherent to the structure of the healthcare system or more broadly experienced.

Exploring recipients' experiences within the same demographic and healthcare setting would provide a greater insight into communication barriers specific to national healthcare structures, ensuring that recipients' needs are met. Highlighting areas for improvement, as well as enabling comparisons between those monitored by primary healthcare providers and those followed directly by transplant centres. It is also important to note that communication concerns identified in this review were not limited to interdepartmental exchange and they extended to other aspects of the participant's journey. This included issues such as unclear or inconsistent information provided to recipients, difficulties in understanding follow-up requirements, lack of continuity when seeing different clinicians, and recipients feeling excluded from decision-making or unsupported during transitions between phases of care.

While heterogeneous in its findings, some participants of this review report a lack of awareness and understanding of the long-term complications associated with HSCT and the monitoring practices of LTFU care. This was correlated with the information they received, which was often focused more on the transplant procedure and immediate risks than on the potential long-term complications. For some, this was sufficient and an appropriate amount of information to maintain their health and well-being, but others wanted more information about the longer-term implications of treatment. This finding suggests that there is an unmet informational need for some recipients, which aligns with the literature on unmet information needs among HSCT recipients following transplantation (Hahn et al., 2017; Yanling et al., 2023).

However, the specific nature of the unmet informational needs remains unclear, beyond a general desire for more information regarding the potential long-term complications. The findings of this study support recommendations that HSCT providers should increase recipients' awareness of the potential long-term complications (Giaccone et al., 2020). As lower informational need has been associated with improved quality of life (QOL) and reduced anxiety and depression among cancer survivors (Vetsch et al., 2017). The findings of this review also support the findings of Eheman et al. (2009), that patients have different information seeking needs, with some participants actively avoiding information. Clinicians should therefore be mindful and attuned to recipients' specific needs and manage information provisions accordingly.

Another notable finding was the variability in how monitoring practices impact fear of cancer recurrence (FCR), particularly regarding the number of screening tests undertaken. Some participants felt reassured by the amount of screening, while others believed their FCR was

exacerbated by insufficient screening. FCR was also influenced by clinicians' communication following the tests. These findings are comparable to those in breast and ovarian cancer survivors, who found attending monitoring clinics as both reassuring and anxiety-provoking (Kyriacou et al., 2017; Stark et al., 2004). FCR is a major unmet need among cancer survivors (Bergerot et al., 2022), particularly in relation to anxiety and worry HSCT patients report experiencing between LTFU visits (Austin-Ketch & Paplham, 2015).

Given the increased risk of treatment-related mortality and HSCT recipients' heightened awareness of late complications, attentional bias may explain the impact on FCR (Custers et al., 2015; King et al., 2024). Hypervigilance to negative health symptoms and physical concerns is associated with increased and sometimes improper use of healthcare services (Vachon et al., 2021), and greater observance of screening practices is linked to higher FCR (Ozga et al., 2015). However, a study of 335 allogeneic HSCT recipients found no mean differences in FCR between those who did or did not attend recommended screening, despite 95% of survivors reporting living with moderate (84%) to severe (11%) FCR. The only significant difference in FCR score was found in female participants who had not attended a cervical smear post-transplant (Brice et al., 2020). The relationship between FCR and LTFU screening practices is complex and given the paucity of research in this area (Reed et al., 2021), it is unclear if screening attendance or avoidance causes FCR or results from it. While the findings of this review suggest a weak connection between LTFU monitoring and FCR, further research is required to understand the relationship in its entirety.

Regardless of causation, FCR heightens the importance of LTFU attendance for some participants and influences their need to control their health. While health-promoting behaviours (e.g., healthy diet, weight management, not smoking, moderate alcohol use, avoiding excessive sun exposure) are within patients' control, a study of 664 HSCT survivors found no significant improvement in health behaviours after treatment (Bishop et al., 2010). HSCT recipients were less likely to participate in positive health behaviours such as physical activity (Kirsch et al., 2014), and those engaging in negative health behaviours were more likely to experience FCR (Fisher et al., 2016). Although HSCT may provide a "teachable moment" for behaviour change (Demark-Wahnefried et al., 2005; Rabin et al., 2009), research suggests that neither the event itself nor FCR is sufficient to bring about change (McBride et al., 2008; Williams et al., 2013). Teachable moments may need to be actively created by clinical personnel during consultation (Williams et al., 2013). Effective management of FCR is associated with improved quality of life, and recommendations included educational and support programs both

prior to and post HSCT, as well as screening for FCR at LTFU appointments (Brice et al., 2020). However, studies report insufficient access to psychological support in HSCT centres (Dignan et al., 2021; Hashmi et al., 2018; Salooja et al., 2016), and therefore, recipients may not have received the appropriate support to mitigate FCR impact. While this review highlights recipients' perceived need to control health, what this entails and its relationship with FCR and the educational support remains unclear, warranting further research.

As the first review exploring the experiences of HSCT recipients attending long-term monitoring clinics, this study has several strengths, including moderate to high confidence in the findings and a reproducible search strategy. Nonetheless, the findings are limited by the paucity of research in this area. Given the primary studies included in this review were conducted in different countries with varying healthcare structures, the findings may not fully reflect recipients' experiences within specific healthcare settings. In England, for example, healthcare is funded through taxation and national insurance contributions, and patients are not required to pay directly or obtain insurance. Thus, the financial implications of attending LTFU care found in this review may not be applicable for HSCT recipients in England. Furthermore, cervical and mammogram screening for HSCT recipients in England relies on national screening programmes, which recipients cannot control. This has been identified as problematic, especially for recipients needing screening outside the remit of the national programmes (Dignan et al., 2021). Therefore, findings related to screening practices and FCR cannot be conclusively stated as representative of recipients' experiences in England, particularly as only one included study was conducted in the UK, and theme four ("once you have cancer, you're always thinking do I have it again") was based on studies from the USA, Germany and Singapore.

The UK-based study (de Vere Hunt et al., 2021) contributed to the first three themes: maintaining clinical relationships (theme 1), logistic implications (theme 2) and informational needs (theme 3). However, it is important to note that participants in this study were recruited from a clinic dedicated to monitoring graft versus host disease (GvHD). As GVHD is both a leading risk factor for recurrence-related mortality and frequent long-term complication in allogeneic HSCT recipients (Bhatia et al., 2021), these recipients were likely under more intensive and ongoing clinical active care. This heightened level of monitoring and the complexity of their condition may have increased their awareness of the importance of maintaining strong clinical relationships and logistical challenges associated with frequent follow-up.

Furthermore, the complex, unpredictable, and multifaceted nature of GvHD presents significant challenges for healthcare professionals in providing comprehensive information about all possible complications (Murray et al., 2023). While it is essential for recipients to be informed about potential risks prior to transplantation (Bompoint et al., 2023), it is often not feasible to cover every eventuality in advance. In practice, information is frequently sought or provided only when a specific knowledge gap or new complication arises (Ormandy, 2011). This may help explain why some recipients reported a lack of informational awareness prior to transplantation, with their informational needs only becoming fully apparent after experiencing GvHD or other complications. The same reasoning can be applied to the recipients that reported a general lack of awareness of treatment-related complications observed in the German study by Pariesk et al. (2021), which also recruited participants from a dedicated GvHD clinic. As such, it remains unclear whether recipients without GvHD, or those with less complex post-transplant healthcare pathways, would report the same intensity of information needs or experiences.

Caution is also needed when applying these findings to recipients' LTFU experiences in general. Studies in this review recruited participants from 100+ days post-transplantation. As recipients initially enter an acute phase of monitoring before transitioning to LTFU (Suárez-Lledó & Rovira, 2024), some participants may not have been formally discharged to LTFU care at the time of their respective studies. As a result, some experiences may reflect acute rather than LTFU care, which have different monitoring objectives and time intervals. Acute care involves frequent monitoring for immediate risk and complications, while LTFU involves less frequent monitoring for late complications, commencing several months after transplantation (Suárez-Lledó & Rovira, 2024). This distinction may influence recipients' experiences, but it is difficult to disentangle within this review, particularly as HSCT centres often combine both acute and LTFU services within the same clinic (Salooja et al., 2016).

Despite growing international research on LTFU care for HSCT recipients, their experiences within England's healthcare structure remain largely unknown. This gap is critical because England's publicly funded healthcare system differs significantly from others, especially regarding access to screening, continuity of care, and financial burden. Understanding how recipients navigate LTFU within this context is essential to ensure services meet their needs, address communication barriers, and support sustainable care models as survivor numbers increase. Without this insight, policies and practices may overlook key challenges unique to HSCT recipients in England.

### 4.6 Chapter Summary

This chapter systematically reviewed and synthesised qualitative evidence on HSCT recipients' experiences of LTFU care, addressing a significant gap in the literature. Employing a hermeneutic phenomenological framework and rigorous qualitative evidence synthesis, the review integrated findings from four studies across diverse healthcare systems, including the UK, USA, Germany, and Singapore. The analysis identified four central themes shaping recipients' experiences: the importance of patient-provider relationship, logistical challenges in monitoring practices, varied informational needs, and the prevailing fear of cancer recurrence.

Methodologically, the chapter adhered to best-practice guidance for qualitative synthesis, including transparent search strategies, critical appraisal using the CASP tool, and confidence assessment via GRADE-CERQual. The inclusion of studies from different countries enabled comparative insights but also introduced limitations regarding the transferability of findings to HSCT recipients in England.

The findings contribute to the thesis by illuminating how relational, organisational, and psychological factors intersect to shape LTFU care experiences. They highlight the central role of clinical liaison nurses, the impact of logistical barriers, and the need for tailored information provision. However, the limited number of studies and the international diversity of healthcare structures constrain the transferability of results, particularly for recipients in England, where service models and financial implications differ.

Given these limitations, the chapter highlighted the necessity for further research within the English healthcare system to clarify whether the identified themes reflect local experiences or broader international patterns. Accordingly, the next chapter builds upon this review by exploring HSCT recipients' experiences of LTFU specifically in England, enabling a more nuanced understanding of service provision and unmet needs in the national context.

# Chapter 5. Written Accounts Study of HSCT Recipients' Experiences of LTFU Care in England

## 5.1 Chapter Introduction

A systematic review with qualitative evidence synthesis in Chapter 4 identified key themes and gaps in the broader literature on HSCT recipients' experiences of LTFU care. This chapter examines LTFU care specifically within England's healthcare structure, aiming to explore how survivors navigate follow-up and the factors influencing engagement and well-being. This focus is warranted due to considerable variability in service provision across England and the limited specificity of existing guidelines. Employing a qualitative, phenomenological approach (see Chapter 3) and reflexive thematic analysis of written accounts, the chapter presents context-specific insights into care coordination, relationship continuity, and late effects screening, as published in the Journal of Cancer Survivorship (see Appendix 25).

The chapter begins with the study's rationale and methods, then presents findings organised around key themes, and concludes with a discussion of implications for person-centred LTFU care in England.

## 5.2 Study Rationale and Aim

HSCT is a life-changing procedure for a range of malignant and non-malignant haematological diseases, offering the possibility of cure but also exposing recipients to significant risk of late mortality and morbidity (Majhail et al., 2015; Maziarz, 2021; see Section 2.2.1). As outlined in Chapter 2, LTFU care is now recognised as essential for monitoring, early detection, and prevention of late complications (FACT-JACIE, 2018a; Majhail et al., 2012; Rotz et al., 2024; see Section 2.2.3). However, as survival rates improve and the population of HSCT recipients grows, the focus of care is shifting from acute clinical management to the broader, ongoing challenge of supporting survivors' long-term health, well-being, and quality of life (Battiwalla et al., 2017; see Section 2.3.1).

Despite policy ambitions and accreditation standards, the delivery of LTFU care remains highly variable, with persistent gaps in the provision of tailored, person-centred support (Dignan et al., 2021; NHS, 2022; see Section 2.2.3, 2.5.1, and 2.6). Current guidelines often lack specificity regarding the content and mode of support, leaving transplant centres considerable discretion in how they address recipients' needs (FACT-JACIE, 2018b; Rotz et al., 2024; see Section 2.2.3, 2.5.1, and 2.5.2). This variability is particularly problematic given the complex, multi-

dimensional late effects experienced by HSCT recipients, which span physical, psychological, and social domains (Diesh-Furlanetto et al., 2021; Kenyon et al., 2023; Savani et al., 2011; see Section 2.3.2 and 2.3.3).

A critical limitation of much existing research and service provision is the tendency to approach LTFU care from a predominantly biomedical perspective, focusing on surveillance for physical complications while underemphasising the psychological and social dimensions of survivorship (see Section 2.4.1). As highlighted in the health psychology literature and in Chapter 2, survivors' experiences of LTFU are shaped not only by clinical outcomes but also by their beliefs, coping strategies, and the meanings they ascribe to their health and future (see Section 2.4.1 and 2.4.2). Theoretical perspectives such as the Health Belief Model (Rosenstock, 1974), Social Cognitive Theory (Bandura, 2001), and constructs like illness perceptions and intolerance of uncertainty (Freeston et al., 1994; Mishel, 1988), offer valuable insights into how recipients interpret risk, engage with follow-up, and navigate the uncertainties of survivorship (see Section 2.4.2). For instance, recipients' engagement with LTFU is influenced by their perceived susceptibility to late effects, their confidence in managing health, and their ability to tolerate ambiguity about future risks. These psychological processes can either facilitate or hinder ongoing participation in follow-up, and are themselves shaped by the information, support, and relationships available within the healthcare system (see Section 2.4.3).

Empirical evidence, including the systematic review presented in Chapter 4, demonstrates that HSCT recipients' experiences of LTFU are profoundly shaped by these psychological and contextual factors. Recipients report varied informational needs, fluctuating levels of engagement, and persistent fears of recurrence or late complications. The quality of relationships with healthcare professionals, the clarity of information, and the logistical realities of accessing care all interact with recipients' psychological resources and vulnerabilities (see Section 2.3.2 and 2.5.2).

While international guidelines and the extensive body of multi-national research on late effects provide a broad understanding of LTFU needs (Majhail et al., 2012; Rotz et al., 2024), they are based on evidence and clinical experience from diverse healthcare systems. This breadth can mask important contextual differences, particularly those arising from the unique organisational, policy, and funding structures of the NHS in England (see Section 2.2.2 and 2.6). The NHS context introduces distinctive challenges and opportunities, including the move towards personalised, stratified, and remote models of care, and ongoing variation in access to

multidisciplinary teams, psychological support, and information provision. Given these complexities, there is a pressing need for research that moves beyond description to critically engage with the psychological and theoretical underpinnings of LTFU experiences, and that is grounded in the realities of navigating the healthcare system in England (see Section 2.7).

Understanding how recipients make sense of their health, manage uncertainty, and negotiate the demands of follow-up is essential for designing interventions and services that are genuinely person-centred and responsive to individual needs. Situating recipients' accounts within established health psychology frameworks and the specific context of the NHS, this study aims to identify not only the practical and informational needs of survivors, but also the underlying beliefs, emotions, and coping strategies that influence their long-term outcomes. In doing so, it addresses a critical gap in the literature and provides an empirical foundation for the development of more nuanced, theoretically informed, and person-centred models of LTFU care, an imperative as the NHS moves towards personalised, stratified, and increasingly remote approaches to survivorship support (see Section 2.6 and 2.7).

This study therefore aims to explore and interpret HSCT recipients' experiences of LTFU care in England, with particular attention to the psychological and social processes that shape engagement, adaptation, and well-being. The goal is to generate actionable insights for the design and delivery of more responsive, equitable, and person-centred LTFU services.

## 5.3 Method

### *5.3.1 Research Design Overview*

As discussed in Chapter 3, this study employed a qualitative, phenomenological design to explore HSCT recipients' experiences of LTFU care in England. Data were collected via online written narratives and analysed using reflexive thematic analysis (RTA), as outlined by Braun and Clarke (2022). RTA was selected for its flexibility and its capacity to capture the complexity of lived experiences, making it well-suited to the study's aim of generating person-centred insights.

The rationale for this design, including its phenomenological orientation and epistemological positioning, is discussed in Sections 3.3 and 3.4.

### *5.3.2 Study Participants*

| No. | Gender | Age at TP | TP Type | Time since TP (years) | LTFU frequency | LTFU care model | LFTU at hospital of TP |
|---|---|---|---|---|---|---|---|
| 1 | Male | 55 | Allo PBS | 8.3 | Yearly | Clinic | Yes |
| 2 | Female | 60 | Allo PBS | 2.8 | 3 monthly | Hybrid | Yes |
| 3 | Female | 50 | Allo PBS | 2.7 | 6 monthly | Clinic | Yes |
| 4 | Female | 28 | Allo HSCT | 27.1 | 5 yearly | Clinic | Yes |
| 5 | Male | 43 | Allo HSCT | 6.4 | 8 weekly | Clinic | Yes |
| 6 | Male | 63 | Allo PBS | 4.4 | 6 monthly | Clinic | Yes |
| 7 | Female | 61 | Allo HSCT | 3.7 | 3 monthly | Haem OP | Yes |
| 8 | Male | 49 | Allo HSCT | 4.8 | Yearly | Clinic | Yes |
| 9 | Male | 65 | Hap HSCT | 1.2 | 8 weekly | Clinic | Yes |
| 10 | Female | 42 | Allo HSCT | 10.1 | 3 monthly | Clinic | Yes |
| 11 | Female | 3 | Auto HSCT | 33.6 | Yearly | Clinic | No |
| 12 | Male | 50 | Hap SCT* | 10.9 | 2 yearly | Clinic | Yes |
| 13 | Female | 34 | Allo PBS | 1.6 | 2 monthly | Hybrid | Yes |
| 14 | Female | 54 | Allo HSCT | 1.1 | 4 weekly | Clinic | Yes |
| 15 | Female | 31 | Allo PBS | 2.7 | 3 monthly | Clinic | Yes |
| 16 | Male | 25 | Allo HSCT* | 10.8 | Yearly | Clinic | Yes |
| 17 | Female | 46 | Allo PBS | 7.8 | Yearly | Haem OP | No |

**Table 5.1 Study Two Participant Characteristics**
*****multiple transplants; Allo, allogeneic; Auto, autologous, HSCT, haematopoietic stem cell transplant; PBS, peripheral blood stem cells transplant; Hap SCT, haploidentical stem cell transplant; Clinic, designated LTFU clinic; Hybrid, coordinated care between LTFU clinic and primary care providers; Haem OP, haematology outpatients; TP, transplant centre.

As shown in Table 5.1 above, seventeen HSCT recipients (7 males, 10 females) participated in the study, responding to social media advertisements and providing informed consent. Participants' age at transplant ranged from 3 to 65 years (mean age 44.64 years), with an average time since transplant of 8.24 years (range 1.16–33.58 years).

The sample reflected a range of LTFU care experiences. Thirteen participants received follow-up care through a designated LTFU clinic, two attended general haematology outpatient departments, and two described a hybrid model involving both specialist clinics and primary care providers. Most participants (15) received LTFU care at the same hospital where their transplant occurred, though only eight identified this as their local hospital. Two participants

received LTFU at a hospital that was not the site of their transplant, one of which was their local hospital. In total, eight participants travelled to attend, with distances ranging from 5.5 to 70 miles.

The frequency of LTFU appointments varied widely, from once every 4 weeks to once every 5 years, highlighting the diversity of follow-up experiences. This variation in care models, geography, and appointment intervals reflects the complexity of LTFU service provision in England and provides a rich foundation for exploring how recipients engage with and adapt to long-term care.

### *5.3.3 Participant Recruitment*

The recruitment and data collection process commenced following the granting of ethical approval (see Section 3.6), in accordance with institutional research governance procedures. The study was disseminated and data were collected via Jisc Survey Online (JSO) between June to November 2021, reflecting a commitment to methodological rigour and participant accessibility.

Upon receipt of ethical approval from Teesside University Ethics Committee (see Section 3.6), recruitment was initiated through targeted notifications posted on selected social media platforms (see Appendix 26). Specifically, permission to share the study notification was granted by two private group pages: one for survivors of HSCT and another representing a UK support group for a condition frequently treated with HSCT. In addition, a UK-based charity promoting stem cell donation advertised the study via its social media page (see Appendix 27). All advertisements included a link for potential participants to access further information. Upon accessing the study link, individuals were first presented with the participant information sheet (see Appendix 3), followed by the consent form (see Appendix 5). Only those who provided informed consent proceeded to participate.

Given the aim of this study, the population of interest comprised HSCT recipients residing in England. Inclusion criteria specified that participants must have been aged 18 years or older at the time of data collection, reside in England, and be at least on year post-transplantation. The latter criterion was adopted to ensure that participants had entered the long-term monitoring phase of post-transplant care and had sufficient opportunity to attend at least one LTFU appointment.

Recruitment was conducted using convenience sampling, a non-probability approach commonly employed in qualitative research to facilitate access to participants based on their availability and willingness to participate (Stratton, 2021). This strategy was considered appropriate given the practical constraints associated with accessing a specific clinical population and the exploratory nature of the research. In keeping with the qualitative orientation of the study and the objective of generating a rich and diverse dataset, no predetermined sample size was set. Recruitment continued until the researcher and supervisor jointly determined that sufficient data had been collected to address the research question with confidence (Braun & Clarke, 2013, 2021a, 2021b). This approach reflects a move away from the traditional concept of data saturation, which is typically defined as the point at which no new knowledge is generated (Morse, 2015), towards a focus on analytic sufficiency as discussed in the literature (Braun & Clarke, 2021a; O'Reilly & Parker, 2013; Nelson, 2017). The concept of saturation has been critiqued for implying an objective endpoint, which does not align with the interpretive and iterative nature of qualitative research.

Data sufficiency in this study was assessed through several strategies. First, the richness and diversity of the dataset were evaluated to ensure a wide range of participant experiences and perspectives were represented, with an emphasis on capturing a richly textured understanding in qualitative research (Vasileiou et al., 2018). Second, the researcher and supervisor engaged in ongoing reflexive dialogue throughout data collection and analysis, considering whether emerging themes were well-supported, coherent, and analytically robust, in accordance with the reflexive thematic analysis framework advocated by Braun and Clarke (2022). As analysis progressed, it became apparent that additional written accounts were not yielding substantially new insights, indicating thematic stability. This concept is described by Srivastava and Hopwood (2009), who characterise qualitative analysis as an iterative and evolving process. This approach enabled continuous assessment of whether the dataset was sufficiently nuanced and comprehensive to address the research question meaningfully, prioritising analytic sufficiency over saturation (Braun & Clarke, 2021). Practical and ethical considerations, including time and resource constraints, were also considered (Braun & Clarke, 2006, 2013, 2021a, 2021b; Braun et al., 2021; Sandelowski, 1995), and recruitment ceased when it was agreed that further data collection would likely result in repetition rather than deeper understanding.

### *5.3.4 Data Collection*

HSCT recipients' experiences were obtained using online written accounts, collected via Jisc Survey Online (JSO). Following consent, participants were invited to complete demographic questions (see Appendix 28), including gender, type of HSCT, month and year of transplant, age at transplant, and whether LTFU appointments occurred at their local hospital. If appointments did not occur locally, participants were asked to indicate the distance required to travel. Additional questions included whether LTFU was conducted at the same hospital as the transplant, and the frequency of LTFU appointments. After completing these questions, participants were directed to the main research question (see Appendix 29), which was designed to elicit detailed accounts of their experiences.

Participants were asked one open-ended question: "Please tell me about your experiences of attending designated long-term late effects monitoring appointments following stem cell transplantation". To support participants, meaningful prompts, based on the findings of the systematic review, were provided to guide reflection on areas of LTFU care they may have wished to consider. No time restrictions were imposed, and participants could amend or add to their accounts prior to final submission. Upon submission, all participants received a debrief sheet (see Appendix 7), which summarised the study and provided contact details for further support, in line with best practice for ethical research conduct.

Although qualitative research is traditionally associated with interviews or observations (Creswell & Poth, 2018), written accounts are also recognised as a valid source of qualitative data (Braun & Clarke, 2013; Braun et al., 2021a). Semi-structured written accounts can serve as a primary source of qualitative data, offering depth and nuance comparable to interview transcripts (Lamprell et al., 2025). While all data collection methods were considered, the decision to proceed with textual data was influenced by the Covid-19 pandemic. This study was initiated in April/May 2021, and during this period the UK had entered the second year of the pandemic and had already experienced two unprecedented lockdowns and multiple social distancing measures (Institute for Government Analysis, 2022). At the time, future face-to-face research was uncertain, especially given that HSCT recipients were classed as *clinically vulnerable* due to low immune systems and requirements to *shield.* Online interviews were considered, but at the time were felt inappropriate. Instead, inviting HSCT recipients to participate in online written accounts was deemed less intrusive.

Whilst the pandemic influenced the choice of method, it was not the only driving factor. Online written accounts allow for the inclusion of recipients who may choose to abstain from face-to-face research (Braun et al., 2021), thereby expanding the potential participation reach. This method can also capture a wide range and diversity of experiences within an unexplored population (Braun et al., 2021), allowing for the generation of data central to participants' experiences of LTFU care. Collecting written data online has also been found to be particularly suitable when researching sensitive topics (Sperber et al., 2023), which is a fundamental consideration given that several potential long-term complications are of a sensitive nature, for example, infertility and sexual intimacy. Additionally, the absence of the interviewer in online written accounts may help to reduce social desirability effects (Duffy et al., 2005), as participants can respond more candidly without the perceived pressure of a researcher's presence.

In practice, this approach yielded a substantial volume of narrative data reflecting participants' post-transplant LTFU care experiences. Most entries ranged from 200 to 400 words, with some shorter (around 100 words) and others longer (up to 600+ words). Across the 17 contributors, the average length of each response was approximately 340–350 words, equating to roughly one A4 page per participant when formatted using standard academic conventions. This volume of data offers a rich foundation for thematic analysis, which is widely recognised as a flexible and robust method for examining patterns within qualitative health research (Braun & Clarke, 2006). Written accounts of this length are considered sufficient for qualitative inquiry, particularly when the goal is to capture personal narratives and lived experiences.

It is important to note, however, that written qualitative data differs in several respects from interview transcripts, particularly in terms of length and detail. Written qualitative data is often shorter than interview transcripts due to the nature of how the data is produced and the constraints of the method. Interview transcripts typically result from audio recordings of extended conversations, which are then transcribed verbatim. This process captures not only the content but also the nuances of speech, pauses, and interactions, often producing 20–40 pages of single-spaced text per interview (Braun & Clarke, 2006). In contrast, written accounts are composed directly by participants, who tend to be more concise and focused on their responses. Written narratives are often more reflective and targeted, allowing participants to distil their thoughts without the conversational detours common in interviews (Lamprell et al., 2025). The combination of detailed personal reflections and the chosen method of reflexive

thematic analysis (RTA), as discussed in the next sub-section, provides a rigorous and meaningful approach to understanding LTFU care from the recipient's perspective.

### *5.3.5 Analysis*

A reflexive thematic analysis approach was used to analyse the data, guided by Braun & Clarke's (2022) framework. This method was selected for its flexibility and suitability in capturing lived experiences, perceptions, and meanings (Braun & Clarke, 2021b; van Manen, 2016), qualities that align with the study's aim to explore HSCT recipients' experiences of LTFU care. Reflexive TA enables the identification of patterns across a dataset through a recursive process of coding and theme development. Themes are constructed to reflect the universal essence of the phenomenon under investigation, while remaining grounded in the particularities of individual accounts (Braun & Clarke, 2022).

The substantial volume of collected data provided a strong foundation for reflexive TA, which is widely recognised as a flexible and robust method for examining patterns within qualitative health research (Braun & Clarke, 2022; Saunders et al., 2023). While some entries were shorter than others, this conciseness did not compromise the quality of the analysis, as shorter written accounts can still offer rich, focused insights into participants' experiences (Braun & Clarke, 2006, 2022). TA is well suited to such data, as it emphasises identifying patterns and meanings across a dataset rather than relying on volume alone. According to Braun and Clarke (2006), TA is adaptable and can be applied to various forms of qualitative data, including brief written narratives, provided the data is sufficiently detailed to support meaningful coding and theme development.

Importantly, reflexive TA acknowledges the active role of the researcher in interpreting data, embracing subjectivity as a resource rather than a limitation (Braun & Clarke, 2022). This is particularly relevant in hermeneutic phenomenological research, where the researcher's positionality and prior knowledge are integral to the interpretive process (Olmos-Vega et al., 2023). Given the researcher's lived experience as an HSCT recipient, reflexive TA provided a framework that supported both analytical rigour and personal insight (Braun & Clarke, 2022). Integrating theoretical commitments with experiential understanding, this approach enabled the development of rich, nuanced interpretations that reflect both the complexity of the data and the unique perspective brought by the researcher.

Despite its strengths, reflexive TA has been subject to critique, particularly regarding potential inconsistencies and lack of transparency when reflexivity is not adequately documented (Braun & Clarke, 2022). To address these concerns, a rigorous reflexive practice was adopted, including journaling, peer debriefing, and iterative engagement with the data (as discussed in Section 3.4 and 3.7). These strategies ensured that interpretations remained ethically grounded and methodologically transparent. By leaning into the strengths of reflexive TA, the study was able to generate meaningful insights into the complex and emotionally charged terrain of LTFU care. Reflexivity was not only a methodological requirement but also an ethical and epistemological commitment to honouring the voices of participants and the realities they shared. Braun and Clarke (2022) process of reflexive thematic analysis follows six distinct phases, summarised in Figure 5.1.

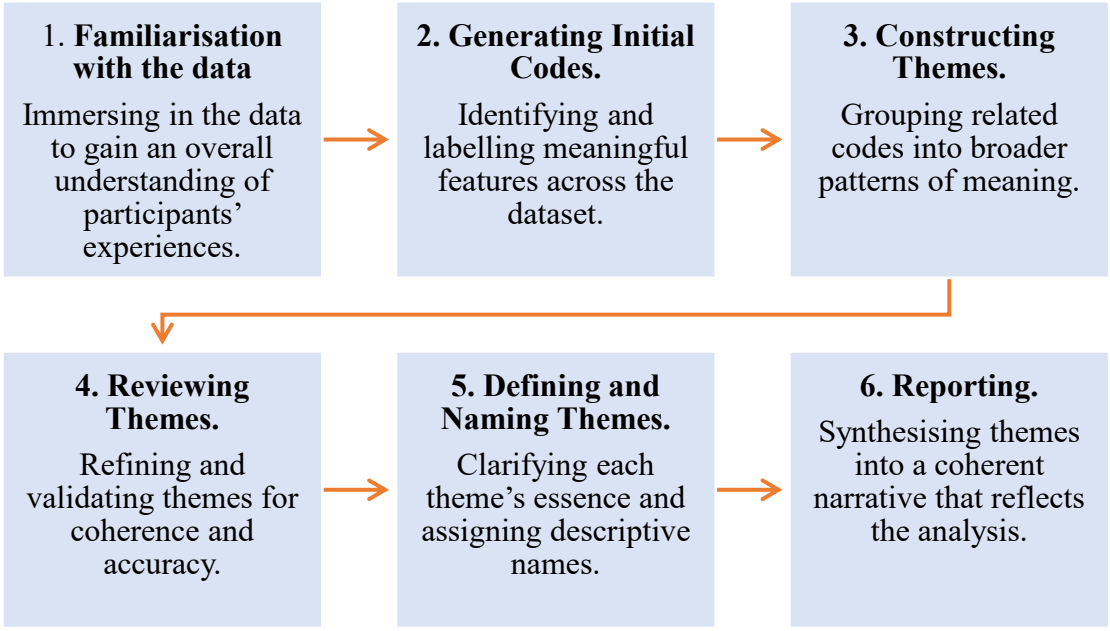


**Figure 5.1 The six-phases of Reflexive Thematic Analysis.**

As stated, the reflexive thematic analysis process begins with familiarisation with the data, achieved by reading and re-reading the participants' written accounts and immersing oneself into the dataset to develop a thorough and nuanced understanding (Braun & Clarke, 2022). This process involved critically engaging with the dataset, considering not only the meanings participants attributed to their experiences but also being reflexive about the researchers' interpretations. Notes were made for each dataset, followed by summary notes, which assisted in identifying potential universal meanings in preparation for phase two: data coding. Throughout this process, analytic memos and data annotations were created to capture emerging ideas, patterns, and reflections (see Appendix 2 for example), supporting the development of

codes and themes in line with best practice in reflexive thematic analysis (Braun & Clarke, 2022).

Data coding involves identifying and labelling meaningful segments of text in relation to the research question (Braun & Clarke, 2022). To facilitate coding, each written account was uploaded into the qualitative data analysis tool, MAXQDA (Kuckartz & Rädiker, 2019). The researcher systematically worked through each account, identifying potentially meaningful aspects of recipients' experiences of LTFU care and assigning appropriate codes (see Appendix 30). The analysis was inductive in orientation, meaning it was driven by the dataset itself rather than shaped by pre-existing theoretical constructs (Braun & Clarke, 2022). Initially, codes were applied to descriptive (semantic) content, and as the researcher worked iteratively and systematically through the data, more implicit (latent) codes were developed. Each final code represented a distinct observation from the dataset (Braun & Clarke, 2021b), enabling progression to phase three: constructing themes.

A theme, as defined by Braun & Clarke (2021b, p. 14) "are patterns of shared meaning, united by a central concept or idea", and developed by grouping codes that share underlying meaning. Each code and its associated data (e.g., quotes, observations, notes) were examined, and where patterns of shared meaning were identified, they were clustered together, forming the initial themes. These preliminary themes were continuously reviewed (phase four), and once developed, defined and refined (phase five) until the final themes were both distinctive and coherent, forming a comprehensive overarching analysis of the data (see Appendix 31). Once the final themes had been established, the research was then able to move onto the final stage (phase six): report writing.

As previously noted, the lead researcher has direct experience with LTFU care. To minimise researcher bias, a reflexive journal was maintained throughout the study (see Appendix 1). Bias can occur when researchers approach their work with a limited or skewed viewpoint, potentially giving preference to specific groups or ideas while overlooking others (Gao, 2020). By engaging in reflexive practices, researchers can critically examine how their own perspectives and the surrounding context shape and influence the way they conduct and interpret their research (Olmos-Vega et al., 2022). The extent to which reflexivity can minimise researcher bias is debated as some researchers argue that it enables a more connected understanding of the data and leads to improved research outcomes (Gilgun, 2008). Others contend that transparency alone does not guarantee accurate representation of participant and that reflexivity does not

eliminate subjectivity or fully mitigate implicit influence (Finlay, 2002; Pillow, 2003). Although maintaining are reflexive journal does not remove researcher bias, it provided the opportunity to reflect on pre-existing knowledge about LTFU. Allowing for critical evaluation of how prior knowledge might influence analytical interpretation and ensuring that findings and recommendations were grounded in the data. In addition, supervision was provided throughout the research and analytical process.

### 5.4 Findings

Four themes were drawn from the data analysis central to recipients' experiences of LTFU care in England (see Figure 5.2). These included the ambiguity surrounding the transition to LTFU, reflected in participants questions such as "Will there be a change in my care, or will appointments just become less frequent?"; the reassurance offered by ongoing care coordination, captured in the sentiment "It is good to know I am still in the system"; the value placed on relationship continuity, expressed through statements like "A good knowledge of me, my health and what is important to me"; and the challenges associated with late effects screening, particularly the lack of preparatory information, as noted in "There was not much information about what to expect or be aware of."

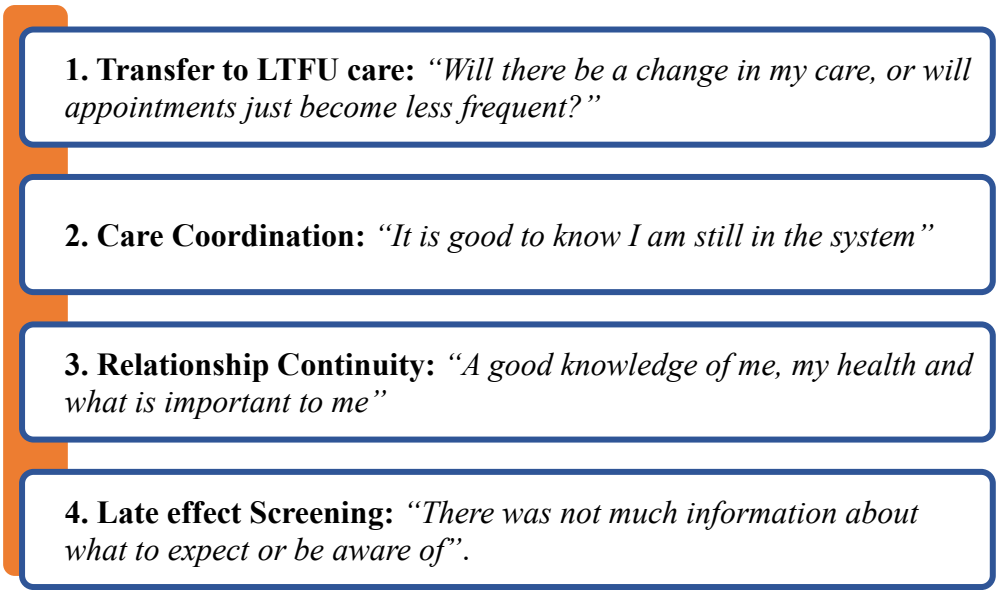


**Figure 5.2 Patients' experiences of LTFU care in England**

#### *5.4.1 Transfer to LTFU Care: "Will there be a change in my care, or will appointments just become less frequent?"*

Participants' experiences revealed a lack of clarity surrounding the transition from acute post-transplant care to LTFU care. Although participants described acute and LTFU as two distinct

appointment practices, the boundary between them was often blurred. This ambiguity left many unsure whether they had formally entered a new phase of care or were simply experiencing a gradual reduction in clinical contact. For some, the absence of a formal handover or explicit communication meant the transition felt passive and unmarked. Rather than being introduced to a new phase of care, participants often experienced a gradual lengthening of time between appointments, which they interpreted as a possible shift to LTFU care.

> *[I] do not feel that I've officially entered 'long term' follow-up yet. I am not sure if this will be officially marked by a change in my care or whether my appointments will just become less frequent.* (P13)

> *Intervals between appointments seem to be related to years' post-transplant; 2 months after 2 years, 3 months after 3 years and so on.* (P7)

This uncertainty was compounded by the variability in how and when LTFU care was initiated. In some cases, participants perceived the commencement of LTFU monitoring only after acute complications had resolved. The transition was not driven by time alone, but by a change in clinical needs, particularly when conditions like chronic graft-versus-host disease had stabilised. Others described a more gradual shift based on clinical indicators such as blood results.

> *I only started long-term effects clinics about five years ago after the [chronic graft-versus-host disease] had finally settled down.* (P16)

> *Started long term effects clinics at 15 months post-transplant. Increased to 12 months once bloods at normal level for 2 clinics at 3 years post-transplant.* (P6)

In contrast, those who experienced ongoing complications or relapses found that discussions about long-term effects were deferred. The immediate demands of acute care took precedence, leaving participants unsure whether any LTFU care had been initiated at all. This was reinforced by others whose complex clinical journeys delayed or obscured the transition.

> *I'm not sure that my long-term / late effect monitoring has happened… I had an early relapse and then another several years later… we didn't talk about late effects as there was still too much going on.* (P10)

*I have never reached 100% donor which is why I think I have been so closely monitored… I am hoping as my blood results have been within normal range in the last 2 appointments the time period will lengthen between consultations.* (P2)

For others, the transfer to LTFU care was more clearly signposted by logistical changes, such as being moved from a transplant centre to a local hospital. In these cases, the shift in clinical responsibility, coupled with a reduction in appointment frequency, was interpreted as the beginning of long-term monitoring. In some instances, the transition was not always accompanied by a change in care content or structure, reinforcing the sense that LTFU care was more implied than actively introduced.

*Not sure when long-term monitoring started… I was transferred by transplant hospital to a local hospital 4 years after the transplant and this obviously marked long-term follow-up as appts went to yearly.* (P17)

*I do get monitored at [hospital] every year and think the additional late effects is 5 yearly but could be less.* (P4)

Across these varied experiences, the transfer process was characterised by a lack of formal recognition. Participants often relied on indirect cues, such as changes in appointment frequency or provider, to infer their status. Such experiences highlight the passive nature of the transition and the emotional toll of unclear care boundaries. Despite this ambiguity, participants found reassurance in simply remaining within a healthcare pathway.

See Appendix 32 for theme coding matrix.

### *5.4.2 Care Coordination: "It is good to know I am still in the system"*

Participants described three different modes of care coordination, specialist-led, hybrid, and primary care-led. While the structure and delivery of care varied, the reassurance of remaining within a defined healthcare pathway was central to participants' emotional well-being and sense of safety. This continuity of care was often perceived as a protective factor against anxiety.

*After the appointments I feel more reassured and it is good to know I am 'still in the system' rather than being signed off as I think this would make me more anxious.* (P3)

For many, care coordination was managed by a specialist team within a designated transplant centre, where LTFU activities were structured and consistent. These activities included regular blood testing, timely medical referrals, and prescription management. Participants valued the multidisciplinary nature of these clinics, which allowed for multiple aspects of care to be addressed in a single visit, reducing fragmentation and enhancing efficiency.

> *The transplant nurses and pharmacy assistants are always available in the clinic, and this makes the whole visit process work very smoothly as they can book anything and order drugs all on the same day.* (P14)

> *I feel I get a very thorough check at my annual appointment as all my bloods get checked. The care I receive is outstanding and I can call at any time if I have a query. The benefit of attending is that I get notified very quickly if anything appears abnormal.* (P4)

The presence of familiar and responsive staff contributed to a sense of being well cared for. Participants often described their interactions with clinical teams as respectful, attentive, and holistic, with clinicians demonstrating detailed knowledge of their medical history and personal circumstances. This relational continuity built trust and reinforced the perception of high-quality care, and in some cases removed the need for GP contact and involvement in post-transplant care.

> *I have had little contact with my local GPs since most issues were dealt with by the haematology department, including long-term prescriptions.* (P1)

Despite the benefits of specialist-led care, logistical challenges were frequently reported. Participants described long waiting times, travel burdens, and rigid appointment schedules as sources of fatigue and inconvenience. These challenges were particularly pronounced for those living at a distance from their transplant centres or managing work and caregiving responsibilities alongside their healthcare needs.

> *Sometimes it can take a long time in the clinic - i.e., to have blood done and then have to wait to see the consultant, so that can be tiring, but it's a necessary evil.* (P14)

> *I find them very organised, but it is time-consuming - only on a Wednesday morning and generally takes the best part of the day [when including] travel.* (P3)

In response to these constraints, a hybrid model of care emerged, particularly during the COVID-19 pandemic. This model combined remote consultations with localised testing, enabling participants to access care more flexibly. Many found this approach more convenient and less stressful, especially when travel posed a significant barrier. Remote care was frequently described as efficient and adaptable, with participants appreciating the ability to tailor appointments to their personal circumstances. The shift to virtual consultations also reduced waiting times and alleviated the stress typically associated with hospital visits.

> *[LTFU clinic] has liaised well with a more local hospital allowing me to have blood tests locally and have my consultations by phone when this is more convenient and I am able to request phone or face-to-face to suit me.* (P13)

> *Although the distance isn't horrendous, the journey is, and I find it stressful. But because of covid, most appointments are now video calls, which I prefer... All blood tests are now done at my doctor's surgery prior to video calls.* (P2)

However, not everyone preferred the hybrid model of care. For some, particularly those experiencing anxiety, physical attendance offered a level of reassurance that remote consultations could not replicate. Being seen in person was associated with a greater sense of thoroughness and emotional relief. In contrast, the primary care-led model, where responsibility for LTFU was transferred entirely to local providers, was linked to a loss of specialist input and diminished confidence in care. One participant described feeling dismissed and unheard by their new consultant, which led to a deterioration in both physical and mental health. The absence of coordinated care and lack of access to specialist support contributed to feelings of isolation and vulnerability.

> *I have a lot of health anxiety, so attending these appointments is helpful in alleviating worries and I feel better having physically seen someone and been checked.* (P15)

> *My confidence going forward in relation to my health is non-existent right now, which impacts my mental well-being…if there [was] support, telephone or email, with a post-transplant specialist, I would feel so much better as I would have that reassuring support when needed, but instead, I often end up quite unnecessarily unwell for much longer.* (P17)

Access to clinical personnel, predominately clinical nurse specialists (CNS), via phone or email was consistently highlighted as an essential support service. This direct line of communication provided reassurance, facilitated timely responses to concerns, and reinforced the sense of being actively monitored.

> *I have access to a [clinical nurse specialist] by phone and email, which is absolutely essential to my feeling of being looked after and knowing that I can contact somebody with any concerns.* (P13)

> *I feel the care I receive is excellent and I know that I can always get a quick response, especially from the nurses if I phone or email them at any time.* (P14)

Across all models of care coordination, participants emphasised the emotional reassurance of remaining within a structured healthcare pathway. This sense of being "still in the system" was closely tied to procedural efficiency and the presence of familiar, responsive staff. Built on sustained connections and trust, these relational aspects of care form the basis of the next theme.

See Appendix 33 for theme coding matrix.

### *5.4.3 Relationship Continuity: "A good knowledge of me, my health and what is important to me"*

Some participants described experiencing a continuous relationship with healthcare professionals involved in their LTFU care. These relationships, often developed over time, were characterised by consistency and familiarity, which contributed to a sense of being understood and supported. In some cases, this continuity extended to the consultant who had overseen the transplant itself, creating a seamless transition into post-transplant care. This sustained involvement of the same clinician was seen as a key factor in receiving care that was not only efficient but also attentive and personalised. Participants valued the depth of understanding that came from seeing the same healthcare professional over time. This familiarity allowed clinicians to provide care that was perceived as holistic and sensitive to individual needs. Even when logistical challenges, such as waiting times, were present the quality of the interaction and the expertise offered were considered to outweigh any inconvenience.

*I usually see my main consultant, who has seen me throughout my transplant process, and this is helpful as he has a good knowledge of me, my health and what is important to me.* (P15)

*I have developed a good relationship and rapport with the doctors I see in the clinic. They always impress me with their sensitive and intelligent approach to their patients… There is often a wait to be seen but that is no problem for such high-quality advice.* (P1)

For other participants, relationship continuity was maintained with clinical nurse specialists rather than clinicians. These relationships were highly valued and contributed to a sense of being well cared for during appointments. The nurses' thoroughness and attentiveness reinforced participants' confidence in the care they received. The consistent presence of knowledgeable clinical staff also shaped healthcare-seeking behaviours, with many participants choosing to contact their transplant teams directly rather than consult their general practitioners. This preference stemmed from a belief that GPs lacked the specialised knowledge needed to manage the complex and evolving nature of post-transplant health, whereas transplant teams were seen as better equipped to understand and address these needs.

*I get seen by a specialist nurse whom I have known for a long time, they are very thorough, and I feel well looked after when I am there.* (P16)

*As I still speak to my team fairly regularly, I've found myself raising most medical issues with them and have not considered going to my GP for anything else… a stem cell transplant has so many potential effects that a GP might not be able to rule out transplant-related issues… So, the transplant team becomes like a surrogate GP.* (P13)

*I'm very happy with the support I get from my [the clinical] team - They're friendly, helpful and responsive, and I would much rather talk to them than a GP as GPs don't have the experience and always end up calling the Haem Team anyway.* (P7)

However, not all participants were able to maintain this continuity. One participant described how the transfer of long-term monitoring responsibilities to their local, non-transplant hospital disrupted the relationship they had previously established with their transplant team. The absence of familiarity and understanding at the new centre led to feelings of being dismissed and unheard. This breakdown in relational continuity contributed to a loss of trust and the

perception that care had become impersonal and procedural, rather than supportive and responsive.

> *At my last [appointment] in the new hospital and the first [appointment] seeing a [new] consultant… he dismissed everything I said or asked about and I felt like he had belittled my experiences… The care that I received in my transplant hospital was on the whole good in the sense I was listened to, so I thought this would continue but feel that late effects clinics are just lip service or a tick box exercise.* (P17)

Relationship continuity was a cornerstone of participants' positive LTFU experiences, building trust, personalisation, and a sense of being genuinely cared for. Familiar clinicians and nurses enabled holistic care that extended beyond clinical expertise to emotional reassurance. However, where continuity was disrupted, participants felt dismissed and unsupported, revealing how relational consistency shapes perceptions of care quality.

See Appendix 34 for theme coding matrix.

### *5.4.4 Late Effects Screening: "There was not much information about what to expect or be aware of"*

Participants described a lack of preparation and guidance from hospitals regarding the duration and complexity of recovery following the transplant. The absence of clear expectations contributed to uncertainty, particularly around the timeline of recovery and the nature of long-term complications. While the quality of care was generally viewed positively, participants felt that more could have been done to prepare them for the extended and often unpredictable recovery process. In addition to uncertainty about recovery, participants reported limited information about the possible late effects of treatment. This lack of awareness left some feeling unprepared for the long-term health challenges that could arise, and unsure of what to expect from monitoring appointments.

> *I don't think the hospital really prepares you for how long the whole transplant recovery process can really take… but overall, I think the care has been and still is very good.* (P14)

> *I don't think I was told about some of the possible late effects, and I don't think there was much information about what to expect or be aware of.* (P10)

For some, the knowledge of late effects developed gradually, either through personal experience of complications or through evolving medical recognition over time. Participants who had undergone transplants many years ago noted that awareness of late effects had increased, but often only after their own symptoms had already emerged. Others gained insight through discussions with clinic personnel, particularly regarding age-specific screening tests. However, concerns were raised about whether these screenings were carried out at the appropriate time. This uncertainty led some participants to take a proactive role in managing their own care, including keeping personal records of what should be monitored.

> *Having had my transplant years ago, I can say that over recent years more and more late effects have been noticed… When I first had my transplant, there weren't many recognised late effects apart from infertility and long-term graft-versus-host disease.* (P4)

> *I have not yet reached many of the 'milestones' at which specific late effects need to be monitored for, however these are mentioned from time to time and I try to write them down as I don't always feel confident that this will be remembered at the right time by my medical team.* (P13)

In addition, some participants experienced delays or difficulties in accessing screening tests that had been discussed during appointments. This raised concerns about whether future tests would be carried out, particularly when they were not considered urgent or life-threatening. The impact of these delays extended beyond physical health, affecting participants' confidence in the system and their sense of being adequately supported. The need to take ownership of care often stemmed from inconsistencies in monitoring practices across different centres. Participants described initiating referrals themselves, especially when concerned about the long-term effects of treatment. This self-directed approach reflected a proactive effort to ensure that potential complications were not overlooked.

> *Some of the follow up discussed in the late effect clinic hasn't happened yet.* (P10)

> *I've had a difficult experience trying to get referred for a fertility assessment, which is distressing in itself but also makes me worry about other things I might need in the future, which aren't a matter of life and death but do affect quality of life greatly.* (P13)

> *I have been proactive in getting myself referred to the [hospital] to a specific cardio-oncology service… I know now that people who are on the drug I went on are now routinely offered more monitoring at some hospitals, e.g. annual heart check, whereas I didn't have that kind of thing, so things maybe lay undetected for some time.* (P10)

Furthermore, the unknown impact of treatment on future health was stated as contributing to pre-appointment anxiety for screening tests, which was intensified by waiting times. Participants also reported experiencing anxiety prior to attending LTFU appointments due to concerns regarding post-transplant complications, particularly the risk of relapse. This anxiety heightened by the anticipation of screening examinations and the scrutiny of test results.

> *I'm on the waiting list for a bone scan and I'm a bit concerned about this because I don't know how good my bones are because of early menopause and cardiac complications.* (P10)

> *I still feel quite shellshocked several years after diagnosis and anxious in the lead-up to appointments [regarding] relapse. This anxiety is increased by… wondering what consultants and I should be looking out for in the blood results.* (P3)

Despite generally positive views of care quality, the lack of clarity around long-term complications and inconsistent screening practices contributed to feelings of vulnerability and uncertainty. Over time, some individuals developed awareness through personal experience or informal channels. Despite this, many felt compelled to self-advocate and manage their own care to compensate for systemic shortcomings. Having written documentation identifying and detailing future monitoring and screening requirements was highlighted as an unmet informational need.

See Appendix 35 for theme coding matrix.

### 5.5 Discussion

The aim of this study was to explore and understand HSCT recipients' experiences of LTFU care in England. The written accounts of seventeen participants suggest that recipients experience uncertainty regarding the commencement of LTFU care. Several reported that they were not officially notified of LTFU, instead, they assumed the transition had occurred due to a change in healthcare provider or reduction in appointment frequency. This uncertainty was

mitigated when care continuity was maintained with the clinical transplant team, either directly or through a hybrid approach with primary care providers, and this continuity was central to their experiences. A healthcare pathway strengthened by sustained relationships with clinical personnel was perceived as essential for receiving efficient, attentive, and holistic LTFU care. However, recipients also reported feeling unprepared and lacking knowledge of potential late effects associated with HSCT and the LTFU process. Written documentation identifying and detailing LTFU and screening requirements was highlighted as a potentially beneficial resource. The participants' accounts depict the complexities, uncertainty, and psychological impact encountered as they navigate the LTFU healthcare pathway.

The findings of this study indicate that recipients perceive clinical personnel as not discussing the transition from acute to LTFU care with HSCT survivors. Rather than being explicitly informed, recipients often assume the transition has occurred, and even then, many recipients question if LFTU has officially started. This finding complements the broader findings from Chapter 4, particularly the importance of clear communication, information provision, and continuity of care (de Vere Hunt et al., 2021; Hwang et al., 2012; Parisek et al., 2021; Sharin et al., 2020). The lack of clarity around LTFU commencement also reinforces arguments presented in Chapter 2 and despite the existence of international and national guidelines, policy and practice often fail to clearly define the boundaries and processes of LTFU care (Dignan et al., 2021; Majhail et al., 2012; Salooja et al., 2016). As discussed in Section 2.2.3, this results in significant variation in how and when patients are transitioned to LTFU, ambiguity in roles and responsibilities, and inconsistent communication and support for recipients (Dignan et al., 2021; Morken et al., 2022).

Uncertainty about the commencement of LTFU is significant, given that recipients are encouraged to take an active part in their own follow-up care (Hahn et al., 2017; Kenyon et al., 2023). However, it is not reasonable to expect recipients to participate actively if they are unaware that LTFU has commenced. Recognising progression along the HSCT healthcare pathway and entry into the screening and preventive phase is essential for encouraging engagement and self-management. As highlighted by the Health Belief Model (Rosenstock, 1974) and Social Cognitive Theory (Bandura, 2001), which emphasise the importance of perceived risk, self-efficacy, and outcome expectations in motivating engagement and self-management (Christalle et al., 2019; Diesch-Furlanetto et al., 2021).

While recipients are aware of the screening practices and adverse health complications post-HSCT, there was no reference to health promotion within their accounts. Educating recipients about the potential risk factors and the mitigating benefits of health promotion activities to improve health trajectory is stated as being the primary preventive measure in LTFU care (Hahn et al., 2017; Khera, 2023; Tichelli & Rovó, 2015). This absence of health promotion discourse may reflect a missed opportunity for "teachable moments" (see Section 2.5.3), as well as a lack of proactive engagement by clinical personnel in supporting behaviour change.

While recipients should be encouraged to participate in their own long-term care, the implications of highlighting adverse health complication with a hypervigilant cohort of patients must also be considered, and adequate support must be implemented to ensure no detriment to psychological well-being. This aligns with the literature on fear of cancer recurrence (FCR) and the psychological burden of survivorship (Austin-Ketch & Paplham, 2015; Bergerot et al., 2022; Brice et al., 2020; Simard et al., 2013; Yang et al., 2023), reinforcing the need for sensitive, tailored communication (see Section 2.3.2). Given these gaps in proactive health promotion and the need for psychological support, structured interventions that clarify roles and provide consistent information may help address both informational and emotional needs.

To facilitate the transition from acute to LTFU care and ensure continuity for patients, Hashmi et al. (2015) and Majhail et al. (2012) recommend providing recipients with survivorship care plans. These plans, such as those developed by the American Society of Clinical Oncology (n.d.), are intended to define the roles and responsibilities of all preventative care providers, thereby optimising the efficiency of LTFU. They also serve as reminders for consultants and patients regarding appropriate surveillance practices tailored to individual risk factors. Although survivorship care plans have been associated with improved survival rates (Majhail et al., 2020), findings from this study suggest that such plans are often unavailable, as recipients report a need for written documentation detailing monitoring and screening requirements. Additional barriers to the implementation of survivorship care plans, from the clinician's perspective, include lack of awareness of their existence, the uncertainty regarding roles and responsibilities, and the perceived length or complexity of the plans (Morken et al., 2022).

This gap reflects the policy-practice disconnect identified in the literature (Dignan et al., 2021; Salooja et al., 2016) and the unmet informational needs highlighted in Study 1 (see Chapter 4). One possible explanation is the phased-in approach to LTFU with the same healthcare provider, where roles and responsibilities may not be clearly redefined. As noted by Dignan et al (2021)

and Salooja et al. (2016), some centres integrate both acute and LTFU services within the same clinic, which can blur the boundaries of care. The ongoing need expressed by recipients for written monitoring and screening guidance therefore highlights a significant unmet information need.

Survivorship care plans may also help address the psychological challenges that some recipients in this study reported when attending LTFU appointments. For some, attending appointments, receiving blood count results, and waiting for clinical tests were notable sources of anxiety, largely driven by uncertainty surrounding each aspect of the process. Supporting the findings of Hwang et al. (2012) and further corroborated by Hall et al. (2024) and Mutsaers et al. (2020), who identified that anxiety that among HSCT recipients and cancer survivors more broadly is associated with fear of cancer recurrence (FCR) and with perceptions of inadequate or uncertain screening practices. The lack of psychological support available from HSCT clinics may further contribute to this anxiety (Dignan et al., 2021), while threat-related attention bias, in which individuals become hyper-attuned to potential health threats, can also intensify anxious responses (Azriel & Bar-Halm, 2020). For example, HSCT recipients may become overly focused on screening practices due to concerns about adverse health complications and FCR (Parisek et al., 2021; Sharin et al., 2020), and higher levels of FCR are associated with increased vigilance regarding screening (Ozga et al., 2015). As screening is a preventative measure designed to identify and treat complications early, incorporating clear information about these practices into survivorship care plans may reduce FCR-related anxiety. Nevertheless, the ongoing unmet need for written guidance on monitoring and screening may itself contribute to anxiety, as patients report lower anxiety levels when their informational needs are adequately met (Vetsch et al., 2017).

These findings align with key health psychology principles, including Illness Uncertainty Theory (Mishel, 1988) and the Health Belief Model (Rosenstock, 1974), which explain how ambiguity in health status and unmet informational needs can heighten anxiety and shape engagement with follow-up care. Illness Uncertainty Theory highlights how unclear symptoms, prognosis, and medical processes such as waiting for blood count results or navigating inconsistent screening protocols can lead to psychological distress. The Health Belief Model suggests that engagement with follow-up care is influenced by perceived vulnerability and the perceived effectiveness of screening; when these perceptions are undermined, motivation may decline. Bandura's concept of self-efficacy further suggests that lacking information or support can reduce confidence in managing health, heightened anxiety and shape engagement with

follow-up care (Bandura, 2001). Freeston et al. (1994) emphasise that intolerance of uncertainty can itself intensify distress, as seen in heightened vigilance and threat-related attention among HSCT recipients. Addressing these psychological processes through clear communication and supportive interventions, such as survivorship care plans, is therefore essential for promoting psychological well-being and effective self-management in HSCT survivors. Survivorship care plans may thus serve as a bridge between psychological support and structural care delivery, helping to mitigate anxiety while reinforcing continuity and coordination across different models of LTFU care.

Three models of LTFU care were described in recipients' accounts: direct monitoring by the transplant centre, a hybrid model involving both transplant and primary care providers, and care delivered solely by local primary or secondary providers. This variation reflects existing literature, which shows that UK transplant centres adopt diverse approaches to monitoring practices (Dignan et al., 2021). Recipients under direct transplant centre monitoring report long waits between appointments and time-consuming clinic visits, consistent with the findings from de Vere Hunt et al. (2021) and Hwang et al. (2012). Those receiving hybrid care described greater convenience and reduced stress due to shorter travel distances and waiting times. Despite differences in care delivery, most recipients found reassurance in remaining on a coordinated healthcare pathway as access to specialised, efficient, and responsive care reinforced this sense of security. This aligns with findings from a systematic review of how patients perceive cancer follow-up care, which highlighted that regular specialist contact and timely access to tests were key sources of reassurance (Lewis et al., 2009). In this study, continuity of care was closely linked to maintaining trusted relationships with healthcare professionals.

Maintaining a continuous relationship with LTFU healthcare professionals was also central to recipients' experiences and was viewed as essential for receiving efficient and attentive care, consistent with findings from other studies (de Vere Hunt et al., 2021; Hwang et al., 2012; Parisek et al., 2021; and Sharin et al., 2020). One participant described how the loss of relational continuity led to diminished trust, feelings of abandonment, and a perceived decline in care quality. For some, continuity with clinical nurses, rather than doctors, was particularly valued, as nurses were seen as the primary facilitator of care and communication, consistent with the findings from de Vere Hunt et al. (2021) and Pariesk et al. (2021). This relational continuity also shaped help-seeking behaviour, with participants often avoiding General Practitioners (GP)

involvement either because their health needs were met by transplant clinics or due to concerns about GPs' lack of expertise in LTFU care, a pattern also observed by McErlean et al. (2024).

The limited involvement of primary care providers in LTFU care may present challenges for transplant centres in the future, especially considering evolving NHS policy. The 2025 NHS "Fit for the Future" Plan builds on earlier commitments to Personalised Stratified Follow-Up (PSFU) pathways by advancing community-first, digitally enabled models of survivorship care. These models shift greater responsibility to primary care providers to deliver tailored support closer to patients' homes (Department of Health and Social Care, 2025). While primary care professionals express willingness to support LTFU care, they report feeling underprepared and uncertain about their role in relation to transplant centres and not fully equipped to manage (Liemburg et al., 2022; Tichelli & Rovó, 2015). For hybrid models to succeed, it is essential that primary care teams receive appropriate training and support to recognise and respond to late effects following HSCT, which is an essential component of high-quality survivorship care (Giaccone et al., 2020). These challenges reveal that the success of LTFU care depends not only on structural coordination but also on the relational continuity that patients rely on for reassurance and support.

Recipient experiences further illustrate how both the organisation of LTFU care and the consistency of relationships with healthcare professionals shape perceptions of safety. While direct monitoring involved logistical burdens, it provided reassurance through specialist access. Hybrid models eased stress by improving convenience. Across models, recipients valued consistent relationships, particularly with clinical nurses, as central to feeling supported and receiving attentive care. These patterns reflect broader literature on cancer follow-up care, which identifies regular specialist contact and timely access to tests as key sources of reassurance (Lewis et al., 2009) and align with health psychology principles. Bandura (2001) emphasises that individuals are more likely to manage their health effectively when they feel supported by knowledgeable and consistent care providers. Mishel (1988) points out that uncertainty in medical processes, such as unclear communication or unpredictable outcomes, can contribute to heightened anxiety. Freeston et al. (1994) further argue that when people struggle to tolerate uncertainty, they may become overly focused on potential health threats, which can intensify emotional distress. Together, these insights reinforce the need for LTFU models that integrate both structural coordination and psychological safety, ensuring continuity of care not only in logistics but also in relationships.

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This study demonstrates several strengths that enhance its contribution to the literature on HSCT survivorship and LTFU care. Methodologically, it aligns with established qualitative research frameworks by employing a hermeneutic phenomenological approach and reflexive thematic analysis, enabling a rich exploration of participants lived experiences (Alsaigh & Coyne, 2021). The decision to collect data via online written accounts offered participants the flexibility to reflect and respond in their own time, which is particularly valuable when addressing sensitive and complex health topics (Taquette & Souza, 2022). Reflexivity was rigorously maintained through journaling and peer debriefing, enhancing the transparency and credibility of the analysis. The sample population further strengthens the study's relevance and depth, with participants varying in gender, age at transplant, and time since transplant.

Despite its strengths, this study has several limitations that should be considered when interpreting the findings and assessing their transferability. Although the sample included variation in gender, age, and time since transplant, it lacked data on ethnicity and socioeconomic status. These are key social determinants of health that influence access to care, provider communication, and psychological outcomes (Haynes & Loblay, 2024; see Section 2.5.4). Their absence restricts exploration of potential disparities in LTFU experiences and limits the inclusivity of the findings. Geographical diversity was also limited. All participants resided in England and received care within a narrow range of regions. This constrains the study's ability to examine regional disparities and reduces transferability beyond the NHS England context, although this was the intended scope. While seventeen participants provided sufficient qualitative depth, a larger sample would have enabled broader representation of LTFU care models and facilitated comparisons, particularly between hybrid and primary/secondary-only approaches (Gürsoy & Vatansever, 2025). The complexity of late effects further complicates interpretation, as some recipients may have remained under active care due to ambiguity in the transition from acute to LTFU care. Additionally, some participants underwent transplantation prior to the 2015 accreditation change, when centres were not required to monitor long-term outcomes and their accounts may not reflect current practices.

Recruitment via online support groups limited participation to those active on social media, potentially excluding less digitally engaged individuals and reducing demographic diversity (Benedict et al., 2019; Braun et al., 2021). Written accounts, selected for their appropriateness during the pandemic, encouraged thoughtful responses (Braun & Clarke, 2013), but the absence of alternative formats such as interviews may have excluded those less comfortable with writing, affecting sample diversity and data richness (Gill et al., 2008). While written responses

provided direct access to participants' language and avoided transcription errors, the use of prompts may have constrained expression or introduced bias (Hansen & Świderska, 2024). Nonetheless, several participants addressed topics beyond the prompts, suggesting minimal impact.

These limitations affect both the transferability and depth of the findings. Limited regional data and underrepresentation of care models may have obscured specific challenges or innovations (Brown et al., 2025; Drisko, 2024). The exclusion of less digitally literate individuals may also mean that the experiences of more vulnerable or isolated recipients are underrepresented (Western et al., 2025). Future research should adopt multi-modal recruitment strategies and offer varied participation formats, such as interviews or voice-recorded responses, to enhance inclusivity and capture a broader range of perspectives (Oates, 2012). These approaches would support a more demographically and geographically diverse sample, strengthening the transferability of findings.

### 5.6 Chapter Summary

The exploration of HSCT recipients' experiences of LTFU care in England addressed how individuals navigate the transition to LTFU, their engagement with the healthcare pathways, and the psychological and informational factors influencing well-being. Using a qualitative, phenomenological design and reflexive thematic analysis of written accounts, the study found that recipients often face uncertainty regarding the commencement of LTFU care, while deriving reassurance from sustained relationships with healthcare professionals. Efficient care coordination and continuity were valued, but participants reported unmet informational needs, particularly around screening and preventive practices.

While the written account methodology enabled broad participation, it also highlighted the need for deeper investigation into the specific informational needs of recipients. Addressing these gaps through further research will strengthen the thesis by providing a more comprehensive understanding of how communication and information provision shape LTFU experiences and outcomes. These findings reinforce the importance of ongoing inquiry into recipients' informational needs and preferences, which will be the focus of the next chapter, advancing the development of more effective and person-centred LTFU care strategies.

# Chapter 6. In-Depth Interview Study of Informational Needs Among HSCT Recipients Navigating LTFU Care in England

## 6.1 Chapter Introduction

As highlighted in the preceding two chapters, *information* plays a central role in recipients' experiences of LTFU care. Participants in both the systematic review with qualitative evidence synthesis (Chapter 4) and the written accounts study (Chapter 5) reported receiving insufficient information about late effects and the LTFU care process. This lack of information contributed to the uncertainty they experienced during the transition from acute to LTFU care. This uncertainty suggests a persistent unmet informational need that warrants further investigation. Accordingly, this chapter presents the third study of this thesis, which aims to explore and understand the informational needs of HSCT recipients attending LTFU care in England.

This chapter begins by outlining the rationale and aims of this qualitative study, which adopts a hermeneutic phenomenological approach as described in Chapter 3. It then details the methods used to address these aims, followed by the presentation and discussion of findings. This study was presented at the 50$^{th}$ Annual Meeting of the European Society for Blood and Marrow Transplantation Patient Advocacy Oral Session (see Appendix 36).

## 6.2 Study Rationale and Aim

Undergoing HSCT marks a pivotal stage in the treatment of several haematological conditions (see Section 2.2.2), but it does not signal the end of the healthcare journey. Instead, recipients face a prolonged period of structured survivorship care to manage significant long-term risks and late effects (see Sections 2.2.3 and 2.3). Survivorship Care Plans (SCPs), once advocated to support the transition from acute post-transplantation care to LTFU care, typically include treatment summaries, screening schedules, and preventive care recommendations (Majhail et al., 2012; McCabe et al., 2013; Tichelli et al., 2021). However, findings from the systematic review (Chapter 4) and recipients' written accounts (Chapter 5) reveal that SCPs are frequently unavailable or inconsistently implemented. More recently, international recommendations have withdrawn formal endorsement of SCPs for HSCT recipients, citing concerns about their comprehensiveness and applicability (Rotz et al., 2024), contributing to variability in care delivery and hindering efforts to promote self-management and psychological readiness.

Within the NHS, the shift towards personalised follow-up pathways emphasises the importance of empowering patients in their long-term health management (NHS, 2016, 2020). However,

Study 2 of this thesis found that recipients often rely on indirect cues, such as reduced appointment frequency or changes in care location, to infer their transition into LTFU care. This ambiguity undermines active patient participation and highlights a persistent unmet need for clear, consistent information.

Informational needs are closely linked to psychological outcomes and quality of life. Cancer survivors with fewer information barriers report better psychological well-being, including reduced anxiety and depression (Bevans et al., 2017; Vetsch et al., 2017). While HSCT-specific research remains limited, existing studies have focused primarily on inpatients or caregivers (Kaziunas et al., 2015; Vetsch et al., 2017), leaving a gap in understanding recipients' needs post-transplantation. Study 2 revealed that recipients often feel unprepared for the complexity and duration of recovery and lack clarity about the commencement and structure of LTFU care. These findings align with broader survivorship literature, which identifies gaps in information provision on nutrition, fatigue, sexual health, and psychological support (Pulewka et al., 2021; Yanling et al., 2023). Crucially, informational needs influence not only knowledge acquisition but also patient engagement, coping strategies, and health behaviours. Anxiety around screening appointments and test results is often exacerbated by uncertainty and fear of recurrence (Austin-Ketch & Paplham, 2015). These patterns persist even when information has previously been provided (Hawkins et al., 2008) and addressing late effects and self-care informational needs has been shown to enhance quality of life (Nakajima & Kamibeppu, 2022).

Theoretical frameworks help explain these responses. Illness Uncertainty Theory (Mishel, 1988), Intolerance of Uncertainty Theory (Freeston et al., 1994), and Uncertainty Management Theory (Brashers, 1995) suggest that ambiguity in health trajectories can lead to reassurance-seeking, avoidance, or selective engagement with information. These theories highlight the importance of tailored, timely, and reinforced information provision throughout the survivorship pathway. Health literacy, defined as the ability to access, understand, appraise, and apply health information, is increasingly recognised as a critical determinant of patient experience and engagement (Holden et al., 2021; Kim et al., 2016; Housten et al., 2021). In cancer survivorship, health literacy shapes how recipients interpret information about late effects, navigate care pathways, and make decisions about self-management (Samoil et al., 2021). Low health literacy is associated with poorer outcomes, reduced adherence to follow-up protocols, and increased psychological distress (Holden et al., 2021; Park et al., 2025). Interventions targeting health literacy have been shown to improve understanding, support self-management, and enhance quality of life (Housten et al., 2021).

Study 2 found that recipients who retained relational continuity with transplant teams felt more secure and empowered, whereas those who experienced discontinuity reported anxiety, disengagement, and diminished trust. These findings suggest that health literacy is shaped not only by individual capacity but also by the clarity, accessibility, and relevance of information provided by healthcare systems. Literature emphasises that health literacy is dynamic and context-dependent, evolving as patients interact with health systems and encounter new challenges (Nutbeam, 2008; Sørensen et al., 2012). Interventions such as tailored education, decision aids, and peer support have been shown to enhance engagement and reduce disparities (McCaffery et al., 2016; Rowlands et al., 2015).

Understanding why information is needed, rather than simply what is needed, is essential for improving care. Ormandy (2011) argues that informational needs arise from a perceived gap in knowledge required to achieve a specific goal within a given context and timeframe. Study 2 supports this view, revealing that recipients' needs are shaped by lived experiences, emotional states, and interactions with healthcare systems. Psychological and behavioural theories such as the Transactional Model of Stress and Coping (Lazarus & Folkman, 1984), Self-Determination Theory (Deci & Ryan, 1985; Ryan & Deci, 2017), and the Health Belief Model (Rosenstock, 1974; Champion & Skinner, 2008) offer insight into how unmet informational needs influence coping, motivation, and health behaviours. For example, recipients who maintain strong relationships with clinical personnel report greater engagement and psychological well-being, aligning with Self-Determination Theory's emphasis on autonomy, competence, and relatedness. The Health Belief Model illustrates how perceptions of susceptibility, severity, benefits, and barriers shape engagement in health-promoting behaviours (Champion & Skinner, 2008; Rosenstock, 1974). In HSCT, these perceptions influence adherence to follow-up regimens and self-management, as recipients weigh ongoing risks against the value and challenges of continued care (Diesch-Furlanetto et al., 2021; Kenyon et al., 2023). Social Cognitive Theory further emphasises personal agency, observational learning, and self-efficacy, key factors in navigating complex care routines and making informed decisions (Bandura, 2001; Bevans et al., 2017; Persoon et al., 2019).

In addition, the Candidacy Framework conceptualises access to care as a negotiated and dynamic process (Dixon-Woods et al., 2006). Recipients often feel uncertain about their eligibility for ongoing care, especially when transitioning from transplant centres to primary care providers. This uncertainty is compounded by inconsistent communication, lack of formal

handover, and perceived gaps in provider expertise (Dignan et al., 2021; Hashmi et al., 2017). Recipients described feeling dismissed or misunderstood by non-specialist services and expressed reluctance to engage with providers lacking transplant-specific knowledge (McErlean et al., 2024). These experiences reflect how candidacy is negotiated within institutional contexts, where patients must assert their need for care and navigate ambiguous boundaries of responsibility.

The absence of written documentation and structured education contributes to a sense of ambiguity of the healthcare system. Recipients unsure whether they have formally entered LTFU care may not perceive themselves as legitimate candidates for support, particularly when care is fragmented or depersonalised. This uncertainty can affect health-seeking behaviour, engagement with screening, and psychological resilience (Bevans et al., 2017; Vetsch et al., 2017). When relational continuity with transplant teams is maintained, it can instil a sense of security and empowerment, whereas discontinuity has been associated with increased anxiety and disengagement from care (Dignan et al., 2021; McErlean et al., 2024). These findings suggest that candidacy is shaped by both institutional practices and relational dynamics.

Taken together, informational needs, relational continuity, and the negotiation of candidacy highlight the need for a person-centred approach to understanding HSCT recipients' experiences of LTFU care (Kenyon et al., 2023; Santana et al., 2018). Critically analysing the interplay between information needs, health literacy, psychological and behavioural frameworks, and sociological perspectives, this study seeks to address persistent gaps in knowledge, practice, and policy. The rationale is grounded in the recognition that effective survivorship care must move beyond biomedical surveillance to embrace the complexities of patient experience, empowerment, and adaptation (Bandura, 2001; Deci & Ryan, 1985; Dixon-Woods et al., 2006; Ryan & Deci, 2017).

This study aims to examine HSCT recipients' informational needs in relation to purpose, context, and timeframe, retrospectively from the commencement of LTFU care. It seeks to understand these needs as shaped by lived experiences, rather than assumptions about what healthcare professionals believe patients should know (Ormandy, 2011). Providing a comprehensive foundation for interpreting recipients' informational needs and their impact on engagement, coping, and health outcomes. This perspective may help transplant centres better address recipients' needs post-HSCT, improving information provision and enhancing the quality of survivorship care.

## 6.3 Method

### *6.3.1 Research Design Overview*

Consistent with the approach adopted in earlier chapters, this phase of the research utilised a qualitative, phenomenological design to examine HSCT recipients' informational needs in relation to purpose, context, and timeframe, retrospectively from the commencement of LTFU care. Data were collected through semi-structured interviews and analysed using reflexive thematic analysis (Braun & Clarke, 2022). This continuity in design ensures methodological coherence across the thesis and allows for in-depth exploration of participants lived experiences. The rationale for this approach, including its phenomenological orientation and epistemological positioning, is explained in Section 3.3.

### *6.3.2 Study Participants*

In total, fourteen HSCT recipients (5 males, 9 females) from across England consented to participate in this study, each providing informed consent. Participants' age at transplant ranged from 34 to 68 years (mean age: 50.4 years), and the average time since transplant was 6.2 years (range: 2.6 – 13 years). The sample reflected a range of transplant experiences. Twelve participants received allogeneic HSCT, one received a cord blood HSCT, and one underwent a haploidentical HSCT. At the time of data collection, five participants had a confirmed diagnosis of GvHD. All participants confirmed that they had entered LTFU care and had attended at least one LTFU appointment prior to participation.

Participants described varied models of LTFU care. Seven received follow-up through a designated LTFU clinic, six experienced a hybrid model involving both specialist clinics and primary care providers, and one attended a general haematology outpatient's department. At the time of data collection, thirteen participants reported the interval between LTFU appointments as ranging from once every three months to annually.

Regarding information provision, half of the participants received details about potential late complications in booklet format, six received verbal information, and one reported receiving no information.

See Table 6.1 for a full overview of participant characteristics.

| No. | Gender | Age at TP | TP Type | TSTP (years) | Late effects Information Provided | LTFU Frequency | LTFU Care Model | Demographic Location |
|---|---|---|---|---|---|---|---|---|
| 1 | Female | 46 | Allo | 8.5 | None | Annual | Haem OP | North West |
| 2 | Male | 63 | Allo | 6.4 | Verbal | Annual | Clinic | North West |
| 3 | Female | 68 | Allo | 7.7 | Booklet | 9 monthly | Clinic | North West |
| 4 | Female | 34 | Allo | 3.3 | Booklet | 6 monthly | Hybrid | London |
| 5 | Female | 53 | Allo | 13 | Booklet | 3 monthly | Clinic | Yorkshire |
| 6 | Female | 44 | Allo | 2.8 | Verbal | 3 monthly | Hybrid | South West |
| 7 | Female | 36 | CB | 6.7 | Booklet | Annual | Hybrid | Midlands |
| 8 | Male | 37 | Allo | 2.8 | Booklet | 3 monthly | Clinic | London |
| 9 | Female | 60 | Allo | 5.6 | Verbal | 6 monthly | Hybrid | Midlands |
| 10 | Female | 53 | Allo | 2.7 | Verbal | 6 monthly | Hybrid | South West |
| 11 | Male | 50 | Haplo | 13 | Verbal | Annual | Clinic | London |
| 12 | Male | 53 | Allo | 6.8 | Booklet | - | Clinic | South West |
| 13 | Female | 66 | Allo | 5 | Verbal | 6 monthly | Hybrid | South West |
| 14 | Male | 43 | Allo | 2.6 | Booklet | 6 monthly | Clinic | North East |

**Table 6.1 Study Three Participant Characteristics**
TP, transplant; TSTP, time since transplant; LTFU, long-term follow-up; LE, late effects; Allo, allogeneic haematopoietic stem cell transplant; CB, cord blood haematopoietic stem cell transplant; Haplo, haploidentical haematopoietic stem cell transplant; Haem OP, haematology outpatients; Clinic, designated LTFU clinic; Hybrid, coordinated care between LTFU clinic and primary care providers.

### *6.3.3 Participant Recruitment*

Participants were recruited from online social media platforms including closed Facebook support groups for HSCT survivors and registered charities channels. The charities approached included Anthony Nolan and the Myelodysplastic Syndrome UK Patient Support Group (MDS UK). These charities were chosen due to Anthony Nolan being the UK's largest stem cell registry charity with a dedicated family and family channel, and MDS UK, as HSCT is the only known curative treatment for Myelodysplastic Syndrome and the charity has a dedicated closed patient and family group. Administrators of three other closed Facebook support groups were contacted, but either there was no response to my initial or follow-up correspondence or permission to recruit was denied. The two named charities provided permission and as a result Anthony Nolan posted an introductory statement about the research study, along with the participant recruitment poster (see Appendix 37), on to their Patients and Families page on 15 May 2023 (see Appendix 38). MDS UK granted permission for the researcher to post directly

into their closed MDS UK Patient Support Group Community Facebook group (see Appendix 39). A subsequent post, with an introductory statement about the researcher and the study, accompanied by the participants recruitment advert, was made on the 1 June 2023 (see Appendix 40).

The recruitment advert was also posted on the researchers' private Instagram page (see Appendix 41) and social media platform 'X' (formerly known as Twitter) (see Appendix 42). The poster invited potential participants to contact the researcher directly via an expression of interest email. All potential participants who expressed interest in the study were initially sent the participant information sheet (see Appendix 4) and consent form (see Appendix 6). Participants were asked to read the information sheet and only those who provided informed consent via return email proceeded to participate. Participants were given at least three weeks to consider participating before a follow-up was sent and if still no response no further contact was made.

To participate in the study, individuals were required to meet specific inclusion criteria. All participants had to be HSCT recipient, at least 18 years of age at the time of data collection, residing in England, and were at least two years post-transplantation. The latter criterion was chosen to ensure that the long-term monitoring phase of post-transplant treatment had been reached, and ample time had been allowed for participants to attend at least one LTFU appointment.

A convenience sampling approach was employed to recruit participants who were readily accessible and willing to participate. There was no predefined sample size, and recruitment ceased when sufficient data to answer the research questions had been obtained (Braun & Clarke, 2021a; Braun et al., 2021; Sandelowski, 1995). As discussed in the Study 2 (see Section 5.3.3), data sufficiency was assessed using a multi-faceted approach tailored to qualitative inquiry. This involved evaluating the richness and diversity of participant accounts, engaging in reflexive dialogue with supervisors throughout the analytic process, and monitoring for thematic stability as the data collection progressed.

The recruitment process commenced once ethical approval was granted (see Section 3.6 and Appendix 11), and ran from May 2023 to January 2024, much longer than initially anticipated due to the initial low participation. As discussed in Section 3.6, two ethical amendments were sought to address the low recruitment issue. The first ethics approval amendment was made in

July 2023 to introduce a £20 Amazon voucher as an incentive to participate. The implementation of such an incentive was deliberated, due to initial apprehensions of being perceived as coercive; however, it was decided that it was not and utilised the incentive to improve participant engagement levels. At the same time, to allow for increased participation an ethical amendment was also sought to extend the right to withdraw date and the project end date to 31 October 2023 and 30 November 2023 respectively. On receipt of amendment approval from the ethics board (see Appendix 12), and in a bid to increase participation an amended recruitment advert was posted on the researchers public Instagram page (see Appendix 43). This private page had seen an increased following since the initial recruitment adverts on both charity social media pages and groups.

Despite this second recruitment drive resulting in additional participants, data sufficiency was not determined to have been reached, and a subsequent ethics amendment was sought. This second amendment requested an extension to the right to withdraw date and the project end date to 29 February 2024 and 31 March 2024 respectively. Again, on receipt of amendment approval from the ethics board (see Appendix 13), a final attempt to increase participation was made via the researcher' public Instagram page (see Appendix 44). This had the desired effect, and no further amendments were sought and recruitment ceased in March 2024.

### *6.3.4 Data Collection*

All data were collected via semi-structured interviews, a research method frequently employed by researchers to comprehend individuals' subjective experiences and understanding (Kvale, 2012). This method was selected for this study as it enabled the researcher to establish a hermeneutic relationship with participants, which allowed for a deeper understanding of LTFU care needs from the recipients' perspective (DeJonckheere & Vaughn, 2019). Data collection commenced on receipt of the informed consent form (see Appendix 6). Signed consent forms were received by participants printing, signing, and then returning a scanned copy or photo of the completed form by email to the primary researcher. All interviews were held over Microsoft Teams and structured around an interview schedule (see Appendix 45). To ensure the interview schedule was both comprehensive and theoretically grounded (Braun & Clarke, 2013), the researcher developed a mind-map of key areas where informational needs might emerge for HSCT recipients transition from acute to LTFU care (see Appendix 46). This approach was informed by the findings presented in Chapter 4 and 5. The researcher also made reflexive notes during the interview process, acknowledging their own subjectivity to aid in data analysis. Interviews ranged in duration for 30 to 69 minutes, with an average length of 45 minutes. At

the end of each interview, all participants received a verbal debrief, which was followed up in written format (see Appendix 8), sent via email.

### *6.3.5 Analysis*

Prior to analysis, all interview recordings were transcribed verbatim and anonymised to protect participant confidentiality by the primary researcher. This process involved careful attention to detail, ensuring that identifiable information was removed while preserving the integrity and nuance of participants' narratives. Transcription also served as an initial phase of familiarisation, allowing the researcher to engage deeply with the data from the outset and begin forming early impressions of recurring ideas and emotional tones. As with Study 2, all transcripts were uploaded into MAXQDA software to support analysis.

Reflexive thematic analysis (TA) as guided by Braun & Clarke (2022), was again employed to analyse the interview data. While the analytic framework remained consistent with that used for Study 2 (see Section 5.3.5), the nature of the interview data introduced distinct opportunities and considerations. The dialogic format of the interviews enabled a more expansive and nuanced exploration of participants' experiences. The spoken format allowed for the capture of tone, hesitation, emphasis, and emotional reactions, elements that enriched the interpretive process. The six-phase process of reflexive thematic analysis, as outlined in Section 5.3.5, was followed. Familiarisation began with the transcription of all interviews by the researcher, allowing for initial immersion in the data. This process was deepened through listening to recordings and re-reading transcripts, with reflexive journaling used throughout to support interpretation and maintain awareness of positionality (see Appendix 47 for example).

Early data codes were generated inductively (see Appendix 48), capturing both explicit content and underlying meaning. These codes were then refined and organised, leading to the development of core codes and the emergence of themes (see Appendix 49). As themes began to take shape, the researcher engaged in analytic note-taking to further support interpretation and sustain reflexive awareness (see Appendix 50 for examples). This layered engagement was particularly important given the shared experiences between the researcher and participants, which at times facilitated deeper disclosure but also required heightened reflexive awareness.

## 6.4 Findings

This section presents the findings from fourteen interviews exploring HSCT recipients' informational needs in LTFU care in England. The analysis generated three main themes and

two sub-themes, which are illustrated in (see Figure 6.1). The themes do not stand alone but form part of a broader narrative about how participants experience, interpreted, and responded to the information they received, or did not receive, about the long-term health implications and monitoring practices post HSCT.

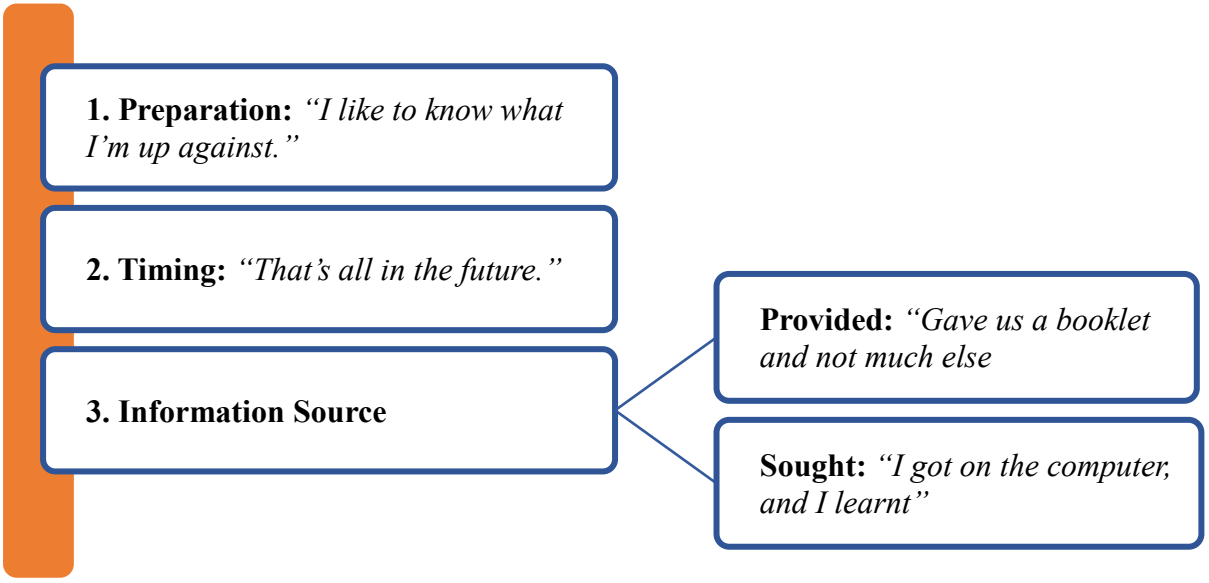


**Figure 6.1 Information Needs of HSCT Experiences of LTFU Care in England.**

The first theme, *Preparation*, reflects a retrospective desire for clearer, earlier information about the potential late effects and monitoring practices. The quote "I like to know what I'm up against" captures how participants felt that being better informed might have helped them feel more equipped to manage future complications. The second theme, *Timing*, explores the gap between receiving information and knowing when or how to use it. "That's all in the future" illustrates how the relevance of information often shifts depending on individual circumstances and health status. The third theme, *Information Source*, focuses on how participants access information. Two sub-themes formed, *Provided,* which reflects the limited formal information offered, and *Sought,* which highlights the proactive efforts participants made to seek out additional knowledge, often turning to online resources. Together, these themes offer insight into the emotional, practical, and relational dimensions of navigating LTFU care.

### *6.4.1 Preparation: "I like to know what I'm up against."*

A strong desire to be prepared and *better-informed* (P5) about potential late effects and monitoring practices from the outset was a common theme among the participants. Many described entering LTFU care with limited insight into what lay ahead, particularly in relation

to late effects and ongoing monitoring. While most recalled receiving some information, either verbally or in written form, it was often focused on the transplant procedure itself and the immediate risks, such as relapse, graft-versus-host disease (GvHD), and secondary cancer. There was little, if any, reference to the broader health implications that might emerge over time. As a result, participants described having little awareness of what to expect and feeling underprepared and uncertain about how to manage their health in the long term.

> *I didn't have a full awareness, I think, going into having this procedure of all the types of health implications that could possibly happen after transplant, apart from the immediate ones like GvHD… I don't think anyone really explained the full aspect of what a transplant would mean kind of longer term.* (P7)

> *Understanding what this looks like and what is the sort of expected impact on my life longer term that I think, you know, hasn't really sort of been revisited particularly.* (P8)

Where information about longer-term complication was provided, it was often described as minimal or incidental. One participant likened it to a *"footnote"* (P8), while another felt it was *"fobbed off"* (P4) until such complications arose. Another simply stated, *"It would be useful to know what the potential long-term effects can be"* (P2), reflecting a broader concern that such information was either absent or insufficient. These accounts highlight how long-term risks were not adequately addressed, leaving participants feeling unprepared for what lay ahead. Many expressed a need for clearer guidance on late effects and monitoring practices, not only to understand potential risks but also to take preventative action. Some participants emphasised the importance of having practical knowledge in advance, including knowing what actions to take if complications arose and feeling equipped to respond effectively. Others highlighted that having a clearer understanding of what to expect could lead to better outcomes, suggesting that being well-informed plays a key role in navigating post-transplant care. As illustrated by one participants account, the lack of information and clear expectations left them unprepared, turning what was initially described as a minor issue into an unsettling experience.

> *I like to be armed with information so that I can be productive. I don't like to be on the back foot. I like to know what's happening. So, I would have loved to have known everything that I might have to do, and what I might have to do yearly, monthly, or whatever.* (P1)

*A better-informed patient deals with it. If you read that you might get a small infection, at first you think, 'oh right, well they said that might happen, that's fine'. Then suddenly, a small infection - bloody hell, I'm dying! What's wrong with me? I was really frightened because they didn't tell you what to expect.* (P5)

Without consistent and comprehensive guidance, many participants described taking personal responsibility for managing their health after transplant. The sense of self-management was often shaped limited trust in the system and recognition that care was not always coordinated or tailored to individual needs. Several participants emphasised the importance of being proactive, describing how they developed personal strategies to stay informed and organised. These included tracking blood test results, preparing lists of questions for consultants, and keeping written records of symptoms and appointments.

For some, this approach was driven by concerns that important details might be missed or overlooked by busy clinical teams. One participant explained how they created a personalised checklist to keep track of age-related health actions, expressing doubt that anyone else would reliably manage those timelines. Others described compiling their own list of blood test results after noticing irregularities, unsure whether clinicians had the capacity to monitor them closely due to workload pressures.

*I've tried to keep my own list of, like ok, so when I'm [age] I need to try and remember to do this, and like when this happens I need to do that, because I don't feel confident that someone else is going to bag those things up at the right times and I feel like that's on me.* (P4)

*I get everything electronically now and it comes with the with the ranges and some of mine are low and high, so I've made a list of them... but now that everything comes out electronically, I was wondering if they had time to look at them because they are so busy.* (P3)

Some participants expressed a need for more specific information about the risks and health implications relevant to them personally. Rather than generalised statistical data, they wanted guidance that reflected their individual circumstances and helped them understand what they might face because of their transplant. One participant, for example, spoke about wanting clarity on their increased risk of developing secondary cancers and other long-term health issues.

Another described feeling overwhelmed by percentages and probabilities, preferring instead a straightforward list of actions they could take to support their health and reduce future risk.

> *I would like to understand, you know, what increased risk I would have of such [secondary cancers] and such future health issues as a result of the transplant.* (P14)

> *I don't want a list of things and percentage of how likely you get it. What I need is the list that just says, you know, to put yourself in the best position possible what you could consider doing [this]... you know, is there anything I can do.* (P9)

The need for clearer guidance extended beyond risk awareness to include practical tools for ongoing monitoring. Participants described how the information they received helped them recognise that complications *can arise at any time* (P13) and that regular screening was essential. In response, several suggested that a structured monitoring plan, similar to the vaccination schedule provided at the start of LTFU, would be beneficial. Such plans were seen as helpful for coordinating appointment across multiple clinics, supporting self-monitoring, and providing a clear reference for what to expect in the years ahead. One participant described how a forward-looking plan would help them anticipate future stages of care and know what to watch for. Another reflected on the uncertainty of follow-up schedules and the reassurance that more regimented approach could offer. These accounts highlight how structured planning could reduce confusion, support continuity of care, and help recipients feel more confident in managing their health.

> *It would be useful to have something similar that takes you through the next stages. [Provides medical example]… to have like a forward plan as to what [is] happening and what you should look out for.* (P2)

> *What would have been ideal is if I had a regimental plan of action… because I have a post-transplant one year and a haematology the next, so they see me every year, but you doubt sometimes whether everyone really knows what they're doing.* (P11)

These reflections on preparation show that readiness depends not just on receiving information, but on its relevance to the moment. Participants often lacked long-term insight and sought clear, actionable guidance to feel confident. Many took charge amid system gaps, relying on self-management and structured planning to navigate recovery. The usefulness of information

emerged gradually, shaped by emotional readiness, lived experience, and the need to know what comes next. This dynamic relationship between information and preparedness highlights the value of timely, relevant, and empowering support.

See Appendix 51 for theme coding matrix.

### *6.4.2 Timing: "That's all in the future"*

Participants consistently described the early stages of their transplant journey as a time of intense information delivery, particularly the pre-transplant consultation and consenting process. This moment, while intended to prepare patients for both the procedure and its potential long-term risk, was often experienced as overwhelming, both cognitively and emotionally.

The volume of information provided during the early stages of the transplant journey was described by participants as excessive and difficult to process. Many felt overwhelmed by the sheer amount of content, with one participant noting it was *"too much to take in"* (P8). This cognitive burden was evident in participants accounts, with some describing the experience as *"mind boggling"* (P12) and recalling that they were *"practically overloaded with information"* (P6). The unfamiliarity of medical terminology and the emotional weight of the transplant decision compounded the difficulty of absorbing and retaining information.

> *I got loads of stuff but that was when I went in for my stem cell, absolutely tonnes of information… Read a little bit but then I was not really in a headspace to read a lot of it.* (P10)

> *You get overloaded... there's all these new terminologies... so much information at one time... just being told in little sections I think is better.* (P12)

Participants often deferred engagement with information that related to long-term risks or future planning, focusing instead on the immediate demands of the transplant. This deferral was not due to disinterest, but rather a reflection of their limited capacity to process future-oriented content at the time.

> *A lot of things were mentioned and obviously I was given loads of like leaflets and booklets… Obviously at that time I'm thinking, oh well, that's all in the future. I can't plan*

*all of this now. That will happen in the future, and I definitely do feel now like, oh what were all those things.* (P4)

*When you're a patient going through this procedure... you're presented with statistics... I think you can't actually get any information in your brain because you're just scared.* (P7)

Some participants described selective attention to positive information, consciously or unconsciously filtering out negative or complex details. Others noted that their ability to ask questions or engage with risk-related information only emerged later in their recovery.

*They could say ten negatives and one positive, and I just focused on the positive... that's probably the same with literature... there was some positives there and that's what stuck with me.* (P12)

*I didn't have the physical or mental capacity to ask about the [risks]... it's only since I started getting better that I started asking.* (P1)

For several participants, the need for clearer and more detailed information only became apparent after transitioning into LTFU care. During this phase, clinical teams often referred health concerns deemed unrelated to transplantation to general practitioners (GPs). However, this delineation was not always clear to patients, who struggled to determine whether their symptoms were transplant-related, or general health issues. The lack of guidance created confusion and uncertainty about where to seek appropriate care.

This uncertainty was compounded by the complexity of late effects and overlapping symptoms, which made it difficult for participants to assess the relevance of their health concerns. Many described a tendency to rationalise any new or ongoing symptoms as transplant-related, even when they might not be. As one participant put it, *"when you don't know, you don't know"* (P9), highlighting the pervasive ambiguity that shaped their decision-making. This lack of clarity often led participants to default to the transplant team for initial guidance, with the expectation that they would be redirected to the GP if necessary.

*The transplant team would say, you know, this is probably not related to your stem cell transplant go and see your GP.* (P14)

*I've [had] some issues recently that I thought well, who do I go to, to my GP to [transplant team]? Quite often say this is a GP issue, you'll need to go through your GP.* (P7)

Participants also highlighted a lack of proactive communication about potential long-term effects, which further contributed to uncertainty. Without a clear understanding of what symptoms might be expected post-transplant, recipients often resorted to reporting everything during annual checks, leaving it to clinicians to determine relevance.

*I would say that from beyond six months to the two-year mark, it's like, well, what is it, is that a generic health problem or is it related to the transplant? But I think I just defaulted to the transplant team and allowed them to direct me back to the GP if required.* (P14)

*They don't tell you what the long-term effects could be so how do you know whether its relevant. I mean when I go to my annual check, I just tell them everything I'll let them work out whether it's related or whether not.* (P2)

Participants felt overwhelmed by complex, excessive information during the transplant process, often deferring long-term risks due to emotional strain. In recovery, ambiguity around which health concerns were transplant-related led to confusion and reliance on the transplant team, highlighting the need for clearer communication and better guidance on late effects.

See Appendix 52 for theme coding matrix.

### *6.4.3 Information Source: From "Gave us a booklet and not much else" to "I got on the computer, and I learnt"*

Another central theme to patients' informational experiences was how information was sourced. Information was either provided to, or actively sought, by recipients (See Appendix 53 for theme coding matrix).

#### *Provided: "Gave us a booklet and not much else"*

The majority of recipients reported that information about acute post-transplant complications and screening practices was verbally communicated, typically during the initial consent appointment. In approximately half of cases, the information was reaffirmed through booklets or leaflets, which were often focused on the immediate recovery phase and medical risks. However, these materials were described as limited in scope with some participants noting that

they were either overly clinical, difficult to interpret, or lacking in practical guidance. For many, the initial consent appointment and accompanying literature were the only formal source of information provided, leaving participants to navigate the complexities of long-term recovery largely on their own.

> *They obviously told you that there was a possibility that the [original diagnoses] could come back and everything, but not a lot of other information to be honest. You needed to know all the ins and outs of [transplant] but afterwards, there was just not that information given.* (P8)

> *All the literature and all the terminology is great for if you're in that field but just a normal Joe Bloggs, you know, basically he just wants to know, how best to deal with it, you know, what to expect, what are the side effects going to be, is it normal that you feel extra tired?* (P12)

No participants described having long-term health implications revisited after the initial consent appointment. As a result, participants felt that the longer-term consequences of HSCT, including late effects, hormonal changes, and psychosocial impacts, had not been adequately communicated by their clinical team. Instead, their understanding developed gradually through personal experiences as they progressed along the healthcare pathway.

> *I don't think anyone really explained the full aspect of what a transplant would mean kind of longer term… I was never told about menopause I remember that.* (P7)

> *There was some discussion of what kind of happens long term but a lot of that the [consultant] wanted to wait to see how I was doing. So, I knew bits, but I've sort of found out more as I have gone through the post-transplant process.* (P8)

A couple of participants recalled receiving verbal confirmation of the monitoring practices at the point of transition to LTFU, but this was typically limited to physical health checks and cancer screening. The emphasis was on surveillance rather than education, and participants were left unclear what monitoring entailed or how to interpret its significance.

*When I got to LTFU I was told it will be just to check that everything's still okay and reminders about any additional vaccinations because I had some, but also any other cancer checks.* (P2)

*They said to me that I'll be on the late effects clinic. I just presumed to check your bloods and everything, which is what they did when I attended, and they just asked me how I was feeling type of thing.* (P6)

Despite the lack of structured information, most participants did not express urgency or distress about this gap. This was largely due to the knowing they remained under monitoring for *"life"* (P2-4, and P7) and therefore felt reassured in the knowledge that they maintained direct contact with their clinical team. This enabled participants to have their informational needs met directly from the clinical transplant team, when required. The availability of contact numbers, email addresses, and familiar staff provided a sense of security and continuity, helping participants feel supported even in the absence of formal education about late effects.

*You know how it was explained to me was that they will keep me coming in and there's the contact if there's any issues in the meantime and feel free to contact them if there's any concerns.* (P14)

*I've got their e-mail address, and I know that they're very responsive so that I think has been something that's been quite reassuring for me in the back of my head this whole time.* (P4)

Some recipients felt confident initiating contact due to personal background or familiarity with healthcare systems, while others highlighted the importance of having a named point of contact to help interpret symptoms or concerns related to transplant recovery.

*I'm fortunate with my background; I'm not afraid of phoning up and questioning about what's going on, so I probably have an advantage compared to other people who have no knowledge at all and just sit there waiting to be told.* (P13)

*I think if I had a point of contact, that would have helped. Just someone I could ask whether anything going on with me was related to the transplant... because for a long time the doctors were saying it's probably due to the transplant.* (P1)

Across participants accounts, information provisions following transplant was consistently described as limited. Beyond the initial consent appointment and the provisions of a single booklet or leaflet, which was typically focused on short-term recover, there was little structured or ongoing information available. This lack of comprehensive resources frequently left participants to navigate the complexities of long-term recovery largely on their own. In response, many turned to informal sources of information to fill the gaps in their understanding and to manage the uncertainties of life after transplant.

***Sought: "I got on the computer, and I learnt"***

Participants frequently described turning to online search engines and digital platforms to obtain additional information about their condition, particularly in relation to late effects, symptom management, and treatment options. This self-directed learning was often prompted by gaps in clinical communication, a lack of tailored resources, or unclear verbal instructions during monitoring. For many, internet searching became not just supplementary, but essential.

> *I didn't know what [condition] was all about, but I got on the computer, and I learnt… You need to look on the internet because that's the only way you're going to learn. Nobody's going to sit you down and say this is going to happen, you have to learn.* (P5)

> *I've obviously read stuff; you know all the [booklets] and some of the blood cancer websites to sort of understand some of the likely longer-term complications.* (P8)

> *I'd like to know what they are looking out for. I discovered last time using Doctor Google that the test is looking for a specific thing that can affect post-transplant patients... but it would have been useful to know that that was coming up.* (P2)

In some cases, this proactive research directly influenced clinical outcome. One participant, who was initially told that there was no other treatment aside from surgery available for graft-versus-host-disease, found a specialist online who provided research papers that were later used by their UK consultant to guide treatment.

> *I found this specialist in Australia, and I messaged him. He sent me all this research papers back and I sent them all to my consultant who said right we'll use that treatment.* (P5)

However, the pursuit of information online was not without negative emotional consequences. One participant, receiving care from a non-specialised haematology department, described distress upon discovering disparities in LTFU care across different hospitals and regions. This comparison led to feelings of exclusion and helplessness.

> *I did have the sort of post-transplant booklet, and I looked a lot up and I am afraid Dr Google isn't always the best place to look, it sends you into a panic sometimes.* (P13)

> *When I have looked online, I've looked at like different hospital protocols and they're all different to [my hospital]… So now I just don't look cause it's like a form of torture. It's like why I do I have to look at that when I know they're getting everything that they need?* (P1)

Online support groups and social media platforms, particularly Facebook, emerged as another key source of information for recipients. These spaces were used for health validation, symptom management, sharing experiences, and clarify monitoring practices. Connecting with other recipients was seen as "*useful"* (P4), especially for clarification of symptoms and assisting in identifying possible causes. For some, peer-to-peer learning was described as more informative than clinical interactions.

> *I'm turning to like you know Facebook stem cell transplant groups and saying who's got experience of this [symptom]... that's actually quite useful to try and help with working out what it is.* (P4)

> *I participate in a support group and there are plenty of people on there that are in the same position as me… I wanted to know if any of the other post-transplant patients had got [symptom] too, so I find it helpful.* (P2)

However, these platforms also presented risks. A couple of participants reported heightened anxiety from reading about recurrence or complications, leading them to disengage from online communities. One recipient described how a conversation with a nurse helped reframe their perspective and reduce panic.

*I'm on a Facebook group and obviously there were people that were saying oh it's come back and everything like this, so I don't happen to look at it too much anymore because it scares me.* (P6)

*I was part of one on Facebook but I'm not part of that now because I just found them all so negative… It made me panic more like oh this could happen but [the nurse] said well what about all the thousands that are getting on with life like you're getting on with life and I haven't got bad things that happened, so yeah I got rid of all of that.* (P10)

Conversely, for another participant, exposure to others' experiences online prompted them to seek medical attention, leading to a hospital admission unrelated to their primary condition.

*Some people have such a difficult time… Struggling in general with after effects that you just think you just don't know!… That's what took me [to get checked] and it was nothing to do with [condition] at all, but I got admitted to the main hospital.* (P9)

These accounts illustrate the dual nature of online information-seeking: it can empower and inform but also overwhelm and distress. The variability in digital literacy, emotional resilience, and access to professional guidance shapes how recipients engage with online resources.

### 6.5 Discussion

This study is the first to qualitatively explore recipients' experiences of LTFU care to examine recipients' informational needs in relation to purpose, context and timeframe. Findings indicate a strong need for recipients to be more prepared, especially regarding treatment-related late-effects and for LTFU monitoring practices. This need was shaped by the time interval between information awareness, utilisation, and the source of information. This unmet informational need regarding late effects corresponds with those identified in previous research (Pulewka et al., 2021; Yanling et al., 2023), however, it also offers new insight of the preparation practices recipients undertake, and the influence of clinical information management for this cohort of patients.

These findings also highlight the role of health literacy in shaping recipients' ability to interpret, evaluate, and act upon clinical information. Health literacy, defined as the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions, is a critical determinant of patient experience and engagement (Nutbeam, 2008). In

this study, recipients' ability to manage uncertainty and prepare for future health events was influenced not only by the availability of information but also by their capacity to comprehend and apply it. For some, the volume and complexity of information presented during consultations exceeded their processing ability, leading to avoidance or disengagement. This suggests that improving health literacy through clearer communication, tailored education, and reinforcement may reduce informational burden and enhance patient autonomy.

In addition, recipients of HSCT described a need to be prepared for all possible late effects. Part of the rationale for LTFU monitoring is to address uncertainty regarding the health implications stemming from transplantation. As recipients expressed confusion about the long-term effects of transplantation and the associated follow-up care, this uncertainty influenced their information-seeking behaviours, consistent with Brashers et al. (2002). This study argues that the comprehension, accuracy, and objectiveness of clinical information provided before and at the start of LTFU care significantly shape recipients' uncertainty.

During the transplant consent consultation, some recipients reported receiving information about to potential long-term health implications. This information was combined with details about the transplant procedure itself, and many found the volume overwhelming. According to Illness Uncertainty Theory (Mishel, 1988), excessive health-related information can increase uncertainty, particularly when patients lack the cognitive resources or emotional readiness to process it. This study supports that view, showing that recipients often coped by deprioritising or avoiding information about long-term implications, a strategy consistent with the Transactional Model of Stress and Coping (Lazarus & Folkman, 1984). These behaviours reflect emotion-focused coping, where individuals manage distress by limiting exposure to perceived threats. Over time, recipients re-engaged with information, seeking clarity and control, an adaptive shift toward problem-focused coping. This transition demonstrates the importance of timing and reinforcement in information delivery, suggesting that revisiting key topics post-transplant may better align with recipients' psychological readiness and reduce uncertainty.

This uncertainty was further compounded by contradictions in clinical guidance. While recipients were initially informed, they could contact the transplant clinical team with any concerns, many later encountered conflicting advice directing them to General Practitioners (GPs) for non-transplant-related issues. This shift created confusion about which health concerns were considered transplant-related and which health provider was appropriate to

consult. Such contradictions not only disrupted continuity of care but also introduced new layers of uncertainty, particularly when recipients were unsure whether their symptoms warranted specialist attention. According to Babrow et al. (1998), conflicting information can intensify uncertainty by undermining trust in the reliability of guidance. In this study, recipients' uncertainty may have been exacerbated by unclear boundaries between specialist and generalist roles, suggesting that more explicit communication about clinical responsibilities and referral pathways could help reduce informational ambiguity and improve patient confidence in navigating care.

These informational contradictions could also stem from the transition from acute to LTFU follow-up care. Given that recipients' reassurance of direct clinical contact was based on previous positive interactions of using the service, it could be surmised they hold a general expectation of service accessibility. This is a similar finding to other cancer survivors' (Krishnasamy et al., 2011), who have a service expectation of being able to contact a specialised healthcare professional regarding any health concerns between follow-up appointments. Monitoring requirements differ between acute and LTFU care, as acute care prioritises immediate signs of relapse or recurrence. This urgency warrants the need for recipients to have direct access to the clinical team to seek medical guidance. The monitoring requirements for LTFU is preventative, rather than reactive, and therefore there is less urgency from the clinical team's perspective. Clarifying the difference between the two monitoring phases to recipients may reduce the uncertainty caused by contradictory information from the outset.

Additionally, the transition from acute to LTFU care represents a critical juncture in patient engagement. Recipients who do not perceive themselves as legitimate candidates for ongoing support may disengage from services or delay seeking help. This aligns with the Candidacy Framework (Dixon-Woods et al., 2006), which posits that access to care is shaped by how individuals interpret their eligibility and how institutions respond. In this study, ambiguous transitions and inconsistent messaging contributed to uncertainty about care boundaries and roles. Clarifying the structure and expectations of LTFU care may help recipients navigate these transitions more confidently and maintain engagement with appropriate services.

These findings also reflect the behavioural implications of unmet informational needs. According to Self-Determination Theory (Deci & Ryan, 1985; Ryan & Deci, 2017), patients are more likely to engage in health-promoting behaviours when their psychological needs for autonomy, competence, and relatedness are supported. In this study, recipients who felt

confident in their understanding of LTFU care were more likely to participate actively in monitoring and self-care. Conversely, those who experienced contradictory guidance or lacked clarity about provider roles expressed confusion and disengagement. Unmet informational needs may undermine perceived competence and reduce motivation to engage with LTFU care, while addressing these gaps through consistent messaging and personalised education may promote greater self-efficacy and long-term adherence.

Survivorship care plans may also be a strategy to minimise uncertainty experienced by recipients. Some participants expressed that such plans would help them manage their future monitoring. Providing recipients with follow-up care plans is recommended within the literature to ease the transition between acute and LTFU care (Majhail et al., 2012; Suárez-Lledó & Rovira, 2024). Previous literature, however, found that care plans do not contribute to improved patient-reported outcomes (Brennan et al., 2014; Grunfeld et al., 2011), or address unmet informational needs (Vetsch et al., 2017). This may be because the recommended content, treatment summaries and preventive care and screening practices, in these plans may be too generalised (Denzen et al., 2019). An opportunity therefore exists to increase the versatility of care plans, incorporating the LTFU process into them. Making a clear distinction between acute and follow-up care may also increase care plan efficacy (Morken et al., 2022).

In addition to reducing uncertainty, survivorship care plans have the potential to support behavioural action by clarifying expectations and reinforcing health-promoting routines. When designed to reflect individual risk profiles and care pathways, SCPs may enhance recipients' sense of control and reduce reliance on information-seeking. However, their effectiveness depends on how well they support patients' psychological needs and health literacy. Plans that are overly generic or poorly integrated into clinical conversations may fail to engage recipients meaningfully. Future versions should consider behavioural theory and patient feedback to ensure SCPs function not only as informational tools but as facilitators of engagement and empowerment.

An indirect contributing factor to the uncertainty experienced by recipients is the impact of social media for information needs. Recipients stated using online support groups for health validation, symptom management or clarity of monitoring practices. However, the implications of online use were mixed in this study. Some recipients reported using online support groups highlighted the multi-faceted nature of late effects associated with HSCT. However, the increased awareness of the unknown led for many to the uncertainty of the health symptoms

could be related to HSCT, which in turn caused anxiety and worry for some. This finding is consistent with other studies, that participating in online cancer communities can increase anxiety (DiFonzo et al., 2012; Park et al., 2020). For other recipients, engaging with fellow recipients through social media had a reportedly positive influence on their health and was perceived as a source of empowerment for self-care, which has also been positively related with increased information (Vetsch et al., 2017).

However, there is a fine line that separates the positive and negative benefits of online use, and to manage the uncertainty surrounding online use recipients should be made aware of both implications. The dual impact of social media also reflects broader issues of health literacy and information appraisal. Recipients who lacked the ability to critically evaluate online content were more vulnerable to anxiety and misinformation, while those with higher health literacy used digital platforms to validate experiences and enhance self-care. This suggests that digital health literacy, an extension of traditional health literacy, is increasingly relevant in survivorship care. Transplant centres may consider offering guidance on navigating online resources, helping recipients distinguish credible information from anecdotal or misleading content.

Whilst this study provides detailed accounts of HSCT recipients informational needs, limitations exist regarding the transferability of findings. Most recipients received LTFU care through dedicated clinics, limiting insights from those managed by primary healthcare providers, whose approaches to follow-up may differ in terms of resources, expertise, and continuity of care. This restricts the transferability of findings, as patients in primary care settings may face different challenges, have varying access to transplant-specific information, and rely more heavily on General Practitioners for long-term monitoring and support. Studies have shown that primary care providers often lack specialised training in transplant-related late effects and may struggle with care coordination and access to patient records, which can impact the quality and consistency of follow-up care (Cimino & Snyder, 2016; Liss et al., 2011, Majeed et al., 2008). As such, future research should aim to include a broader range of care settings to capture the diversity of follow-up experiences and ensure that recommendations for improving informational support are inclusive and applicable across healthcare contexts.

Additionally, two-thirds of participants were older than fifty, and while this group reflected diverse transplant experiences, their informational needs may differ from younger recipients. Research indicates older recipients often seek guidance on transplant after care, whereas younger individuals prefer information on physical health and sexual well-being (Pulewka et

al., 2021). This aligns with broader patterns in information-seeking behaviour, where younger adults explore a wide range of topics, and older adults focus on deepening existing knowledge (Coleman, 2018). The need for information specific to late effects and long-term monitoring may heighten the uncertainty and desire to be prepared for future health events. Ghodraty Jabloo et al. (2017) found that uncertainty in older cancer survivors is often intensified by gaps in knowledge, particularly regarding long-term outcomes. These findings suggest that age may influence the type and depth of information required, and future research should explore how information management and uncertainty vary across age groups. Understanding these nuances can help healthcare providers tailor communication and support, enhance informed decision-making and improve care quality for diverse HSCT populations.

In addition to care setting and age, the diversity of the sample population warrants further reflection. While participants varied in gender, age, transplant type, and geographic location, the sample lacked representation from ethnic minority groups and younger adults under 30. This limits the ability to generalise findings across all HSCT recipients, particularly those whose cultural, linguistic, or generational contexts may shape different informational needs and health-seeking behaviours. Research has shown that ethnic minority patients often face additional barriers to accessing transplant-related information, including language differences, cultural perceptions of illness, and systemic inequities in care provision (George et al., 2014; Boulware et al., 2002). Similarly, younger recipients may engage differently with digital health resources and may prioritise information on fertility, employment, and psychosocial adjustment (Pulewka et al., 2021).

These limitations in diversity may also influence the types of informational gaps identified. For instance, participants in this study largely described experiences within structured LTFU clinics, which may not reflect the challenges faced by recipients in under-resourced or rural settings. Moreover, the predominance of older, White British participants may have shaped the emphasis on preparation and monitoring, whereas other groups might prioritise different aspects of survivorship care. This observation is supported by Garcia et al. (2024), who found that disparities in transplant outcomes and access are influenced by socioeconomic and racial factors, highlighting the importance of inclusive sampling in survivorship research. Future research should aim to recruit more diverse samples to explore how informational needs vary across cultural, socioeconomic, and generational lines. Doing so would enhance the inclusivity and applicability of recommendations and ensure that survivorship care is responsive to the full spectrum of patient experiences.

Another potential limitation of this study concerns the depth and reliability of the data obtained through participant interviews. While semi-structured interviews allowed flexibility, some participants may have provided surface-level responses due to discomfort, recall limitations, or limited awareness of the scope of LTFU care. These challenges are common in qualitative research, where factors such as language, cultural discourse, and interviewer-participant dynamics can constrain the richness of data (Coleman, 2018). Additionally, response bias should be considered, as participants who agreed to take part may have had particularly strong opinions or experiences, either positive or negative, about LTFU care. This self-selection can lead to non-representative sampling, where individuals with neutral or less memorable experiences are underrepresented. As a result, the data may reflect more extreme views, skewing the interpretation of informational needs and care experiences. This concern resonates with findings in survivorship research, where Beeken et al. (2011) highlight how emotional engagement and psychosocial factors among HSCT survivors can influence self-reporting and introduce bias into qualitative findings. Moreover, social desirability bias may have shaped how participants described their interactions with healthcare providers, especially when they continued to receive care from the same institutions. This is consistent with findings in patient-reported outcomes research, where response styles such as extreme responding can distort trait estimation and lead to biased interpretations (Zhu et al., 2025). To improve the validity of future research, studies could incorporate anonymous surveys or triangulate interview data with clinical records to better capture the complexity of patient experiences and reduce bias.

The findings of this study may also be limited by the overlap of LTFU clinical services with acute monitoring. Participants confirmed at consent that they had entered LTFU and attended at least one LTFU appointment, but in their accounts often referred to experiences with acute care in addition to LTFU monitoring. Throughout the data collection process, this limitation was minimised by the researcher asking exploratory questions, but in some cases, participants were unable to distinguish the difference between acute and LTFU care experiences. It may be advantageous for future research to explore the experiences of transition from acute to LTFU care, as opposed to focusing on just informational needs. This shift in focus could provide deeper insights into the challenges faced by patients during this critical transition period. By understanding their experiences more comprehensively, researchers may identify specific areas for improvement that could enhance patient outcomes and satisfaction.

Despite these limitations, a strength of this study is the design. The qualitative exploration provided a rich, in-depth account and analysis of recipients' information needs. As a result, this

study not only identified unmet needs but also explored the motivation behind the need. Understanding the specific purpose behind the informational need has been described as essential to enhancing information provision (Ormandy, 2011). As the findings of this study demonstrates, it is not a question of *what* information is needed, rather, *why* the information is needed. This distinction allows for a more tailored approach in addressing those needs, ensuring that the information provided is relevant, actionable and consistent. Consequently, future interventions can be designed with a focus on the underlying motivation to be prepared for future heath events that drive the demand for information, leading to more effective support for recipients.

This study explores HSCT recipients' experiences of LTFU care in England, focusing on their information needs in relation to purpose, context, and timeframe. It found that recipients often feel unprepared for potential late-effects and monitoring practices, which contributes to uncertainty about future health implications. Clinical information management, including comprehension, accuracy, and objectivity of the information received, plays a critical role in shaping this uncertainty. Overwhelmed during consultations, recipients frequently seek additional information to regain a sense of control. The study demonstrates that informational needs extend beyond content to include context, timing, and psychological relevance. The findings offer a more nuanced understanding of how recipients interpret, seek, and apply information. Addressing these needs requires a multifaceted approach that supports health literacy, reinforces autonomy, and acknowledges the emotional and behavioural dimensions of survivorship. Future research and clinical practice should continue to explore how information provision can be tailored to meet these complex needs, ensuring that HSCT recipients are not only informed but empowered.

### 6.6 Chapter Summary

This chapter extends previous inquiry by qualitatively examining the informational needs of HSCT recipients as they transition into and navigate LTFU care. Drawing on semi-structured interviews conducted across England, the study explores not only what information is needed, but also when, why, and how it is sought, emphasising the role of preparation, timing, and source credibility in shaping recipients' experiences.

Key findings reinforce the importance of proactive preparation for late effects and LTFU monitoring and reveal how clinical information management contributes to uncertainty. The distinction between acute and LTFU care phases emerged as a critical factor in recipients'

understanding of service expectations and access. These insights reinforce the need for a personalised approach to information provision, recognising that recipients' goals, capacities, and contexts vary widely.

Overall, the study demonstrates that HSCT recipients often feel unprepared for LTFU care due to unmet informational needs, which in turn heightens uncertainty and affects their engagement with health services. Tailored, timely, and psychologically attuned information delivery is essential, not only to inform, but to empower recipients in managing their health and navigating care pathways. Such support has implications for psychological well-being, self-management, and long-term health outcomes.

As the next chapter will demonstrate, integrating these findings with prior research offers a more comprehensive understanding of HSCT survivorship. It highlights how informational needs and care transitions intersect to shape recipients' perceptions, behaviours, and outcomes over time.

# Chapter 7. Synthesis of Findings and Theoretical Interpretation

## 7.1 Chapter Introduction

This chapter brings together findings from components of this programme of work to offer a comprehensive synthesis of HSCT recipients' experiences of LTFU care in England. It begins by outlining the scope and rationale for the synthesis, before presenting insights drawn from the written accounts (Chapter 5) and interviews (Chapter 6). These findings illuminate key aspects of LTFU care, including ambiguity in care transitions, models of care and coordination, relationship continuity, and informational needs.

*Future Uncertainty* emerges as the central theme of recipients experiences of LTFU care. This encompasses both *Service Navigation Uncertainty* and *Health Uncertainty*, which shape how recipients' engage with and interpret their care experiences. Subsequent sections explore the evolution of these uncertainties over time, introduce the constructs of the *Ambiguous Outpatient* and *Relevance Ambiguity*, and situate the findings within established theoretical frameworks.

This chapter also applies and adapts Dixon-Woods et al. (2006) Candidacy Framework to explain how recipients negotiate access and eligibility for care within LTFU pathways. This offers a nuanced understanding of recipients experiences and positioning within the healthcare system in England.

## 7.2 Synthesis of Findings

This programme of work comprises three independent studies: a systematic review with qualitative evidence synthesis focusing on HSCT recipients' experiences of LTFU care in general (Study 1), a qualitative exploration of written accounts from recipients of LTFU care in England (Study 2), and a qualitative interview study examining the informational needs of HSCT recipients attending LTFU care in England (Study 3). While the systematic review with qualitative evidence synthesis provided valuable context regarding the broader literature on HSCT recipients' experiences, its findings were derived from studies conducted in diverse international settings with varying healthcare systems and demographic profiles. As a result, the transferability of these findings to the specific context of LTFU care in England is limited. To ensure the synthesis is both contextually relevant and methodologically coherent, the focus is placed on the primary qualitative studies (Study 2 and Study 3), which directly explore the lived experiences and informational needs of HSCT recipients in England.

This approach allows for a more nuanced and context-specific integration of findings, supporting the development of recommendations tailored to the realities of HSCT recipients, enhancing the practical applicability of findings for healthcare professionals, policy makers, and providers within NHS England's HSCT clinical settings.

### *7.2.1 Overview of Key Themes Across Studies*

In line with the focus outlined above, the synthesis presented in this section draws exclusively on the findings from Study 2 (written accounts) and Study 3 (interviews). This overview highlights the key themes that characterise recipients' engagement with LTFU care from each previous study, providing a contextually grounded foundation for subsequent interpretive synthesis and recommendations. Study 2 (Chapter 5) employed a phenomenological approach to examine recipients' experiences of LTFU care in England, generating four central themes:

1. **Transfer to LTFU Care:** ***"Will there be a change in my care or will appointments just become less frequent?"*** Participants experienced ambiguity and lack of clarity around the transition from acute post-transplant care to LTFU care. The shift was often passive, leading to uncertainty about whether a new phase of care had begun, with some only recognising the transition through logistical changes or stabilisation of clinical conditions.

2. **Care Coordination:** ***"It's good to know I am still in the system"*** Remaining within a structured healthcare pathway provided reassurance. Specialist-led care was valued for its thoroughness and continuity, but logistical challenges were evident. Hybrid models offered flexibility through remote consultations and Primary care-led models sometimes led to feelings of abandonment and reduced confidence in care. Access to clinical nurse specialists by phone or email was seen as essential for reassurance and timely support.

3. **Relationship Continuity:** ***"A good knowledge of me, my health and what is important to me"*** Sustained relationships with healthcare professionals, especially those involved since the transplant, strengthened trust and a sense of being cared for. Familiarity enabled holistic, personalised care. Disruptions to this continuity, such as transfers to new hospitals or consultants, could lead to feelings of being dismissed and unsupported.

4. **Late Effects Screening:** ***"There was not much information about what to expect or be aware of"*** Participants reported a lack of preparation and guidance regarding the duration and complexity of recovery, as well as limited information about possible late effects. This led to uncertainty and a need for self-advocacy, with some keeping personal records or proactively seeking referrals. Written documentation of future monitoring needs was highlighted as an unmet need.

Study 3 extended this inquiry by focusing specifically on the informational needs of HSCT recipients attending LTFU care. Three main themes and two sub-themes emerged:

1. **Preparation:** ***"I like to know what I'm up against"*** Participants expressed a strong desire for clearer, earlier information about potential late effects and monitoring practices. Many felt underprepared for long-term complications, having received only minimal or incidental information. This led to a reliance on self-management strategies, such as tracking test results and preparing questions for clinicians. There was a call for more personalised, practical guidance and structured monitoring plans to support ongoing care.

2. **Timing:** ***"That's all in the future"*** The early transplant journey was marked by information overload, making it difficult to process or retain details about long-term risks. Participants often deferred engagement with future-orientated information, focusing on immediate concerns. As recovery progressed, ambiguity about which symptoms were transplant-related led to confusion about where to seek care. The need for clearer, ongoing communication about late effects became apparent only after transitioning into LTFU care.

3. **Information Source.** Two sub-themes emerged within this domain:

   **Provided:** ***"Gave us a booklet and not much else"*** Most information was delivered verbally or via booklets at the initial consent appointment, focusing on immediate risks. There was little structured or ongoing information about long-term consequences, leaving participants to navigate recovery largely on their own. The reassurance of ongoing monitoring and access to clinical teams mitigated some of this gap.

**Sought:** ***"I got on the computer, and I learnt"*** Many participants turned to online resources and peer support groups to fill informational gaps. While this empowered some, it also led to anxiety and distress for others, especially when encountering negative experiences or inconsistent care protocols. Peer-to-peer learning was sometimes more informative than clinical interactions, but the variability in digital literacy and emotional resilience influenced how participants engaged with these resources.

In summary, Study 2 found that recipients of LTFU care experienced ambiguity around the transition to LTFU care, valued coordinated and continuous relationships with specialist teams, but often faced logistical challenges and inconsistent information about late effects screening. Study 3 revealed that patients had significant unmet informational needs, expressing a desire for clearer, earlier, and more personalised guidance about long-term risks and monitoring. Information was often limited to initial booklets or verbal instructions, leading many to seek answers online or through peer groups. Both studies highlight the importance of clear communication, structured care pathways, and accessible, ongoing information to support patients' confidence and self-management after transplant. Together, these themes provide the foundation for the next stage of synthesis, where converging, diverging, and emerging insights are explored to develop a deeper understanding of recipients' experiences, most notably, the overarching theme of *Future Uncertainty*.

### *7.2.2 Converging and Diverging Insights: The Emergence of Future Uncertainty*

This synthesis identifies *Future Uncertainty* as the emerging insight central to HSCT recipients' experiences of LTFU care in England, referring to recipients' pervasive sense of uncertainty regarding the trajectory of their care following transition into LTFU care. This uncertainty manifested in two principal forms: *Service Navigation Uncertainty*, relating to patients' ability to understand and move through healthcare systems, and *Health Uncertainty*, concerning their knowledge of ongoing risks, late effects, and self-management. Through a synthesis of converging and diverging insights from both written accounts and interviews, this analysis demonstrates how specific aspects of care, such as clarity and preparation in transition, continuity and coordination, informational gaps, self-advocacy, timing and information overload, and the emotional impact of informal information sources, each contribute to these forms of uncertainty. See Table 7.1 for a summary for how each synthesised insight was informed by the original themes from Study 2 and Study 3, with a brief explanation of the analytical connections.

| Synthesised Insight (Type) | Study 2 Themes (How they contributed) | Study 3 Themes (How they contributed) | Brief Explanation | Mapped to Sub-Theme |
|---|---|---|---|---|
| **Clarity and Preparation in Transition to LTFU Care (Converging)** | Transfer to LTFU care (Theme 1): Highlighted ambiguity and lack of formal communication in the transition process. | Preparation (Theme 1): Showed patients' desire for clearer, earlier information about late effects and monitoring. | Both studies revealed that unclear transitions and insufficient preparation contribute to uncertainty at key points. | Navigation & Health Uncertainty |
| **Continuity and Coordination of Care (Converging)** | Care Coordination (Theme 2), Relationship Continuity (Theme 3): Emphasised reassurance and safety from structured pathways and relationships. | Preparation (Theme 1): Indirectly reinforced the need for ongoing support and reassurance in care. | Structured care and sustained relationships enabled confidence; disruptions increase anxiety and uncertainty. | Navigation Uncertainty |
| **Addressing Informational Gaps in Long-Term Care (Converging)** | Late Effects Screening (Theme 4): Revealed lack of information about what to expect and inconsistent screening practices. | Preparation (Theme 1), Information Source (Provided & Sought) (Theme 3): Showed limited formal information and the need for patients to seek information themselves. | Persistent gaps in information provision led to uncertainty about late effects, monitoring, and self-management. | Navigation & Health Uncertainty |
| **Patient Self-Advocacy and Information Seeking (Converging)** | Late Effects Screening (Theme 4): Patients described taking proactive roles to manage gaps in care and information. | Information Source (Provided & Sought) (Theme 3): Highlighted patients' active efforts to find information online or through peers, and self-management strategies. | Patients respond to gaps by developing self-management strategies and seeking information from informal sources. | Health Uncertainty |
| **Timing and Information Overload (Diverging)** | - | Timing (Theme 2): Described how information overload at the outset led to deferral of engagement with long-term information. | Early information overload hinders patients' ability to process and act on guidance, increasing navigation uncertainty. | Navigation Uncertainty |
| **Emotional Impact of Informal Information Sources (Diverging)** | - | Information (Sought) (Theme 3b): Illustrated the emotional consequences (anxiety, reassurance, withdrawal) of seeking information from informal sources. | Informal sources can both empower and distress, amplifying health uncertainty and emotional responses. | Health Uncertainty |

**Table 7.1 Summary Table of Synthesised Findings from Study 2 and Study 3.**

To illuminate how uncertainty shapes the LTFU experience, the following analysis maps each converging and diverging insight onto the emerging insights of *Service Navigation Uncertainty* and *Health Uncertainty* (see Figure 7.1). Insights such as clarity and preparation in transition to LTFU care, continuity and coordination of care, addressing informational gaps, and timing and information overload are shown to underpin service navigation uncertainty. Reflecting recipients' challenges in understanding care pathways, roles, and access points within the healthcare system. In parallel, clarity and preparation in transition, addressing informational gaps, patient self-advocacy, and the emotional impact of informal information sources are explored as key contributors to health uncertainty. These factors highlight the challenges recipients face in anticipating, interpreting, and managing ongoing health risks. In situating each insight within these domains, the analysis demonstrates the complex and interdependent ways in which system-level processes and individual strategies interact to produce uncertainty throughout the LTFU healthcare pathway.

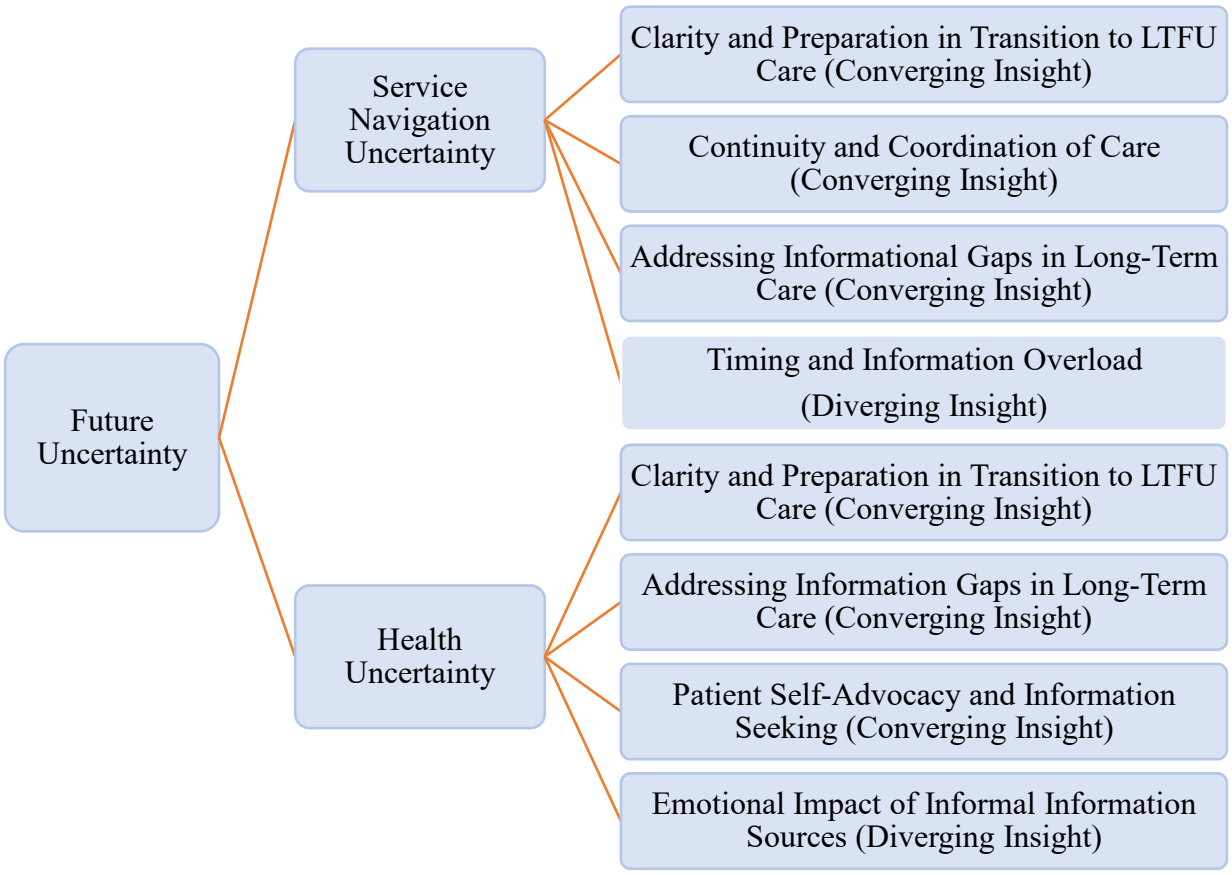


**Figure 7.1 Future Uncertainty in LTFU Care: Thematic Map of Recipient Experiences and Insights**

***Service Navigation Uncertainty***

*Service Navigation Uncertainty* emerged as a theme in participants' accounts of LTFU care, reflecting the challenges they faced in understanding, accessing, and coordinating services across different stages of their post-transplant journey. This section explores how clarity and preparation, continuity and coordination of care, informational gaps, and the timing and volume of information collectively shaped participants' experiences of navigating the healthcare system. Drawing on contrasting narratives from Studies 2 and 3, the analysis highlights how system-level structures and communication practices either mitigated or exacerbated uncertainty, influencing patients' confidence, autonomy, and sense of support within the LTFU care pathway.

For some participants in Study 2, clarity and preparation in service navigation were experienced as reassuring and supportive. As one participant explained, *"The care I receive is outstanding and I can call at any time if I have a query"* (P4, Study 2), highlighting how accessible support and open communication channels can reduce uncertainty and encourage confidence in navigating the system. This sense of clarity stands in stark contrast to the experience described in Study 3, where another participant reflected*, "They didn't put it down on anything... they just told me that I will only be seen yearly and a nurse told me that"* (P1, Study 3). Here, the lack of formal communication and written guidance led to confusion about follow-up and responsibilities, intensifying service navigation uncertainty.

Coordination between services also shaped participants' experiences. In Study 2, one participant noted *"[LTFU clinic] has liaised well with a more local hospital allowing me to have blood tests locally… this is more convenient, and I am able to request phone or face-to-face to suit me."* (P13, Study 2), demonstrating how effective collaboration between providers can ease navigation and reduce logistical burdens. This is notably different from the account in Study 3: *"I've kind of ended up under two hospitals ... and the systems don't you know get together"* (P4, Study 3), where fragmented care and poor coordination increased uncertainty and made it difficult to know where to turn for support. Informational gaps further compounded navigation challenges. The absence of written information was captured in Study 3: *"I didn't get a leaflet that said you'll going to have this"* (P12, Study 3), leaving the participant unsure about what to expect and how to prepare for LTFU care. When clarity was lacking, some participants resorted to self-advocacy and independent information seeking. As described in Study 3, *"You've got to find things out yourself… there's not always somebody there to help*

*you, so I've spent most of my time on google"* (P5, Study 3), reflecting the increased burden placed on individuals to navigate the system alone. This is less evident in Study 2, where direct access to a Clinical Nurse Specialist or similar support was available, reducing the need for self-management and enhancing the sense of being cared for.

Service navigation uncertainty is revealed through both positive and negative experiences of continuity and coordination, with each participant offering a distinct perspective. One participant in Study 2 describes *"I was transferred by transplant hospital to local hospital 4 years after transplant and this obviously marked long term follow up as appointment went to yearly and even more sporadic… and are very unorganised"* (P17, Study 2), highlighting how abrupt transitions and poor organisation can disrupt continuity and leave patients feeling unsupported. In contrast, another participant reflects on the benefits of clear scheduling and communication: *"My next appointment is agreed with the consultant during that visit and then I received a digital letter through the hospital's appointment system"* (P14, Study 2), demonstrating how proactive planning can support continuity and reduce uncertainty. However, logistical barriers persist, as a third participant shares, *"Getting time off of work and travelling can be a pain!"* (P16, Study 2), highlighting how practical challenges can undermine even well-coordinated care.

Turning to Study 3, one participant expresses frustration with ambiguous responsibility: *"Nobody wants to take responsibility and they all like just passing me between each other... I don't know who to go back to"* (P1, Study 3), revealing the confusion and anxiety that arise when roles are unclear, and oversight is lacking. Another participant describes the challenge of fragmented care: *"Last time... they asked my GP to arrange the blood test... that result never got to the [hospital]... it's not a perfect situation"* (P2, Study 3), highlighting how poor coordination between providers can leave patients managing their own care. In contrast, a third participant finds reassurance in accessible communication: *"Just having an e-mail address ... reassures me and makes me think I can access this when I need to"* (P4, Study 3), suggesting that even small acts of coordination can mitigate uncertainty. These varied experiences show that where care is joined up and communication is clear, uncertainty is reduced. Where systems are fragmented or roles are unclear, patients must self-advocate and navigate complexity, often at emotional and practical cost.

Following these challenges of coordination and role clarity, it becomes evident that addressing informational gaps in long-term care is crucial, as the absence or inconsistency of information

directly leads to service navigation uncertainty for patients. One participant in Study 2 shares, *"I was never too sure what to expect"* (P12, Study 2), highlighting how a lack of clear guidance about follow-up processes leaves patients uncertain about their care journey. Another participant notes, *"Some of the treatment feels more joined up than others, some feels too compartmentalised"* (P10, Study 2), illustrating how inconsistent information and fragmented communication between services can make it difficult to understand who is responsible for different aspects of care. A third participant in Study 2 adds, *"I had to request constantly my clinic letter which came with no blood results and for a few months had to chase them up too"* (P17, Study 2), showing how missing or delayed information forces patients to self-advocate and creates anxiety about their health management. These accounts show how inconsistent or missing information not only disrupts the continuity of care but also places an additional burden on recipients to seek clarity and manage their own health. This often results in heightened anxiety and uncertainty throughout LTFU process.

This pattern of uncertainty is further reflected in Study 3, where participants describe similar challenges arising from the absence of written or structured information, especially following changes in staff or care arrangements. For example, one participant shares, *"No, nothing. Just to talk with the nurse who subsequently left... she said you just ring up and ask for the long-term nurse,"* (P1, Study 3), revealing how unclear guidance leaves patients unsure about who to contact or what to expect. Another explains, *"I think a better informed patient does better if they know what's ahead of them and they all should be told right after your transplant we're going to keep monitor and don't worry we never going to leave you,"* (P6, Study 3), emphasising the reassurance that comes from clear, ongoing information and the uncertainty that arises when it is lacking. A third participant notes, *"I think it would have been ideal if I had a regimental plan of action, you know, where it said, you're going to have this on these dates"* (P11, Study 3), showing that structured, anticipatory information can reduce uncertainty and help patients navigate their care more confidently. Together, these quotes demonstrate that informational gaps, whether in written guidance, communication, or clarity about processes, are a key driver of service navigation uncertainty in long-term care.

Compounding these challenges, the timing and sheer amount of information provided to patients can also create confusion and uncertainty. As described by participants in Study 3, experiencing both too much and too little information at critical points in their care journey. One participant explains, *"They throw a lot of things about the longer term risks of other cancers and various things and you're like well ok but yeah, I don't know what to do with that*

*information really,"* (P8, Study 3) revealing how being presented with a large volume of complex information at once can be overwhelming and make it difficult to discern what is relevant or actionable. Another participant observes, *"I think probably you do have to keep a bit of… responsibility for yourself like for reminding different things,"* (P4, Study 3) suggesting that unclear timing and the burden of managing fragmented information force patients to self-manage and keep track of their own care, which can add to their uncertainty. A third participant adds, *"I didn't know what GvHD was… what a shock I got when I started to read and thought nobody ever told us about this"* (P5, Study 3) which demonstrates how a lack of clarity about transitions and timing can heighten confusion about what to expect and how to navigate the system. Together, these quotes show that both poorly timed information and information overload contribute to service navigation uncertainty, leaving patients unsure about what to expect and how to manage their long-term care.

Overall, participants' experiences of service navigation reveal a complex interplay between structural organisation, communication practices, and individual agency. While some accounts illustrate how proactive coordination, accessible support, and clear information can promote a sense of security and ease in navigating care, others expose the disorienting effects of fragmented systems, ambiguous roles, and informational voids. These disparities highlight the importance of consistent, joined-up care and timely, transparent communication in reducing service navigation uncertainty.

***Health Uncertainty***

*Health Uncertainty* captures the emotional and cognitive challenges patients face in anticipating, interpreting, and managing their long-term health following HSCT. This section explores how clarity and preparation during the transition to LTFU care, the presence or absence of comprehensive information, the need for self-advocacy, and reliance on informal sources all contribute to patients' sense of uncertainty. Drawing on narratives from Studies 2 and 3, the analysis highlights how gaps in communication, fragmented care, and inconsistent guidance can leave patients feeling vulnerable and unsupported as they navigate complex and evolving health risks.

To begin, participants' reflections on the transition into LTFU care reveal how early experiences of clarity, or the absence thereof, can significantly shape their perceptions of ongoing health risks. These formative moments influence patients' expectations, their interpretations of symptoms, and their engagement with follow-up care. The following accounts from Study 2

illustrate how structured communication and consistent follow-up can offer reassurance, while also highlighting how uncertainty persists when the timing and content of information are unclear or insufficient. One participant described, *"After the appointments I feel more reassured and it is good to know I am 'still in the system' rather than being signed off, as I think this would make me more anxious"* (P3, Study 2), emphasising how ongoing engagement and clear follow-up can provide reassurance and reduce anxiety about future health. Another participant noted, *"I have not yet reached many of the 'milestones' at which specific late effects need to be monitored for,"* (P13, Study 2) illustrating how uncertainty about the timing and nature of long-term monitoring can leave patients unsure about what to expect and when to seek help. A third participant reflected, *"There is always a sense of trepidation before a visit as it usually involves getting blood results to show improvement or not, so I either come home in a good mood, or frustrated"* (P14, Study 2) demonstrating how the anticipation of follow-up appointments can be both reassuring and anxiety-inducing, depending on the clarity of information provided.

Experiences from Study 3 support and extend these concerns, offering further insight into how the absence of clear guidance during the transition to LTFU care can intensify health uncertainty. One participant shared, *"what are the side effects going to be? Is it normal if you get night sweats for example or is it normal that you feel extra tired"* (P12, Study 3), revealing how a lack of clear guidance during the transition to LTFU care can heighten uncertainty about health status and late effects. Another participant observed, *"I think people will lookout for certain things but there's longer term effects, so things like fatigue I still struggle with to this day,"* (P7, Study 3) emphasising the importance of ongoing information and preparation for managing late effects. Together, these accounts demonstrate that when clarity and preparation are lacking during the transition to LTFU care, patients are left with heightened health uncertainty, unsure about what to expect, how to monitor their health, and when to seek help.

This sense of uncertainty is further compounded by persistent informational gaps throughout the long-term care journey. While the transition phase is critical, participants also described how the absence of clear, timely, and comprehensive information beyond this point continued to affect their ability to understand and manage ongoing health risks: *"I don't think I was told about some of the possible late effects, and I don't think there was much information about what to expect or be aware of."* (P10, Study 2). Addressing these gaps is fundamental to reducing health uncertainty, as illustrated in the following accounts. In Study 2, one participant reflected, *"I have other conditions so sometimes feel like my care is incomplete,"* (P15, Study 2) highlighting how a lack of integrated information about all aspects of health can leave patients

feeling unsupported and anxious about whether their needs are being fully addressed. Another participant described, *"Still feel quite shellshocked several years after diagnosis and anxious in lead up to appointments regarding relapse"* (P3, Study 2) illustrating how uncertainty about what information will be provided, and when, can heighten anxiety about ongoing health risks. A third participant noted, *"Would like to know the efficacy of the vaccine – not optimistic!"* (P7, Study 2) showing how gaps in information about specific aspects of care can leave patients feeling uncertain about their protection and future health.

Accounts from Study 3 offer further evidence of how informational gaps persist across different stages of the LTFU experience. Participants described how the lack of comprehensive, accessible, and sustained information left them unprepared for the long-term effects of treatment and unsure about how to manage their health independently. One participant explained, *"I didn't have a full awareness I think going into having this procedure of all the types of health implications that could happen after transplant, apart from the immediate ones like GvHD"* (P7, Study 3), revealing how the absence of comprehensive information at the outset can leave patients unprepared for the long-term effects. Another participant reflected, *"I'm sure they probably explained to me, but I can't remember to be honest… maybe just a simple leaflet which says this is what the late effects clinic is all about"* (P11, Study 3), highlighting how the lack of accessible, ongoing information can leave patients uncertain about what to expect and how to manage their health. Together, these accounts show that when informational gaps exist, whether in integration of care, communication, or clarity about processes, patients are left with heightened health uncertainty, unsure about what to expect, how to monitor their health, and when to seek help.

Beyond the absence of information itself, participants also described how these gaps often required them to take on the burden of navigating their care independently. In this context, patient self-advocacy and information seeking emerged as key responses to health uncertainty. One participant described, *"I was totally reliant on the hospital to tell me what we should be doing and what we shouldn't be doing,"* (P5, Study 3) highlighting how, in the absence of clear, ongoing guidance, patients may feel left to navigate complex decisions alone. Another participant explained, *"I just have no confidence in nothing. I said if ever I am ill again I'll just get someone to take me to [transplant hospital] because I'm not getting anywhere with the GP"* (P3, Study 3) revealing how lack of coordinated information can force patients to advocate for themselves and seek alternative routes to care. A third participant observed, *"I've had to learn, I didn't know what [condition] is… I got on the computer, and I learnt"* (P6, Study 3)

demonstrating how patients may proactively seek out external resources and networks to fill gaps left by fragmented or inconsistent care. Together, these accounts from Study 3 show that health uncertainty often drives patients to become active seekers and advocates, filling gaps left by the system and taking responsibility for their own care when information or support is lacking.

While these acts of self-advocacy can be empowering, they also carry a significant emotional toll. Participants described the psychological strain of relying on informal sources to fill the void left by inconsistent or absent professional guidance. The emotional impact of this reliance emerged as a key diverging insight, further intensifying health uncertainty for many. One participant described, *"It's almost like every time you do need to go to the GP about something you're having to explain your whole history again and again to different GPs,"* (P7, Study 3) revealing how the absence of accessible professional support leads to feelings of isolation, frustration, and the burden of having to repeatedly advocate for oneself in the healthcare system. Another participant shared *"I don't have enough trust [in] the system so I feel like I just need to be alert and I'm probably going to do better if I keep on top of it myself and keep reading stuff"* (P4, Study 3), highlighting the emotional strain and vulnerability that come with self-education, especially when facing serious health risks without clear guidance. The process of searching for answers online or through peer networks can be both empowering and distressing, as patients may encounter conflicting or frightening information. A third participant observed, *"I've spoken to people on Facebook that I know had transplant at the same time as me and their care is totally different… I just don't look because it's almost like a form of torture"* (P17, Study 3), suggesting that the need to rely on informal sources often stems from inequities in formal care, which can further amplify feelings of uncertainty, frustration, and unfairness. Collectively, these experiences show that when formal information is absent or inconsistent, turning to informal sources can both alleviate and exacerbate emotional uncertainty, leaving patients to navigate their health concerns with heightened worry and less reassurance.

In summary, these accounts reveal that health uncertainty is shaped not only by the availability and clarity of information but also by the degree to which patients are supported in interpreting and acting upon it. When formal guidance is lacking or inconsistent, individuals are often left to navigate complex health risks independently, relying on self-advocacy and informal sources that can both empower and overwhelm. These experiences emphasises the need for integrated, anticipatory communication and sustained support throughout the LTFU journey. As the following section explores, such uncertainty is not static, it evolves over time and is mediated

by patients' adaptive strategies and shifting informational needs. Understanding these temporal and adaptive patterns is therefore essential to designing responsive, patient-centred models of long-term care.

## 7.3 Navigating Transition, Ambiguity, and Adaptation in LTFU Care

A central finding of this thesis is the pervasive and evolving uncertainty experienced by HSCT recipients as they transition from acute post-transplant care to LTFU care. This section synthesises empirical patterns and theoretical insights to provide a holistic understanding of how recipients navigate transition, ambiguity, and adaptation throughout the LTFU journey.

### *7.3.1 Temporal and Adaptive Patterns: Ambiguous Outpatient*

Recipients' experiences of LTFU care in England reveal a dynamic and evolving relationship with outpatient services, shaped by uncertainty and adaptation over time. Central to this experience is a persistent sense of service navigation uncertainty, characterised by a lack of clarity about when and how to access appropriate care, who holds responsibility for monitoring, and what constitutes the boundaries of LTFU. This section introduces the construct of the *Ambiguous Outpatient* to capture these uncertainties, particularly as they relate to LTFU monitoring practices and their implications for healthcare access. The construct unfolds across three temporal phases: continuity, transition, and adaptation. Each phase reflects distinct psychological and behavioural responses to service ambiguity, especially in relation to responsibility, access, and clarity, and illustrates how service navigation uncertainty evolves and intensifies over time.

The first of these, the continuity phase, is marked by perceived stability and a masked transition into LTFU care. Participants describe a sense of ongoing support from transplant teams, even as the frequency of appointments begins to change. This phase illustrates how familiarity and relational continuity can obscure the recognition of a formal shift into LTFU care. Participants report being *"not sure"* (P10, Study 2) when LTFU care *"officially"* (P13, Study 2) commenced, and as one participant explained, *"I started off being really pleased when the sort of the appointments was being spread out further… I feel like the standard of care, when I needed it, was so good that they would not just be cutting me free"* (P2, Study 3), suggesting that continuity masked the transition. Another noted, *"I feel the care I receive is excellent and I know that I can always get a quick response, especially from the nurses if I phone or email them at any time"* (P14, Study 2), reinforcing how the reassurance provided by familiar clinical relationships delayed the recognition of a shift into LTFU.

This perception of continuity was further reinforced by participants belief that monitoring is *"life-long"* (P3 and P4, Study 3), shaped by their experiences of acute care. With health needs seemingly met and clinical relationships intact, participants expressed minimal urgency to the specifics of LTFU monitoring. Any uncertainty that did arise was mitigated by the presence of *"high-quality"* (P1, Study 2) relational continuity with the transplant team. For many, this proficient continuity reduced reliance on primary healthcare providers: *"I have had little contact with my local GPs since most issues were dealt with by the haematology department, including long-term prescriptions."* (P1, Study 2) and blurred the distinction between acute and LTFU care. The intervals between appointments, *"seem to be related to years' post-transplant: 2 months after 2 years, 3 months after 3 years and so on."* (P7, Study 2), were often the only discernible markers of change. These evolving appointment intervals, shaped more by time elapsed than by clinical milestones, exemplify the ambiguous and adaptive nature of outpatient LTFU care.

Overtime, this sense of continuity began to shift. Participants started to question the boundaries of their care and reassess their understanding of monitoring responsibilities. This marks the beginning of the transition phase, where the need for clearer information and greater autonomy becomes more pronounced. Participants began to reassess their existing knowledge of the monitoring practices and expressed a growing need for more information, particularly regarding the cancer-screening requirements. Their desire for clarity was driven by a need to understand individual responsibilities and to take greater ownership of future monitoring. Uncertainties centred on whether screening practices would be initiated by the transplant team, what the clinical team was monitoring for, and how to interpret previously provided verbal instructions. As one participant put it, they are *"not afraid of phoning up and asking questions or going in and asking"* (P13, Study 3), illustrating the shift from passive reassurance to active information-seeking. Receiving written monitoring plans was seen as beneficial for enhancing self-management, *"to have like a forward plan as to what is happening and what you should look out for."* (P2, Study 3). This shift toward active information-seeking and personalised planning reflects the evolving, patient-led adaptation to outpatient care, where temporal cues and ambiguous responsibilities increasingly shape the monitoring experience.

As uncertainty around LTFU practice intensified, participants increasingly sought information to better understand the processes involved. Many participants described a strong desire to be *"armed with information"* (P17, Study 3), feeling that being well-informed enabled them to be more proactive and productive in managing their care. For example, one participant explained,

*"I think I find it helpful to read through stuff before an appointment because it gives me more opportunity to think about the questions I want to ask"* (P8, Study 3). This behavioural shift towards information-seeking was often triggered by specific uncertainties, such as questions about cancer screening requirements. As one participant reflected, *"I do think it's good to have a handle on one's own care and monitoring, but it would help to have a written copy of all the things that can be identified for future monitoring/screening."* (P13, Study 2). These accounts highlight how gaps in clarity or consistency prompted individuals to actively seek out, record, and clarify information to navigate their LTFU care more confidently.

While seeking information initially provided a sense of control, it also exposed inconsistencies and gaps in service provision that had previously gone unnoticed. This growing awareness marked the beginning of the adaptive phase, marked by a move from passive reassurance to active information-seeking. In the adaptive phase, participants were required to navigate ambiguity more independently and manage the emotional impact of disrupted continuity and unclear responsibilities. Gaining additional information about monitoring practices led to some participants to experience anxiety, predominately in relation to cancer-screening and LTFU appointments.

The increased awareness of screening requirements, especially those outside national screening programmes or inconsistencies between different centres, was one reported source of anxiety for participants. This anxiety was exacerbated for some participants due to the waiting times for screening and the unknown impact of treatment on health. For other participants, it is the uncertainty surrounding cancer-screening attendance, as some questioned if they were attending enough screening given the potential implications of HSCT on future health. One participant described that while monitoring practices *"are mentioned from time to time and I try to write them down as I don't always feel confident that this will be remembered at the right time by my medical team."* (P13, Study 2), highlighting the confusion caused by shifting service boundaries. Another participant reflected on transferring to their local hospital *"consultant dismissed everything I said or asked about and I felt like he had belittled my experience"* (P17, Study 3), capturing the emotional impact of disrupted continuity.

Across the phases of continuity, transition, and adaptation, participants' experiences of LTFU care were consistently hindered by uncertainty in knowing which health service to approach and whether their symptoms were HSCT-related. This persistent ambiguity affected their

confidence and ability to navigate care at every stage, setting the foundation for the following discussion of how relevance ambiguity further amplifies these challenges in LTFU care.

### *7.3.2 Interplay and Amplification: Relevance Ambiguity*

Health uncertainty, closely intertwined with service navigation uncertainty, often emerged early in the transplant journey and persisted into LTFU care. While participants were informed of potential long-term complications during the transplant consent process, this information was often vague. As one participant from Study 2 reflected, *"I don't think I was told about some of the possible late effects, and I don't think there was much information about what to expect or be aware of"* (P10, Study 2). The information provided primarily focused on immediate complications and the importance of cancer screening. Although the consent process included information on risks, the emphasis on acute complications and cancer surveillance left many participants underprepared for the unpredictable and often delayed onset of late effects. *"No information on what to expect, what I might come down with, what might happen, what I would do if it did happen, nothing!"* (P1, Study 3). This lack of clarity increased health uncertainty, especially once participants began to recover from the immediate implications of HSCT, and transitioned into LTFU care.

In the continuity phase, participants felt reassured by continued access to specialist care. The transplant team often became a *"surrogate GP"* (P13, Study 2), particularly given the perceived lack of expertise in primary care. *"I would much rather talk to them than a GP as GPs don't have the experience and always end up calling the transplant team anyway"* (P7, Study 2). This dependable access instilled a sense of safety*: "The care I receive is outstanding and I can call at any time if I have a query"* (P4, Study 2). However, this reliance also discouraged engagement with GPs. One participant shared, *"I just have no confidence in nothing I said if ever I am ill again I'll shall just get someone to take me to [transplant hospital] because I'm not getting anywhere with the GP"* (P3, Study 3). This dependable access to specialist teams provided reassurance but also discouraged engagement with primary care, which was often viewed as lacking expertise. As participants increasingly bypassed GPs, the boundaries of responsibility for long-term care became unclear. This reinforced relevance ambiguity, where specialist care felt essential while the role of primary care remained uncertain, amplifying both health and service navigation uncertainty during LTFU.

As participants' health stabilised, they entered the transition phase, reassessing their understanding of long-term risks and recognising gaps in their knowledge: *"They don't actually*

*tell you what the long-term effects could be so how do you know whether it's relevant?"* (P2, Study 3). This reassessment was often prompted by new symptoms, secondary diagnoses, or attempts to revisit earlier information that seemed insufficient at the time. Participants expressed a desire for more personalised, actionable guidance. One participant stated, *"I would like to understand, you know, what increased risk I would have of such [secondary cancers] and such future health issues as a result of the transplant"* (P14, Study 3). These reflections prompted participants to question whether they had truly understood the scope of long-term risks at the outset of their treatment.

In the adaptive phase, the unpredictable nature of late effects became a persistent source of anxiety. This unpredictability amplified health uncertainty and led to a desire for more personalised information and guidance. *"Every time there's a twinge or there's something I automatically think is it a result of the transplant? Is it something failing, am I relapsing, or is it just the fact that I'm getting older?"* (P3, Study 3). Participants expressed a need for tailored advice to help them mitigate future risks: *"I don't want a list of things and percentage of how likely you get it. What I need is the list that just says, you know, to put yourself in the best position possible you could consider doing this"* (P9, Study 3). This desire for actionable, individualised guidance reflects a shift from passive reliance on clinical teams to active engagement with personal health management: *"I have been proactive in getting myself referred to the [hospital] to a specific cardio-oncology service"* (P10, Study 2). This growing emphasis on personalised, proactive strategies shows how relevance ambiguity amplifies health uncertainty, prompting patients to reinterpret vague clinical guidance through the lens of their evolving risk perceptions.

In this context, the internet emerged as both a resource and risk. For some participants, online information and support groups were empowering, *"I'm turning to like you know Facebook stem cell transplant groups and saying who's got experience of this [symptom]... that's actually quite useful to try and help with working out what it is."* (P4, Study 3). For others, they experienced heightened anxiety, especially when participating in online support groups. However, the ambiguity and variability of online content often complicated participants' ability to interpret symptoms and predict health outcomes The overwhelming volume and variability of information online intensified emotional responses and complicated participants' ability to discern credible risks: *"I'm on a Facebook group and obviously there were people that were saying oh it's come back and everything like this, so I don't happen to look at it too much anymore because it scares me."* (P6, Study 3). The emotional volatility triggered by online

content illustrates how relevance ambiguity is amplified in informal information spaces, where patients must navigate fluctuating signals to make sense of their health risks.

The uncertainty participant report in relation to health becomes more apparent and intensified when they need to distinguish between transplant-related and general health conditions. This need to distinguish transplant-related symptoms from general health issues was a key driver of uncertainty. *"How do you know whether [symptom is] relevant…when I go to my annual check I just tell them everything, I'll let them work it out"* (P2, Study 3). Without clarity, participants struggled to decide whether to approach their GP or the transplant team, often delaying care or seeking reassurance from both. *"What is it, is that a generic health problem or is it related to the transplant?... I just defaulted to the transplant team and allowed them to directly back to the GP if required."* (P14, Study 3). Participants came to understand that access to LTFU services was often contingent on whether symptoms were deemed transplant-related, adding another layer of complexity to their decision-making.

Assessing symptoms that warrant medical attention, navigating the LTFU clinical process, and having claims accepted or deferred are central to recipients' experiences. Uncertainty, determining whether symptoms relate to HSCT, given the wide range of late effects and overlapping conditions, adds confusion and intensifies concerns about future health and its management. These experiences reflect a Relevance Ambiguity Feedback loop, where uncertainty about symptom relevance leads to hesitation or over vigilance, reinforcing doubt and complicating decision-making. This dynamic is illustrated in the following excerpt:

> *I've been having some issues recently that I thought well who do I go to? Do I go to my GP?... So it's nice just to have somebody on the end of an e-mail, who will quite often say this is a GP issue, you'll need to go through your GP, but quite often it's difficult for stem cell recipients to know who to go to for what information because you kind of, you rationalise any ongoing health issues "oh that's because I've had a stem cell transplant" and sometimes it's not, but quite often it is.* (P7, Study 3)

### *7.3.3 Theoretical Interpretation of Future Uncertainty in LTFU Care*

The theme of *Future Uncertainty* in LTFU care reflects a complex interplay between psychological responses and structural ambiguities. This uncertainty is conceptualised through two interrelated constructs: the Ambiguous Outpatient and the Relevance Ambiguity feedback loop. Together, these constructs offer a multidimensional framework for understanding how

HSCT recipients navigate evolving care landscapes, shifting responsibilities, and unpredictable health trajectories.

The Ambiguous Outpatient construct captures how patients' engagement with outpatient services is shaped by inconsistent clarity regarding their role within the healthcare system. Rather than experiencing a clearly defined transition, patients often move through three adaptive phases: continuity, transition, and adaptation. These phases are shaped by relational continuity, perceived control, and access to information. This progression challenges the assumption of a predictable or uniformly experienced shift into LTFU care and instead highlights the interpretive labour patients must undertake to make sense of their care status. This aligns with Mishel's (1988) Illness Uncertainty Theory, which posits that uncertainty arises when individuals are unable to assign meaning to illness-related events due to insufficient cues or inconsistent information. In the context of LTFU care, this uncertainty is not only cognitive but also structural, as patients are often left to infer their care status from indirect signals such as reduced appointment frequency or changes in provider communication.

The psychological impact of this ambiguity is further illuminated by the Intolerance of Uncertainty Theory (Freeston et al., 1994), which identifies a dispositional incapacity to endure the aversive response triggered by the perception of uncertainty. Individuals with low tolerance for uncertainty are more likely to experience anxiety and engage in maladaptive coping strategies, such as avoidance or excessive reassurance-seeking. Participants who lacked clear information about their monitoring responsibilities often shift between passive reassurance and active information-seeking, reflecting the tension between perceived safety and emerging doubt.

This behavioural shift is also consistent with Self-Determination Theory (Deci & Ryan, 1985; Ryan & Deci, 2017), which highlights how autonomy, competence, and a sense of connection contribute to motivation and engagement. When patients are denied clear information or opportunities to participate in decision-making, their sense of agency is undermined, leading to disengagement or over-reliance on specialist teams. Similarly, Social Cognitive Theory (Bandura, 2001) highlight the role of self-efficacy in shaping health behaviours. In the absence of clear guidance, patients may struggle to feel confident in their ability to manage their health, which can hinder proactive engagement with care.

The Health Belief Model (Rosenstock, 1974) and Cognitive Dissonance Theory (Festinger, 1957) provide further insight into how perceptions of risk and internal conflict influence behavioural responses. When patients perceive themselves to be at high risk of relapse or late effects but receive little guidance or inconsistent messages from providers, they may experience cognitive dissonance. This dissonance can manifest as either avoidance of care or heightened vigilance, both of which were evident in participants' accounts of cancer screening and symptom monitoring.

The Relevance Ambiguity Feedback Loop builds on these psychological foundations by conceptualising the cyclical nature of health uncertainty. As patients attempt to interpret symptoms and determine their relevance to transplant-related risks, they often encounter inconsistent guidance, overlapping symptom profiles, and unclear service boundaries. This ambiguity triggers emotional and cognitive responses such as hypervigilance, hesitation, and anxiety, which in turn reinforce the perception of uncertainty. The Transactional Model of Stress and Coping (Lazarus & Folkman, 1984) is particularly relevant here, as it frames symptom interpretation as a process of cognitive appraisal and coping. Participants' responses to uncertainty were shaped by their perceived susceptibility to late effects, their confidence in navigating care, and the quality of communication with providers. The Candidacy Framework (Dixon-Woods et al., 2006) adds a critical sociological dimension to this analysis, which is discussed further in Section 7.4. It conceptualises access to care as a negotiated and contingent process, shaped by structural, relational, and interpretive factors.

Taken together, the Ambiguous Outpatient and Relevance Ambiguity Feedback Loop constructs offer a robust and critically informed framework for understanding *Future Uncertainty* in LTFU care. They move beyond surface-level descriptions to engage with established psychological and sociological theories, illustrating how uncertainty is both a product of systemic design and individual adaptation. Figure 7.2 provides a schematic synthesis of these dynamics, which maps the temporal progression through the three adaptive phases and illustrates how patients' engagement with care is shaped by shifting perceptions of stability, role clarity, and self-management demands. As patients move further from structured, specialist-led care, they increasingly occupy an ambiguous space between acute and generalist services. This space is often characterised by fragmented oversight and limited guidance, which intensifies the experience of *Future Uncertainty* and reinforces the need for integrated, transparent, and patient-informed LTFU pathways.

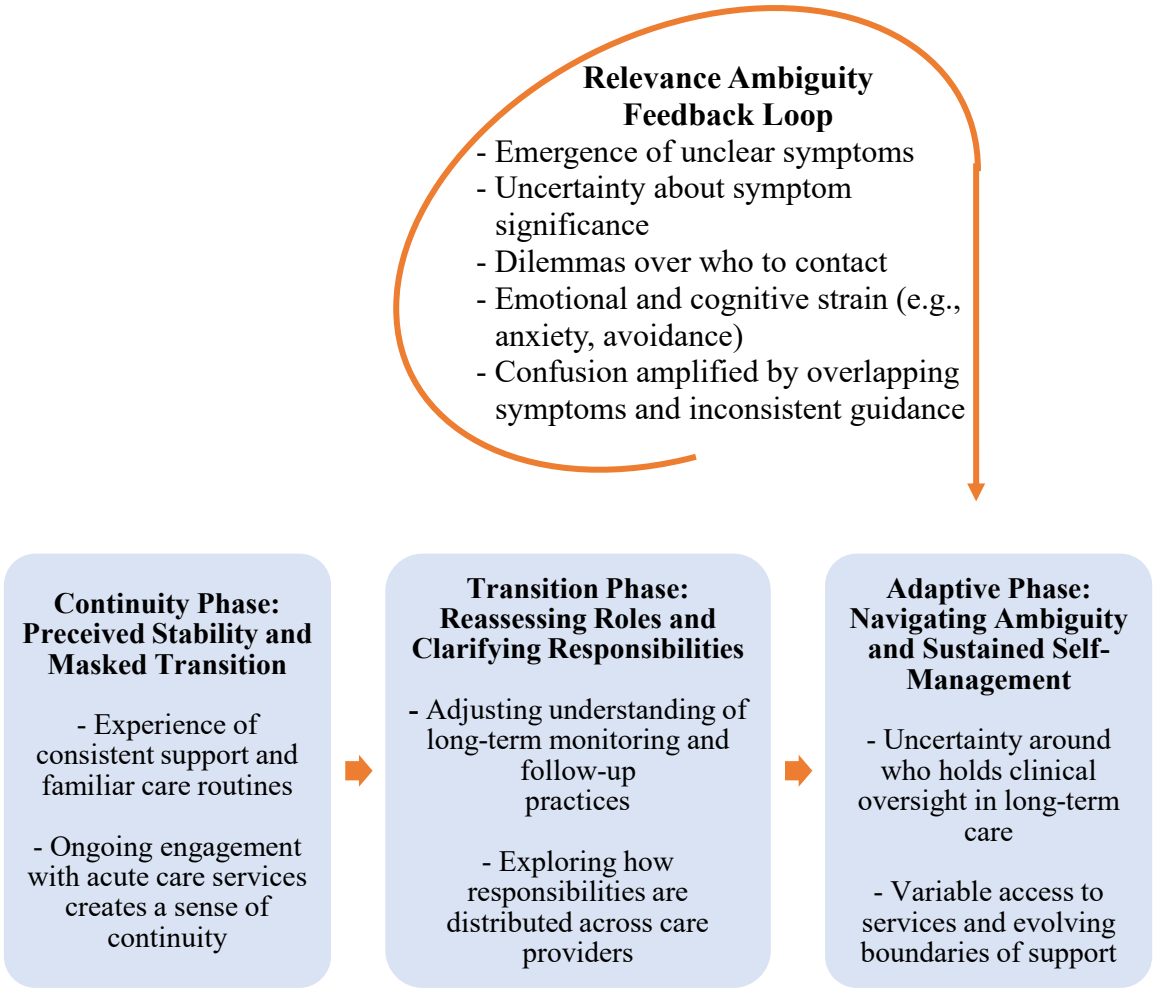


**Figure 7.2 Schematic Representation of Ambiguous Outpatient Trajectories and the Relevance Ambiguity Feedback Loop**

This schematic representation of the Ambiguous Outpatient trajectories and the Relevance Ambiguity feedback loop highlights the need for more responsive, person-centred approaches to LTFU care. These approaches must address not only biomedical risks but also the interpretive and emotional engagement recipients undertake in managing survivorship. This schematic also highlights the limitations of current LTFU models, which often assume a passive recipient and a standardised care trajectory, failing to account for the complex, negotiated, and emotionally charged nature of post-transplant care

### 7.4 Application of the Candidacy Framework

The Candidacy Framework (Dixon-Woods et al., 2006) outlines seven interrelated stages through which individuals navigate their eligibility for healthcare, see Figure 7.3 . It begins with Identification, where individuals recognise a need for medical attention. This leads to Navigation, which involves understanding available services and the ability to access them. Once services are located, Permeability refers to how easily individuals can engage with these

services. Following this, Appearances involve presenting oneself and one's symptoms in a way that legitimises the need for care. The next stage, Adjudication, is where healthcare professionals assess and validate candidacy. If care is offered, the stage of Offers and Resistance capture the dynamic of acceptance or refusal. Operating Conditions encompass the broader institutional and contextual factors that shape how candidacy is produced, sustained, or constrained.

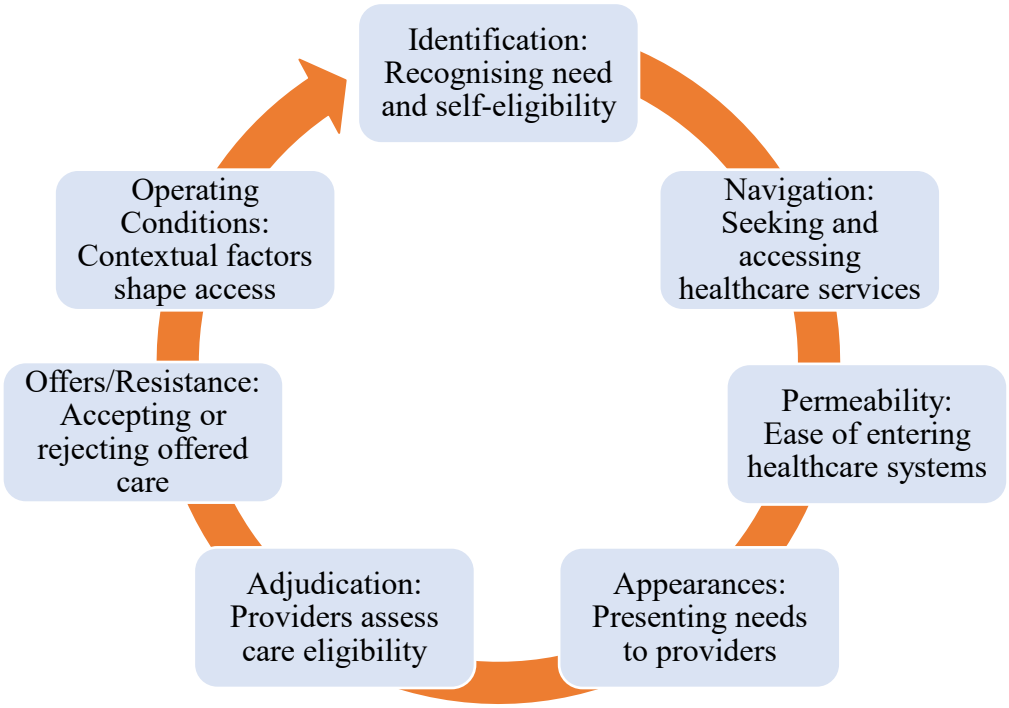


**Figure 7.3 Healthcare Access Process: Stages of Candidacy**

### *7.4.1 Rationale for Using the Framework*

The Candidacy Framework (Dixon-Woods et al., 2006) serves as an overarching conceptual lens that integrates the psychological and structural dimensions of uncertainty in LTFU care. While individual theories such as Illness Uncertainty Theory, Intolerance of Uncertainty Theory, the Transactional Model of Stress and Coping, Self-Determination Theory, and Health Belief and Social Cognitive Theories each illuminate specific aspects of recipients' emotional responses, coping behaviours, and motivational processes, the Candidacy Framework synthesises these insights by conceptualising access to care as a negotiated and dynamic process. It captures how recipients interpret their eligibility for support, navigate ambiguous transitions, and respond to fragmented systems, all while managing the emotional labour of self-advocacy and uncertainty. In doing so, it bridges the gap between individual psychological experiences and broader institutional practices, offering a comprehensive understanding of how

survivors engage with, or disengage from, LTFU care. This integrative capacity makes the Candidacy Framework particularly valuable for interpreting the interplay between personal agency, relational continuity, and systemic responsiveness across the survivorship trajectory.

### *7.4.2 Mapping Synthesised Theme to Framework Dimensions*

The experiences of HSCT recipients navigating LTFU care in England are best understood through the Candidacy Framework. As discussed in Section 7.3, the framework conceptualises access to healthcare as a negotiated and contingent process, shaped by individual, relational, and structural factors. In this section, the seven dimensions of candidacy are systematically aligned with the thematic findings from both Studies 2 and 3, providing a nuanced account of how survivors engage with, interpret, and respond to LTFU care.

Participants' accounts revealed persistent uncertainty regarding the commencement of LTFU care, reflecting the Identification stage of candidacy. Transitions from acute post-transplant monitoring were rarely marked by formal handovers or explicit communication. Instead, recipients often inferred their eligibility for ongoing care through indirect cues, such as reduced appointment frequency or changes in provider roles. This ambiguity led to a passive construction of candidacy, compounded by variability in how and when LTFU care was initiated. The Navigation of LTFU services was emotionally and logistically demanding. While some benefited from specialist-led pathways with clear continuity, others faced fragmented or hybrid models requiring self-coordination. Limited guidance and inconsistent information, especially for those distant from transplant centres, added to the burden. Hybrid models offered flexibility but did not always replicate the reassurance of in-person care.

Access to services was further shaped by Permeability, with institutional rigidity and geographic barriers limiting engagement. Recipients reported difficulties securing timely appointments, inconsistent screening, and limited responsiveness from non-specialist providers. Familiar and responsive staff improved perceived access, but logistical and structural barriers remained a source of fatigue. The Appearances stage was influenced by relational continuity and being known by clinicians enabled confident articulation of concerns, while unfamiliar providers, particularly in primary or emergency care, often led to feelings of dismissal and emotional withdrawal. Care in these settings was perceived as procedural rather than supportive. Adjudication of eligibility was typically based on clinical stability or resolution of complications, with decisions made using biomedical markers and little transparency. Recipients were often uncertain about their status and future care. Responses to care offers

reflected the Offers and Resistance dimension, with some accepting specialist-led follow-up and others resisting primary care involvement due to concerns about expertise and safety. Emotional fatigue, lack of personalised guidance, and fear of being misunderstood led some to disengage from services. Finally, Operating Conditions, including geography and care coordination, shaped access, engagement, and institutional variability led to inconsistent experiences. The organisation of care and continuity of relationships influenced perceptions of safety and support, with direct monitoring offering reassurance and hybrid models easing logistical stress.

These findings demonstrate the value of candidacy theory in interpreting recipients' experiences. Access to LTFU care is shaped not only by clinical practices but also by relational dynamics and informational clarity. This mapping emphasises the need for clearer transitions, relational continuity, and structurally responsive models that recognise the emotional and logistical dimensions of survivorship. It reflects the participant-centred and reflexive approach that underpins this thesis.

### *7.4.3 Identified Gaps and Limitations in the Original Framework*

As the findings of this programme of work demonstrate, the relevance of health concerns to HSCT recipients evolve over time and directly influence their candidacy to healthcare access. The Candidacy Framework developed by Dixon-Woods et al. (2006) conceptualises candidacy as a series of negotiations between individuals and healthcare providers, progressing through distinct phases. These begin with individuals recognising symptoms as warranting medical attention, followed by identifying available health service, considering ease of access, and presenting their claim to providers. Access is then contingent upon the authentication of the claim's credibility, and individuals' acceptance or rejection of healthcare options. Additional factors, such as source availability and the patient-provider relationship, further shapes this process. (Dixon-Woods et al., 2006; Hunter et al., 2013; van der Boor & White, 2020)

Applying the candidacy framework to the findings of this programme of work enhances our understanding of HSCT recipients' experiences of LTFU care. However, the findings also reveal areas where the framework does not fully capture the nuances of these experiences, particularly regarding the identification of candidacy. In the context of LTFU care, recipients often face persistent ambiguity about what constitutes a legitimate claim for medical attention (Dixon-Woods et al., 2006; Tookey et al., 2018).

According to the candidacy framework, understanding how individuals recognise health concerns as needing medical attention is central to understanding how individuals assert a claim of candidacy (Dixon-Woods et al., 2006). This framework was originally conceptualised through the exploration of healthcare access among socio-economically disadvantaged individuals and identifies that a claim of candidacy typically follows a health crisis. Subsequent studies have introduced additional constructs, such as prior experiences (Hunter et al., 2013), legitimacy (Mackenzie et al., 2013), and health literacy (van der Boor & White, 2020) to further explain how health concerns are recognised for claim of candidacy. This study proposes the construct of relevance ambiguity to supplement the candidacy framework.

Relevance ambiguity describes the uncertainty patients experience when determining whether a health concern is relevant enough to assert a claim, often due to ambiguous or incomplete information. This is closely linked to health literacy as participants of Study 3 (see Chapter 6) frequently expressed uncertainty in recognising symptoms that might indicate a need for medical attention, given the unpredictable nature of late complications associated with HSCT. Claims of candidacy may also be influenced by participants gaining an increased awareness of the potential adverse health effects, as greater awareness of health recognition through health literacy has been related to increased likelihood of seeking medical attention (van der Boor & White, 2020). Whilst relevance ambiguity may explain how individuals recognise health concerns; the ambiguous nature of long-term complications remain a barrier. Therefore, the construct of the ambiguous outpatient is introduced to capture the lack of clarity reported by participants regarding LTFU monitoring practices and their implications for accessing healthcare.

This area of ambiguity overlays the stages of permeability of services, appearance at services, and adjudication by professions within the candidacy framework (Dixon-Woods et al., 2006). It is characterised by recipients not actively seeking out care but instead being automatically transitioned into LTFU care. Over time, this leads to unclear boundaries around available services, the process of presenting health concerns, and the criteria for validating claims. Such ambiguity can result in delayed or missed care, emotional distress, and a reliance on trusted relationships with clinical teams to navigate uncertainty (Koehn et al., 2024; Sinnott et al., 2024; Tookey et al., 2018).

For recipients already within the LTFU system, candidacy does not necessarily begin with identification. Instead, their experiences are shaped by this ambiguous outpatient area, where

the lack of clarity around service boundaries and validation processes reinforces uncertainty. The proposed supplementary constructs of 'relevance ambiguity' and 'ambiguous outpatient' offer new insights that may enhance the candidacy framework, particularly for evaluating healthcare access within LTFU care. Further research is needed to clarify and validate the application of these constructs across diverse patient populations and healthcare systems.

### 7.5 Adaptation of the Candidacy Framework

To better reflect the complexities of LTFU care transitions in HSCT recipients, the candidacy framework has been adapted in two key ways. These adaptations respond to participant accounts of ambiguity, fragmented continuity, and interpretive challenges in accessing care. This thesis suggests proposed changes to the framework including the reframing of the Identification stage as 'Relevance Ambiguity', and the introduction of the 'Ambiguous Outpatient Area' as a contextual overlay spanning the stages of Permeability, Appearances, and Adjudication (see Figure 7.4). The visual representation helps clarify how these stages interact and where candidacy becomes particularly unstable and difficult to navigate, building on the limitations identified in Section 7.3.3.

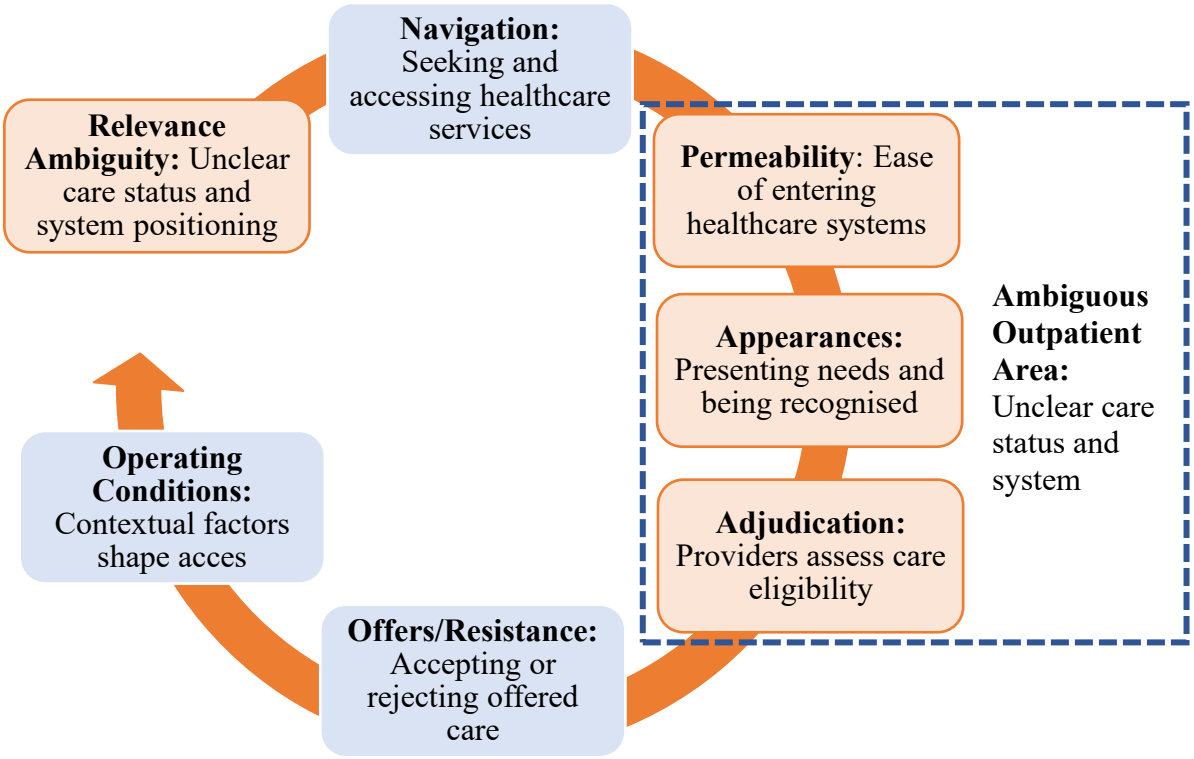


**Figure 7.4 Modified Stages of Candidacy in HSCT Recipients' Healthcare Access Process**
Adapted from Dixon-Woods et al. (2006), this figure illustrates modifications to the framework.

### *7.5.1 Proposed Modifications*

The first proposed modification to the candidacy framework is the reframing of the original stage of Identification as 'Relevance Ambiguity'. This change is grounded in participant accounts that revealed persistent uncertainty about their status following active treatment. Rather than clearly identifying themselves as candidates for continued care, individuals described a state of ambiguity, expressing uncertainty about whether they were still under specialist oversight, whether their symptoms warranted attention, or whether they had transitioned into self-managed care. This ambiguity was compounded by inconsistent messaging, a lack of personalised guidance, and emotional strain associated with interpreting one's own eligibility. Reframing this stage as 'Relevance Ambiguity' better reflects the conditional and transitional nature of candidacy in LTFU care contexts. It foregrounds the informational and emotional labour required to navigate care transitions and highlights how candidacy is not simply self-recognised but negotiated within a context of uncertainty and fragmented continuity.

The second proposed modification to the candidacy framework is the introduction of the 'Ambiguous Outpatient Area' as a contextual overlay spanning the stages of Permeability, Appearances, and Adjudication. This addition is grounded in participant experiences of being "in-between", not formally discharged but no longer under acute care management. Individuals described attending clinics without clear purpose, receiving mixed signals about their care status, and struggling to understand whether they were still eligible for specialist input. These findings point to a structural and symbolic space where candidacy is particularly unstable. and where the framework's standard progression becomes insufficient to capture lived experience.

Within this zone, the stage of Appearances is especially affected. In the original candidacy framework (Dixon-Woods et al., 2006), Appearances refers to the stage where individuals present themselves and their concerns to healthcare services. It includes the ability to articulate symptoms and communicate the impact of those symptoms to professionals, with emphasis on the individual's capacity to make their health needs legible to the system. However, findings from this thesis reveal that appearing at services is not sufficient for candidacy to be acknowledged. Participants described situations where they did present their needs, but were met with uncertainty, dismissal, or lack of validation. This shows that candidacy is not only about the act of presenting, but also about how that presentation is interpreted and legitimised by professionals. As such, Appearances has been modified to reflect this interpretive dimension: 'Presenting needs and being recognised'. This refinement shifts the focus from individual effort

to the interactive and contingent nature of recognition, which reflects the power dynamics and professional discretion that shape whether a person is seen as a legitimate candidate for care. The 'Ambiguous Outpatient Area' overlay draws attention to how systemic permeability, interpretive labour, and local operating conditions shape the adjudication of candidacy. It also highlights the emotional and logistical challenges faced by individuals navigating fragmented pathways, reinforcing the need for clearer structures and more consistent support during the transition to LTFU care.

### *7.5.2 Implications for Understanding LTFU Care Engagement*

The adapted candidacy framework offers a more nuanced lens through which to understand how HSCT recipients engage with LTFU care. Through the reframing of Identification as Relevance Ambiguity and introducing the Ambiguous Outpatient Area, the framework captures the conditional, interpretive, and emotionally charged nature of post-transplant healthcare navigation. These modifications reflect the lived realities of recipients who often find themselves negotiating eligibility, legitimacy, and recognition within fragmented and inconsistent care systems (Dixon-Woods et al., 2006, see Section 5.6), and extend the framework's applicability to long-term survivorship contexts.

Access to LTFU care is shaped not only by availability or proximity but also by how recipients interpret their candidacy and how services respond. The concept of 'Relevance Ambiguity' highlights how uncertainty about care status, such as whether one is still under specialist oversight or has transitioned to self-management, can inhibit help-seeking and delay engagement. Participants described being unsure whether their symptoms warranted attention, often due to contradictory guidance or lack of personalised information. This aligns with findings that recipients frequently struggled to determine which provider to consult and whether their concerns were considered transplant-related (Diesch-Furlanetto et al., 2021, see Section 6.2). The 'Ambiguous Outpatient Area' further illustrates how structural vagueness, including unclear discharge protocols or passive transitions, can destabilise candidacy. Many recipients inferred their LTFU status from logistical cues such as reduced appointment frequency or changes in clinic location, rather than formal communication (Dignan et al., 2021, see Section 5.6). This passive transition undermines clarity and contributes to disengagement, particularly when individuals feel they are in-between services without a defined role or pathway.

Continuity in LTFU care involves more than sustained contact with services. It encompasses relational trust, interpretive clarity, and emotional reassurance. The adapted framework shows

how disrupted continuity, whether through ambiguous transitions or interpretive dismissal, can erode engagement. Participants frequently expressed that being still in the system provided psychological safety and reduced anxiety, even when the purpose of appointments was unclear (Parisek et al., 2021, see Section 5.6). However, continuity was often compromised by inconsistent messaging and unclear boundaries between specialist and generalist roles. Recipients were sometimes directed to general practitioners for non-transplant-related issues, despite earlier assurances of specialist availability. This contradiction disrupted care pathways and introduced new layers of uncertainty, particularly when symptoms were difficult to categorise (McErlean et al., 2024, see Section 6.5). The framework's emphasis on sense-making effort, or how candidacy is negotiated and legitimised, helps explain why continuity must be actively maintained through clear communication, consistent support, and validation of patient concerns (Foster et al., 2020).

The modification of Appearances to 'Presenting needs and being recognised' shifts the focus from individual effort to the relational and contingent nature of recognition. Participants often described presenting their concerns only to be met with dismissal or ambiguity, revealing that candidacy is not solely about self-presentation but about how that presentation is interpreted by professionals. This interpretive dimension reflects broader power dynamics and highlights the emotional effort involved in seeking care. The framework's alignment with psychological models such as the Health Belief Model (Rosenstock, 1974), Social Cognitive Theory (Bandura, 2001), and Self-Determination Theory (Deci & Ryan, 1985; Ryan & Deci, 2017) provides further insight into patient agency. As discussed in Sections 5.5 and 6.5, recipients' engagement with LTFU care was influenced by their perceived susceptibility to late effects, confidence in managing health, and ability to tolerate uncertainty. Those with higher health literacy and psychological readiness were more likely to re-engage with services and adopt problem-focused coping strategies, while others employed avoidance or emotion-focused coping in response to overwhelming or contradictory information (Bevans et al., 2017; Vetsch et al., 2017).

The framework also helps explain how agency is shaped by systemic factors. The emotional and epistemic labour required to interpret eligibility, navigate fragmented pathways, and advocate for recognition places a significant burden on recipients. This burden increases when services fail to provide clear, consistent, and personalised guidance, as enabling agency in LTFU care requires more than encouraging self-management and instead calls for structural support, relational continuity, and interpretive clarity (Dixon-Woods et al., 2006, see Section

2.4.2). These insights have important implications for the design and delivery of LTFU services. Candidacy should not be assumed or passively conferred. It must be actively supported through transparent transitions, clear eligibility criteria, and consistent messaging. Survivorship care plans, when tailored to individual risk profiles and integrated into clinical conversations, may help clarify expectations and reinforce engagement (Majhail et al., 2012; Rotz et al., 2024, see Section 6.5). However, generic or poorly implemented plans may fail to address informational needs or support behavioural activation. This is consistent with findings from previous research highlighting the limitations of standardised survivorship models and the need for personalised, context-sensitive approaches (McCaughan et al., 2019; Foster et al., 2017).

The adapted framework also highlights the need for services to recognise and respond to the emotional and interpretive dimensions of engagement. This includes acknowledging the psychological impact of ambiguous transitions, validating patient concerns, and ensuring that recognition is not contingent solely on clinical presentation but on relational and contextual understanding. These insights reinforce the importance of designing LTFU systems that are not only clinically effective but also emotionally attuned and structurally coherent (Santana et al., 2018, see Section 2.7).

### 7.6 Chapter Summary

This chapter synthesises two qualitative studies to clarify how HSCT recipients experience LTFU care in England, with a particular focus on uncertainty, care transitions, and information needs. Uncertainty was pervasive, often arising from indirect communication and fragmented care pathways, and limited formal information. In response recipients developed a range of coping strategies shaped by health literacy and psychological readiness, while sustained relationships with specialist teams helped to reduce anxiety and support continuity.

To better capture the conditional and negotiated nature of access to care in LTFU contexts, the chapter adapted the Candidacy Framework (Dixon-Woods et al., 2006), introducing two supplementary constructs, the ‘ambiguous outpatient’ and ‘relevance uncertainty’. The ambiguous outpatient area describes a space in which recipients are automatically transitioned into LTFU care without clear initiation or boundaries, leading to confusion around service availability, presentation of health concerns, and validation of needs. Relevance uncertainty reflects the difficulty recipients face in determining whether their health concerns are relevant or validated within the LTFU system, often resulting in delayed or missed care and emotional distress. Triangulation of interviews and written accounts enhanced the credibility of findings

and highlighted the need for person-centred, adaptive models of care, providing actionable recommendations for LTFU care services and policy.

This synthesis provides the foundation for the next chapter, where discussion, recommendations, and conclusions will be explored, highlighting the implications of these findings for enhancing LTFU care for HSCT recipients in England.

# Chapter 8. Discussion, Recommendations, and Conclusion

## 8.1 Chapter Introduction

This chapter examines the central finding of this thesis, the persistent experience of uncertainty among HSCT recipients in LTFU care in England. It considers how both service navigation and health uncertainty shape recipients' engagement with care and overall well-being. These uncertainties are not isolated; they interact and evolve over time, influencing how recipients interpret their health status, access services, and manage long-term risks.

This chapter opens by revisiting the thesis aim and objectives, followed by a critical discussion of the findings in relation to existing literature. It then outlines the novel theoretical contributions of the thesis, including the adaptation of the Candidacy Framework and the development of the constructs 'ambiguous outpatient' and 'relevance uncertainty'. It concludes by presenting the practical implications for clinical practice, offering recommendations for service and identifying priorities for future research into HSCT survivorship and LTFU care in England.

## 8.2 Revisiting the Research Aim and Objectives

The aim of this thesis was to explore how HSCT recipients' experience LTFU care in England. The research focuses on structural and informational factors that shape engagement, adaptation, and well-being. To address this aim, the research was guided by the following objectives:

1. To systematically review and qualitative evidence synthesise the existing literature on HSCT recipients' experiences of LTFU care generally, identifying common themes and knowledge gaps.
2. To explore and interpret the lived experiences of HSCT recipients attending LTFU care in England, with attention to psychological, informational, and structural factors.
3. To identify and analyse the specific informational needs of HSCT recipients as they transition into and navigate LTFU care.
4. To generate evidence-based recommendations for clinical practice and service design that support person-centred, responsive LTFU care for HSCT recipients in England.
5. To highlight areas for future research and clinical development in the field of HSCT survivorship and LTFU care.

The thesis addressed these objectives through a multi-method qualitative design comprising three qualitative phenomenological studies. First, a systematic review with qualitative evidence synthesis (Chapter 4) fulfilled Objective 1 by establishing what was currently known about HSCT recipients' experiences of attending LTFU care in general, and identifying knowledge gaps. Second, a study of written accounts (Chapter 5) addressed Objective 2 by exploring the experiences of HSCT recipients in England, with attention to informational and structural factors. Third, semi-structured interviews (Chapter 6) addressed Objective 3 by examining the informational needs of HSCT recipients as they transition into and navigate LTFU care. Collectively, the findings from these studies informed Objectives 4 and 5, generating evidence-based recommendations for clinical practice and highlighting priorities for future research and development in HSCT survivorship and LTFU care.

## 8.3 Discussion of Findings in Relation to Existing Literature

The discussion presented in this chapter are grounded in the synthesised findings outlined in Chapter 7, which integrate and interpret the results of both Study 2 (written accounts) and Study 3 (interviews). Drawing together insights from these complementary qualitative approaches, the synthesis provides a comprehensive and nuanced understanding of HSCT recipients' experiences of LTFU care in England.

While the primary focus of this discussion is on the integrated themes that emerged from the synthesis, specific findings from each study are referenced where relevant to illustrate the development of key arguments or to highlight the diversity of participant experiences. This approach reflects best practice in multi-method qualitative research, ensuring that the discussion is both holistic and firmly anchored in the data generated across the programme of work.

### *8.3.1 Alignment and Contrasts with Prior Research*

This programme of work is the first to qualitatively explore the experiences of HSCT recipients undergoing LTFU care across multiple healthcare service providers within England. Prior studies have largely focused on recipients treated outside of the UK (Hwang et al., 2012; Parisek et al., 2021; Sharin et al., 2020), or within single-centre studies such as those conducted in dedicated GvHD clinics (de Vere Hunt et al., 2021). Given the paucity of research in this area, this thesis offers new insights and a deeper understanding of the experiences of HSCT recipients as they navigate LTFU care in England.

A central finding of this research is the pervasive experience of *Future Uncertainty* among HSCT recipients, which can be understood as comprising both *Service Navigation Uncertainty* and *Health Uncertainty*. Health uncertainty is the recipient's lack of clarity about future health status after HSCT, including concerns about relapse, late effects, and symptom identification. Service navigation uncertainty refers to confusion about how to access and engage with healthcare services during LTFU care, including uncertainty about care pathways, provider responsibilities, and transitions between services. Recipients may not know when LTFU care begins, who is responsible for ongoing monitoring, or how to access specialist support and information about late effects. Previous research has consistently identified uncertainty as a key concern for individuals following HSCT, especially in relation to future health, late effects, and symptom identification (de Vere Hunt et al., 2021; Diesch-Furlanetto et al., 2021; Hwang et al., 2012; Kenyon et al., 2023; Parisek et al., 2021; Sharin et al., 2020; Sun et al., 2021). This thesis builds on these studies by demonstrating that uncertainty about health outcomes and the structure of care services are not isolated phenomena but interrelated and mutually reinforcing.

While these forms of uncertainty have been recognised individually, their interaction and combined impact on recipients' experiences have received less attention in the literature. Research in the wider HSCT literature has identified the relationship between health uncertainty and its impact on self-management and recovery in the acute phase of post-transplant treatment (Dunn et al., 2016). Previous research on this cohort of patients have not specifically identified the relationship between health uncertainty and the uncertainty recipients experience when navigating the LTFU healthcare pathway. Studies have focused primarily on uncertainty in relation to physical health and late effects but have not examined how service navigation uncertainty interacts with health uncertainty to shape engagement and adaptation to LTFU care (Dignan et al., 2021; Hashmi et al., 2017; Nakajima & Kamibeppu, 2022). As detailed in Chapter 7, these uncertainties are mutually reinforcing and evolve throughout the LTFU journey. This dynamic interplay is further supported by theoretical frameworks such as Intolerance of Uncertainty Theory (Freeston et al., 1994), Illness Uncertainty Theory (Mishel, 1988), and the Candidacy Framework (Dixon-Woods et al., 2006), which together explain how ambiguity in both health status and care pathways can compound vulnerability and influence patient behaviour.

Critically, these findings highlight the limitations of traditional biomedical models, which tend to focus on physical complications while overlooking the psychological and structural dimensions of survivorship (Cheon et al., 2021; Richardson et al., 2016; Timko Olson et al.,

2024). Theoretical frameworks such as Intolerance of Uncertainty Theory (Freeston et al., 1994), Illness Uncertainty Theory (Mishel, 1988), and Uncertainty Management Theory (Brashers, 1995), as well as the Transactional Model of Stress and Coping (Lazarus & Folkman, 1984), provide a foundation for understanding how ambiguity in health and care pathways can lead to anxiety, maladaptive coping, and disengagement (El-Jawahri et al., 2017; Germain et al., 2020; Grønvold et al., 2024; Newcomb et al., 2024; Wu et al., 2023). The candidacy framework further emphasises how institutional practices and informational gaps contribute to uncertainty and self-advocacy (Dixon-Woods et al., 2006). Health behaviour models support the idea that perceptions of risk, benefit, and barriers shape engagement with care (Bandura, 2001; Champion & Skinner, 2008; Christalle et al., 2019; Rosenstock, 1974). This thesis advances these theoretical perspectives by showing that uncertainty is co-constructed through both individual psychological responses and clinical practices.

Expanding on these findings, recipients frequently described the transition into LTFU care as ambiguous and passive, often marked by less frequent appointments or changes in care location rather than formal communication. This observation is strongly supported by findings in the thesis, where participants reported that the transition to LTFU care was rarely explicitly communicated, but instead inferred through indirect cues. Such ambiguity in care transitions has been documented in prior studies, which note that recipients often rely on indirect signals rather than formal handover, leading to feelings of being “in limbo” and undermining psychological readiness for long-term survivorship (Dignan et al., 2021; Hashmi et al., 2017; Hawkins et al., 2008). The literature further suggests that this lack of formal communication can exacerbate informational gaps and reinforce uncertainty, particularly when written documentation or survivorship care plans are unavailable or inconsistently implemented (Majhail et al., 2012; Rotz et al., 2024). These findings demonstrates the importance of clear, proactive communication and structured education to support patient engagement and adaptation during the transition to LTFU care.

Prior research has similarly characterised this period as a ‘transitional phase’, further highlighting the challenges recipients face. The inadequate preparation for transition, along with the importance of retaining clinical relations and coordinated care for accessing specialised care, has been highlighted in the literature (Parisek et al., 2021). This is further reflected in studies such as Dignan et al. (2021), Hashmi et al. (2017), and Hawkins et al. (2008), which show that recipients often feel they are facing unclear pathways and insufficient information about ongoing support during this phase. This thesis confirms these findings and further

identifies that ambiguity in transitions, fragmented care pathways, and unclear roles within the NHS context intensify service navigation uncertainty. This thesis also notes that transitions are frequently passive, marked by reduced appointment frequency or changes in care location, rather than formal communication or written documentations. Such ambiguity can delay engagement with LTFU services and undermine psychological readiness for survivorship, reinforcing the need for structured education and proactive communication during care transitions.

In terms of care delivery, the study identified three models of LTFU care: specialist-led, hybrid, and primary care-led. Specialist-led care was consistently valued for its thoroughness and continuity, providing emotional reassurance. This aligns with findings from Corcoran et al. (2015), Dignan et al. (2021), and Tichelli et al. (2021a), which highlight the benefits of specialist-led clinics for continuity of care, access to expert knowledge, and psychosocial support. Hybrid models, especially those adopted during the COVID-19 pandemic, offered flexibility through remote consultations but sometimes lacked depth and continuity. Recent literature notes that while hybrid and remote models can increase accessibility and convenience, they may also result in fragmented care and reduced opportunities for in-depth assessment and relationship-building (Hashmi et al., 2017; Rotz et al., 2024). Primary care-led models could lead to feelings of abandonment and reduced confidence, emphasising the importance of relational continuity and specialist involvement. Studies such as Dignan et al. (2021), Hawkins et al. (2008), and Hashmi et al. (2017) report that recipients managed primarily in general practice settings often experience uncertainty, lack of specialist input, and diminished trust, reinforcing the need for coordinated, multidisciplinary approaches.

This emphasis on relational continuity is further supported by previous studies, which show that ongoing relationships with specialist teams are essential for maintaining health and psychological well-being (de Vere Hunt et al., 2021; Hwang et al., 2012; Parisek et al., 2021; Sharin et al., 2020). Disruptions to continuity, such as transfers between hospitals or consultants, often leave recipients feeling suspended between care phases or abandoned, driving a consistent preference for specialist-led LTFU care over General Practitioner (GP)-led models. This preference is motivated by the need for skilled care and reassurance regarding disease recurrence and late effects, and access to expert knowledge (Brandenbarg et al., 2017a, 2017b; Michel et al., 2009; Schutze et al., 2018; Tucholka et al., 2018).

Alongside these considerations, a notable barrier was the lack of preparation for late effects screening and inconsistent information about monitoring practices. Recipients expressed a need for written documentation and structured plans to support ongoing care and reduce anxiety. The absence of survivorship care plans or written documentation frequently left recipients uncertain about monitoring requirements and transitions into LTFU care. Inconsistent screening practices and delays further contributed to anxiety and a sense of vulnerability, leaving many unprepared for the duration and complexity of recovery. Studies have shown that inconsistent or poorly timed information can hinder adaptation and increase psychological distress (Dignan et al., 2021; Hawkins et al., 2008; Yanling et al., 2023). Tailored, proactive education and structured care plans are essential for empowering recipients, improving engagement, and reducing anxiety during long-term recovery.

While gaps in information and preparation are significant, they are compounded by additional barriers to accessing care, such as limited information about late effects, insufficient expertise among non-specialist personnel, and logistical challenges, which have been well documented in prior studies (Hwang et al., 2012; Parisek et al., 2021; Sharin et al., 2020). This thesis corroborates these barriers within the clinical setting in England and offers new insight into how recipients negotiate claims for health assistance. It further highlights that fragmented care pathways, unclear roles, and inconsistent communication between transplant centres and primary care providers exacerbate these barriers. Access to LTFU care is frequently contingent on whether health conditions or symptoms are explicitly related to HSCT, and recipients report difficulty in identifying such claims due to the ambiguous nature of long-term complications associated with HSCT. This challenge is compounded by the lack of written documentation and survivorship care plans, which leaves recipients uncertain about their eligibility for ongoing support and can result in feelings of abandonment or being in a suspended state (Majhail et al., 2012; Rotz et al., 2024). Clear communication, structured education, and coordinated multidisciplinary care are essential for helping recipients navigate these complexities and assert their need for appropriate follow-up and support.

Another significant implication is the critical role of health literacy and the timing of information provision. The ability of recipients to engage with and act on information is shaped not only by the content provided, but also by their readiness, context, and the clarity of communication from healthcare professionals. This aligns with broader survivorship literature, which shows that low health literacy is associated with poorer outcomes and increased psychological distress (Holden et al., 2021; Nakajima & Kamibeppu, 2022; Nutbeam, 2008;

Sørensen et al., 2012; Vetsch et al., 2017). The findings of this thesis reinforce the importance of tailored, timely, and reinforced information, as well as the need for ongoing support to help recipients navigate the complexities of LTFU care.

Taken together, these findings highlight the need for person-centred, adaptive models of LTFU care, with clear communication, tailored information, and sustained relational continuity to support engagement, well-being, and long-term outcomes for HSCT survivors. Evidence from both this thesis and prior studies indicate that person-centred approaches improve patient satisfaction, engagement, and outcomes, particularly when care is tailored to individual preferences, values, and needs (Kenyon et al., 2023; NHS Long Term Plan, 2019, 2025; Santana et al., 2018; The Health Foundation, 2015). Routine use of patient-reported outcome measures (PROMs) and patient-reported experience measures (PREMs) is increasingly recognised as essential for capturing the full spectrum of survivorship, including psychosocial, emotional, and existential concerns (Basch et al., 2016; Kenyon et al., 2023; Lines et al., 2015). The thesis further notes that service redesign should prioritise integrated care pathways, proactive psychological support, and equitable access to multidisciplinary teams, as highlighted by Dignan et al. (2021), NHS (2022), and Hemming et al. (2024). Addressing these gaps will require coordinated action from clinicians, service providers, and policymakers to ensure that HSCT survivors receive comprehensive, person-centred support throughout their long-term recovery.

A further challenge identified was that timing and information overload were recurrent, with many recipients' deferring engagement with future-oriented information until recovery progressed. Early in the transplant journey, information overload made it difficult for recipients to process or retain details about long-term risks, contributing to gaps in self-management and heightened uncertainty. This thesis highlights that recipients often felt overwhelmed by the volume and complexity of information provided during the acute phase, leading to difficulties in understanding and retaining details about late effects and long-term follow-up requirements (Hawkins et al., 2008; Nakajima & Kamibeppu, 2022; Vetch et al., 2017). This challenge is compounded by the lack of tailored, phased education and the absence of written care plans, which can leave recipients unprepared for the duration and complexity of recovery. Research has shown that the timing, mode, and relevance of information delivery are critical for supporting self-management and reducing anxiety, with proactive, structured education improving engagement and psychological adjustment (El-Jawahri et al., 2017; Kenyon et al., 2023).

As a result of these informational and timing challenges, recipients' experiences of LTFU care evolved through phases, such as continuity, transition, and adaptation, each reflecting psychological and behavioural responses to service ambiguity. The findings describes how these phases are marked by changes in care structure, informational clarity, and relational continuity, with recipients moving from stable engagement to periods of uncertainty and adaptation (see Section 7.2.1). The Ambiguous Outpatient construct illustrates how patients adapt their engagement with care as clarity shifts over time, moving from perceived stability to active information-seeking and, eventually, to navigating ambiguity and sustained self-management. This progression is supported by health psychology frameworks such as the Intolerance of Uncertainty Theory (Freeston et al., 1994), and the Candidacy Framework (Dixon-Woods et al., 2006), which explain how psychological and behavioural responses evolve in the face of service ambiguity and shifting care pathways. The thesis further notes that recipients often develop self-management strategies and seek information proactively as they adapt to ongoing uncertainty and fragmented care (El-Jawahri et al., 2017; Nakajima & Kamibeppu, 2022; Vetsch et al., 2017).

Importantly, this thesis highlights the role of patient self-advocacy and information seeking in response to informational gaps and fragmented care. Many recipients rely on self-management strategies, such as tracking test results and seeking information online or through peer groups. Recipients often turn to informal sources, such as online forums and peer support groups, to fill gaps left by inconsistent or insufficient information from healthcare providers. While these strategies can empower, they may also intensify uncertainty and psychological distress, especially when recipients encounter conflicting advice or negative experiences (El-Jawahri et al., 2017; Nakajima & Kamibeppu, 2022; Vetsch et al., 2017). The emotional impact of informal information sources is a significant contributor to health uncertainty. Prior studies support the view that proactive, tailored education and clear communication from clinical teams are essential to reduce reliance on informal sources and support psychological well-being during long-term recovery (Kenyon et al., 2023; Majhail et al., 2012; Rotz et al., 2024).

This persistent uncertainty has been shown to negatively affect recipients' quality of life, with cancer survivors who report higher levels of uncertainty are known to experience higher levels of distress and anxiety, including scan-related anxiety (Eisenberg et al., 2015; Parker et al., 2016; Patel et al., 2024; Yang et al., 2023). This thesis also notes that uncertainty can be compounded by fragmented care pathways, informational gaps, and lack of relational continuity, further intensifying distress and impacting quality of life (Dignan et al., 2021;

Kenyon et al., 2023; Rotz et al., 2024). These findings demonstrate the broader impact of uncertainty on HSCT recipients' well-being and reinforce the importance of addressing its causes. Proactive communication, tailored education, and integrated care models are recommended in the literature to help mitigate uncertainty and improve LTFU care outcomes (Kenyon et al., 2023; NHS Long Term Plan, 2019, 2025; Santana et al., 2018).

The unpredictable nature of HSCT health complications, including the physical, can significantly heighten feelings of uncertainty (Amler et al., 2015; Chakraborty et al., 2023). Although distress related to uncertainty may reduce over time following HSCT (Chakraborty et al., 2023), this thesis finds that anxiety and distress for some participants remain closely tied to both intolerance of uncertainty and illness-related uncertainty. Drawing on Intolerance of Uncertainty Theory (Freeston et al., 1994) and Illness Uncertainty Theory (Mishel, 1988), the findings illustrate how varying levels of tolerance for uncertainty shape psychological adjustment and engagement with LTFU care. Rather than categorising participants as inherently intolerant, this thesis explores how individual differences in managing uncertainty contribute to distress and influence LTFU care experience.

This thesis expands current understanding of HSCT survivorship by offering the first multi-method qualitative account of LTFU care across multiple service providers in England. It builds on existing literature by demonstrating that health uncertainty and service navigation uncertainty are not isolated concerns but interrelated and evolving experiences that shape engagement, psychological well-being, and self-management. Previous studies have acknowledged uncertainty in relation to late effects or physical health, but this thesis shows how ambiguity in care pathways and transitions intensifies these concerns and contributes to fragmented care. The findings challenge traditional biomedical models and extend psychological and behavioural frameworks by illustrating how uncertainty is co-constructed through clinical practices, institutional structures, and individual responses.

### *8.3.2 Novel Contribution*

This thesis makes several novel contributions to the field of HSCT survivorship and LTFU care, spanning theoretical, empirical, methodological, and practical domains. These contributions are situated within the context of recent literature and are mapped to the relevant chapters of the thesis. Foremost among these is the central theoretical advancement of the adaptation and extension of the Candidacy Framework (Dixon-Woods et al., 2006) to the context of HSCT LTFU care (see Section 7.3 and 7.4).

While the candidacy framework has been used to understand access to healthcare in other chronic and marginalised populations (Koehn et al., 2024; Sinnott et al., 2024; Tookey et al., 2018; van der Boor & White, 2020), this thesis is the first to apply and adapt it to the nuanced, conditional, and emotionally charged context of HSCT survivorship in England. In doing so, this thesis introduces two new constructs that address key gaps in the conceptualisation of survivorship: "relevance ambiguity" and the "ambiguous outpatient". These additions respond to recent calls for frameworks that better capture the complexity of access and engagement in survivorship care (Koehn et al., 2024; Sinnott et al., 2024; Tookey et al., 2018; van der Boor & White, 2020). The ambiguous outpatient construct captures the lack of clarity regarding monitoring practices and the implications for accessing healthcare, while the relevance ambiguity feedback loop describes the cyclical and intensifying nature of uncertainty as recipients interpret ambiguous symptoms and navigate service boundaries. These constructs are grounded in the findings presented in Chapter 7, which detail how recipients move through phases of continuity, transition, and adaptation, often encountering ambiguous care pathways and unclear eligibility for support.

Together with the adapted Candidacy Framework, the relevance ambiguity and the ambiguous outpatient constructs provide a new lens for understanding how uncertainty evolves and intensifies as recipients move through the LTFU pathway. This approach builds on previous literature that emphasises the negotiated and dynamic nature of healthcare access (Dignan et al., 2021; Hashmi et al., 2017). Offering a more nuanced understanding of how recipients negotiate eligibility and recognition within fragmented care pathways. It highlights the interplay between individual psychological responses, institutional practices, and informational gaps, and helps to explain the persistence of uncertainty and the need for proactive communication and tailored support throughout the LTFU journey.

Empirically, this thesis is the first to provide a comprehensive, multi-method qualitative account of HSCT recipients' experiences of LTFU care across multiple service providers in England. Previous research has been limited to single-centre studies or non-UK contexts (de Vere Hunt et al., 2021; Parisek et al., 2021; Sharin et al., 2020). Triangulating written accounts and in-depth interviews, this thesis offers a contextually grounded understanding of the lived realities of HSCT survivors navigating the NHS. Notably, the research identifies and theorises the dynamic interplay between service navigation uncertainty and health uncertainty, showing how these forms of uncertainty are mutually reinforcing and evolve over time. This dual focus is novel and aligns with recent calls for more nuanced models of uncertainty in survivorship

(Langmuir et al., 2023; Pomare et al., 2019). The thesis also provides rich participant narratives that illustrate how recipients adapt to or struggle with fragmented care, ambiguous transitions, and inconsistent information. This level of empirical depth is rarely achieved in previous studies, which often rely on survey data or single-method designs (Pulewka et al., 2021; Yanling et al., 2023).

In addition to its empirical contributions, this thesis adopts a reflexive, hermeneutic phenomenological methodology, integrating reflexive thematic analysis and triangulation across multiple qualitative methods. This approach enables a deep exploration of subjective experience, context, and meaning, and enhances the credibility and transferability of findings. Reflexivity is foregrounded throughout the research process, including the researcher's positionality as an HSCT recipient (see Section 3.4), in line with best practice in qualitative health research (Braun & Clarke, 2022; Olmos-Vega et al., 2022). The integration of written accounts and interviews achieves methodological triangulation, further strengthening the robustness of findings (Carter et al., 2014; Meydan & Akkaş, 2024).

Practically, the thesis identifies key gaps in the delivery of LTFU care for HSCT recipients in England, grounded in lived experience. It highlights persistent issues such as unclear care transitions, inconsistent information provision, and disrupted relational continuity. Based on these findings, the thesis offers actionable recommendations for practice (see Section 8.6), including clear communication about transitions, provision of written care plans, regular check-ins with familiar clinical staff, and better support for health literacy and digital navigation. These recommendations align with current NHS policy shifts and recent literature advocating for tailored, person-centred survivorship care (Kenyon et al., 2023; Housten et al., 2021; Park et al., 2025).

Extending its contribution to the wider literature, this programme of work directly addresses gaps and priorities identified in recent peer-reviewed literature. There is a growing consensus that person-centred, flexible, and contextually responsive survivorship care is essential (Kenyon et al., 2023; NHS, 2025; Santana et al., 2018). The research advances understanding of uncertainty as a determinant of engagement and health behaviour, a theme highlighted in recent studies (Berrigan et al., 2023; Guan et al., 2023). The dual impact of digital information-seeking is increasingly recognised as a challenge and opportunity in cancer survivorship (Housten et al., 2021; Park et al., 2025), and the study provides evidence and practical recommendations for addressing these challenges in the context of HSCT LTFU care.

## 8.4 Implications of the Research

The findings of this programme of work have several implications to theory, practice, and future research in HSCT survivorship and LTFU care.

### *8.4.1 Theoretical Implications*

The findings of this programme of work have significant theoretical implications for understanding healthcare access and engagement for HSCT recipients in LTFU care. These implications predominantly relate to the uncertainty participants experience in relation to service navigation, their intolerance of uncertainty, and their future health. At its core, the research demonstrates that participant experiences of LTFU care resonate with Illness Uncertainty Theory (Mishel, 1988) and Intolerance of Uncertainty Theory (Freeston et al., 1994). Recipients' inability to predict their long-term health leads to confusion and doubt, impacting overall quality of life (Clayton & Kruzel, 2023). To manage this uncertainty, participants take measures such as information gathering to either take control or eliminate ambiguity. Although intolerance to uncertainty does not typically manifest at the commencement of LTFU care, it tends to surface over time, often after a new health diagnosis or when seeking to understand more about monitoring practices.

Building on these theoretical perspectives, this programme of work extends the Candidacy Framework (Dixon-Woods et al., 2006) by introducing the new constructs of relevance ambiguity and the ambiguous outpatient area. These additions better reflect the conditional, interpretive, and emotionally charged nature of LTFU care transitions. As experienced by recipients who often find themselves negotiating eligibility, legitimacy, and recognition within fragmented and inconsistent care systems. Recent literature has similarly called for access frameworks to be adapted to the complexity of chronic illness and survivorship (Koehn et al., 2024; Sinnott et al., 2024; Tookey et al., 2018; van der Boor & White, 2020), highlighting the need for models that account for ambiguity and the evolving nature of patient needs.

A key theoretical implication of this thesis is the demonstration of how psychological and sociological theories can be integrated to provide a more comprehensive understanding of engagement and agency in survivorship care. The findings show that uncertainty about care status, ambiguous transitions, and inconsistent information provision can inhibit help-seeking and delay engagement. The emotional and behavioural responses observed in this thesis, such as anxiety, avoidance, and reliance on trusted clinical relationships, are well explained by these

theoretical perspectives and are consistent with empirical studies of cancer and transplant populations (Diesch-Furlanetto et al., 2021; Fritzson et al., 2024; Guan et al., 2021; Yang et al., 2023). Integrating these perspectives enables a richer understanding of how recipients interpret risk, cope with ambiguity, and engage with healthcare systems over time.

This thesis advances theoretical understanding by extending the Candidacy Framework to better reflect the realities of LTFU care for HSCT recipients, integrating psychological and sociological theories to explain engagement and adaptation, and highlighting the importance of health literacy, timing, and relational continuity. These insights provide a strong foundation for future research and intervention development, and highlights the need for theoretically informed, person-centred approaches in survivorship care. By addressing the complexities and uncertainties inherent in LTFU care, this work contributes to the ongoing evolution of theory and practice in the field of cancer and transplant survivorship.

### *8.4.2 Practical Implications*

The findings of this programme of work have several important implications for clinical LTFU care of HSCT recipients in England. One of the most salient implications is the need for clear, ongoing communication about the transition from acute to LTFU care, including explicit information about the purpose, scope, and expectations of LTFU services. Persistent uncertainty regarding when LTFU care commences, what it entails, and who is responsible for ongoing monitoring and support was a consistent theme (*Service Navigation Uncertainty*) among participants. This ambiguity can lead to anxiety, disengagement, and missed opportunities for timely intervention. Addressing this issue is crucial, as structured communication and clear care pathways have been shown to improve patient satisfaction, engagement, and outcomes in cancer and transplant survivorship care (Bevans et al., 2017; Dignan et al., 2021; Kenyon et al., 2023). When recipients are well-informed and confident about their care trajectory, clinical teams can strengthen their sense of security and partnership, which is essential for effective LTFU management and for building trust in the healthcare system.

Relational continuity was found to provide reassurance, build trust, and support adherence to monitoring and follow-up. When continuity was disrupted, recipients reported increased vulnerability and disengagement, highlighting the emotional and practical importance of ongoing, familiar support. Prioritising relational continuity ensures that recipients have ongoing access to knowledgeable and responsive personnel, which is crucial for maintaining engagement and supporting positive health outcomes. The wider literature supports this,

demonstrating that multidisciplinary and continuous care is essential for managing late effects and the psychological burden faced by HSCT survivors (Baskin et al., 2023; Corcoran et al., 2015; McCaughan et al., 2021). As strong clinical relationships can help recipients feel less isolated and more empowered to participate in their care, which is particularly important as they navigate the uncertainties of survivorship.

Many recipients felt unprepared for the complexity and duration of recovery and reported unmet informational needs even years after transplant. Providing information that is revisited and adapted to recipients' changing needs and psychological readiness over time is vital. This approach empowers recipients to manage their health, reduces uncertainty, and supports informed decision-making. Tailored information and education have been shown to improve health literacy, self-management, and long-term outcomes for cancer and transplant survivors (El-Jawahri et al., 2017; Nakajima & Kamibeppu, 2022; Vetsch et al., 2017). When recipients are equipped with the right information at the right time, they are better able to anticipate challenges, seek appropriate support, and maintain a proactive approach to their health, which can contribute to improved quality of life and reduced psychological distress.

Supporting health literacy and self-management is also critical for effective LTFU care. Recipients' ability to manage their health and engage with LTFU care is closely linked to their health literacy and confidence in navigating the system. Supporting recipients in developing the skills and knowledge needed to interpret information, monitor for late effects, and make informed decisions about when and how to seek help is particularly important as self-managed and hybrid models of care become more common. Improved health literacy enables recipients to participate actively in their care, which can lead to better health outcomes and greater satisfaction with services. Research in survivorship and chronic care consistently demonstrates that higher health literacy is associated with improved adherence, reduced anxiety, and better quality of life (Holden et al., 2021; Sørensen et al., 2012). By investing in health literacy initiatives, clinical teams can help bridge gaps in understanding and empower recipients to take greater control over their long-term well-being, which is especially relevant as healthcare systems move towards more patient-driven models.

Ambiguity regarding the roles of transplant teams, primary care providers, and other specialists was a source of confusion and disengagement for many recipients. Clear delineation of responsibilities, including when to contact the transplant team versus the GP, should be communicated to recipients and reinforced throughout the LTFU pathway. This clarity helps

ensure that recipients access the right support at the right time, preventing gaps in care and reducing frustration. Well-defined care pathways and role clarity are associated with more effective service delivery and improved patient outcomes (Dignan et al., 2021; Kenyon et al., 2023). When recipients understand who to turn to for specific concerns, they are more likely to seek timely help and avoid unnecessary delays or misunderstandings in their care, which can have a direct impact on both their physical and psychological health.

The research highlights the need for person-centred care that is responsive to individual preferences, values, and needs. Flexibility in appointment scheduling, mode of consultation (in-person, remote), and access to support services can help accommodate the diverse circumstances of HSCT recipients and improve engagement and satisfaction. Person-centred approaches are associated with better psychological well-being and more effective self-management (Santana et al., 2018). By embedding flexibility and responsiveness into LTFU pathways, clinical teams can ensure that care remains relevant and accessible as recipients' needs evolve over time, thereby supporting sustained engagement and optimal outcomes.

Taken together, these practical implications are directly supported by the qualitative findings and participant accounts in this thesis and are further validated by the wider peer-reviewed literature. Implementing these changes is significant because they address the core barriers to effective survivorship care identified in both this thesis and the broader field: uncertainty, fragmented communication, lack of tailored information, and insufficient support for self-management. By addressing these issues, clinical teams can improve patient engagement, psychological well-being, and long-term health outcomes for HSCT recipients, contributing to more effective and equitable survivorship care.

These practical implications directly inform the recommendations for clinical practice, which are outlined in Section 8.6.

### *8.4.3 Implications for Future Research and Recommendations*

The findings of this programme of work highlight several critical gaps and priorities for future research in HSCT survivorship and LTFU care. These recommendations are tightly linked to the synthesised evidence and participant accounts presented in Chapter 7.

A principal gap identified in this research is the persistent and multifaceted uncertainty experienced by HSCT recipients throughout the LTFU pathway, encompassing both *Service*

*Navigation Uncertainty* and *Health Uncertainty* (see Section 7.2.2). This uncertainty was found to undermine engagement, psychological well-being, and self-management (see Section 7.2.3 and 7.2.4). Despite its centrality, there remains a notable lack of targeted psychological and service-level interventions designed to address both forms of uncertainty in an integrated manner. As highlighted in Chapter 2, current LTFU models and guidelines tend to focus on biomedical monitoring and physical late effects, with limited attention to the psychological and structural sources of uncertainty (see Sections 2.4.1 and 2.5.1). While theoretical frameworks such as Illness Uncertainty Theory (Mishel, 1988) and Intolerance of Uncertainty Theory (Freeston et al., 1994) provide a foundation for understanding these experiences, there is a need for future research to develop and evaluate interventions that address both illness-related and service navigation uncertainty in tandem. This direction is justified by the evidence that uncertainty is a pervasive barrier to engagement and well-being for HSCT survivors, and that addressing it requires both psychological and systemic solutions (see Section 2.6.2).

Findings revealed that recipients frequently experience ambiguity and frustration when referred to general practitioners for health concerns not directly related to HSCT (see Chapter 7). Many expressed uncertainties about whether their symptoms were transplant-related and reported a lack of confidence in GPs' ability to manage or identify potential late effects. Future research should apply the Candidacy Framework (Dixon-Woods et al., 2006) to explore how prior interactions with general practitioner's shape recipients perceived eligibility to seek primary care for HSCT-related issues. Understanding these dynamics is essential for informing policy and practice aimed at improving continuity and coordination of care.

This thesis was limited by a lack of ethnic, socioeconomic, and age diversity among participants, as well as a predominance of recipients receiving care in specialist LTFU clinics (see Section 8.5). Future studies should aim to recruit more diverse samples, including those managed primarily in primary care settings, younger adults, and individuals from minority backgrounds. This recommendation is supported by recent reviews and is justified by the need to ensure that future recommendations for LTFU care are inclusive, equitable, and applicable across the full spectrum of HSCT survivors. Employing longitudinal and mixed-methods designs could provide richer insights into how experiences and needs evolve over time, and triangulation with quantitative data, such as patient-reported outcome measures, could strengthen the evidence base for practice change.

As healthcare systems continue to evolve, there is a need for research that critically examines the impact of policy initiatives such as the NHS "Fit for the Future" plan on the delivery and experience of LTFU care. The evidence generated in this thesis demonstrates that policy ambitions for person-centred, stratified, and digitally enabled care are not always realised in practice (see Section 7.4.2). Ongoing evaluation of how these changes affect engagement, access, and outcomes for HSCT recipients will be essential to ensure that future service developments are responsive to the needs and preferences of survivors.

This thesis provides the foundations for future research by offering a rigorous, multi-method qualitative exploration of HSCT recipients' experiences of LTFU care in England, capturing the nuanced interplay between service navigation and health uncertainty that has been largely overlooked in previous studies. Integrating health psychology and sociological frameworks such as Intolerance of Uncertainty Theory (Freeston et al., 1994), Illness Uncertainty Theory (Mishel, 1988), and the Candidacy Framework (Dixon-Woods et al., 2006), this work establishes a biopsychosocial perspective that moves beyond traditional biomedical models (see Sections 2.4 and 2.7). The empirical insights and theoretical integration presented here create a robust conceptual scaffold for developing and validating a comprehensive model of LTFU experiences in larger and more diverse samples, which can inform improvements in clinical practice, policy, and survivor support by identifying key intervention points to reduce uncertainty and enhance long-term outcomes.

The future research directions outlined above will help advance understanding, support evidence-based improvements in clinical practice, and inform policy, with the goal of enhancing the quality of life for HSCT recipients in LTFU care.

### 8.5 Research Strengths and Limitations

This is the first known multi-method exploring HSCT recipients' experiences of LTFU care England. Previous research has focused on samples from Germany (Parisek et al., 2021), Singapore (Sharin et al., 2020), and the USA (Hwang et al., 2012), but none have explored general LTFU clinics in England, as opposed to a single-centre GvHD clinic (de Vere Hunt et al., 2021). This thesis provides novel insights, particularly regarding the persistent uncertainty around care transitions, information provision, and relational continuity. The findings highlight the need for clearer communication, sustained clinical relationships, and tailored support to improve person-centred outcomes in LTFU care. The study highlights barriers such as fragmented pathways, inconsistent messaging, and limited relational continuity, offering

actionable evidence for service redesign. Addressing these issues can reduce disengagement and anxiety while enhancing recipients' confidence, engagement, and ability to self-manage. This aligns with Kenyon et al. (2023), which advocates for responsive, collaborative services that prioritise continuity and clear communication to improve long-term outcomes for HSCT survivors.

The hermeneutic phenomenological approach adopted in this programme of work offers several strengths. It enabled a deep exploration of the universal essence of HSCT recipients' experiences (Creswell & Poth, 2018), providing rich, subjective accounts that highlighted the challenges encountered during transitions along the LTFU pathway (Neubauer et al., 2019). It's interpretative nature facilitated nuanced engagement with the data, revealing meanings not immediately apparent. The multi-method approach, strengthened by triangulation (Carter et al., 2014; Hesse-Biber et al., 2015; Meydan & Akkaş, 2024), enhanced the trustworthiness of the findings. Ongoing reflexive practice, including critical self-awareness and examination of positionality, and engagement with participants' accounts, contributed to the creditability and depth of the study by supporting deeper understanding and enhancing contextual sensitivity. The researcher's perspective as an HSCT recipient was balanced by continual reflection on preconceptions and biases, supporting an open and receptive approach to the data. This iterative interpretative process, intrinsic to phenomenological research, enabled evolving insights and deeper comprehension (Guerrero-Castañeda et al., 2019). Reflexive thematic analysis further supported this, allowing the researcher's understanding of the data to develop and shift over time (Braun & Clarke, 2022).

While this thesis offers important insights into the experiences of HSCT recipients in England, several limitations affect the transferability and broader applicability of its findings. These limitations are particularly relevant to the age and ethnic composition of the participant sample, as well as the settings in which follow-up care was received. The participant sample across Studies 2 and 3 comprised 33 individuals, with a mean age of 47.26 years at the time of transplant (range 3–68 years). This age distribution, while reflecting the demographic profile of many HSCT recipients in England and other high-income countries, is consistent with data showing that the majority of HSCTs are performed in adults aged 40–70 years (Kazmi et al., 2025; NHSE Specialised Services, 2021; Passweg et al., 2021; Pugh et al., 2025). This limits the ability of this thesis to fully capture the perspectives and needs of younger adults and paediatric recipients. Younger participants, especially those in adolescence or early adulthood, often face distinct challenges in LTFU care, including concerns around fertility, education,

employment, and psychosocial adjustment (Diesch-Furlanetto et al., 2021; Richardson et al., 2016; Vetsch et al., 2017), which may not be as salient for older adults. The underrepresentation of these groups means that the findings may not adequately reflect the unique barriers, informational needs, or care preferences of younger recipients, who are known to experience different risk perception, and engagement with healthcare services (Pulewka et al., 2021; Richardson et al., 2016).

Moreover, the wide age range (3–68 years) reflects considerable diversity in participant experiences, although the qualitative synthesis may have been shaped by the concerns and priorities of the older majority. Previous research suggests that older recipients are more likely to seek advice related to transplant aftercare, while younger people tend to prioritise information about physical health and topics such as sexual well-being (Pulewka et al., 2021). This pattern is consistent with broader trends in information-seeking, where younger adults are often interested in a broader spectrum of issues, whereas older adults typically focus on deepening their understanding of areas already familiar to them (Coleman, 2018). This predominance of older participants also limits the ability to explore how LTFU experiences and needs evolve across the life course, or how age at transplant interacts with other factors such access to age-appropriate information, continuity of care across services, and the capacity for self-management.

The limited demographic variation within the participant sample presents a notable constraint in the capacity of this thesis to explore the full spectrum of LTFU care experiences. Ethnicity data for written account participants was not captured, and all interviewees were identified as White British. Socioeconomic status was not recorded. This lack of diversity restricts the ability to examine how cultural, linguistic, and systemic factors may influence LTFU care among minority ethnic groups or individuals from varied socioeconomic backgrounds. Existing literature highlights that these populations often encounter additional barriers in healthcare access, communication, and information provision, and may hold different expectations or preferences regarding LTFU care (Absolom et al., 2021; Dignan et al., 2021; Majhail et al., 2012; Richardson et al., 2016; Vasileiou et al., 2018). Therefore, the findings may not be transferable to more diverse populations and risk overlooking intersectional challenges such as language barriers, health literacy gaps, and experiences shaped by potential structural inequities within the healthcare system.

A further limitation is that many participants received LTFU care through specialist clinics, with limited representation from those managed in primary or non-specialist secondary care settings. This sampling bias may underrepresent the challenges, informational needs, or care experiences of recipients outside specialist pathways, particularly those in under-resourced, rural, or community-based settings (Dignan et al., 2021). The findings may therefore reflect the experiences of those with greater access to specialist expertise and continuity, rather than those navigating fragmented or less well-resourced care environments. In addition, recruitment via online support groups and written accounts may have inadvertently excluded individuals who are less digitally literate or less engaged with online platforms, potentially underrepresenting the experiences of more vulnerable or isolated recipients, as well as those from lower socioeconomic backgrounds or older age groups who may have less access to digital resources (Benedict et al., 2019; Braun et al., 2021; Gill et al., 2008).

Recruitment challenges further limited the inclusion of autologous transplant recipients, as recruitment channels such as Anthony Nolan and condition-specific support groups primarily reached allogeneic transplant recipients. Efforts to access autologous-focused groups were unsuccessful, resulting in limited participation from this subgroup despite attempts to broaden recruitment. The underrepresentation of autologous recipients means that the findings may not fully capture the diversity of survivorship experiences, particularly regarding differences in care pathways, late effects, and informational needs (Dignan et al., 2021; Rotz et al., 2024). Consequently, the thesis recommendations may be less applicable to this subgroup, and future research should prioritise targeted recruitment strategies to ensure that the perspectives of all HSCT recipient groups are adequately represented.

Methodologically, while the use of reflexivity and peer debriefing helped manage researcher bias, the dual role of the researcher as both HSCT recipient and investigator may still have indirectly influenced data interpretation, as complete objectivity is unattainable in qualitative research (Braun & Clarke, 2022; Finlay, 2002). Triangulation, although enhancing credibility, introduced the risk that some nuances or minority perspectives may have been lost during synthesis (Annells, 2006; Carter et al., 2014). The integration of findings from written accounts and interviews required careful negotiation of divergent perspectives, and there remains the possibility that the process of synthesis may have inadvertently privileged certain themes over others (Braun & Clarke, 2022).

The lack of standardisation in post-transplant care protocols may also have affected the comparability of participant experiences (Rotz et al., 2024). Some participants may have been under active care while contributing to the study, and several described experiences that blurred the boundaries between acute and LTFU care, particularly those with graft-versus-host disease, where acute and follow-up care are often integrated (Dignan et al., 2021). Although exploratory questions were used to clarify these distinctions, some participants struggled to differentiate between care types. Additionally, some had received transplants prior to the 2018 FACT-JACIE accreditation amendment, which established the requirement for transplant centres to manage LTFU care, meaning some accounts may not reflect current monitoring practices.

Despite these limitations, this thesis advances understanding of HSCT recipients' experiences of LTFU care in England and demonstrates the value of a rigorous, reflexive, and multi-method qualitative approach. The identified gaps and challenges point to clear priorities for future research and service development, and the following section outlines practical recommendations to support more inclusive, person-centred, and equitable LTFU care.

### 8.6 Practice Recommendations

Based on the synthesis of this thesis findings, the following practice recommendations are proposed to address the key challenges identified in LTFU care for HSCT recipients. These recommendations aim to reduce uncertainty, improve psychological and informational support, and promote more person-centred, coordinated care pathways. For a detailed mapping of each recommendation to its supporting findings and themes, see Appendix 54.

1. **Address psychological impact of uncertainty in LTFU care:** Recognise and proactively address the psychological burden of future uncertainty, including ambiguous care pathways, informational gaps, and evolving health risks. Embed psychological screening and support into LTFU pathways. Consider targeted interventions for illness-related uncertainty and intolerance of uncertainty.

2. **Clarify and communicate the transition to LTFU care:** Ensure that the transition from acute post-transplant care to LTFU care is clearly communicated to recipients, with explicit information about what LTFU entails, when it begins, and what changes to expect. This can reduce ambiguity and help recipients engage more confidently with their care pathway.

3. **Clarify roles and responsibilities between specialist and primary care**: Clearly delineate the responsibilities of transplant teams and primary care providers in LTFU. Educate recipients about who to contact for different health concerns and ensure that primary care providers are equipped with the knowledge and feel confident to support HSCT recipients.

4. **Enhance information provision and health literacy:** Deliver information about late effects, monitoring, and self-management in a timely, staged, and personalised manner. Avoid overwhelming recipients at the outset; instead, revisit and reinforce key information as needs evolve. Support recipients in developing health literacy and confidence to interpret and act on health information.

5. **Tailor information and support to individual preferences**: Recognise that information needs and preferences vary widely. Some recipients want detailed information, while others prefer only essential facts. Tailor communication and support accordingly and revisit these preferences over time.

6. **Provide personalised, written care plans**: Offer all HSCT recipients a written care plan at the commencement of LTFU. This plan should include individual risk factors, monitoring schedules, and clear guidance on when to contact the transplant team versus primary care. Written documentation addresses the persistent unmet need for information and supports self-management.

7. **Discuss the benefits and risks of online information and peer support:** Educate recipients about the potential benefits and pitfalls of seeking information online and through social media groups. Encourage critical appraisal of online content and provide guidance on accessing reliable sources.

8. **Promote education and training for primary care providers**: Provide targeted education and resources to primary care professionals about the complexities of LTFU care, late effects, and the specific needs of HSCT recipients. This can improve care quality, recipients' trust in primary care, and reduce unnecessary reliance on transplant centres.

## 8.7 Conclusion

This programme of work set out to explore how haematopoietic stem cell transplantation (HSCT) recipients experience long-term follow-up (LTFU) care in England, with a particular focus on the psychological, informational, and structural factors that shape engagement, adaptation, and well-being. Through a multi-method qualitative approach, including a systematic review with qualitative evidence synthesis, written accounts, and in-depth interviews, this thesis has provided a comprehensive and nuanced understanding of the realities of LTFU care from the recipient perspective.

The findings reveal that *Future Uncertainty* is the overarching theme shaping HSCT recipients' experiences of LTFU care, manifesting as both *Service Navigation Uncertainty* and *Health Uncertainty*. Participants described ambiguity and lack of clarity during the transition from acute to LTFU care, the value of sustained relationships with specialist teams, and the challenges posed by disrupted continuity, inconsistent information, and fragmented care pathways. Persistent gaps in tailored, timely information and the emotional impact of informal sources were also highlighted.

This thesis makes several original contributions to knowledge. The proposed adaptation and extension of the Dixon-Woods et al. (2006) Candidacy Framework to LTFU care introduces new theoretical tools for understanding how patients negotiate eligibility and recognition within fragmented pathways. Empirically, this is the first comprehensive, multi-method qualitative account of HSCT recipients' experiences of LTFU care across multiple service providers in England. The research also synthesises the dynamic interplay between service navigation and health uncertainty, and offers actionable recommendations for service improvement, including clear communication about care transitions, provision of written care plans, and support for health literacy.

Theoretically, this thesis advances understanding of uncertainty as a determinant of engagement and health in survivorship care, integrating psychological and sociological theories to provide a richer account of how recipients interpret risk and engage with healthcare systems. Practically, the findings highlight the need for person-centred, adaptive models of LTFU care that prioritise relational continuity, clear communication, and tailored information provision.

While this thesis offers important new insights into HSCT recipients' experiences of LTFU care in England, it is not without limitations. As outlined in Section 8.5, the study's transferability

is constrained by the lack of participant diversity and the predominance of specialist clinic settings, among other factors. These limitations highlight the need for future research to adopt more inclusive sampling strategies and to explore experiences across a broader range of care contexts. Addressing these gaps will be essential for developing more equitable, transferable, and evidence-based improvements in LTFU care.

In summary, this thesis has illuminated the complex, dynamic, and often ambiguous landscape of LTFU care for HSCT recipients in England. By centring the voices and experiences of survivors, it has highlighted the centrality of uncertainty, the importance of relational continuity, and the persistent gaps in information and support that shape engagement and well-being. As one participant poignantly expressed, “When you don’t know, you don’t know”: a sentiment that captures the essence of the challenges faced by recipients navigating LTFU care. The theoretical and practical contributions of this thesis provide a strong foundation for future inquiry, policy development, and service improvement, with the goal of ensuring that all HSCT recipients receive care that is not only person-centred, responsive, and empowering, but also emotionally attuned and structurally responsive.

# Chapter 9. Reflexive Narrative: The View from Within

## 9.1 Chapter Introduction

This chapter offers a reflexive account of my research journey, examining how my dual role as both a HSCT recipient and a researcher shaped the design, conduct, and interpretation of this thesis. Reflexivity was not a discrete stage but a continuous thread woven throughout the research process (see Section 3.4), supporting methodological transparency and enhancing the credibility of the findings (Braun & Clarke, 2022; Olmos-Vega et al., 2023).

## 9.2 Reflexivity in Research Design and Practice

### *9.2.1 Researcher Positionality and Philosophical Commitments*

My lived experience as an HSCT recipient provided valuable contextual understanding of LTFU care. This perspective heightened my sensitivity to issues of uncertainty, information needs, and relational continuity, which where key themes that emerged from participant accounts. I was acutely aware of the need to ensure that personal insight informed, rather than dominated, the research. To achieve this, I consistently linked reflections on my own experiences to methodological decisions and ethical considerations, including those related to participant safeguarding, which were informed by my awareness of the emotional impact of LTFU care. This included the developed of ethically sound procedures and materials that prioritised psychological safety and well-being (see Section 3.6), while ensuring that the thesis focus remained on participants' voices rather than my own narrative (Finlay, 2002).

The interpretivist and constructionist paradigm underpinning this thesis recognises that knowledge is co-constructed through context, relationships, and interpretation (Crotty, 1998; Grix, 2019; see Section 3.2). Adopting a hermeneutic phenomenological methodology and reflexive thematic analysis (Braun & Clarke, 2022) enabled me to engage deeply with participants' accounts while remaining critically aware of my own influence on the research process. Reflexivity was treated as a methodological resource, supporting transparency and rigour rather than serving as an autobiographical account (Olmos-Vega et al., 2023).

### *9.2.2 Balancing Personal Insight with Academic Analysis*

Throughout this programme of work, I was mindful to use my personal experience as a lens for understanding, not as the primary narrative. While my background heightened my sensitivity to issues of uncertainty and information needs, I used these insights to inform the development of this research and the interpretation of data (see Sections 5.3.5 and 6.3.5), rather than to

validate my own story. Reflexive journaling and analytic memoing (see Section 3.4) allowed me to document how my positionality influenced data collection and analysis, and to critically examine moments where my perspective might have shaped interpretation. This practice aligns with best practice in qualitative research, where reflexivity is essential for maintaining analytical distance and ensuring that findings are grounded in participants' accounts (Alvesson & Sköldberg, 2017; Braun & Clarke, 2022).

There were moments when separating the researcher from the recipient was emotionally challenging. Participants' frustrations around hormonal changes and fertility, for instance, mirrored my own experiences. I empathised deeply and felt anger that these issues remain inadequately addressed. I reminded myself that findings must be supported by data, not emotion, and used journaling to reflect on these overlaps. Guilt also surfaced as an emotional challenge for me. Participants frequently expressed surprise, coupled with reassurance, upon learning the length of time since my transplant. Despite this, hearing participants' experiences of ongoing health-related challenges, especially in relation to chronic GvHD, made me feel guilty for having had a relatively smooth journey. Processing this guilt was difficult, but I reminded myself that the research was about amplifying recipients' voices, not mine. Consequently, I found I naturally began to withhold details about my own transplant timeline unless asked. This lack of disclosure, in turn, impacted participants' engagement as when I did disclose my history, they saw me not just as a researcher, but as someone who truly understood. This empathy enriched the interviews and allowed for deeper exploration of themes of uncertainty and service navigation, which later emerged as core underlying themes impacting recipients experiences.

To further balance personal insight with academic analysis, I sought regular feedback from supervisors and peers and triangulated my interpretations with those of others (see Section 3.7). Having lived with the implications of HSCT since adolescence, I was particularly attuned to themes of uncertainty and information gaps. I was aware that HSCT carried long-term risks such as secondary cancers and chronic GvHD, and like many participants in this thesis, I often found it difficult to discern whether symptoms were signs of ageing or something more serious. What surprised me was how common this uncertainty was among other recipients, and that I wasn't alone in these thoughts. This realisation was both validating and unsettling. I documented these reflections in my journal, questioning whether my interpretations were rooted in personal experience or genuinely reflected participants' accounts. I cross-checked

these insights against multiple data sources to ensure findings were grounded in participants' voices, not my own.

At times, I struggled with the emotional demands of research, which in hindsight did impact my health and well-being. These demands were exacerbated by my dyslexia and the challenge of processing vast amounts of information, but I also did not realise I was experiencing symptoms of a known late effects. Listening to others face challengers in accessing appropriate health support validated the need for me to push for further investigation and receive the support I needed.

### *9.2.3 Reflexivity, Writing, and Research Impact*

Writing this thesis required careful consideration of how to represent participants' experiences authentically and ethically. I aimed to balance description and interpretation, ensuring that the emotional weight of participants' stories was conveyed without overshadowing the academic analysis. Selecting quotes was always an interpretive act, and I remained conscious of the responsibility to honour participants' trust while maintaining methodological transparency (Braun & Clarke, 2022).

This reflexive approach directly enhanced the research impact of the thesis. Through critical interrogating of my own assumptions and positionality, I was able to identify and address potential biases, thereby strengthening the credibility and trustworthiness of the findings (Carter et al., 2014; Lincoln & Guba, 1985). The integration of personal insight with academic analysis enabled a more nuanced understanding of the complexities of LTFU care and informed the development of actionable recommendations for practice (see Section 8.6). Moreover, by making the interpretive process transparent, this narrative contributes to ongoing dialogue about the role of reflexivity in qualitative health research and supports the development of more inclusive, person-centred models of care.

### *9.2.4 Quality, Rigour, and Ethical Reflexivity*

The quality of this research was underpinned by a commitment to methodological rigour and ethical reflexivity. Rigour was maintained through continuous reflexive practice, peer debriefing, and detailed documentation of analytic decisions (see Section 3.7 and Table 3.1). These strategies served as safeguards against complacency and helped ensure that the findings were credible and trustworthy. While member checking was not systematically incorporated, I remain aware of the limitations this may introduce and the need for ongoing reflexive growth.

Ethical considerations were central throughout the research process. As both a peer and a researcher, I was attentive to power dynamics and the possibility of blurring boundaries between my own experiences and those of participants, recognising that such dynamics can influence trust, disclosure, and the interpretation of data (Braun & Clarke, 2022). Ensuring voluntary participation, confidentiality, and the right to withdraw at every stage was fundamental to respecting participants' autonomy and safeguarding their rights (see Section 3.6). My own well-being was also treated as an ethical priority, with supervision, reflective journaling, and self-care strategies in place to manage the emotional demands of the research. Although the implications to my health were unforeseen and therefore not anticipated, the emotional intensity of engaging with participants' narratives, particularly those that resonated with my own experiences, sometimes led to periods of fatigue, anxiety, and self-doubt. In retrospect, I believe that the onset of the known late effect contributed to these challenges, compounding the cognitive and emotional demands of qualitative research. These experiences highlighted the importance of ongoing self-care and reflexive awareness, both to safeguard my own well-being and to maintain a high standard of ethical and engaged research practice.

### 9.3 Researcher Growth and Reflexive Learning

Engaging in reflexive practice has deepened my understanding of the complexities of LTFU care and highlighted the importance of methodological transparency. Throughout this process, my assumptions were challenged and my perspective broadened. I initially believed my experiences of uncertainty and information gaps were unique, but participants' accounts revealed these feelings were widely shared. This realisation prompted me to re-examine my interpretations and ensure they were grounded in the data rather than personal bias. Reflexivity, as an ongoing and iterative process, permeated every aspect of this research (Braun & Clarke, 2022; Olmos-Vega et al., 2023).

Critical self-reflection and a commitment to maintaining boundaries between my own experiences and those of participants enabled me to navigate the complexities of insider research. Regular journalling, supervision, and triangulation of interpretations helped me recognise when my assumptions or emotions might influence the research process. This awareness ensured that personal insight informed, but did not overshadow, the analysis and interpretation of data.

Looking back, I recognise that I underestimated the challenges of participant recruitment. At the time, recruitment decisions were based on the restrictions imposed following the COVID-19 pandemic and the delay in progress due to the unexpected passing of my father. If I were to repeat the study, I would seek NHS ethical approval and recruit from LTFU clinics and haematology outpatient departments to broaden participation. I would also consider expanding the thesis aim to include healthcare professional perspectives to add depth to the findings.

Overall, this thesis has shaped my identity as a qualitative researcher. It has further reinforced my appreciation of reflexivity, the value of lived experience, and the ethical responsibility involved in representing participants' voices with care and integrity. Emphasising the importance of maintaining balance, this programme of work has also drawn attention to the need to prioritise my own health and well-being alongside professional commitments as my research career continues to develop.

### 9.4 Reflexivity as a Thread Throughout the Thesis

Throughout this chapter, I have demonstrated how reflexivity informed each stage of the research process, not as a standalone activity but as a continuous and embedded practice. Reflexive engagement shaped the development of philosophical and methodological commitments (see Section 3.2 to 3.4), supported transparency and trustworthiness through structured journaling and positionality statements (see Section 3.4), and guided the interpretive process during data analysis and theme development (see Sections 5.4.1 and 7.2.1). Ethical reflexivity ensured the well-being of both participants and researcher (see Section 3.6), while quality and rigour were maintained through ongoing reflexive practice, peer debriefing, and critical self-awareness (see Section 3.7). Collectively, these practices illustrate how reflexivity functioned as a methodological resource and guiding principle, shaping the integrity, depth, and ethical foundation of this thesis.

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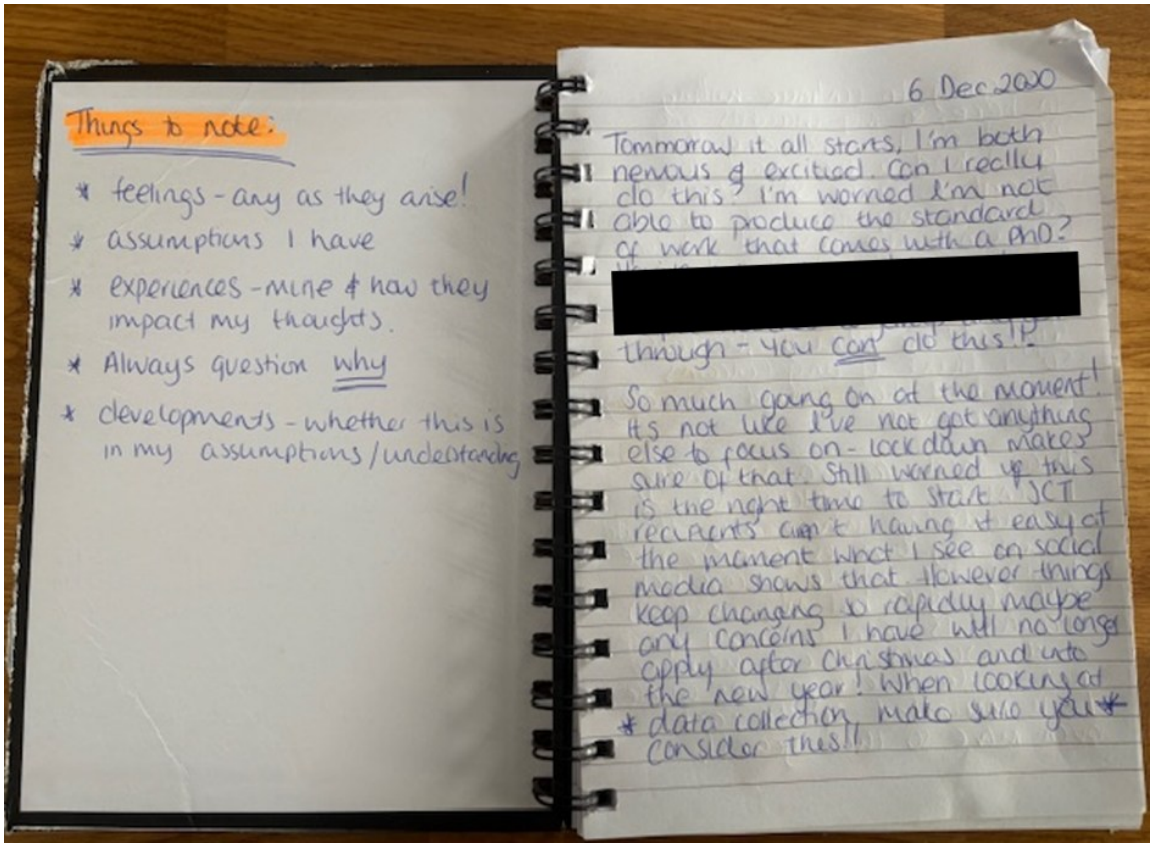
# Appendices

## Appendix 1: Reflexive Journal Notes Example (First Entry 06/12/2020)



Things to note:

* feelings - any as they arise!
* assumptions I have
* experiences - mine & how they impact my thoughts.
* Always question why
* developments - whether this is in my assumptions/understanding

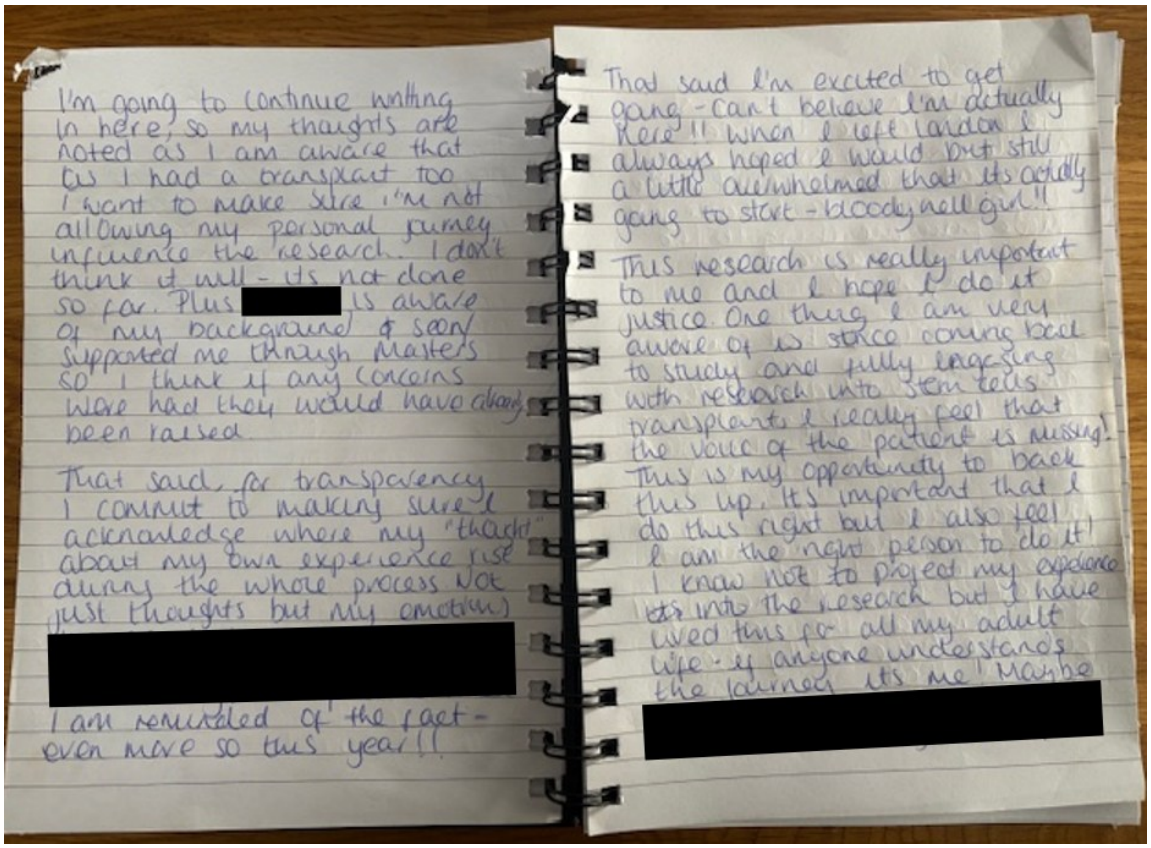
6 Dec 2020

Tommorow it all starts, I'm both nervous & excited. Can I really do this? I'm worried I'm not able to produce the standard of work that comes with a PhD?

[redacted]

through - you can do this!!

So much going on at the moment! Its not like I've not got anything else to focus on - lockdown makes sure of that. Still worried if this is the right time to start. JCT recruitments aren't having it easy at the moment what I see on social media shows that however things keep changing so rapidly maybe any concerns I have will no longer apply after Christmas and into the new year! When looking at * data collection, make sure you * consider this!!



I'm going to continue writing in here, so my thoughts are noted as I am aware that as I had a transplant too I want to make sure I'm not allowing my personal journey influence the research. I don't think it will - its not done so far. Plus [redacted] is aware of my background & seen supported me through Masters so I think if any concerns were had they would have already been raised.

That said, for transparency I commit to making sure I acknowledge where my "thoughts" about my own experience rise during the whole process Not just thoughts but my emotions

[redacted]

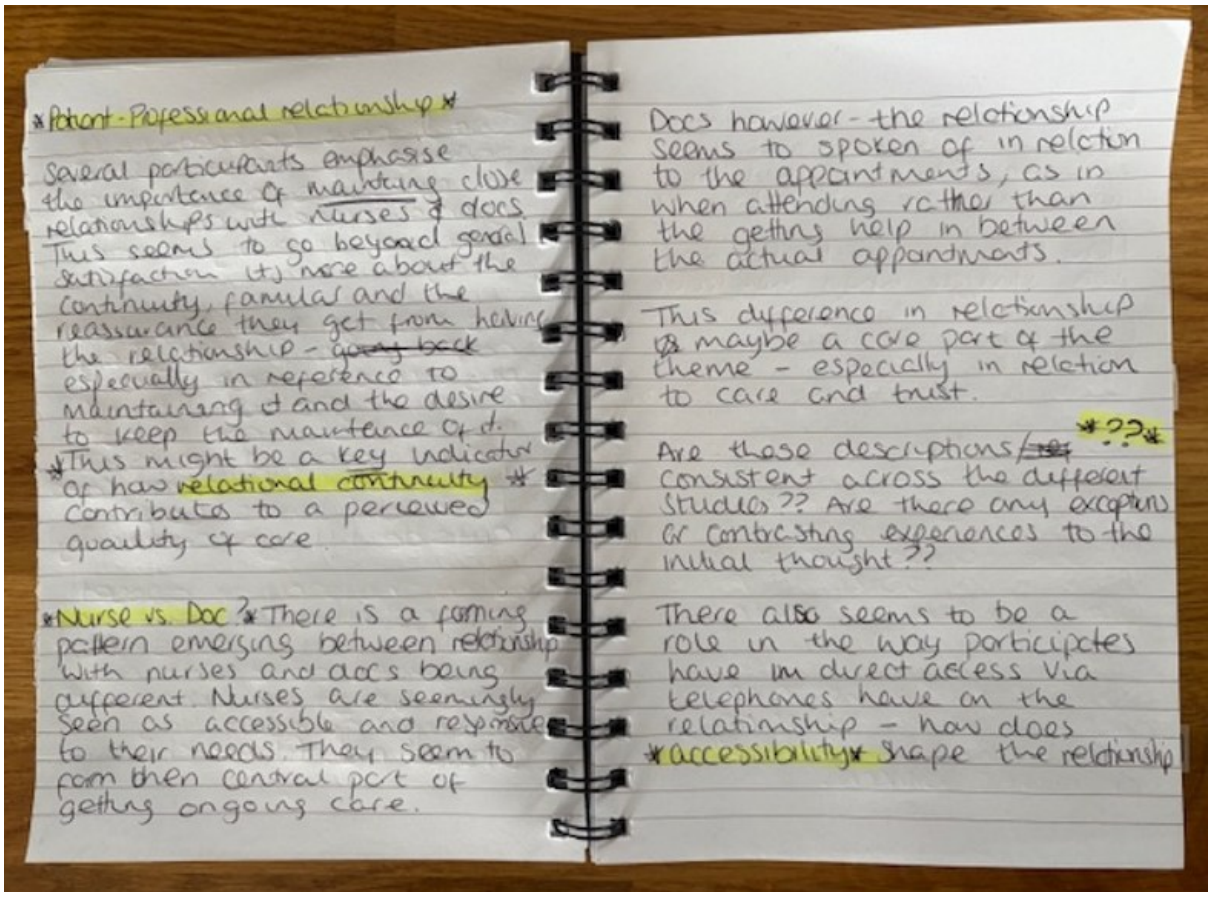
I am reminded of the fact - even more so this year!!

That said I'm excited to get going - can't believe I'm actually here!! When I left London I always hoped I would but still a little overwhelmed that its actually going to start - bloody hell girl!!

This research is really important to me and I hope I do it justice. One thing I am very aware of is since coming back to study and fully engrossing with research into stem cells transplants I really feel that the voice of the patient is missing! This is my opportunity to back this up. It's important that I do this right but I also feel I am the right person to do it! I know not to project my experience into the research but I have lived this for all my adult life - if anyone understands the journey its me! Maybe

[redacted]

## Appendix 2: Analytic Memoing Example



**Appendix 3: Participant Information Sheet Study 2**

# The lived experience of long-term late effects monitoring for haematopoietic stem cell recipients in England: A qualitative exploration

## Participant Information Sheet

**Researcher: Blossom Bell (PhD Psychology)**
*I would like to invite you to take part in a research study. Before you decide I would like you to understand why the research is being done and what it would involve for you. Please ask if there is anything that is not clear, contact details provided below.*

As per the NHS standard contract for haematopoietic stem cell transplant (HSCT) specifications, all transplants shall take place in a JACIE (Joint Accreditation Committee of the International Society for Cellular Therapy Europe and European Society for Blood and Marrow Transplantation) accredited centres. The JACIE Standards (7 Edition) states that centres must either perform long-term follow-up for late effects themselves or monitor long-term follow-up data of its former recipients. To date there is no research exploring the experiences from recipients' perspective of attending long-term monitoring services post-transplant in England, and studies that exist have been conducted outside of the UK.

**What is the purpose of the study?** The aim of this study is to examine patient experiences of HSCT long-term monitoring services post-transplant in England. It is hoped that the study will provide an insight into patients' post-transplant experiences, providing an opportunity to generate knowledge and make recommendations for future research.

**Do I have to take part?** There is no obligation to take part in the study. Once you have read through this information page, you will be asked if you understand the purpose of the study and to give consent should you wish to take part. You are free to withdraw from the study at any time and can ask for your data to be destroyed up until 31 August 2021 without giving a reason.

**What would taking part involve?** If you agree to take part in this study, upon providing consent (page 2), you will be directed to create a *personal identifier,* a personal code you will create for anonymity purposes (page 3). Once created you will be directed to page 4 of the study, which includes 7 questions to ascertain your demographical location and transplant details. The one question on page 5 is to gather the details of your experiences.

You do not have to complete the questions all in one sitting, you may save and return to a section later. Responses will not be submitted until you complete the survey in full. The time it takes to complete the survey will depend on the amount of information you wish to provide, however the more detail provided will enhance the quality of knowledge generated from this study.

**What are the potential disadvantages and risks of taking part in this study?** There are no known disadvantages or risks of taking part in this study, however, you may have questions regarding post-transplant care. If this becomes apparent, then there are organisations you can contact, details of which are provided in the debrief section. In circumstances where you reveal that there is a risk to yourself or others the supervisor will be contacted in accordance with professional body regulations.

What are the possible benefits of taking part? It is hoped that the study will help provide an insight into patients' post-transplant experiences of long-term monitoring services. Therefore, providing an opportunity to generate knowledge, examine if services are meeting recipient requirements and make recommendations for future research.

What if there is a problem? Any complaint about the way you have been dealt with during the study or any possible harm, you might suffer will be addressed. If you have a concern about any aspect of this study, you should ask to speak to Dr Katherine Swainston (K.Swainston@tees.ac.uk) who will do their best to answer your questions.

How will my information be kept confidential? I will follow ethical and legal practice and all information about you will be handled in confidence. All information which is collected about you during the course of the research will be kept strictly confidential. For the final report a pseudonym will be used to conceal your *personal identifier,* a personal code you will create after consenting to participate, and there will be no identifiable characteristics used in the final write up.

What will happen to the results of this study? The data collected will be used for dissertation purposes, presentations at meetings and conferences and academic publications.

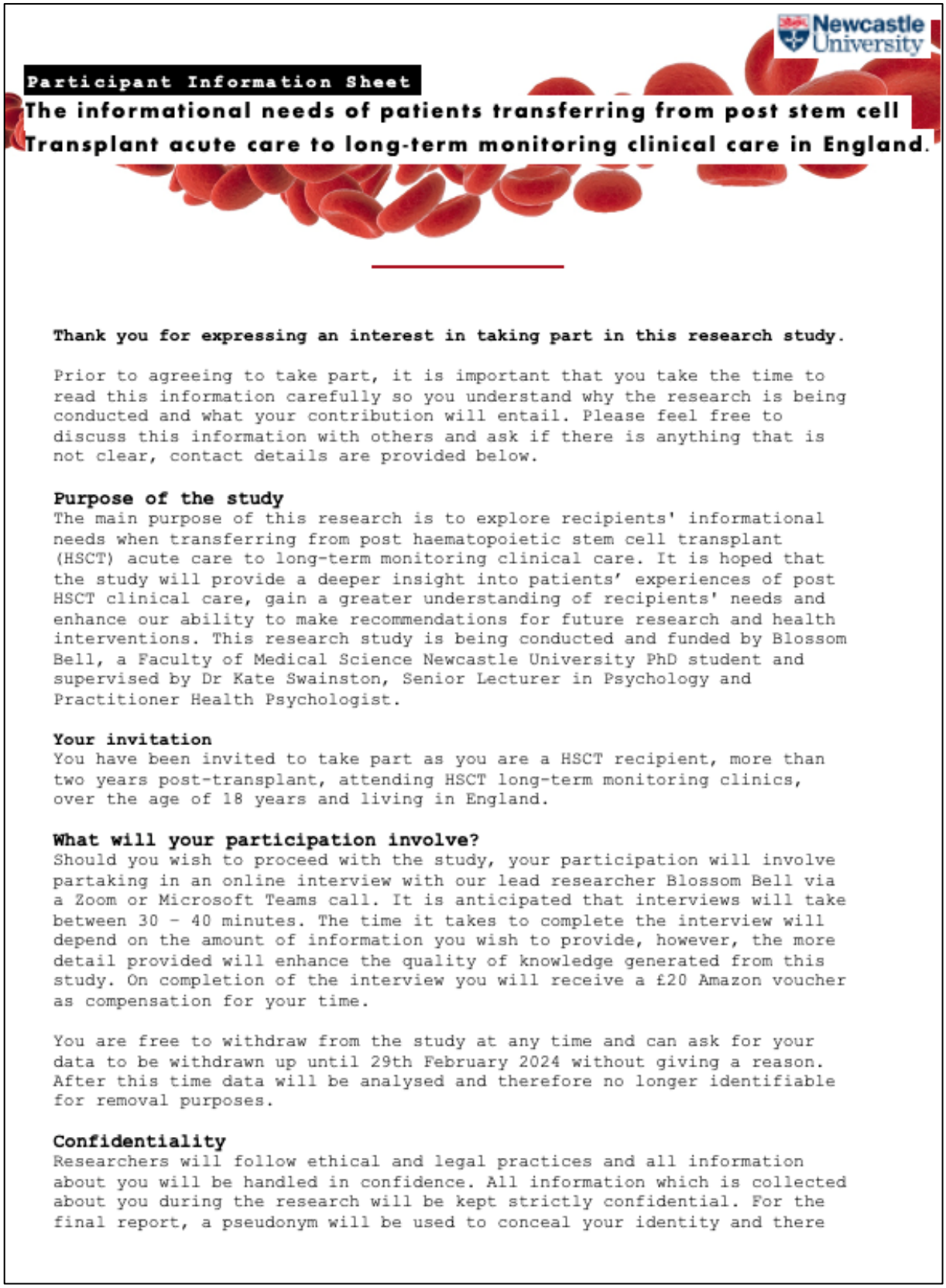
Who has reviewed the study? Teesside University School of Social Sciences, Humanities & Law Research Ethics Committee have reviewed the study.

Contact for Further Information
Blossom Bell B.Bell@tees.ac.uk
Dr Katherine Swainston K.Swainston@tees.ac.uk

*Personal data including special category data obtained for the purposes of this research project is processed lawfully in the necessary performance of scientific or historical research or for statistical purposes carried out in the public interest. Processing of personal data including special category data is proportionate to the aims pursued, respects the essence of data protection and provides suitable and specific measures to safeguard the rights and interests of the data subject in full compliance with the General Data Protection Regulation and the Data Protection Act 2018.*

Thank you for reading this information sheet.

## Appendix 4: Participant Information Sheet Study 3



Participant Information Sheet

**The informational needs of patients transferring from post stem cell Transplant acute care to long-term monitoring clinical care in England.**

**Thank you for expressing an interest in taking part in this research study.**

Prior to agreeing to take part, it is important that you take the time to read this information carefully so you understand why the research is being conducted and what your contribution will entail. Please feel free to discuss this information with others and ask if there is anything that is not clear, contact details are provided below.

**Purpose of the study**

The main purpose of this research is to explore recipients' informational needs when transferring from post haematopoietic stem cell transplant (HSCT) acute care to long-term monitoring clinical care. It is hoped that the study will provide a deeper insight into patients' experiences of post HSCT clinical care, gain a greater understanding of recipients' needs and enhance our ability to make recommendations for future research and health interventions. This research study is being conducted and funded by Blossom Bell, a Faculty of Medical Science Newcastle University PhD student and supervised by Dr Kate Swainston, Senior Lecturer in Psychology and Practitioner Health Psychologist.

**Your invitation**

You have been invited to take part as you are a HSCT recipient, more than two years post-transplant, attending HSCT long-term monitoring clinics, over the age of 18 years and living in England.

**What will your participation involve?**

Should you wish to proceed with the study, your participation will involve partaking in an online interview with our lead researcher Blossom Bell via a Zoom or Microsoft Teams call. It is anticipated that interviews will take between 30 - 40 minutes. The time it takes to complete the interview will depend on the amount of information you wish to provide, however, the more detail provided will enhance the quality of knowledge generated from this study. On completion of the interview you will receive a £20 Amazon voucher as compensation for your time.

You are free to withdraw from the study at any time and can ask for your data to be withdrawn up until 29th February 2024 without giving a reason. After this time data will be analysed and therefore no longer identifiable for removal purposes.

**Confidentiality**

Researchers will follow ethical and legal practices and all information about you will be handled in confidence. All information which is collected about you during the research will be kept strictly confidential. For the final report, a pseudonym will be used to conceal your identity and there

will be no identifiable characteristics used in the final write-up. Only members of the research team where necessary will have access to the raw data and it will be stored in a secure file on a password-protected computer. Once data is analysed, findings will be presented in a report that may be shared within professional and academic networks, but no identifying details of participants will be accessible. The data collected will be used for dissertation purposes, presentations at meetings and conferences and academic publications.

**Why should I take part?**
This research seeks to add to the limited information known about HSCT recipients' clinical care experiences including informational needs as they transfer from acute port-transplant clinical care to long-term monitoring care. It is important to consider recipients' experiences so that support can be developed that meets recipients' needs.

**What are the potential disadvantages of taking part?**
Due to the nature of the study, you should consider carefully before deciding whether you would like to continue. Questions will be asked about your experiences of transferring from acute clinical to long-term monitoring care, which may be upsetting for some individuals. If you feel uncomfortable at any time during the interview you may stop or skip questions without explanation.

Furthermore, participation in this study may raise questions regarding post-transplant care. If this becomes apparent, there are organisations you can contact, details of which are provided after the interview during a debrief session. In circumstances where you reveal that there is a risk to yourself or others, the study supervisor will be contacted in accordance with professional body regulations.

**Ethical approval**
This study has received ethical clearance from the Faculty of Medical Science Newcastle University Research Ethics Committee.

**Contact**
Should you wish to remove your data from the study at any point prior to analysis, all you need to do is contact a member of the research team as listed below before the 29th February 2024. Alternatively, please do not hesitate to contact the research team if you would like to receive any further information or clarification of the study or data usage, or if you would like to file a complaint,

**Blossom Bell** B.Bell3@newcastle.ac.uk

**Dr Kate Swainston** Kate.Swainston@newcastle.ac.uk

**The Next Step**
Thank you for taking the time to read this information sheet. If you would like to participate in this study, please see the consent document attached to the invitation email.

**Appendix 5: Consent Form Sheet Study 2**

## Page 2: Page 2: Consent Form

**Researcher: Blossom Bell (PhD Psychology)**

Thank you for agreeing to take part in this research. In agreeing to participate you have the following rights and protections as laid down in the British Psychological Society's ethical guidelines.

- Your participation is entirely voluntary
- You may withdraw your data from this research at any point until 31 August 2021
- Nobody, except myself and my research supervisor will have access to this anonymised material in its entirety.

**In agreeing to the terms of this consent form, participants should be aware that any anonymised material is for dissertation, presentations at meetings and conferences and academic publications use.**

1. I confirm that I have read and understood the participant information sheet. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. * *Required*

○ I agree

2. I understand that my participation is voluntary and that I am free to withdraw at any time up until 31 August 2021, without giving any reason. To withdraw your data please contact myself: B.Bell@tees.ac.uk * *Required*

○ I agree

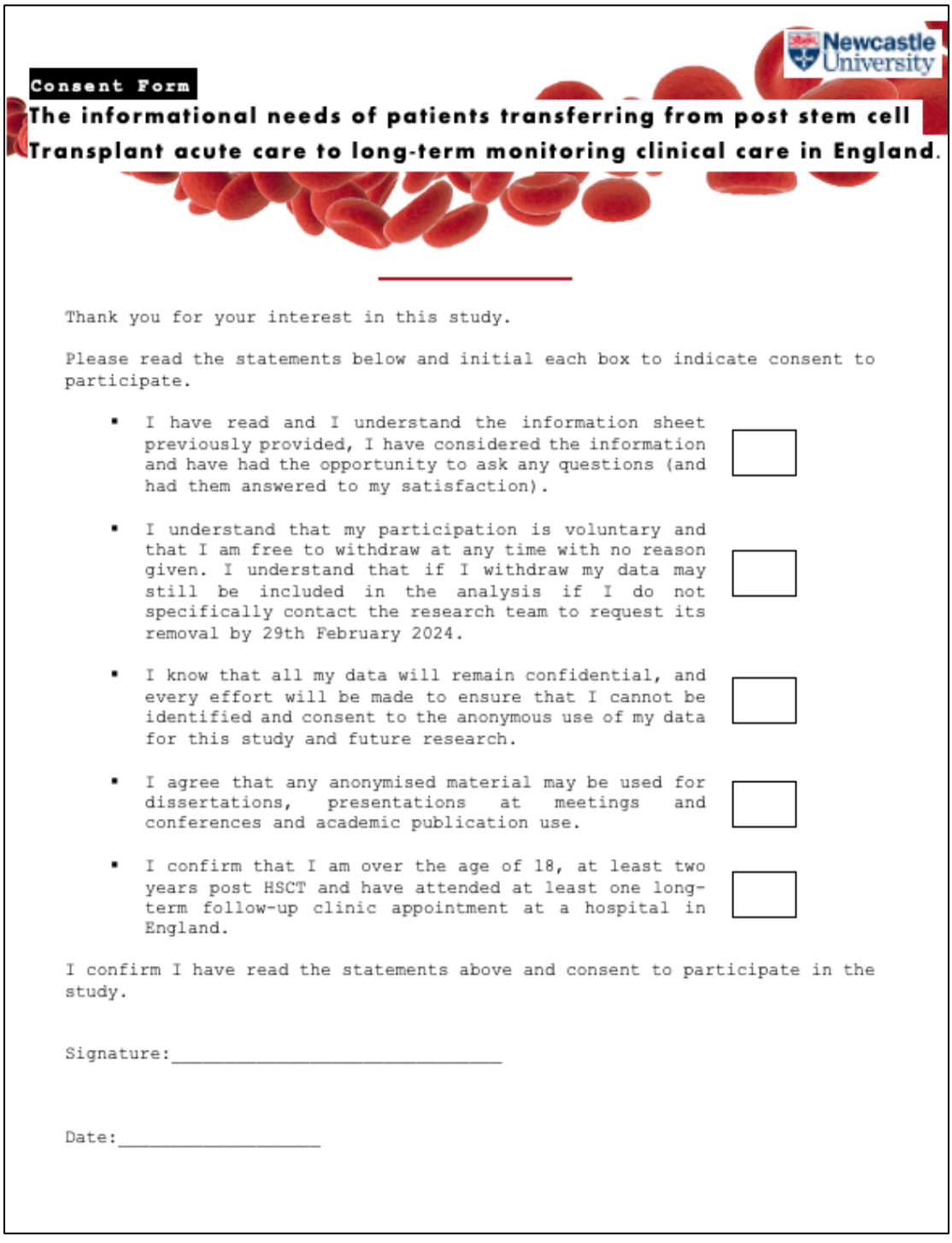
3. I agree to take part in the above study, and am over the age of 18, one year or more

4 / 13

post-transplant and live in England. * *Required*

○ I agree

## Appendix 6: Consent Form Study 3



Consent Form

**The informational needs of patients transferring from post stem cell Transplant acute care to long-term monitoring clinical care in England.**

Thank you for your interest in this study.

Please read the statements below and initial each box to indicate consent to participate.

- I have read and I understand the information sheet previously provided, I have considered the information and have had the opportunity to ask any questions (and had them answered to my satisfaction). ☐
- I understand that my participation is voluntary and that I am free to withdraw at any time with no reason given. I understand that if I withdraw my data may still be included in the analysis if I do not specifically contact the research team to request its removal by 29th February 2024. ☐
- I know that all my data will remain confidential, and every effort will be made to ensure that I cannot be identified and consent to the anonymous use of my data for this study and future research. ☐
- I agree that any anonymised material may be used for dissertations, presentations at meetings and conferences and academic publication use. ☐
- I confirm that I am over the age of 18, at least two years post HSCT and have attended at least one long-term follow-up clinic appointment at a hospital in England. ☐

I confirm I have read the statements above and consent to participate in the study.

Signature:_____

Date:_____

## Appendix 7: Debrief Sheet Study 2

**Study Title:** The lived experience of long-term late-effects monitoring for haematopoietic stem cell recipients in England: A qualitative exploration

**Researcher:** Blossom Bell (PhD Psychology)

**Aim of research**: To examine patient experiences of post haematopoietic transplant long-term monitoring and late effect services.

I would like to thank you for taking part in this study and reiterate all information provided by yourself will be treated with strict confidentiality. Under no circumstances will your name, if provided, or any identifying characteristics be included in any subsequent reports or publications. A pseudonym will be used to concerl your personal identifier code.

Should you wish to withdraw your data at a later date, you can use your personal identifier to do so without being identified.You can withdraw your data without giving a reason up until 31 August 2021 by contacting the researcher or supervisor via email address below.

If you have any further questions about this study, I would be more than happy to assist and can be contacted via e-mail: B.Bell@tees.ac.uk. Alternatively, my supervisor can be contacted via email: K.Swainston@tees.ac.uk.

Any concerns regarding post-transplant care please speak with your General Practitioner in the first instance. For more general information please refer to the list below of organisations that may be helpful following this study.

**Anthony Nolan** – UK based organisation that offer support to transplant patients before, during and after treatment.

Anthonynolan.org

General Enquires 0303 303 0303

For patients and carers https://www.anthonynolan.org/patients-and-families

**Be the match** – International organisation that provides support throughout transplant process.

Bethematch.org

Patient Support Centre Email patientinfo@nmdp.org

Post-Transplant Care information available at https://bethematchclinical.org/post-transplant-care/

*Thank you again for your participation*

## Appendix 8: Debrief Sheet Study 3

Newcastle University

**Debrief**

**The informational needs of patients transferring from post stem cell Transplant acute care to long-term monitoring clinical care in England.**

**Thank you for taking part in the research study.**

I would like to emphasise that all information provided by you will be treated with strict confidentiality. Under no circumstances will your name or identifying characteristics be included in any subsequent reports or publications. A pseudonym will be used to conceal your real name.

If you have any further questions about this study, I would be more than happy to assist and can be contacted via e-mail on B.Bell3@newcastle.ac.uk. Alternatively, my supervisor can be contacted via email on Kate.Swainston@newcastle.ac.uk.

You can withdraw your data without giving a reason up until 29th February 2024 by contacting the researcher or supervisor via email.

Any concerns regarding post-transplant care please speak with your General Practitioner or transplant team in the first instance. For more general information please refer to the list below of organisations that may be helpful following this study.

- **Anthony Nolan**
  UK based organisation that offer support to transplant patients before, during and after treatment.

  Website: www.anthonynolan.org
  General Enquires: 0303 303 0303
  For patients and carers www.anthonynolan.org/patients-and-families

- **Be the Match**
  An international organisation that provides support throughout the transplant process.

  Website: www.bethematch.org
  Patient Support Centre email: patientinfo@nmdp.org
  Post-transplant care information available at
  https://bethematchclinical.org/post-transplant-care/

Thank you for your participation.

## Appendix 9: Ethical Approval Study 2

Teesside University

**Confirmation of research ethics Clearance**

**Dear** Blossom Bell

**Re: Project Title:** The lived experience of long-term late- effects monitoring for haematopoietic stem cell recipients in England: A qualitative exploration **; Review Reference:** 2021 Jun 6091 Bell

Your application has been reviewed and I can confirm that **this study has received research ethics Clearance** and can proceed as soon as you receive this confirmation.

This document can be used as evidence of authorisation.

Please note that if you need, in the future, to make any amendments to your study details now that it has been approved, you should contact the Chair Dr Katherine Swainston to notify the Committee and then forward the required amendments as a document to ERMHelp@tees.ac.uk so that the amendments can be added to your approved application.

Yours sincerely,

Dr Katherine Swainston

*on behalf of*

SSSHL Research Ethics sub-Committee

Page 1 of 1

## Appendix 10: Ethical Approval (amendment) Study 2

**From:** donotreply@infonetica.net <donotreply@infonetica.net>
**Date:** Friday, 17 September 2021 at 16:06
**To:** Bell, Blossom <B.Bell@tees.ac.uk>
**Subject:** Confirmation of approval of requested amendments to Project ID: 6091 , The lived experience of long-term late-effects monitoring for haematopoietic stem cell recipients in England: A qualitative exploration

**Approval of a requested amendment(s) to a previously approved application**

Dear Blossom Bell

RE: Project ID 6091 , Project title: The lived experience of long-term late- effects monitoring for haematopoietic stem cell recipients in England: A qualitative exploration

Your request to make amendments to a previously approved application on the project above has been approved.

This email can be used as evidence of this approval.

Yours sincerely,

Prof Matthew Cotton

*on behalf of*

SSSHL Research Ethics sub-Committee

## Appendix 11: Ethical Approval Study 3

**Ethics Application Approval 2499/29673**

N

nethics <fmsethics@newcastle.ac.uk>

Monday 24 April 2023 at 13:47

**To:** Blossom Bell (PGR)

**Cc:** nethics

Hi

"Your application has been approved, with the following Reviewer comment....."

| | |
|---|---|
| *The PIS should also include information of who is doing this research (Department )and who is funding the study.* | *Added this information into the "purpose of the study" paragraph. I am self-funding my PhD with a post-graduate student finance loan which I am responsible for repaying in due course therefore I had stated as myself funding the study, I hope that is applicable* |

*Apologies I was not clear*
*I meant the department not the person*

Please accept this email as confirmation of approval and an official letter of approval will be sent to you in due course.

As your study has now been approved, please add the following text to your information sheets and debrief sheets:

*This study was approved by the Faculty of Medical Sciences Research Ethics Committee, part of Newcastle University's Research Ethics Committee. This committee contains members who are internal to the Faculty. This study was reviewed by members of the committee, who must provide impartial advice and avoid significant conflicts of interests.*

**Callula Smith**
#mynameis: Ca-loo-la

Operations Officer

*Baddiley Clark Building on Monday – Thursday 09:00 – 17:00 and Friday 09:00 – 16:30.*

Call or send me a chat message on Teams

Newcastle University

## Appendix 12: Ethical Approval (amendment 1) Study 3

**From:** Marjorie Holbrough <marjorie.holbrough@newcastle.ac.uk> on behalf of nethics <fmsethics@newcastle.ac.uk>
**Date:** Monday, 24 July 2023 at 15:46
**To:** Blossom Bell (PGR) <B.Bell3@newcastle.ac.uk>
**Cc:** nethics <fmsethics@newcastle.ac.uk>
**Subject:** Ethics amendment approval - 2499_1

Hi Blossom

Amendment 2499_1: The informational needs of patients transferring from post haematopoietic stem cell transplant acute care to long-term monitoring clinical care in England; a qualitative exploration.

Your application amendment has been approved.

Best wishes
Marjorie

Marjorie Holbrough
PAS Officer
Professional and Administrative Services
Faculty of Medical Sciences

Call or send me a chat message on Teams

## Appendix 13: Ethical Approval (amendment 2) Study 3

**From:** Marjorie Holbrough <marjorie.holbrough@newcastle.ac.uk> on behalf of nethics <fmsethics@newcastle.ac.uk>
**Date:** Wednesday, 25 October 2023 at 14:01
**To:** Blossom Bell (PGR) <B.Bell3@newcastle.ac.uk>
**Cc:** nethics <fmsethics@newcastle.ac.uk>
**Subject:** Ethics amendment approval - 2499_2/29673

Hi

Amendment 2499_2: The informational needs of patients transferring from post haematopoietic stem cell transplant acute care to long-term monitoring clinical care in England; a qualitative exploration

Your application amendment has been approved, please accept this email as confirmation of approval.

Best wishes
Marjorie

Marjorie Holbrough
Operations Co-ordinator
FMS Operations
Henry Wellcome Building
Faculty of Medical Sciences

## Appendix 14: Data Management Plan

| 0. Project title, author, version and date | | |
|---|---|---|
| *Project: Exploring HSCT recipients' experiences of long-term follow-up care in England* | | |
| *Author: Blossom Bell* | *Version: 2* | *Date: 2 June 2023* |

**1. Description of the data**

**1.1 Type of study**

*This is a qualitative hermeneutic phenomenological study exploring lived experiences of HSCT recipients attending LTFU care. It involves a multi-method sequential design including written accounts and semi-structured interviews.*

**1.2 Assessment of existing data**

*A qualitative evidence synthesis was conducted to assess existing knowledge. Gaps were identified in the UK-specific experiences and informational needs, which informed the design of subsequent data collecting phases.*

**1.3 Types of data**

- *Qualitative data from written accounts and semi-structures interviews*
- *Transcripts of audio recordings*
- *Metadata including pseudonyms, interview dates, and thematic codes*
- *MAXimum project files used for coding and analysis*

**1.4 Format and scale of the data**

- *File formats: Microsoft Word (.docx), Microsoft Excel (.xlsx.). PDF. Sonocent Project File (.atp)*
- *Formats are suitable for long-term preservation and sharing*
- *Estimate of number of participants and storage size not known as this time.*

**2. Data collection / generation**

*Focus on the good practice and standards for ensuring new data are of high quality and processing is well documented.*

**2.1 Methodologies for data collection / generation**

*Data collected via secure online submissions platform Jisc Survey online for written accounts. All written transcripts PDF downloaded and uploaded into NVivo for analysis. All documents, transcripts and codes saved University One Drive account. Study 2, the interviews, all expression of interest to participant conducted via email. Microsoft Teams or Zoom platforms used for interviews and audio-recorded using Sonocent. Interviews will be transcribed into Word. All files saved on University One Drive account.*

**2.2 Data quality and standards**

*Consistency and quality of data collection / generation will be controlled and documented, through standardised interview protocols, peer debriefing with supervisors, reflexive journaling to document interpretive decisions and use of NVivo for consistent coding and theme development.*

**3. Data management, documentation and curation**

*Focus on principles, systems and major standards. Focus on the main kind(s) of study data. Give brief examples and avoid long lists.*

**3.1 Managing, storing and curating data.**

*Data are stored on Newcastle University's secure OneDrive. Files are encrypted and password-protected. Regular backups are maintained.*

**3.2 Metadata standards and data documentation**

*Metadata includes: participant pseudonyms, interview dates and formats, transcripts (audio and written), thematic codes, and analysis notes. All metadata will be stored alongside the data in secure university-managed One Drive.*

**4. Data security and confidentiality of potentially disclosive information**

*This section should be completed if your research data includes **personal data relating to human participants in research**. For other research, the safeguarding and security of data should also be considered. Information provided will be in line with your ethical review. Please note this section concerns protecting the data, not any potential patients.*

**4.1 Main risks to data security**

*Risks include unauthorised access to personal data and accidental disclosure. These are mitigated by the encryption of all personal data, secure storage on university-managed systems, separation of consent forms from data files, ethical approval, and regular supervision meetings.*

## 5. Data sharing and access

*Identify any data repository(-ies) that are, or will be, entrusted with storing, curating and/or sharing data from your study, where they exist for particular disciplinary domains or data types. Information on repositories is available here.*

**5.1 Suitability for sharing** *Data is not suitable for sharing with other users. Consent provided for the anonymised material to be user for dissertation, presentations at meetings and conferences and academic publication only.*

**5.2 Discovery by potential users of the research data**

*N/A*

**5.3 Data preservation strategy and standards**

*Data will be stored in Newcastle One Drive for the duration of the research and archived according to University policy on completion.*

**5.4 Restrictions or delays to sharing, with planned actions to limit such restrictions**

*Restrictions due to confidentiality and consent agreements will be addressed by anonymising data, aggregating sensitive responses, including data sharing provisions in consent form and explaining risks and safeguards to participants*

## 6. Responsibilities and Resources

*Are there any resources (e.g. storage/ training) that you will require to fulfil the plan?*

*Only resources already available to the researcher including One Drive, Microsoft Word, , Sonocent, MAXimum Qualitative Data Analysis, Jisc Survey online and ethics support.*

## 7. Relevant institutional, departmental or study policies on data sharing and data security

| Policy | URL or Reference |
|---|---|
| Data Management Policy & Procedures | https://www.ncl.ac.uk/media/wwwnclacuk/research/files/ResearchDataManagementPolicy.pdf |
| Information Security | *https://services.ncl.ac.uk/itservice/policies/InformationSecurityPolicy-v2_1.pdf* |
| Other | |

## Appendix 15: Journal of Patient Experience Publication

*Research Article*

Journal of Patient Experience
Volume 11: 1-9
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# A Systematic Review and Metasynthesis of Hematopoietic Stem Cell Transplant (HSCT) Patient's Experiences of Long-Term Monitoring Clinics from the Patient's Perspective

**Blossom Bell, MSc[1], Stacie Thursby, MSc[2], Helen Limbrick, PhD[3], and Katherine Swainston, PhD[4]**

**Abstract**

This study aimed to synthesize all qualitative evidence on the experiences of hematopoietic stem cell transplant (HSCT) patients attending long-term monitoring clinics from their perspective. A systematic search of the literature was undertaken across 8 databases. The Critical Appraisal Skills Program was used to evaluate each study's quality. Confidence in the Evidence from Reviews of Qualitative Research was employed to assess confidence in each finding. Three themes from 4 qualitative studies were identified relating to patients' experiences, "[It's] important to maintain a good relationship with the nurses and doctors," "There's always the thing about the logistics," and "Once you have cancer, you're always thinking do I have it again?". The findings suggest that HSCT patients' experiences of long-term follow-up care clinics are influenced by the patient-provider relationship and the logistical set-up of monitoring practices, and weakly connected with fear of cancer recurrence. Future research is needed to understand the impact of each finding of this review, specifically in relation to patients' country of residence to gain a greater understanding of their monitoring support needs.

**Keywords**

stem cell transplant, patients' experiences, long-term monitoring, cancer recurrence

## Introduction

A hematopoietic stem cell transplant (HSCT) is a potentially curative treatment option for malignant hematological disorders. It is a procedure that replaces defective stem cells with new healthy ones, mainly sourced from either a donor (allogeneic) or the patient (autologous), to restore lost hematopoietic function.[1] It was estimated that more than 1.5 million HSCTs were performed worldwide between 1957 and 2019, and annual rates continue to increase without plateau.[2] In 2019, Europe (and collaborating countries) reported 48,512 HSCTs (41% allogeneic and 59% autologous) performed, a 2.2% increase compared to 2018 (n= 47,468).[3] The continuing annual increase of HSCTs performed, combined with improved survival rates within the first year of transplant has substantially increased the number of HSCT survivors. In the United States alone, it is estimated that there will be just over half a million HSCT survivors by 2030.[4] HSCT survivorship does not mark the end of the care trajectory for HSCT patients due to the increased risk of treatment-related mortality.

While advances in medical treatments and patient management have contributed to reducing mortality rates for HSCTs patients, rates remain higher than the general population. Treatment-related complications include infections, relapse,

[1] Population Health Sciences Institute, Newcastle University, Newcastle upon Tyne, UK
[2] Northumbria Healthcare NHS Foundation Trust, North Tyneside General Hospital, Rake Lane, Tyne and Wear, North Shields, UK
[3] School of Social Sciences, Humanities & Law, Teesside University, Middlesbrough, Tees Valley, UK
[4] School of Psychology, Faculty of Medical Sciences, Newcastle University, Newcastle upon Tyne, UK

**Corresponding Author:**
Blossom Bell, Population Health Sciences Institute, Newcastle University, Baddiley-Clark Building, Newcastle upon Tyne, NE2 4AX, UK.
Email: B.Bell3@newcastle.ac.uk

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graft-versus-host disease (GVHD), subsequent cancer, and organ dysfunction. Relapse is frequently reported in studies as being the leading cause of mortality. Nonrelapse mortality was primarily related to post-transplantation infections and secondary cancers.[5–7] In recognition of these late effects and the impact on mortality, transplant centers (TCs) must provide long-term follow-up (LTFU) for post-HSCT patients.[8] Accreditation standards stipulate that TCs are required to monitor recipients' endocrine, reproductive, cardiovascular, renal, and respiratory function, and for osteoporosis and secondary cancer risks. Monitoring should be carried out by dedicated clinics structured in line with international guidelines and literature, which includes recommended screening practices and test frequencies. The guidelines also recommend that LTFU clinics encourage health promotion behaviors such as maintaining a health diet and weight, refrain from smoking, moderate alcohol use, and avoiding excessive sun exposure.[9]

Despite the international guidelines and accreditation standards, the continuation of post-transplant LTFU by TC is known to be variable. Studies examining the implementation of such guidelines and literature from TC's perspective found variations in service, including fragmented care, access to cancer screening and inclusion of psychological support. Funding, patient demographics, and lack of capacity and physicians were the reasons behind monitoring disparities.[10–12] In recognition of a growing population of HSCT survivors, transplant-related mortality risk and known variation in TC care, the focus has shifted to the management and healthcare infrastructure of long-term monitoring to deliver a patient-centered service.[13,14] If TCs are going to provide a patient-centered service then understanding HSCT patients' experiences of attending long-term monitoring appointments is crucial to achieving this objective. Despite this, to date, a systematic review of qualitative studies has not been conducted, and the literature lacks an overview of findings on patients' experiences.

This systematic review aims to appraise and synthesize the qualitative evidence of HSCT patients' experiences of long-term monitoring clinics to ascertain what is currently known, identify gaps in the literature, and make recommendations for future research. The review protocol is registered with PROSPERO [Registration number CRD42021231860).

## Method

A systematic search was undertaken using the population, context, outcome framework to identify keywords in the review question. Once the keywords were identified a list of all synonyms were developed to form the basis of the search strategy. Eight databases were searched (Psych Info, Medline, The Allied and Complementary Medicine Database, CINAHL, Psychology and Behavioral Science Collection, Scopus, Embase, and Proquest Nursing and Allied Health Source). Year parameter was set for articles published from January 2006 to December 2022, in line with the first published recommended screening and preventive practice for HSCT survivors.[15] The initial search retrieved 425 references. After the removal of duplicates, the title and abstract of the remaining 203 papers were screened blindly by 2 reviewers (the first and last authors) in software for systematic reviews, Rayyan© (www.rayyan.ai). Reviewers used the following inclusion criteria: (i) patients received a stem cell transplant + 100 days prior to the study, (ii) qualitative studies to include phenomenology, ethnography, grounded theory, generic qualitative or mixed methods which examined patients' experiences specific to long-term monitoring services, (iii) English language. Ten papers were selected for full-text review by the first and second authors and any disagreements were resolved in discussion with the third author. Papers were excluded if they (i) did not elicit responses directly from patients and (ii) focused on monitoring late-effects symptoms only or (iii) experiences not related to LTFU care. In total 6 articles were removed (Figure 1).

Four studies were included for the final synthesis (Table 1). Seventy HSCT patients were included in the 4 studies, 3 of which included only patients who received an allo-HSCT, with only 1 study including one allo-HSCT patient.[16–19] Mean time since transplant across the studies ranged from 2.7 to 8.13 years (range 0.25-20 years). The studies were undertaken in the UK, USA, Germany, and Singapore. One study recruited participants from a designated LTFU clinic, 2 recruited from a clinic dedicated to GVHD, and 1 recruited participants from their hospital registry. The Critical Appraisal Skills Program (CASP) tool for qualitative research was used for quality appraisal by the first and second authors. The guiding methodology for this study was thematic synthesis, as outlined by Thomas and Harden, to elicit a rigorous high-level analytical abstraction of common themes across studies.[20] The eligible studies were inputted verbatim into MAXQDA 2022 software for storing, coding, and data search. All text labeled as "results" or "findings" in each study were examined line-by-line for meaning and content by the first and second authors and free codes were generated. The free codes generated that reflected the patients experiences of attending LTFU clinics were then grouped into related areas to construct descriptive themes which captured the meaning of groups of the initial free codes. The descriptive themes were then synthesized, and analytical themes were developed to generate additional concepts and understanding of patients experiences beyond the findings of the primary studies. To ensure that all patients' experiences had been captured, the studies were read several times and discussed at length between the first and second author. Any interpretive disagreements were discussed with and resolved by the third author. The Confidence in the Evidence from Reviews of Qualitative (GRADE-CERQual) research was used to determine the overall confidence in the study findings.[21] An estimation of moderate and high confidence for the findings was reached (Table 2).

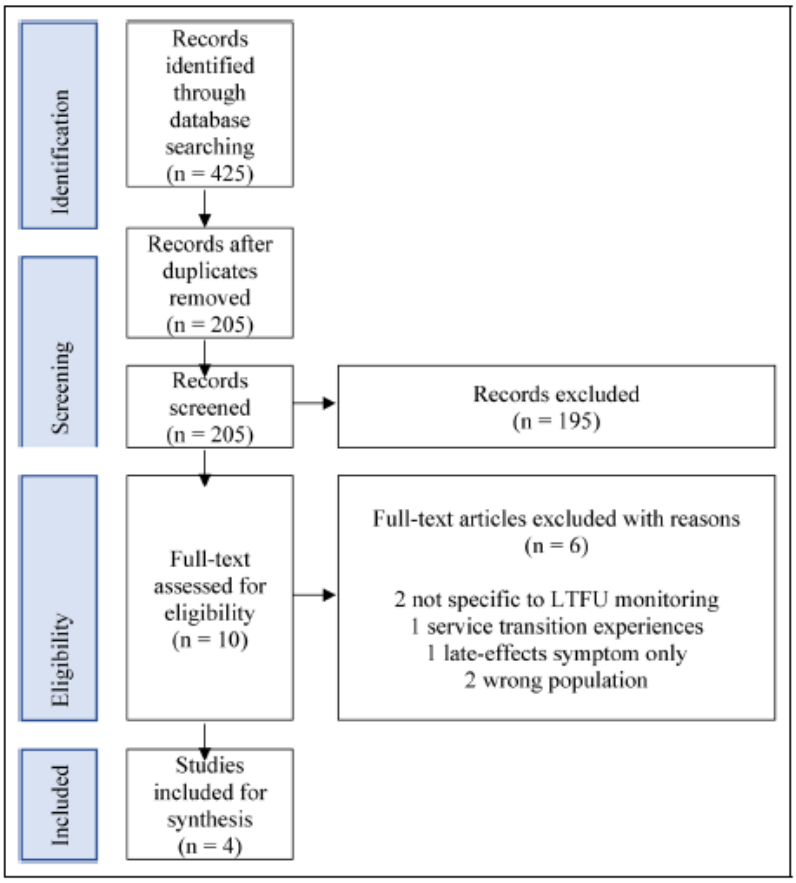


**Figure 1.** PRISMA results.

## Results

The synthesis of results identified 3 analytical themes regarding recipients' experiences of monitoring clinics. These were (i) "*[It's] important to maintain a good relationship with the nurses and doctors*", (ii) "*There's always the thing about the logistics*", and (iii) "*Once you have cancer, you're always thinking do I have it again?*".

"*[It's] important to maintain a good relationship with the nurses and doctors*": Patients establishing relationships with clinical personnel was seen as a crucial element to receiving personal and attentive care, as well as maintaining health. Speaking to staff who already knew their medical history was both comforting and increased efficiency for patients. Furthermore, patients trusted personnel directives and valued them as a source of information.

While there was a general validation of the importance of a patient/provider relationship, patients frequently highlighted a distinction between the nurse-patient and doctor-patient relationships. Establishing close relationships with clinical liaison nurses was associated with maintaining clinical support. Nurses are seen as the primary facilitator of patient care and the main communicator among healthcare professionals. In contrast, establishing close relationships with clinical doctors was correlated with building patients' confidence and becoming proactive in their care and a source of comfort. However, establishing such a relationship was hindered by patients not seeing the same clinician each time. Furthermore, if physicians were not specialists, many patients felt that they were not as informed or helpful in addressing their needs.

"*There's always the thing about the logistics*": While some patients reported being satisfied with the organization and structure of clinics, others identified several logistical problems. In 1 study, several patients experienced long waiting periods, either at clinical appointments or with associated services such as hematology and pharmacy; however, sympathy for busy staff and the urgent needs of others mitigated levels of frustration caused. Other patients reported struggling with the length and frequency of appointments,

**Table 1.** Summary of Included Studies.

| Study No. | Authors/Year/ Country | Population | Aim | Method | Themes identified by primary study authors | CASP (10) |
|---|---|---|---|---|---|---|
| 1 | Hwang et al,(2012). USA | 22 allo-HSCT patients (11 males and 11 females). Age range 22-69 years. Mean time since transplant was 5.2 years (range 2.4-8 years). | To explore the attitudes of long-term survivors of HSCT about their healthcare use and information needs | Thematic analysis using grounded theory approach. Three focus groups and 12 structured interviews conducted. | Late effects; healthcare issues; health education and outreach; personal factors; social factors | 10 |
| 2 | Parisek et al, (2021). Germany | 32 allo-HSCT survivors (16 males and 16 females) and 18 partners. Age range of survivors was 25-68 years. Mean time since transplant was 2.7 years (range 1.2 - 5 years). Attended GVHD clinic for routine follow-up or second opinions. | To explore in-depth HSCT survivors' experiences and needs post-transplant. Partners included to provide further information. | Framework method of analysis of semistructured telephone interviews. | Diversity of long-term treatment side-effects as a major challenge in alloHSCT survivorship care; Time post-discharge as a dynamic process with individual peaks of burden; Transparent communication and support with patient empowerment; Continuity in the care system and help with claiming social benefits as cornerstones of optimal survivorship care. | 10 |
| 3 | Sharin et al, (2021). Singapore. | 8 HSCT patients (1 auto & 7 allo-HSCT) (3 males and 5 females). Age range 27-67 years. Mean time since transplant was 8.13 years (range 4-20 years). At least one visit to long-term follow-up clinic. | To explore the experiences of HSCT survivors attending a long-term follow-up clinic | Qualitative thematic analysis of one-to-one semistructured interviews. | Comprehending the experiences; acknowledging the meaningfulness of the experience; managing threats to a new life after transplant | 10 |
| 4 | de Vere Hunt et al, (2021). UK | 8 allo-HSCT patients (2 males and 2 females). Age range of survivors 46-68 years. Mean time since transplant 3 years (range 0.25-15 years). Attended GVHD clinic. | Exploration of patient perspectives of their HRQOL and experiences of service provision in a multidisciplinary specialist care clinic. | Qualitative thematic analysis of one-to-one semistructured interviews. | Themes related to QOL issues in GVHD; 'Restricted as to what I can do'; Troubling symptoms—"*you can sort of get GVHD anywhere*"; Confusion and uncertainty regarding GVHD symptoms —"*Is this the GVHD?*"; Unpredictable course and uncertainty regarding the future; Adapting to the sick role Themes related to patient experience of the healthcare service provision; Personal care and close relationship with BMT nurses; Efficiency versus long waiting times—"on the case straight away"; Information provision—"*went into it with a bit of a rosy view*"; The role of support groups | 10 |

CASP, Critical Appraisal Skills Program; GVHD, graft-versus-host disease; HRQOL, health-related QOL.

**Table 2.** CERQual Summary of Qualitative Findings Table.

Objective: To explore and synthesize the qualitative evidence pertaining to HSCT patients' experiences of long-term monitoring clinics and associated impact on FCR

Perspective: Experiences of HSCT patients' attending long-term monitoring clinics and associated impact on FCR

| Summary of review findings | Supporting quotes (with study number) | Studies contributing to the review findings | *CERQual assessment of confidence in the evidence* | Explanation of CERQual assessment |
|---|---|---|---|---|
| "Important to maintain good relationship with the nurses and doctors": Patients establishing relationships with clinical personnel was seen as a crucial element to receiving personal and attentive care, as well as maintaining health | *You know, as far as sort of care and attention is concerned from the people … I can't fault it really."* (4)<br>*you see … how important to maintain good relationship with others who cares for you even the nurses and doctors* (1)<br>*I've had ready access to XXX, the post-transplant nurse co-ordinator, and she's been very good; seems very knowledgeable and very encouraging… so I think a personal relationship is important. And the fact that she has access to all of the other colleagues that she can then go and speak to and get back to me.* (4)<br>*I really have to praise it—this wonderful system of building a bridge between hospital care and care at home. There is someone who takes the time to tell us what to look out for at home.* (2)<br>*"Every time I build a relationship with a doctor they leave soon after. It is really annoying. Because you always talk a bit about yourself. First, the doctor is a stranger to you, then, during the second visit, you start to get to know them, and again during the third visit, and when you want to meet them for the fourth time they are gone."* (2)<br>*"I feel very comfortable [with the cancer specialists]—like they really do care about you. [O]ne year I got real sick, and I ended up going to a [noncancer specialist]. And they made me feel like they weren't solving the problem"* (1)<br>*in terms of the expertise and the consultants I see, I've got no real issue. It's just that I see lots of different people rather than the same person* (4) | 1, 2, 3, 4 | High confidence | Four studies with no or very minor concerns about coherence, relevance, adequacy, and methodological limitations. |
| *"There's always the thing about the logistics"*: Patients identified several logistical problems with attending monitoring clinic appointments, such as, delays, length, frequency, and financial consequences. | *"I've been impressed basically in terms of, you know, efficiency… it all seems to be, you know, well organized, efficient, or reasonably efficient when I go, you know, you're never seen exactly on time but, you know, you do get seen… people do spend time with you… from my point of view it seems to work quite well; very well, not just quite well; very well"* (4)<br>*'Occasionally, it doesn't happen very often now, but there are occasions where it is a long wait… But then I know that when I was poorly I had the attention of my consultant… there was no rush if you know what I mean, so I appreciate that there would be someone somewhere in with somebody who's very poorly and is taking a long time more, which I understand'* (4)<br>*'I see my [eye doctor and a doctor for] GVHD… [Appointments] pile up during the day…I'm here from 8:00 in the morning until 4:00 in the afternoon… [Y]ou just get tired of waiting and sitting'* (1)<br>*"All these appointments are not cheap. It is very expensive. If having more appointments as the days goes by, it means the expenses will be more for us. Sometimes I even ask them whether it is important for these appointments. I understand all these, I need to spend"* (3)<br>*"The once that I asked to see a dermatologist I was able to see her that same day, so that was reassuring"* (4)<br>*Participants reported a lack of communication between their treating specialists, GPs and the emergency departments they attended. GPs and local emergency departments were often not aware of the special needs of allo HSCT-survivors* (2)<br>*"I'll call cancer care and I'll Google the cancer patient resources. There is help, but only for people in treatment. It's like they've forgotten the people after they've survived"* (1) | 1, 2, 4 | High confidence | Four studies with no or very minor concerns about coherence, relevance, adequacy, and methodological limitations. |

*(continued)*

**Table 2.** (continued)

| Objective: To explore and synthesize the qualitative evidence pertaining to HSCT patients' experiences of long-term monitoring clinics and associated impact on FCR | | | | |
|---|---|---|---|---|
| Perspective: Experiences of HSCT patients' attending long-term monitoring clinics and associated impact on FCR | | | | |
| Summary of review findings | Supporting quotes (with study number) | Studies contributing to the review findings | *CERQual assessment of confidence in the evidence* | Explanation of CERQual assessment |
| *"Once you have cancer, you're always thinking do I have it again?"*. Patients reported a fear of recurrence and uncertainty of the future, feelings of which were associated with monitoring practice. | *'I feel very covered. I feel very safe in [how much] screening they do'* (1)<br>*'If you did less [screening], you'll always have that in your head, '[Do] I have something?' Once you have cancer you're always thinking …do I have it again'* (1)<br>*"The ultrasound image showed up something on my thyroid. And then they [= the treating clinician] say to you: 'Well, we'll definitely have to investigate that. You were getting radiation therapy and some tumors can come back.' And my reaction was: danger, danger, danger!"* (2) | 1, 2, 3 | Moderate confidence | Two studies with no or very minor concerns about coherence, relevance, adequacy, and methodological limitations. One study with no or very minor concerns about, relevance, adequacy, and methodological limitations but a minor concern with coherence. |

Abbreviations: CERQual, confidence in the evidence from reviews of qualitative; HSCT, hematopoietic stem cell transplant; FCR, fear of cancer recurrence; GVHD, graft-versus-host disease; GP, general practitioners.

usually requiring patients to commit to a full day, which meant prolonged times away from employment and preventing patients from making life-meaning plans. The frequency of appointments also had a financial implication for patients as attending was costly, causing some patients to question if some appointments were even needed. However, maintaining their health led patients to accept the financial implications as part of the care trajectory.

Despite the delays and organizational issues, patients did report clinics responding quickly to their concerns, especially if worries were regarding GVHD and clinics were formulated as a multidisciplinary team. The quick referrals and appointment access streamlined the process and provided reassurance. However, patients reported communication issues between monitoring clinics and other medical departments, including general practitioners (GPs) and accident and emergency care (A&E). Patients perceived other departments to lack the medical knowledge and experience of the long-term consequences of HSCT and that this barrier prevented their needs from being met or intensified feelings of abandonment.

*"Once you have cancer, you're always thinking do I have it again?"*. Due to concerns regarding late complications and fear of recurrence, patients expressed the need to control their health which caused them to become more observant of the importance of long-term monitoring, screening practices, and tests. Concerning screening participation, some patients reported being satisfied and reassured with the level of screening undertaken. However, for other patients, the fear of recurrence fueled them to believe that they were not participating enough. How physicians reported the findings of screening tests was also anxiety-provoking, especially concerning physicians thinking out loud or not communicating in nonspecialists' terms, consequently leading patients to fear that something was wrong and causing them distress.

## Discussion

This qualitative metasynthesis provides the first known systematic review of qualitative studies exploring the experiences of HSCT patients attending long-term monitoring clinics. This review revealed that the relationship status with healthcare professionals and logistical arrangements impacted HSCTs' experiences in long-term monitoring clinics. Furthermore, attending appointments and participating in screening activities was reassuring for some but problematic for others due to concerns, worry or fear of cancer recurrence (FCR).[22]

Patients perceived liaison nurses as the primary facilitator of patient care and the main communicator among healthcare professionals, and establishing close relationships was essential to maintaining clinical support. However, this perceived reliance on liaison nurses may be influenced by the clinical management structure rather than a relationship status. Out of 19 TCs in the United Kingdom, ten were physician-led, 3 nurse-led, and 6 combined.[10] Furthermore, physician availability may influence the dependence on liaison nurses as it

has been reported that physicians within monitoring clinics are allocated less than one-third of their time (31.7%) on HSCT-related tasks, with much of their time being spent in general hematology.[23] Nevertheless, the findings of this study suggest that patients view clinics as their primary care providers, which may become problematic given the expected number of survivors over the next decade and if TCs monitor follow-up via primary healthcare providers. Therefore, this represents an opportunity for increased research focused on understanding patients' and providers' expectations and roles within the 2 main monitoring processes stated in the TC accreditation manual.

Accreditation standards state that TCs perform long-term monitoring directly or coordinate care directly with referring physicians to prevent patients from being lost for follow-up.[9] TCs choosing the latter may be hampered by the lack of communication patients reported between clinics, GPs, and A&E departments. The communication barrier prevented patients' needs from being met or intensified feelings of abandonment. Consistent with other work, poor communication in healthcare can lead to various adverse outcomes, including patient dissatisfaction and discontinuity of care.[24] However, each primary study originated from different countries with varying healthcare systems. Researching patients' experiences within the same demographic location will provide a greater understanding of any communication barriers specific to the national healthcare structure to ensure patients' needs are being met or identify areas for improvement. This will also enable the assessment of variation in patients' experiences monitored via primary healthcare providers compared with patients being monitored directly by TCs.

Another notable finding was the variability in how monitoring practices impact FCR, especially concerning the number of screening tests undertaken. Some patients felt reassured by the amount of screening undertaken; for others, their FCR led them to believe that they were not attending enough. FCR was also reported to have been impacted by physicians' consultations following the test. While the findings in this study were heterogeneous; they are comparable to survivors of breast cancer who perceived attending monitoring clinics as contradictory; attendance was reassuring while also exacerbating their FCR.[25] Given the increased risk of treatment-related mortality and HSCT patients' heightened awareness of late complications, attentional bias could explain the impact on patients' FCR.[26,27] Patients who report being more observant of screening practices has been found to be positively associated with increased levels of FCR.[28] However, in a study of 335 allogeneic transplant patients no mean differences in FCR were found in patients who did or did not attend recommended screening despite 95% of survivors reported living with moderate (84%) to severe (11%) FCR. The only significant difference in FCR score was found in female participants who had not attended a cervical smear post-transplant.[29] The relationship between FCR and LTFU screening practices is complex and given the paucity of research in this area,[30] it is unclear if screening attendance or avoidance causes FCR or results from it. While the findings of this review suggest a weak connection between LTFU monitoring and FCR further research is required to understand the relationship in its entirety.

Regardless of the underlying causation, FCR heightens the importance of LTFU attendance for patients in this review as well as influences the need to control their health. Participating in health-promoting behaviors such as maintaining a healthy diet and weight, refrain from smoking, moderate alcohol use, and avoiding excessive sun exposure are all in patients' control. However, a study of 664 HSCT survivors found that despite increased health monitoring, there was no significant improvement in health behaviors after treatment.[31] In addition, HSCT survivors were less likely to participate in positive health behaviors such as physical activity,[32] and cancer survivors who participated in negative health behaviors were more likely to experience FCR.[33] Effectively managing patients' FCR was associated with improving survivors' quality of life and recommendations for FCR management included educational and support programs both prior to and post HSCT and screening for FCR at LTFU appointments.[29] Yet, studies into TCs monitoring procedures have reported insufficient access to psychological support; therefore, patients may not have received the appropriate support to mitigate FCR impact.[10–12] While the findings of this review highlight patients need to control health, what this actually means and its relations with FCR and the educational support available is unclear from our findings and further research is recommended.

As the first review exploring the experiences of HSCT patients attending long-term monitoring clinics this study has several strengths, including moderate/high confidence in the findings and a reproducible search strategy. Nonetheless, the findings are limited due to the paucity of research in this area, and that only 4 primary studies were identified that included HSCT patients experiences of attending LTFU clinics. Furthermore, the primary studies included in this review were from different countries with different healthcare structures; therefore, the findings may not be a true reflection of patients' experiences within specific healthcare settings. For example, patients' experiences of screening practice and FCR were drawn from 3 studies and included patients in the US, Singapore, and Germany. Therefore, for HSCT patients based in other countries, the experiences may be different. Take the UK for example, cervical and mammogram screening for HSCT patients relies on national screening programs, which access to is stated as problematic.[10] It is therefore recommended that more research into patients experiences of LTFU care conducted in different countries to gain a greater understanding of HSCT patients experiences within specific health care structures.

Secondly, although studies included a high-quality score, 2 papers recruited participants from a clinic dedicated to monitoring GVHD; therefore, patients were under active care, which may have resulted in more attendance

requirements resulting in a heightened awareness of logistical issues. It is therefore recommended that future research should focus on patients in LFTU but not under active care to get a fuller understanding of this cohort of patients' experiences. In addition, 1 paper was published in 2012 and while TCs had a responsibility to monitor patients post-transplant it was not made mandatory until 2015.[8] Therefore, the patients experiences within this paper may not reflect changes in LTFU practices since 2015. Finally, this review included studies with patients at 100+ days from transplant; however, patients may not have been formally discharged to long-term monitoring services at this stage. It is difficult to distinguish between post-HSCT monitoring and long-term monitoring as TCs sometimes incorporate both services into the same clinic.[12]

## Conclusion

The findings suggest that HSCT patients' experiences of LTFU care clinics are influenced by the patient-provider relationship and the logistical set-up of monitoring practices. Opportunities exist to extend future research to understand the impact of each finding further and should focus on 2 key areas; examine patient and providers' expectations and roles of monitoring services and cross-departmental communication specific to patients' demographical location. Further understanding of roles, responsibilities and communication needs may reduce patient reliance on LTFU clinics for general healthcare needs, promote self-management where applicable, and identify barriers and facilitators to find potential solutions. In addition, the findings suggest a connection between monitoring clinics and patients' FCR, however further research, including the potential relationship with associated health behaviors, is required to understand the relationship entirely and to gain a greater understanding of HSCT patients' support needs.

### Authors Contributions

BB conceived the study and conducted the searches. BB, KS, and HL conducted the screening. BB and ST conducted the thematic synthesis. The first draft of the manuscript was written by BB and all authors commented on previous versions of the manuscript. All authors read and approved the final manuscript.

### Ethical Approval

Ethical approval was not required for this systematic review because primary data was not collected.

### Funding

The authors received no financial support for the research, authorship, and/or publication of this article.

### Informed Consent

Informed consent for patient information to be published in this article was not obtained because the information used was sourced from publicly accessible documents.

### Statement of Human and Animal Rights

This article does not contain any studies with human or animal subjects.

### ORCID iD

Blossom Bell https://orcid.org/0000-0002-8993-7021

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## Appendix 16: PROSPERO Registration

NIHR | National Institute for Health Research

PROSPERO
International prospective register of systematic reviews

A systematic review exploring how post haematopoietic stem cell transplant (HSCT) long-term monitoring and associated health threats impact recipients lived experience.

*Blossom Bell, Katherine Swainston, Helen Limbrick, Jill Taylor*

### Citation

Blossom Bell, Katherine Swainston, Helen Limbrick, Jill Taylor. A systematic review exploring how post haematopoietic stem cell transplant (HSCT) long-term monitoring and associated health threats impact recipients lived experience.. PROSPERO 2021 CRD42021231860 Available from: https://www.crd.york.ac.uk/prospero/display_record.php?ID=CRD42021231860

### Review question

How does post haematopoietic stem cell transplant (HSCT) long-term monitoring and associated health threats impact recipients lived experience.

### Searches

Databases: PsycINFO, MEDLINE, Scopus, CINAHL, EMBASE, Psychology and Behavioral Science Collection, The Allied and Complementary MEDicine, Proquest Nursing and Allied Health Source. The search will be supplemented by the following grey literature sources – MEDNAR and Google Scholar.

Search dates: 2006 to 2021

The search strategy will include only terms relating to the experiences of haematopoietic stem cell transplant recipients' post-transplant. The search terms will be adapted for use with specific bibliographic databases in combination with database specific filters where applicable.

### Search strategy

https://www.crd.york.ac.uk/PROSPEROFILES/231860_STRATEGY_20210118.pdf

### Types of study to be included

Qualitative or mixed method studies only

### Condition or domain being studied

Stem cell transplant recipients experience physical, psychological and psychosocial late-effects following transplant. This systematic review will aim to answer the following questions;

• How do HSCT recipients experience late-effects following transplant.

• The impact of long-term monitoring and effect on the late-effects experienced

• The psychological impact of long-term monitoring

### Participants/population

Patients who have received a haematopoietic stem cell transplant and are more than 100 days post-transplant.

### Intervention(s), exposure(s)

The main aim of this systematic review of qualitative studies is to collate evidence in the literature reporting on patients' experiences of long term monitoring services and associated health threats following HSCT.

### Comparator(s)/control

Not applicable

### Main outcome(s)

The present research will help to identify common concerns experiences by those who have received a stem

## Appendix 17: PROSPERO Registration Update July 2024

NIHR | National Institute for Health and Care Research

**PROSPERO**
International prospective register of systematic reviews

# A systematic review exploring how post haematopoietic stem cell transplant (HSCT) long-term monitoring and associated health threats impact recipients lived experience.

*Blossom Bell, Katherine Swainston, Helen Limbrick, Stacie Thursby*

**Citation** 1 change
Blossom Bell, Katherine Swainston, Helen Limbrick, Stacie Thursby. A systematic review exploring how post haematopoietic stem cell transplant (HSCT) long-term monitoring and associated health threats impact recipients lived experience.. PROSPERO 2024 Available from https://www.crd.york.ac.uk/PROSPERO/view/CRD42021231860

## REVIEW TITLE AND BASIC DETAILS

**Review title**
A systematic review exploring how post haematopoietic stem cell transplant (HSCT) long-term monitoring and associated health threats impact recipients lived experience.

**Review objectives**
How does post haematopoietic stem cell transplant (HSCT) long-term monitoring and associated health threats impact recipients lived experience.

## SEARCHING AND SCREENING

**Searches**
Databases: PsycINFO, MEDLINE, Scopus, CINAHL, EMBASE, Psychology and Behavioral Science Collection, The Allied and Complementary MEDicine, Proquest Nursing and Allied Health Source. The search will be supplemented by the following grey literature sources – MEDNAR and Google Scholar. Search dates: 2006 to 2021
The search strategy will include only terms relating to the experiences of haematopoietic stem cell transplant recipients' post-transplant. The search terms will be adapted for use with specific bibliographic databases in combination with database specific filters where applicable.

**Study design**
Qualitative or mixed method studies only

## ELIGIBILITY CRITERIA

**Condition or domain being studied**

Stem cell transplant recipients experience physical, psychological and psychosocial late-effects following transplant. This systematic review will aim to answer the following questions;

- How do HSCT recipients experience late-effects following transplant.
- The impact of long-term monitoring and effect on the late-effects experienced
- The psychological impact of long-term monitoring

**Population**

Patients who have received a haematopoietic stem cell transplant and are more than 100 days post-transplant.

**Intervention(s) or exposure(s)**

The main aim of this systematic review of qualitative studies is to collate evidence in the literature reporting on patients' experiences of long term monitoring services and associated health threats following HSCT.

**Comparator(s) or control(s)**

Not applicable

## OUTCOMES TO BE ANALYSED

**Main outcomes**

The present research will help to identify common concerns experiences by those who have received a stem cell transplant. It is anticipated that the synthesis of these studies will help inform and assist transplant centres in delivering a managed service that is patient-centred.

*Measures of effect*

Not applicable

**Additional outcomes**

None

*Measures of effect*

Not applicable

## DATA COLLECTION PROCESS

**Data extraction (selection and coding)**

The titles and abstracts of studies retrieved using the search strategy detailed above, as well as from additional sources will be independently screened by two reviewers to identify studies which may be eligible.

The first reviewer will initially screen all titles and abstracts removing any duplicates, with a second reviewer screening a random 20% of titles and abstracts. Titles and abstracts will be screened against an inclusion / exclusion criteria. All studies excluded at this stage will be documented, including reasons for exclusion.

The full text of those which are potentially eligible will be retrieved and independently assessed for eligibility by two independent reviewers. For the full sift, 100% of titles will be screened by each reviewer. In any cases of disagreement between the first and second reviewer this will be resolved through discussion with a third reviewer.
A data extraction form will be designed in Microsoft Excel to record the following details: lead author, year of publication, country, qualitative methodology, sample size, participant characteristics (age, gender, ethnicity, time since diagnosis, stage of diagnosis), and emerging themes. The extraction form will be piloted with two included studies, and if necessary will be adapted to ensure that it is fit for purpose. Two reviewers will independently extract data, and in cases of disagreement, a third reviewer will be used.

**Risk of bias (quality) assessment**
Included studies will be quality assessed using the CASP checklist for qualitative studies. Two reviews will independently assess each included study for quality, and in cases of disagreement this will be resolved through discussion with a third reviewer.

## PLANNED DATA SYNTHESIS

**Strategy for data synthesis**
The findings from the included qualitative studies will be synthesised using methods for the synthesis of qualitative research. Verbatim quotations relevant to the aims of this systematic review will be extracted onto a Microsoft Excel spreadsheet, along with information on the themes, and sub-themes they related to in the original study. The extracted quotations will be coded according to their meaning and context with one reviewer responsible for coding extracted quotations into overarching themes for the included studies. Two other researchers will check the coding of the themes and sub-themes for consistency.

**Analysis of subgroups or subsets**
None planned

## REVIEW AFFILIATION, FUNDING AND PEER REVIEW

**Review team members** 1 change

- Mrs Blossom Bell, Teesside University
- Dr Katherine Swainston, Teesside University
- Dr Helen Limbrick, Teesside University
- Miss Stacie Thursby, Northumbria Healthcare

**Review affiliation**
Teesside University

**Funding source**
No funding

**Named contact**
Blossom Bell. Department of Psychology, School of Social Sciences, Humanities & Law, Borough Road, Middlesbrough, Tees Valley, TS1 3BA

b.bell@tees.ac.uk

## TIMELINE OF THE REVIEW

**Review timeline** 1 change
Start date: 04 January 2021. End date: 31 May 2022

**Date of first submission to PROSPERO**
18 January 2021

**Date of registration in PROSPERO**
21 January 2021

## CURRENT REVIEW STAGE

**Publication of review results** 1 change
The intention is to publish the review once completed.The review will be published in English

https://journals.sagepub.com/doi/10.1177/23743735241229378

**Stage of the review at this submission** 1 change

| Review stage | Started | Completed |
|---|---|---|
| Pilot work | ✓ | ✓ |
| Formal searching/study identification | ✓ | ✓ |
| Screening search results against inclusion criteria | ✓ | ✓ |
| Data extraction or receipt of IP | ✓ | ✓ |
| Risk of bias/quality assessment | ✓ | ✓ |
| Data synthesis | ✓ | ✓ |

**Review status**
The review is completed.

## ADDITIONAL INFORMATION

**PROSPERO version history**

- Version 1.2 published on 24 Jul 2024
- Version 1.1 published on 15 May 2021
- Version 1.0 published on 21 Jan 2021

**Review conflict of interest**
None known

**Country**
England

**Medical Subject Headings**

Hematopoietic Stem Cell Transplantation; Humans

**Revision note** 1 change
Review complete and published

**Disclaimer**
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Any enquiries about the record should be referred to the named review contact

## Appendix 18: PRISMA 2020 Checklist

| Section and Topic | Item # | Checklist item | Location where item is reported |
|---|---|---|---|
| **TITLE** | | | |
| Title | 1 | Identify the report as a systematic review. | Title |
| **ABSTRACT** | | | |
| Abstract | 2 | See the PRISMA 2020 for Abstracts checklist. | NA |
| **INTRODUCTION** | | | |
| Rationale | 3 | Describe the rationale for the review in the context of existing knowledge. | 4.2 |
| Objectives | 4 | Provide an explicit statement of the objective(s) or question(s) the review addresses. | 4.3.7 |
| **METHODS** | | | |
| Eligibility criteria | 5 | Specify the inclusion and exclusion criteria for the review and how studies were grouped for the syntheses. | 4.3.2 |
| Information sources | 6 | Specify all databases, registers, websites, organisations, reference lists and other sources searched or consulted to identify studies. Specify the date when each source was last searched or consulted. | 4.3.1 |
| Search strategy | 7 | Present the full search strategies for all databases, registers and websites, including any filters and limits used. | 4.3.1 |
| Selection process | 8 | Specify the methods used to decide whether a study met the inclusion criteria of the review, including how many reviewers screened each record and each report retrieved, whether they worked independently, and if applicable, details of automation tools used in the process. | 4.3.3 |
| Data collection process | 9 | Specify the methods used to collect data from reports, including how many reviewers collected data from each report, whether they worked independently, any processes for obtaining or confirming data from study investigators, and if applicable, details of automation tools used in the process. | 4.3.6 |
| Data items | 10a | List and define all outcomes for which data were sought. Specify whether all results that were compatible with each outcome domain in each study were sought (e.g. for all measures, time points, analyses), and if not, the methods used to decide which results to collect. | 4.3.6 |
| | 10b | List and define all other variables for which data were sought (e.g. participant and intervention characteristics, funding sources). Describe any assumptions made about any missing or unclear information. | Partial 4.3.6 |
| Study risk of bias assessment | 11 | Specify the methods used to assess risk of bias in the included studies, including details of the tool(s) used, how many reviewers assessed each study and whether they worked independently, and if applicable, details of automation tools used in the process. | 4.3.5 |
| Effect measures | 12 | Specify for each outcome the effect measure(s) (e.g. risk ratio, mean difference) used in the synthesis or presentation of results. | NA |
| Synthesis methods | 13a | Describe the processes used to decide which studies were eligible for each synthesis (e.g. tabulating the study intervention characteristics and comparing against the planned groups for each synthesis (item #5)). | 4.3.6 |
| | 13b | Describe any methods required to prepare the data for presentation or synthesis, such as handling of missing summary statistics, or data conversions. | 4.3.6 |

| Section and Topic | Item # | Checklist item | Location where item is reported |
|---|---|---|---|
| | 13c | Describe any methods used to tabulate or visually display results of individual studies and syntheses. | Tables 4.5 to 4.8 |
| | 13d | Describe any methods used to synthesize results and provide a rationale for the choice(s). If meta-analysis was performed, describe the model(s), method(s) to identify the presence and extent of statistical heterogeneity, and software package(s) used. | 4.3.6 |
| | 13e | Describe any methods used to explore possible causes of heterogeneity among study results (e.g. subgroup analysis, meta-regression). | 4.5 |
| | 13f | Describe any sensitivity analyses conducted to assess robustness of the synthesized results. | NA |
| Reporting bias assessment | 14 | Describe any methods used to assess risk of bias due to missing results in a synthesis (arising from reporting biases). | NA |
| Certainty assessment | 15 | Describe any methods used to assess certainty (or confidence) in the body of evidence for an outcome. | 4.3.7 |
| **RESULTS** | | | |
| Study selection | 16a | Describe the results of the search and selection process, from the number of records identified in the search to the number of studies included in the review, ideally using a flow diagram. | 4.3.3 |
| | 16b | Cite studies that might appear to meet the inclusion criteria, but which were excluded, and explain why they were excluded. | 4.3.3 |
| Study characteristics | 17 | Cite each included study and present its characteristics. | 4.3.4 |
| Risk of bias in studies | 18 | Present assessments of risk of bias for each included study. | 4.3.5 |
| Results of individual studies | 19 | For all outcomes, present, for each study: (a) summary statistics for each group (where appropriate) and (b) an effect estimate and its precision (e.g. confidence/credible interval), ideally using structured tables or plots. | Tables 4.5 to 4.8 |
| Results of syntheses | 20a | For each synthesis, briefly summarise the characteristics and risk of bias among contributing studies. | 4.4 |
| | 20b | Present results of all statistical syntheses conducted. If meta-analysis was done, present for each the summary estimate and its precision (e.g. confidence/credible interval) and measures of statistical heterogeneity. If comparing groups, describe the direction of the effect. | NA |
| | 20c | Present results of all investigations of possible causes of heterogeneity among study results. | 4.5 |
| | 20d | Present results of all sensitivity analyses conducted to assess the robustness of the synthesized results. | NA |
| Reporting biases | 21 | Present assessments of risk of bias due to missing results (arising from reporting biases) for each synthesis assessed. | NA |
| Certainty of evidence | 22 | Present assessments of certainty (or confidence) in the body of evidence for each outcome assessed. | 4.3.7 |
| **DISCUSSION** | | | |
| Discussion | 23a | Provide a general interpretation of the results in the context of other evidence. | 4.5 |

| Section and Topic | Item # | Checklist item | Location where item is reported |
|---|---|---|---|
| | 23b | Discuss any limitations of the evidence included in the review. | 4.5 |
| | 23c | Discuss any limitations of the review processes used. | 4.5 |
| | 23d | Discuss implications of the results for practice, policy, and future research. | 4.5 |
| **OTHER INFORMATION** | | | |
| Registration and protocol | 24a | Provide registration information for the review, including register name and registration number, or state that the review was not registered. | 4.3 |
| | 24b | Indicate where the review protocol can be accessed, or state that a protocol was not prepared. | 4.3 |
| | 24c | Describe and explain any amendments to information provided at registration or in the protocol. | 4.3 |
| Support | 25 | Describe sources of financial or non-financial support for the review, and the role of the funders or sponsors in the review. | NA |
| Competing interests | 26 | Declare any competing interests of review authors. | NA |
| Availability of data, code and other materials | 27 | Report which of the following are publicly available and where they can be found: template data collection forms; data extracted from included studies; data used for all analyses; analytic code; any other materials used in the review. | NA |

## Appendix 19: Full-text Review Exclusion Summary

| No | Reference | Include / Reject | Primary Researcher Comment | First Supervisor Comment |
|---|---|---|---|---|
| 1 | Beeken, R. J., Eiser, C., & Dalley, C. (2011). Health-related quality of life in haematopoietic stem cell transplant survivors: A qualitative study on the role of psychosocial variables and response shifts. Quality of Life Research, 20(2), 153–160. https://doi.org/10.1007/s11136-010-9737-y | Reject | **Not LTFU monitoring**. Focuses on psychosocial variables and response shifts, not on LTFU monitoring. | KS - Exclude |
| 2 | Braamse, A. M. J., van Meijel, B., Visser, O. J., Huijgens, P. C., Beekman, A. T. F., & Dekker, J. (2017). Help-seeking behaviour of patients with haematological malignancies treated with autologous stem cell transplantation. European Journal of Cancer Care, 26(6), e12679. https://doi.org/10.1111/ecc.12679 | Reject | **Wrong population.** Focuses on help-seeking behaviour in patients treated with autologous stem cell transplantation, not post-100 days HSCT recipients. | KS - Exclude |
| 3 | Brauer, E. R., Pieters, H. C., Ganz, P. A., Landier, W., Pavlish, C., & Heilemann, M. V. (2019). Improving to where?: Treatment-related health risks and perceptions of the future among adolescents and young adults after hematopoietic cell transplantation. Supportive Care in Cancer, 27(2), 635–642. https://doi.org/10.1007/s00520-018-4350-7 | Reject | **Late effects only**. Focuses on treatment-related health risks and perceptions, not on monitoring or service provision. | KS - Exclude |
| 4 | Brice, L., Gilroy, N., Dyer, G., Kabir, M., Greenwood, M., Larsen, S., ... & Kerridge, I. (2017). Haematopoietic stem cell transplantation survivorship and quality of life: Is it a small world after all? Supportive Care in Cancer, 25(2), 421–427. https://doi.org/10.1007/s00520-016-3418-5 | Reject | **Not LTFU monitoring**. General survivorship and quality of life, lacks focus on LTFU clinic or monitoring | KS - Exclude |

| | | | | |
|---|---|---|---|---|
| 5 | de Vere Hunt, I., Kilgour, J. M., Danby, R., Peniket, A., & Matin, R. N. (2021). "Is this the GVHD?" A qualitative exploration of quality of life issues in individuals with graft-versus-host disease following allogeneic stem cell transplant and their experiences of a specialist multidisciplinary bone marrow transplant service. *Health and Quality of Life Outcomes, 19*(1), 11-11. https://doi.org/10.1186/s12955-020-01651-2 | Include | HSCT recipients attending outpatient clinic. Experiences of healthcare service provisions extractable from the data | KS - Include |
| 6 | Hwang, J. P., Roundtree, A. K., Giralt, S. A., & Suarez-Almazor, M. (2012). Late effects and healthcare needs of survivors of allogeneic stem cell transplantation: A qualitative study. *BMJ Supportive & Palliative Care, 2*(4), 344-350. https://doi.org/10.1136/bmjspcare-2012-000277 | Include | HSCT recipients attending outpatient clinic. While study includes symptoms / late-effect conditions, the experiences of healthcare service is extractable from the data | KS - Include |
| 7 | Jim, H. S. L., Quinn, G. P., Gwede, C. K., Cases, M. G., Barata, A., Cessna, J., ... & Pidala, J. (2014). Patient education in allogeneic hematopoietic cell transplant: What patients wish they had known about quality of life. Bone Marrow Transplantation, 49, 299–303. https://doi.org/10.1038/bmt.2013.158 | Reject | **Wrong population.** Focuses on patient education and pre-transplant expectations, not post-100 days HSCT recipients. | KS - Exclude |
| 8 | Panek-Hudson, Y., Garcia, T., Hotchkin, T., Vella, A., Ritchie, D., Conyers, R., … & Krishnasamy, M. (2021). The TransAllo study: Factors influencing attendance at and experiences of a long-term follow-up clinic post-allogeneic bone marrow transplant for patients transitioning from paediatric to adult services. *The Australian Journal of Cancer Nursing, 22*(2), 12-18. https://doi.org/10.33235/ajcn.22.2.12-18 | Reject | **Service transition.** Focuses on transition from paediatric to adult services, not the LTFU services themselves. | KS - Exclude |
| 9 | Parisek, M., Loss, J., Holler, E., Barata, A., Weber, D., Edinger, M., Wolff, D., Schoemans, H., & Herrmann, A. (2021). “This graft-vs.-host disease determines my life. that's it.” - A qualitative analysis of the experiences and needs of allogenic hematopoietic stem cells transplantation survivors in Germany. *Frontiers in Public Health, 9*, 687675-687675. https://doi.org/10.3389/fpubh.2021.687675 | Include | Post HSCT recipients attending routine follow-up or GVHD clinic. Extractable data regarding healthcare provisions available. | |
| 10 | Sharin, U. B. M., Hwang, C. C. J., Ang, W. H. D., & Lopez, V. (2020). The haematopoietic stem cell transplant survivors’ sense of coherence about their experiences: A qualitative study. *Supportive Care in Cancer, 28*(9), 4275-4283. https://doi.org/10.1007/s00520-019-05273-3 | Include | Extractable data detailing recipients’ experiences of attending a long-term follow-up (LFU) clinic | KS - Include |

## Appendix 20: Data Extraction Form

| Reference: Hwang et al., 2012 (USA) | | | |
|---|---|---|---|
| Population | Aim / Method | Themes | Results / Findings (interpretations & direct quotes inc.) |
| 22 Allo-HSCT patients (M = 11 / F = 11).<br><br>Age range 22-69 yrs.<br><br>Mean time since transplant was 5.2 yrs (range 2.4-8 yrs). | To explore the attitudes of long-term survivors of HSCT about their healthcare use and information needs<br><br>Thematic analysis using grounded theory approach. Three focus groups and 12 structured interviews conducted | Healthcare issues | Participants felt that they participated in appropriate screening, including colonoscopies, bone marrow biopsies, blood tests, bone density tests, chest x-rays and CAT scans. *'I feel very covered. I feel very safe in [how much] screening they do' (male, age 29).*<br>Fears of recurrence fuelled a few participants to suspect that they might not participate in enough screenings. *'If you did less [screening], you'll always have that in your head, '[Do] I have something?' Once you have cancer you're always thinking …do I have it again' (female, age 52).*<br>Patients valued providers as sources of information and trusted their directives. However, they often wanted more interaction with cancer specialists who helped them during treatment. *'I feel very comfortable [with the cancer specialists] – like they really do care about you. [O]ne year I got real sick, and I ended up going to a [non-cancer specialist]. And they made me feel like they weren't solving the problem' (male, age 49).*<br>Despite insurance, their costs could be prohibitive. *'Having to go to the doctor so many times…my out-pocket spending is just so much' (female, age 40).*<br>Participants described how difficult it was to manage the logistics of making appointments with multiple providers. *'They always schedule my appointments on top of each other so, you know, sometimes…I'm here all day' (female, age 22).*<br>Often it required taking time off from work for themselves and their care providers in order to accommodate appointments. *'I see my [eye doctor and a doctor for] GVHD...*<br>*[Appointments] pile up during the day…I'm here from 8:00 in the morning until 4:00 in the afternoon...*<br>*[Y]ou just get tired of waiting and sitting' (male, age 23).* |
| | | Health education and outreach | Participants reported medical providers served as primary sources of information. *'I had a fabulous oncologist, and I had her sit down and explain everything—the side effects, the AML [acute myelogenous leukaemia]—just explain it to me where I can understand it' (male, age 51).*<br>Participants wanted to know more about the spectrum of expected late effects and the best methods for mitigating them. *'[I would] like information about … life expectancy–I guess taking–like my medications, how many years can I take it*<br>*without doing damage to my body' (male, age 49).*<br>Others admitted that avoiding information helped curb the stress and fear that can accompany knowing every possible risk and harm. *'[S]ometimes, the less you know, the less you worry about' (male, age 62).*<br>Many participants felt that they could not find the information and services that they needed. They felt left out by the system targeting patients with cancer currently undergoing treatment, rather than for people dealing with late effects after treatment. *'I'll call cancer care and I'll Google the cancer patient resources. There is help, but only for people in treatment. It's like they've forgotten the people after they've survived' (female, age 40).* |

**Appendix 21: Study 1 Synthesised Theme 1: First- and second-order constructs**

| **Synthesised Theme 1: "It's important to maintain a good relationship with nurses and doctors"** | |
|---|---|
| Primary author(s) interpretations of the original findings | Examples of the direct participant quotes |
| Relationships are re-evaluated after HSCT, for some patients they establish close relationships with other patients and healthcare professionals (Sharin et al., 2020) | "you see… how important to maintain good relationship with others who cares for you even the nurses and doctors" |
| Personal and attentive care was central to patient's experiences. Patients gain comfort and increased efficiency from speaking to healthcare professionals who were familiar with their medical history rather than having to 'start again' with new healthcare professional each time (de Vere Hunt et al., 2021) | "Having those individual contacts rather than, you know, just ring up and you'll get a team cos it happens every time. You know, cos otherwise... you know, if you have that, you know, every time, you know, you're explaining your problem and your history over and over again, whereas...the individuals get to know you and remember your history." |
| Continuous care, which included assistance with social support or home care management, was provided by liaison nurses who patients could contact when they needed. (Parisek et al., 2021) | "I really have to praise it - this wonderful system of building a bridge between hospital care and care at home. There is someone who takes the time to tell us what to look out for at home." |
| The main facilitator for multidisciplinary care and maintaining communication between different healthcare services was seen to come from the liaison nurses. This continuing and tailored support was greatly appreciated by recipients' and their families (Parisek et al., 2021) | "You always have the feeling that you can call the team of the liaison nurses if you need to."<br><br>"You just feel well looked after within this system of liaison nurses." |
| Recipients reported that liaison nurses provided a lot of support in maintaining health, particularly in areas of medication adherence, how to reduce infection risk or general health advice. (Parisek et al., 2021) | *Not provided.* |

| | |
|---|---|
| The close relationship with clinical nurse was the most frequent example provided of personal and attentive care. Patients gave several descriptions of the usefulness of having direct telephone contact with nurses, that facilitated efficient care (de Vere Hunt et al., 2021) | “Oh my gosh, they are wonderful. Because I have a transplant nurse... who I can call ... like I called her when something else flared up a little while ago...I was in there and they saw me straight away... If I had lots of questions that I could give someone a call and maybe get some answers or... yeh, or reassurance or whatever.” |
| | “I’ve had ready access to XXX, the post-transplant nurse co-ordinator, and she’s been very good; seems very knowledgeable and very encouraging... I think that it’s probably the availability of XXX on the end of the phone that, you know, within 24/48 h, but usually, you know, within that working day you can have a friendly voice that knows you, so I think a personal relationship is important. And the fact that she has access to all of the other colleagues that she can then go and speak to and get back to me. So, she has been really helpful as an access to information and just practical, you know, prescriptions and things like that.” |
| Consultants served as primary sources of information. (Hwang et al., 2012) | ‘I had a fabulous oncologist, and I had her sit down and explain everything—the side effects, the AML [acute myelogenous leukaemia]—just explain it to me where I can understand it’ |
| Recipients’, overall, were very positive about the attentive care they had received from the clinic doctors. One issue, is that patients report not seeing the same doctor each time (de Vere Hunt et al., 2021) | "I’ve had situations where one of the consultants has called me several times after the clinic appointment once he’s had a look at my bloods and things to suggest that we alter the medications before the next clinic...in fact one of them phoned me only this morning to make sure that an adjustment be made to the meds yesterday was going OK.” |
| | “In terms of the expertise and the consultants I see, I’ve got no real issue. It’s just that I see lots of different people rather than the same person” |

| | |
|---|---|
| The importance of seeing the same treating clinician at follow-up was stressed. This allowed patients to build a doctor-patient-relationship, based on mutual trust and helped patients gain confidence in their prescribed care and openly their healthcare needs (Parisek et al., 2021) | "Every time I build a relationship with a doctor they leave soon after. It is really annoying. Because you always talk a bit about yourself. First, the doctor is a stranger to you, then, during the second visit, you start to get to know them, and again during the third visit, and when you want to meet them for the fourth time they are gone." |
| Patients often reported seeking more interaction with treating cancer specialists. Several interactions of dealing with non-specialist were described which patients believe were not informative or helpful in addressing their needs (Hwang et al., 2012) | "I feel very comfortable [with the cancer specialists] – like they really do care about you. [O]ne year I got real sick, and I ended up going to an [non-cancer specialist]. And they made me feel like they weren't solving the problem" |

**Appendix 22: Study 1 Synthesised Theme 2: First- and second-order constructs**

| **Synthesised theme 2: "There's always the thing about the logistics"** | |
|---|---|
| Primary the author(s) interpretations of the original findings | Examples of the direct participant quotes |
| Despite patients reporting efficient care, there was descriptions of clinical delays and long waiting time. However, such discussions were delivered with an undertone of sympathy opposed to frustration (de Vere Hunt et al., 2021) | "I've been impressed basically in terms of, you know, efficiency... it all seems to be, you know, well organised, efficient, or reasonably efficient when I go, you know, you're never seen exactly on time but, you know, you do get seen... people do spend time with you, you know, the nurses are very helpful, you know, always willing to, you know, answer your questions, respond, help where they can. Yeh, and it seems to... well, from my point of view it seems to work quite well; very well, not just quite well; very well"<br><br>"Occasionally, it doesn't happen very often now, but there are occasions where it is a long wait... But then I know that when I was poorly I had the attention of my consultant... there was no rush if you know what I mean, so I appreciate that there would be someone somewhere in with somebody who's very poorly and is taking a long time more, which I understand"<br><br>"Got to wait quite a long time, and then even after seeing the doctor got to wait for pharmacy… It's really waste XXX all day because it's the middles of the part of the day is in the hospital, so it's really you can't do anything that day" |
| Making appointments with multiple providers was difficult for patients. Resulting in time off work for both the patients and their carers to be able to accommodate. (Hwang et al., 2012) | "They always schedule my appointments on top of each other so, you know, sometimes...I'm here all day"<br><br>"I see my [eye doctor and a doctor for] GvHD... [Appointments] pile up during the day…I'm here from 8:00 in the morning until 4:00 in the afternoon... [Y]ou just get tired of waiting and sitting" |

| | |
|---|---|
| Despite insurance being available, the cost might prevent attendance. (Hwang et al., 2012) | "Having to go to the doctor so many times… my out-of-pocket spending is just so much" |
| Attending LTFU is costly, but the expense is accepted as necessity to maintain health. (Sharin et al., 2020) | "All these appointments are not cheap. It is very expensive. If having more appointments as the days goes by, it means the expenses will be more for us. Sometimes I even ask them whether it is important for these appointments. I understand all these, I need to spend" |
| Having a dermatologist within the multidisciplinary team enabled the efficient and effective care of GvHD (de Vere Hunt et al., 2021) | "I think that the [hospital] has been good in terms of having, you know, a dermatologist on the team." |
| | "The once that I asked to see a dermatologist I was able to see her that same day, so that was reassuring." |
| Several participants reported a lack of communication between their clinicians, GPs and the emergency departments they attended. Participants often had to advocate for themselves as GPs and emergency departments were not aware of the special needs of HSCT recipients. Calls for better information exchange and GP education. (Parisek et al., 2021) | "Involving the patient's GP [=is important]. They should set aside an hour or two between the GP and the specialist. The GP is the extended arm [=of the specialist]. Aren't they? This would not cost a lot… that they know exactly what they are doing" |
| Patients reported being left out of a system that concentrated on patients currently undergoing treatment, rather than for patients dealing with long-term complications following treatment (Hwang et al., 2012) | "I'll call cancer care and I'll Google the cancer patient resources. There is help, but only for people in treatment. It's like they've forgotten the people after they've survived" |

**Appendix 23: Study 1 Synthesised Theme 3: First- and second-order constructs**

| **Synthesised theme 3: "Small print after the event and the broad brushstrokes before-hand"** | |
|---|---|
| Primary the author(s) interpretations of the original findings | Examples of the direct participant quotes |
| Participants reported that clinicians had informed them at a HSCT was difficult and time-consuming. However, surprised and, for some, shocked at the degree and intensity of side-effects and the impact it had on their lives. A significant number of patients only realised after transplant that it would not provide a quick cure, and that the period after was a crucial and burdensome part of the journey to recovery (Parisek et al., 2021) | I have to admit, I did not expect the treatment complications.<br><br>And that was a totally new experience to acknowledge or to learn to acknowledge that you are not cured but that the process of healing was continuing and that the time after the transplant was a very important time |
| Information provisions varied, some participants felt they received sufficient information, while others would have appreciated more. In the main, participants felt unprepared for GvHD, if being prepared was possible. While GvHD was discussed, information focused on the actual transplant procedure. While some appreciated this staged approach, others felt that they should have received more information as their perception was worse than their actual experience. (de Vere Hunt et al., 2021) | "So, the information I was given, the leaflet or booklet like GvHD, was very good and I read carefully, and if I don't understand or have a question, so I ask the doctor and things like that. So, didn't really much problem I had."<br><br>"I think I was a bit naive because I was... I had focused more on what could happen straight after the transplant...And I think I was just so pleased I'd completely forgotten about what could happen later, yeh. So, it was... it was a little bit of a shock... I think I was more told about what could happen straight afterwards. So, I was told the worst scenario is when I'd had... after I'd had the transplant, rather than what could happen further down the line, yeh. There was more focus on that."<br><br>"I think that it was certainly mentioned but not stressed, and I think that I probably had sufficient information. I think once I had had the transplant then interestingly, I was given the book; I think it's called Seven Steps or something, which is the Anthony Nolan guide, which goes into it into a lot detail. So, in some ways I feel a bit as though I was given the small print after the event and the broad brushstrokes before- hand" |

| | |
|---|---|
| | "I think maybe we could have had a little bit more of an explanation as to what it is and what causes it, and what was like the treatments that are about that we could have... that we would be given... I think we could have been given more information just as to what to expect, cos I was expecting, you know, like the ... I thought I was going to end up looking like, you know, blobs and lumps and bumps... In actual fact, it wasn't as bad as I thought it was going to be, but I really thought that I was going to look hideous...They told me everything that was going to happen to me when the stem cells went in, and they were right about that, but that little bit afterwards I think I could have maybe done with a little bit more information just to ... to sort of like put my mind at rest as to know what to expect because it was an unknown quantity." |
| Informational needs varied, some wanted to receive all available details of diagnosis, prognosis and treatment option. For other, they wanted minimal information to gain an understanding but not too much that it would scare them. (Parisek et al., 2021) | You get so much information that you cannot really understand what has just happened. The first information came like a landslide."<br><br>"It's a very personal thing [=information needs and preferences]. Everybody is different. Clearly there are things I need to know. But there are also things when I think, just leave them. I don't want to know. Yes, I would worry too much" |
| Participants sought more information regarding the range of potential late effects, and practical advice on how to mitigate them. For others, avoiding information assisted in reducing stress and fear that can be associated with knowing all the potential risks (Hwang et al., 2012) | '[I would] like information about ... life expectancy–I guess taking–like my medications, how many years can I take it without doing damage to my body'<br><br>'[S]ometimes, the less you know, the less you worry about' |
| Several participants report not adhering to and being overwhelmed by instructions and limitations. Clarifying the reasons for these limitations in priority order and providing implementation instructions were perceived as beneficial to increasing adherence to prescribed care. (Parisek et al., 2021) | "Maybe not just what you shouldn't do, but also an explanation why [=certain things should be done] would be good."<br><br>"I was looking for hours to find the right sunscreen and to check all the products, to understand the pros and cons and check the ingredients for those I should stay away from. Maybe you could improve that a bit by making sure you have a product to start with and then you can go and look for others to continue with." |

**Appendix 24: Study 1 Synthesised Theme 4: First- and second-order constructs**

| **Synthesised theme 4: "Once you have cancer, you're always thinking do I have it again"** | |
|---|---|
| Primary the author(s) interpretations of the original findings | Examples of the direct participant quotes |
| Survivors put more emphasis on managing their health following the transplant. They expressed a need to control their health as they were concerned about late complications. They became more vigilant about the importance of attending follow-up appointments and undergoing health screenings and tests (Sharin et al., 2020) | *After your transplant, when it's time to go for follow-up you go. It's important not to forget your appointment. When you are okay you still must continue with the treatment. When the doctor says six months, I say okay.* |
| Participants report frequent healthcare visits for screening for recurrences or second cancers. In general, patients felt they participated in adequate amounts of screening. While for a few, the fear of recurrence fuelled the notion that they might not be participating in enough. (Hwang et al., 2012) | *I feel very covered. I feel very safe in [how much] screening they do*<br>*If you did less [screening], you'll always have that in your head, [do] I have something? Once you have cancer, you're always thinking ...do I have it again* |
| Several patients emphasised the significance of physicians being cognisant of their communication methods and the reception of information. Several participants indicated that professionals verbalised their observations during examinations or while reviewing test results, sometimes conveying their conclusions without directly addressing patients or adapting the material to ensure it was comprehensible and less anxiety-inducing. As a result, survivors promptly perceived that an issue had arisen, leading to significant distress. (Parisek et al., 2021) | *The ultrasound image showed up something on my thyroid. And then they [= the treating clinician] say to you: 'Well, we'll definitely have to investigate that. You were getting radiation therapy, and some tumours can come back.' And my reaction was: danger, danger, danger!* |
| Due the nature of late complications being unpredictable, participants express feelings of certainty about their future and surviving HSCT is associated with managing threats of fear of recurrence and maintaining physical function. (Sharin et al., 2020) | *I am quite pessimistic. I feel like a relapse is inevitable. It is just a matter of time… It haunts me.* |

## Appendix 25: Journal of Cancer Survivorship

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# The lived experience of long-term follow-up clinical care for haematopoietic stem cell recipients in England: a qualitative exploration

**Blossom Bell**[1] · **Katherine Swainston**[1]

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## Abstract

**Purpose** Despite a haematopoietic stem cell transplant (HSCT) being a potentially curative treatment option for malignant and non-malignant disorders, patients may develop complex physical and psychological post-transplant complications. Consequently, transplant centres remain responsible for patients' life-long monitoring and screening practices. We sought to describe how HSCT survivors experience long-term follow-up (LTFU) monitoring clinics in England.

**Method** A qualitative approach was adopted with data collected from written accounts. Seventeen transplant recipients were recruited from across England, and the data was analysed using thematic analysis.

**Results** Data analysis elicited four themes: Transfer to LTFU care: 'will there be a change in my care, or will appointments just become less frequent?'; Care Coordination: 'it is good to know I am still in the system'; Relationship continuity: 'a good knowledge of me, my health and what is important to me'; and Late-effects Screening: 'there was not much information about what to expect or be aware of'.

**Conclusions** HSCT survivors in England experience uncertainty and lack of information regarding the transfer from acute to long-term care and clinic screening practices. However, patients gain reassurance from remaining on a healthcare pathway and maintaining relationships with healthcare professionals.

**Implications for cancer survivors** HSCT recipients entering LTFU monitoring clinics are a growing population of cancer survivors. Understanding and acknowledging this cohort of patients' needs may inform the development of tailored support to help patients navigate the complicated healthcare pathway.

**Keywords** Stem cell transplant · Patients' experiences · Long-term monitoring · Late effects

## Background

A haematopoietic stem cell transplant (HSCT) is a potentially curative treatment option for malignant and non-malignant haematological disorders, such as leukaemia, lymphoma, and hemoglobinopathies [1]. The standard procedure involves eradicating a patient's bone marrow cells (myeloablation) using high-dose chemotherapy, sometimes combined with radiotherapy (conditioning), and then intravenously reintroducing healthy haematopoietic stem cells to restore normal marrow cellularity. Replacement haematopoietic stem cells can either be obtained from the peripheral blood or bone marrow of the patient (autologous transplant) or a donor (allogeneic transplant). Donor haematopoietic stem cells can also be obtained from umbilical cord blood [2].

Despite being a high-cost and specialised procedure, the prevalence of HSCT procedures performed worldwide continues to rise [3]. In the United Kingdom (UK) alone, 3566 HSCTs were performed in 2020, a 63% increase compared to the number undertaken in 2000 [4]. This increase is attributed to advancements in immunogenetics and immunobiology, reduced intensity conditioning regimens, disease identification and clinical risk, and patient management [5, 6]. Furthermore, these attributes have contributed to decreased transplant-related mortality, especially in the early (day + 100) and intermediate (+ 1 year) post-transplant

✉ Blossom Bell
b.bell3@newcastle.ac.uk

Katherine Swainston
kate.swainston@newcastle.ac.uk

[1] Newcastle University, Newcastle Upon Tyne, UK

phase. However, for allogeneic recipients, mortality remains high decades post-HSCT, with life expectancy remaining below that of the general population [7, 8]. Survivors are at risk of developing late complications, such as secondary cancers, late infections, graft-versus-host disease (GvHD), and psychosocial issues, which can manifest months to years after HSCT [9]. The detrimental effect of post-transplant complications (i.e. late-effects) has consequently shifted focus to the health management and preventative practices of HSCT survivors by transplant centres and other health-care professionals [10].

In England, there are currently twenty-eight designated centres providing HSCT, which the National Health Service (NHS) England (i.e. the NHS lead in England) states must have accreditation in accordance with the Foundation for the Accreditation of Cellular Therapy and the Joint Accreditation Committee International Society for Cellular Therapy and European Society for Blood and Marrow Transplant Research standards [11]. Since 2015, the accreditation standards have specified that transplant centres must have policies or standard operating procedures for long-term follow-up (LTFU) care and monitor recipients for post-transplant late effects. As a minimum, either directly or coordinated with primary care providers, transplant centres are required to monitor recipients endocrine, reproductive and respiratory functions, cardiovascular risk factors, and renal impairment, as well as monitor for signs of osteoporosis and secondary cancers [12]. To assist with the management of LTFU patients' needs and optimise efficiency as recipients transition from the acute post-transplant phase to LTFU care, the standards recommend the establishment of dedicated clinics and endorse specific sources of reference when establishing clinical guidelines, including the international guidance on recommended screening and preventative practices for long-term HSCT survivors and the integration of these guidelines into clinical practice [13, 14].

Despite the acknowledgement that the efficiency of the transition from acute post-transplant care to LTFU care is essential to the quality of care received and that a multi-disciplinary approach to care should be employed [15], the provisions for LTFU care for HSCT patients are known to be variable [16, 17]. In the UK, there is a dearth of research examining the implementation of LTFU provisions, with only one study being identified. Twenty-five allogeneic transplant centres in the UK, of which 21 were in England, responded to a 2019 web-based survey examining service organisation, access to specialist services, including screening and vaccination, and team and patient engagement of LTFU provisions [18]. Twenty-one (84%) transplant centres had developed a dedicated LTFU clinic, whilst one centre referred recipients to general haematology outpatients for monitoring, another had no formal LTFU clinic, and two centres failed to answer the question. A hybrid approach, between primary or secondary care providers and transplant centres, to LTFU care was adopted by 44% of centres. Monitoring is evidently taking place; however, deficiencies exist, including limited access to services, biased screening activities limited to within transplant physicians' control, and lack of psychological support. Insufficient financial resources, different healthcare structures, and transplant centres specific interests in LTFU were reported as possible reasons for the deficiencies. Further research correlating LTFU services with patient-reported outcomes was recommended as one potential solution to addressing current deficiencies in services.

Literature observing the LTFU monitoring from recipients' perspectives post-2015 is limited, with only three qualitative studies identified [19–21]. All three studies found that recipients established close relationships with clinical personnel, which was seen as a crucial element to receiving personal and attentive care, as well as maintaining health. Furthermore, recipients identified several logistical problems with attending monitoring clinic appointments, such as delays, length, frequency, and financial consequences. Studies found that recipients reported a fear of recurrence and uncertainty of the future, feelings which were associated with monitoring practice. However, variation in country-specific and hospital healthcare structure does not allow for the findings to be generalised to HSCT recipients based in England. Furthermore, two studies recruited recipients from dedicated GvHD clinics; therefore, patients may be under active care resulting in more attendance requirements and heightened awareness.

At present, it remains unknown how HSCT survivors experience LTFU care within the NHS England care structure. This poses a barrier as it cannot be determined if transplant centres are adequately and effectively implementing long-term monitoring requirements from a recipient's perspective, especially considering the known deficiencies reported by transplant centres. Given the paucity of knowledge and lack of UK-based research since the 2015 accreditation change, this study aims to explore the experiences of LTFU care services from the perspective of HSCT recipients treated in centres based in England.

## Methods

### Design

A qualitative design underpinned by a phenomenological approach was adopted to understand the lived experiences of post-transplant LTFU clinical care for HSCT recipients. The philosophy of phenomenology reinforced the methodological principles, to transform through reflection

on the meaning, quality, and texture of participants' experiences [22]. This involved analysing participants' experiences from their perspective through their thoughts and feelings and identifying recurring themes across the data set. Open-ended written accounts of experiences were obtained online, a method chosen due to its ability to capture a 'wide-angle' spread and diversity of experiences within an unexplored population [23].

## Participants

Seventeen recipients (7 males, 10 females) of HSCT were recruited via purposive sampling from across England. Sample size guidelines suggest a range of between 15 and 50 qualitative written accounts for participant-generated textual data of life experiences. It was deemed on receipt of 17 written accounts that data saturation had been reached as no further themes were generated from the data [24]. The inclusion criteria were that participants were at least 18 years of age at the time of data collection and at least 1-year post-transplant to ensure the long-term monitoring phase of treatment had been reached. Participants' age at transplant ranged from 3 to 65 years (mean age 44.64 years), and the average time since transplant was 8.24 years (range 1.16–33.58 years) (see Table 1). Thirteen participants received LTFU care from a designated LTFU clinic, two attended general haematology outpatient's department for LTFU, whilst a further two received a hybrid approach where LTFU care is provided by both a designated LTFU clinic and primary care providers. Of the seventeen participants, fifteen received LTFU care at the same hospital as their transplant, eight of which were reported as being their local hospital. Two participants receive LTFU at a different hospital from where they had their transplant; for one, this was their local hospital. In total eight participants did not receive LTFU care at their local hospital and must travel to attend, a distance which ranged from 5.5 to 70 miles one way (mean distance of 34.4 miles). The interval between LTFU appointments at the time of data collection ranged from once every 4 weeks to once every 5 years (mean time once every 9 months).

## Materials

Materials comprised a participant information sheet, consent form, instruction sheet, and debrief. The written account document comprised one open-ended question: 'Please tell me about your experiences of attending designated long-term late-effects monitoring appointments following stem cell transplantation'. Further instruction was provided as suggestions for areas of reflection: 'You may want to consider areas such as: how and when you entered long-term monitoring; details of appointment

**Table 1** Participant characteristics

| Participant number | Gender | Age at transplant | Transplant type | Time since transplant (years) | LTFU monitoring frequency | LTFU care model | LTFU at same hospital as transplant |
|---|---|---|---|---|---|---|---|
| 1 | Male | 55 | Allo PBS | 8.3 | Yearly | Clinic | Yes |
| 2 | Female | 60 | Allo PBS | 2.8 | 3 monthly | Hybrid | Yes |
| 3 | Female | 50 | Allo PBS | 2.7 | 6 monthly | Clinic | Yes |
| 4 | Female | 28 | Allo BMT | 27.1 | 5 Yearly | Clinic | Yes |
| 5 | Male | 43 | Allo BMT | 6.4 | 8 weekly | Clinic | Yes |
| 6 | Male | 63 | Allo PBS | 4.4 | 6 monthly | Clinic | Yes |
| 7 | Female | 61 | Allo BMT | 3.7 | 3 monthly | Haem OP | Yes |
| 8 | Male | 49 | Allo BMT | 4.8 | Yearly | Clinic | Yes |
| 9 | Male | 65 | Hap SCT | 1.2 | 8 weekly | Clinic | Yes |
| 10 | Female | 42 | Allo BMT | 10.1 | 3 monthly | Clinic | Yes |
| 11 | Female | 3 | Auto BMT | 33.6 | Yearly | Clinic | No |
| 12 | Male | 50 | Hap SCT* | 10.9 | 2 yearly | Clinic | Yes |
| 13 | Female | 34 | Allo PBS | 1.6 | 2 monthly | Hybrid | Yes |
| 14 | Female | 54 | Allo BMT | 1.1 | 4 weekly | Clinic | Yes |
| 15 | Female | 31 | Allo PBS | 2.7 | 3 monthly | Clinic | Yes |
| 16 | Male | 25 | Auto BMT* | 10.8 | Yearly | Clinic | Yes |
| 17 | Female | 46 | Allo PBS | 7.8 | Yearly | Haem OP | No |

*multiple transplants with the last type received indicated; *Allo PBS*, allogeneic peripheral blood stem cell transplant; *Allo BMT*, allogeneic bone marrow transplant; *Hap SCT*, haploidentical stem cell transplant; *Auto BMT*, autologous bone marrow transplant; *Clinic*, designated LTFU clinic; *Hybrid*, coordinated care between LTFU clinic and primary care providers; *Haem OP*, haematology outpatients

arrangements; appointment objectives; feelings and thoughts prior to and after each appointment; services expectations; how you feel about the care you receive; advantages and disadvantages to health; any issues or concerns; benefits of attending; future expectations etc.'. Participants could amend/add to their accounts as many times as required prior to final submission. Demographic data, collected for the purposes of providing sample information only, included gender, type of HSCT, month and year of transplant, age at transplant, if LTFU appointments occurred at their local hospital, and if not, then how far they have to travel, whether LTFU occurred at the same hospital as their transplant, and how often then attend LTFU appointment.

### Procedure

Following ethical approval from Teesside University, the study materials were distributed via Jisc Survey Online (JSO). Two social media private group pages, one for survivors of HSCT and another for survivors of a condition often treated with HSCT, gave permission to post a recruitment advert for the study. In addition, a UK-based charity promoting stem cell donation advertised the study via their social media page. All adverts provided a link to JSO. On accessing the link, participants were initially provided with the participant information sheet and then the consent form. Once consent was given, participants were asked the demographic data questions followed by the open-ended question. Once written accounts had been submitted, all participants were provided with a debrief sheet which summarised the study and provided contact details for further support.

### Data analysis

The data were analysed using thematic analysis, chosen due to its flexibility and suitability to evaluate a wide range of data items, including textual data [25, 26]. The inductive approach allowed for the identification of themes and patterns and analysed. To ensure the themes adequately represented the data set, the researcher engaged in reviewing and defining the themes, ensuring the themes represent the coded data, the central theme, and the whole data set. It should be acknowledged that the lead researcher (BB) has direct experience with HSCT post-transplant and late-effects monitoring. A reflective journal was maintained throughout, and supervision was provided throughout the research process by KS. A second analysis of the data was undertaken by KS, and all members of the research team were involved in refining and naming themes.

## Findings

Four themes were drawn from the data analysis: transfer to LTFU care: 'will there be a change in my care, or will appointments just become less frequent?'; Care Coordination: 'it is good to know I am still in the system'; Relationship continuity: 'a good knowledge of me, my health and what is important to me'; and Late-effects Screening: 'there was not much information about what to expect or be aware of'.

### Theme 1: Transfer to LTFU care: 'will there be a change in my care, or will appointments just become less frequent?'

Participants' accounts described two different appointment practices: post-transplant and LTFU monitoring. Central to experiences was uncertainty surrounding the official transfer between follow-up and monitoring. Participants reported being unsure if transfer between monitoring practices would be acknowledged by receiving a change in care or implied through decreased frequency between appointments.

> [I] do not feel that I've officially entered 'long term' follow-up yet. I am not sure if this will be officially marked by a change in my care or whether my appointments will just become less frequent. (P13)

LTFU, for some participants, was stated or perceived to have commenced when they experienced a change in treatment needs.

> I had both transplants at [stated hospital] but unfortunately relapsed from both quite quickly, it was only a combination of [low-dose irradiation] [and] monoclonal antibody therapy [for chronic graft-versus-host disease] that I am in remission now. I only started long-term effects clinics about five years ago after the [chronic graft-versus-host disease] had finally settled down. (P16)

However, active treatment for post-transplant complications prevented clinical late-effects discussions from occurring, leading participants to question if any long-term monitoring had been received.

> I'm not sure that my long-term / late effect monitoring has happened… I had an early relapse and then another several years later… we didn't talk about late effects as there was still too much going on. (P10)

For others, LTFU monitoring appeared to have commenced when the clinical responsibility was transferred to another healthcare provider and/or when appointment frequency gradually decreased to annually.

> Not sure when long-term monitoring started… I was transferred by transplant hospital to a local hospital 4 years after the transplant and this obviously marked long-term follow-up as appts went to yearly. (P17)

The uncertainty participants described surrounding the official or perceived commencement of LTFU monitoring was mitigated by the acknowledgement of remaining within a healthcare pathway, regardless of the care mode employed.

### Theme 2: Care Coordination: 'it is good to know I am still in the system'

Participants described three different modes of care coordination, and whilst the experiences varied, generally, participants expressed gratitude for remaining within a healthcare pathway regardless of the mode of delivery and experienced less perceived anxiety.

> It is good to know I am 'still in the system' rather than being signed off as I think this would make me more anxious. (P3)

Most participants had LTFU care activities organised and executed by a specialist team within a designated transplant centre. Planned care activities included regular blood testing, medical referrals, and prescription distribution. Participants appreciated the multi-disciplinary approach for its efficiency and effectiveness.

> The transplant nurses and pharmacy assistants are always available in the clinic, and this makes the whole visit process work very smoothly as they can book anything and order drugs all on the same day. (P14)

Furthermore, the competency of service provided by the LTFU clinics removed general practitioner (GP) contact and involvement in post-transplant care.

> I have had little contact with my local GPs since most issues were dealt with by the haematology department, including long-term prescriptions. (P1)

However, the appointment structure influenced the participants' experiences. Participants reported tiresome waits between appointments, and whilst waiting was an accepted part of the process, it was exacerbated by travel requirements and work commitments, especially for participants attending clinic(s) not local to their residential location.

> Sometimes it can take a long time in the clinic – i.e., to have blood done and then have to wait to see the consultant, so that can be tiring, but it's a necessary evil. (P14)
>
> I find them very organised, but it is time-consuming - only on a Wednesday morning and generally takes the best part of the day [when including] travel. (P3)

For others, care activities were provided through a hybrid approach: transplant centres maintained the clinical responsibility by holding consultations remotely but relied on primary healthcare providers to carry out tests, especially in relation to blood tests, with participants only having to attend transplant centre for specialist tests. Participants found the approach convenient and flexible to their needs.

> [LTFU clinic] has liaised well with a more local hospital allowing me to have blood tests locally and have my consultations by phone when this is more convenient and I am able to request phone or face-to-face to suit me. (P13)

The approach became more frequent during the pandemic, which participants reported preferring as it removed stress associated with travelling to the hospital and reduced waiting times.

> Although the distance isn't horrendous, the journey is, and I find it stressful. But because of covid, most appointments are now video calls, which I prefer... All blood tests are now done at my doctor's surgery prior to video calls. (P2)

However, for some, the lack of physical attendance impacts health anxiety symptoms, and physically being seen was described as alleviating these symptoms.

> I have a lot of health anxiety, so attending these appointments is helpful in alleviating worries and I feel better having physically seen someone and been checked. (P15)

For another participant, the responsibility for LTFU healthcare needs was transferred to their primary care providers in its entirety. This transfer resulted in a loss of a specialist and a multi-disciplinary approach to care coordination, which impacted the participant's confidence regarding their future health and heightened their desire for specialist support via telephone or email, a service available to other participants. Having immediate and direct contact with clinical personnel was reported to be an essential supportive service, especially if enquiries were of a concerning or urgent nature and associated with receiving efficient and effective care.

> My confidence going forward in relation to my health is non-existent right now, which impacts my mental well-being…if there were support, telephone or email, with a post-transplant specialist, I would feel so much better as I would have that reassuring support when needed, but instead, I often end up quite unnecessarily unwell for much longer. (P17)
>
> I have access to a [clinical nurse specialist] by phone and email, which is absolutely essential to my feeling

of being looked after and knowing that I can contact somebody with any concerns. (P13)

Remaining within the post-transplant care pathway, regardless of the mode of delivery, was essential to participants' experiences and obtaining supporting needs: a pathway strengthened by a continuous relationship with healthcare providers.

### Theme 3: Relationship continuity: 'a good knowledge of me, my health and what is important to me'

Some participants experienced a continuous relationship with LTFU healthcare professionals that have developed over time and remained consistent. For some, this included a relationship with the same consultant that oversaw the transplant that had continued into LTFU care. This continuity was reported to be an essential component of receiving efficient and attentive care that was holistic in nature. Receiving this care combined with expert knowledge was reported to mitigate any inconvenience caused by attending.

I usually see my main consultant, who has seen me throughout my transplant process, and this is helpful as he has a good knowledge of me, my health and what is important to me. (P15)
I have developed a good relationship and rapport with the doctors I see in the clinic. They always impress me with their sensitive and intelligent approach to their patients…There is often a wait to be seen but that is no problem for such high-quality advice. (P1)

For other participants, a prolonged continuous relationship was established with clinical nurse specialists, rather than consultants, and contributed to participants receiving conscientious and attentive care whilst in appointment attendance.

I get seen by a specialist nurse whom I have known for a long time, they are very thorough, and I feel well looked after when I am there. (P16)

However, frequent and continuous relationships with clinical personnel prevented participants from seeking healthcare assistance from primary healthcare providers, specifically GPs. This reluctance is linked to a perceived notion that GPs have insufficient expertise to manage long-term monitoring requirements due to the complicated nature of late effects.

As I still speak to my team fairly regularly, I've found myself raising most medical issues with them and have not considered going to my GP for anything else… a stem cell transplant has so many potential effects that a GP might not be able to rule out transplant-related issues… So, the transplant team becomes like a surrogate GP. (P13)

Furthermore, liaising with GPs was stated as being futile as they would inadvertently liaise with the TC.

I'm very happy with the support I get from my [the clinical] team – They're friendly, helpful and responsive, and I would much rather talk to them than a GP as GPs don't have the experience and always end up calling the [hospital] anyway. (P7)

However, for one participant, the transfer of long-term monitoring responsibilities to their local and non-transplant hospital resulted in the loss of the continuous relationship previously experienced whilst under the care of the transplant team and expected to be adopted at the new centre. However, this absent relationship resulted in a loss of trust and feelings of abandonment, as well as contributed to the insufficient implementation of the long-term monitoring guidelines.

At my last [appointment] in the new hospital and the first [appointment] seeing a [new] consultant… he dismissed everything I said or asked about and I felt like he had belittled my experiences… The care that I received in my transplant hospital was on the whole good in the sense I was listened to, so I thought this would continue but feel that late effects clinics are just lip service or a tick box exercise. (P17)

### Theme 4: Late-effects Screening: 'there was not much information about what to expect or be aware of'

Patients reported a lack of preparation from hospitals regarding the time frame of recovery following the transplant.

I don't think the hospital really prepares you for how long the whole transplant recovery process can really take… but overall I think the care has been and still is very good. (P14)

Furthermore, participants reported uncertainty about the amount of information they received regarding the possible late effects or what participants could expect from attending monitoring appointments.

I don't think I was told about some of the possible late effects, and I don't think there was much information about what to expect or be aware of. (P10)

For some, the knowledge of late effects developed over time either due to the personal development of late-effect complications or because of the evolving list of recognised medical late effects.

> Having had my transplant [27 years] ago, I can say that over recent years more and more late effects have been noticed… When I first had my transplant, there weren't many recognised late effects apart from infertility and long-term graft-versus-host disease. (P4)

For others, late-effects knowledge developed from discussions with LTFU clinic personnel, which focused on specific age determined screening tests. However, participants report lack of confidence in clinics remembering to action the tests at the appropriate time age interval, resulting in participants being proactive in their care needs.

> I have not yet reached many of the 'milestones' at which specific late effects need to be monitored for, however these are mentioned from time to time and I try to write them down as I don't always feel confident that this will be remembered at the right time by my medical team. (P13)

In addition, participants report still waiting for screening tests discussed in clinic to occur or expressed difficulty in obtaining. This impacted participants' concerns in receiving potential future screening tests, especially if such tests are not considered life limiting.

> Some of the follow up discussed in the late effect clinic hasn't happened yet. (P10)
> I've had a difficult experience trying to get referred for a fertility assessment, which is distressing in itself but also makes me worry about other things I might need in the future, which aren't a matter of life and death but do affect quality of life greatly. (P13)

The need to take ownership of their own care needs for some participants was stated to occur due to the reported knowledge of the inconsistent approach to monitoring practices across centres. This included taking control of obtaining medical referrals to specialist clinics, underpinned by concerns regarding the impact of treatment on health.

> I have been proactive in getting myself referred to the [hospital] to a specific cardio-oncology service… I know now that people who are on the drug I went on are now routinely offered more monitoring at some hospitals, e.g. annual heart check, whereas I didn't have that kind of thing, so things maybe lay undetected for some time. (P10)

Furthermore, the unknown impact of treatment on future health was stated as contributing to pre-appointment anxiety for screening tests, intensified by waiting times.

> I'm on the waiting list for a bone scan and I'm a bit concerned about this because I don't know how good my bones are because of early menopause and cardiac complications. (P10)

Participants also reported experiencing pre-appointment anxiety prior to attending LTFU appointments due to concerns regarding post-transplant complications, specifically relapse. The anxiety experienced is enhanced by the pending examination of screening test and the scrutinisation of results.

> I still feel quite shellshocked several years after diagnosis and anxious in the lead-up to appointments [regarding] relapse. This anxiety is increased by… wondering what consultants and I should be looking out for in the blood results. (P3)

The limited knowledge of late-effects and participants' desire to take ownership and be proactive in post-transplant screening activities were described as warranting more support. Having written documentation identifying and detailing future monitoring and screening requirements was highlighted as a potential beneficial need.

## Discussion

The aim of this study was to explore haematopoietic stem cell transplant recipients' experiences of long-term follow-up monitoring across England. The themes generated from the patients' written accounts of their experiences were the uncertainty regarding the transfer to LTFU care, reassurance gained from remaining on a healthcare pathway, efficient and effective continuous relationships with healthcare professionals, and the lack of information and expectation surrounding late-effect screening practices. The findings are consistent with the results of previous studies that close personal relationships with clinics were essential to receiving personal and attentive care to maintain health and that for some patients fear of recurrence and uncertainty was associated with monitoring practices [19–21]. However, the patients' accounts depict the complexities, uncertainty, and psychological impact on HSCT recipients as they navigate the LTFU healthcare pathway to ensure continuity of care.

An important finding of this study is the lack of primary care providers, specifically GPs, involvement in LTFU care. Participants reported either not seeking GP involvement due to clinics meeting their health needs or a reluctance based on their perception that primary care providers do not possess the necessary experience and knowledge to monitor LTFU care efficiently. Regardless of the underlying cause, the lack of involvement of primary care providers in LTFU care may become problematic for transplant centres in the future, as the continued rise in the number of transplants performed annually, combined with transplant centres' responsibility to coordinate LTFU care and the more frequent use of a hybrid approach, may

increase pressures on services. It is, therefore, essential that primary care providers working within the hybrid approach have the necessary knowledge and expertise of the late effects that can arise after HSCT, which is essential in delivering efficient survivorship care [15] and merits further research. This is especially important considering the NHS Long Term Plan to incorporate a Personalised Stratified Follow-Up pathway within all cancer services, which aims to provide support closer to patients' residential locations, implying more ownership on primary care providers to provide LTFU care [27]. First, future research may consider exploring the current level of knowledge held by primary care providers and identifying potential educational and training needs, if required. As for recipients' perception of primary care providers, the present study design of written accounts did not allow for exploration within the data collective phase; therefore, further research in this area would be beneficial.

The findings of this study suggest that primary consultants are not discussing the transition process with HSCT survivors, given the ambiguity surrounding the official commencement of LTFU from acute post-transplant care for participants, as recommended in the guidance literature [13, 14]. This results in a loss of continuity of care for some patients; a direct contradiction to the accreditation standard's aims to prevent losing patients at follow-up [12]. To facilitate the transition from acute to LTFU care and to ensure continuity of care for patients, Hashmi et al. (2015) and Majhail et al. (2012) recommend providing patients with survivorship care plans. Such plans, like the treatment summary and survivorship care plan created by the American Society of Clinical Oncology [28], should define the roles and responsibilities of preventative care providers to optimise LTFU efficiency and serve as a reminder for consultants and patients of the appropriate surveillance practices tailored to individual risk factors. However, since patients in this study highlighted a need for written documentation identifying and detailing future monitoring and screening requirements suggests that such an instrument remains unavailable and worthy of further investigation. Future research may consider exploring the availability and content of survivorship care plans among a wider and demographic diverse sample of participants. Although this sample represented HSCT recipients, recruiting via online support groups limited the reach of participants to only those participating in social media, which may have resulted in a less demographically diverse and biased sample as recruiting participants online inadvertently excludes HSCT patients not actively engaged in online social media platforms [23, 29].

Survivorship care plans could also support the psychological impact some recipients in this study report experiencing from attending LTFU appointments. Attending appointments, receiving blood count results, and waiting for clinical tests have all been stated as a source of anxiety for some recipients, and it is largely the uncertainty surrounding each entity that gives rise to this anxiety. The lack of psychological support offered by clinics could be why recipients are experiencing this impact [18]. However, as patients report less anxiety when they have a low level of informational needs, patients should be encouraged to participate in their own long-term care since attitudes towards their illness, treatment, and health behaviours are an important factor [30]. There is little reference within the guidelines to the health behaviours of recipients and how health behaviour can assist with the monitoring services, especially regarding the promotion and maintenance of health. Further research in the area and the potential application of health promotion within survivorship care plans is warranted. However, the implications of highlighting long-term health after HSCT with a hypervigilant cohort of patients must be considered, and adequate support must be implemented to ensure no detriment to psychological well-being.

In addition to those previously stated, there are several limitations to this study. Firstly, whilst all care models were represented in the sample and data saturation was met at 17 participants, the study would have benefited from a larger sample size to convincingly demonstrate patterns across the data set, specifically the data provided by the haematology outpatients and hybrid care model group [24]. In addition, not all participants provided data regarding their demographic location, preventing the identification of any potential regional difference within the sample. Secondly, whilst utilising open-ended written accounts allowed recipients to express matters important to them whilst providing the researchers access to their language and terminology, reducing the potential of being lost in transcription [23], incorporating prompts may have limited the freedom of expression. Recipients may have felt required to answer the question rather than document their experiences as prioritised in their thoughts in full. Thirdly, the post-transplant care pathway is not uniform for all patients; the complexity of late effects means that there is potential that some recipients were still under active care when completing the written account. Finally, some participants received transplants prior to the 2015 accreditation change; therefore, there is no responsibility on transplant centres to monitor their LTFU care; consequently, some accounts may not reflect recipients' experiences transplanted post 1 June 2015.

In conclusion, based on the written accounts of HSCT patients included in this study, uncertainty regarding the transfer to LTFU care, reassurance gained from remaining on a healthcare pathway, efficient and effective continuous relationships with healthcare professionals, and the lack of information and expectation surrounding late-effect

screening practices summarises their experiences in long-term monitoring clinics in England. Opportunities exist to extend future research to understand the impact of each finding further and should focus on three key areas; (1) exploring primary care providers existing knowledge of late-effects and patients' experiences of using primary care providers for LTFU care, (2) the availability and content of survivorship care plans for HSCT recipients, and (3) exploration of recipients' health behaviours post-transplant and relationship with monitoring services, to gain a greater understanding of HSCT patient supports needs.

**Author contribution** All authors contributed to the study's conception and design. Material preparation and data collection and analysis were performed by Blossom Bell. Data analysis was performed by Blossom Bell and Dr Katherine Swainston. The first draft of the manuscript was written by Blossom Bell, and all authors commented on previous versions of the manuscript. All authors read and approved the final manuscript.

**Data availability** All data generated or analysed during this study are included in this published article.

## Declarations

**Ethics approval** Approval was granted by the Ethics Committee of Teesside University (21/06/2021 / Reference No: 6091).

**Consent to participate** Informed consent was obtained from all individual participants included in the study.

**Consent for publication** The authors affirm that all individual participants included in the study provided informed consent for publication.

**Competing interests** The authors declare no competing interests.

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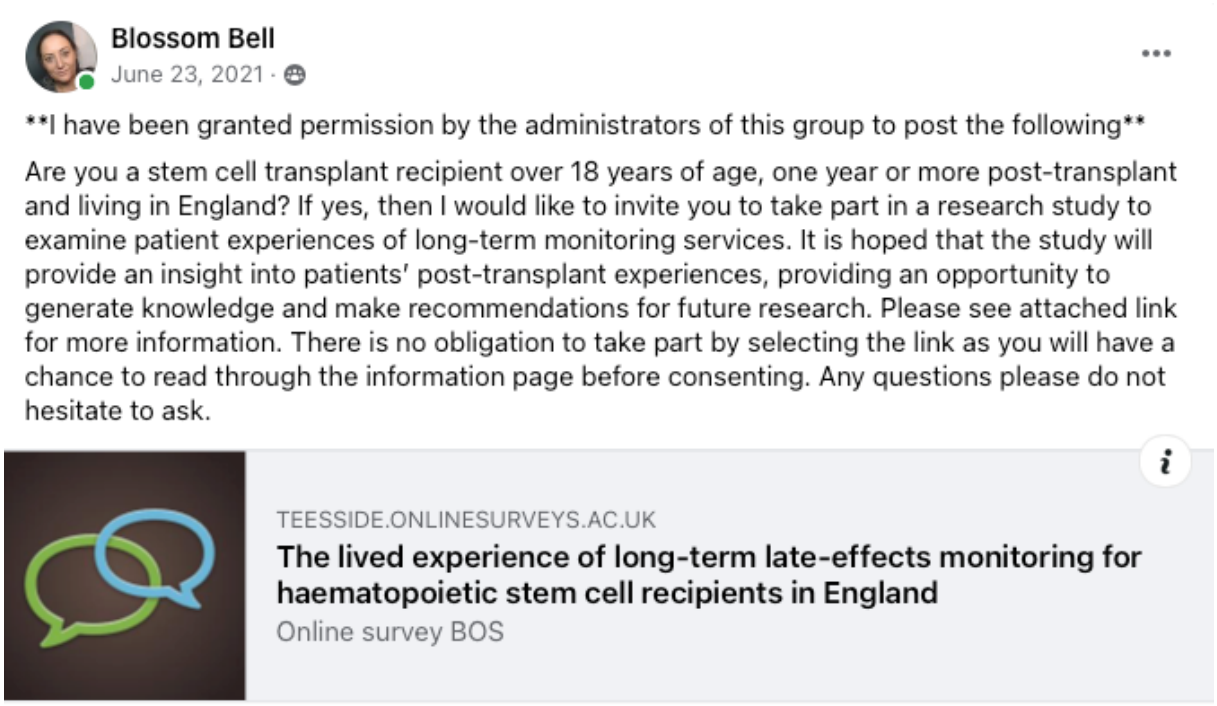
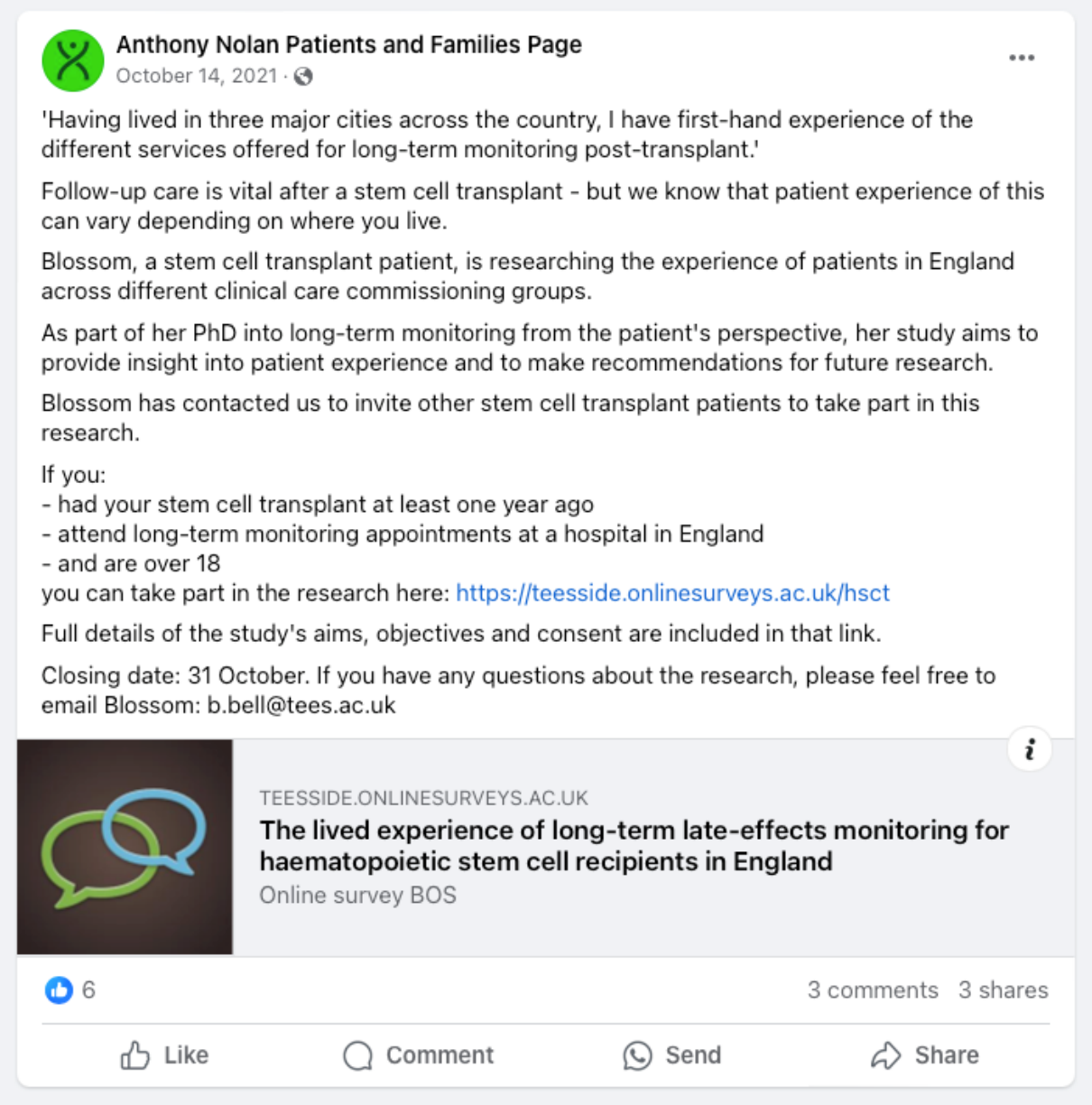
## Appendix 26: Study 2 Social Media Recruitment Notification



## Appendix 27: Charity Recruitment Advert Study 2.



## Appendix 28: Demographic / Transplant Details Study 2

5. What is your biological sex?

- ☐ Male
- ☐ Female
- ☐ Prefer not to say

6. What type of haematopoietic stem cell transplant did you receive? * *Required*

- ☐ Allogeneic bone marrow transplant
- ☐ Allogeneic peripheral blood stem cell transplant
- ☐ Autologous bone marrow transplant
- ☐ Autologous peripheral blood stem cell transplant
- ☐ Haploidentical stem cell transplant
- ☐ Not known
- ☐ Other

6.a. If you selected Other, please specify:

7. Month and Year of Transplant (MM/YY) * *Required*

8. Age at transplant, in years * *Required*

9. In relation to your home address, do you attend a designated long-term late-effects monitoring clinic at your local hospital? * *Required*

- ○ Yes
- ○ No

9.a. If No, how far (in miles) do to you have to travel to attend clinic?

10. Do you attend your long-term late-effects monitoring clinic appointments at the same hospital you received your transplant? * *Required*

- ○ Yes
- ○ No

11. How often do you attend long-term late-effects monitoring clinic appointments? * *Required*

- ○ Once every 3 months
- ○ Once every 6 months
- ○ Once a year
- ○ Once every 2 years
- ○ Other

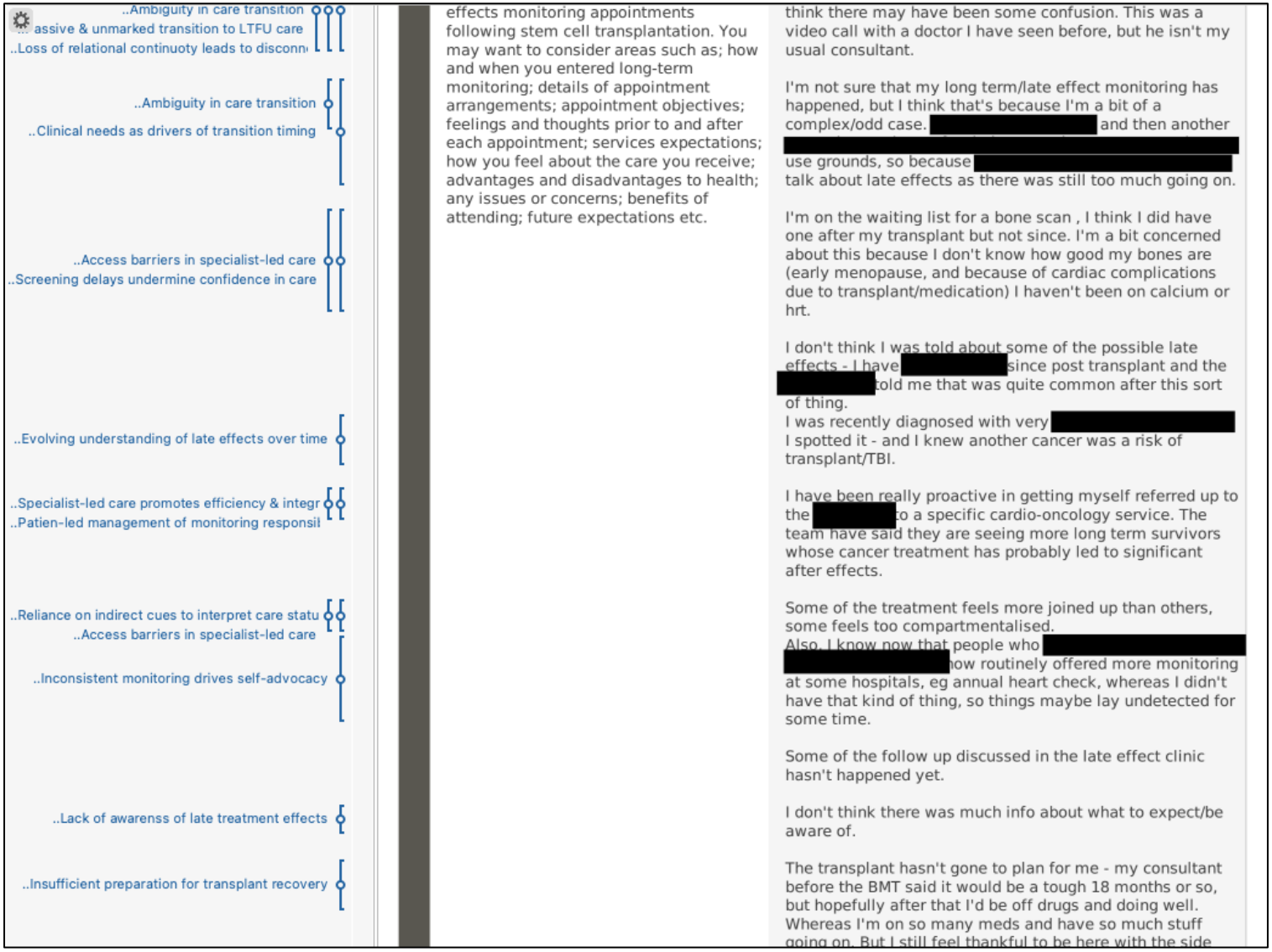
11.a. If you selected Other, please specify:

**Appendix 29: Main Research Question Study 2**

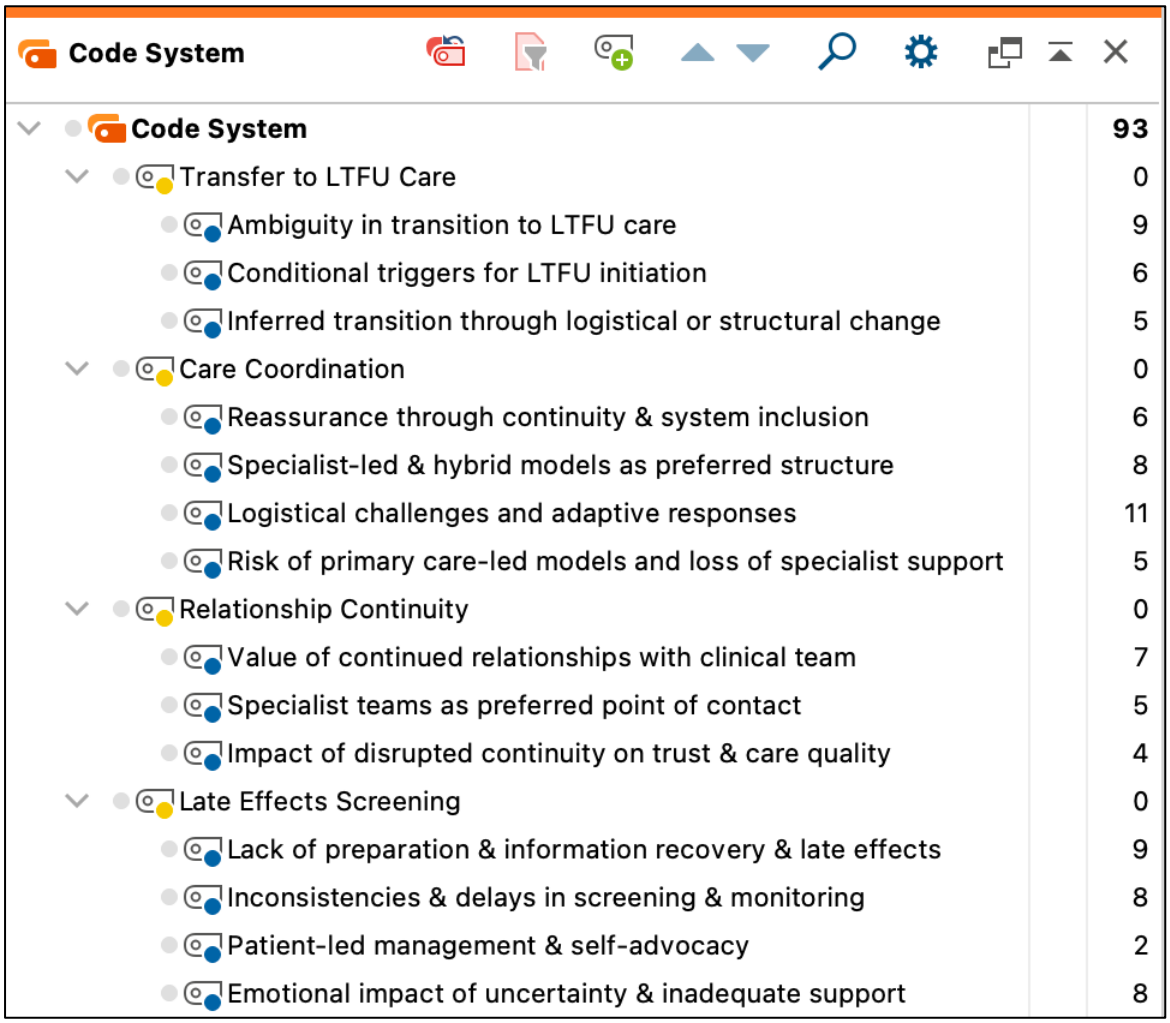
## Page 5: Page 5: Your Experiences

12. Please tell me about your experience of attending designated long-term late-effects monitoring appointments following stem cell transplantation. You may want to consider areas such as; *how and when you entered long-term monitoring; details of appointment arrangements; appointment objectives; feelings and thoughts prior to and after each appointment; services expectations; how you feel about the care you receive; advantages and disadvantages to health; any issues or concerns; benefits of attending; future expectations etc.* ✱ *Required*

## Appendix 30: Sample Coding Study 2



## Appendix 31: Final Themes and Codes, Study 2



**Appendix 32: Coding Matrix, Study 2, Theme 1**

| **Theme 1: Transfer to LTFU Care:** ***"Will there be a change in my care, or will appointments just become less frequent "*** | | | |
|---|---|---|---|
| | **Codes** | | |
| **Participant** | **Ambiguity in transition to LTFU** | **Conditional triggers for LTFU initiation** | **Inferred transition through logistical or structural change** |
| **1** | | | |
| **2** | ✓ | ✓ | |
| **3** | ✓ | | |
| **4** | ✓ | | ✓ |
| **5** | | | |
| **6** | ✓ | ✓ | |
| **7** | ✓ | | |
| **8** | | | |
| **9** | | | |
| **10** | ✓ | ✓ | ✓ |
| **11** | ✓ | | ✓ |
| **12** | | | |
| **13** | ✓ | | |
| **14** | ✓ | | |
| **15** | | | |
| **16** | | ✓ | |
| **17** | ✓ | ✓ | ✓ |

**Appendix 33: Coding Matrix, Study 2, Theme 2**

| **Theme 2: Care Coordination: *"It's good to know I am still in the system"*** | | | | |
|---|---|---|---|---|
| | **Codes** | | | |
| **Participant** | **Reassurance through continuity & system inclusion** | **Specialist-led & hybrid models as preferred structure** | **Logistical challenges and adaptive responses** | **Risk of primary care-led models & loss of specialist support** |
| **1** | ✓ | ✓ | | |
| **2** | | ✓ | ✓ | |
| **3** | ✓ | | ✓ | |
| **4** | ✓ | ✓ | | |
| **5** | | | | |
| **6** | | | | |
| **7** | | ✓ | ✓ | |
| **8** | | | ✓ | |
| **9** | | | ✓ | |
| **10** | | | | |
| **11** | ✓ | | | |
| **12** | | | | |
| **13** | ✓ | ✓ | ✓ | ✓ |
| **14** | ✓ | ✓ | ✓ | |
| **15** | | ✓ | ✓ | |
| **16** | | ✓ | ✓ | |
| **17** | | | | ✓ |

**Appendix 34: Coding Matrix, Study 2, Theme 3**

| **Theme 3: Relationship Continuity:** ***"A good knowledge of me, my health and what is important to me"*** | | | |
|---|---|---|---|
| | **Codes** | | |
| **Participant** | **Value of continued relationships with clinical team** | **Specialist teams as preferred point of contact** | **Impact of disrupted continuity of trust & care quality** |
| **1** | ✓ | | |
| **2** | | ✓ | |
| **3** | | | |
| **4** | | | |
| **5** | | | |
| **6** | | | |
| **7** | | ✓ | |
| **8** | | | |
| **9** | | | |
| **10** | | | |
| **11** | | | |
| **12** | | | |
| **13** | ✓ | ✓ | |
| **14** | ✓ | ✓ | |
| **15** | ✓ | | |
| **16** | ✓ | | |
| **17** | ✓ | | ✓ |

**Appendix 35: Coding Matrix, Study 2, Theme 4**

| Theme 4: Late Effects Screening: *"There was not much information about what to expect of be aware of"* | | | | |
|---|---|---|---|---|
| | Codes | | | |
| Participant | Lack of preparation & information on recovery & late effects | Inconsistencies & delays in screening & monitoring | Patient-led management & self-advocacy | Emotional impact of uncertainty & inadequate support |
| 1 | ✓ | | | |
| 2 | | | | |
| 3 | | | | ✓ |
| 4 | ✓ | | | |
| 5 | ✓ | | | ✓ |
| 6 | | | | |
| 7 | | ✓ | | |
| 8 | | | | |
| 9 | | | ✓ | |
| 10 | ✓ | ✓ | ✓ | ✓ |
| 11 | | | | |
| 12 | | ✓ | | |
| 13 | ✓ | ✓ | ✓ | ✓ |
| 14 | ✓ | | | ✓ |
| 15 | | | | |
| 16 | ✓ | | | |
| 17 | | ✓ | | ✓ |

## Appendix 36: Conference Oral Presentation Study 3

# O169 THE INFORMATIONAL NEEDS OF POST HAEMATOPOIETIC STEM CELL TRANSPLANT PATIENTS IN ENGLAND: A QUALITATIVE EXPLORATION

Blossom Bell[1], Kate Swainston[1]

[1]**Newcastle University, Newcastle upon Tyne, United Kingdom**

**Background:** Haematopoietic stem cell transplant (HSCT) recipients report experiencing a lack of informational awareness of the late effects and expectations of long-term follow-up care post transplantation. The aim of this research is to examine patients' goals and situational understanding to explore informational needs.

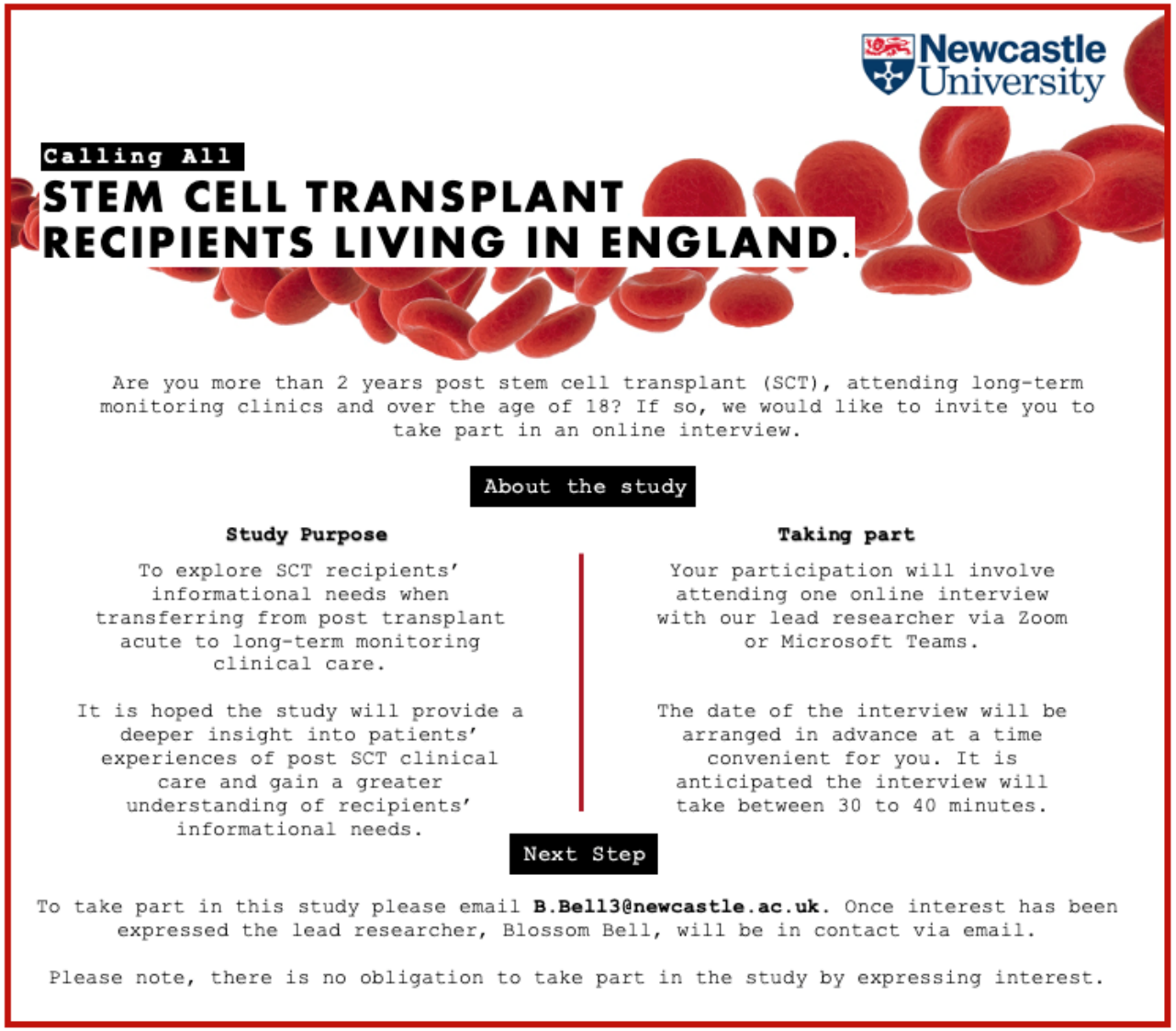
**Methods:** A qualitative study of twelve semistructed individual online interviews conducted between May to December 2023. The data was analysed using thematic analysis.

**Results:** Data analysis elicited three main themes and two sub-themes; (1) Preparation: *like to know what I'm up against;* (2) Timing: *that's all in the future* and (3) Information Source: (a) *gave us a booklet and not much else;* and (b) *I got on the computer, and I learnt*. Preparation in the knowledge of potential long-term late-effects and monitoring requirements relates to patients' perceived ability to manage any future potential complications. However, patients' ability to retain this information should be considered and where possible kept separate to transplant related information. Too much information at one time leads to patients being overwhelmed and important future information being dismissed and/or forgotten, especially if the information is delivered verbally. Where booklets have been provided patients report insufficient content leading to seeking alternative sources of information. Such additional informational sources include participating in online patient support groups, which some find beneficial to their learning, for others it is anxiety provoking.

**Conclusions:** This research highlights that patient's need for information is driven by a desire to feel prepared for all the potential long-term late-effects and monitoring needs. To provide a service that is personalised in its approached, health professionals must consider all patients information goals and not assume a one standard approach is sufficient for everyone.

**Disclosure:** Nothing to declare.

**Appendix 37: Participant recruitment poster Study 3**



## Appendix 38: Anthony Nolan Recruitment Study 3

**Anthony Nolan Patients and Families Page**
May 15, 2023 ·

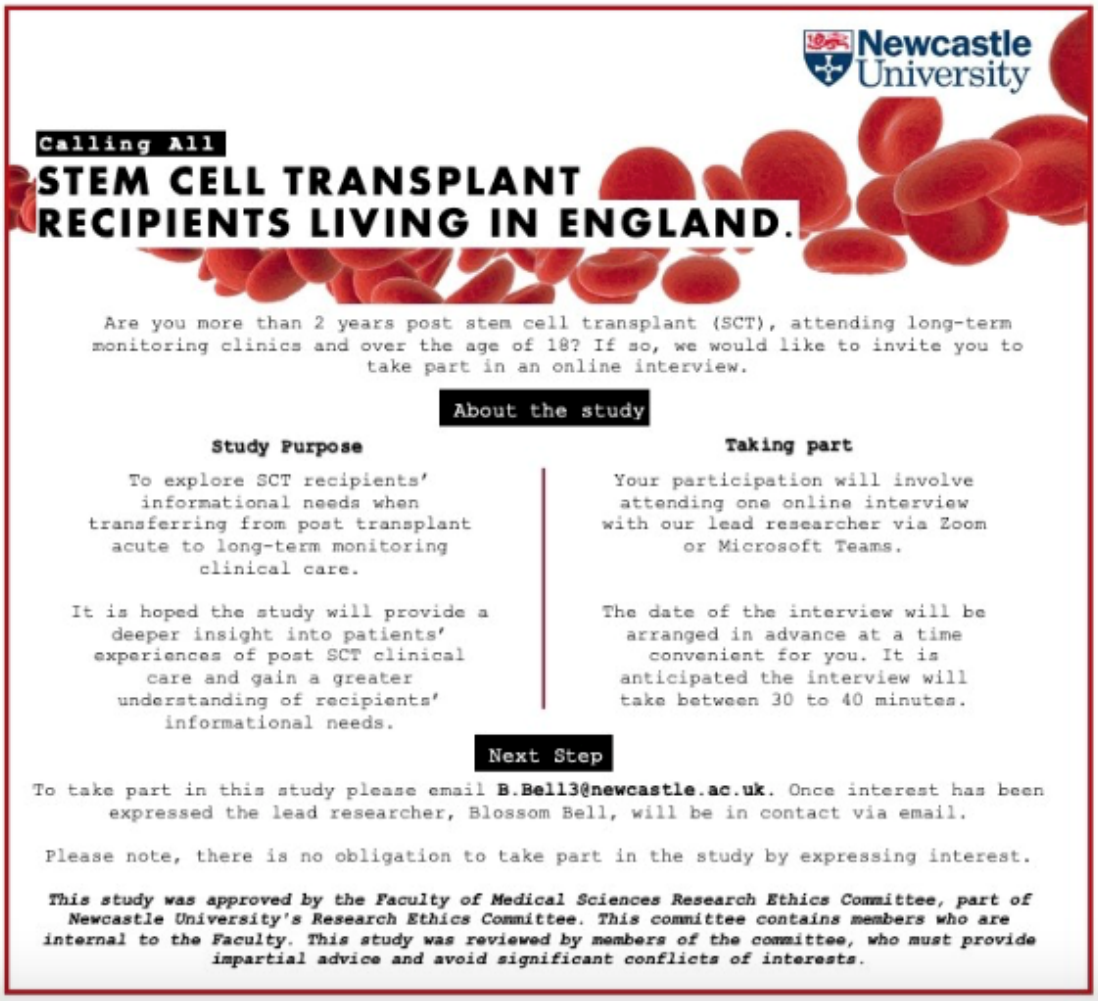
Back in Oct 2021, Anthony Nolan assisted Blossom, a stem cell transplant patient, in inviting other stem cell transplant patients to take part in a research study as part of her PhD into long-term monitoring from the patient's perspective.

Once again, Blossom has contacted Anthony Nolan to invite other stem cell transplants to take part in a second research study exploring patients' informational needs as they transfer from acute post-transplant care to long-term follow-up care. The study aims to provide a deeper insight into patients' experiences of post-HSCT clinical care, better understand recipients' needs, and enhance the ability to make recommendations for future research and health interventions.

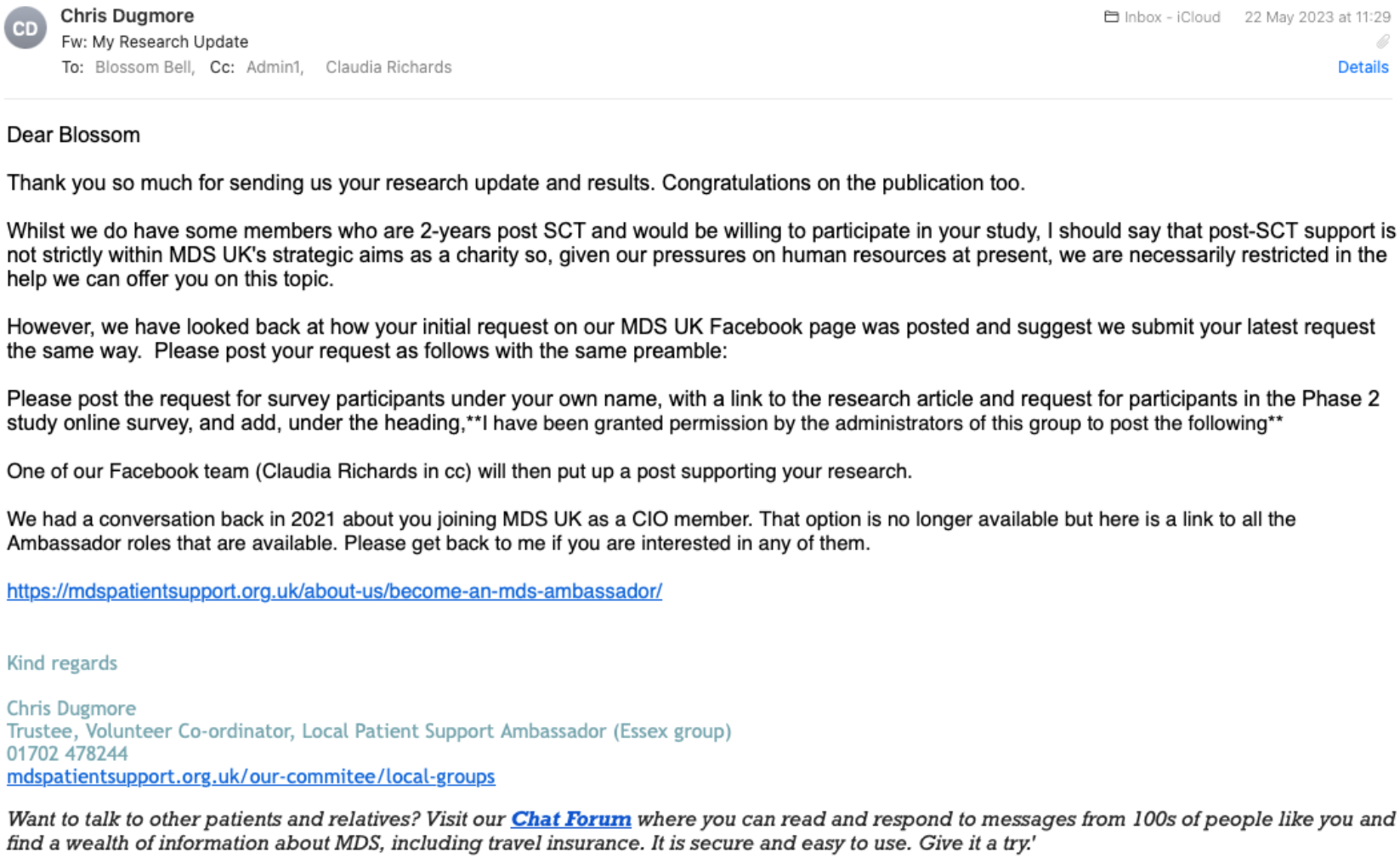
If you:
- had a stem cell transplant before June 2021
- have attended at least one long-term monitoring appointment at a hospital in England
- and are over the age of 18

You can take part in the research by contacting Blossom directly at b.bell3@newcastle.ac.uk. Your participation will involve attending one online interview with Blossom via Zoom or Microsoft Teams.

For more information about late effects after a stem cell transplant please visit our webpage: https://www.anthonynolan.org/.../late-effects-after-a...



## Appendix 39: Recruitment Advert Permission Study 3



**Chris Dugmore**
Fw: My Research Update
To: Blossom Bell, Cc: Admin1, Claudia Richards

Inbox - iCloud 22 May 2023 at 11:29
Details

Dear Blossom

Thank you so much for sending us your research update and results. Congratulations on the publication too.

Whilst we do have some members who are 2-years post SCT and would be willing to participate in your study, I should say that post-SCT support is not strictly within MDS UK's strategic aims as a charity so, given our pressures on human resources at present, we are necessarily restricted in the help we can offer you on this topic.

However, we have looked back at how your initial request on our MDS UK Facebook page was posted and suggest we submit your latest request the same way. Please post your request as follows with the same preamble:

Please post the request for survey participants under your own name, with a link to the research article and request for participants in the Phase 2 study online survey, and add, under the heading,**I have been granted permission by the administrators of this group to post the following**

One of our Facebook team (Claudia Richards in cc) will then put up a post supporting your research.

We had a conversation back in 2021 about you joining MDS UK as a CIO member. That option is no longer available but here is a link to all the Ambassador roles that are available. Please get back to me if you are interested in any of them.

https://mdspatientsupport.org.uk/about-us/become-an-mds-ambassador/

Kind regards

Chris Dugmore
Trustee, Volunteer Co-ordinator, Local Patient Support Ambassador (Essex group)
01702 478244
mdspatientsupport.org.uk/our-commitee/local-groups

*Want to talk to other patients and relatives? Visit our **Chat Forum** where you can read and respond to messages from 100s of people like you and find a wealth of information about MDS, including travel insurance. It is secure and easy to use. Give it a try.'*

## Appendix 40: MDS UK Patient Support Group Community Page Post Study 3

(For poster image see Appendix 37)

**MDS UK Community**

Blossom Bell · Admin · 1 June 2023 ·

**** I have been granted permission by the administrators of this group to post the following****

Hi all, quick introduction to myself for new members. I was diagnosed with MDS in 1991 and had a bone marrow transplant in 1992. I am currently studying towards a PhD researching patients' experiences of long-term follow-up care post stem cell transplantation.

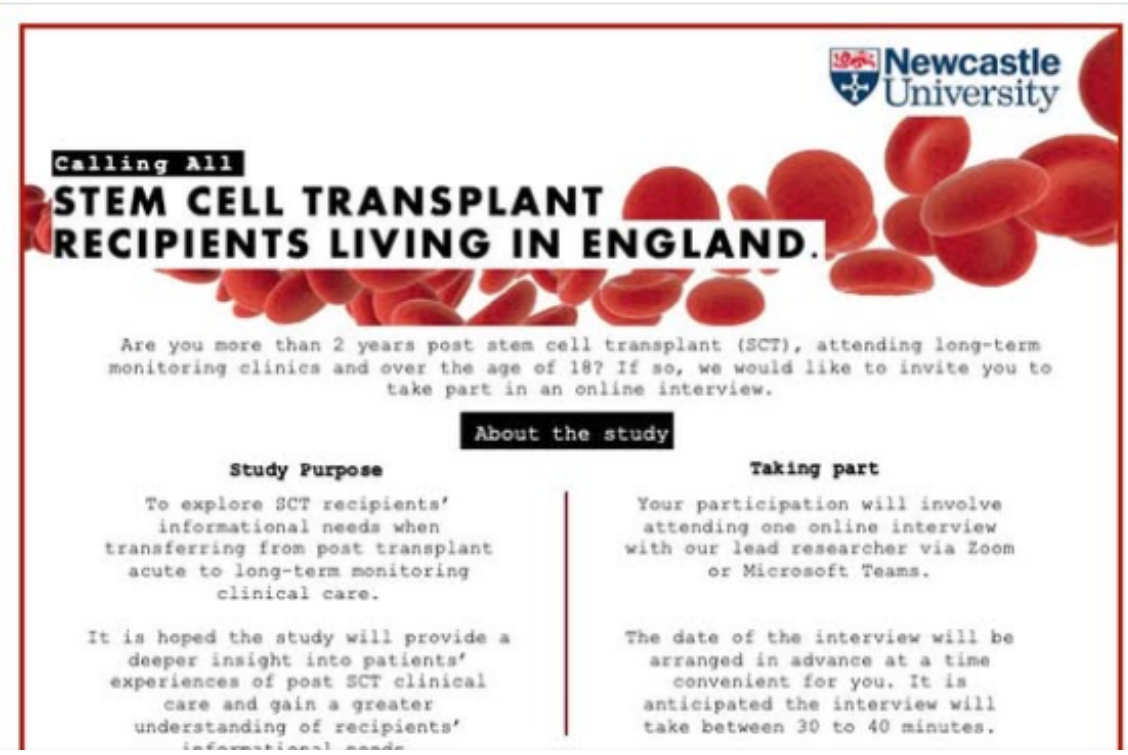
You may recall back in Oct 2021 that I asked participants of this group to consider participating in the first stage of my research. Well, I am pleased to announce that this research has since been published in the Journal of Cancer Survivorship – thank you to everyone who took part. Link to the research article below.

https://link.springer.com/article/10.1007/s11764-023-01399-w

As I now move onto stage 2 of my research, I would like to ask members of this group who received a stem cell transplant more than 2 years ago to consider participating in the next set of data collection.

I am exploring the informational needs of patients as they transfer from acute post-transplant clinical care to long-term monitoring care. Your participation will involve attending one online interview with me via Zoom or Microsoft Teams. See the advert below for more information.

Thanks again for your time in reading this post. If you have any questions, please do not hesitate to contact me either by posting a question below or emailing me at b.bell3@newcastle.ac.uk



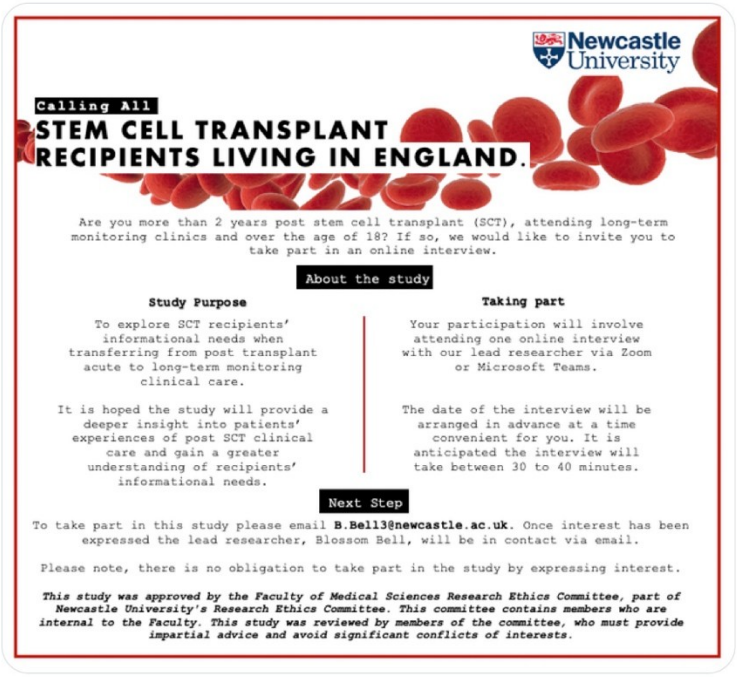
**Appendix 41: Instagram Private Page Advert Study 3**

Note. Account handle was changed from @afterstemcell to @HSCTUK since the commencement of the study.

**Appendix 42: 'X' (formally known as Twitter) Private Page Advert Study 3**

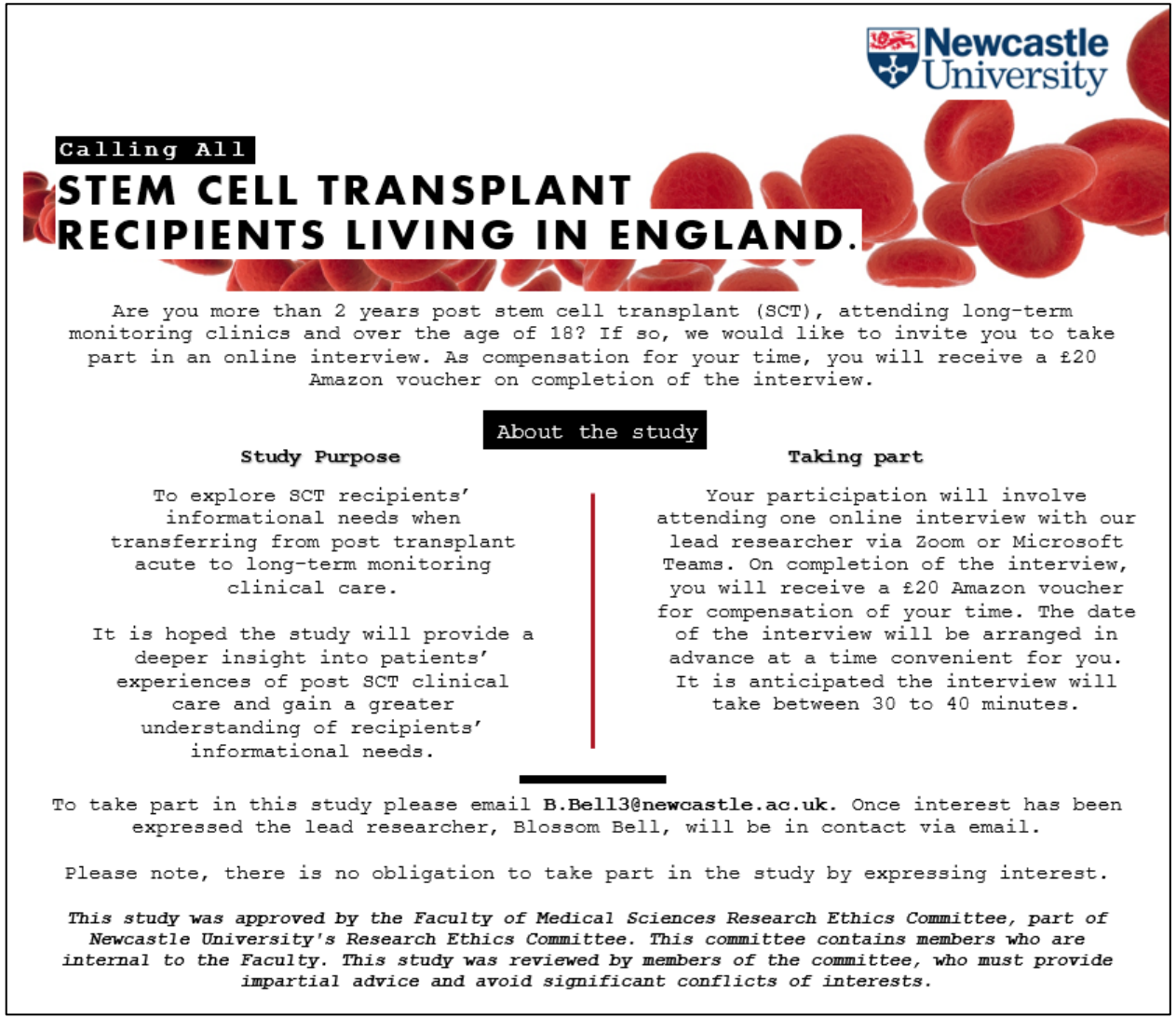
**After Stem Cell Transplant...** · 02/05/2023 ···

Are you a stem cell transplant recipient living in England? If so, please consider taking part in this research. Email b.bell3@newcastle.ac.uk for more information. #stemcelltransplant #HSCT #livingaftercancer #stemcell




1 43

**Appendix 43: Amended Recruitment Poster and Instagram Second Post Study 3**



Newcastle University

Calling All

# STEM CELL TRANSPLANT RECIPIENTS LIVING IN ENGLAND.

Are you more than 2 years post stem cell transplant (SCT), attending long-term monitoring clinics and over the age of 18? If so, we would like to invite you to take part in an online interview. As compensation for your time, you will receive a £20 Amazon voucher on completion of the interview.

## About the study

**Study Purpose**

To explore SCT recipients' informational needs when transferring from post transplant acute to long-term monitoring clinical care.

It is hoped the study will provide a deeper insight into patients' experiences of post SCT clinical care and gain a greater understanding of recipients' informational needs.

**Taking part**

Your participation will involve attending one online interview with our lead researcher via Zoom or Microsoft Teams. On completion of the interview, you will receive a £20 Amazon voucher for compensation of your time. The date of the interview will be arranged in advance at a time convenient for you. It is anticipated the interview will take between 30 to 40 minutes.

To take part in this study please email **B.Bell3@newcastle.ac.uk.** Once interest has been expressed the lead researcher, Blossom Bell, will be in contact via email.

Please note, there is no obligation to take part in the study by expressing interest.

***This study was approved by the Faculty of Medical Sciences Research Ethics Committee, part of Newcastle University's Research Ethics Committee. This committee contains members who are internal to the Faculty. This study was reviewed by members of the committee, who must provide impartial advice and avoid significant conflicts of interests.***


hsctuk

hsctuk I am posting this again in the hope that my followers who have had a stem cell transplant would consider participating in the second stage of my data collection for my PhD research into patients' experiences of long-term post-transplant monitoring.
*
I am primarily seeking to find out what sort of information patients received regarding long-term follow-up care.
*
I hope to use the information gained to design an information package that is targeted at patients' needs.
*
If you have received your transplant prior to 31st Oct 2021 then please consider taking part. It involves attending one online interview via Zoom on a day/time convenient to you - this includes in the evening or at weekends if required.
*
For more information please DM me your email address or email me directly at B.Bell3@newcastle.ac.uk and I will forward you more information.
*

106 w

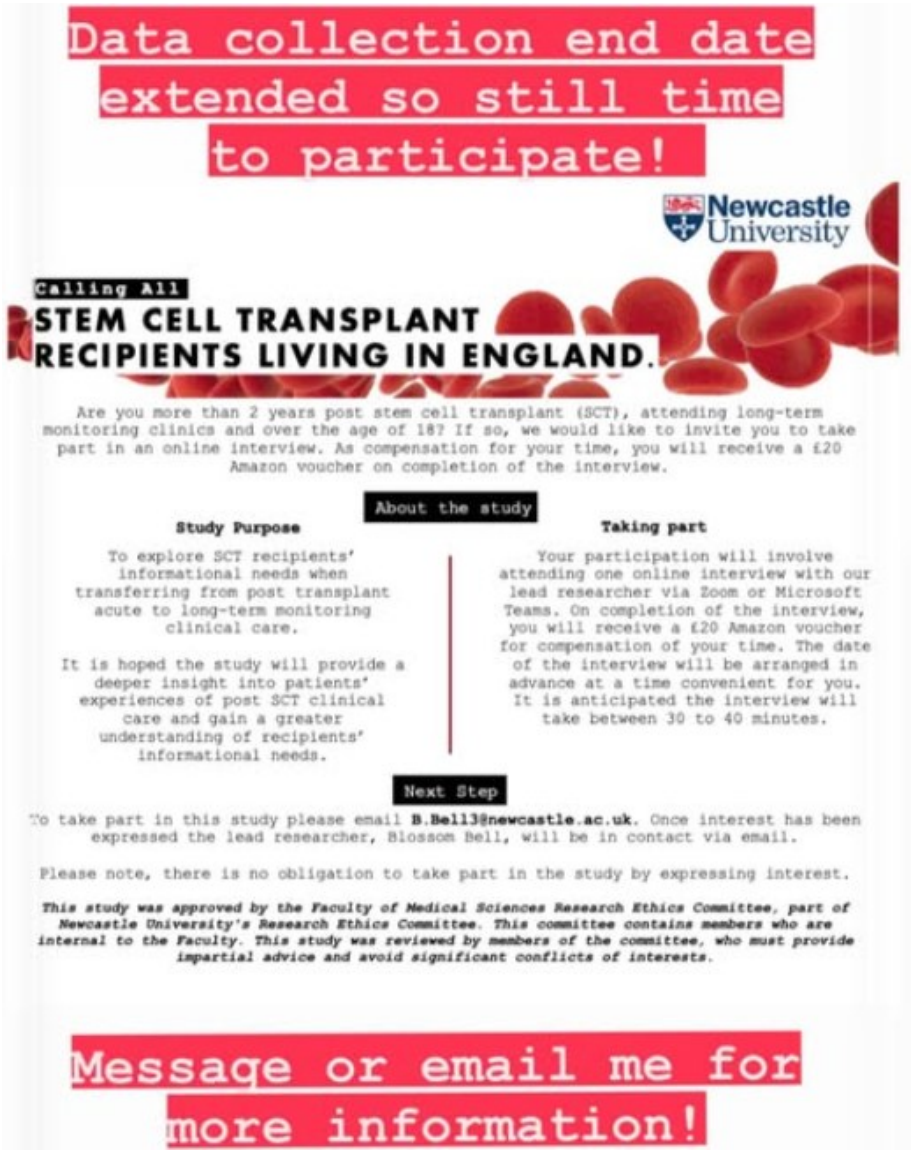
View Insights  Boost Post

1 like
15 August 2023

Add a comment...  Post

## Appendix 44: Instagram Third Post Study 3

Poster details remains that of Appendix 43.



## Appendix 45: Interview Schedule Study 3

**Interview Schedule**

**Title: The informational needs of patients transferring from post haematopoietic stem cell transplant acute care to long term monitoring clinical care in England: a qualitative exploration.**

**Researcher:** Blossom Bell
**Research Supervisor:** Dr Kate Swainston

**Introduction**

- Introduce researcher
  - Own transplant back in 1992
  - Having lived in multiple cities in the UK, I experienced multiple levels of post stem cell transplant care & GP awareness
  - Researching SCT patients experiences since 2016
  - Keen to get voices heard - PhD
- Explain aim of this second set of data research
  - To explore patients informational needs when transferring from post transplant acute to long-term monitoring clinical care.
  - It is hoped the study will provide a deeper insight into patients' experiences of post SCT clinical care and gain a greater understanding of recipients' informational needs.
- Remind participants of their right to withdraw or not answer any questions
  - 31st Oct 2023
- Confirm consent to participate
  - I confirm I have received your consent to participate, are you happy to continue?

**Interview**

1. **To start with, can you provide me with a brief overview / timeline from when you had your transplant to entering long-term follow care?**
   i. **Type of transplant,**
   ii. **Hospital – was it your local?**
   iii. **When did you have your transplant?**
   iv. **Age at transplant?**
   v. **What stage did you enter long-term care?**

2. **How did you know that you had transitioned from acute post-transplant care to long-term monitoring?**
   - If formally told, how did that make you feel?
   - If not formally informed, how did this impact you?

3. **When were you first made aware of the long-term monitoring care process?**
   - How were you informed?

4. **Can you tell me what that period of transition from acute to long-term follow-up was like for you?**
   - What do you think contributed to those feelings?

5. **How did you know that you had transitioned from acute post-transplant care to long-term monitoring?**
   - If formally told, how did that make you feel?
   - If not formally informed, how did this impact you?

6. **What information/support, if any, did you receive during this transitional stage?**
   - What would you have liked to have received?
   - Any suggestions on content and delivery?
   - Do you feel you received the information at the right time? If not, when do you think is an appropriate time

7. **Is there any further additional information/support that you received after the transitional stage?**

8. **What advice would you give to other recipients starting out on the transplant journey regarding long-term follow-up care?**

9. **Is there anything else you would like to add?**

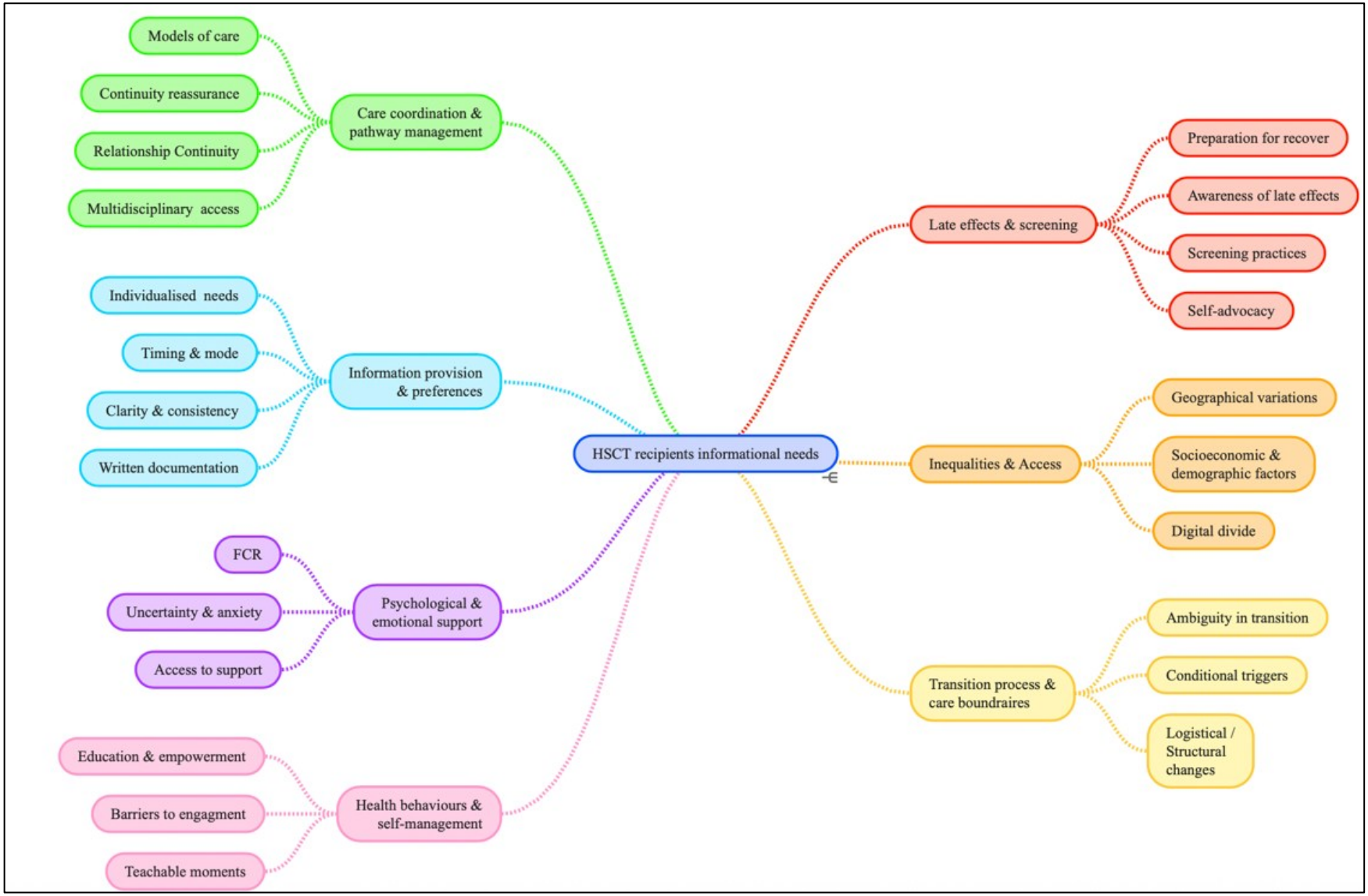
**Prompt questions**

- Can you tell me a little more about that?
- Can you give me an example of this?
- Can you tell me how that impacted you?
- Was there anything else you felt/experienced?

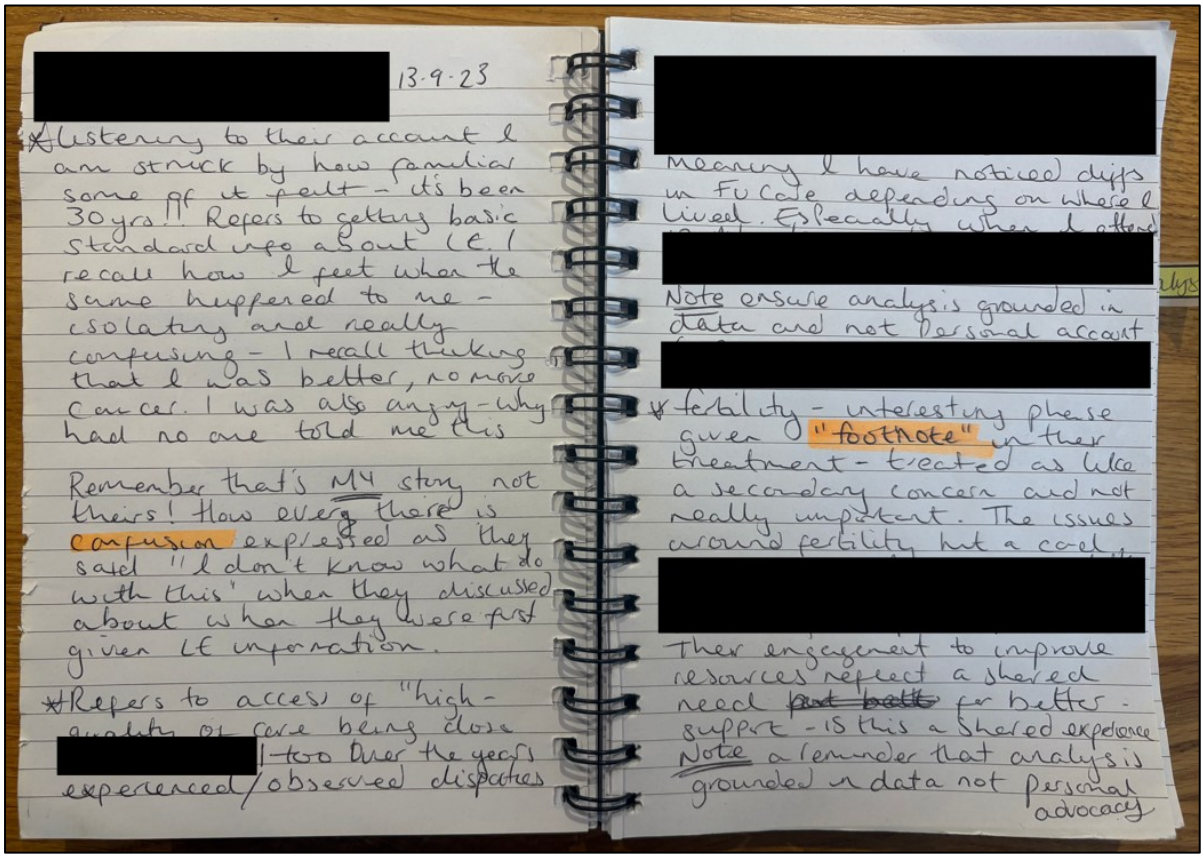
**Debrief**

- Verbal debrief (followed up with written debrief in an email)
- Thank participants for their time
- Remind participants of their right to withdraw and reiterate withdrawal process.

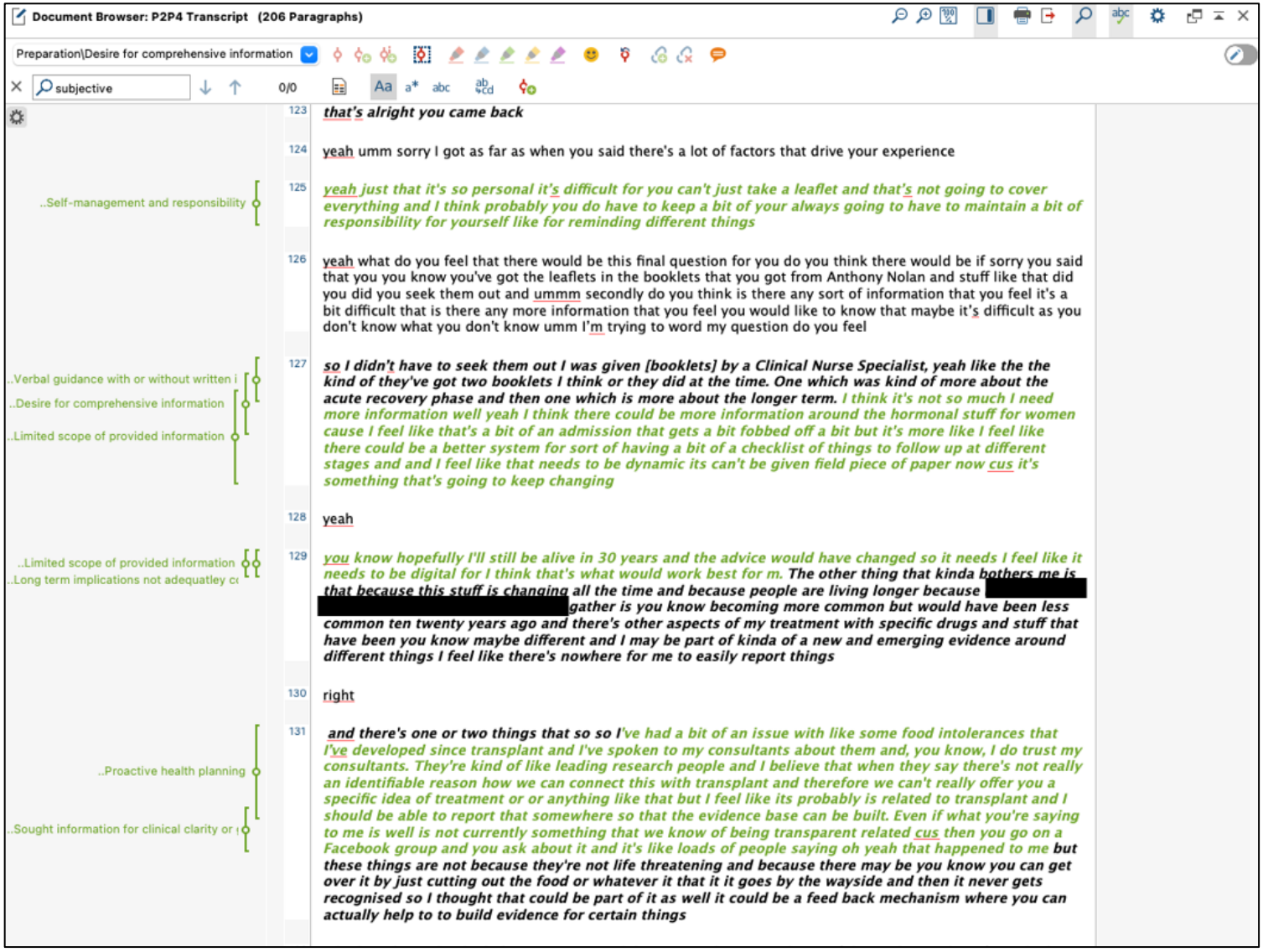
**Appendix 46: Mind-map - Key areas where informational needs might emerge**



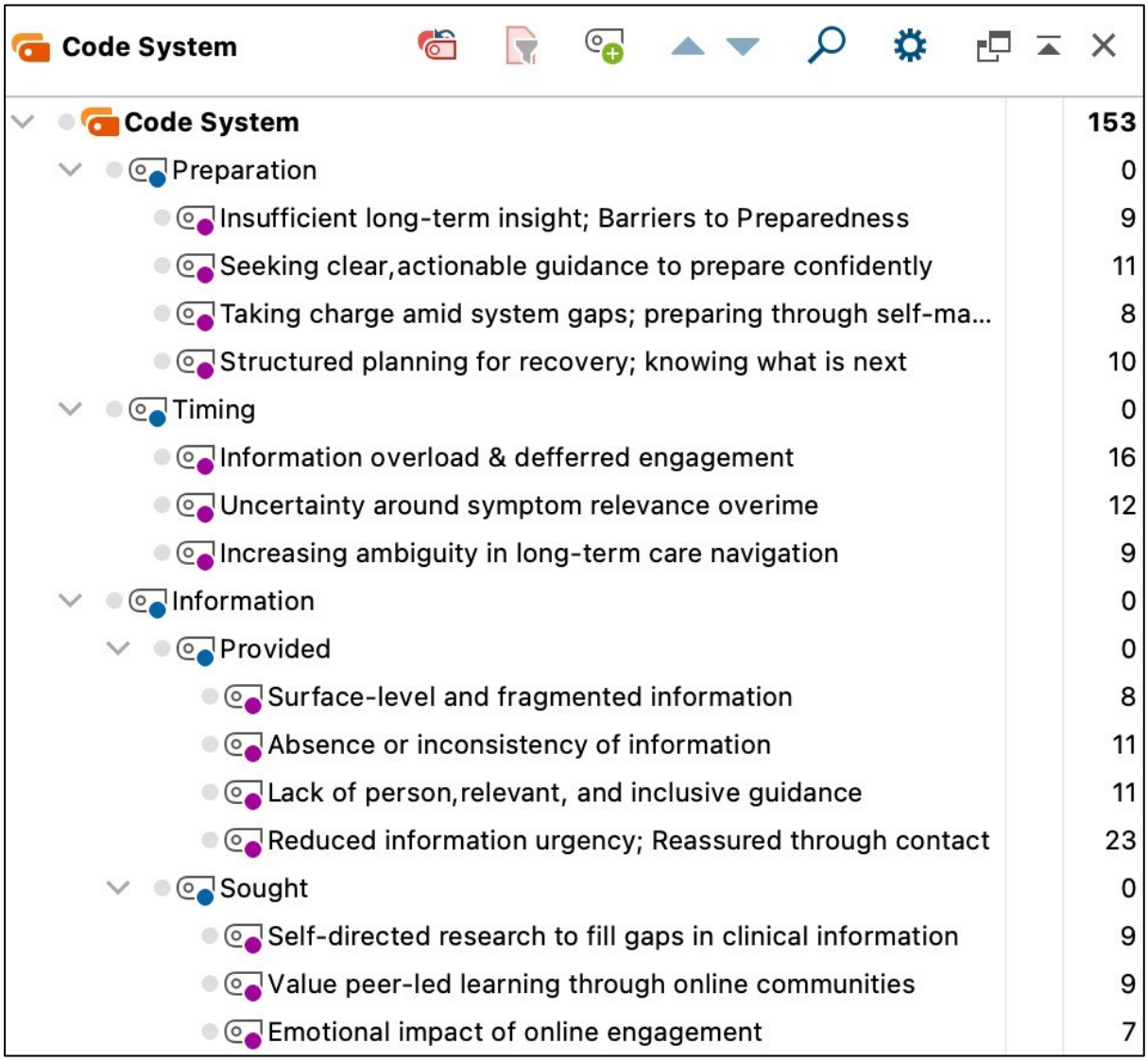
## Appendix 47: Study 3 Reflexive Journal Example



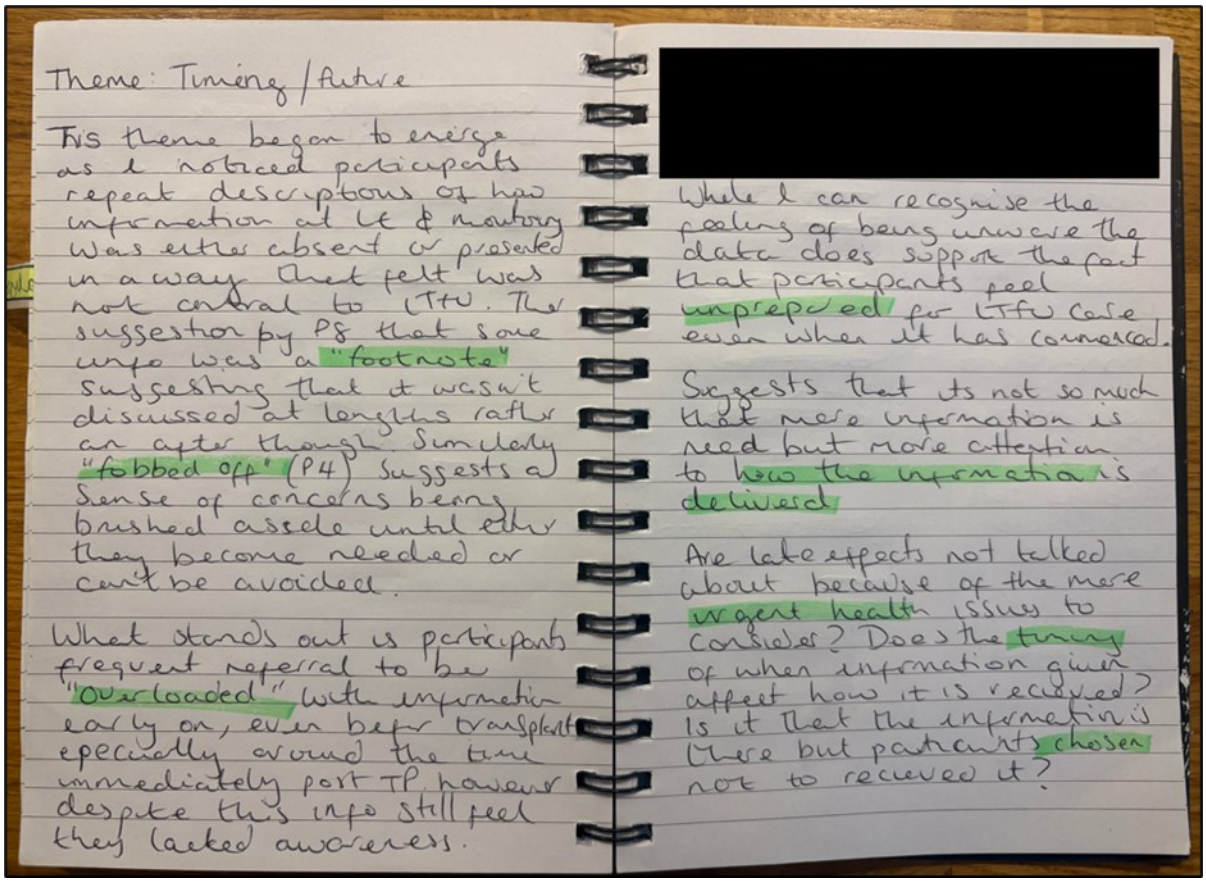
## Appendix 48: Study 3 Sample Coding



**Appendix 49: Study 3 Final Themes and Codes**



**Appendix 50: Study 3 Sample Analytic Notes Example**



Theme: Timing / future

This theme began to emerge as I noticed participants repeat descriptions of how information at LE & monitoring was either absent or presented in a way that felt was not central to LTFU. The suggestion by P8 that some info was a "footnote" suggesting that it wasn't discussed at length rather an after thought. Similarly "fobbed off" (P4) suggests a sense of concerns being brushed aside until either they become needed or can't be avoided.

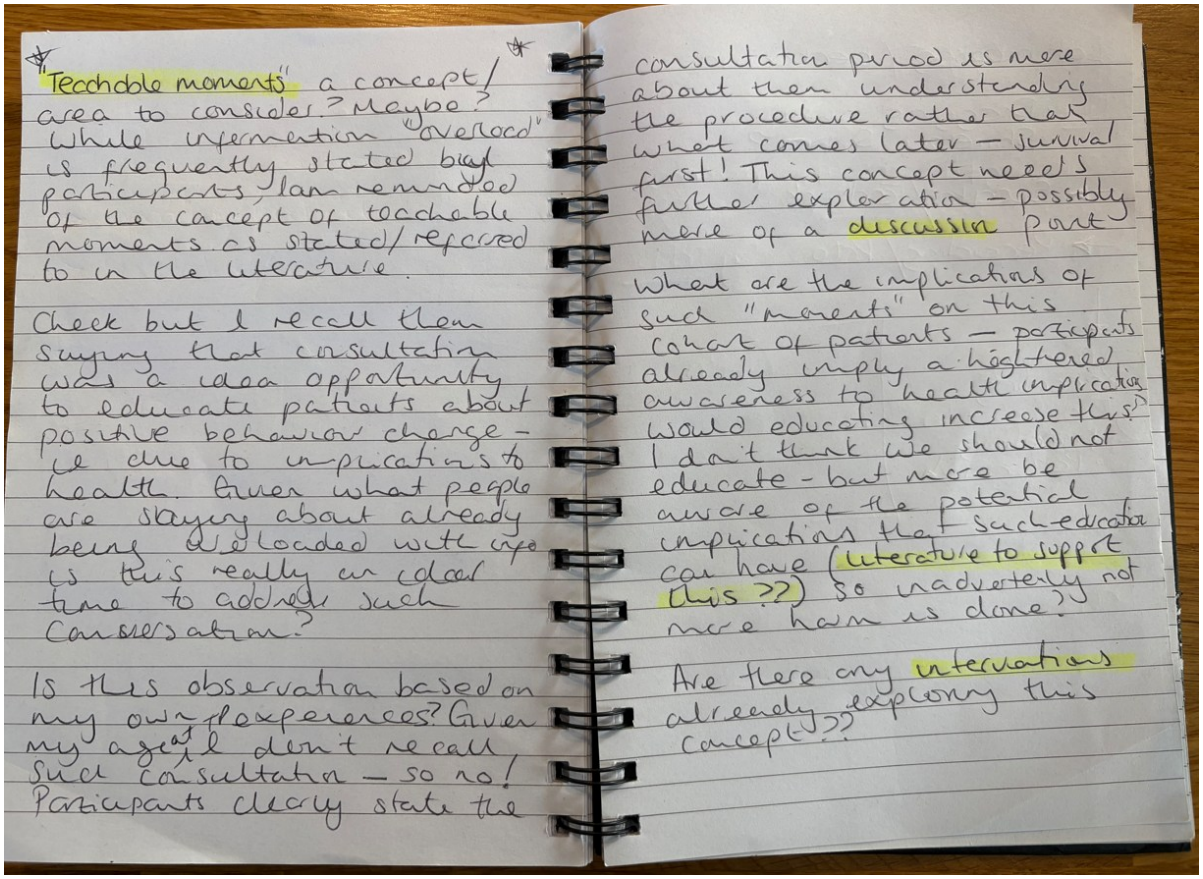
What stands out is participants frequent referral to be "overloaded" with information early on, even before transplant especially around the time immediately post TP however despite this info still feel they lacked awareness.

[redacted]

While I can recognise the feeling of being unaware the data does support the fact that participants feel unprepared for LTFU care even when it has commenced.

Suggests that its not so much that more information is need but more attention to how the information is delivered.

Are late effects not talked about because of the more urgent health issues to consider? Does the timing of when information given affect how it is received? Is it that the information is there but patients chosen not to received it?



"Teachable moments" a concept/ area to consider? Maybe? While information "overload" is frequently stated by participants, I am reminded of the concept of teachable moments as stated/ referred to in the literature.

Check but I recall them saying that consultation was a good opportunity to educate patients about positive behaviour change - ie due to implications to health. Given what people are saying about already being overloaded with info is this really an ideal time to address such conversations?

Is this observation based on my own preconceptions? Given my age I don't recall such consultation - so no! Participants clearly state the consultation period is more about them understanding the procedure rather than what comes later - survival first! This concept needs further exploration - possibly more of a discussion point

What are the implications of such "moments" on this cohort of patients - participants already imply a heightened awareness to health implications would educating increase this? I don't think we should not educate - but more be aware of the potential implications that such education can have (literature to support this ??) so inadvertently not more harm is done?

Are there any interventions already exploring this concept ??

**Appendix 51: Study 3, Theme 1, Coding Matrix**

| **Theme 1: Preparation: *"I like to know what I'm up against"*** | | | | |
|---|---|---|---|---|
| | **Codes** | | | |
| Participant | **Insufficient Long-Term Insight: Barriers to Preparedness** | **Seeking Clear, Actionable Guidance to Prepare Confidently** | **Taking Charge Amid System Gaps: Preparing Through Self-Management** | **Structured Planning for Recovery: Knowing What's Next** |
| **1** | ✓ | ✓ | ✓ | ✓ |
| **2** | | ✓ | ✓ | ✓ |
| **3** | ✓ | ✓ | ✓ | |
| **4** | ✓ | ✓ | ✓ | ✓ |
| **5** | ✓ | ✓ | ✓ | ✓ |
| **6** | | ✓ | ✓ | |
| **7** | ✓ | | | ✓ |
| **8** | ✓ | ✓ | ✓ | ✓ |
| **9** | | ✓ | | ✓ |
| **10** | ✓ | ✓ | ✓ | ✓ |
| **11** | ✓ | | | ✓ |
| **12** | | | | |
| **13** | ✓ | ✓ | | |
| **14** | ✓ | ✓ | | ✓ |

**Appendix 52: Study 3, Theme 2, Coding Matrix**

| **Theme 2: Timing: *"That's all in the future"*** | | | |
|---|---|---|---|
| | **Codes** | | |
| Participant | **Information Overload and Deferred Engagement** | **Uncertainty Around Symptom Relevance overtime** | **Increasing Ambiguity in Long-Term Care Navigation** |
| **1** | ✓ | ✓ | ✓ |
| **2** | ✓ | ✓ | ✓ |
| **3** | | | |
| **4** | ✓ | ✓ | ✓ |
| **5** | ✓ | | |
| **6** | ✓ | ✓ | |
| **7** | ✓ | ✓ | ✓ |
| **8** | ✓ | ✓ | ✓ |
| **9** | ✓ | ✓ | ✓ |
| **10** | ✓ | | ✓ |
| **11** | ✓ | ✓ | ✓ |
| **12** | ✓ | | |
| **13** | ✓ | ✓ | |
| **14** | | ✓ | ✓ |

**Appendix 53: Study 3, Theme 3, Coding Matrix**

**Theme 3: Information Source**

| | **Provided:** ***"Gave us a book and not much else"*** | | | | **Sought:** ***"I got on the computer, and I learnt"*** | | |
|---|---|---|---|---|---|---|---|
| | **Codes** | | | | **Codes** | | |
| Participant | **Surface-level and fragmented information** | **Absence or inconsistency of information delivery** | **Lack of personalised, relevant, and inclusive guidance** | **Reduced information urgency; Reassurance through accessible contact** | **Self-directed research to fill gaps in clinical information** | **Valuable Peer-led learning through online communities** | **Emotional impact of online peer engagement** |
| **1** | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ |
| **2** | ✓ | ✓ | | ✓ | ✓ | ✓ | ✓ |
| **3** | | ✓ | ✓ | ✓ | ✓ | ✓ | |
| **4** | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | |
| **5** | | ✓ | ✓ | ✓ | ✓ | ✓ | |
| **6** | ✓ | ✓ | | ✓ | | | ✓ |
| **7** | ✓ | ✓ | ✓ | ✓ | | ✓ | |
| **8** | ✓ | ✓ | ✓ | | ✓ | | ✓ |
| **9** | | ✓ | | ✓ | | ✓ | ✓ |
| **10** | ✓ | ✓ | ✓ | | ✓ | | ✓ |
| **11** | | ✓ | ✓ | ✓ | ✓ | ✓ | |
| **12** | ✓ | ✓ | ✓ | | | | |
| **13** | | ✓ | | ✓ | | | ✓ |
| **14** | | ✓ | ✓ | ✓ | ✓ | | |

**Appendix 54: Mapping of LTFU Care Recommendations to Synthesised Findings.**

| Recommendation | Synthesised Findings | | | | | |
|---|---|---|---|---|---|---|
| | Clarity and Preparation in Transition to LTFU Care | Continuity and Coordination of Care | Addressing Informational Gaps in Long-Term Care | Patient Self-Advocacy and Information Seeking | Timing and Information Overload | Emotional Impact of Informal Information Sources |
| 1. Address psychological impact of uncertainty in LTFU care | ✓ | ✓ | ✓ | | | ✓ |
| 2. Clarify and communicate the transition to LTFU care | ✓ | ✓ | ✓ | ✓ | | |
| 3. Clarify roles and responsibilities between specialist and primary care | ✓ | | ✓ | ✓ | | ✓ |
| 4. Enhance information provision and health literacy | | | ✓ | ✓ | ✓ | ✓ |
| 5. Tailor information and support to individual preferences | | | ✓ | | ✓ | ✓ |
| 6. Provide personalised, written care plans | ✓ | | ✓ | | ✓ | ✓ |
| 7. Discuss the benefits and risks of online information and peer support | | | ✓ | ✓ | ✓ | ✓ |
| 8. Promote education and training for primary care providers | ✓ | | | ✓ | | ✓ |