Reframing Professional Practice in Palliative Care through Cultural Humility: Insights from a Participatory Action Research Study

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Abstract

Background:

Palliative care is founded on principles of dignity, compassion, and respect. However, for many older people who are sexual and gender diverse, end-of-life care remains shaped by inequity, invisibility, and fear of discrimination. Despite equality legislation and person-centred frameworks, heteronormative assumptions and systemic barriers persist within healthcare practice. These barriers undermine the ethos of palliative care, which is to recognise and respond to everyone's unique identity, experiences, and values.

Aim:

The thesis explores *cultural humility* as a conceptual and practical framework for reframing professional practice in palliative care. It examines how healthcare staff understand and engage with cultural humility, and how it may contribute to more inclusive, equitable, and person-centred care for older people who are sexual and gender diverse.

Methods:

A qualitative participatory action research design was used, engaging six members of healthcare staff and the researcher as co-researchers over a 15-month period. Four iterative cycles of action and reflection were undertaken using focus groups, reflective exercises, and diaries. Reflexive thematic analysis guided data interpretation and synthesis.

Findings:

Cultural humility emerged as a multidimensional and ongoing process involving self-awareness, reflexivity, vulnerability, and empathy. Participants described a shift from cultural knowledge to cultural engagement, underpinned by a

willingness to unlearn assumptions and critically reflect on practice. Organisational barriers, including hierarchical structures and competing priorities, were identified alongside opportunities to embed cultural humility within education, supervision, and leadership. From this collaborative inquiry, the *Cultural Humility in Palliative Care framework* and *HEARt Model* were developed to guide practitioners in applying cultural humility within palliative care settings.

Conclusion:

This study positions cultural humility as a lifelong, relational practice essential to ethical and person-centred care. By distinguishing it from static notions of competence, the research contributes new insights into how reflective, participatory approaches can strengthen inclusivity and equity within palliative care, reaffirming its core commitment to compassion, dignity, and justice at the end of life. Ultimately, it proposes that cultural humility, when practised authentically, has the potential to transform both the giver and receiver of care.

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Finally, I am deeply grateful to my parents for their encouragement to pursue learning at any stage of life. I dedicate this thesis to them and to the memory of my late Aunt Rhoda, who died before she could see the finished work.

Declaration

I declare that this thesis is my own work and has not been submitted for the award of a higher degree elsewhere.

As the candidate, I have already achieved 180 credits for assessment of taught modules within the blended learning PhD programme.

Throughout the thesis, images have been generated to support the text. Included visual representations have been created using a generative artificial intelligence (AI) tool – Napkin AI (2025) and SmartArt in Microsoft PowerPoint. A selection of text prompts used to create the images are available in Appendix 1.

1. Chapter One: Introduction and Thesis Overview

1.1. Introduction

The continuing dominance of heteronormative ideals (where heterosexuality is positioned as the default and preferred orientation) continues to shape societal norms and organisational practices, including healthcare. Societal bias contributes to the marginalisation of people with diverse sexual orientations and gender identities across the care continuum, including at the end of life (MacCarthy et al., 2021; Sprik & Gentile, 2020).

Despite the legal protections enshrined in the UK Equality Act (2010), older people who are sexual and gender diverse often encounter discriminatory attitudes, implicit bias, and systemic marginalisation within palliative care settings (Kneale et al., 2021). These experiences reflect a broader failure to recognise and respond to the complexity of diverse identities. As a result, decisions about whether to engage with healthcare services are often shaped by fear, mistrust, and previous experiences of exclusion.

The consequences are distrust by older people who are sexual and gender diverse in the medical establishment and staff, avoidance of healthcare encounters, and a reluctance to disclose sexual orientation or gender identity leading to delayed access, unmet needs, and the denial of appropriate and timely care (Barber et al., 2023; Cloyes et al., 2018; McNeill et al., 2023). Such inequalities sharply contradict the principles hospice and palliative care organisations endeavour to uphold, including the provision of inclusive care to all individuals, and the recognition of each person’s unique identity, rather than treating them uniformly (Acquaviva, 2017; Cecily Saunders International, 2021; National Health Service (NHS) England, 2021).

Person-centred healthcare requires approaches that extend beyond generic models of care to actively prioritise patients as individuals, each shaped by distinct cultural, social, and personal contexts (Fisher, 2020). In an increasingly

diverse global society, this demands that healthcare staff are not only clinically competent but also equipped to engage with empathy, cultural sensitivity, and relational awareness. The ability to recognise and respond to difference is no longer optional; it is central to delivering care that is both ethical and effective. In the context of healthcare environments, the need for culturally responsive care has become increasingly urgent, particularly within palliative care settings, where patients and their support networks navigate complex emotional, spiritual, and cultural dimensions.

This thesis explores the meaning of cultural humility in professional practice among healthcare staff working in palliative care, with a focus on its contribution to equitable, inclusive, and person-centred care. Throughout this study, I seek to understand how staff may engage with cultural humility in their daily work and how it contributes to more inclusive, person-centred palliative care experiences.

Drawing on a reflexive approach, I convey the motivations underpinning this research and my positionality within the study and co-production of knowledge. I conclude the current chapter with an outline of the overarching aim and objectives, research questions, and structure of the thesis.

1.2. Motivation for the Research

Experiences during clinical placements deeply influence future care practices. During my nurse training, a key incident on an oncology ward, where discriminatory attitudes were expressed towards a trans woman, catalysed my commitment to advocating for inclusive and culturally sensitive palliative care. Within the ward setting, I found it challenging to voice concerns due to perceived hierarchical dynamics and the risk of unsettling established interpersonal relationships.

Furthermore, the decision to focus on older adults is directly informed by the demographic profile of East Suffolk, which has one of the oldest populations in England (Office for National Statistics, 2023). The county's disproportionately high number of residents over the age of 65 (one in four) makes ageing-related

experiences, needs and inequalities especially visible in the local context. Census figures from 2021 report an increase in same sex civil partnerships for those individuals aged 55 to 64 (20%) and over 65 years (19%) (Healthy Suffolk, 2026). While ageing is a prominent feature of the region, the experiences of older people who identify as sexual and gender diverse may remain largely invisible within local discourse and service provision.

In the United Kingdom, professional and regulatory organisations such as the General Medical Council (GMC) (2025) and the Nursing and Midwifery Council (NMC) (2025a) state in their codes of conduct that it is the responsibility of all healthcare staff to serve as advocates for individuals who experience prejudice, stereotyping, or stigmatisation (GMC, 2025; NMC, 2025a). The provision of non-judgemental and equitable patient care, which is person-centred, and holistic in its focus and delivery, is the benchmark (sometimes referred to as gold standard) approach aimed for within health and social care (Care Quality Commission, 2024; Department of Health, 2013; The Health Foundation, 2016).

This experience has continued to shape my development as a nurse, as well as on a personal level. In seeking ethical and equitable professional practice, I have embarked on an individual journey to enhance my own inclusive care provision, by recognising and identifying culturally appropriate and sensitive practice by all health and social care staff, and particularly those involved in palliative care. The thesis emerges from that journey, aiming to understand and promote culturally humble practices amongst healthcare staff.

1.3. Researcher Positionality

I bring a multifaceted identity and personal experience to the research. Initially, I gave little heed to who I was in terms of my cultural heritage, values, and beliefs. I have always recognised my ethnicity as White British, brought up in a family with roots in Northern Ireland. Yet, this became blurred when I discovered I was adopted as a baby. My birth mother is White, British, and English, my adopted parents White, British and Northern Irish. What does that make me? The answer is not a simple mathematical calculation and outcome. Fundamentally, I am

who I am, someone born in the United Kingdom, who is British, with English and Irish roots.

I am also a woman (born female), exposed to a variety of cultures in childhood by my parents through overseas travel, living in Europe for four years, and my father's profession as a clergyman. Throughout my childhood, I was taught to appreciate the value of education, music, art, and the cultural heritage of other countries. As a result, I have recognised that my cultural heritage is not the dominant culture; that does not exist. Humankind is a compilation of cultures, evolving over time, as traditions, values and beliefs are passed down through the generations.

I am also privileged in that I have had access to education all my life and always found employment of my choosing. My adoptive parents were scholars, and it is because of the value they placed on lifelong learning that I have continued my relationship with education beyond my formative school years. Qualifying as a registered nurse when I turned 50 was a life-time achievement. I currently work in a dual role capacity: as a specialist palliative care nurse, serving communities in the east of England (Suffolk/Norfolk) and as practice/clinical educator.

1.4. Participants as Co-Researchers

Referrals to specialist palliative care services often overlook the complexity of patients' sexual and gender identities. Within my professional context, colleagues at times described uncertainty and limited confidence when engaging in conversations about cultural identity. Many expressed apprehensions about saying the wrong thing or making assumptions about patients' backgrounds. These reflections indicate a broader tension within practice; between the desire to offer inclusive, person-centred care and the discomfort that can arise when navigating cultural difference.

These professional realities informed my choice of a research methodology focused on reflection, dialogue, and collaborative meaning-making. The study design aimed to create a safe and reflexive space in which healthcare staff could

explore their own responses to cultural insensitivity and, through discussion and shared interpretation, co-construct a more insightful understanding of cultural humility in professional practice.

In this study, I positioned participants as co-researchers, engaging with them in the interpretive processes of knowledge generation and sense-making (Boylorn & King, 2008). As healthcare staff, they held expertise in both clinical care and the provision of palliative care services, grounding the research in lived professional experience. Their engagement extended beyond participation to active collaboration in exploring, analysing, and interpreting the data. Together, we sought to clarify how understandings of cultural humility were negotiated and enacted within everyday professional practice, set against the context of palliative care.

From my position as the academic researcher, I approached this work reflexively, recognising that knowledge is co-constructed through our interactions and shaped by our individual standpoints. I remained attentive to how my own assumptions, professional background, and interpretive lens influenced the research process. I valued the participants' insights not only as contributors of data but as partners in shaping, challenging, and enriching the collective understanding that underpinned the thesis.

1.5. Aim, Objectives, and Research Questions

The aim of the research was to explore cultural humility as a practice in palliative and end-of-life care for healthcare staff working in community and hospice settings, and its contribution to professional practice and equitable and inclusive patient care, using a participatory action research approach. The intention was to foster a collaborative environment where healthcare staff engaged in palliative care services could share and discuss their understandings, interpretations, and significance of cultural humility as a practice supporting and enhancing professional practice to enrich person-centred patient care.

The following objectives were defined to meet the research aim:

- Identify the relevance and importance of culture and humility in the context of patient care
- Understand cultural variations of providing palliative care to diverse populations
- Work collaboratively in developing group and individual reflective activities
- Encourage co-researchers to reflect on the inclusion of cultural humility within their individual professional practice
- Determine, collaboratively, the value and potential of cultural humility in addressing inequitable care experienced by vulnerable or marginalised population groups

The study was conducted to explore the following research questions:

i. What is the meaning of cultural humility for UK based community and hospice palliative care staff?

ii. Why is engaging with cultural humility relevant for fostering change in professional practice and palliative care for older people who are sexual and gender diverse?

1.6. Thesis Overview

The thesis consists of six chapters:

- *Chapter One: introduction and thesis outline*

In the introductory chapter, I outline the structural framework of the thesis, establishing a foundation for the subsequent analysis, critique, and engagement with cultural humility as a transformative lens through which to encourage, promote, and enhance professional practice and the delivery of person-centred, holistic palliative care.

- *Chapter Two: background and context*

In Chapter Two, I discuss the current landscape of palliative care for older people who are sexual and gender diverse and their families, highlighting the intersecting influences of culture and humility within healthcare practice. How these factors shape clinical encounters is explored. The constructs of cultural competency and cultural humility in professional practice are outlined, tracing the conceptual shift from static skill acquisition to ongoing relational engagement.

- *Chapter Three: scoping review*

In Chapter Three, I present a scoping review of existing literature examining the concept of cultural humility, with the aim of identifying current knowledge across global health and social care contexts. The review follows the Joanna Briggs Institute (JBI) methodology for scoping reviews. In parallel, a concept analysis employing Rodgers' Evolutionary Method synthesises the defining attributes of cultural humility. Together, the scoping review and concept analysis inform and shape the interpretation of research findings, as well as the subsequent discussion and conclusion chapters.

- *Chapter Four: philosophical foundations and methodology*

In Chapter Four, I outline the methodological approach adopted in the research study, alongside the epistemological and ontological perspectives that underpin its design. It presents the rationale for selecting Participatory Action Research as the guiding framework and details the processes of data collection and analysis.

- *Chapter Five: the findings*

The analysis and presentation of findings are based on data from the focus group series, group activities, and individual reflections. A reflexive thematic analysis (RTA) approach is employed to analyse the data and frame the findings in relation to the research aim, objectives, and questions.

- *Chapter Six: discussion, recommendations, and conclusions*

In the final chapter, I discuss the research findings in relation to the guiding research questions and the broader body of research evidence. It critically considers the strengths and limitations of the study and articulates its contribution to knowledge, professional practice, policy, and future research. The chapter concludes with a synthesis of key insights and a final summative reflection.

2. Chapter Two: Background and Context

2.1. Defining Palliative Care

The purpose of the current chapter is to discuss the intersection of culture and humility in healthcare, particularly in relation to palliative care for older people who are sexual and gender diverse. Palliative care encompasses comprehensive, person-centred support for individuals and families facing life-limiting illnesses unresponsive to curative treatment. The intent of palliative care is to enhance quality of life and alleviate suffering across physical, emotional, spiritual, and psychosocial dimensions (Payne et al., 2022; Radbruch & Payne, 2009; World Health Organization (WHO), 2020). While traditionally associated with end-of-life care for people with cancer, palliative care is equally critical for individuals with other life-limiting conditions, such as cardiac, respiratory, and neurological diseases.

In this thesis, I adopt a broad definition of palliative care, inclusive of end-of-life services, emphasising the goal of enabling individuals to live well as their health declines and to die with dignity (Marie Curie, 2018). Central to this care is the delivery of dignified, unbiased support, free from the influence of personal values and beliefs held by healthcare staff (Watson, 1988). The UK framework for palliative and end-of-life care (Ambitions for Palliative and End of Life Care) underscores the importance of recognising every person as an individual (Ambition One) and ensuring equitable access to care regardless of cultural background, location, or personal circumstances (Ambition Two) (NHS England, 2021).

Palliative care must be universally accessible, addressing the diverse needs of individuals across all cultures and communities, regardless of age, (dis)ability, gender, sexual orientation, race, religion, or other protected characteristics (Equality and Human Rights Commission (EHRC), 2021). Recognising these characteristics supports the delivery of holistic, person-centred care, empowering both patients and healthcare staff to make informed decisions and

ensuring care is delivered with dignity, compassion, and respect (The Health Foundation, 2016).

2.2. Professional Practice in Palliative Care

Holistic, person-centred care is underpinned by the enactment of professional practice, whose definition within healthcare remains contested across the literature. Regulatory bodies in the UK and Australia conceptualise professional practice as encompassing attitudes and behaviours, marked by autonomous, evidence-informed decision-making among practitioners who share common educational foundations and professional values (Australian NMC, 2023; NMC, 2025a).

This framework highlights the importance of maintaining therapeutic and collaborative relationships. Yoder (2017) further characterises professional practice as acting in the best interests of patients and families, upholding ethical standards - such as integrity, accountability, duty, and honour - and showing cultural sensitivity. Expanding this view, Cao et al. (2023) identify professional practice as multidimensional, dynamic, and culturally oriented.

Engaging in professional practice enables healthcare staff to lead high-quality care, drive change, and exercise sound judgement within environments that foster professional conduct (NMC, 2018). As a cornerstone of person-centred care, it prioritises dignity, compassion, and respect for individuals' privacy, cultural beliefs, and preferences - principles embedded in the Royal College of Nursing's (RCN) guidance on equality, diversity, and personalised care (RCN, 2024). When enacted, professional practice supports the consistent delivery of safe, effective, and person-centred outcomes, supporting individuals, families, and carers in achieving optimal health and well-being. The work of Dame Cicely Saunders on end-of-life care reflects this ethos through its focus on symptom management and the maintenance of quality of life until death (Hospice UK, 2025).

Contemporary scholarship on professional practice has shifted from a focus on measurable competencies to a more holistic orientation grounded in values, communication, and relational ethics. The UK Health & Care Professions Council (HCPC) advocates for viewing professional practice not merely as a skill set but as a way of being (HCPC, 2014). Practitioners are thus entrusted with sustaining their professional integrity through lifelong learning, modelling best practice, cultivating supportive care environments, and advancing person-centred, evidence-informed approaches (NMC, 2018).

2.3. Palliative Care for Older People who are Sexual and Gender Diverse

In the context of the thesis, older people who are sexual and gender diverse are individuals, aged 65 and over, identifying as lesbian, gay, bisexual, transgender, queer (or sometimes questioning), often referred to by the acronym LGBTQ+ (Stonewall, 2024). These individuals may have specific needs at the end of life, influenced by cultural traditions such as family expectations, religious practices around dying, and receiving culturally appropriate care from members of a community (Tobin et al., 2022).

Reports on the state of the health of people who identify as sexual and gender diverse indicate their continuing marginalisation in society through law and by medical diagnosis, shaping the experience of living into older age (Marie Curie, 2017; McDermott et al., 2021). Furthermore, evidence indicates that individuals who identify as sexual and gender diverse experience disproportionately higher rates of life-limiting illnesses compared to their heterosexual counterparts. The disparity is partially attributed to chronic stressors associated with homophobia, systemic discrimination, and social marginalisation (Beach et al., 2019; Marie Curie, 2017).

A sizeable proportion of older people who are sexual and gender diverse reached adulthood prior to the decriminalisation of homosexuality in England and Wales in 1967 (Hospice UK, 2018). As a result, many have endured prolonged periods of concealment and internalised fear, stemming from the potential repercussions

of disclosing their sexual orientation or expressing their gender identity. According to Miller and Tabor (2024), the experiences of aging as an individual with diverse sexual orientations and gender identities are distinctly shaped by exposure to both past and ongoing inequitable treatment. Historically, literature suggests homosexuality and sexual minorities are “deviant, sinful and outside the law” (Herek et al., 2007, p. 172), with Hsieh and Shuster (2021) adding that being a person who is sexual and gender diverse individual has often resulted in being labelled with an illness, thereby enabling the medical establishment and society in general to “pathologize, stigmatise, and discriminate against sexual and gender minorities” (p. 319). Beach et al. (2019) concluded that older people who are sexual and gender diverse experience challenges accessing healthcare that deals appropriately with their sexual identity.

Additionally, past experiences of negative interactions with healthcare staff can influence engagement with and how they access health services in later life. A report published by Marie Curie (2017) identified key issues and concerns experienced by individuals with diverse sexual orientations and gender identities at the end of life as:

- anticipating discrimination
- complexities of religion and end-of-life care
- assumptions about identity and family structure
- varied support networks
- unsupported grief and bereavement
- increased pressure on carers with diverse sexual orientations and gender identities

A UK 2018 government survey of people with diverse sexual orientations and gender identities highlighted respondents’ disproportionate dissatisfaction with healthcare providers, perpetuated by a lack of awareness amongst staff members of specific health needs of people who are sexual and gender diverse (Government Equalities Office, 2018). More recently, research highlights ongoing concerns about the influence of social discrimination on the equitable and

timely provision of palliative care services for older people who are sexual and gender diverse (Tobin et al., 2022).

Taking this into consideration, it is vital for healthcare staff to enhance their understanding of how people with diverse sexual orientations and gender identities relate to, define, and identify with their bodies, sexuality, and relationships. Consequently, staff delivering palliative care are encouraged to work collaboratively to achieve "what we would want for our own families" (National Palliative and End of Life Care Partnership, 2021, p.9). However, negative attitudes towards individuals who are sexual and gender diverse and their chosen family continue to persist because of societal and cultural norms, including within palliative care (Ayhan et al., 2020). According to Maingi et al. (2018), research highlights the clear need for inclusive and culturally appropriate end-of-life care, caregiver support, bereavement services, and legal protection. The provision of personalised palliative care to people with diverse sexual orientations and gender identities is not necessarily about creating bespoke services. Rather, as suggested in research from Bristowe et al. (2018) and Sprik and Gentile (2020), it is about considering the skills, knowledge and attitudes needed to deliver person-centred care, in conjunction with healthcare staff reflecting on their own attitudes and behaviours.

The remainder of the chapter discusses the intersection between culture and humility, and how they may influence the lived experience of healthcare for older people who are sexual and gender diverse, particularly in the context of palliative care. In this discussion, I emphasise the importance of culturally appropriate and sensitive approaches that healthcare staff can adopt to ensure inclusive and equitable professional practice, thus enhancing care experiences for patients and families.

2.4. The Role of Culture in Palliative Care

Palliative care can be improved by acknowledging cultural background, race, and ethnicity, appreciating differences within and between groups, and integrating this understanding into clinical practice (Cain et al., 2018). Human

diversity contributes to the persistence of different lifestyles and beliefs, through what has come to be understood as culture. An awareness of the individual needs of patients and their support network, set within their own cultural context, is essential in the delivery of holistic (or person-centred) care by healthcare staff.

In palliative care, where relational sensitivity and trust are critical, this underscores the need for staff to reflect on how their own cultural positioning intersects with and influences interactions with patients and families. When healthcare staff fail to acknowledge the values and meanings people attribute to their own lives, health and well-being, care provision becomes inequitable and inappropriate, lacks cultural awareness, and sensitivity. Evidence suggests healthcare staff should be supported and provided with in-practice support and tools to develop an awareness and appreciation of patients' cultural values, beliefs, and practices to provide care that is individualised, person-centred, and holistic (Periyakoil, 2019).

A variety of definitions exist for culture. In their Lancet Commission publication, Napier et al. (2014) indicate that culture can be conceptualised as "systems of value" (p. 1607), which are sometimes unacknowledged and are dynamic and fluid in nature. Hong (2009) articulates culture as "networks of knowledge, consisting of learned routines of thinking, feeling, and interacting with other people, as well as a corpus of substantive assertions and ideas about aspects of the world" (p.4). The characterisation of culture is therefore shaped through social construction and relies on the shared understanding among individuals who are interconnected by, but not solely defined by, race, ethnicity, or nationality (Hong, 2009).

Cultural contexts influence how individuals identify themselves, determine the role of family, gender, and sexual related norms, how younger and older individuals are viewed in society, and attitudes towards the biomedical healthcare approach, or alternative and complementary healing practices (Periyakoil, 2019). Patients' and families' cultural backgrounds influence how

they understand, experience, and respond to health interventions across the life continuum (Periyakoil, 2019). Individuals' cultural contexts influence communication methods, decision-making approaches, responses to symptoms, treatment preferences, and emotional expressions during the end-of-life phase (Bosma et al., 2010).

The influence of culture extends to the ways in which the range of personal, social, and cultural characteristics intersect and how individuals define themselves and are perceived by others (Napier et al., 2017). Intersection, and the associated term *intersectionality*, has roots in the USA, and within the context of healthcare is widely associated with health inequity for vulnerable or marginalised populations (Crenshaw, 1998; Wesp et al., 2019). Crenshaw (1998) emphasised the importance of addressing the needs and problems of the most disadvantaged individuals (or population groups), by understanding how personal characteristics interact and shape the experiences of everyone in everyday life and society (Funer, 2023). For people who identify as sexual and gender diverse, intersectionality focuses on their marginalised social position at the intersections of race, ethnicity, gender, sexuality, disability, and age (Wesp et al., 2019). Although research exploring intersectionality within palliative care is still limited, scholars such as Hudson et al. (2024) and Wright et al. (2023) highlight its value in drawing attention to the complex interplay of factors that shape people's experiences of illness, dying, and death.

An intersectional perspective encourages consideration of how overlapping aspects of identity (such as race, gender, age, and socioeconomic status) interact with cultural and structural influences. By engaging with these differences, healthcare staff are better able to understand the patient's perspective and how they make sense of their illness. Such an approach supports the development of care practices that are more closely aligned with how patients perceive and experience their care (Napier et al., 2017).

Cultural practices have the potential to foster belonging and shared meaning. Yet in practice, people often enact cultural norms in ways that privilege their own

experiences while marginalising others, thereby undermining inclusive participation. These tensions illustrate how everyday practices can reinforce boundaries that exclude rather than embrace diversity. Healthcare staff who do not engage with the intersecting aspects of identity, such as race, gender expression, and generational experience, risk overlooking key dimensions of patients' lives.

Gender expression, for example, reflects how individuals outwardly present their identity through appearance, behaviour, voice, and mannerisms. Generational experience captures the shared social, cultural, and historical events that shape the attitudes and expectations of people born in the same era. When these intersecting factors are ignored, patients' lived realities of health and illness can be obscured, leading to care that is less responsive, inclusive, or person-centred. The oversight risks undermining the development of respectful, reciprocal relationships that are foundational to person-centred care. These are built on mutual recognition of dignity, trust, and shared responsibility, involving active listening, cultural sensitivity, and collaborative decision-making, allowing both patients and providers to contribute meaningfully to care processes. Overlooking these relationships can perpetuate systemic inequalities and reinforce feelings of exclusion or mistrust among marginalised groups, as a lack of cultural understanding between a patient, their family, and healthcare staff inhibits the communication of preferences and goals for treatment or care (Barnes et al., 2020).

2.5. Humility in Healthcare and Professional Practice

Clinical expertise in practice is vital for patient safety, the delivery of evidence-based care, and beneficial health outcomes. However, patients also want healthcare staff who recognise them as individuals, with their unique needs and values, attitudes, and beliefs, shaped by a lifetime of experiences (Zinan, 2021).

In research conducted by Wadhwa and Mahant (2022), humility was identified as a fundamental attribute for healthcare staff. According to Roberts and Cleveland (2017), humility is defined as the recognition of one's limitations, arguing that

accepting these limitations is crucial. Furthermore, Worthington et al. (2017) emphasise that practising humility can play a significant role in mitigating biases, fostering cross-cultural knowledge exchanges, and encouraging a focus on others by healthcare staff. Literature suggests humility is not a trait that can be learnt; yet, by changing or reassessing one's way of thinking, healthcare staff may cultivate an accurate self-awareness and empathise with others (Tangney, 2000; Worthington, 2007).

Humility within healthcare practice encompasses a recognition of staff's individual experiences, including personal errors and uncertainties, and a willingness to seek guidance when confronted with gaps in knowledge (Wadhwa & Mahant, 2022). The intrapersonal dimensions of humility involve internal processes within an individual. These refer to how humility is cultivated and experienced on a personal level. In contrast, the interpersonal dimensions focus on how healthcare staff and patients communicate, connect, and collaborate. The systemic dimensions go even further by critically examining and reshaping the structures, policies, and organisational cultures that contribute to inequity in healthcare.

Together, these interpersonal and systemic aspects contribute to a broader understanding of humility beyond the individual, placing it within the relational and structural contexts where care is delivered. These outer dimensions foreground healthcare staff's awareness of their positionality (both within organisational settings and the wider sociocultural landscape) and invite a deeper engagement with patients' lived experiences.

Through practices such as inquiry, active listening, respect, and empathy, healthcare staff are encouraged to foster therapeutic alliances, or collaborative engagement, that honour complexity and promote openness (Wadhwa & Mahant, 2022; Zinan, 2021). Although clinical expertise and ability are still foundational, a patient-centred approach allows healthcare staff to move beyond diagnostic categories and respond to the specific needs, fears, and

concerns that shape everyone's experience of illness (Huynh & Dicke-Bohmann, 2020; Wadell, 2017).

2.6. Culturally Competent Professional Practice

In recent years, there has been considerable international focus on the training of healthcare staff, particularly medical and nursing professionals, therapists, and social workers, to become culturally competent. Healthcare staff deliver care by acquiring the necessary skills, knowledge, and awareness to effectively engage with patients reflecting a variety of values, beliefs, and behaviours (Purnell, 2018). Although there is no standard definition of cultural competency recognised across the literature, the definition by Cross et al. (1989) is the most widely accepted: "cultural competence is a set of congruent behaviours, attitudes, and policies that come together in a system, agency, or among professionals and enables that system, agency, or those professionals to work effectively in cross-cultural situations" (p.28).

Healthcare staff delivering culturally competent care should show a set of behaviours and attitudes enabling them to work effectively in cross-cultural situations (Sullivan, 2015). Furthermore, a growing body of research is emerging on the experiences of people who identify as sexual and gender diverse with palliative care, and how cultural competency education and training may contribute towards the identification of needs, preferences, and goals of care (Cloyes & Candrian, 2021; Marie Curie, 2017).

According to MacKenzie and Hatala (2019), cultural competency involves acquiring appropriate knowledge of diverse cultures, norms, and values, enabling healthcare staff to effectively address the specific health needs of individuals. Increasingly, cultural competence is characterised as a skill that can be taught, trained, and achieved (Stubbe, 2020). Emerging evidence points to the possibility that culturally competent healthcare staff may be involved in practices inadvertently upholding cultural biases and stereotypes through a lack of both understanding and appropriate application, thus perpetuating

inequalities in the provision of healthcare services (Barnes et al., 2020; Greene-Moton & Minkler, 2020; Loue, 2022; Nyamwaya, 2022; Ruud, 2018).

Placing emphasis on culturally competent care has led to the implementation of formal guidelines and standards of practices into the education and training of healthcare staff internationally, particularly in western countries such as the USA, Canada, and Australia (Govere & Govere, 2016; Sullivan, 2015; US Department of Health and Human Services, 2024).

In the USA, fundamental cultural competency guidelines have been designed to guide training practices for healthcare staff working with people who identify as sexual and gender diverse (Pratt-Chapman et al., 2022). Yet, recent evidence suggests that due to the huge variations in training types and reported outcomes, determining the effectiveness of cultural competency guidelines remains inconclusive (Hsiang et al., 2024; Yu et al., 2023). In Australia, research has highlighted the significance people who identify as sexual and gender diverse assign to healthcare providers showing culturally affirming clinical practices (such as positive attitudes, affirming practice, and knowledge and education), through a cultural competence approach (Bishop et al., 2022).

In the UK, the independent regulator of health and social care services (Care Quality Commission (CQC)) considers cultural competence as culturally appropriate care, focusing on person-centred care, dignity and respect, and informed consent (CQC, 2025). Monitoring includes determining whether cultural competency training is available for healthcare staff and providers. However, at the time of this research study, cultural competency is not aligned with mandatory training requirements for healthcare staff. Cultural competency is encouraged as part of individual continuing professional development through approaches including online learning (NHS England, 2025a).

Recently though, the growing international critique of cultural competency frameworks, including in the UK, has led to a re-evaluation of its contribution to holistic and person-centred care. There has been increasing interest within healthcare towards cultural safety and cultural humility. Cultural safety is a

framework that originated in New Zealand and has been adopted in Australia to confront and address the systemic racism experienced by Indigenous populations (Lokugamage et al., 2023). It represents a decolonizing approach within the healthcare sector, specifically aimed at improving the provision of care for Indigenous individuals accessing Western-style healthcare systems (Moloney et al., 2023).

However, this current study focuses on cultural humility as a more reflective and dynamic process than cultural competence or cultural safety. Increasingly, healthcare staff are encouraged to interrogate their own cultural backgrounds and consider how these may shape implicit biases, assumptions, and limitations within clinical practice (Cáceres-Titos et al., 2025; Hurley et al., 2022; Sprik & Gentile, 2020).

2.7. From Competence to Humility in Practice

Cultural competency implies the attainment of a certain level of skill, knowledge, and awareness; an idea reflected in Benner's (1982) framework of professional development, describing progression from *novice* to *expert*. However, healthcare staff may inadvertently assume a position of authority (as an expert) when engaging with individuals from diverse backgrounds, creating barriers to mutual understanding and inclusive care.

This perpetuates *othering*, where differences are neither acknowledged nor respected, allowing for the perpetuation of discrimination, stigmatisation, and marginalisation (Akbulut & Razum, 2022; Canales, 2000). To address these concerns, the training and development of healthcare staff has transitioned to a practice model centred on the needs of others (*other-orientated*), highlighting the importance of self-awareness and reflexivity in holistic and person-centred care.

This shift has led to the emergence of cultural humility, a concept attributed to two female doctors in the USA, Melanie Tervalon and Jann Murray-García (1998), advocating for its inclusion in medical student training. They described cultural

humility as a stance that "incorporates a lifelong commitment to self-evaluation and self-critique, to redressing the power imbalances in the patient-physician dynamic, and to developing mutually beneficial and non-paternalistic clinical and advocacy partnerships with communities on behalf of individuals and defined populations" (p.117). Consequently, healthcare staff shift their emphasis away from reaching fixed cultural competencies. Instead, they prioritise each patient as a unique individual, shaped by diverse experiences, values, and beliefs concerning well-being, illness, and care at end of life.

Cultural humility differs from cultural competency in that it emphasises a practice-oriented approach, encouraging healthcare staff to prioritise person-centred care. Therefore, staff ensure the complexities of diverse cultures are acknowledged and addressed in care delivery. FitzGerald and Hurst (2017) suggest that when delivering person-centred care, healthcare staff need to be aware of negative evaluations or attitudes about patients and their families, all of which contribute to perpetuating discrimination and stigma.

Research exists linking the practice of cultural humility to the mitigation of implicit bias in healthcare, particularly in relation to racial and ethnic diversity (Charles et al.,2017). Masters et al. (2019) developed a coaching tool to help healthcare staff acknowledge everyone has implicit biases and how to reduce these through mindful reflection. Figure 1 is a visual adaptation of the 5Rs of Cultural Humility framework (generated by Napkin AI (2025) with prompts detailed in Appendix 1).

Current authors suggest that the practice of cultural humility is an ongoing process that spans a lifetime, shaped by every interaction between patients and their providers. The process is founded on the adoption of an open mindset, a commitment to being other-focused, and a readiness to engage with individuals from diverse backgrounds, while also being mindful of the possible influences of stigma and prejudice (Fahlberg et al., 2016). How stigma can influence the provision of person-centred healthcare is discussed later in Chapter Five -

section 5.5.1 (as part of the focus group findings) and Chapter Six - section 6.2.2 (Cultural Ruptures and Othering).

5Rs of Cultural Humility

Reflection
What did I learn from each person in that encounter?

Respect
Did I treat everyone involved in that encounter respectfully?

Regard
Did unconscious biases drive this interaction?

Relevance
How was cultural humility relevant in this encounter?

Resiliency
How was my personal resiliency affected by this interaction?

Made with Napkin

Figure 1. The 5Rs of Cultural Humility [AI generated image] (adapted from Masters et al., 2019)

2.8. Chapter Summary

In this chapter, I have highlighted the persistent barriers faced by older adults who identify as sexual and gender diverse in accessing timely, equitable, and culturally attuned healthcare, particularly within palliative care settings. It has underscored the centrality of culture and humility in shaping person-centred care. This prevailing emphasis on cultural competence within healthcare practice reveals a significant conceptual gap; namely, the underdeveloped integration of cultural humility. A transformative shift is needed, from viewing culture as a static body of knowledge to be mastered (cultural competency), toward embracing cultural humility as a lifelong process of self-reflection, continuous learning, and relational accountability. Such a transition is essential

for fostering genuinely equitable and responsive palliative care in increasingly diverse clinical contexts.

In response to these challenges, in Chapter Three, I shift focus to cultural humility as a conceptual and practical framework in professional practice for enhancing person-centred care. Through a rigorous engagement with existing literature, the chapter deepens the exploration of cultural humility's defining attributes and examines its relevance across health and social care contexts. Such a foundation enables meaningful integration of cultural humility into professional practice, fostering more inclusive, relational, and responsive approaches to palliative and end-of-life care.

3. Chapter Three: Scoping Review

3.1. Introduction

In the current chapter, I present a scoping review of current literature on the concept of cultural humility, outlining the rationale for the chosen methodology, followed by data analysis, discussion, and concluding recommendations.

Chapter Two introduced culture as a dynamic and multifaceted concept (section 2.4), highlighting its significant role in shaping the interactions of healthcare staff with diverse populations. Culture influences not only how individuals treat others, but also how they expect to be treated (Care Quality Commission, 2025). There are those influences on how health beliefs are formed and when, how, and why individuals, groups, or communities access health services. Culture is also a key determinant in persisting health inequalities experienced by marginalised, underserved, or vulnerable populations. In other words, health inequalities affected by race, ethnicity, gender, sexual orientation, (dis)ability, or socio-economic status (Napier et al., 2014).

In response to increasing global population diversity, there has been growing international emphasis on training health and social care staff in cultural competence. As outlined in Chapter Two (section 2.6), that training seeks to equip staff with the knowledge, skills, and cultural awareness necessary to provide respectful and responsive care. However, conceptualising competence as an endpoint, suggesting mastery of another's culture or achieving Benner's (1982) *expert* level, has faced growing critique. Increasingly, research shows that such an approach may inadvertently reinforce cultural stereotypes and systemic biases, thereby contributing to inequitable healthcare delivery (Greene-Morton & Minkler, 2020; Lekas et al., 2020).

Considering these concerns, there is a growing drive to shift towards more other-oriented frameworks in the training of healthcare staff. An increased emphasis on cultural humility, first introduced by Tervalon and Murray-García (1998), has led to calls for its inclusion in medical education, highlighting its relevance in

fostering respectful and person-centred care. Unlike cultural competence, cultural humility encourages lifelong learning, self-reflection, and the active redress of power imbalances in clinical relationships. It has since been recognised for its potential to reduce racial, social, and health inequalities, not only in the USA, but also in countries with Indigenous populations, such as Canada, Australia, and New Zealand. As Elbanna et al. (2023) suggest, cultural humility represents a broader orientation towards others, increasingly adopted across disciplines including health and social care, education, veterinary science, pastoral support, and librarianship.

3.2. Purpose and Aim

The purpose of this scoping review was to identify the types of available evidence on cultural humility within the broad context of health and social care. By highlighting the distinguishing characteristics of cultural humility through concept analysis, the aim was to synthesise evidence describing key attributes of cultural humility to present a current understanding and interpretation (JBI, 2020).

3.3. Overview of Methodology

Informed by the methodological frameworks of Arksey and O'Malley (2005), Levac et al. (2010), and the JBI guidance (Peters et al., 2020a), this scoping review facilitated the conceptual analysis and interpretation of cultural humility. As highlighted by Munn et al. (2018), scoping reviews are particularly valuable for examining the breadth and characteristics of existing research on a topic and for mapping emerging areas of evidence. They enable a systematic exploration of the extent of the literature, with a specific emphasis on identifying, clarifying, and analysing key concepts, definitions, and theoretical foundations.

Unlike systematic reviews, which focus on synthesising high-quality evidence to answer narrowly defined review questions, scoping reviews draw on diverse sources and methodological approaches. The flexible design allows for the integration of findings from varied, or heterogeneous, datasets making them

ideal for examining complex or evolving concepts (Peters et al., 2020a). The scoping review was conducted following a series of steps under guidance from the JBI methodology, replicated in Figure 2, using Napkin AI (2025).

Steps to Conduct a Scoping Review

1 Define Question
Clearly articulate the research question to guide the review.

2 Set Criteria
Establish rules for including or excluding studies.

3 Search Strategy
Develop a plan to find relevant studies.

4 Screen Evidence
Evaluate and select studies based on criteria.

5 Extract Data
Collect relevant information from selected studies.

6 Analyze Data
Interpret and synthesize the extracted data.

7 Present Results
Communicate findings in a clear and concise manner.

Figure 2. Scoping review process [AI generated image] (adapted from Pollock et al., 2024, p.3)

The scoping review was instrumental in mapping the characteristics, scope, and prevalence of the literature, with concept data analysis used to identify and synthesise overarching attributes and meanings of cultural humility across the literature. Concept analysis, when integrated into a scoping review, enables the identification of a concept's critical elements as they exist within a specific temporal and disciplinary context (Rodgers, 2000; Walker & Avant, 2013).

The decision to use concept analysis was guided by Rodgers et al. (2018), defining it as "inquiry designed to clarify or define a concept by identifying its constituent components and related elements" (p. 452). On identification of the

literature, data analysis was twofold: numerical analysis (charting/ mapping the evidence and results) and textual data analysis using concept analysis.

The concept analysis approach allows the systematic analysis, organisation and synthesis of textual information. Originating in the field of education, Wilson (1963) first introduced the method to help sixth-form students preparing for university entrance exams. He emphasised the importance of examining the various uses and interpretations of a concept to promote deeper understanding.

Concepts are dynamic and evolve in response to changes in practice, context, and discourse (Rodgers, 2000; Tofthagen & Fagerstrøm, 2010). The meaning of cultural humility therefore shifts across disciplines, geographical settings, and time. Although discipline-specific language helps define professional boundaries, shared terms can still be interpreted differently (Hellman, 2024). For example, in psychotherapy, Hook et al. (2017) describe cultural humility as a core element of multicultural orientation, shaping how therapists recognise and respond to cultural differences in therapeutic relationships. In contrast, Hurley et al. (2022) frame cultural humility within U.S. library services as both an organisational strategy for equity, diversity, and inclusion and a personal stance of openness to others' perspectives. These differences show the importance of developing a full understanding of a concept.

Within a scoping review, concept analysis complements the mapping of existing literature by enabling a systematic examination of a concept's attributes, uses, and contextual meanings. This helps clarify conceptual boundaries and deepen theoretical understanding (Walker & Avant, 2013). Importantly, the purpose of concept analysis is not to produce a single, fixed definition. As Rodgers (2000) emphasises, the process does not yield a "crystal clear" (p. 97) conclusion; rather, it supports ongoing conceptual clarification that can guide further development and application within the field.

Given varying applications, textual data analysis using Rodgers' (2000) evolutionary method was selected to synthesise current understandings of cultural humility. The inductive approach emphasises clarification of a concept

as it is used in practice, allowing for an exploration of its attributes across different contexts. In doing so, it helps uncover the essential components of the concept, as well as its antecedents (conditions necessary for its emergence) and its consequences or outcomes. Furthermore, the method supports the distinction of cultural humility from related, and sometimes overlapping terms such as cultural awareness, cultural responsiveness, cultural safety, or cultural sensitivity (Tofthagen & Fagerstrøm, 2010).

3.4. Defining the Review Questions

In developing the review questions, consideration was given to the purpose and remit of the scoping review, along with the overarching research study aim:

- to foster a collaborative environment where healthcare staff engaged in palliative care services share and discuss their understandings, interpretations, and significance of cultural humility as a practice that supports and enhances professional practice and enriches person-centred patient care

The guidance for undertaking scoping reviews with concept data analysis of literature recommends broad, yet comprehensive, review questions (Peters et al., 2020a; Walker & Avant, 2013). Therefore, in accordance with the guidance, the review questions were defined as:

i. How is cultural humility conceptualised in the context of health and social care?

ii. What are the key attributes of the concept of cultural humility as described in the published literature?

3.5. Setting the Inclusion and Exclusion Criteria

To ensure the scoping review was conducted systematically and in an organised way, inclusion and exclusion criteria were set using the Population, Concept, Context mnemonic (PCC) widely recommended in the conduct of scoping reviews (Peters et al., 2020a) as detailed in Table 1.

Table 1. Scoping review PCC mnemonic

Population (P)	professionally registered healthcare staff/healthcare professionals/social workers
Concept (C)	any literature with the principal aim to describe or define the concept of cultural humility
Context (C)	health and social care settings (medicine, nursing, allied health professions, therapy/counselling, or social work)

Sources offering definitions, conceptual discussions, or identifying characteristics of cultural humility were assessed against, and retained according to, the inclusion and exclusion criteria outlined in Table 2. The search was limited to literature published from 1998 onwards, marking the introduction of cultural humility into healthcare discourse by Tervalon and Murray-García (1998).

To ensure rigour, a university faculty specialist librarian was consulted twice to help in identifying relevant electronic databases, Medical Subject Headings (MeSH), and search terms, thereby supporting the consistency, validity, and reliability of the search strategy.

3.6. Search Strategy

To identify literature on cultural humility in the context of health and social care, a broad search of the literature was conducted during the period January 2023 to October 2023, using the criteria laid out in Table 2.

Table 2. Search inclusion and exclusion criteria

Inclusion Criteria	***Exclusion Criteria***
Literature with the principal aim of describing or defining the concept of 'cultural humility'. Sources must explicitly state the term 'cultural humility'	Literature dealing exclusively with cultural competence, cultural safety, cultural sensitivity, or does not explicitly use the term 'cultural humility'
Date range: Published from 1998 onwards	**Date range:** Published prior to 1998

Inclusion Criteria	*Exclusion Criteria*
Language: International literature published and written in English or with full English translation available	**Language:** Non-English language sources without translation
Professions including: Medicine, nursing, occupation health, physiotherapy, psychology and psychiatry, counselling and therapy, social work	**Professions including:** Veterinary medicine, pharmacy, dentistry, dietetics, teaching (all levels), complementary therapies, library services
Types of sources: Any existing published literature, e.g. • primary research studies • systematic reviews • meta-analyses • letters, guidelines, text, and opinion papers unpublished • grey literature material • theses and dissertations with a central focus on cultural humility	**Types of sources:** Sources of evidence dealing exclusively with cultural competence, cultural safety, cultural sensitivity, or awareness Literature with a focus on faith or spirituality, or personal vignettes Literature evaluating or testing tools, training programmes, outcomes measures, or overseas immersion programmes
Location: No geographical restrictions	**Location:** None applied

A search of evidence was conducted across eight databases including: APA PsycInfo, Cumulated Index for Nursing and Allied Health Literature (CINAHL), EBSCO (Academic Search Ultimate), MedLine, ProQuest, Science Direct, SCOPUS, and Web of Science. Additionally, a preliminary search of PROSPERO, the Cochrane Library and the University of York Centre for Reviews and Dissemination was conducted to identify current or underway systematic reviews or scoping reviews on the topic.

At the time of conducting the searches, no published scoping reviews on cultural humility in palliative care were identified, and one scoping review protocol by Singh et al. (2022) was sourced in the field of occupational therapy. The results of that scoping review were published in March 2025 (Kokorelias et al., 2025). The focus was on how cultural humility could be integrated into rehabilitation practice and align with the Canadian Practice Process Framework for occupational therapy.

The search used key words, combined with AND/OR as detailed in Table 3. No MeSH terms for "cultural humility" were available across the databases. The truncation option ("cultur* humility") was used in the database searches.

Table 3. Search key words with Boolean operators

Options	***Search key words with Boolean operators***
1	"Cultural Humility" AND definition OR define OR meaning OR description
2	"Cultural Humility" AND health care OR healthcare OR hospital OR health service OR health facility
3	"Cultural Humility" AND care

The search strategy, including identified key words and index terms, was adapted for each database. For a full search conducted in CINAHL see Appendix 2. Zotero software was used to manage search results, backed up by written records. Eligibility was determined using a two-level process: all titles and abstracts initially examined according to the inclusion and exclusion criteria. For eligible sources, a full-text article/source review was conducted. The search results located a high volume of sources. Therefore, eligibility criteria were refined during the title and screening process.

3.7. Screening of Evidence

The database search and scanning additional records resulted in 3142 retrieved sources. Figure 3 details the selection process, represented in the PRISMA (2020) flow diagram and adapted for scoping reviews (Page et al., 2021; Tricco et al., 2018). Forty one sources were retained following full-text screening for data extraction and further analysis. Appendix 3 details all sources included in the final selection stage.

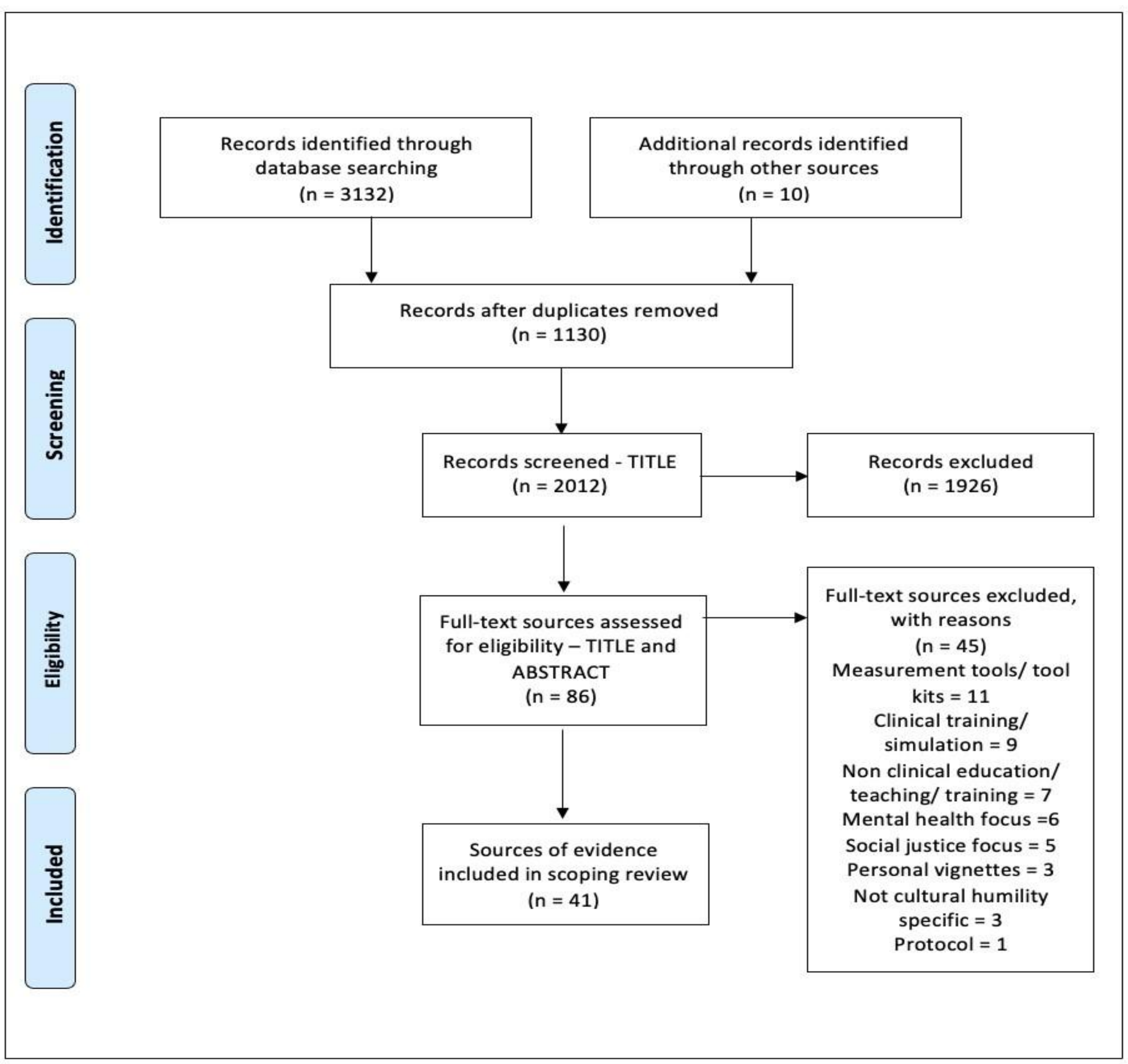

Figure 3. PRISMA diagram (adapted from JBI guidance, Tricco et al., 2018)

3.8. Data Extraction

Following the 2020 JBI scoping review guidelines (updated in 2024), and exemplars found in the literature, a data extraction form was developed (Table 4) (Peters et al., 2020a). Using the form helped identify elements aligned with the PCC mnemonic, while also supporting data extraction relevant to the concept analysis and review questions - including uses of the concept, defining attributes, antecedents, and consequences. The JBI framework recommends extraction fields such as author/year, participants/population, concept, and context (e.g., care setting or geographical location). Appendix 4 presents the completed data extraction for one included study randomly selected.

Table 4. Example data extraction form (adapted from JBI guidance – Peters et al., 2020a)

<table>
<tr><td colspan="2">Article title:</td><td></td></tr>
<tr><td colspan="2">First author:</td><td></td></tr>
<tr><td colspan="2">Year of publication:</td><td>(post May 1998 and pre-October 2023)</td></tr>
<tr><td colspan="2">Geographical focus:</td><td>(Country of originating source of evidence)</td></tr>
<tr><td colspan="2">Type of evidence:</td><td>(this could be empirical evidence, theoretical papers, book chapters, text & opinion papers)</td></tr>
<tr><td colspan="2">Field of practice
(P = population &
C = context)</td><td>(discipline of health and social care)</td></tr>
<tr><td>Definition by Tervalon and Murray-García (1998) included</td><td>YES or NO</td><td>Approach to concept
(framework, practice, or process)</td></tr>
<tr><td colspan="2">Definition (C = concept)</td><td>(include author's definition/interpretation of the concept)</td></tr>
<tr><td>Attributes identified</td><td>YES or NO</td><td>(details of attributes identified)</td></tr>
<tr><td colspan="2">Include in scoping review</td><td>YES/NO</td></tr>
</table>

3.9. Data Charting

After completing evidence screening, selection and data extraction, data charting began. Stage one of the analytical process involved presenting all selected data in tables for clear illustration. Presentations included: year of publication, geographical focus, approach to concept (framework, practice, or process), distribution across disciplines in health and social care, and types of evidence. These are detailed in Table 5.

The majority (95%) of included sources in the scoping review were North American in origin, with the emphasis being on publications from the USA (81%). The other two geographical regions included were Australia (2.5%) and an Irish/European collaboration (2.5%).

Table 5. Demographic details of selected sources

Extracted data	***Results of included source in Scoping Review***	
Year of publication	1998 = 1 1999 to 2011 = 0 2012 = 1 2013 = 3 2014 = 1 (cut-off for published sources included in 2016 concept analysis by Foronda et al.) 2015 = 1 (TOTAL = 7 pre-2016)	2016 = 6 2017 = 2 2018 = 3 2019 = 5 2020 = 7 2021 = 6 2022 = 4 2023 = 1 (TOTAL = 34 from 2016 onwards)
Geographical focus	USA = 33 sources Canada = 5 sources USA & Canada = 1 source Ireland/Europe = 1 source Australia = 1 source	
Approach to concept	Framework = 20 sources Practice = 11 sources Process = 10 sources	
Discipline (by % split)	Nursing = 24% Mental health professions = 22% (psychology/psychiatry/psychotherapy and counselling/therapies) Social work = 17% General healthcare = 15% Allied health professionals = 12% (such as physiotherapy, occupational therapy) Medicine = 10%	

Much of the growth in literature since 2016 was found to be in the disciplines of nursing, (24%), mental health/psychology (22%), and social work (17%). Consistent with the objectives of scoping reviews, the included sources represented a broad scope of evidence type, which in turn facilitated bringing together evidence from different or diverse sources (JBI, 2020).

3.10. Textual Data Analysis

Stage two of data analysis in the scoping review utilised concept analysis. The defining attributes, antecedents and consequence of the concept of interest

(cultural humility) were identified using this analytical method. Rodgers' evolutionary method was used to guide this section of the scoping review.

3.10.1. Rodgers' Evolutionary Method

The chosen data analysis method was selected as opposed to Walker and Avant's (2013) approach due to its alignment with the epistemological positioning of this study and the nature of the concept under investigation.

Walker and Avant's (2013) method adopts a structured, reductionist stance aimed at generating clear, operational definitions, treating concepts as fixed entities that can be broken down into essential attributes. In contrast, Rodgers' (2000) evolutionary approach views concepts as dynamic, context dependent, and continually shaped by disciplinary, social, and temporal influences. Rather than seeking a definitive endpoint, Rodgers' method examines how a concept is currently understood and used within the literature, exploring its attributes, antecedents, consequences, and contextual variations. This evolutionary perspective provides an interpretive lens for analysing how the concept is constructed, interpreted, and applied in practice.

As an approach, the Rodgers' evolutionary method is particularly appropriate for exploring cultural humility, a concept that has emerged across healthcare, education, and social justice scholarship and continues to evolve alongside shifting understandings of power, identity, and structural inequities. Its application within palliative care, especially for older people who are sexual and gender diverse, requires sensitivity to intersecting influences such as age, stigma, and systemic inequities, reinforcing the need for a method that accommodates complexity and contextual variation.

All included sources were read thoroughly, searching for keywords interpreting or describing cultural humility. Sources were coded manually using Microsoft Excel spreadsheets, identifying context (discipline of health and social care), antecedents, attributes, and consequences. Key identifying words and phrases

used by authors were clustered together and arranged into categories. An example of the coding process is available in Appendix 5.

Attributes are those characteristics commonly encountered in a concept's definition or used to describe it. Antecedents are described as events or incidents which occur, or are in place, before a concept can emerge or happen; and consequences are the resulting events, incidents, or outcomes because of the concept (Lam Wai Shun et al., 2022). The identification of antecedents and consequences was important at the data extraction and analysis stages because they were helpful in further refining the defining attributes.

3.10.2. Overview of Definitions

To begin the concept data analysis, a search of dictionary definitions of cultural humility was conducted. The search produced one result, published online by the Collins Dictionary (2020). Cultural humility was defined as "a humble attitude to cultures other than your own, which leaves you open to learning about them and what is important to them".

Tervalon and Murray-García's 1998 article was noted as the most frequently cited source in this review about the concept to date. They defined cultural humility as: "a lifelong commitment to self-evaluation and self-critique, to redressing the power imbalances in the patient-physician dynamic, and to developing mutually beneficial and non-paternalistic partnerships with communities on behalf of individuals and defined population" (p.123) (under section 2.7).

The influential publication by Tervalon and Murray-García was retrieved in all the electronic database searches. All retrieved sources selected for analysis cited this editorial paper, with over two-thirds (*n*=28) making use of the authors' definition in the context of their own work. Papers not using this definition (*n*=13) were from the disciplines of psychology and psychotherapy, allied health professions, and social work. Authors in these fields of healthcare redefined cultural humility relevant to therapists engaged in work with clients, focusing

more on interpersonal and intrapersonal aspects, multicultural orientation and, as suggested by Mosher et al. (2017), "ways of being with clients that prioritize and value diverse cultural identities" (p.222).

To understand a concept clearly, evidence from literature highlights the importance of understanding contextual forces influencing a specific idea at a particular point in time (Rodgers, 2000; Tofthagen & Fagerstrøm, 2010). One concept analysis of cultural humility, published in 2016 by Foronda et al., was retrieved from all the searches. The concept analysis included sources of evidence published between 1998 and 2014. Therefore, it was appropriate in the context of this scoping review to reappraise current societal meaning and understanding of cultural humility.

Results from this scoping review (January – October 2023) highlight the growth in literature on cultural humility since Foronda et al.'s 2016 review, peaking in 2020 and 2021 (Table 5). Thirty-six sources included in this review were published post 2014 and not included in the concept analysis by Foronda et al. (2016). In the latter period (2020-2021) there were five notable authors publishing works on cultural humility: namely Danso, Davis, Foronda, Hook, and Mosher across the disciplines of counselling and therapy, psychology, nursing and social work respectively. Capturing available evidence at a particular moment in time enabled a greater appreciation of the concept's evolution, reflecting its fluidity, dynamism, and ever-changing nature (Salokivi et al., 2022).

3.10.3. Defining Attributes

Although definitions varied across the literature from medicine, nursing, allied health professions, mental health, and social work, key terms used to describe or define cultural humility were identified, extracted, and grouped into categories. Appendix 6 shows the links between authors and the generated categories.

The results indicate attributes are considered as inherent values or meanings underlying the concept in the context of health and social care. Pollock et al.

(2023) recommend visual presentation with supporting narrative in scoping reviews. From the data analysis, four overarching domains were conceptualised as pillars and labelled to represent the defining attributes of cultural humility:

- The '**SELF**' individual/intrapersonal
- With '**OTHERS**' interpersonal/collective
- The '**BEING**' intrinsic nature/ essence of
- The '**FEELING**' aspirational principles

Initially, the framework was visualised as a quartet of discrete domains, positioned around cultural humility as the central construct. However, this representation implied independence between all domains, which did not reflect the dynamic and integrative nature of the concept as evidenced in the literature. Continued engagement with the data highlighted the interdependent and fluid relationships between these domains. Consequently, the framework was refined to emphasise their interconnectedness, illustrating cultural humility as an ongoing, relational, and iterative process enacted within professional practice.

The attributes are visually presented in Figure 4 as the *Cultural Humility in Palliative Care Framework*; a creative way to convey the results of the textual data analysis, using concept analysis. To assist visualising the analysed data, Napkin AI (2025) has been used to create images. When prompted, Napkin AI responded with a series of images. After a first image was created, it was refined by editing text (principally image titles and formatting). A summary of the prompts used to generate a selection of images created for the thesis is available in Appendix 1.

These pillars were subsequently brought together and named as the *HEARt* model using key attributes extracted and identified during data analysis of retrieved literature:

- **H** = humility
- **E** = empathy and evaluation (of self)
- **A** = accountability and awareness

- **R** = respect and reflection
- **t** = brings everything together

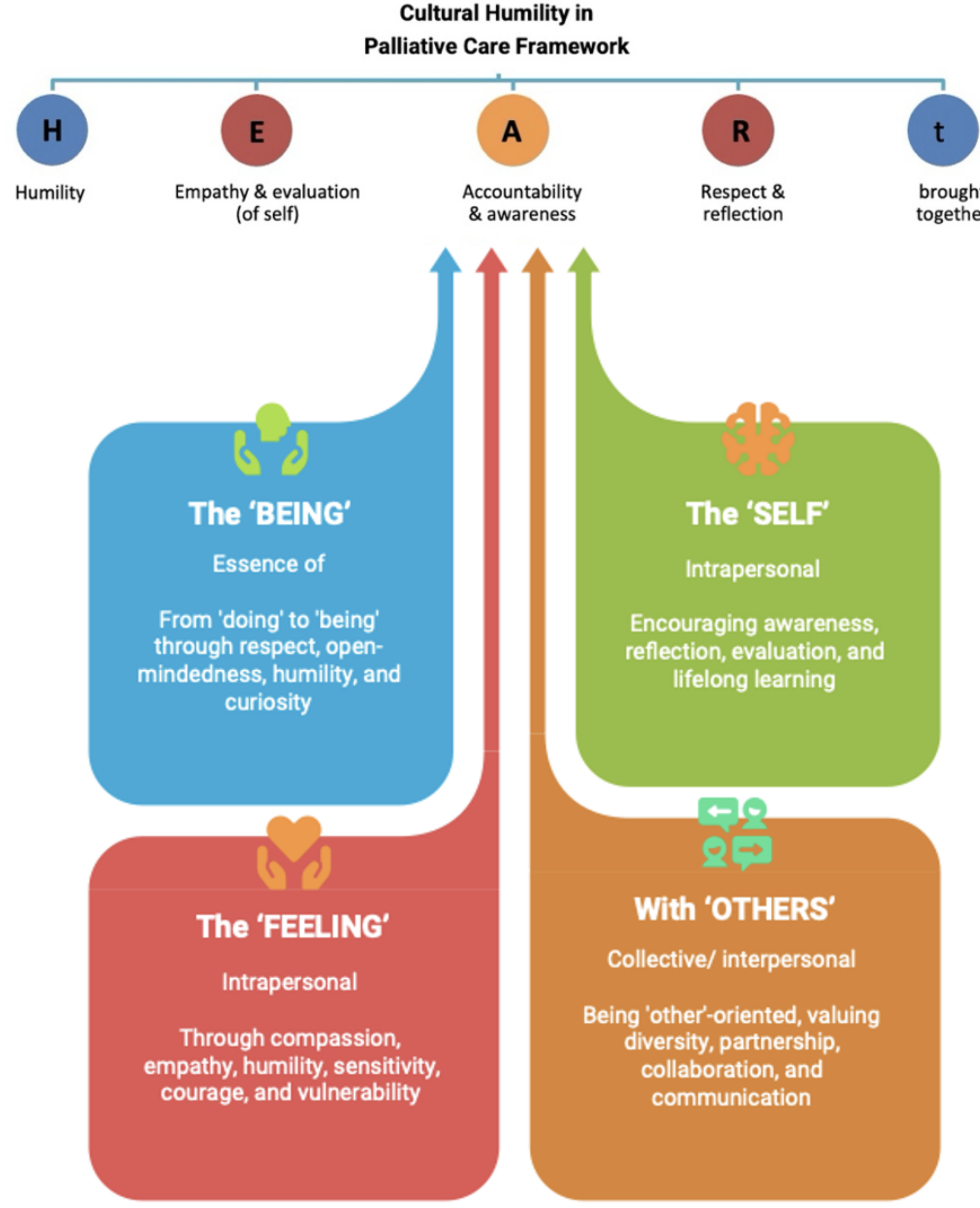

Figure 4. Cultural Humility in Palliative Care Framework (the HEARt Model) [partly AI generated image]

The HEARt acronym was subsequently developed as a mnemonic to support recall and application among health and social care staff. It encapsulates the core attributes identified from the literature:

- Humility (H)
- Empathy and self-evaluation (E)
- Accountability and awareness (A)
- Respect and reflection (R)

The lowercase 't' signifies the co-existence and integration of these elements within practice, bringing the attributes together.

Three overarching categories were identified. First, *individual-related* attributes encompassed internal processes such as accountability, self-awareness, evaluation, reflection, and a commitment to ongoing learning. Attributes allocated to *the 'SELF'* (individual or intrapersonal) pillar include critical self-awareness, self-reflection and self-evaluation, a commitment to lifelong learning, and accountability (Issacson, 2014; Neubauer et al., 2016; Hammell, 2013; Yeager & Bauer-Wu, 2013).

Second, *action-oriented* attributes, representing the enactment of cultural humility in practice, included being other-oriented, collaboration, and partnership. The attributes allocated under the *with 'OTHERS'* pillar of the framework (interpersonal and collective) are other-orientated, partnership, collaboration, communication, and valuing diversity and differences (Danso, 2018; Mosher et al., 2016; Mosher et al., 2017; Yancu & Farmer, 2017).

Third, *attitudinal and value-based* attributes captured the dispositional elements of the concept, including humility, respect, open-mindedness, courage, and vulnerability. These groupings align with the interpersonal and intrapersonal dimensions of humility discussed in Chapter Two (Section 2.5). The intrapersonal dimension relates to internal cognitive and reflective processes, whereas the interpersonal dimension emphasises relational engagement and action within healthcare practice.

Attributes allocated under *the 'BEING'* and *the 'FEELING'* pillars are representative of values describing the essence and aspirational principles, or the intrinsic nature, of cultural humility highlighted throughout the literature: notably being respectful, humble, egoless, curious, and open-minded (Abe, 2020; Agner, 2020; Bennett & Gates, 2019). The '*FEELING*' pillar encompasses the attributes of compassion, empathy, humility, sensitivity, courage, and vulnerability (Chávez, 2022; Markey et al., 2021; Nguyen et al., 2020; Zhu et al., 2021). These attributes reflect a transition in the relational context from the *doing* to *being* with patients by health and social care staff.

The *Cultural Humility in Palliative Care* framework and the HEARt model emerged from the scoping review through sustained engagement with literature exploring the conceptualisation and application of cultural humility. During the analytical phase, particularly in defining the attributes of the concept, the framework was developed as a visual representation of the identified attributes. They were derived through the identification of recurrent keywords and phrases across the literature. As Rodgers (2000) suggests, such linguistic patterns function as representations or expressions of a concept, offering insight into its underlying meaning. These extracted terms were systematically grouped according to their primary focus.

3.10.4. Antecedents

Antecedents were identified by repeated themes, phrases and words consistently noted in the retrieved sources, as detailed in Table 6.

The position of *expert* (as referred to in Benner's (1982) novice to expert model) is reached by assuming mastery, or competence, signifying the attainment of knowledge and skills until an end point is reached (Campinha-Bacote, 2019; Chang et al., 2012). Patients continue to experience power imbalances due to healthcare staff keeping control over them, reinforcing their role as knowledgeable authorities in healthcare, often regarded as aligned with the dominant mainstream culture (Fisher-Borne et al., 2015; Issacson, 2014).

Table 6. Identified antecedents with descriptions

Antecedent identified	***Description***
Assuming mastery	• Competence suggests knowledge and skills with end point • Reaching 'expert'
Power imbalances	• Maintaining control • Epistemic privilege of practitioners • Being part of the dominant mainstream culture
Cultural insensitivity	• Lack of awareness or understanding • Holding 'a priori' assumptions
Ethnocentrism	• Ignorance and tolerance • Arrogance
Othering	• Them vs Us

Cultural insensitivity is the lack of awareness or a failure of healthcare staff to understand, respect, or appropriately respond to what is already known about patients' cultural beliefs, values, and practices. The consequences are miscommunication, mistrust, poor treatment adherence, and health disparities (Jiang & Samah, 2025). A lack of cultural awareness can manifest as discrimination, unequal access to care, or the imposition of biased care plans, resulting in negative patient experiences and worsened health outcomes, especially for marginalised communities (Vandecasteele et al., 2024).

Ethnocentrism, by definition, is the tendency to look at the world from one's own cultural perspectives, believing that culture is superior to others perpetuated by arrogance, ignorance, or tolerance (Campinha-Bacote, 2019; Chang et al., 2019). The final antecedent is that of *othering*: a stance taken of *them versus us* (Campinha-Bacote, 2019). Situations such as these often arise without

conscious effort or even awareness by individuals. It is based on the conscious or unconscious assumption that a certain identified group poses a threat to the favoured group and is heightened by biases, stereotyping, labelling or stigmatisation (Cherry, 2022; Hook et al., 2013; Hook et al., 2016; Powell & Menendian, 2016).

3.10.5. Consequences

Across the literature, the consequences of engaging with cultural humility were consistently expressed as:

- therapeutic alliances
- mutuality of relationships between patients and healthcare staff
- mutual empowerment and optimal patient care
- cultural decentering (shifting the focus away from a dominant cultural perspective to consider alternative viewpoints and experiences)
- the mitigation of power and influence

Therapeutic alliances (trusting and collaborative relationships) were a consequence of trust and mutual respect between patients and healthcare staff (Lee et al., 2022; Mosher et al., 2017). Mutual empowerment and optimal care encouraged individualised treatment, improved patient satisfaction, medical adherence, and better health outcomes (Bangs et al., 2022; Lee et al., 2022). The mutuality, or interdependence, of relationships resulted from collaboration and cultural decentering (Markey et al., 2021). The latter was revealed through culturally inclusive practices, models and assumptions, social inclusion, and intercultural working (Chávez, 2022).

Lastly, mitigation of power and influence was attainable when healthcare staff relinquished their role of expert about patients’ culture or lived experiences, instead becoming a student of the patient, and contributing to the reduction in health inequalities (Foronda, 2020; Issacson, 2014; Keselman & Awais, 2018).

3.11. Discussion

Using a scoping review approach, relevant evidence was identified and both descriptive (e.g., year of publication, geographical location, approach to concept, discipline) and definitional data were extracted to map how cultural humility is interpreted across health and social care. The primary aim was not to produce an operational definition but to explore current interpretations of the concept across the literature and to delineate its principal characteristics.

Using a scoping review to identify relevant evidence and extract both numerical and definitional data, this synthesis provides an overview of how cultural humility is interpreted within health and social care by identifying its key attributes. The aim was not to generate an operational definition, but to explore current interpretations of the concept across the literature and delineate its principal characteristics.

The evidence base made up literature from medicine, nursing, physical therapy, occupational health, medical art therapy, mental health disciplines (psychology, psychotherapy, counselling), and social work. Notably, no publications were retrieved from other allied health fields such as dietetics, radiography, or paramedic science, and there was a marked scarcity of research within oncology and palliative care. Most sources originated from the USA, reflecting the concept's introduction and initial integration into medical education by Tervalon and Murray-García (1998).

Using the scoping review process to chart (or map) extracted data, the 1998 definition by Tervalon and Murray-García emerged as the most influential within the health and social care literature. A considerable number of the sources referenced this foundational definition, emphasising lifelong self-reflection, critical examination of power imbalances in patient-provider relationships, and the promotion of collaborative partnerships as central components of cultural humility.

It is important to note the limited representation of published literature from regions outside North America, including the United Kingdom and Europe, within the scoping review. The imbalance is likely due to the heightened recognition of cultural humility in the USA as a critical factor in addressing racial and health inequalities, particularly reflected in the surge of scholarly publications during 2020 and 2021. The growth in literature coincided with intensified racial tensions following events such as the death of George Floyd and the exposure of ethnic health disparities during the COVID-19 pandemic (Bangs et al., 2022; Chávez, 2022; Henderson et al., 2022; Lee & Haskins, 2022).

Among the limited international literature, Australian research highlighted cultural humility as a framework for social workers engaging with Aboriginal People who identify as sexual and gender diverse (Bennett & Gates, 2019). Additionally, a pan-European study examined the application of cultural humility to promote inclusivity and enhance multidisciplinary team collaboration (Markey et al., 2021).

Literature widely framed cultural humility as a process-oriented concept, contrasting with outcome-oriented models focused on achieving competency through skill acquisition. A process-oriented perspective prioritises the continuous journey of learning rather than a fixed endpoint. Kolb and Kolb (2017) support this view, proposing that knowledge evolves through ongoing experience and reflection, underscoring the necessity of lifelong learning for cultural humility to meaningfully enhance cross-cultural interactions, patient-centred care, and social inclusion.

The analysis reveals a critical observation. The core attributes of cultural humility are not discrete or hierarchical, but rather interdependent and co-constitutive. As illustrated in Figure 5, these attributes coexist in a dynamic equilibrium, with no single pillar exerting dominance over the others. The interconnectedness indicates a broader conceptual shift in the literature, which increasingly positions cultural humility as a relational and reflexive practice rather than a static set of competencies.

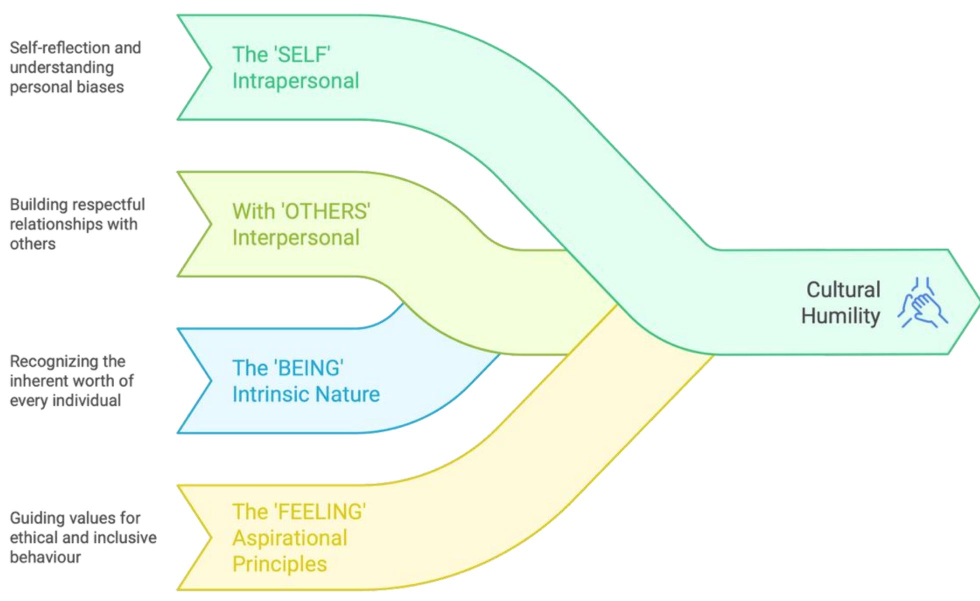

Figure 5. Inter-related pillars of Cultural Humility

Notably, the dual orientation toward the 'SELF' and toward with 'OTHERS' emerges as foundational across studies, suggesting that effective integration of cultural humility in healthcare settings requires both inward reflection on personal biases and outward engagement with diverse patient experiences. The duality reinforces the notion that cultural humility is sustained through continuous self-awareness and empathetic interaction, rather than achieved through isolated skill acquisition, the key purpose of cultural competency.

The process-oriented nature of cultural humility is illustrated in Figure 6. It begins at the intrapersonal level (the 'SELF' pillar), where healthcare staff cultivate awareness of their own beliefs, values, assumptions, and biases to avoid viewing patients through a singular cultural lens. As this awareness develops, the approach extends to the interpersonal or collective level (with 'OTHERS' pillar) enabling healthcare staff to recognise and respond to the diverse cultural identities and values that matter to patients and their families (Hook et al., 2013).

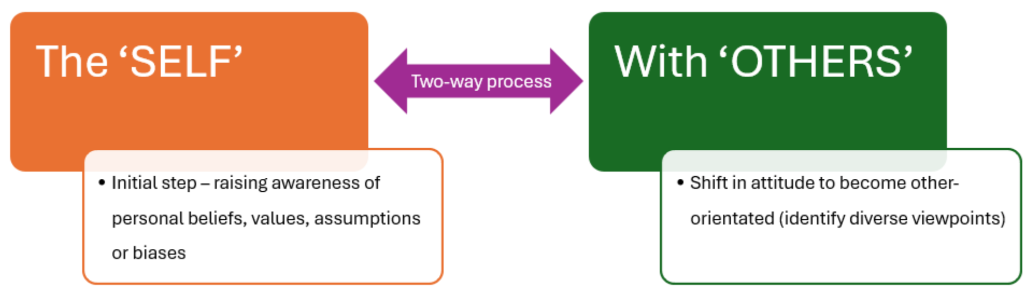

Figure 6. A representation of the process-orientated approach through Cultural Humility

Hughes et al. (2020) emphasise the importance of fostering attitudes conducive to cultural understanding, grounded in lifelong learning, accountability, and commitment. A patient-centred approach further promotes collaborative relationships, encapsulated by Keselman and Awais (2018) as the willingness to "relinquish your own power and to let your client guide you to where you need to go to help her" (p. 82). Consequently, individuals from marginalised or underserved populations are empowered to educate those in positions of privilege (or those with clinical expertise) about their cultural heritage and lived experiences.

In health and social care, scholars including Campinha-Bacote (2018), Foronda (2020), Keselman and Awais (2018), and Lekas et al. (2020) describe cultural humility as a continual learning process that involves openness to learning from others, recognition of one's knowledge limitations, and ongoing self-reflection and critique. Zhu et al. (2021) note the need for consistency in practice, cautioning against "turning on and off" cultural humility (p. 80) and describing it as "always achieving, but never achieving" (p. 88). Cultural humility requires curiosity, tolerance for uncertainty, and prioritising the patient's agenda over that of healthcare staff (Gottlieb, 2021).

Within social work and psychotherapy, cultural humility forms a core element of multicultural orientation frameworks, underpinning effective therapeutic engagement. Hook et al. (2017) encourage therapists to adopt "a stance of cultural humility" (p. 200), which fosters sensitive communication by shifting the

focus from “what is wrong?” to “what has happened?” to the individual, thereby avoiding reductionist views based on medical diagnoses or illness (Gottlieb, 2021, p.476).

The use of humility and its variations (e.g., being humble, having a humble mind) across disciplines merits attention. As discussed in Chapter Two (section 2.5) humility here is not about negating pride or showing low self-esteem but relates specifically to cultural interactions and experiences. Chang et al. (2012) advocate for the importance of humility as both a process and goal in intercultural communication and interactions. Often regarded as a virtue, humility plays a significant role in fostering respectful relationships and has the potential to enhance patient care by making it more culturally sensitive (Worthington, 2007). Humility is therefore conceptualised as the connecting element facilitating the intersection of the attributes depicted in Figure 6 and forms the cornerstone to the HEARt model.

The early published theoretical papers on cultural humility highlight the importance and value of humility in practice, paving the way for a shift in scholarly literature towards an emphasis on being other-orientated as healthcare staff are encouraged to engage with multiculturally orientated or cross-cultural and sensitive practice. A stance of humility enables healthcare staff to focus on cultural differences and being open to others (other-orientated). It encourages the intersection of with ‘OTHERS’ and the ‘FEELING’ pillars from the Cultural Humility in Palliative Care framework and HEARt model.

According to Tervalon and Murray-García (1998), humility is understood to play a crucial role in the ongoing process of self-reflection, lifelong learning, addressing the power dynamics between patient and provider, and in the establishment of therapeutic and mutually respectful partnerships and relationships. Subsequently, as suggested by Hook and Davis (2019), cultural humility is a facet of humility, while Chávez (2022) and Gottlieb (2021) suggest it enables a transition from cultural exclusion (superiority of one cultural group over others)

to cultural relativism (a stance recognising that no culture is inherently superior to another).

Differences in individuals' experiences of the world emphasise the value of giving priority to alternative perspectives by cultivating open-mindedness and committing to lifelong learning. Cultural relativism in palliative care emphasises the need to honour patients' cultural beliefs, values, and traditions when navigating end-of-life decisions (Ezekiel, 2024). It encourages healthcare providers to move beyond a one-size-fits-all approach, recognising that concepts like autonomy, pain management, and spiritual care vary widely across cultures (El Khoury, 2025).

Healthcare staff recognise their limitations and exhibit humility by acknowledging gaps in their knowledge. A willingness to admit uncertainty is essential for improving patient outcomes and enhancing individual clinical skills through continuous learning. Humility enables healthcare staff to shift from being an expert about the patient's culture, to a student of the patient, and committing to equality and equity in the therapeutic relationship.

According to Agner (2020), humility serves as a catalyst for healthcare staff to acknowledge the influence of power dynamics on their interactions with patients and families. Furthermore, as highlighted in a study conducted by Hook et al. (2013) into perceptions of a therapist's cultural humility, humility enables healthcare staff to learn from every encounter, whilst preventing tokenism (the practice of making a cursory or symbolic effort to employ inclusive practices to give the appearance of inclusiveness and fairness).

In their discussion on cultural humility in palliative care, Neubauer et al. (2016) stress the importance of humility, wherein healthcare staff acknowledge their limitations in understanding the intricacies of diverse cultural groups and the diverse identities that may affect or influence individual patients. Every person who is being cared for carries within them a part of the cultural context that has affected their identity. Humility is increasingly recognised as a core attribute in

palliative care, fostering respectful and empathetic relationships between healthcare providers, patients, and families facing life-limiting illnesses. It involves acknowledging the limits of medical knowledge and control, embracing uncertainty, and prioritising the patient's values, preferences, and lived experience (Schill & Caxaj, 2019).

Humility in professional practice aligns closely with cultural humility principles, promoting sensitivity to diverse cultural and existential needs at the end of life. Healthcare staff willing to adopt a stance of humility approach care with openness, vulnerability, and a willingness to listen deeply, thereby enhancing trust and shared decision-making (Singh et al., 2023). In palliative care settings, humility helps mitigate hierarchical power dynamics traditionally inherent in healthcare by encouraging providers to stand alongside rather than above patients, facilitating genuine partnership in care (Zinan, 2021). Consequently, this orientation supports holistic care that honours the psychosocial, spiritual, and cultural dimensions of the patient's experience, reflecting the essence of palliative care.

In the mental health professions, significant importance is placed on a clinician's humility, especially in the context of managing microaggressions and therapeutic ruptures that may arise while engaging with patients. Variations in values, cultural biases (the microaggressions), and a lack of willingness to engage in dialogues that are culturally sensitive and appropriate may result in disruptions (the ruptures) within the clinician-client relationship (Hook et al., 2016; Mosher et al., 2017).

The importance of humility as opposed to competence is highlighted by Hook et al. (2016), with Loue (2022) placing emphasis on the significance of an individual's humility rather than competence. They advocate for healthcare staff to undertake critical self-reflection about their personal characteristics and areas requiring growth. Furthermore, practitioners are encouraged to engage in reflective practice, remain open to vulnerability, and foster collaborative relationships that promote mutual benefit and shared understanding.

To promote social inclusion in health and social care, Chávez (2022) emphasises the importance of humility as the quality of being modest in a rapidly changing cultural context, recognising one's own vulnerability, and being willing to acknowledge and learn from mistakes. Encouraging humility in all clinical encounters leads to a mindset of curiosity and respect for diverse cultures, advocating for the implementation of socially inclusive practices. Healthcare staff are urged to relinquish their expert role and instead concentrate on building partnerships that are mutually advantageous.

Despite widespread support for the inclusion and infusion of cultural humility into clinical practice, certain authors, particularly in the field of social work, posit that cultural humility, along with cultural competence, may contribute to the reinforcement of biases, stereotypes, and paternalistic clinical relationships due to an overemphasis on one's own perspective. Danso (2016) contends that cultural humility mirrors fundamental principles found in anti-oppressive social work and education, thereby providing minimal advantages to clinical practice.

Cultivating an awareness or a suitable degree of knowledge is essential for engaging in culturally humble practice, and as argued by Nguyen et al. (2020), it is recommended that competence exists alongside humility. Additionally, the absence of a clear conceptual understanding and a universally recognised definition across disciplines in health and social care is seen as a barrier to the incorporation of cultural humility as a process-oriented practice.

While the broader literature suggests that culturally humble healthcare staff uphold principles of diversity, equality, and equity, findings from the scoping review reveal a lack of cultural humility application and integration at the organisational or systemic level. A gap may hinder culturally responsive clinical practice by reinforcing structural inequalities within healthcare organisations and systems.

3.12. Recommendations

The contribution of this scoping review lies in synthesising the defining attributes of cultural humility and identifying its antecedents and consequences across the literature. This analysis establishes an initial foundation for further conceptual development and supports deeper exploration of how cultural humility is understood within health and social care.

By organising these attributes into a coherent framework, the review enhances conceptual clarity while enabling meaningful application in professional practice. This structured model helps healthcare staff navigate culturally diverse settings and accommodates the varied interpretations of cultural humility that exist across disciplines, acknowledging and respecting contrasting viewpoints.

Cultural humility should not be regarded as a practice which is exclusively either intrapersonal or interpersonal, identified by the 'SELF' or with 'OTHERS' pillars of the Cultural Humility in Palliative Care framework. Additionally, the practice of, and infusion into clinical practice of cultural humility requires more than the 'BEING' (the essence of and intrinsic nature of) and the 'FEELING' (aspirational principles) focus for healthcare staff. Informed by a scoping review of current literature, the Cultural Humility in Palliative Care framework and the HEARt model serve as key starting points to support staff orientate towards becoming other-orientated, in a way that does not reinforce mastery of skills or culture-specific knowledge. Furthermore, the framework and model may play a role in helping healthcare staff to promote and deliver holistic and person-centred patient care.

An appreciation of how context and time influence the understanding and interpretation of cultural humility may serve to facilitate the application of the framework and model in professional practice. Obtaining data to broaden knowledge of the concept's use and integration at the organisational or system level will help to widen its contribution towards the multicultural orientation of professional practice.

3.13. Strengths and Limitations

The scoping review was conducted following guidance outlined by the JBI, covering multiple databases across a wide selection of disciplines in health and social care. They were systematically searched and all databases used were appropriate. The comprehensive nature of the search and the multiple duplicate records between databases reduced the risk of missing vital sources.

However, there are some limitations to the current review. An initial literature search highlighted the scarcity of sources on cultural humility specifically in palliative care (for example - CINAHL search retrieved two results (TITLE only) and 13 results (TITLE and ABSTRACT). For this reason, the search was broadened to include the health and social care context. The scoping review was limited by the inclusion of English language papers only, as well as sources focusing on either an interpretation or description of cultural humility. Documents published in other languages, as well as those focused on education and training, outcome measures, or patient and staff experiences, may not have been retrieved during the database search.

Because most of the included publications originated from the USA, the scoping review may reflect a degree of content bias, potentially shaping the extraction, analysis, and interpretation of the findings. The available literature was largely theoretical in nature, presenting subjective interpretations of cultural humility informed by individual authors' perspectives. In addition, the inclusion and exclusion criteria narrowed the scope of the review to theoretical discussions rather than practical applications in clinical settings or evaluations of outcome measures used by healthcare staff

In contrast to systematic reviews, where formal quality appraisal is a required component, this scoping review did not conduct such assessment. Current methodological guidance indicates that assessing the quality or potential bias of included sources in a scoping review is optional rather than required (Peters et al., 2020a; Pollock et al., 2024). In line with this guidance, all retrieved sources

were instead reviewed and discussed in consultation with academic supervisors to ensure rigour and transparency in the interpretation of the evidence

In alignment with JBI methodological guidance, this review aimed to explore broader questions than those addressed in traditional systematic reviews (Peters et al., 2022). The primary aim was to describe and map the existing literature based on the characteristics and factors outlined in the review's aims, review questions, and inclusion criteria. Additionally, the review sought to examine the scope of current knowledge surrounding cultural humility and to identify and discuss its defining features (Peters et al., 2022; Peters et al., 2020a; Peters et al., 2020b).

In the context of the thesis, it is acknowledged the landscape relating to cultural humility will have continued to evolve since the literature searches were conducted. Research outside of the context of health and social care was not included in the review and analysis, which may contribute to a more in-depth and diverse interpretation and understanding of the concept. It is also acknowledged that cultural humility and its relationship with closely related terms such as cultural competence, cultural safety, or cultural sensitivity were not considered in this scoping review of the literature.

3.14. Chapter Summary

Evidence on cultural humility within health and social care contexts was systematically examined as part of the scoping review. The analysis involved charting, mapping, and synthesising the existing literature to identify the defining attributes of cultural humility, thereby generating an updated and critically informed understanding of the concept. Analysis, synthesis, and discussion indicate that cultural humility, while widely referenced in health and social care, lacks a single, universal definition. It emerges as an evolving, context-dependent process: one that can be cultivated over time. Despite its growing relevance, cultural humility stays deeply rooted in individual awareness, interpretation, and practice. Understanding this complexity is crucial for advancing equitable, and culturally sensitive and responsive palliative care.

Cultural humility provides a pathway towards delivering person-centred, context-responsive healthcare. By committing to lifelong learning and critical self-reflection, healthcare staff can actively counteract the risks of cultural homogenisation, othering, and fragmentation. Rather than relying on assumptions or moral judgments, they learn directly from those they care for: deepening cultural insight and enhancing clinical relationships (Nyamwaya, 2022). Embracing humility (within cultural humility) requires recognising one's own biases and appreciating the complex intersection of identity, culture, and health beliefs.

Central to the study was the co-creation of knowledge on cultural humility with participants as co-researchers, reflecting the participatory ethos of the methodology. Insights from the scoping review were used to help inform interpretation of focus group and reflective activity findings (Chapters Five and Six), without unduly influencing them.

Chapter Four sets out the philosophical foundations of the research and outlines the rationale for selecting Participatory Action Research as the guiding methodological approach.

4. Chapter Four: Philosophical Foundations and Methodology

4.1. Introduction

In this chapter, I set out the philosophical foundations underpinning the research design and my rationale for choosing Participatory Action Research as the methodological approach. I describe the population, sample and recruitment methods, data collection, and data analysis methods. I also discuss the role of reflexivity and my positionality as researcher and participant (as a co-researcher). I conclude with measures taken to address research quality, rigour, and trustworthiness.

There are a range of underpinning values and principles in palliative care (and more generally across the wider healthcare spectrum) helping to inform and shape the research approach for this study. They include emphasis on interdisciplinary team working, professional and personal empowerment, addressing power imbalances between healthcare staff and patients, and the desire to deliver empathetic, compassionate, and equitable patient care. These values and principles are evident in a range of different research approaches and methods, including collaborative processes whereby people work together as co-researchers.

In the context of this study, as introduced in Chapter One (section 1.4), a co-researcher is a position that promotes participant involvement in the research process. Participants are invited to tell their own stories and bring an insider perspective to cultural humility as it is practised in palliative care. Treating participants as co-researchers enables the study to draw directly on their experiential knowledge, transforming them from objects of inquiry into active contributors who both ask questions and observe the research process (Given, 2008). Their active involvement stimulates dialogue, encourages others to share and interpret experiences, and positions the researcher as a learner, making the research process itself an opportunity for collective learning and meaning-making.

The aim is to bring about change, whether that be at the individual, organisational or wider societal level. In the context of this study, research is undertaken within the field of community and specialist palliative care in the UK by involving, listening to, and working with healthcare staff providing the care.

4.2. Underpinning Philosophical Position

Qualitative constructivist and participatory paradigms underpinned the research, presented later in the chapter. The constructivist approach to culture emphasises that cultural knowledge, values, and norms are not innate or universally shared, but emerge through social interaction and are shaped by individual and collective experiences (Schwandt, 1998). Across the literature, culture is conceptualised as dynamic and fluid, emerging from the ongoing processes of meaning-making and negotiation within specific social, historical, and organisational contexts (as discussed in Chapter Two - section 2.4). Such an approach aligns well with qualitative and participatory methodologies, as it acknowledges the subjectivity of lived experience and the diverse ways individuals understand and enact culture in practice.

I purposefully shaped the study's design to explore cultural humility in professional practice, with a particular focus on palliative care for older people who are sexual and gender diverse. Through the lens of constructivism and participatory paradigms, and Participatory Action Research as the selected methodology, the research investigated not only how cultural humility was understood and could be applied in practice, but also how it might serve as a catalyst for more inclusive, person-centred care.

At the centre of this approach was a commitment to collaboration. Participants, positioned as co-researchers, were invited to share their perspectives, articulate lived experiences, and contribute meaningfully to the generation of new knowledge. In doing so, the research established a space in which participants were acknowledged as legitimate and valuable contributors to the co-construction of knowledge. The engagement process was intended to cultivate a sense of empowerment, affirming the role of cultural humility in transforming

both professional practice and the experiences of patients and families within palliative care settings.

4.3. Research Approach

It is widely acknowledged that research can be approached in many ways, most commonly through quantitative, qualitative, or mixed methods (Bryman, 2016; Grix, 2019; Jahn & Dunne, 2007). These approaches reflect differing assumptions about reality, knowledge, and the relationship between researcher and subject.

Quantitative research, grounded in a realist and positivist tradition, views individuals as objective units, and prioritises control, measurement, and generalisability (Crotty, 2015; Flick, 2014). In healthcare, this approach has been critiqued for overlooking the nuanced, subjective experiences of patients and practitioners (Bunniss & Kelly, 2010; Corry et al., 2019). In contrast, qualitative research aims to understand how individuals interpret their experiences, offering rich insights into human behaviour and social meaning (Creswell & Creswell, 2017; Denzin & Lincoln, 1998; Grix, 2019). It employs flexible methods such as interviews and observations to explore thoughts, emotions, and interactions within real-life settings where people live, work, and interact.

In this study, I adopt a qualitative approach to explore and understand participants' perceptions and lived experiences, aiming to capture the complexity of personal and social realities rather than predict or control them (MacDonald, 2012; Pring, 2015; Struebert, 2011).

4.4. Methodological Choice

Methodology refers to the theoretical and philosophical framework underpinning how research is conceptualised, conducted, and interpreted. It encompasses the rationale behind the selection of research strategies and methods and serves as a guiding framework that shapes the overall design and execution of a study (Braun & Clarke, 2013; Glesne, 1999; Silverman, 2013). Methodology is not only concerned with procedural aspects but also reflects the broader

ontological and epistemological assumptions of the researcher. A methodology provides a framework for addressing key questions such as why the research is conducted, what is being studied, from where data is derived, and how and when data is collected and analysed (Scotland, 2012).

Crucially, methodology is informed by the researcher's underlying worldview (the research paradigm*)*, encapsulating a set of interconnected beliefs, values, and assumptions about knowledge and reality (Braun & Clarke, 2013; Creswell & Creswell, 2017; Denzin & Lincoln, 1998). Reason (1994) describes a worldview as "a set of agreed ideas and practices to which members of the … community conform" (p. 40), highlighting its communal and contextual nature. The worldview guiding the research process serves not as a rigid set of rules, but as a flexible orientation shaped by the researcher's disciplinary background, prior experiences, academic influences, and philosophical stance (Creswell & Creswell, 2017).

The paradigms and chosen methodology guide how knowledge is explored and interpreted (Mackenzie & Knipe, 2006). In this study, the constructivist and participatory paradigms inform the methodology and methods, aligning them with the research aim and objectives, and acknowledging my positionality as researcher, co-researcher, and nurse engaged in palliative care.

4.5. Philosophical Foundations

Philosophical beliefs about reality and knowledge are shaped by individual perspectives. As previously discussed, the researcher's own beliefs inform the paradigm, methodology, and methods chosen for a study. These stem from fundamental philosophical assumptions about the nature of reality (ontology), the nature of knowledge (epistemology), and how knowledge is acquired (methodology) (Heron & Reason, 1997). Guba and Lincoln (1994) outline three key questions that help researchers clarify their worldview:

i. What is the nature of reality? (ontology)
ii. What is the relationship between the knower and what can be known? (epistemology)
iii. How can knowledge be acquired? (methodology)

In this study, these philosophical considerations guide how I, as the researcher, understand reality, what kinds of knowledge are possible, and how validity is determined, thereby guiding the choice of methods (Brearley & Walshe, 2020). While some scholars debate whether ontology and epistemology should be treated separately or as interlinked, many agree that ontology precedes and shapes epistemology (Bates & Jenkins, 2007; Grix, 2019; Marsh et al., 2010). Marsh et al. (2010) emphasise that ontology concerns the fundamental question of being, while Grix (2019) stresses that differing ontological assumptions can lead to varied research outcomes.

Philosophical positions are not always neatly aligned with a single tradition (Niglas, 2010), and worldviews evolve over time through experience and interaction (Guba & Lincoln, 1998). Ontological beliefs shape epistemological positions, which in turn inform methodological decisions (Cohen et al., 2018). As Saunders et al. (2012) argue, assumptions about knowledge and reality are made at every stage of the research process, influencing the framing of research questions, methodological choices, and interpretation of findings.

4.5.1. Ontology

Ontology refers to the philosophical assumptions a researcher holds about the nature of reality and what can be known about it (Crotty, 2015). In the context of research, ontological beliefs shape the lens through which the researcher views the world and influence all subsequent methodological choices. A relativist ontology underpins this study, positing that reality is not objective or singular, but rather constructed through human interaction and interpretation. That is, reality is seen as multiple, context-dependent, and shaped by the social, cultural, and historical environments in which individuals operate (Creswell & Creswell, 2017; Guba & Lincoln, 1998).

Within a relativist ontology, it is assumed that individuals engage in a continual process of meaning-making, and that their understandings of the world are formed through shared experiences and negotiated understandings. Crotty (2015) contends that reality becomes intelligible only when it is made meaningful, highlighting the centrality of sense-making in the construction of social reality. Meaning is not inherent in objects or events but arises through interpretive engagement between individuals and their environments. Consequently, reality is not discovered but constructed; a view that aligns with social constructivist thinking, which sees knowledge and reality as co-produced through language, interaction, and cultural practices (Burr, 2015).

Within this study, the relativist ontology acknowledges that each participant (as co-researcher) brings their own unique perspective, shaped by personal experience, values, and contextual factors. Therefore, it is expected that multiple interpretations of reality will emerge, each valid within its own frame of reference. The role of the researcher is not to uncover a single, objective truth, but to understand and represent the diversity and complexity of these lived realities (Bunniss & Kelly, 2010).

This ontological position also requires the researcher to engage in critical self-reflection, recognising the influence of their own background, identity, and positionality in shaping the research process and interpretation of findings. My own ontological assumptions have developed through both lived experience and social conditioning. Social conditioning tells us what to believe, while lived experience shows us how we interpret and make sense of the world.

Drawing on Struebert's (2011) concept of the "received view" (p.4), my understanding of reality has been shaped by early influences such as family, education, and cultural heritage. As a white, British woman of Irish descent from a middle-class and educated background, my worldview has been shaped by values, norms, and epistemic traditions. These intersecting influences contribute to how I interpret participants' experiences and construct meaning from the data.

In adopting a relativist ontology, I accept that there is no fixed or universal reality, but rather a plurality of truths, each situated within specific social and historical contexts (Flick, 2014). Such a position enables the recognition of diverse voices and experiences; an especially valuable perspective in healthcare research, where understanding the nuanced realities of individuals is essential for meaningful and empathetic engagement. It also legitimises subjective knowledge as a valid and necessary part of inquiry, challenging the notion that only empirical or measurable phenomena make up factual knowledge (Flick, 2014).

Relativist ontology holds that reality is not a single, unchanging entity but depends on the conceptual or cultural lens through which it is viewed, and seeks to illuminate the richness, depth, and variation of human experience, acknowledging the co-constructed and evolving nature of social reality. Thus, the ontological stance of relativism taken in this study does not aim to generalise or predict outcomes.

4.5.2. Epistemology

Epistemology concerns the nature of knowledge, how it is constructed, and the relationship between the knower and what is known (Crotty, 2015; Guba & Lincoln, 1994). A subjectivist epistemological stance guides this study, aligning with a relativist ontology outlined previously. From this perspective, knowledge is not discovered as an objective truth existing independently of human consciousness. Rather, knowledge is understood through individual interpretation, social interaction, and contextual understanding (Grix, 2019).

The construction of knowledge is grounded in real-world phenomena and the meanings individuals attribute to their experiences. These meanings are inherently subjective, shaped by personal histories, social contexts, and ongoing sense-making processes. As individuals engage with their environments and with others, they actively interpret the world around them, drawing on empathy, shared cultural understandings, and lived experience. Hammersley (2013) emphasises this inward process, noting that fellow human beings are

understood “from the inside” (p.34) through empathy, shared experience, and culture, rather than viewing them as passive objects of study.

Within a subjectivist epistemology, knowledge is understood as being shaped through social interactions which stays fluid. Epistemology is often shaped by the researcher's own perspectives, assumptions, and interpretive lens. In qualitative health research this is particularly relevant, where individuals (healthcare staff, carers, or service users) do not passively receive knowledge, but actively construct it through reflection, interaction, and practical application (Thomas et al., 2014). Therefore, this suggests that evidence is not static or universally applicable, but rather situated and co-produced, shaped by the complexity and variability of human experience.

For this study, the researcher (myself) and co-researchers (participants) are recognised as active participants in the co-construction of knowledge. The subjective lens through which everyone perceives the world will inevitably influence how multiple realities are interpreted. These interpretations are informed by each participant’s unique biography, cultural background, professional identity, and social location (Crotty, 2015). My own epistemological positioning is shaped by a lifetime of receiving, processing, and interpreting knowledge, informed by individual experiences, relationships, education, and professional practice. Reflecting on one’s own positioning is not viewed as a limitation but as a valuable resource that enhances the depth and authenticity of the research process.

Furthermore, as Crotty (2015) suggests, understanding the social world is constructed through a diversity of perspectives, and the *truths* that emerge are negotiated through shared dialogue and mutual recognition. Rather than striving for objective certainty, this study seeks to explore the multiple meanings and layered understandings that arise from the lived experiences of those involved. Knowledge, therefore, is conceptualised not as an external entity to be uncovered but a shared, dynamic, and interpretive process, embedded in the social and cultural fabric of everyday life.

4.6. Chosen Paradigm

Within numerous research disciplines, including the health and social sciences, four dominant paradigms have traditionally been recognised: positivism, post-positivism, critical theory, and constructivism, with the latter three often categorised as postmodern paradigms (Guba & Lincoln, 1998).

Subsequently, this classification has expanded to incorporate a participatory paradigm, introduced by Heron and Reason in the late 1990s (Guba & Lincoln, 1998; Heron & Reason, 1997). The participatory paradigm has been developed in response to evolving research priorities focused on understanding the lived experiences of diverse and often marginalised groups, including people who identify as sexual and gender diverse, and interrogating the inequalities that arise from power imbalances within human relationships (Creswell & Creswell, 2017). It is a worldview (or paradigm) characterised by an emphasis on the creation of knowledge through collaboration, co-creation, and shared meaning-making between the researcher and participants.

Despite ongoing debate within the research community, there remains no universal consensus about the definitive number of paradigms that may inform and guide research, nor are all paradigms compatible; for instance, positivism is often viewed as fundamentally incompatible with participatory approaches. Given that social interaction and dialogic engagement are foundational to knowledge construction, and that much of qualitative research is conducted with, rather than on, people (as in the case of this research), my epistemological stance principally aligns with the constructivist paradigm. In doing so, this position recognises that knowledge is co-created through transactional and interpersonal dialogue with participants as co-researchers.

The constructivist paradigm is underpinned by guiding principles that align with my philosophical beliefs. As articulated by Crotty (2015), constructivist researchers acknowledge that meanings emerge through active engagement with the world under study. Constructivist theory emphasises how individuals make sense of their experiences based on historical and social contexts, where

meaning generation is inherently socially influenced and occurs through interaction within human communities.

Accordingly, research methods consistent with this paradigm often involve open-ended inquiries designed to elicit rich, contextualized perspectives from participants. Creswell and Creswell (2017) further suggest that constructivist researchers achieve understanding through immersive data collection, inductively deriving meaning from the settings and individuals involved.

In this study, I adopt a constructivist paradigm which entails an explicit recognition of subjectivity. Findings are inherently influenced by the researcher's values and experiences and are co-created throughout the research process. The interplay between experience and knowledge formation is supported by Heron and Reason (1997), who argue that experiential knowledge, gained through active participation, is central to understanding phenomena. Truth, from this perspective, is generated through personal, lived experience rather than solely through logical deduction or detached observation (Borkman, 1976).

The emphasis on participation and experiential knowledge is echoed in the participatory paradigm, where knowledge is not merely observed but is lived and enacted by research participants (Heron & Reason, 1997). The importance of experiential learning is further emphasised by Kolb and Kolb (2017) and reinforced by Hamilton and Varey (2020), asserting that knowledge is continuously constructed through individual experience, thereby shaping, and informing one's worldview.

At the outset of this research, I positioned myself within the constructivist paradigm as articulated by Guba and Lincoln (1998). However, as the study progressed, it became clear that my methodological approach was shaped by constructivist and participatory paradigms, coexisting, and functioning in parallel. The convergence is illustrated in Table 7 where key elements drawn from the works of Guba and Lincoln (1998), Heron and Reason (1997), and Creswell and Creswell (2017) are presented.

Table 7. Key qualities and values influencing philosophical underpinnings and methodological choice (adapted from Guba & Lincoln, 1994; 2005)

Item	Constructivism	Participatory
Ontology	Relativism (multiple mental constructions, which are co-constructed realities)	Participative reality (subjective - objective)
Epistemology	Subjectivity – findings influenced by values and experience 'Findings' created inductively (as the research progresses)	Experiential and practical knowing Co-created findings
Methodology	QUALITATIVE Interaction between and among researcher and participants Interpretative and explanatory	QUALITATIVE/MIXED METHODS Collaborative action inquiry Shared experiential context
Inquiry Aim	Understanding and reconstruction	Human flourishing (choosing, acting, transforming)
Nature of knowledge	Reconstruction which is individual or collective Democratic agreement sought	Living & practical knowledge
Voice	'Passionate participant' as facilitator of multiple perspective reconstruction	Mixed voices Reflexivity which is dependent on analytical subjectivity and self-awareness Secondary voices informing theory, narrative, and other presentational forms

Legend: Mixed voices = key values I share as researcher and co-researcher

The values and principles of both paradigms resonating most strongly with my research stance are highlighted. These paradigms have collectively contributed to framing, guiding, and informing this study, particularly in relation to:

- The influence of researcher values and experience on findings
- The co-creation of knowledge and the inclusion of diverse participant voices
- Dynamic interactions between researcher and participants
- The pursuit of collaborative action inquiry
- The role of the 'passionate participant' in fostering human flourishing

4.7. Methodological Choice: Participatory Action Research

Having reflected on my ontological and epistemological positioning, I have adopted a qualitative participatory action research framework for approaching this study. Participatory Action Research is a collaborative form of human inquiry in which individuals and communities are engaged in the co-construction of knowledge through ongoing cycles of planning, acting/observing, reflection, and replanning (Figure 7).

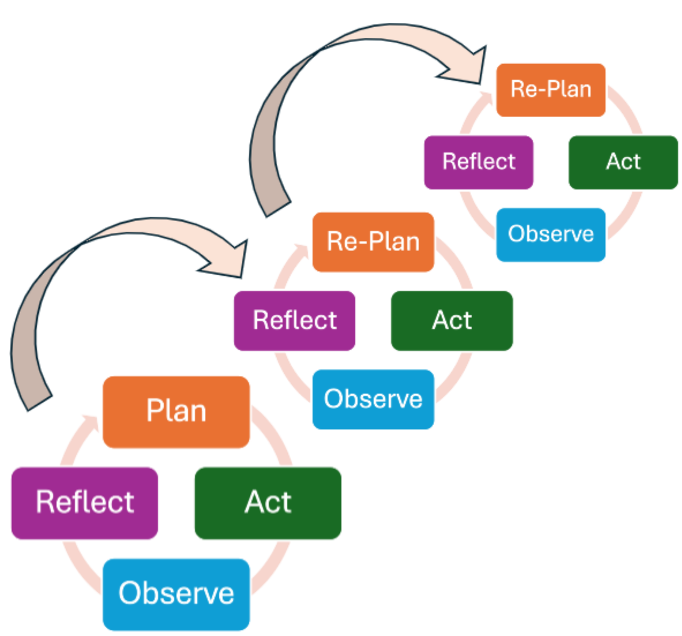

Figure 7. The action research iterative cycles (adapted from Kemmis, McTaggart & Nixon, 2014, p.31)

Reason (1994) describes Participatory Action Research as a process cultivating both individual and collective capacity for inquiry, while fostering a desire for continued participation and self-determined change within particular contexts. The rest of this section outlines the application of Participatory Action Research within the context of this study, discusses its key characteristics, and provides an overview of its relevance in addressing the research aim and objectives.

A defining feature of Participatory Action Research is the emphasis placed on participation, empowerment, and action-oriented change. Participatory Action Research aims not only to generate knowledge, but also to facilitate meaningful transformation amongst participants involved. A collaborative ethos aligns with interdisciplinary approaches to professional practice in palliative care, making it particularly relevant in healthcare contexts.

Reason (1994) positions Participatory Action Research more broadly as “co-operative and experiential inquiry” (p.1), highlighting the relational and participatory foundations upon which it is built. Similarly, Reason and Bradbury (2008) articulate that research with an emphasis on action does not originate from a desire to impose change *on* others. Rather, it arises from a commitment to enact change *with* others. In choosing Participatory Action Research, this methodology reflects my philosophical approach using a multi-paradigm perspective, integrating both constructivist and participatory paradigms, previously discussed in section 4.6 (Chosen Paradigm). They are working collaboratively, acknowledging that knowledge is co-created through dialogue, grounded in lived experience, and directed toward action and social betterment.

The development of Participatory Action Research is most attributed to the foundational contributions of Kurt Lewin, Orlando Fals Borda, and Paulo Freire (Breda, 2014). Fals Borda and Freire argue that researchers must begin participatory inquiry by reflecting critically on their own assumptions, worldviews, and positions of power. Lewin, on the other hand, introduces the concept of cyclical inquiry, involving iterative phases of planning, action, and reflection.

The participatory action research approach focuses on problem-solving in real-world settings, and seeks to understand the role of attitudes, stereotypes, and structural forces (such as social, political, and economic) in shaping both individual and group behaviour (Breda, 2014). McIntyre (2008) builds on this by emphasising the importance of group dynamics and the belief that individuals, through critical examination of their own realities, will organise to bring about change.

Within healthcare, Participatory Action Research is particularly relevant for addressing systemic inequalities by involving those directly affected in shaping the research process and outcomes (Baum et al., 2006). Schubotz (2020) reinforces the ethical imperative to include the voices of under-represented and marginalised groups in research. While their inclusion may present recruitment challenges, these individuals have crucial experiential knowledge and should not be excluded or viewed as lacking the ability to contribute meaningfully to research focused on issues of inequality, inclusion, and social justice.

Situated within the healthcare context, action-oriented research methodologies, such as Participatory Action Research, offer a holistic framework for understanding health and the lived experience of illness. Hughes (2008) describes this as a means of gaining a "holistic way of understanding health" (p.381) by considering the individual in their broader personal, social, and environmental context. Action-orientated research is an approach that rejects reductive, disease-centred models and instead acknowledges patients as whole persons by integrating their physiological, psychological, emotional, and spiritual wellbeing. Participatory Action Research also draws attention to the importance of therapeutic and empathetic relationships between healthcare staff and patients as central to the delivery of meaningful care. These are also key principles underpinning palliative care delivery and practice.

Participatory Action Research provides a practice-oriented framework for generating knowledge grounded in lived experience and collective inquiry (Hynes, 2013). It facilitates interdisciplinary collaboration through iterative

cycles of data collection, reflection, and action (Swantz, 2008). This study uses Participatory Action Research because it can help bridge the gap between theory and practice, and for its ability to connect theory with practice and reveal the systems and relationships that shape care delivery (Froggatt & Hockley, 2011).

Participatory Action Research involves a cycle (or cycles) of planning, action, and reflection, allowing researchers and participants to explore and respond to real-world issues before implementing and evaluating change (Froggatt & Hockley, 2011). In palliative care, this approach supports collaborative evidence generation and context-specific improvements in practice (Glasson et al., 2008). Kemmis (2009) highlights that meaningful change in clinical settings requires attention to three connected areas: what healthcare staff do, how they reflect on their work, and the broader social and structural conditions shaping that work. These pillars are conceptualised as the interdependent "sayings, doings, and relatings" (Kemmis, 2009, p.463), which must be addressed collectively to effect meaningful and sustainable transformation in healthcare practice.

4.7.1. Rationale for Choosing Participatory Action Research

Within healthcare, professional practice is grounded in evidence-based knowledge, yet it must also prioritise the individual needs and values of patients and their support network (Abernethy, 2015; Sackett et al., 2000). As a registered nurse, I have observed instances where patients who identify as sexual and gender diverse are stereotyped by staff (clinical and non-clinical); experiences profoundly shaping my professional and research interests.

In this study, I advocate for person-centred, individualised care, reducing the emphasis on task-driven or label-centric approaches. In palliative care, the imperative to maximise quality of life for those with life-limiting illness, and to support their families, demands that healthcare staff embrace collaborative partnerships, action, and empathy. Set against this context, participatory and collaborative research that aims at “transforming reality” through action is especially valuable (Rahman, 1993, p.75).

Consistent with Schubotz (2020), there has been a growing trend in healthcare research to involve non-clinical experts (patients, family members, and other stakeholders) in meaningful ways. Their inclusion ensures that those often excluded from research, yet having essential lived experience, have their voices heard. In his typology of participatory research, Heron (1996) explains that in Participatory Action Research, researchers from more privileged positions collaborate with those from less privileged contexts. In this study, while all co-researchers (as clinical and non-clinical healthcare staff) share similar professional privileges, our diverse experiences and backgrounds create meaningful differences in perspectives.

The participatory and action-oriented values underpinning this research support the active involvement of those in the knowledge-generating process who may perpetuate or witness health-related discrimination, stigma, or health inequality. Bongiorno (2014) affirms Participatory Action Research as a powerful method for enhancing professional practice. Through iterative engagement, co-researchers begin with individual viewpoints that, through collaborative dialogue, merge into a shared, emergent perspective. Through collaboration, the process enables the reconciliation of the imperative for empirical evidence with the need to honour lived experience; a harmonious integration of both without privileging one over the other (Hamilton & Varey, 2020).

For me as a researcher, Participatory Action Research is significant not only for its methodological rigour but also for its capacity to foster trust, communication, mutual learning, and respect among co-researchers, despite our differences (Brown, 1982, in McIntyre, 2008). I was particularly drawn to the relational and democratic ethos of Participatory Action Research, where knowledge is not extracted but co-constructed. Within this collaborative framework, participants are not positioned as passive subjects of inquiry but as active, engaged contributors in shaping, interpreting, and disseminating meaning. Participatory Action Research reflects my own values as both a nurse and a researcher, and it aligns closely with the aim and objectives of this study, which look not only to

generate knowledge, but to do so in ways that are inclusive, participatory, and grounded in shared experience.

Reflecting on the depth and form of collaboration in this study, I draw upon Schubotz's (2020) adaptation of Arnstein's (1969) *ladder of citizen participation*. The ladder is a conceptual model originally developed to illustrate the distribution of power in decision-making processes related to social policy and urban development. Applied within a healthcare and palliative care context, the model helps me critically position the participatory nature of this study and interrogate how power, voice, and agency are shared throughout the research process.

As a clinician-researcher, I am acutely aware of how historically marginalised voices, particularly individuals identifying as sexual and gender diverse, have often been excluded or overlooked in health-related research. Therefore, using this model allows me to better understand how inclusive and collaborative my own approach is in practice. I recognise that this research sits between what Schubotz terms *co-design* and *co-production/peer research* (levels three and four illustrated in Figure 8).

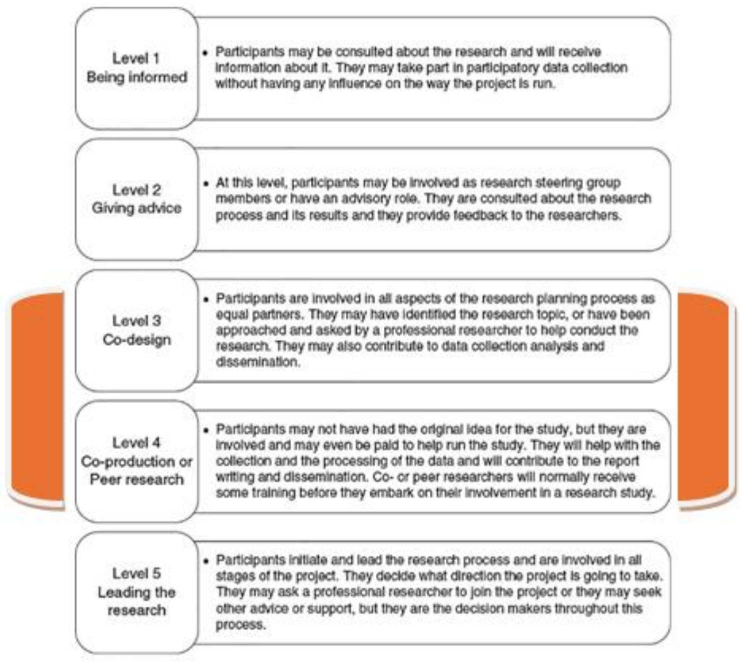

Figure 8. Forms of participation & levels of involvement (adapted from Schubotz, 2020)

I initiated the study and developed its original aim, objectives, and research questions, but the co-researchers actively contributed to shaping its direction. They added meaningfully to data collection, analysis, and interpretation, drawing on their lived experience to influence both the content and the process of knowledge generation. We made decisions together about how to share the findings within the scope of this PhD, guided by a shared commitment to ethical dissemination and real-world impact. Collaboration and reflexive engagement reflect the principles of Participatory Action Research and aligns with the values of palliative and person-centred care (empathy and mutual respect) and the ethical inclusion of voices often marginalised in clinical settings.

4.7.2. Ethical Considerations and Approvals

All research involving human participants requires a robust ethical framework. In participatory research, where roles between researcher and participant can blur, maintaining ethical integrity requires continuous reflexivity, careful management of relationships and expectations, and responsiveness to emerging issues (MacDonald, 2012; Schubotz, 2020). Given the relational nature of qualitative inquiry, principles such as respect, care, and integrity were central to this study.

I conducted the study in line with the UK Academy of Social Sciences (2015) guidelines, emphasising the avoidance of harm, informed consent, confidentiality, and anonymity. Ethical approval was granted by Lancaster University's Research Ethics Committee (Appendix 7 and Appendix 8) under reference FHM-2022-0658-RECR-1, with site-specific approvals obtained prior to recruitment (Appendix 9). I also adhered to Lancaster University's Code of Practice for Research Ethics and Governance.

Throughout the study, I upheld my responsibility to act with compassion, reflexivity, and accountability. Informed consent was ongoing. We collaboratively developed ground rules and a group agreement, which helped shape the direction of the research (Appendix 15). I ensured all co-researchers received and understood the study information in advance, with signed consent obtained prior to the introductory session (Appendix 13).

I adopted a reflexive and sensitive approach throughout, mindful of the potentially emotive nature of the research and its impact on participants. Co-researchers were invited to use a disturbance diary as a supportive and reflexive tool (Appendix 14). Emotional or time-related burdens were acknowledged and discussed during focus groups, and I encouraged the use of clinical supervision or wellbeing services where needed for everyone involved, including myself. These services were all detailed in the participant information sheet. I stayed flexible with scheduling and followed organisational lone-working policies to ensure safety during data collection.

Confidentiality and anonymity were prioritised, though I was transparent about their limitations in a group setting. We openly discussed the implications of sharing individual experiences, particularly around sensitive topics, and agreed on how to maintain privacy and respect throughout. I used pseudonyms and removed identifying details from transcripts or recorded Teams sessions and written minutes to protect anonymity. I was committed to accurately representing contributions from all co-researchers. I took care to protect identities when using individual comments from the recorded focus group sessions. Consent for sharing material was revisited throughout the study, ensuring co-researchers felt informed and in control of their contributions.

4.7.3. Researcher Reflexivity

Reflexivity, understood as the critical self-awareness of the researcher's influence on the research process (Bryman, 2016), was a vital part of my approach. It required ongoing self-awareness of both my subjective interpretive responses (individual perspectives shaped by one's cultural, social, and personal background) and outward behaviours during the study (Dowling, 2006).

My role as a researcher involved two interrelated modes of engagement: *first-person* and *second-person* inquiry (Marshall, 2016). First-person inquiry involved cultivating self-awareness and critically examining my own perspectives, assumptions, and behaviours through reflexive practice. Second-person inquiry

focused on facilitating collective exploration by bringing people together to form a community of inquiry around shared questions and concerns.

As a specialist palliative care nurse working in the community, I was aware that I brought to the research both professional knowledge and lived experience of the concept under investigation. I acknowledged that my values, assumptions, and clinical perspectives could influence the research process. In keeping with the principles of Participatory Action Research, my reflexivity extended beyond personal reflection to include a shared, relational process, where power, positionality, and meaning-making were continually examined in collaboration with co-researchers (Kindon et al., 2007).

I engaged in reflexive practice throughout all stages of the study, staying attentive to how these factors shaped the research design, data collection, and analysis. I introduced reflexivity in Chapter One (section 1.3) and will elaborate further in Chapters Five and Six. I acknowledged all co-researchers' reflections as unique records of experience and remained mindful of the interpretive responsibility involved in presenting them. I also recognised the emotional and intellectual demands of conducting the study and kept regular contact with my supervisors, promptly raising any concerns.

4.8. Methods

To support this participatory, action-oriented inquiry, I selected focus groups and solicited participant diaries as the primary methods, as both reflect the study's core values of collaboration and reflection. These approaches align well with Participatory Action Research, offering rich, nuanced data while facilitating shared meaning-making and individual insight.

Although semi-structured interviews were initially considered, the collective and interactive nature of focus groups, combined with the introspective depth of diaries, better suited the study's aim:

- Collaborative exploration and sense-making of cultural humility as a concept

- Real-world application as a practice for healthcare staff
- Contribution to professional practice, ensuring the delivery of equitable and inclusive palliative care

As Kidd and Kral (2005) note, action-oriented research seeks to bring together those affected or concerned by an issue relating to professional practice to explore it collaboratively. In this study, co-researchers engaged with the complexities of professional practice in palliative care and patient care, through group discussion and reflective writing, fostering critical awareness, shared accountability, and a multi-faceted understanding of experience.

4.8.1. Research Setting

My research was conducted with two organisations found in the East of England. Although a third site was invited to take part in the research, no expressions of interest were received from staff based there. Of the two chosen sites, the first organisation (site one) was a charitable organisation commissioned to deliver specialist palliative care services, encompassing both community-based and inpatient settings. The second organisation (site two) supplied NHS services, inclusive of generalist palliative care in community and inpatient settings.

The community teams serve a large geographical area, largely rural with several large towns. The low population density is predominantly white British, with an older demographic profile reflecting the area's appeal as a retirement destination. There are logistical challenges in accessing services due to the rural nature of the region. Patients often need to travel considerable distances to reach care facilities, while community-based healthcare staff face similar challenges in delivering care to individuals in their homes (HSIB, 2023).

According to the recently published European Association for Palliative Care (EAPC) Atlas of Palliative Care 2025, the UK has a reported rate of 1.27 specialist palliative care services per 100,000 inhabitants (Garralda et al., 2025). However, the atlas does not account for regional or geographical variations within the UK. Despite this, the UK's service provision compares favourably to several other

European countries, including Germany (1.12), Belgium (1.54), Sweden (1.89), and Switzerland (2.1 per 100,000 population) (Garralda et al., 2025).

In the aftermath of Brexit and the COVID-19 pandemic, a considerable number of individuals originating from Eastern and Southern European countries (mainly the Czech Republic, Poland, Latvia, Romania, the Russian Federation, and Portugal), have either returned to their countries of origin, or moved elsewhere. These demographic shifts have contributed to a reduction in both the availability and cultural diversity of the health and social care workforce.

A 2023 report by the Healthcare Safety Investigation Branch (HSIB) highlights notable variation and inequity in the provision of palliative care services across England. Across Suffolk and South Norfolk, there exists an expectation among patients and families for access to traditional hospice-based care. However, given the presence of only two hospices in the region, most palliative care is delivered within community-based settings, placing increased demand on local and mobile services (HSIB, 2023).

4.8.2. Population

Initially, I intended to recruit and involve participants who were qualified nurses, nursing associates, or assistant practitioners registered with the NMC at the two sites. As introduced in Chapter One (Section 1.4), participants were invited to act as co-researchers, engaging collaboratively in the interpretation and co-construction of knowledge and meaning. The inclusion criteria focused on those directly involved in the delivery of palliative care or those with a demonstrated professional interest in the field. As the study progressed, eligibility criteria were broadened to reflect the multidisciplinary nature of palliative care.

The expanded participant group included healthcare staff from both health and social care sectors, such as doctors, allied health professionals (e.g., physiotherapists, occupational therapists, paramedics), social workers, counsellors, therapists, chaplains, and care coordinators. An inter-professional and inclusive approach aimed to capture diverse perspectives that mirror the collaborative nature of palliative care practice.

4.8.3. Sampling Strategy

In qualitative research, including participatory research approaches, sample size is not determined by statistical power but rather by the richness, relevance, and depth of the data needed to understand the phenomenon under investigation (Patton, 2015). The emphasis is placed on information-rich cases that offer meaningful insight, rather than numerical generalisability (Creswell & Poth, 2024).

Participatory Action Research prioritises collaboration and co-creation of knowledge, and thus participants are not merely study subjects but co-researchers. As such, the sample is often purposefully selected to include individuals who are directly involved in, or affected by, the issue under study (McIntyre, 2008). Known as purposive sampling, this sampling selection enables the inclusion of participants who bring lived experience, contextual knowledge, and shared interest in the research aims (Palinkas et al., 2015). Staller (2021) defends the use of purposive sampling because the researcher exercises their judgement by intentionally inviting people or selecting locations that can help to yield the most relevant and plentiful data alongside the selection of the broadest range of perspectives possible.

Sample sizes in Participatory Action Research tend to be small to moderate, reflecting the intensive and iterative nature of the research process. A participant group typically ranges from six to 20 individuals, depending on the research scope, complexity, and logistics of participation (McIntryre, 2008). Sample adequacy is reached not through statistical saturation but through the point of data sufficiency, when the research questions are adequately addressed, and further data is unlikely to yield additional insights (Braun & Clarke, 2021).

Moreover, Participatory Action Research often includes multiple phases (or cycles) of engagement, meaning participants may be involved across various stages, from planning and data generation to reflection and action. Cyclical and collaborative engagement also means that sample size can be fluid, adapting as

the inquiry evolves and as participation deepens or expands (Reason & Bradbury, 2008).

The intention underpinning the sampling strategy was to recruit a group of up to ten participants from a range of health and social care professions, each of whom would engage as co-researchers in the study. Purposeful sampling was employed to maximise opportunities for diversity across key characteristics, including gender, professional and personal background, clinical expertise, and level of seniority. Purposive sampling was adopted to foster a broad spectrum of experiences and perspectives, thereby enriching the depth and relevance of the participatory inquiry.

In selecting purposive sampling, I acknowledged its inherent limitations in terms of transferability to the broader population. Nevertheless, this sampling strategy was intentionally employed to access what Cohen et al. (2018) describe as "knowledgeable people" (p.219). Notably, individuals whose professional roles, clinical expertise, and experience in palliative care positioned them to provide rich, contextually grounded insights. The intent was to gain in-depth and insightful understandings from those best placed to inform the research focus, aim and objectives.

In addition to purposive sampling, a snowball sampling technique was employed to enhance participant recruitment. Co-researchers were invited to recommend other individuals who they believed could contribute valuable and relevant insights to the study. In doing so, this facilitated the identification of potential co-researchers beyond the initial sampling frame, thereby broadening the diversity and richness of perspectives within the research group.

4.8.4. Recruitment

Participant recruitment for this study was initiated by consulting with the education team at site one and the research and development (R&D) team at site two. I started recruitment following the receipt of all necessary approvals from

both organisations, as well as from the local integrated care board (2022GC03) overseeing site two (Appendix 9).

To help recruitment, I developed an invitation flyer to promote the study and provide contact details for potential participants seeking further information (see Appendix 10). The flyer was sent out across both sites through internal communication channels, including intranet news bulletins and physical displays on staff notice boards. A member of the senior leadership team at site one and the R&D officer at site two functioned as gatekeepers for their respective organisations, collating contact details about staff expressing an interest in joining the study and sending their details onto me.

Potential participants expressing interest were either sent an information pack via email or provided with a hard copy in person. The pack included: covering letter, participant information sheet, consent form, and proposed prompt sheet for the first focus group session (Appendices 11 - 13). To meet informed consent requirements, participants were provided with comprehensive information to enable an informed decision about participation. Consent forms were returned either electronically as email attachments or handed to me directly in person. The participant information sheet detailed the study's purpose, methodology, and participant involvement.

Participants were afforded adequate time to ask questions and to deliberate on their decision between receipt of the information and the commencement of the focus groups. I took steps to ensure participation was entirely voluntary, with no coercion or undue influence exerted on potential participants. No incentives were offered beyond the provision of basic stationery materials.

Participants were fully informed of their right to withdraw from the study at any time, without the need to supply a reason. If a participant chose to withdraw after data collection and analysis had begun, I assured them that every reasonable effort would be made to remove their data, provided this was still possible prior to the final compilation of the thesis.

In response to the recruitment campaign, ten expressions of interest were returned to me. Once potential participants had reviewed the information pack, seven agreed to attend the introductory session. Following on from that, five participants expressed their continued interest, totalling six co-researchers including myself moving on to the focus group stage. A profile detailing sociodemographic and professional characteristics is summarised in Table 8.

Table 8. Participant demographics

Demographics/ Pseudonym & Participant ID	Gender	/ Profession	Job Role	Clinical Background	Organisation
Clara **P1 – participant**	F	Registered nurse	Clinical nurse specialist (CNS)	Community, oncology, and palliative care	Hospice services
Mac **P2 – participant**	M	Registered nurse	Practice educator	Community CNS, clinical team lead	Hospice services
Diana **P3 – participant**	F	Occupational therapist	Research officer	Frailty and falls prevention	NHS care provider
Bianca **P4 – participant note-taker/ admin**	F	Administrator	Care co-ordinator	Medical Librarian	Hospice services
Dorothea **P5 - participant**	F	Occupational therapist	Senior Leadership Team	Community occupational therapist	Hospice services
Me - Siobhán **P6 – researcher & facilitator**	F	Registered nurse	Hospice community nurse	Community nursing, oncology & palliative care	Hospice services

4.8.5. Data Collection

Data collection took place between November 2022 and February 2024. Focus groups were held via Microsoft Teams (Microsoft Corporation, 2025) every six to eight weeks, unless rescheduled due to conflicting commitments (personal/ professional) or illness. All participants were familiar with using this method for meetings.

At the introductory session I explored everyone's preference for either holding subsequent sessions online or face to face in person. The group decided collectively to meet online, as this reduced time commitments for travelling, and enabled each participant to attend from a setting of their choice, given that the

sessions were held after core working hours (9am – 5pm). Each session lasted approximately 90 minutes in the evening to accommodate all co-researchers' clinical commitments. Alongside the focus groups, I invited co-researchers to keep solicited diaries, intended as a tool for reflexive engagement throughout the data collection period. Figure 9 provides a visual representation of the data collection timeline.

4.8.5.1. Focus groups

Focus groups were chosen for their ability to foster interactive dialogue, collective reflection, and shared meaning-making within a safe, supportive environment (Nyumba et al., 2018). They aligned closely with the participatory ethos and philosophical foundations of the study, which emphasised collaboration, co-construction of knowledge, and the exploration of multiple realities (Kitzinger & Barbour, 1999). Co-researchers came from a range of roles and settings (hospice, community, clinical education, and leadership), yet all shared a commitment to promoting inclusive, person-centred palliative care.

The shared aim provided cohesion and enriched the collaborative process. The focus group format enabled co-researchers to share their experiences, reflect together, challenge assumptions, and engage with one another's perspectives in ways not typically afforded by one-to-one interviews.

I remained responsible for organising these sessions in a prompt fashion and sending out invitations and joining instructions, along with details of any preparatory work. A summary of the iterative cycles and where the relevant focus group session sat within the overall process is visually summarised in Figure 10.

Furthermore, I was mindful of issues we might face with technical problems during the online sessions, such as poor or loss of connectivity and failure to capture non-verbal data. To try and mitigate losing valuable non-verbal data, I sought recording consent from all co-researchers at the beginning of each online session.

Figure 9. Timeline summary of data collection period

Visual representation of PAR cycles

Repeating cycles of planning/ action/ reflection

PLANNING
Introductory Session – November 22

CYCLE 1

Researcher - Recruitment – invitation to participate
Participants - Expression of Interest

ACTION - REFLECTION
Meeting 1 (M1) - Feb 23
Meeting 2 (M2) - May 23

CYCLE 2

M1 - exploring CULTURE and HUMILITY
M2 - Consider value/ importance of Cultural Humility through discussion & group activities

ACTION - REFLECTION
Meeting 1 (M3) - July 23
Meeting 2 (M4) - Oct 23

CYCLE 3

M3 - Group definition of CULTURE
M4 - link with Stigma ('Who do YOU think you are?')

PLANNING - ACTION - REFLECTION
Meeting 1 (M5) - Jan 24
Meeting 2 (M6) - Feb 24

CYCLE 4

M5 - Implementation & implication for practical application
M6 - Final data collection session - with summing up to date

PLANNING - ACTION - REFLECTION
October 2024 - March 2025

CYCLE 5

Data Analysis
Ongoing member checking – recap at beginning of each FG session

ACTION & REFLECTION
April 2025 onwards

CYCLE 6

Data analysis
Dissemination of findings to all co-researchers – member checking
Invitation to feedback on findings
Thesis drafting

Figure 10. Visual summary of participatory action research cycles and focus group schedule

Additionally, with all participants' consent, each session was formally minuted. These minutes served as concise summaries and, together with the materials used (such as PowerPoint slides and reflective activities) were circulated to all attendees after each focus group. Permission was granted to use audio-visual and written materials for analytical purposes and ongoing reflexivity. All material generated was stored in accordance with university research ethics guidelines and under obligations of the UK Data Protection Act (2018) (HM Government, 2018).

Everyone was given the opportunity to share their preferences about session formats; we agreed to PowerPoint presentations being used sparingly, as discussion topic guides and for reflection after the sessions. A summary of supporting material for all focus groups is detailed in Table 9 (with exemplars in Appendices 16 and 18 - 20).

Table 9. Resources to support online sessions

Material type	***Focus Group session***	***Examples***
Agendas	ALL	*See Appendix 16*
PowerPoint presentations	1 - 4	*'Cultural Humility in Palliative care'*
Online videos	1 - 4	*'Love has no label'* *LOVE* *'What is CULTURE? Universal and Personal!* *CULTURE* *'Humility Doesn't Mean'* *HUMILITY* *Example of stigma (leprosy)* *Free & Equal campaign*
Journal articles/ reports/ books	2 & 3	*Tervalon & Murray Garcia (1998)* *Sprik & Gentile (2019)* *Marie Curie (2016)* *Napier et al. (2014)*

Material type	***Focus Group session***	***Examples***
Activities: - **Teams Polls** - **Word search** - **Cultural Humility 'Onion Ring'** - **Mnemonic for Culture Humility** - **'Who do YOU think you ARE?'**	 1 2 4 4 5/6	 *Poll used to generate word cloud* *CLARE/CLAIRE 'avatars'* *Self-identification worksheet*
Reflective activities	ALL	*Solicited diary prompts* *Self-identification worksheet* *Self-reflection and contemplation questions*
Other resources	ALL 3	*Group agreement* *UNESCO definitions for culture/humility*

As previously discussed in section 4.7.2, all participants, as co-researchers, contributed to a shared group agreement setting out expectations of behaviour, respect for each other and keeping confidentiality (later circulated within the session notes - Appendix 15).

An overview of the study was presented by me. Informed consent was checked and obtained, and the importance of confidentiality reiterated, as detailed in the participant information sheet. The group collectively agreed I would fulfil the role of facilitator for all online meetings. Consistent with participatory principles, I facilitated each session with care to maintain psychological safety, encourage equitable participation, and manage emotional sensitivity (Baker & Hinton, 2001; Braun & Clarke, 2013). Additionally, I monitored group dynamics, addressed any apparent tensions (shown verbally or non-verbally), and supported mutual respect, staying attentive to my dual position as both academic researcher and co-researcher. I would act and intervene if there was unpleasant confrontation, or open hostility apparent in the group. However, these situations did not arise during any of the online sessions.

The chosen format of focus groups supported co-researcher-led inquiry and encouraged everyone to raise personally and professionally significant issues. While individual perspectives were valued, group discussions remained grounded in a collective and engaged process. The sessions specifically explored how cultural humility might be understood and integrated into professional practice in palliative care settings.

4.8.5.2. Solicited diaries

A reflective approach to data collection was central to this study and included the use of solicited participant diaries. These diaries captured co-researchers' evolving experiences, thoughts, and expectations throughout the study. In qualitative research, diaries are recognised as valuable, flexible tools for gathering rich, iterative data (Bartlett & Milligan, 2015; Braun & Clarke, 2013; Halliday et al., 2021). As the academic researcher, I encouraged everyone (including myself) to make entries in their diaries. Co-researchers were aware their content would be analysed and later reviewed collaboratively before dissemination (Jacelon & Imperio, 2005).

Co-researchers adopted a semi-structured diary format using a prompt sheet I provided, containing open and closed questions aligned with the study's aim and objectives (Appendix 17). We were all encouraged to record entries following each focus group and during the intervening periods. I engaged in this activity to document ongoing reflections on my multifaceted role as researcher, participant and co-researcher, facilitator, and healthcare staff. I also kept a separate reflective diary to capture personal observations, decision-making processes, and both professional and personal development throughout the study, and particularly so during the focus group sessions and ongoing analysis of data. The diary/ journal entries facilitated timely and nuanced insights, mitigating the risk of recall bias (Bartlett & Milligan, 2015).

4.8.6. Data Analysis and Synthesis

I assumed overall responsibility for data analysis, which occurred iteratively throughout the planning, action, and reflection cycles of the study. I used

Reflexive Thematic Analysis to guide the identification, development of, and generation of themes from data gathered during Cycles One to Four, including focus group transcripts and reflective feedback from the co-researchers' diaries. The collaborative approach supported the study's aim and objectives: fostering learning and collaboration, envisioning positive social change, and embracing diverse perspectives (Schubotz, 2020). I shared all relevant data and thematic developments within the findings with the co-researchers during and following the reflective and evaluation phases of Cycles Five and Six.

Reflexive Thematic Analysis enabled me to generate, define, and label themes from coded patterns of shared meaning through deep engagement with the data, informed by my experience, values, and reflexive awareness (Braun & Clarke, 2021). In Cycle Five, I chose to undertake the coding process manually, due to the volume of data generated by transcripts from the focus group recordings, minutes, and support material. The process involved watching back the Teams recordings in conjunction with hard copy transcripts to make notes about behaviours, body language, or reactions amongst all the co-researchers, including myself.

Once annotations were made in the Teams transcripts, I then began to bring groups of data together sharing similarities as mind maps. Subsequently, I revisited the transcripts to identify co-researcher quotes to support the groups of data. The iterative nature of analysis further refined the synthesis of data sharing similarities (or common features) to become patterns of meaning. For an example of coding and the analysis process for the theme *Facing our Vulnerability*, see Appendix 22.

The resulting themes (including the final labels) aligned with the study's aim and objectives, recognising the need to identify and challenge unspoken assumptions throughout the analytic process (Braun & Clarke, 2020). The process of allocating data to groups with common or shared meaning was part of the iterative (continual) process of analysis. As encouraged by Braun & Clark (2020), I played an active role in the identification of patterns of meaning (or

“generating initial themes” (p.16)), selecting those which were of interest for me to convey. The grouping and labelling of the themes (or theme generation) changed several times during Cycle Five, which I have summarised in Table 10. The final analysis throughout Cycle Five reflected prolonged immersion, critical reflection, and the iterative nature of interpretation. RTA’s reflexive orientation complemented the cyclical, evaluative nature of Participatory Action Research by encouraging transparency and scrutiny of my assumptions shaping the research focus.

Table 10. Iterative process of labelling themes

Mind mapping stage	***Quotes identification stage***	***Final labels given to themes***
Change	The Ebb and Flow of Change	The Power of change adapted to **The Power to Change**
Communication	The power of communication	Not chosen as a theme (absorbed into other themes)
Conflicting Priorities	Conflicting Priorities	**Competing Priorities**
Humility	Grouped together with Respect to become the essence of Humility and Respect	**Humility as a Personal Value**
Respect		
Me, my culture, and I	Me, my culture, and I	**The Nature of Culture**
Vulnerability	Our own vulnerabilities	**Facing our Vulnerability**

Data synthesis in Cycle Six was guided by Hynes’ (2013) model of first and second-person inquiry. First-person inquiry involved my personal reflection, self-awareness, and examination of underlying beliefs and assumptions, while second-person inquiry centred on collaborative dialogue with the co-researchers to explore shared concerns and inform action. As Marshall (2016) notes, first-person inquiry requires a willingness to question established thought patterns and personal convictions. These forms of inquiry were particularly appropriate for exploring how cultural humility might be fostered in professional

practice to address ongoing health inequalities and forms of discrimination or stigma experienced by people who identify as sexual and gender diverse in palliative care.

4.8.7. Data Management

I managed all data in accordance with the UK Data Protection Act (2018). I sought co-researchers' permission for any future use of material generated during the study. Electronic data were encrypted and stored securely on Lancaster University's OneDrive, accessible only via a password-protected computer. Hard copy materials, including reflexive diaries and handwritten group outputs, were stored in a locked filing cabinet at my residence, with sole access kept by me. The data management process was also made explicit in the participant information sheet so that all participants were kept fully informed (Appendix 11).

4.9. Chapter Summary

In this chapter, I have outlined the philosophical foundations and practical approaches shaping the study, situating the research within a constructivist ontology and a subjectivist epistemology. Participatory Action Research was the chosen methodology for collaboration, co-construction of knowledge, and action-orientated change, showing how the methodology aligns with palliative care values such as mutual respect, shared decision-making, and interdisciplinary teamwork.

The chapter described the study's methods: purposive and snowball sampling to recruit interdisciplinary co-researchers, iterative data collection through online focus groups and solicited diaries, and Reflexive Thematic Analysis conducted within cyclical planning, action, and reflection. Details of ethical safeguards, data management procedures, and reflexive practices that acknowledged and made transparent my positionality as researcher, participant, and co-researcher have been laid out. How these influenced conducting the research and data analysis have also been stated.

In Chapter Five, I present the themes generated from the data analysis, illustrating how co-researchers' dialogues and reflections came together into core insights about cultural humility in professional practice and offering the empirical grounding for subsequent discussion and recommended actions.

5. Chapter Five: The Findings

5.1. Introduction

In Chapter Four I outlined Participatory Action Research as the research methodology and methods of data collection used for this study, as well as a summary of the iterative cycles (Figure 10, Chapter Four - section 4.8.5.1).

In this chapter, I present an account of the findings resulting from data analysis undertaken through Cycle Five, highlighting both individual and collective professional experiences and articulating our understanding of cultural humility as a theoretical concept and an applied practice. Data analysis and synthesis in Cycle Five were driven by the research questions (as outlined in Chapter One - section 1.5):

i. What is the meaning of cultural humility for UK based community and hospice palliative care staff?

ii. Why is engaging with cultural humility relevant for fostering change in professional practice and palliative care for older people who are sexual and gender diverse?

I adhered to the participatory action research methodology through a sequence of four iterative cycles of focus groups and reflexive activities (personal and group) involving preparation, planning, action, and reflection (as described in Chapter Four). The ‘action’ undertaken by all of us as co-researchers is outlined within each cycle, capturing our engagement, experiences, the sharing of individual and collective understanding, and the processes of evaluation and reflection (both personal and collaborative) across Cycles One to Four, with feedback addressed in Cycle Five.

5.2. Introducing the Themes

As presented and summarised in Table 11, data analysis, incorporating reflexive thematic analysis, resulted in the generation of themes being identified, defined, and then labelled reflecting their connection to cultural humility in healthcare.

The themes are:

- The nature of culture
- Humility as a personal value
- Facing our vulnerability
- Competing priorities
- The power to change

Table 11. Five themes and their identifying characteristics

THEME	CHARACTERISTICS (description of)
The nature of culture	• Recognising and appreciating differences and variations of culture • Culture is seen as what shapes people as individuals, and how we impart our culture to others (using a variety of communication types)
Humility as a personal value	• Intrinsic personal values held by individuals to be able to learn about, cultivate, and grow with cultural humility • Delivery of patient care which is culturally humble in its approach
Facing our vulnerability	• Engaging with cultural humility through self-critique takes courage and can make an individual feel vulnerable • Cultural humility can enhance empathetic engagement
Competing priorities	• Dealing with differences in values and priorities from the organisational and individual/ personal perspective • How these are communicated to a wider audience
The power to change	• Moving from the position of: TEACH-KNOW-DO to BE AWARE-CULTIVATE-GROW

The following sections elaborate on the collaborative work conducted by us all as co-researchers throughout the iterative cycles of Participatory Action Research and the connections to the research questions. Contributions from the co-researchers have been accurately and truthfully presented by including verbatim colloquial language, spelling, and grammar recorded by Microsoft Teams and by watching back the recorded sessions. While the transcripts provided a foundation for analysis, I applied my own insights and interpretive judgment to deepen the understanding of the data. Pseudonyms have been used with direct quotes and related content from the sessions and reflexive work, thereby protecting co-researchers' anonymity (Holmes, 2020).

5.3. Cycle One: Preparation and Planning

As presented in Figure 11 (replicated fully in Appendix 23), cycle one of data collection began with the introductory meeting held in November 2022.

Figure 11. Cycle One: introducing Cultural Humility through preparation and planning

I previously supplied a summary of participant demographics in Table 8 (section 4.8.4). Table 12 details co-researcher attendance across the focus groups.

Table 12. Attendance record at focus groups

Demographics /Pseudonyms & Participant ID	***Introductory session CYCLE ONE***	***Session M1 – CYCLE TWO*** *(M = meeting)*	***Session M2 – CYCLE TWO***	***Session M3 – CYCLE TWO***	***Session M4 – CYCLE THREE***	***Session M5 – CYCLE THREE***	***Session M6 – CYCLE FOUR***
Clara P1 - participant	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Mac P2 - participant	Yes	Yes	Yes	Yes	Yes	Yes	Yes (withdrew at this point)
Diana P3 - participant	Yes	No – apologies given	No – apologies given	Yes (withdrew at this point			
Bianca P4 – participant/ note-taker/ admin	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Dorothea P5 – participant		Yes (joined study at this stage)	Yes	Yes	Yes	Yes	Yes
Me – Siobhán P6 – researcher & facilitator	Yes	Yes	Yes	Yes	Yes	Yes	Yes

Five co-researchers including myself, attended the first focus group. Apologies were noted when a co-researcher was unable to attend a planned session. The co-researchers consented to pseudonyms being chosen on their behalf. As the academic researcher, it was important for me to understand why the other co-researchers wanted to be involved in the research, ensuring the data generated through participation, and the knowledge shared and created aligned with the aim and objectives of the study.

Reasons for engagement and involvement were expressed as:

- Learning, exploration and raising awareness of cultural humility
- Being inclusive and appreciating diversity in care provision
- Contributing to improving and changing practice with cultural humility
- Supporting vulnerable or underserved patient groups
- Engaging in active listening and peer collaboration
- Showing mutual respect throughout the research process

Material intended to support discussions on raising awareness of cultural humility were also made available to everyone. These resources featured articles by Tervalon and Murray-García (1998), which highlighted the distinctions between cultural humility and cultural competence in medical training. Furthermore, an article by Sprik and Gentile (2020) was shared. The article advocates for cultural humility as a strategy to alleviate health disparities experienced by patients who identify as sexual and gender diverse. The intention of making these articles available before the session in February 2023 (M1) was to encourage dialogue and debate within the group and between all co-researchers.

A summary of all action and activities undertaken during Cycle One is presented below in Table 13. I have detailed activities taking place in-session as activity/ action with details (the how).

Table 13. Details of Cycle One Action and Activities

Session ID	Details (the how)
CYCLE ONE ***Introductory session (Nov 2022)***	Individual introductions and sharing reasons for involvement Compiling shared expectations, ground rules and behavioural guidelines to promote respect, accountability and effective communication Issues of confidentiality outside of the focus groups emphasised

5.4. Cycle Two: Action and Reflection - the Meaning of Cultural Humility

The action and reflection *stages* of the participatory action research cycles continued through focus group sessions M1 to M5 (February 2023 – January 2024). Beginning our exploration into the meaning of cultural humility, we worked collaboratively to understand the constructs of culture and humility, with an emphasis on the healthcare context. Exploration and discussion remained iterative across all sessions, allowing our shared understanding and knowledge to deepen and evolve. As illustrated in Figure 12, the sessions on culture and humility (M1, M2 and M3 - February 2023 to July 2023) resulted in the generated themes of *the nature of culture* and *humility as a personal value*.

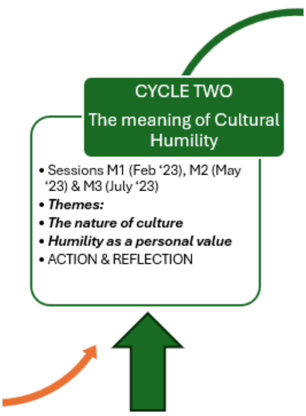

Figure 12. Cycle Two: understanding Cultural Humility through action and reflection

The action and activities involved in providing data contributing to the generation of these two themes are detailed in Table 14.

Table 14: Details of Cycle Two Action and Activities

Session ID	Details (the how)
CYCLE TWO ***M1*** ***(Feb 2023)***	Teams poll activity: each co-researcher posted three words which summed up their interpretation/ understand of CULTURE. Generation of word cloud (Figure 13) Debate and discussion on concepts of CULTURE and HUMILITY – what do they mean to individual co-researchers – supported by reflective activities distributed prior to session (Appendix 19) Co-researchers' feedback and comments on previously supplied articles (Tervalon & Murray-Garcia (1998), and Sprik & Gentile (2021)) Comparison made with transcript of global words taken from online video (What is CULTURE? Universal and Personal) (Appendix 18) Definitions about humility presented, discussed and distilled down to two (through group consensus) (Figure 15 and Figure 16)
CYCLE TWO ***M2*** ***(May 2023)***	Questions included: 1. Why should we be bothered about culturally humble care? - "lessen emphasis on task orientated care" (Mac – M1) - "learn and address shortcomings" (Mac – M1) - "coming to terms with looking after a more diverse group" (Clara & Mac – M1) 2. What does the literature say about 'cultural humility'? Reiteration of culturally humble care as the "desire" and cultural humility as the "awareness" (Mac – M1) 3. How are we going to define and interpret culture? Examples used from Napier et al. (2014) and UNESCO (2001) Exemplar of 'Onion Ring' provided (Appendix 18) CLARE/ CLAIRE mnemonics discussed and suggestions from co-researchers articulated (from Mac - CLARIBEL as an alternative) (Appendix 18)
CYCLE TWO ***M3*** ***(July 2023)***	Group agreement signed-off (no further changes/ amendments required) Presentation of group 'CULTURE' definition – no revisions required (section 5.4.1 – p.113) Questions posed during session for discussion/ debate included: 1. How could culturally humble CLARE/ CLAIRE be used to encourage cultural humility in practice? 2. How do individual perceptions and understanding of cultural humility align with published work? 3. What does stigma mean to you? 4. How would you recognise stigma? 5. What are the consequences of stigma in healthcare?

Session ID	Details (the how)
CYCLE TWO ***M3*** ***(July 2023)***	Sharing of individual 'Onion Ring' work (Appendix 18) (Different perspectives revealed across group – the layers were not the same for everyone) – reflecting the nature of individual interpretation What is at the heart of the 'Onion Ring'? What constitutes the central/ core ring? *"full inclusion achieved and positive patient and family experience"* (Dorothea – M3) Other layers of 'Onion Ring' illustrated how inclusion could be achieved through cultural humility: - Humility - Reflective practice - Life-long learning - Addressing power imbalances Engagement in self-reflection and critique

5.4.1. Theme One: The Nature of Culture

The first theme refers to how we recognised and appreciated the differences and variations in culture at the individual, collective and societal levels. Culture, as recognised by all co-researchers, influences the development of individuals. During M1 (February 2023), we collectively explored and debated individual interpretations and perceptions of the word *culture*. The discussions were started through a group activity conducted on Teams Polls, which allowed co-researchers to propose three words they felt were representative of culture. We then compared the poll results with the transcript of my pre-session video on global culture (see Appendix 18).

As depicted in Figure 13, the words *customs*, *lifestyle*, and *traditions* emerged as the popular responses. The words proposed in the Teams Poll highlighted our Western cultural background and upbringing, a sentiment voiced by Clara, who noted that "most of our words were very Western and stem from a privileged background" (session M1). These observations were further elaborated on by Mac who emphasised the nuanced distinctions existing among various cultures, saying "...a lot of cultures are centred around food, e.g. nomad communities. If you're privileged you don't have to follow food and live by it" (session M1).

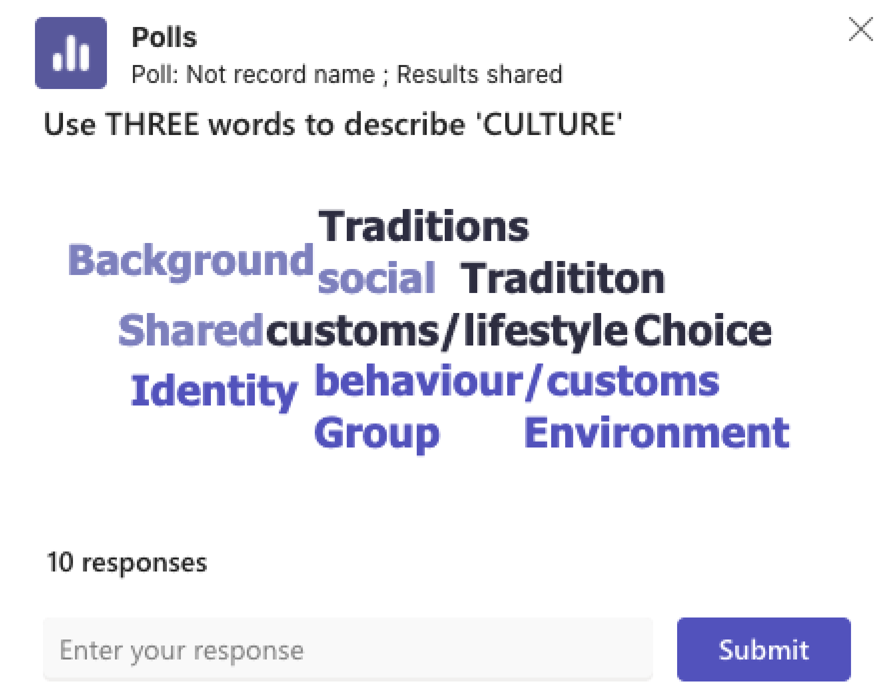

Figure 13. Word Poll results to describe 'culture'

As we debated the meaning of culture further in M2 (May 2023) and M3 (July 2023), we noted and acknowledged a shift in how we understood and interpreted culture. Figure 14 helps to visualize the transition in the group's patterns of meaning about culture; the words *identity*, *lifestyle*, and *shared* were the links between the two sessions.

As a group we concluded that culture can be understood broadly at the corporate/collective or shared level but also more narrowly; at the individual level, and its interpretation is influenced by context. Dorothea felt culture is "… what makes you you" and "the way you live and what makes that you", with Mac adding "it's a group thing, it's a way of living and it can be faith related or can be specific" (session M2). Clara echoed Mac's words, adding "it can be about people's values, individual values or as you say group values … country values, faith values" (session M2).

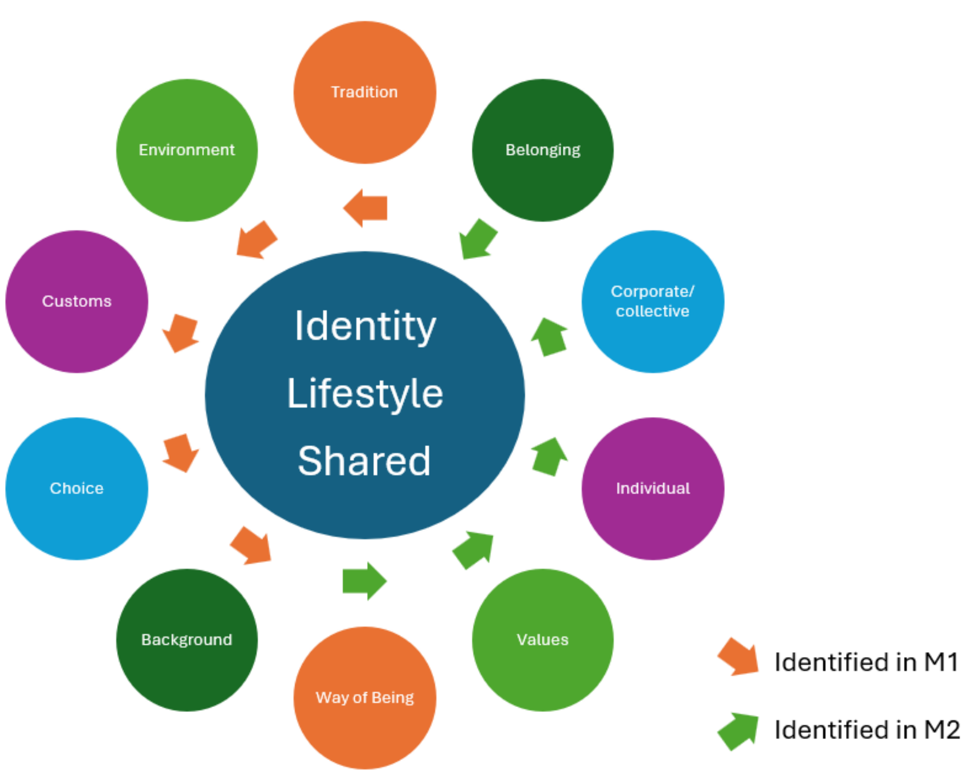

Figure 14. Transition in understanding 'culture'

Over time people may come to view culture differently, as we did across the sessions, with Dorothea suggesting that as "people grow up they kind of decide whether the culture that perhaps they were born into or that they have grown into is one that they want for themselves or not" (session M2). We recognised that a person's culture, or their cultural perspective, may be predetermined by the environment they live in, summed up by Dorothea in session M2 (May 2023) as "people feeling that they might need to have to conform, reject or rebel from a culture" they are born into or "a particular identify that ... is associated with their culture".

When healthcare staff see patients in their own environment, they may have cues, resulting in, as suggested by Dorothea, "a confidence thing about talking about" matters relevant and important to a patient (session M2). Healthcare staff could feel uncomfortable in conversation as they fear highlighting issues of cultural importance when engaging with patients and their support network, lack the confidence to talk empathetically about diverse cultural perspectives, or

worry about emphasising sensitive cultural differences, which in turn may lead to making assumptions.

Placing culture in the context of healthcare, Dorothea felt that “there’s often a lot of expectation and assumption about cultures, about what we understand” (session M2). In other words, the level of knowledge that healthcare staff have about other cultures, such as rituals, attitudes towards health and ill-health, forms of communication (including verbal and non-verbal language).

Mac emphasised the significance of healthcare staff considering an individual's cultural background, because culture is “individual, but whatever is important to them is important to me” (session M2). We concluded that healthcare staff should recognise culture as “individual” (Mac), it is about “lifestyle” (Dorothea) and “what is important to the individual” (Clara). These session M2 (May 2023) focus points enabled us to develop our collective interpretation of culture as the sessions progressed:

> To understand culture, we need to see it as something unique and personal. As clinicians, we acknowledge the recognition of culture within palliative care, ill-health and well-being is fundamentally about the individual. It is about discovering what is important to every individual, ensuring their values are upheld and respected, and their chosen lifestyle is accommodated for, and accepted without compromise, conflict, or criticism. (session M3 - July 2023)

5.4.2. Theme Two: Humility as a Personal Value

The second theme generated from sessions M2 and M3 in Cycle Two, suggested *humility as a personal value*, and was important for all co-researchers learning about cultural humility. Having collectively explored our understanding of culture, as it relates to both an individual and in society more generally, we repeated the process for defining humility, agreeing collectively it was simpler to define. I had selected a range of humility definitions from the wider literature for the group to consider and discuss (Figure 15).

Figure 15. Definitions of humility from literature

For all co-researchers to truly grasp the essence of humility, we first needed to adopt a humble stance throughout the learning process. We explored how each definition resonated with personal values, influenced everyday interactions with patients, families, and colleagues, and shaped the quality of patient care.

Through our collective discussion, we distilled the list down to two core definitions, Waddell (2017) and Sacks (2022) (Figure 16).

Figure 16. Preferred definitions of humility from the literature

Collectively, we identified the humility of healthcare staff as fundamental to delivering authentic and holistic, person-centred care. Consequently, we adopted Sacks's (2022) definition as our guiding conceptualisation of humility in this exploration of cultural humility in healthcare. We revisited the phrase culturally humble care introduced in session M1 (Cycle Two – February 2023) when considering the individual constructs of culture and humility. Mac suggested to the group that "one is an awareness and one is a desire" (session M1), with the awareness being cultural humility and the desire is to give, or provide, care which is culturally humble.

During session M1, we agreed that humility is essential for healthcare staff to provide culturally humble care, a sentiment echoed by Mac in subsequent sessions: "I've always found it frustrating that I'd probably like humility to be an attribute that people have to become nurses" and that humility means "to actually say I'm wrong to say I don't know" (session M2).

For healthcare staff, being humble suggests it is an acceptance of how other people are and to respect differences, through a willingness to be educated, supporting colleagues and patients, and focusing on establishing and maintaining mutual, or therapeutic, partnerships. Respect for others, colleagues, peers and patients alike featured often during group reflections and dialogue.

5.5. Cycle Three: Action and Reflection - Practice Change with Cultural Humility

The resulting themes from the data analysis of the subsequent sessions (M4 and M5) were:

- Facing our vulnerability
- Competing priorities
- The power to change

These are presented in Figure 17. During ongoing discussions exploring our understanding of cultural humility, we acknowledged the role played by biases

(or blind spots) and actions such as discrimination and stigma have, both at the individual and societal level in healthcare.

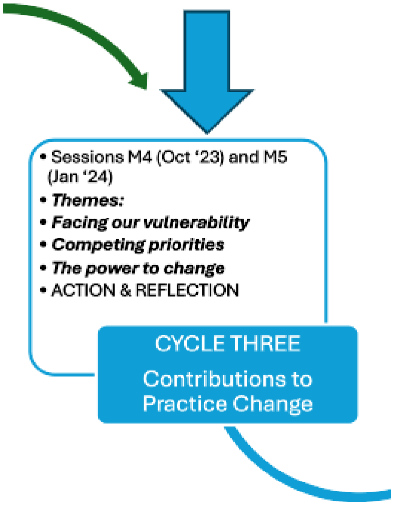

Figure 17. Cycle Three: contributions to change through action and reflection

The action and activities involved in providing data contributing to the generation of these three themes are detailed below in Table 15.

5.5.1. Theme Three: Facing our Vulnerability

The third theme of *Facing our Vulnerability* (our own discomfort in ourselves) focus emerged through our experience of self-evaluation and self-reflection throughout the focus groups and as we applied these to our clinical roles. Tervalon and Murray-García (1998) described these activities as "ongoing, courageous, and honest process of self-critique and self-awareness" (p.120). Experiences shared by individual co-researchers to the group included acknowledging assumptions and having courage to disclose when we do not know things, being non-judgemental, recognising shortfalls through reflection, fearing the perception that others may have of self, and embracing change so that we become other-orientated.

Previously in Cycle Two (session M3 - July 2023), stigma was introduced into group discussions, and support material supplied ahead of session M4 (October 2023).

Table 15: Details of Cycle Three Action and Activities

Session ID	Details (the how)
CYCLE THREE ***M4*** ***(Oct 2023)***	Opportunity to discuss importance of raising self-awareness through reflection and critique Self-identification worksheet – reflection and completion (Appendix 20 and Table 16) Implications for professional practice explored through following questions: 1. What types of actions or values reveal cultural humility to you? 2. One way to recognise cultural humility in myself is to …? 3. One time I have witnessed or experienced genuine cultural humility was …? 4. Cultural humility can directly benefit me, my colleagues, and patients because …?
CYCLE THREE ***M5*** ***(Jan 2024)***	Questions for contemplation and discussion included: Cultural humility may be a characteristic difficult for individuals to recognise and accurately report "Cultural humility liberates us as individuals from the expectations of cultural expertise" (Ortega & Faller, 2011, p.173) Is cultural humility just a re-branding of 'anti-oppressive practice'? (Danso, 2016) Does practising cultural humility translate into respect for diversity? Is it necessary to have awareness or sufficient knowledge of a culture to show respect for it? Can we ever achieve cultural humility? Is it necessary to have a 'tool' to support the implementation of cultural humility? Can you learn cultural humility? (question posed by supervisors) Is cultural humility a transition from 'mastery to accountability'? (Fisher-Borne, 2015) Is cultural humility an additional component of culturally responsive care? (Lee at al., 2020)

Cycle Three began with each co-researcher completing an individual piece of work - a self-identification worksheet entitled *Who do YOU think you ARE?* by Asnaani (2023) (see Appendix 20). The resource is part of a series of readily available reflective activities which the author encourages be used for self-

reflection purposes. It is possible to access the resources both online and in hardcopy format. I have included my responses below in Table 16 - without any changes.

There were very personal accounts shared of stigma experienced by three of the co-researchers (Clara, Dorothea, and Mac) during session M4 (October 2023). Dorothea has faced stigma for having a strong and active Christian faith; Mac has been mistaken for being gay because he chose nursing as a career, and both Clara and Dorothea witnessed the impact of AIDS and HIV related stigma through their work with patients at a charitable hospital in the south of England during the 1980s.

Table 16. Example of the 'Who do YOU think you ARE?' worksheet by Asnaani (2023)

Identifying Factor	**How Others Identify Me**	**How I identify**
Age/generational influences	Middle aged 'getting on a bit'	In my 50s
Development disabilities	None – based on initial impressions	None
Disabilities (other)	None obvious – based on initial observations	None
Religion and spirituality	They wouldn't know without asking	Non-practising Christian of Protestant faith
Ethnic and racial identity	White British	Caucasian
Socioeconomic status/ social class	Middle Class – based on education/ dialect	Educated to degree level and registered professional
Sexual orientation	Heterosexual (based on the fact that I have a long term male partner)	Heterosexual/ straight
Indigenous heritage	Assume British	As an adopted child this heritage is mixed
National origin	British	English with Irish ancestry
Gender	Woman/ female	Same

Mac reflected on the preconceived notions about him held by a patient, stating:

> When I tell people I was a male nurse, there's an automatic assumption that I had to be gay … I took no offense to that whatsoever, because overriding that was that I didn't want to do anything to upset him. I wanted it to be right for him. (session M4)

Dorothea shared a couple of her experiences with HIV patients at the charitable hospital. She recalled staff working hard to avoid stigmatising patients particularly those from African communities. Staff and patients shared lunch together and got involved in dance groups. The sharing and the power of touch had a profound impact on many of the women, most of them refugees, as well as the male patients: "the whole kind of importance of being touched and how important that was because it represented so much about not being stigmatised" (Dorothea - session M4).

Clara humorously recounted a home visit to a gay couple, highlighting their astonishment when she accepted refreshments from them without hesitation. Conversely, Dorothea highlighted the expectations of some staff in an inpatient unit about a patient who was a prisoner. The healthcare team felt they needed to be informed about the patient's criminal history, resulting in some ward staff refusing to provide care due to feelings of vulnerability, and an inability to overlook his previous actions.

In addition to exploring how negative attitudes, beliefs, or discrimination can affect delivery of person-centred care, the co-researchers openly reflected on the impact exploring and appreciating cultural humility has had on past events in their personal and professional lives. Both Dorothea and Mac talked about the experience of being in the minority: Mac as a male nurse and Dorothea working overseas in the Caribbean. Session M4's group activity 'Who do YOU think you ARE?' (Asnaani, 2023) allowed Mac to reflect on the person from his past and who he was now: becoming a nurse was the catalyst of change for Mac.

For Dorothea, she has been able to reflect on her position as both an individual with a strong Christian faith and in a professional capacity leading on her organisation's inclusion and diversity practices. Dorothea has been on a journey with "the whole concept of judgement and being judged", recognising that "a person's choices and past doesn't affect their entitlement to the best possible care" (session M4). Similarly, Clara, who declared herself agnostic, described herself as an individual very tolerant and quite neutral about religion, always asking people what was important to them and what their expectations of her were for their care.

Shared personal reflections within the group illuminated specific episodes of care shaped by the negative attitudes of healthcare staff. Emotions such as anger and sadness towards colleagues were mentioned, with Mac reflecting on the experience:

> I have asked myself how I feel about not challenging my colleagues. During conversations at the time I just nodded and grunted at appropriate points just to show I was listening. With the benefit of hindsight I should have challenged this perhaps and explained how I felt about their judging of this gentleman. Many years later the 'me' now would. (post session M4 reflexive activity)

Such reflections called into question the respect previously accorded to colleagues who promoted care characterised by compassion, dignity, and respect.

5.5.2. Theme Four: Competing Priorities

The fourth theme of *Competing Priorities* (individual versus organisational) brings together the potential challenges, or barriers, facing staff engaging with and cultivating cultural humility in their clinical practice. Becoming aware of and acknowledging individual vulnerabilities led a couple of the co-researchers to confront conflict between their own values and beliefs, and the values of the organisation they worked for.

The goal of achieving person-centred care at times conflicted with corporate values, which were shaped by demands for funding revenue, impact evaluations, audits, and quantifiable patient outcomes. Dorothea expressed apprehension about the prioritisation of policies and procedures, as well as the requirement for staff to have specific competencies, which could jeopardise the intrinsic values that individuals contribute to healthcare. Additionally, the pressures faced by patient-facing staff, particularly the focus on task-oriented responsibilities throughout their shifts, were troubling, something which Dorothea alluded to in an earlier session:

> There isn't the space, and I think what's frustrating is that people are so busy as clinical front facing workers, that to have the headspace to do some of this reflection … we need to try and get it on team meeting agendas to just get the conversation going. (session M3 – July 2023)

The goal of providing person-centred care was the primary focus for the group, supported by the understanding that nurturing and embracing cultural humility could serve as a pathway to achieving this aim. Care provision should reflect the ideals of equity, respect for individuals, and inclusivity, ideals particularly important for Mac in his role supporting the ongoing education and development of clinical staff.

Collectively, we acknowledged barriers may exist in the clinical environment including but not limited to multidisciplinary or multi-agency team working, time pressures, and limited opportunity for reflection through clinical supervision. Bianca noted that the integration of cultural humility into practice might meet significant challenges, due to the time and space needed for personal reflection, even with a small group already supporting the initiative.

Previously, Dorothea had emphasised the importance of healthcare staff engaging in reflective practice. Reflective practice may alleviate situations where assumptions are made or preconceived ideas about patients are reinforced. We considered the potential for linking the self-critique and reflection aspects of cultural humility with clinical supervision. Clinical supervision is recognised as

an ongoing process of professional learning and development enabling healthcare staff to reflect on and develop their knowledge, skills, and advancing practice, through regular support from fellow healthcare staff (NHS England, 2023a).

Team dynamics may hinder engagement with cultural humility, as individual values within a team can lead to inconsistent care and disrupt continuity for patients. Clara felt these situations could be addressed by teams engaging in active conversation to promote self-reflection and discussion, in turn providing opportunities to acknowledge and explore individual biases (or blind spots). Her viewpoints on team working were supported by the rest of us.

As previously suggested by Clara in session M2, communication continued to play a pivotal role, sitting alongside ongoing reflection and lifelong learning by healthcare staff. Healthcare staff should not make assumptions, instead they should ask; suggesting they remain curious about knowing the patient. Focusing on communication, especially active listening, and the use of open questioning, enables healthcare staff to discover what is important to others. Encouraging brave conversations, using podcasts and interviews with people from diverse cultures and communities (such as service users) were put forward as facilitators to enhance healthcare staff's level of comfort when encountering cultural differences, which may be challenging to navigate.

5.5.3. Theme Five: The Power to Change

The final theme of *The Power to Change* (unlearning to learn again) highlights cultural humility's potential to advance person-centred care, while capturing our engagement with it throughout the focus group process. Being involved in the participatory action research study has resulted in everyone acknowledging they had become more self-aware, as well as exploring what we do and do not know, through individual and collective curiosity and inquiry.

None of the other co-researchers declared they were familiar with cultural humility, as either a term or a practice, prior to their participation. The lack of knowledge was a key reason for wanting to be involved in the research. Through

active discussion, group activities and personal reflection, all co-researchers went through a transition of learning and raising awareness about cultural humility as a concept, to understanding and appreciating it as a mindset and way of being, which we all felt was imperative for the provision of care.

For Dorothea, some of the points of focus of change through cultural humility for her included the ability to become other-orientated through a process of decentering, whereby we observe and reflect on our own thoughts and feelings, enabling a shift in perspective and taking on a non-judgemental stance of self. Her engagement in the research equipped her with the insight that cultural humility is important for fostering change and addressing power imbalances.

In seeking to address power imbalances between patients and healthcare staff or organisations, what was considered fundamental for the whole group was raising awareness of cultural humility in the clinical environment (at both the individual and organisational level). Raising awareness and understanding therefore leads to a model of care in which healthcare staff strive for equity rather than mere equality, where care is fair for everybody.

The influential 1998 editorial by Tervalon and Murray-García, introduced in Chapter Two (section 2.7), described the core principles of cultural humility: self-evaluation, self-critique, the management of power imbalances, and the development of therapeutic relationships between patients and healthcare staff. These principles provided a vital framework for directing our discussions and reflections during the focus group sessions.

We collectively agreed the sentiments they expressed for healthcare staff's multicultural education were still as relevant in the current era as they were when originally written. However, as noted in an earlier session, Mac had been surprised and concerned about the perceived slow pace of change, prompting the response: "… where are we now? Not much further forward, are we?" (session M2 – May 2023).

Commenting on a series of statements and answering reflective questions (Appendix 21 - Clara and Mac) after session M4, the following thoughts were shared about gaining knowledge of and engaging with cultural humility. It may be difficult for individuals to recognise and accurately self-report their individual cultural humility. Healthcare staff might believe they have cultural humility because they have read about the concept and completed competencies, but receiving feedback from those they support would validate their own awareness of cultural humility. Mac further expanded on how that awareness can impact on practice: “you can have cultural expertise; however, you need to be culturally humble with EACH individual you support. We can never truly be experts as therapists” (written reflection post session M4).

As a group we concluded cultural humility is not learnt. Learning about and having an awareness of cultural humility are the precursors to engaging with it, as well as sharing our individual understanding of the concept. A key point was made by Bianca relating to the use of the word *learn* when we discussed whether cultural humility is learnt. She suggested that a more appropriate approach would be to cultivate or grow our understanding, appreciation, and use of cultural humility in practice.

Both Clara and Dorothea felt encouraging growth was the focus, not teaching or learning in the traditional sense which everyone can do; a shift from *teach-know-do* to *be aware-cultivate-grow*. Clara felt that the integration of cultural humility into her work could lead to meaningful changes in her practice and the quality of care experienced by patients, summing up her own experience with the study, through reflexive feedback as “a journey, mindset, and way of being. I feel that it is impossible to ‘teach’ cultural humility but enabling others to consider the concept/discuss and question each other’s approach to cultural humility would hopefully benefit us all” (written reflection post session M5).

Healthcare staff’s willingness to engage with and cultivate cultural humility can change and enhance their practice, as it encourages the individual to:

i. acknowledge that we do not understand everyone’s values and feelings

ii. be willing to have an openness to accept different viewpoints

iii. have courage to recognise our limitations, especially when it comes to knowing our patients

The over-arching aim of person-centred care, which is culturally humble through the practice of cultural humility, was eloquently summed up by Dorothea as "... to try and improve ourselves is the best patient care we can give ... full inclusion achieved and a positive patient and family experience, regardless of peoples' gender or identity ... For me that's the ultimate goal" (from session M3).

5.6. Cycle Four: Reflection and Planning for Future Action

As depicted in Figure 18, the final cycle of the participatory action research data collection process focused on reflecting on the knowledge shared and co-created to learn about, understand, and appreciate cultural humility within the context of healthcare.

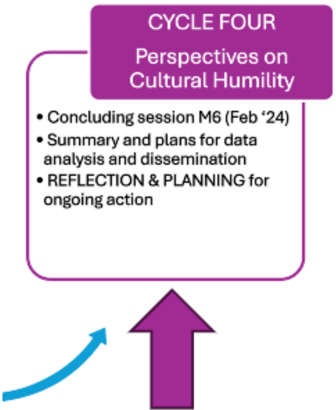

Figure 18. Cycle Four: reflection and future planning for action

The action and activities involved in providing data contributing to Cycle Four are detailed in Table 17. During our closing session, Bianca, Clara, Dorothea, and I engaged in a reflective dialogue on Tervalon and Murray-García's conceptualisation of cultural humility. Together we explored how our individual understandings had evolved, acknowledging cultural humility's central tenet: a

commitment to lifelong learning sustained through continual self-evaluation and critical reflection, informed by each patient encounter in healthcare practice.

Table 17: Details of Cycle Four Action and Activities

Session ID	**Details (the how)**
CYCLE FOUR ***Closing session*** ***M6*** ***(Feb 2024)***	Co-researcher verbal feedback and written reflections returned by email Co-researchers invited to review analysed data by researcher

Cultural humility was considered by Clara as “having value in everyday life. It gives you more insight, more tolerance. It’s for everything” *(*session M6). For Dorothea, she was grateful for what she had learnt and feels she can be more *comfortable being uncomfortable* in herself by setting “a level of comfortable discomfort” (session M6). The process of self-critique involves intentionally turning the lens inward to interrogate one’s own assumptions, blind spots, and potential biases. The reflexive practice encourages individuals to name where their perspective may be limited, not as a form of self-reproach but as a pathway to deeper learning.

Dorothea recognised that for her, cultural humility is the foundation for inclusion, sharing her thoughts about how involvement and learning has helped her to further enhance her work: “I thought I can’t run an inclusion session without it, now I know about it as the foundation” (session M6). Bianca highlighted the potential of the reach and impact of cultural humility for healthcare staff, particularly those working with patients from marginalised, underserved, or vulnerable groups.

In the group, we concluded that the key to delivering person-centred care, which was also culturally humble, was humility and lifelong learning, as alluded to by Dorothea in an earlier session: “... it doesn’t matter how long you’ve been qualified, how many years, what hierarchy you have, that actually ... we are all humble empty vessels, empty minds that need constant reflection and awareness and stuff” (session M2). Furthermore, we recognised the importance

of a partnership between patients and healthcare staff, an issue Mac felt strongly about and had previously articulated to the group:

> We should be there regardless of what their culture, what their value … we should be there for them in line with all of those things … seeing them as an individual supporting them in a way that they want to be supported as best as … we can regardless of … our own beliefs, biases or etcetera, etcetera. (session M2 – May 2023)

All co-researchers acknowledged that engaging with and cultivating cultural humility was not just about respect for diversity; it is respecting everyone as individuals, regardless of race, age, gender, and other protected characteristics. It is the recognition of other peoples' values and beliefs, even when these values may not personally reflect or align with our own.

The importance of embedding cultural values into the delivery of healthcare services was recognised by the group. In acknowledging that diversity is always present, Clara felt personally that cultural humility was an added part of care which is culturally responsive. However, she did suggest there will always be situations or experiences which will challenge the concept of cultural humility, at the personal and professional level.

In addition to learning about, cultivating and growing with cultural humility, Dorothea felt it was important for healthcare staff to have a willingness to be open to being "the culturally humble player" (session M4). Mac was supportive of other healthcare staff being introduced to cultural humility, because his experience made him acknowledge that healthcare, delivered with cultural humility, is "more than being aware of someone's different culture, etc. It is also about you as the clinician and that you are not always the expert" (session M3).

Ultimately, the group collectively concluded that the most effective means of promoting awareness, understanding, and the cultivation of cultural humility into clinical practice was through individual-level initiatives: such as self-reflection, greater appreciation and recognition of cultural differences, respect

for diversity, awareness of the balance (or imbalance) of power in the patient/provider relationship, and the willingness to be open to ongoing and life-long learning.

5.7. Looking Inwards Before Looking Outwards - Reflections

I was mindful that the research questions might limit the scope of discussion during the focus groups. Therefore, it was imperative for me to allow the co-researchers to shape the interpretation of these questions, rather than constraining their responses into specific, predefined categories. The research questions functioned as a framework for data collection across four cycles (Cycles One to Four) of research collected over fifteen months (November 2022 to February 2024).

In presenting the findings, I have considered the interpretations and experiences shared by the co-researchers, and the knowledge gained throughout the data collection series (Harding, 2013). I have represented the voices of the other co-researchers involved, using direct quotes, from across the sessions, authentically representing their narratives, but ensuring confidentiality is kept using pseudonyms.

Focus groups are driven by a researcher's area of interest (Morgan, 1997). Consequently, and aligning with the ethos of Participatory Action Research, in my role as the facilitator, it was important to guide, encourage and nurture the co-researchers throughout. My expectation ahead of starting the sessions was that everyone involved would voluntarily offer their contributions and engage with the data requests. Providing all co-researchers with the chance to express their viewpoints can foster a collective understanding of diverse attitudes, opinions, and experiences. Engagement not only shows what participants *think* about a specific issue, but also *how* they think about it and *why* they think the way they do (Morgan, 1997).

I was hoping for a group of co-researchers who would spark a lively discussion amongst themselves, without much guidance from questions supplied or the

facilitator's direction. As we progressed through the focus group series, the other co-researchers led the discussions, allowing me to direct my attention to specific points of interest raised. My intention was to learn from the other co-researchers, and vice versa, by letting them speak for themselves. The process encouraged the co-construction of knowledge about the meaning of cultural humility, and its real-world application in clinical practice by healthcare staff.

I approached the sessions with my own prior knowledge on cultural humility but made no assumptions about the other co-researchers' level of knowledge. I was aware that none of us shared the other's lived experiences, that I may have less professional experience in healthcare and was taking part in the focus group sessions as an academic researcher and active participant (co-researcher).

Each of us brought different experiences to the research, yet we were united by our involvement in healthcare, as well as our similar ethnicities and educational qualifications. I was aware that participation in focus groups could lead individuals to express solidarity, play devil's advocate, shift the topic of discussion, or display one's special expertise or knowledge at the expense of others. However, I did not need to tackle these issues, and was able to take part as a co-researcher, in a manner that guided, supported, and created space for the co-researchers to contribute. I was not taking part to control or steer any of the conversations. Instead, I was aiming to encourage dialogue, shared learning, and shared decision-making.

5.8. Looking Back to Look Forward - Reflections

Prior to the start of the data collection phase and starting the focus groups, I was acutely aware of my own positioning as both the researcher and facilitator for the forthcoming sessions. Drawing on the work of Chevalier and Buckles (2019), I reflected on their five core skills in the use of participatory research: engaging, grounding, navigating, scaling and sensemaking.

The importance of encouraging everyone to engage in critical dialogue and discussion, whereby there might be agreement, disagreement or debate is

acknowledged. Such interactions ensure all voices are heard and validated, while also providing opportunities for self and collective reflection that may challenge existing viewpoints. McIntyre (2008) suggests this method of participation creates an opportunity to engage with the topics addressed during focus group sessions, allowing for subsequent reflection that can lead to action and change.

I began the focus groups unfamiliar with assuming the role of facilitator, although I had partaken in sessions led by a facilitator. I was understandably nervous at the prospect. I was also very conscious that I would begin the sessions, potentially with a greater level of knowledge about cultural humility. Once the sessions began this was beneficial, as I was able to facilitate and lead discussions through a series of prompts and open questioning techniques. In doing so, everyone was given the opportunity to engage collaboratively, share knowledge, perspectives, and experiences, as well as learn from each other and collectively as a group.

In the role as facilitator, I stayed aware that not all co-researchers engaged equally. At times, a couple of co-researchers dominated our dialogue, without being detrimental to the others. I addressed this imbalance by including activities such as anonymous voting (Microsoft Teams Polls) and elicitation of views and experiences using videos, providing alternative ways of expression that would suit those co-researchers more reserved during open dialogue. As the focus groups progressed, I gained confidence and greater skill in drawing in those less vocal, so that everyone was included in the discussions and activities. Hearing everyone's voice was important, because as individuals we all have different experiences, viewpoints, or perspectives to share or re-evaluate because of collaboration.

Holding the focus groups online allowed all co-researchers to take part from settings, such as a home office or similar, providing a secure and safe environment for them. Using this medium to bring the group together for meetings was possible because healthcare staff are used to engaging in this

way, particularly since remote working was introduced during and in the wake of the COVID-19 pandemic. Consequently, everyone felt comfortable sharing knowledge and ideas, in addition to discussing and debating the meaning of cultural humility and its contribution to changes in professional practice.

Whilst different interpretations and experiences were shared, there were no disagreements to resolve. The situation may have been more challenging had I included patient and public involvement, as this group does find it much more difficult to engage with online meetings, because many people access the software on mobile devices such as phones.

All co-researchers shared an eagerness to contribute and learn from each other, as well as be given the opportunity for self-reflection and inquiry. The process of self-reflection was not always a comfortable experience, especially for Dorothea; she openly shared how reflection, aided by the '*Who do YOU think you ARE?*' activity (Asnaani, 2023), had made her acknowledge personal vulnerabilities. However, given the collaborative nature of the group based on mutual respect, trust and empathy, all co-researchers felt able to share any challenges they had experienced.

We acknowledged we were able to recognise the experience as a feature of participatory and reflexive research - the aim being engaged inquiry and a shared view (Chevalier & Buckles, 2019). The breadth of experiences meant we learnt about differing perspectives, through the various cycles of shared activities and understanding. As a group of individuals brought together, sharing a common purpose (to explore the meaning of cultural humility and its contribution to change in care practices), we showed respect and acknowledged differences in viewpoints and interpretation.

While analysing the online focus groups, I considered the interactions amongst and between us. All co-researchers appeared relaxed, responded very openly to questions, both from myself and each other. As the group sessions evolved, it was possible for me to lead less and be more of an observer, as the dialogue

became more spontaneous, less directed, but remained guided by the research objectives.

5.9. Researcher Positionality - 'Insider' and 'Outsider'

I found it essential to reflect on my positionality throughout the research process (participant/co-researcher/nurse – the *insider* position, and academic researcher – the *outsider* position).

As an insider, I shared being a registered nurse with some of the co-researchers and was a member of healthcare staff involved in palliative care in the East of England, working either for a charitable organisation or social enterprise supplying NHS services. I was also a co-researcher, taking part in this small group to explore, understand, and co-create knowledge about cultural humility. Furthermore, we shared similar demographic characteristics, referred to as a "personal biography" by Holmes (2020, p.6): White British, degree educated, English speaking, and similar age groups.

Being an insider as a participant allowed for acceptance, building rapport, trust, and openness with the co-researchers. Consequently, I was able to ask more meaningful or insightful questions, in turn eliciting thoughtful or considered answers, to produce authentic and rich descriptions from all involved. The insider position was about how we (or us) understood, debated, and enhanced our awareness and engagement with cultural humility.

The consequence was that everyone involved was willing to share views and experiences without fear of judgement due to lack of knowledge or awareness relating to the exploration of the research topic. Yet, as highlighted by Holmes (2020), I stayed conscious of the possibility that the co-researchers could be less forthcoming with sensitive information in my presence than they would be with an external individual (the outsider) with whom they would not engage with again.

As an outsider researcher, I continually reflected on and confronted my own biases instead of denying their existence, ensuring that data collection remained

balanced, respectful, and methodologically sound. Furthermore, it was important to acknowledge the perspectives and experiences shared by all co-researchers from a broader, external viewpoint to facilitate an accurate analysis, interpretation, and presentation of the findings.

As the researcher, I was acutely aware of the balance of power throughout the entire series of focus groups. Each of us brought our own expectations and personal agenda to the focus groups and the overall research, as summarised earlier in the chapter (section 5.3). In my capacity as co-researcher it was important to remember that participation is about how we work together and relate to each other, through shared responsibility, power, and knowledge.

My positionality as a researcher was shaped by my pre-existing knowledge of cultural humility as the research began, which initially cast me in the expert role and created a discernible power imbalance with co-researchers. Over time, however, this dynamic shifted as those involved absorbed new insights into cultural humility and contributed their own perspectives, co-creating a shared knowledge base, simultaneously confronting the fear of being judged and the vulnerability of offering public accounts of their own experiences. Through sustained reflexivity, I worked to cultivate a safe, equitable space that honoured both academic knowledge and lived experience. In doing so, I looked not only to share knowledge but also to practice cultural humility and build understanding together in genuine partnership.

The position as both insider and outsider in qualitative research is, as suggested by Dwyer and Buckle (2009), supported by Holmes (2020), possible, particularly if the researcher shares experiences, opinions, and perspectives with participants at various times. Qualitative researchers adopt a position of being with participants but acknowledge that not all experiences or perspectives can be shared by everyone in a given population.

The dual position of insider-outsider has been described as “the space between” (Dwyer & Buckle, 2009, p.1), and one which I have found myself in during the focus groups and ongoing reflexivity. Mercer (2007) suggests a researcher is

situated on a ”continuum” (p.3) or adopts a position of being a fluid insider/outsider, which Holmes (2020) sums up as “a researcher may inhabit multiple positions along that continuum at the same time” (p.6).

As the research progressed, situations arose such as a shift in the balance of power between me as the researcher/participant/co-researcher and the other co-researchers, the growth and change in knowledge (we learnt from each other), varying numbers of attendees, and ongoing engagement and reflection with the research topic.

5.10. Chapter Summary

The themes of *the nature of culture*, *humility as a personal value*, *facing our vulnerability*, *competing priorities* and *the power to change* were generated due to the creative and dynamic process of data analysis and synthesis.

Through the collaborative exchange of knowledge, experiences, and perspectives enabled by a participatory methodology, this research facilitated a collective effort to raise awareness and deepen personal understanding of cultural humility. It also fostered a broader appreciation of cultural humility as a practical and relational approach within healthcare settings.

The potential for contributing to changes in professional practice was also recognised through the engagement and cultivation of cultural humility. Our collective understanding highlighted that cultural humility, viewed as a mindset or way of being, requires a sustained commitment to self-reflection and critique. It encourages an orientation that prioritises the perspectives of others during patient engagement and involves a dedication to lifelong learning.

At the individual level, cultural humility encourages healthcare staff to be authentic, acknowledge diversity, and respect individuality and difference by focusing on becoming a “culturally humble player” (Dorothea - session M4). Challenges related to the recognition and incorporation of cultural humility at the organisational and societal levels were considered. However, all co-

researchers agreed that starting with individual-led cultural humility offers the greater potential for contributions to changes in professional practice for engagement with patients from marginalised or underserved groups. Why the findings matter in the context of palliative care, and what can be recommended for future delivery of holistic and person-centred care, which is culturally humble, will be presented in the next chapter.

6. Chapter Six: Discussion, Recommendations, and Conclusion

6.1. Introduction

The previous chapter presented the focus groups findings. In this chapter, I discuss the research findings in relation to the guiding research questions and the existing literature. While the study was participatory and collaborative, the discussion presented here reflects my interpretation of the data in the context of existing literature. Nonetheless, I aim to accurately represent the co-researchers' individual and collective understandings, interpretations, and experiences of cultural humility as both a concept and a practice. The chapter concludes with personal reflections on the study's strengths and limitations, its contribution to knowledge, and recommendations for practice and future research.

The purpose of this research was to explore cultural humility for healthcare staff and its contribution to equitable and inclusive palliative care. The study was guided by the following research questions (section 1.5):

i. What is the meaning of cultural humility for UK based community and hospice palliative care staff?
ii. Why is engaging with cultural humility relevant for fostering change in professional practice and palliative care for older people who are sexual and gender diverse?

Collaboration and reflection within the participatory action research framework facilitated the exploration of a range of perspectives and multiple understandings, whilst also enabling individuals to critically reflect on their own positioning about cultural humility as a practice that supports person-centred care. By using a participatory methodology, co-researchers from different clinical backgrounds came together to share multiple understandings and perspectives.

As a group, we collaboratively deconstructed the core conceptual elements of cultural humility (culture and humility) and considered how it could be implemented into clinical practice. The focus group findings were organised into five themes, using reflexive thematic analysis (Braun & Clark, 2021). These themes, as presented in Chapter Five (section 5.2), were:

- the nature of culture
- humility as a personal value
- facing our vulnerability
- competing priorities
- the power to change

The following sections (6.2 through to 6.4) critically examine key issues emerging from the findings, including the multifaceted nature of culture, the imperative to challenge conventional thinking, and the dynamic, evolving practice of cultural humility.

6.2. Cultural Humility Acknowledges the Complexities of Culture

As outlined in Chapter Five (sections 5.5.1 and 5.5.2), caring for patients from diverse cultural backgrounds with palliative care needs, or at end of life, can pose many challenges, leading staff to feel vulnerable because of a lack of appropriate culturally specific knowledge, or through ignorance or uncertainty (Cáceres-Titos et al., 2025; Turkson-Ocran et al., 2022).

This research shows that culture significantly shapes personal values, beliefs, and perspectives, as well as societal perceptions of members in society. Furthermore, in line with scholars such as Friedrichsen et al. (2021) and Mannion and Davies (2018), the significance of an organisation's culture of care was emphasised for its role in offering opportunities, support, and structure to enable personal and professional engagement with cultural humility.

6.2.1. Moving Beyond Individual Values, Beliefs, and Practices

This research finds that culture extends beyond the beliefs, practices, and values of a particular group or population (Napier et al., 2017). Culture

encompasses the communication, behavioural, and engagement practices of healthcare staff across diverse settings and over time. These findings align with wider literature that recognises culture as what makes people individual and emphasises the importance of healthcare staff staying aware of their own cultural perspectives without assuming superiority, or mastery (Campinha-Bacote, 2018; Chang et al., 2012).

Importantly, the study shows that healthcare staff continue to make assumptions, sometimes negative, not only about patients, but also peers and colleagues, and what is explicitly or implicitly known about them. Such assumptions often stem from insufficient knowledge, ineffective communication during the collection of relevant information, or limitations in the quality of equality, diversity, and inclusion training (Chartered Institute of Personnel and Development (CIPD), 2025). The purpose of such training is not to eliminate assumptions completely but to enable individuals to recognise and reflect on their individual or personal biases.

In the context of palliative care, the consequences of cultural misunderstanding are significant. Patients at the end of life may hold deep spiritual (inherited or identity-based) needs that are culturally rooted. When these needs are unmet, whether through assumptions about openness to discussing prognosis or pain management, implicit bias, or lack of awareness, patients can feel unseen, unheard, and unsupported. Cultural humility encourages healthcare staff to approach every patient encounter with openness, recognising that the patient is the expert in their own experience. These findings support the views of authors such as Cain et al. (2018) that culture is neither uniform nor homogeneous. Therefore, generalisations should be avoided when interpreting beliefs and behaviours, particularly those related to illness, dying, and death.

6.2.2. Cultural Ruptures and Othering

This research suggests that cultural humility can help mend cultural ruptures and counteract the effects of othering, where individuals or groups are marginalised and treated as lesser, often leading to unequal care or

unfavourable outcomes (Chapter Two - section 2.7). These situations become even more powerful when cultural humility is considered in tandem with intersectionality, which highlights how overlapping social identities shape experiences of discrimination and privilege (Johnson et al., 2004; Roberts & Schiavenato, 2017). Hook et al. (2017) argue that when variations in cultural values, beliefs, or traditions are not recognised, generalisations and misunderstandings emerge, leading to what they describe as cultural ruptures.

Instances of othering continue to be witnessed in clinical practice by members of the group. Drawing on Canales' (2000) framework for understanding difference, othering is conceptualised as either *exclusionary* or *inclusionary*. Exclusionary othering involves discrimination, stereotyping, or stigmatisation, and is still the form most experienced by patients from vulnerable or marginalised populations, including people who identify as sexual and gender diverse (Cherry, 2022; Hook et al., 2016). These processes reinforce power imbalances between healthcare staff and patients, disrupt interactions, and shape clinical decision-making. Resulting consequences include disparities in pain and symptom management, communication barriers, and the implementation of inappropriate care plans (Akbulut & Razum, 2022; Jacobs, 2022).

Integrating intersectionality into the practice of cultural humility offers a critical lens through which healthcare staff can more effectively respond to cultural ruptures and the process of exclusionary othering (Buchanan et al., 2020; Lekas et al., 2020). While cultural humility encourages self-reflection, openness, and lifelong learning, intersectionality deepens this approach by highlighting how overlapping identities (such as race, gender, class, disability, and sexuality) shape individuals' experiences of marginalisation and privilege (Chapter Two - section 2.4).

Together, these frameworks enable healthcare staff to move beyond fixed (or static) cultural awareness and engage with the complex, systemic factors that influence patient-provider relationships. In moments of cultural ruptures, this

combined approach supports a more reflexive and accountable response, one that acknowledges both personal bias and structural inequalities. Moreover, it challenges reductive assumptions about cultural groups by recognising intra-group diversity and resisting the tendency to homogenise or stereotype (Butler et al., 2023). By embracing both cultural humility and intersectionality, healthcare staff can foster more inclusive, relational palliative care, particularly in settings where power imbalances and social exclusion are most acute (Wright et al., 2023).

This study provides evidence that cultural humility guides healthcare staff to acknowledge and respect patients' cultural values and beliefs. Mitigating cultural ruptures and othering requires curiosity about individual perspectives, alongside ongoing self-reflection, and critical engagement. Engaging with the Cultural Humility in Palliative Care framework and HEARt model, specifically the pillars of the 'SELF' and interactions with 'OTHERS' (see Chapter Three - section 3.10.3) supports the cultivation of an action-oriented stance within clinical practice.

These pillars prompt healthcare staff to engage in ongoing critical self-reflection, interrogating implicit biases and assumptions, while simultaneously fostering an orientation towards others that is grounded in respect, openness, and relational accountability. Dual emphasis encourages healthcare staff to actively value diversity and difference in every encounter, whether with colleagues, patients, or members of their support networks.

In palliative care, where personal values, religious or spiritual beliefs, and cultural practices significantly influence attitudes toward treatment and the experience of dying, cultural humility enables more culturally sensitive, appropriate, and person-centred care (Bell et al., 2019; Markey et al., 2021; Yancu & Farmer, 2017). The results are improved individualised care, strengthened patient autonomy, enhanced emotional well-being, and more effective symptom management.

This research shows that cultural humility plays a vital role in advancing Ambition Two of the UK framework for palliative and end-of-life care: each person gets fair access to care (as outlined in Chapter Two - section 2.1). By fostering a deeper appreciation of how intersecting identities, attitudes, and perspectives contribute to misunderstanding, cultural humility supports the delivery of more person-centred and responsive care. When these intersections are not acknowledged, healthcare staff risk reinforcing the belief that their own culture is dominant; a position Hill (2017) refers to as “white culture” (p. 31). Funer (2023) similarly warns against viewing individuals solely through “typical social identity characteristics” (p. 8), arguing that deeper engagement with complex and overlapping identities helps reduce health disparities.

This research highlights the ongoing challenge in progressing toward inclusive and equitable treatment across population groups, despite national policy efforts such as the NHS Action on Inclusion Health (NHS, 2023b). The findings show that embedding cultural humility within person-centred palliative care holds substantial promise for advancing equity and inclusion in practice. Realising this promise demands sustained organisational commitment, through colleagues, peers, and leadership, to cultivate a deeper, more critical understanding of culture and cultural difference. Such support empowers healthcare staff to deliver care that is not only individualised but also culturally attuned and ethically responsive.

6.2.3. To Be Culturally Competent or Humble?

The cultural competency of healthcare staff, and provision of individualised and culturally appropriate care were apparent in the themes ‘Competing Priorities’ (Chapter Five - section 5.5.2) and ‘The Power to Change’ (Chapter Five - section 5.5.3). The findings show that while raising awareness of cultural differences is important for person-centred care, in palliative care settings it is essential that healthcare staff actively deepen their understanding of cultural variations. To understand means to engage with, and value, patients’ lived experiences, which is fundamental to delivering compassionate, culturally responsive, and truly person-centred care.

This research highlights that individuals attribute personal and unique meaning to their cultural backgrounds. Even within shared cultural categories (such as White British), people may experience and express their culture in distinct ways. Cultural humility encourages healthcare staff to remain open to this intra-cultural diversity, resisting assumptions of homogeneity and instead engaging with each person's lived experience on its own terms. Such an approach shifts the focus from cultural competence as static knowledge to a dynamic, relational practice rooted in respect, reflection, and responsiveness.

The findings focus on the importance of learning about the patient as an individual during every encounter. Staff should balance task-oriented care with an other-oriented approach, shifting focus from their own needs to the patient's perspective. As remarked by Clara in focus group session M3 (July 2023), "… there are lots of restraints, there's lots of things against. It shouldn't stop us, actually, you know, being more humane to each other". Cultural humility encourages healthcare staff to learn about each patient through direct engagement, rather than relying on assumptions. It also calls on staff to remain accountable, not only to themselves, but to their colleagues, patients, and the patients' support networks.

As well as recognising that every person brings their unique cultural experience, this research highlights the limitations of cultural competency. It shows how fixed frameworks can overlook the complexity and individuality of people's backgrounds, and why more flexible, reflective approaches, like cultural humility, are needed in practice. Competency suggests having knowledge about a variety of cultures and patient groups, translating into knowing the lived experiences of a patient (Fisher-Borne et al., 2015).

The wider literature suggests that increasing knowledge (or competency) about a variety of cultures has historically been used to "oppress, subjugate and exploit non-Western and non-dominant populations rather than treat them in more ethical and humane ways" (Loue, 2022, p.99). Achieving a level of competency

may result in healthcare staff continuing to create stereotypical opinions about the diversity of patients they meet.

Previous work undertaken in the field of therapy counselling by Hook et al. (2017) encouraged healthcare staff to engage in sessions with personal and professional humility: by authentic active listening, being curious about their patient, working towards building trust and rapport to foster mutually beneficial and therapeutic relationships (or partnership). Sprik and Gentile (2020) stressed how cultural competency focuses on proficiency, seeks out reliance on information, rather than encouraging healthcare staff to confront implicit and explicit biases. Where there is reliance on stereotypes during encounters, patients risk becoming disempowered as they are not considered experts in their own lived experience nor are their experiences valued (Sprik & Gentile, 2020).

More recently however, Shastri et al. (2025) argue for both cultural competency and humility as approaches to training for healthcare staff caring for older people who are sexual and gender diverse; competency enhances knowledge about the palliative and end-of-life unique care needs of these individuals, and humility raises awareness of the power imbalance between healthcare staff and patients.

Understandings and enactment of cultural humility are continually shaped by the complexities and particularities of each patient encounter. Although cultural humility advocates for an orientation towards the ‘other’, marked by openness to difference and a sincere engagement with diversity, it is essential to recognise that clinical interactions do not always unfold in ways that neatly align with these ideals. Some encounters may unsettle our ability to remain reflexive, empathetic, and responsive, thereby challenging the very foundations of culturally humble practice. As Lekas et al. (2020) suggest, such moments can catalyse a shift from a stance of othering to one of becoming genuinely other-orientated, where difference is not merely acknowledged but actively centred in relational care.

Cultural humility aims to minimize the impact of exclusionary othering and encourages a shift in perspective through thoughtful reflection and knowledge seeking, underpinned by the recognition that fully knowing another's culture is unachievable; a position of inclusionary othering (Buchanan et al., 2020; Canales, 2000; Issacson, 2014). Inclusionary othering is a process using the power within relationships for transformation and collaboration. To ease the shift, this research calls for healthcare staff to be willing to commit to lifelong learning and identify when their culturally specific knowledge is limited, inadequate or inaccurate.

By engaging with the pillars of the 'SELF' through lifelong learning and with 'OTHERS' through collaborative practice, healthcare staff are invited to embrace the 'FEELING' of vulnerability that arises when acknowledging the limits of their knowledge. Cultivating the courage to confront this vulnerability becomes a transformative act; one that enables a shift toward the 'BEING' pillar of the Cultural Humility in Palliative Care framework and HEARt model.

The transition reflects a deepened openness and receptivity in clinical encounters, fostering more inclusive, reflexive, and person-centred care. The study has shown the potential of cultural humility contributing to a shift from exclusionary to inclusionary othering by encouraging healthcare staff to see and work with others from the perspective of inclusion rather than exclusion.

6.2.4. Organisational Culture and Accountability

A significant portion of this research focuses on individual (or intrapersonal) cultural humility. However, based on experiences shared by co-researchers during the focus groups, challenges and barriers limiting the effective engagement with and inclusion of cultural humility among staff persist. Concerns raised by fellow co-researchers include a lack of protected time for reflection and self-directed learning, mandated diversity and inclusion training, and task-orientated patient care.

Additionally, the findings identify the need for improving staff multicultural education to appreciate the importance and significance of inclusivity and

diversity in the workplace, not just in the form of policies, procedures, or training, but through activities such as co-creating learning with patients and communities (compassionate community schemes) or simulation and experiential learning (through the use of role-playing, virtual reality, and scenario-based simulations that reflect real-world cultural dilemmas).

Furthermore, the findings of this participatory action research study encourage organisations to develop culturally sensitive communication strategies, provide translation services, and involve patients and their families in care decisions. Understanding and respecting the cultural backgrounds of staff and patients alike can lead to better adherence to treatment plans, improved communication, and delivery of palliative care which is respectful of cultural variations and patients' wishes.

In this study, all co-researchers expressed concerns about the lack of time and space to engage in meaningful critical self-reflection beyond the clinical environment or the demands of professional registration. These findings support previous research highlighting ongoing challenges faced by healthcare staff in their desire to provide care, which is person-centred, especially for patients receiving palliative care or approaching the end of life (Bloomer et al., 2013; Fernández-Basanta et al., 2023).

Extending the work of Solchanyk et al. (2021), the space described must be a safe place; an environment (physical or relational) where people feel respected and supported to share their thoughts, feelings, and experiences without fearing judgement. Solchanyk et al. (2021) acknowledge the importance of creating a safe environment for medical students to explore and discuss cultural variations. When the space is not conducive to open dialogue, individuals may feel threatened, or vulnerable about challenging their peers' viewpoints. Sprik & Gentile (2020) reiterate the importance of fostering "safe reflection space" (p.407) to encourage dialogue about biases.

The Cultural Humility in Palliative Care framework and HEARt model invite healthcare staff to engage in ongoing critical self-awareness and self-evaluation

(the ‘SELF’ pillar), fostering an openness to recognising and confronting personal vulnerabilities. Emotional courage (represented by the ‘FEELING’ pillar) is essential to the process, particularly when confronting the limits of one’s own knowledge and the discomfort that may accompany such reflection. It is through this deliberate engagement with discomfort that healthcare staff cultivate the ability to be *comfortable with the uncomfortable*: a foundational orientation for culturally humble and responsive care.

An environment in which healthcare staff can interrogate their practice or identify areas for improvement or development requires commitment at the organisational level. These spaces (such as Schwartz Rounds) offer staff the opportunity to share heightened emotions, including feelings of being out of their depth or culturally challenged, while receiving peer support (Flanagan et al., 2020; Golding, 2024; Ng et al., 2023). Research by Bryk et al. (2023) highlights challenges integrating culturally appropriate care within biomedical care models in palliative care services to meet the multidimensional needs of a patient. This study shows that while there is organisational commitment to providing culturally appropriate care, staff directly involved in patient care continue to struggle.

Failure (or a lack of accountability) by organisations to include, or a reluctance to offer adequate opportunities (including education, time, and support) to foster cultural humility in the workplace, has the potential to contribute towards ongoing exacerbations of health inequalities for vulnerable patient groups. Some of the co-researchers highlighted this as a significant concern, particularly in relation to the care of prisoners and people who identify as sexual and gender diverse. Recent work by Fernandes et al. (2020) into the experiences of people with diverse sexual orientations and gender identities in prisons highlights ongoing organisational discrimination and recommends raising awareness amongst staff to improve their knowledge and understanding of the unique needs of this prison population.

Organisational accountability in palliative care services focuses on creating a culture of responsibility and continuous improvement, thereby ensuring the organisation not only meets international or national guidelines but also aligns with the core values of palliative care (as outlined in Chapter Two - section 2.1). The wider literature characterises accountability as a social responsibility, often referred to as social accountability (or social responsiveness). Furthermore, fostering a workplace culture that promotes accountability, and shared responsibility is essential for delivering person-centred, culturally humble care (Cooks-Campbell, 2022).

Organisations such as the World Health Organization emphasise accountability as a foundational structural responsibility in the training and professional development of healthcare staff, advocating for the alignment of educational, research, and service efforts with the priority health needs of the communities served (Bolderston, 2025; WHO, 1995). However, the findings suggest that this accountability is perceived as the responsibility of healthcare staff working directly with patients, rather than non-patient facing staff or organisations.

6.2.5. Policy Planning and Educational Standards

Accountability requires action and, according to Foronda (2020), should involve organisations (whether a care provider or educational provider) in the development and promotion of diverse, inclusive, and equitable learning settings.

Despite national frameworks advocating for inclusion, cultural humility is still underdeveloped in UK healthcare policy. Treating inclusivity as a mere compliance exercise undermines the principles championed by the UK Equality and Human Rights Commission (EHRC, 2020; Pyper & Uwazuruike, 2024). In a report on improving service delivery in health and social care for older people who are sexual and gender diverse, Ward et al. (2010) advocated for the active involvement of individuals from under-represented patient populations, including older people who are sexual and gender diverse as “experts by experience” (p.25). Their inclusion facilitates the articulation and

acknowledgement of concerns, thereby promoting care provision that is both appropriate and responsive to individual needs. This study highlights the need for explicit integration into regulatory standards and educational curricula. The study's findings bring to light concerns from staff about the pace of progress around accountability in the workplace but also in other organisations that share care responsibilities for patients.

A participatory approach is intended to inform and shape service delivery in ways that are genuinely inclusive, while also addressing systemic discrimination and inequitable access to care (Ward et al., 2010). Beach et al. (2019) support this position, with the current study highlighting ongoing concerns about the slow pace of change to ensure the quality and effectiveness of equality training. The research findings stress the urgent need to ensure inclusivity is made explicit by organisations, and that equality and diversity training does not remain too generic, thus potentially reinforcing stereotyping, pre-conceived assumptions or biases held by healthcare staff. Such training often lacks reflexivity and does not address power dynamics, with a tendency to deliver content which focuses on treating all patients the same rather than recognising diversity and difference (Barber et al., 2023; Beach et al., 2019; Clancy & Thomas, 2025).

Recent research by Jerwood et al. (2024) reiterates the ongoing challenges experienced by people who identify as sexual and gender diverse accessing palliative and end-of-life care. Their work candidly states ongoing issues with discrimination and assumptions made by healthcare staff, despite efforts to promote and foster diversity and inclusivity. A noteworthy point is the suggestion of cultural competency training to ensure healthcare staff provide care that is holistic in its approach for these patients. A recent report from the Lancet Oncology Commission emphasises the critical need to integrate relational skills into educational curricula alongside traditional clinical skills in cancer care (Rodin et al., 2025). This integrated approach is essential for delivering patient care that reaffirms dignity, builds trust, and effectively alleviates suffering.

However, as highlighted by the findings, cultural competency and cultural humility diverge fundamentally in their orientation to the patient-clinician relationship. Competency frameworks centre on the accumulation of discrete knowledge about cultural groups, implying that mastery (or reaching expert level) can be achieved, thus reinforcing stereotypes through the othering of patients. Co-researchers emphasised the importance of healthcare staff beginning interactions by listening to patients, rather than approaching them with pre-set agendas, such as the holistic needs assessment commonly used in palliative care information gathering.

In contrast, cultural humility demands an introspective commitment to continuous self-evaluation, power analysis, and recognition of systemic privilege, thereby foregrounding the patient's lived experience and the fluidity of identity. Co-researchers voiced the importance of organisations demonstrating cultural humility by acknowledging their cultural shortfalls (such as diversity of staff, culturally appropriate information sharing and communication).

This research advocates for cultural humility because, as healthcare staff continually examine their own assumptions, they become more attuned to power imbalances (such as assumptions based on identity, limited patient voice in decision-making, overlooking cultural beliefs, or language barriers) in the patient-provider relationship. Cultural humility contributes to the purposeful fostering of genuine partnerships, confronting systemic inequalities, and collaboratively tailoring care to each patient's evolving needs.

One of the co-researchers, Clara, shared how she had been on a journey of "de-centring" herself (session M4 – October 2023). She talked about how healthcare staff may position themselves at the centre of the relationship with patients (at times driven by a sense of ego), and the challenge of reverting that position: "it's quite hard to unlearn that" (M4). She also highlighted the importance of how language is used by organisations: "changing minoritised language is a real decentring shift for white British organisations" (session M4 – October 2023).

Encouragingly, efforts to develop more inclusive and equitable policies are gaining momentum. Organisations such as the US National LGBTQ Task Force and GLAAD contribute to advancing the rights of people who identify as sexual and gender diverse in the USA. They do this through policy briefings and community engagement. In the UK, Stonewall has played a particularly prominent role. Guidance is provided to organisations on how to embed inclusivity within policy and practice. Awareness training for healthcare staff is provided by organisations including GIRES (Gender Identity Research & Education Society) and The OutHouse.

Another avenue supporting diversity and inclusion is the creation of frameworks and guidelines for integrating cultural humility in organisational use. Nyamwaya (2022) published guidelines to promote inclusive practice for team leaders (in any setting), building on hospice and palliative care specific work done by Acquaviva in 2017. Asnaani (2023) has contributed to the inclusion of cultural humility in the psychotherapy profession through her work supporting students and qualified therapists alike.

The US National Coalition for Hospice and Palliative Care guidelines (2018) emphasise the importance of cultural aspects of care, outlined in Domain Six. They promote the practice of cultural humility among interdisciplinary teams. The guidelines also recognise that healthcare staff may sometimes experience conflict with patient or family values. Such conflicts can influence preferences for care, which are addressed in Domain Eight. In a similar vein, the US Standards for Care of Transgender and Diverse People (Coleman et al., 2022) advocate for cultural humility in clinical practice to encourage cultural responsiveness and respect for the intersecting of identity with support needs.

The limited references to, and inclusion of cultural humility in formal documentation suggest organisations, particularly in the UK, may lack familiarity with and understanding of the concept and its potential contributions to promoting equitable and inclusive patient care. There continues to be emphasis placed on diversity and inclusion training, often mandated, in addition to clinical

competencies for healthcare staff to achieve. Organisations may wish to consider being more culturally responsive by providing workshops to encourage staff become more aware of cultural humility and its potential contribution in practice, without them feeling these approaches are being mandated.

Higher education institutions in countries such as the UK, Canada, and the USA are increasingly integrating culturally immersive programmes into healthcare education. These initiatives place cultural humility at the forefront; not only as a key part of person-centred care, but also as a vital strategy for addressing persistent health inequalities (de Leeuw et al., 2021; Gonzales-Walters et al., 2024). Healthcare leaders can set an example by reflecting on their own biases and working towards a working environment based on openness and honesty (Kelsall-Knight, 2022).

In 2024, the NHS Scotland Academy (responsible for education and training to a wide range of health and social care roles and professions in Scotland) introduced the Cultural Humility Digital Resource to support the development of cultural humility values and behaviours. The non-mandatory resource is reported to have been used by 690 learners across a range of healthcare settings and roles (NHS Education for Scotland, 2025).

As Treisman (2018) emphasises, training aimed at fostering awareness and implementation of cultural humility should not be treated as a one-off event or a procedural formality. Instead, the training requires sustained, reflective engagement that is embedded into ongoing professional development and organisational culture. In spite of this, healthcare organisations continue to place greater value on staff being culturally competent as it is measurable and encourages skill acquisition contributing to high-quality care by identifying diverse cultural needs of patients (Osmancevic et al., 2025; Vatwani, 2024).

Encouragingly though, other research continues to raise awareness of the role cultural humility plays in palliative care. The research findings from this study highlight cultural humility's potential to enhance team working across disciplines, peer-to-peer respect, and the involvement of patients with lived

experience. In their exploration of allied health professionals' perspectives, Singh et al. (2023) highlight the importance of a team-based approach to effectively implementing cultural humility in practice for patients with palliative care needs. Shared interdisciplinary learning is a key mechanism for acquiring knowledge about patients and unfamiliar cultural practices. Collaborative teamwork becomes a strategy to reduce the risk of cultural misunderstandings and ruptures, thereby strengthening relationships with patients and their support networks.

By encouraging and promoting an organisational culture of inclusion, and appreciation for diversity, healthcare staff may develop a sense of feeling part of, or belonging to, a more caring environment. Cooks-Campbell (2022) advocates for cultural humility in the workplace as "an orientation to the world and the people around you" (p.4.), enhancing a sense of belonging. Authors including Stamps and Foley (2023) and Muirhead et al. (2025) further articulate that healthcare staff with diverse cultures and attitudes can bring fresh ideas and perspectives to an organisation's cultural outlook. The emphasis on learning and mutual respect through cultural humility has the potential to enhance staff motivation and promote person-centred patient care.

6.3. Reframing Professional Practice

In palliative care, cultural humility potentially offers a transformative way for understanding, delivering, and experiencing care. Neubauer et al. (2016) emphasise the importance of healthcare providers and staff recognising individual and family cultural values in palliative care decision-making. For patients receiving palliative care, needs extend beyond symptom management to encompass dignity, understanding, and connection (Chochinov, 2022; Hadler et al., 2024; Pringle et al., 2015). A person's illness should not define them, rather healthcare staff should see a patient first as a human being, and patient second (Entwistle & Watt, 2013; O'Connor, 2017).

Engaging with cultural humility is central to fostering meaningful change in professional practice and palliative care for older people who are sexual and

gender diverse because it reorients practice away from static notions of cultural knowledge towards a dynamic, reflexive, and relational approach to care.

Sexual and gender diverse older adults have lived through periods of criminalisation, discrimination, and social marginalisation, experiences that continue to shape their interactions with healthcare systems and may contribute to mistrust, identity concealment, and inequities in access to supportive palliative care. Within this context, approaches based solely on cultural competence may be insufficient, as they can imply the possibility of mastering knowledge about others' identities and risk reinforcing static understandings of difference.

Cultural humility instead foregrounds lifelong self-reflection, critical awareness of power relations, and openness to learning from the lived experiences of those receiving care. The findings of this participatory action research study demonstrate that engaging with cultural humility can foster transformative learning among healthcare staff by creating structured opportunities for reflection, dialogue, and collective inquiry into assumptions embedded within everyday practice.

The HEARt model developed through the scoping review of current literature offers a conceptual model for understanding how such change occurs. Through the interrelated dimensions of self-awareness and reflexivity (the SELF), relational engagement with patients and families (with OTHERS), an orientation towards authentic and respectful practice (the BEING), and the emotional courage required to engage with vulnerability and uncertainty (the FEELING), the framework illustrates how cultural humility can be enacted in clinical contexts.

Together these dimensions support healthcare staff to move beyond uncertainty or avoidance towards actively affirming identities, recognising chosen family relationships, and engaging more openly with conversations about sexuality, gender, ageing, and end-of-life care. In doing so, the HEARt model conceptualises cultural humility not merely as an individual attribute but as a

relational and practice-oriented way of being and mindset that can enable shifts in professional understanding, interpersonal engagement, and organisational culture.

Engaging with cultural humility therefore has the potential to foster more inclusive, equitable, and person-centred palliative care by supporting healthcare staff to critically examine the assumptions that shape care, attend more attentively to the diverse experiences of ageing and dying, and create clinical environments in which older people identifying as sexual and gender diverse feel recognised, respected, and supported at the end of life.

This research highlights the value of engaging with cultural humility in everyday practice, demonstrating its contribution to both personal and professional development by fostering greater self-awareness and recognition of individual limitations among healthcare staff; features highlighted in the Cultural Humility in Palliative Care framework and HEARt model (the 'SELF' pillar), through critical self-awareness and self-evaluation. Moreover, the findings suggest that cultural humility is shaped by cultural context and begins as an intrapersonal attribute.

Engaging with cultural humility in professional practice encourages healthcare staff to be more other orientated, by being curious about the individuals in their care; a stance highlighted as an attribute of cultural humility (Chapter Three – section 3.10.3), and depicted in the Cultural Humility in Palliative Care framework and HEARt model under the 'BEING' pillar (Chapter Three - Figure 4). However, its relevance extends beyond the individual, highlighting the need for cultural humility to be actively integrated at both interpersonal and organisational levels. A broader application is essential for fostering inclusive, reflective, and responsive practice across healthcare settings.

Awareness of cultural humility varied amongst the group's co-researchers; a position I reflected on throughout the research process. Peer collaboration provided everyone with equal opportunities to explore the concept and determine how its application and use could benefit their individual professional

practice. Group sessions and reflexive activities afforded everyone time and space to engage with the concept, fostering both individual and collective understanding through dialogue and listening to alternative perspectives. Furthermore, as advocated by Asnaani (2023), learning about cultural humility as a concept, through dialogue and reflection, enabled each co-researcher to become authentically aware of individual strengths and weaknesses (shaped by personal identity and life experiences) which may affect the relationship with patients.

To engage meaningfully with cultural humility in palliative care is to adopt a fundamentally different mindset - one that shifts from knowledge acquisition to relational understanding, from assumption to inquiry, and from mastery to mutual respect (Agner, 2020; Fisher-Borner et al., 2015; Lekas et al., 2020; Yaeger & Bauer-Wu, 2013). The findings show that cultural humility encourages healthcare staff to rethink traditional care models and assumptions. It pushes them to question established professional roles. The focus shifts toward building respectful, responsive relationships with patients. Recognising diversity and inclusion becomes central to delivering effective, yet person-centred palliative care.

Cultural humility should be considered a key part of person-centred care, as it requires healthcare staff to adopt an other-oriented perspective by recognising and engaging with diverse values and belief systems. Rodin et al. (2025) suggest that humility (and cultural humility) can contribute to reimagining patient care (in the context of global cancer care) as equitable, and compassionate, dignified and empathetic “human-centred care” (p.1). There is a transition from static notions of cultural knowledge to a dynamic, ongoing commitment to self-reflection, openness, and inclusive practice (Yeager & Bauer-Wu, 2013). For healthcare staff, it means asking not just *what do I know*? but also *what assumptions am I making*? and *how can I create mutual understanding with the person in front of me*?

Reframing professional practice with cultural humility challenges deeply embedded clinical norms that prioritise efficiency, control, and protocol over the nuanced, person-centred engagement that palliative care calls for (Bryk et al., 2023; Sassen, 2023). Cultural humility offers the possibility for authentic connections by encouraging healthcare staff to engage as learners and partners rather than authoritative experts: features repeatedly spoken of by the whole group.

The findings from this current study show that cultural humility has value for all healthcare professions, not just medical students as advocated by Tervalon and Murray-García (1998). They articulated cultural humility as an approach to deal with ongoing issues of racial discrimination in the USA. Understanding of cultural humility is extended beyond its response to systemic issues such as racial discrimination; it serves as a framework for recognising and respecting the diversity that exists within cultural groups themselves. Acknowledging intra-cultural variations, such as differences in beliefs, practices, identities, and lived experiences among individuals within the same cultural group, is essential for delivering care that is genuinely person-centred.

Cultural humility offers a framework through which healthcare staff can move beyond reductive cultural generalisations and engage with patients as complex, multifaceted individuals. The concept analysis results indicate cultural humility is inherently multi-dimensional and resists categorisation into fixed or linear models. Its effectiveness is contingent upon the practitioner's willingness to engage reflexively with the four interrelated pillars of the Cultural Humility in Palliative Care framework and HEARt model (Figure 4 - Chapter Three). These pillars work synergistically, and the transformative potential of cultural humility is unlikely to be fully realised if any one dimension is neglected. There is the need for a sustained, relational commitment to cultural humility as both a personal and professional practice.

From the research findings, cultural humility is best understood not merely as a framework, practice, or process, as commonly described in the literature

(Bennett & Gates, 2019; Yancu & Farmer, 2017), but as a fundamental orientation: a way of being that shapes how healthcare staff engage with patients, colleagues, and themselves. The way of being orientation demands a commitment to lifelong learning and reflexivity, encouraging staff to critically examine their own values, assumptions, and biases. Cultural humility fosters inclusive, respectful interdisciplinary collaboration by valuing individual differences and promoting active listening, empathy, and openness to unfamiliar contexts (Singh et al., 2023).

Cultural humility is enacted through practice, not merely learned from frameworks. The specific path healthcare staff take will reflect their developing understanding and commitments. Begin with structured self-inquiry, for example using the *Who do YOU think you ARE?* Self-identification worksheet (Appendix 20), to map out identity, values, assumptions, and position in society. Follow with guided reflection on how privilege and professional power influence interactions with patients and their families. Create space to explore instances of discrimination (whether experienced or witnessed) and how those experiences (or events) shape attitudes and behaviours. Proactively identify areas of limited knowledge and cultivate an openness to being challenged rather than defending, not "being rigid-minded" as suggested by Singh et al. (2023, p.9). Treated as an ongoing, reflexive process rather than a one-off skill, cultural humility strengthens the self-awareness of healthcare staff, and leads to more respectful, person-centred palliative care.

The research findings identify the potential for staff to shift emphasis from a task-oriented approach to a presence-centred way of being (being fully present with the patient emotionally, relationally, and attentively). Cultural humility is not a checklist to be completed, but a relational practice grounded in reflection and partnership. It challenges healthcare staff to move beyond the role of expert and engage collaboratively with patients, families, and communities. By examining their own cultural lens, healthcare staff can better understand how their perspectives shape interactions and influence care. The

adjusted (or new) orientation fosters responsiveness, empathy, and a commitment to equity; qualities essential to inclusive palliative care.

The Cultural Humility in Palliative Care framework and HEARt model (including the 'SELF', with 'OTHERS', the 'FEELING', and the 'BEING') emerged from this study as practice-informed frames of reference extending current understandings of cultural humility. They invite healthcare staff to *unlearn* ingrained assumptions to *learn again* with openness, self-awareness, and the courage to confront personal vulnerability. A shift from task-oriented approaches (the *doing)* occurs, resulting in a relational orientation (the with 'OTHERS') grounded in presence and empathy.

While existing models often focus on individual reflection or interpersonal sensitivity, the Cultural Humility in Palliative Care framework and HEARt model offer a more layered and systemic perspective. It locates cultural humility not only within the internal values and behaviours of individual healthcare staff, but also within the organisational cultures and structural conditions that shape care delivery. Crucially, cultural humility is positioned as a fundamental *way of being* for all healthcare staff. The current perspective offered in this study expands beyond its original framing by Tervalon and Murray-García (1998), which focused primarily on medical students and community engagement. Instead, cultural humility is reimagined as a continuous and shared commitment, spanning all levels of care, emphasising its relevance across the entire healthcare system.

Through the integration of the four pillars (the 'SELF', with OTHERS', the 'FEELING' and the 'BEING'), the framework and model challenge one-dimensional or oversimplified interpretations of cultural humility as a personal trait or training outcome. Instead, they position cultural humility as a dynamic, multi-level orientation, one that requires ongoing reflection, relational responsiveness, and structural critique. The theoretical advancement contributes to the evolving discourse on equity-oriented care and offers a practical scaffold for embedding cultural humility across clinical, educational, and policy contexts.

Figure 19 is an illustration of how a selection of the generated themes inter-relate with the Cultural Humility in Palliative Care HEARt model (Chapter Three - section 3.10.3). As highlighted by the findings of the literature review and defining attributes of cultural humility (Chapter Three – section 3.10), the way of being emphasises egolessness, humility, and curiosity, contrasting with the competency-based way of doing (Abe, 2019; Agner, 2020; Bennett & Gates, 2019). Such an approach aligns with literature supporting person-centred care oriented toward the individual (NHS England, 2025b; NMC, 2025b; Rogers, 1995).

Furthermore, this study’s findings suggest cultural humility can support a shift from outcome-oriented to other-oriented models of care. Healthcare staff are encouraged to integrate clinical expertise with a reflective awareness of patients’ unique lived experiences, fostering a commitment to learning both about others through authentic engagement, and about themselves through critical self-reflection.

In palliative care, understanding patients' beliefs, values, and desires is crucial, as these may change rapidly and require careful attention. When caring for people who identify as sexual and gender diverse, affirming identity (such as using preferred names and pronouns), and acknowledging chosen families are essential. Hence, staff are encouraged to critically reflect on their own identities and assumptions, ask respectful questions, and prioritise the individual’s expressed preferences about identity, relationships and end-of-life beliefs or wishes.

Figure 19. Relationship of themes with Cultural Humility in Palliative Care framework

6.4. The Complexity of Cultural Humility

This research emphasises that engaging with cultural humility as a *way of being* requires not only dedicated time for reflexivity but also a sustained commitment to its consistent application in practice. To begin with, raising awareness of the core elements of cultural humility, understood in this context as culture and humility, is essential for facilitating meaningful engagement. The findings deepen understanding of the pivotal roles these elements play within the broader context of palliative care.

A commitment to the practice of self-reflexivity about culture (personally and professionally) and being more aware of personal humility in practice avoids healthcare staff reducing patients to categories, or cultures to checklists (Prasad et al., 2016; So et al., 2024). Rather than a fixed competency, cultural humility appears as a dynamic, relational practice rooted in self-awareness, critical reflection, and responsiveness to diverse lived experiences (Foronda et al., 2016; Tervalon & Murray-García, 1998).

Learning about and engaging with cultural humility to be culturally humble in professional practice is neither linear nor straightforward. The findings indicate that engagement with the concept must be both ongoing and sustained. Such engagement is essential for developing a deeper understanding of its underlying principles. The engagement also enables healthcare staff to critically reflect on how the concept may influence their practice. Over time, this reflection can shape relationships not only with patients but also with colleagues.

As healthcare staff continue to interact with patients, this relationship with cultural humility undergoes an iterative process of learning and adaptation. The broader literature acknowledges that cultural humility needs a lifelong commitment to critical self-reflection, an understanding of the power imbalances existing in patient-provider relationships, and a willingness to address these imbalances (Foronda, 2020; Hook et al., 2016; Tervalon & Murray-García, 1998).

Over time, all co-researchers, including myself, developed and refined our understanding of cultural humility through a combination of individual reflection and collective dialogue and learning. As the wider literature suggests (Clancy & Thomas, 2025; Edwards & Baska, 2020; Foronda, 2020; Oosman et al., 2019; Rosa, 2017), it is not a practice that culminates in a final, fixed destination. Instead, it evolves as the interactions between healthcare staff and patients unfold, continuously shaped by the specific context in which these exchanges take place. Cultural humility demands an ongoing commitment to critical self-reflection, a theme recurrently noted in the literature (Issacson, 2014; Singh et al., 2023; Tervalon & Murray-García, 1998) and personally experienced by all co-researchers throughout the focus group process.

Self-reflection allows individuals to become more aware of personal vulnerabilities (such as limitations or biases) and how individual worldviews may influence interactions with others. The findings highlight the value of embracing discomfort (being *comfortable with the uncomfortable*) emphasising that healthcare staff should feel empowered to recognise when knowledge is limited, or cultural ruptures happen during patient interactions. It becomes about individual ownership.

Agner (2020) highlights how this ownership contributes to improving future interactions with patients from diverse backgrounds. Luther and Flattes (2022) suggest that awareness of personal biases and being comfortable with vulnerability creates capacity for healthcare staff's personal and professional growth. Furthermore, the way in which healthcare staff engage with cultural humility is influenced by personal and professional life experiences, and shaped by an understanding of cultural dynamics, as discussed earlier in the chapter (section 6.2).

Learning about cultural humility in this study did not follow traditional teaching methods, typified by structured teacher-led instruction or through the acquisition of skills and knowledge as is the case with cultural competency (Agner, 2020). Through individual and collective learning and dialogue, we (as co-

researchers) gained insights into the roles of culture and humility in healthcare, leading to both personal and collective growth in understanding how cultural humility is best placed to enhance professional practice. As Hurley et al. (2022) argue, individuals must recognise that their own perspectives may be limited and work actively to remain open to other perspectives, adopting an other-oriented stance.

6.5. Personal Reflections on the Research Process

This research was undertaken to explore and understand cultural humility, not only as a theoretical concept, but as a lived practice within palliative care. A participatory methodology was purposefully chosen to align with the values of co-construction, equity, and reflexivity central to both cultural humility and Participatory Action Research. In adopting this approach, I acknowledge that all co-researchers, including myself, brought diverse experiences, beliefs, and interpretations to the process, shaping both the inquiry and its outcomes.

As set out in Chapter One (section 1.2), my motivation for this work stems from a commitment to person-centred, inclusive care, crystallised during a critical moment in practice when I saw discriminatory treatment of a trans woman in a healthcare setting. The experience highlighted the urgency of addressing cultural humility in clinical care and became a turning point in my personal and professional development. As a heterosexual, cisgender woman, I became increasingly aware of the limitations of my own perspectives and the importance of approaching others' experiences with openness and humility. Through this research, I have been challenged to recognise when and what I do not know, to reflect on my biases, and to develop the courage to address discriminatory attitudes, including those encountered among colleagues.

The research journey has been iterative and non-linear, mirroring the cyclical nature of Participatory Action Research (Kemmis et al., 2014; Mertler, 2014). Focus groups were conducted before completing the scoping review and concept analysis to minimise bias from pre-existing literature and prioritise the

voices of all co-researchers. The methodological choice supported a more authentic exploration of cultural humility as it is understood and experienced by healthcare staff. While my undergraduate studies introduced me to concepts of cultural competence, the collaborative nature of this project deepened my understanding of cultural humility as an evolving, relational practice rather than a fixed skill set.

Reflexivity has been essential throughout this process. It enabled critical engagement with my own positionality and the power dynamics inherent in research. For example, taking the Harvard Implicit Association Test (Greenwald et al., 1998) revealed implicit biases despite my upbringing in a culturally diverse environment, underscoring the necessity of ongoing self-reflection. These insights have informed my efforts to foster inclusive, equitable, and responsive care practices.

Facilitating focus groups with a small cohort of healthcare staff proved both effective and enriching. Providing a supportive environment throughout the focus group series allowed for dialogue unspoken in the clinical/professional healthcare contexts. Together, we navigated the complexities of cultural humility in practice, recognising the limitations imposed by time and structure. While the research produced important foundations, the work of cultural humility is still ongoing. Language was one area of growth: I began this project referring to *sexual and gender minorities* but, through critical reflection, adopted the more inclusive term individuals identifying as *sexual and gender diverse*.

This research has deepened my understanding of cultural humility as an ongoing, reflective, and ethical practice. By critically examining my own assumptions through ongoing reflexivity (Chapter Four - section 4.7.3 and Chapter Five - section 5.9), and engaging collaboratively with others, I have looked to conduct research that is meaningful, inclusive, and capable of informing more equitable palliative care delivery.

6.6. Strengths and Limitations of the Research Study

6.6.1. Strengths

A key strength of this study was the adoption of a participatory action research methodology, which aligned closely with the principles of cultural humility: collaboration, reflexivity, and a commitment to transformative practice. Using this approach enabled the co-construction of knowledge and fostered authentic engagement among all participants. Defining the area of concern and research questions prior to starting the focus groups provided a shared reference point from which co-researchers could build and negotiate meaning.

Over a 15-month period (between November 2022 and February 2024), we met every six to eight weeks, generating material in response to prompts, initially offered by myself, through reflexive activities and in-group tasks (see Appendices 18 and 19), and reconvening to critically interpret and discuss our collective work. The research design facilitated deeper insight into the nature of knowledge and reality, embracing multiple perspectives and interpretations rather than a singular truth. The design also reflects the study's philosophical grounding and commitment to a multiple perspectives approach. Consistent with Kemmis et al. (2014), the participatory action research approach created "communicative spaces" (p.28) in which co-researchers could reflect together on the character, conduct, and consequences of professional practice.

The study successfully met its objectives: developing collaborative reflective activities, supporting co-researchers in identifying strategies for integrating cultural humility into practice, and exploring its potential to drive meaningful change in care delivery. Rigour was ensured throughout the study by the sustained reflexive engagement of all co-researchers. Ongoing analysis was undertaken collectively during the focus group sessions, enhancing credibility through collaborative interpretation. Member checking further contributed to credibility and authenticity by allowing participants to affirm or refine the interpretations detailed in the findings. Together, these strategies strengthened the rigour of the study across all dimensions of trustworthiness.

As a researcher, I moved fluidly between outsider (academic researcher) and insider (participant/co-researcher) roles. Building meaningful relationships and fostering shared ownership of the research process enabled this positional shift without causing friction. Co-researchers actively shaped the inquiry and engaged deeply with cultural humility as an ongoing, relational, and ethically grounded practice. Virtual sessions enhanced accessibility and convenience. Despite the limitations of online engagement, co-researchers reported feeling safe and comfortable sharing their perspectives.

The iterative, non-linear nature of the participatory action research cycles was embraced, allowing the research to remain responsive to emerging insights and group dynamics. The skills needed from a participatory action researcher were central to the study's success. Drawing on the framework proposed by Cornish et al. (2023), I have reflected on these competencies (Table 18). Engaging as academic researcher and co-researcher cultivated a range of interpersonal and reflexive competencies central to Participatory Action Research and the study of cultural humility. I upheld respect for experiential expertise, practiced sustained humility and kindness toward senior colleagues, and remained open to new and enhanced learning from the other co-researchers. Navigating early discomfort and occasional vulnerability in focus groups fostered greater self-awareness, active listening, and the ability to be challenged.

These experiences, together with patience and trust in the iterative, sometimes messy participatory action research process, enabled more authentic contributions. I took practical responsibility for organising and facilitating the study while staying accountable to the group, and I exercised the confidence to moderate power imbalances when dominant voices emerged, ensuring broader participation without escalating tensions. Through this participatory and collaborative process, the study has illuminated how reflective dialogue and co-constructed meaning-making can deepen practitioners' engagement with cultural humility, not only as a professional value, but as a personal commitment.

Table 18. Soft skills of a participatory action researcher (adapted from Cornish et al., 2023)

Soft Skills	***My response and how I achieved the skill set***
Respect for others' knowledge and the expertise of experience	Fundamental – without the respect I would not have my data
Humility and genuine kindness	I was very aware of this, particularly as my colleagues were all more senior healthcare staff at work
Ability to be comfortable with discomfort	I felt uncomfortable (and at times vulnerable) during the early focus group sessions, because I wanted the co-researchers to become as enthusiastic about Cultural Humility as me. But I could not influence them
Trusting the process	Essential – I had to learn to accept the unstructured nature (or messiness) of PAR while keeping focus as the cycles of data collection progressed
Patience	To get authentic and genuine responses or input from co-researchers
Accepting of uncertainty and tensions	This was particularly apparent when co-researchers were unable to attend sessions, or I had to send reminders about individual reflexive activities. Fortunately, there were very few moments of tension across the whole focus group sessions
Openness to learning from collaborators	Genuinely interested in learning from the co-researchers about their views and perspectives
Self-awareness and the ability to listen and be confronted	I became more comfortable with this as focus group sessions evolved, and as we engaged more with cultural humility. I found PAR and cultural humility complementing each other
Willingness to take responsibility and to be held accountable	I had to take responsibility for organising the schedule for group sessions, preparing work in advance, ensuring material was distributed appropriately and promptly
Confidence to identify and challenge power relations	At times one or two co-researchers dominated dialogue, so it was important for me to bring in those less vocal. There were no major disagreements or arguments to contend with

6.6.1. Limitations

A key limitation of this study was the lack of perceived cultural diversity among co-researchers. We identified as White British, heterosexual, cisgender healthcare professionals. There were however differing characteristics amongst all co-researchers in the group including age, occupation, clinical background and professional experience in palliative and end-of-life care.

While the opportunity to take part was initially extended to three local organisations, recruitment focused on two sites that were most accessible to me. Although acute hospital settings were initially considered to broaden the sampling pool, practical constraints - including geographical limitations and the presence of only one acute hospital in the area - shaped the final choice. Inclusion of participants from acute care settings or more culturally diverse healthcare environments may have enriched the data and broadened the scope of findings. Site selection also introduced limitations, as co-researchers were drawn from settings familiar to me as the researcher. While this helped access and rapport, it may have constrained the diversity of perspectives.

Recruitment posed notable challenges, primarily due to perceived time constraints and workload pressures among staff. Although initial interest was expressed, evening sessions proved difficult for some potential participants, resulting in reduced engagement. The small sample may have limited the exploration of cultural humility across diverse contexts and perspectives. As Hurley et al. (2022) controversially suggest, cultural humility is often conceptualised as a framework primarily for White practitioners; a view that remains inconclusive without broader representation. Expanding participant diversity in future research would be essential to critically examine and challenge such assumptions.

The use of online focus groups via Microsoft Teams (Microsoft Corporation, 2025) offered practical benefits, particularly in accommodating geographically dispersed participants (Dawson, 2019; Dos Santos Marques et al., 2021; Richard et al., 2021). However, this format may have limited the depth of dialogue and the development of relational dynamics typically fostered in face-to-face interactions. Opportunities for spontaneous exchange and non-verbal communication (both valuable in qualitative inquiry) were likely diminished. Minor technological challenges did arise (such as failure of internet connection during inclement weather, onscreen freezing, and audio-visual glitches), but these were mitigated through informed consent procedures, session recordings, and detailed meeting minutes.

In choosing a participatory action research methodology and focus groups as methods, alongside a scoping review for conceptual framing, I underestimated the labour-intensive and often unpredictable nature of the process. Participatory Action Research, by design, is iterative and negotiated, and this study was no exception. The cycles often overlapped or ran concurrently, challenging traditional notions of linear research progression. As a less-experienced researcher at the outset, I was naïve about how the process would unfold. I quickly learned that data collection and analysis are rarely confined to distinct phases but instead evolve in response to group dynamics and emerging insights.

The volume of data generated through focus groups and the literature review was, at times, overwhelming. Managing a large and diverse body of literature required ongoing refinement of search and screening criteria to maintain rigour and relevance. Throughout, I remained committed to preserving authenticity and ensuring that co-researchers' contributions were accurately represented. In line with the principles articulated by action research scholars such as Goodnough (2008) and Whitehead (2016), I sought to ensure that the perspectives captured were not homogenised but instead reflected the complexity of multiple realities and value systems.

A further limitation of this study lies in the scope and timing of the scoping review and concept analysis. While these provided a valuable foundation for the conceptual framing of cultural humility, they reflected the literature available at the time of analysis. I acknowledge that more recent publications may offer added insights or alternative perspectives, particularly within the evolving context of palliative care. Future research would benefit from engaging with this emerging body of work to further refine, challenge, or extend the findings presented here.

Although Participatory Action Research promotes co-authorship, the constraints of the thesis requirements precluded formal co-authorship in this instance. Nonetheless, I remained committed to accurately representing the voices of all co-researchers, ensuring they had opportunities to review and provide feedback on the findings. Other limitations include the influence of selective memory and the retrospective construction of meaning, both of which shaped the interpretive process.

The findings are also shaped by my positionality, not only as an academic researcher, but as a co-researcher and active participant in the collaborative creation of knowledge, and my nursing background. These insights do not claim to represent the experiences of all healthcare staff but rather reflect a situated and co-constructed perspective. As such, the transferability of the findings is inherently bounded by the study's specific context, timing, and interpretive methodology.

While patient perspectives are vital to understanding cultural humility in practice, this study focused specifically on the experiences and reflections of healthcare staff. The decision not to include patient voices was shaped by the scope and design of the participatory action research approach, which prioritised collaborative inquiry with practitioners to explore how cultural humility is understood, enacted, and embedded within professional practice.

Future research would benefit from incorporating patient narratives to further enrich and balance the understanding of cultural humility across care relationships. Nevertheless, the perspectives generated in this study offer valuable insight into how healthcare staff engage with cultural humility in practice. While contextually grounded, these reflections may hold relevance for other settings looking to implement culturally responsive approaches to care.

6.7. Contributions to Knowledge

This study is the first known application of Participatory Action Research within the context of palliative care to explore cultural humility both as a theoretical concept, and as a potential catalyst for change in professional practice. It therefore offers several important contributions to knowledge:

1. This study shows the feasibility and value of Participatory Action Research in hospice and community-based palliative care settings, foregrounding collaboration, reflexivity, and collective inquiry.

2. The study contributes to the limited body of evidence on cultural humility within palliative care, as identified in the scoping review of existing literature (Chapter Three), positioning the concept as a meaningful lens through which to examine equitable and person-centred care. The findings highlight the importance of cultural humility over competence because:

- Cultural humility prompts reflection on personal cultural values and perspectives
- Cultural humility facilitates an awareness of biases (whether explicit or implicit)
- Cultural humility is a practice without an endpoint or the culmination of becoming competent (or expert)

3. This study proposes a conceptual evolution of cultural humility, articulated as the Cultural Humility in Palliative Care framework and HEARt model (Chapter Three - Figure 4), developed through empirical engagement, and grounded in a scoping review and concept analysis of the current literature. The framework and

model offer structure for understanding this complexity, bridging theory and practice in ways that are both actionable and transformative.

4. This study offers insight into the individual and collective shifts that can emerge when healthcare staff actively engage with cultural humility as a practice, mindset, and way of being. These findings have implications for practice development and suggest that palliative care providers may benefit from creating dedicated time, space, and learning environments that support ongoing reflection and critical engagement with cultural humility. Such initiatives align with national frameworks for person-centred care, including the Ambitions for Palliative and End of Life Care (NHS, 2021), and may enhance cultural sensitivity and responsiveness of services.

6.8. Recommendations

6.8.1. Practice and Policy

i. Healthcare staff must take personal responsibility for examining attitudes, values, and beliefs that can perpetuate discriminatory practices and undermine authentic person-centred care. Tools like the Cultural Humility Onion Ring exercise (Appendix 18) and the *Who do YOU think you ARE?* self-identification worksheet (Asnaani, 2023) (Appendix 20) provide strong starting points for this work. The HEARt model should serve as a guiding framework, integrated into clinical supervision and reflective practice, to demonstrate how staff actively uphold and promote the core values of palliative care.

ii. A change in organisational culture is essential to promote engagement with cultural humility. Such a transformation encompasses appropriate educational resources to raise awareness of cultural humility, dedicated time, and supportive environments. It is important to create an environment where staff members are given protected time for critical self-reflection and safe spaces that foster discussions and opportunities for new ways of thinking, free from judgement or repercussions. Additionally, training should focus on fostering critical self-reflection rather than solely on the acquisition

of cultural knowledge and expertise through mandated equality, diversity and inclusion (EDI) training.

iii. The resources developed and applied throughout this study serve as foundational elements for a practical toolkit aimed at promoting cultural humility in healthcare. Designed to foster awareness and meaningful engagement, this toolkit will aim to support both individual reflection and team-based learning, advancing inclusive and holistic palliative care practice across healthcare organisations.

iv. Regulatory bodies and educational institutions should be motivated to widen their scope to address issues beyond the evaluation of competencies and knowledge. The principles of cultural humility, integral to person-centred care, must be explicitly stated in professional guidelines and codes of conduct.

6.8.2. Research Directions

This study has highlighted the relevance of cultural humility within palliative care practice, yet several areas warrant further exploration to deepen understanding and enhance application:

i. Participatory research is recommended to examine cultural humility across a broader range of health and social care professions, including interdisciplinary teams. Future studies should also extend to diverse care settings such as acute hospitals, residential and nursing homes, and primary care providers (e.g., GP practices). Crucially, meaningful participation from people who identify as sexual and gender diverse is essential to ensure inclusive and representative inquiry.

ii. Use participatory research to involve patients and their families. By listening to how they understand and experience cultural humility, healthcare teams can learn what really matters to the people they care for. Participatory research helps position cultural humility as a clinically relevant and meaningful concept, supporting its application as an effective approach to

delivering care that is respectful, personalised, and responsive to each patient’s unique needs, particularly within palliative care settings.

iii. Ongoing engagement with emerging literature will be vital to refine, challenge, and extend the conceptual and practical insights presented in this study. As the evidence base continues to evolve, future research should incorporate new perspectives to strengthen theoretical and applied understandings of cultural humility.

iv. Research based on experience in clinical settings is recommended, allowing for an exploration of how education and training initiatives can support staff awareness, reflexivity, and sustained engagement with culturally humble practice.

v. Conceptual exploration of the relationship between holistic, person-centred care and cultural humility may offer valuable insights into how these approaches intersect and inform professional practice.

vi. Evaluation studies are recommended to assess the impact of cultural humility in palliative care, particularly among patient populations experiencing persistent health inequalities and barriers to accessing appropriate and timely services.

6.9. Conclusion to the research

This participatory action research study, conducted over 15 months and six online sessions, brought together six co-researchers from two palliative care organisations in a collaborative inquiry into cultural humility. The participatory action research approach not only expanded current theoretical understanding of the concept but also revealed its practical relevance within clinical settings. Through dialogic focus groups and structured reflexive activities, our small group of co-researchers co-produced knowledge grounded in lived experience and shaped by shared insight, depth and nuance that would have been difficult to achieve through interviews alone.

The interplay between collective dialogue and personal reflection created a space that was both insightful and transformative. Within it, co-researchers were able to examine their assumptions, connect emotionally with the concept, and consider how cultural humility might inform their everyday practice. The dual process of collaborative meaning-making and self-reflection enabled a deeper engagement with cultural humility as a value that informs both identity and care.

From the analysis, five interwoven themes were generated: the nature of culture, humility as a personal value, facing our vulnerability, competing priorities, and the power to change. These themes reflect the complexity of embedding cultural humility in palliative care and highlight the transformative potential of participatory, reflective inquiry.

This study positions cultural humility not as a fixed skill set but as a dynamic, relational, and ethically grounded orientation; one that calls for ongoing dialogue, critical reflection, and a willingness to be changed by others. Even with organisational challenges, the findings support the need for cultural humility to be embraced across clinical, educational, and policy domains. It should not be treated as a procedural obligation but recognised as a guiding ethos. This study's findings add to a growing body of practice-informed work that reimagines care through humility, curiosity, and care that listens and responds. Together, these principles offer a pathway toward more inclusive and compassionate healthcare.

For all the participants as co-researchers, involvement offered a rare opportunity to pause, reflect, and reimagine their practice. Yet the study's relevance reaches beyond those directly involved. The research shows that something important needs to change in healthcare: the way we approach care with humility and openness. Cultural humility, as explored here, is not a destination but a continuous process, one that fosters connection, challenges assumptions, and invites us to listen more deeply. By amplifying the voices of those working within

palliative care, this study contributes to a broader conversation about how we care, why it matters, and what it means to do so with integrity.

In my roles as a nurse, academic researcher, and co-researcher, this journey challenged and encouraged me to confront discomfort, critically examine my assumptions, and cultivate a deeper, more authentic mode of listening than I had previously engaged in. Recognising that the group was culturally similar helped create a safer environment for open and honest self-reflection. Within this shared space, participants could discuss their assumptions, identify areas of implicit bias, and practise being vulnerable. Importantly, they could do so without feeling the immediate need to justify or explain their personal identities.

Cultural humility is no longer just a concept I explored. It has become a lens through which I view care, relationships, and my own professional identity. Collaborating with co-researchers in this study reminded me that knowledge is not something we extract, but something we build together. This study has not only shaped my understanding of cultural humility but also transformed how I show up in practice: with more openness, more curiosity, and a renewed commitment to equity and compassion. I carry these lessons forward, not as conclusions, but as beginnings.

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Zhu, P., Luke, M., & Bellini, J. (2021). A grounded theory analysis of cultural humility in counseling and counselor education. *Counselor Education and Supervision, 60(*1), 73–89. https://doi.org/10.1002/ceas.12197

Zinan, N. (2021). Humility in health care: A model. *Nursing Philosophy*, *22*(3), 1–8. https://doi.org/10.1111/nup.12354

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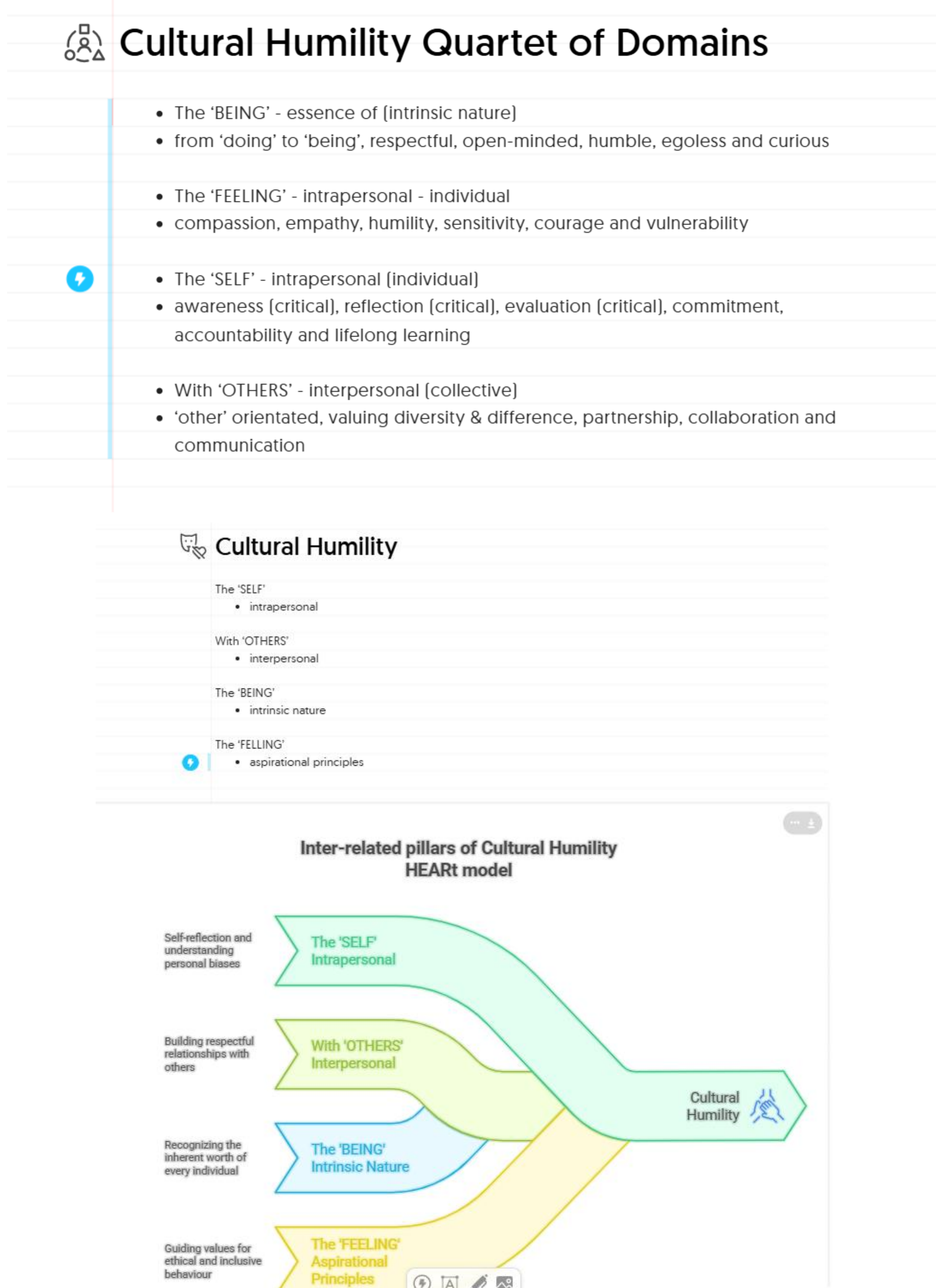
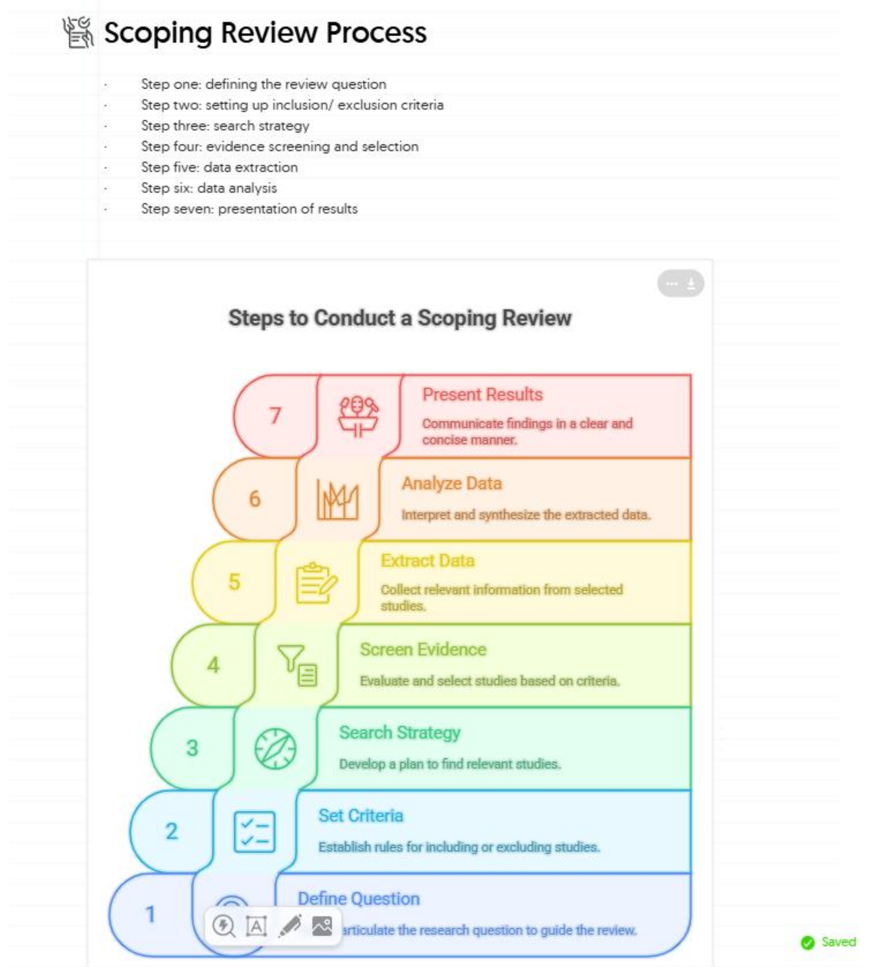
Appendix 1

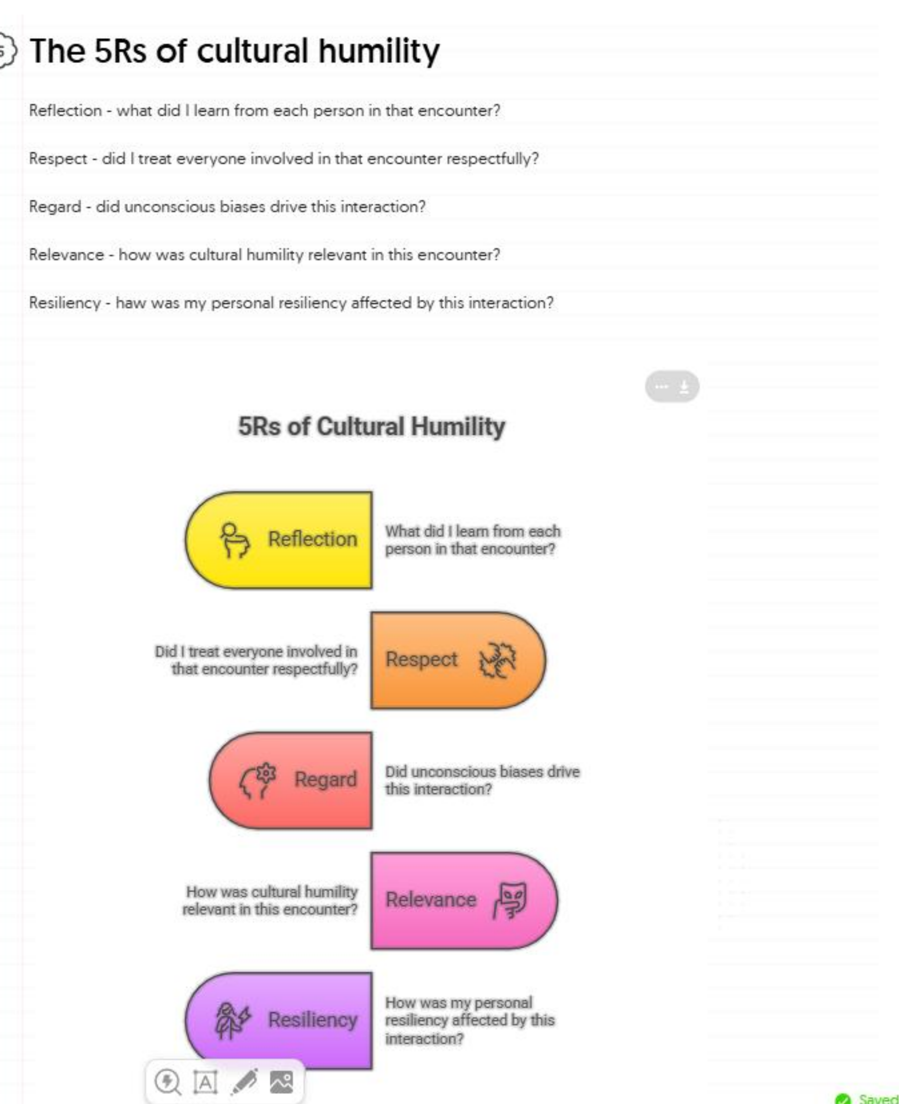
Selection of prompts used to generate images with Napkin AI (2025)

For the Cultural Humility in Palliative Care framework (***HEARt*** model)



For the Scoping Review process and The 5Rs of Cultural Humility





Appendix 2

Scoping Review - CINAHL search strategy

CINAHL Complete Search Strategy			
Sequence #	***Query***	***Limiters/Expanders***	***Results***
S22	(TI "Cultur* humility" AND TX (healthcare OR health care OR hospital OR health services OR health facilities)) AND (S19 AND S21)	Publication date: 19980101 – 20230931 English language Search modes – find all my search terms	2
S21	TI "Cultur* humility" AND MW (healthcare OR health care OR hospital OR health services OR health facilities)	Publication date: 19980101 – 20230931 English language Search modes – find all my search terms	62
S20	TI "Cultur* humility" AND TX (healthcare OR health care OR hospital OR health services OR health facilities)	Publication date: 19980101 – 20230931 English language Search modes – find all my search terms	103
S19	TI "Cultur* humility" AND TX (definition OR define OR meaning OR description)	Publication date: 19980101 – 20230931 English language Search modes – find all my search terms	9
S18	TI Cultur* humility AND TX (definition OR define OR meaning OR description)	Publication date: 19980101 – 20230931 English language Search modes – find all my search terms	0
S17	TI Cultur* humility	Publication date: 19980101 – 20230931 English language Search modes – find all my search terms	204
S16	(((TI "cultural humility) AND MW care) AND (S11 AND S13)) AND (S8 AND S13)) AND (S6 AND S10)	Publication date: 19980101 – 20230931 English language	2

		Search modes – find all my search terms	
S14	(TI "cultural humility" AND MW care) AND (S11 AND S13)	Publication date: 19980101 – 20230931 English language Search modes – find all my search terms	3
S13	TI "cultural humility" AND MW care	Publication date: 19980101 – 20230931 English language Search modes – find all my search terms	57
S12	(TI "cultural humility" AND (definition OR define OR meaning OR description)) AND (S8 AND S10)	Publication date: 19980101 – 20230931 English language Search modes – find all my search terms	3
S11	TI "cultural humility AND (definition OR define OR meaning OR description)	Publication date: 19980101 – 20230931 English language Expanders – apply related words Search modes – find all my search terms	7
S10	TI "cultural humility AND TX (definition OR define OR meaning OR description)	Publication date: 19980101 – 20230931 English language Expanders – apply related words Search modes – find all my search terms	9
S9	TI "cultural humility AND MW (definition OR define OR meaning OR description)	Publication date: 19980101 – 20230931 English language Expanders – apply related words Search modes – find all my search terms	0
S8	TI "cultural humility" AND MW (healthcare OR health care OR hospital OR health services OR health facilities)	Publication date: 19980101 – 20230931 English language Expanders – apply related words Search modes – find all my search terms	62
S7	TI "cultural humility" AND AB (healthcare OR health care OR hospital OR health services OR health facilities)	Publication date: 19980101 – 20230931 English language	42

		Expanders – apply related words Search modes – find all my search terms	
S6	TI “cultural humility” AND TX (healthcare OR health care OR hospital OR health services OR health facilities)	Publication date: 19980101 – 20230931 English language Expanders – apply related words Search modes – find all my search terms	103
S5	MW “cultural humility” AND TX (healthcare OR health care OR hospital OR health services OR health facilities)	Publication date: 19980101 – 20230931 English language Expanders – apply related words Search modes – find all my search terms	0
S4	MW “cultural humility” AND TX (healthcare OR health care OR hospital OR health services OR health facilities)	Publication date: 19980101 – 20230931 English language Expanders – apply related words Search modes – Boolean/Phrase	0
S3	MW “cultural humility”	Publication date: 19980101 – 20230931 English language Search modes – SmartText searching	574
S2	MW “cultural humility”	Publication date: 19980101 – 20230931 English language Search modes – find all my search terms	0
S1	TI “cultural humility”	Publication date: 19980101 – 20230931 English language Search modes – find all my search terms	189

Appendix 3

Full details of Scoping Review retrieved sources

Article Title	*First author*	*Date of Publication and Region*	*Type of Evidence*	*Population*	*Context*	*Concept definition or characteristics*
A grounded theory analysis of cultural humility in counselling and counselor education	Zhu, P., Luke, M. & Bellini, J.	2020 USA (Illinois)	Qualitative grounded theory study	Individuals with doctoral degree in counselling	Healthcare	Yes - characteristics
A qualitative exploration of allied health providers' perspectives on cultural humility in palliative and end-of-life care	Singh et al.	2023 Canada (Toronto)	Qualitative interpretive description study	Allied health professionals	Palliative and end of life care settings	Yes – interpreting and understanding cultural humility, its practice and 'how to'
A theory of cultural humility	Foronda, C.	2019 USA (Florida)	Journal article - theory	Healthcare professionals	Clinical practice and education	Yes – definition and characteristics
Being an intentional healer: cultural humility approach for African Americans	Henderson, R., Miles, M. L. & Murray, D.	2022 USA (California)	Commentary	Health professional and educators	Patient care (African American population)	Yes – definition and characteristics

Article Title	*First author*	*Date of Publication and Region*	*Type of Evidence*	*Population*	*Context*	*Concept definition or characteristics*
Beyond cultural competence, toward social transformation: liberation psychologies and the practice of cultural humility	Abe, J.	2019 USA (California)	Literature review and theory	Mental health practitioners and social workers	Liberation psychology/counselling	Yes – definition and characteristics (individual/interpersonal/ collective levels)
Clarifying concepts: cultural humility or competence	Isaacson, M.	2014 USA (South Dakota)	Mixed methods study (hermeneutic phenomenology and pre-post Likert-type questionnaires)	Senior nursing students	Nursing	Yes – enhanced knowledge transforming personal thinking
Cultural competemility: a paradigm shift in the cultural competence versus cultural humility debate – part 1	Campinha -Bacote, J.	2018 USA	Journal article - theory	Health practitioners	Healthcare	Yes – definition and characteristics
Cultural competence and cultural humility: a complete practice	Nguyen, P. et al.	2020 USA (Virginia)	Journal article - theory	Social workers	Social work/service provision	Yes – definition and characteristics

Article Title	***First author***	***Date of Publication and Region***	***Type of Evidence***	***Population***	***Context***	***Concept definition or characteristics***
Cultural competence and cultural humility: a critical reflection on key cultural diversity concepts	Danso, R.	2016 Canada (Toronto)	Journal article - critical reflection/ theory	Social workers	Practice and education	Yes – definition and characteristics
Cultural competence and cultural humility: a dialogue on adopting a multimodal approach in physical therapy education	Bangs, D. hayward, L. M. & Donlan, P.	2022 USA (Massachusetts)	Position paper	Physical therapists	Clinical education	Yes – definition and characteristics
Cultural Humility	Neubauer, K. et al.	2016 USA (New York State)	Book chapter	Palliative medicine	Palliative care communication	Yes – definition and characteristics
Cultural Humility	Mosher, D. K. et al.	2016 USA (Texas)	Book chapter (literature review)	Healthcare professionals	Clinical encounters	Yes – definition and characteristics
Cultural humility and mental health care in Canadian Muslim communities	Jisrawi, A. N. & Arnold, C.	2018 Canada (Ontario)	Journal article - theory	Mental health practitioners	Counselling	Yes – characteristics (individual/organisational accountability)

Article Title	*First author*	*Date of Publication and Region*	*Type of Evidence*	*Population*	*Context*	*Concept definition or characteristics*
Cultural humility and social inclusion	Chávez, V.	2022 USA (California)	Book chapter	Educators	Education of health professionals	Yes – definition and characteristics (personal/interpersonal/ organisation)
Cultural humility in psychotherapy supervision	Hook, J. N. et al.	2016 USA (Texas)	Journal article - theory	Mental health professionals	Supervision of clinicians	Yes – definition and characteristics (intrapersonal/interpersonal/ multicultural orientation)
Cultural humility versus cultural competence: a critical distinction in defining physician training outcomes in multicultural education	Tervalon, M. & Murray-García, J.	1998 USA (California)	Guest editorial	Physicians	Medical education	Yes – definition and characteristics
Cultural humility: a concept analysis	Foronda, C. et al.	2016 USA (Maryland)	Concept analysis	Healthcare professionals	Healthcare professional education and training	Yes – definition and characteristics (antecedents, attributes, consequences)
Cultural Humility: a therapeutic framework for engaging diverse clients	Mosher, D. K. et al.	2017 USA (Texas)	Journal article - theory & current empirical research	Mental health professionals/therapists	Psychology	Yes – definition and characteristics (intrapersonal/interpersonal)

Article Title	***First author***	***Date of Publication and Region***	***Type of Evidence***	***Population***	***Context***	***Concept definition or characteristics***
Cultural humility: essential foundation for clinical researchers	Yeager, K. & Bauer-Wu, S.	2013 USA (Georgia)	Journal article - theory	Clinical researchers	Research	Yes – definition and characteristics
Cultural Humility: introduction to the Special Issue	Hook, J. N. & Davis, D. E.	2019 USA (Texas)	Journal article - theory	Therapists	Counselling	Yes - definition and characteristics
Cultural humility: measuring openness to culturally diverse clients	Hook, J. N. et al.	2013 USA (Texas)	Quantitative pilot study	Psychology students	Therapy practice (counselling scenarios)	Yes – definition and characteristics
Cultural humility: retraining and retooling nurses to provide equitable cancer care	Nolan et al.	2021 USA (Ohio)	Literature review	Nurses	Nursing	Yes – principles of cultural humility
Cultural humility: the key to patient/family partnership for making difficult decisions	Fahlberg, B. Foronda, C. & Baptiste. D.	2016 USA (Wisconsin)	Journal article - issues in palliative and end of life care	Nurses	Palliative and end-0f-life care	Yes – definition and characteristics

Article Title	***First author***	***Date of Publication and Region***	***Type of Evidence***	***Population***	***Context***	***Concept definition or characteristics***
Engaging cultural humility diffractively	Crath, R. & Rangel J. C.	2020 USA/Canada (Massachusetts /Ottawa)	Journal article - theory	Health practitioners	Healthcare delivery	Yes – definition and characteristics
Exploration of cultural humility in Medical Art Therapy	Keselman, M., & Awais, Y. J.	2018 USA (NE & mid-Atlantic regions)	Qualitative cross-case analysis study	Medical art therapists	Medical art therapy	Yes – defining cultural humility individually
Fostering an ethos of cultural humility development in nurturing inclusiveness and effective intercultural team working	Markey K. et al.	2021 Ireland/Europe	Commentary	Healthcare workforce	Intercultural team working	Yes – definition and characteristics (intrapersonal/interpersonal/ system level)
Fostering positive spaces in public health using a cultural humility approach	Allwright, K. et al.	2019 Canada (Ontario)	Journal article - theory	Nurses	Public health	Yes – definition and characteristics
From Mastery to accountability: cultural humility as an alternative to cultural competence	Fisher-Borne, M. Montana Cain, J. & Martin. S. L.	2015 USA (North Carolina)	Journal article - theory & literature review	Social work professionals	Clinical practice	Yes – definition and characteristics (individual/organisational level)

Article Title	***First author***	***Date of Publication and Region***	***Type of Evidence***	***Population***	***Context***	***Concept definition or characteristics***
Integrating cultural humility into health care professional education and training	Change, E-shien, Simon, M. & Dong X.	2012 USA (Illinois)	Journal article - reflections	Physicians	Cross-cultural communication	Yes – definition and characteristics
Integrating Cultural Humility into the Medical Education Curriculum: strategies for educators	Solchanyk, D. et al.	2021 USA (Chicago)	Observation paper	Undergraduate medical students	Healthcare	Yes – definition
Intersectional cultural humility: aligning critical inquiry with critical praxis in psychology	Buchanan, N. T. Rios, D. & Case, K. A.	2020 USA (Michigan)	Journal article - theory	Psychologists (mental health practitioners)	Counselling	Yes - characteristics
Moving from cultural competence to cultural humility in occupational therapy: a paradigm shift	Agner, J.	2020 USA (Hawaii)	Journal article - theory	Occupational therapists	Clinical and community practice settings	Yes – definition and characteristics

Article Title	*First author*	*Date of Publication and Region*	*Type of Evidence*	*Population*	*Context*	*Concept definition or characteristics*
Not missing the opportunity: strategies to promote cultural humility among future nursing faculty	Hughes, V. et al.	2020 USA (Maryland)	Journal article - theory	Healthcare professionals	Healthcare	Yes – definition and characteristics (intrapersonal interpersonal/system levels)
Occupation, well-being, and culture: theory and cultural humility	Hammell, K. R. W.	2013 Canada (Saskatchewan)	Journal article - theory	Occupational therapists	Client-therapist relationship	Yes – definition and characteristics
Product or process: cultural competence or cultural humility?	Yancu, C. N. & Farmer, D. F.	2017 USA (North Carolina)	Journal article - editorial	Healthcare professionals	Palliative care and hospice providers	Yes – definition and characteristics (intrapersonal and interpersonal)
Rethinking cultural competence: shifting to cultural humility	Lekas, H-M., Pahl, K. & Lewis, C. F.	2020 USA (New York State)	Journal article - theory and practice incorporation	Health practitioners working with young people with mental ill-health	Medicine and public health	Yes – definition and characteristics
Teaching cultural humility for social workers serving LGBTQI Aboriginal	Bennett, B & Gates, T. G.	2019 Australia (Queensland)	Journal article - collaborative writing project/theory	Social work educators	Social work with LGBTQI Aboriginal peoples	Yes - characteristics

Article Title	*First author*	*Date of Publication and Region*	*Type of Evidence*	*Population*	*Context*	*Concept definition or characteristics*
communities in Australia						
The case for a cultural humility framework in social work practice	Gottlieb, M.	2021 USA (New York State)	Literature review	Social workers	Social work	Yes – definition and practice characteristics
Towards a culturally humble practice: critical consciousness as an antecedent	Lee, A. T. & Hill Haskins, N.	2022 USA (Virginia)	Journal article - theory	Clinical professionals (psychologists)	Counselling	Yes – definition and characteristics
Transformational learning through cultural humility	Loue, S.	2022 USA (Cleveland	Book chapter – theory/literature review	Helping professionals	Clinical encounters	Yes – definition and characteristics
Using cultural humility in care provided for LGBTQ people	Ruud, M.	2021 USA (Minnesota)	Book chapter	Care providers	Clinical practice and encounters	Yes – definition and characteristics

Appendix 4

Example of data extraction format

<table>
<tr><td>Source title:</td><td colspan="4">Cultural Humility and Social Inclusion</td></tr>
<tr><td>First Author:</td><td colspan="4">Vivian Chávez</td></tr>
<tr><td>Year of Publication:</td><td colspan="4">2022</td></tr>
<tr><td>Geographical focus:</td><td colspan="4">USA (West Coast)</td></tr>
<tr><td>Type of evidence:</td><td colspan="4">Book chapter – in Handbook of Social Inclusion (Liamputtong. P. (ed.))</td></tr>
<tr><td>Field of practice:
(P = population)
(C = context)</td><td colspan="4">P = Public health practitioners
C = Health and social sciences</td></tr>
<tr><td>Seminal definition by Tervalon and Murray-García (1998) included</td><td colspan="2">YES</td><td>Approach to concept:
(framework, practice, or process)</td><td>Practice</td></tr>
<tr><td>Definition:
(C = concept)</td><td colspan="4">YES
1. “a life-long practice that requires social inclusion practitioners and researchers to be aware of who they are and who they are not” (p.14)
2. Cultural humility is “open to experiences of vulnerability and partnerships as doorways to more effective social inclusion practice” (p.4).
3. “To be humble within a competitive fast-paced cultural is to make oneself vulnerable and make mistakes” (p.3)</td></tr>
<tr><td>Attributes identified:</td><td>YES</td><td colspan="2">Use of language
Systemic
Relational
Organisational</td><td>Lifelong practice
Curiosity
Respect
Deeply personal</td></tr>
<tr><td>Include in Scoping Review</td><td colspan="4">YES</td></tr>
</table>

Appendix 5

Extract of coding process to identify attributes

Context - discipline	Words	Phrases	Definitions/ Quotes	Quote location	Year
Attributes identified from sources					
Psychology	respect	critical self-reflection	"enter as an outsider"	p.30	2020
	intrapersonal	goal and process			
	interpersonal				
	introspection				
	awareness				
	listening				
	partnership				
	communication				
Nursing	process	self-awareness			2020
	flexibility	open-mindedness			
	communication	making biases explicit			
	respect (promoting)	being egoless			
	adaptability	critical self-reflection			
		ongoing lifelong process			
		all individuals hold equal value			
		no end point to learning			
		recognising diversity			
		valuing diversity & understanding differences			
		viewing conflict in a positive way (using a different lens)			
Psychology		ongoing learning	"acceptance of never fully 'knowing' a culture different from one's own"	p.240	2020
		recognising the 'diversity' of the whole person		p.240	
		not a finalised outcome			
		lifelong commitment to learning about/ from others			

Appendix 6

Summary of authors' links to the Cultural Humility in Palliative Care Framework (the HEARt model)

Cultural Humility PILLAR	*Relevant authors*
The 'SELF' – intrapersonal/individual: Awareness (critical) Reflection (critical) Evaluation (critical) Commitment Accountability Lifelong learning	Abe (2019), Agner (2020), Allwright et al. (2019), Bangs et al. (2022), Bennett & Gates (2019), Buchanan et al. (2020), Chang et al. (2012), Crath & Rangel (2021), Danso (2016), Fisher-Borne et al. (2015), Foronda et al. (2016), Gottlieb (2021), Henderson et al. (2022), Hook & Davis (2019), Hook et al. (2016), Hughes et al. (2020), Issacson (2014), Jiswari & Arnold (2018), Keselman & Awais (2018), Lee & Haskins (2022), Lekas et al. (2020), Markey et al. (2021), Mosher et al. (2016), Mosher et al. (2017), Neubauer et al. (2016), Nolan et al. (2021), Rudd (2021), Singh et al. (2023), Solchanyk et al. (2021), Tervalon & Murray-García (1998), Yancu & Farmer (2017), Yeager & Bauer-Wu (2013), Zhu et al. (2021)
With 'OTHERS' – interpersonal/collective: 'Other' orientated Valuing diversity and differences Partnership Collaboration Communication	Abe (2019), Agner (2020), Allwright et al. (2019), Bangs et al. (2022), Bennett & Gates (2019), Buchanan et al. (2020), Campinha-Bacote (2018), Chang et al. (2012), Fahlberg (2016), Fisher-Borne et al. (2015), Foronda (2020), Foronda et al. (2016), Gottlieb (2021), Henderson et al. (2022), Hook & Davis (2019), Hook et al. (2013), Hook et al. (2016), Hughes et al. (2020), Issacson (2014), Jiswari & Arnold (2018), Keselman & Awais (2018), Lee & Haskins (2022), Loue (2022), Markey et al. (2021), Mosher et al. (2016), Mosher et al. (2017), Nolan et al. (2021), Nyugen et al. (2020), Tervalon & Murray-García (1998), Yeager & Bauer-Wu (2013)
The 'BEING' – essence of/intrinsic nature: From 'doing' to 'being' Respectful Open-minded Humble Egoless Curious	Agner (2020), Allwright et al. (2019), Bennett & Gates (2019), Campinha-Bacote (2018), Chávez (2022), Danso (2016), Fahlberg (2016), Foronda (2020), Foronda et al. (2016), Gottlieb (2021), Hook & Davis (2019), Hook et al. (2013), Hook et al. (2016), Hughes et al. (2020), Issacson (2014), Lee & Haskins (2022), Lekas et al. (2020), Markey et al. (2021), Mosher et al. (2017), Nyugen et al. (2020), Rudd (2021), Singh et al. (2023), Solchanyk et al. (2021), Yancu & Farmer (2017), Zhu et al. (2021)

Cultural Humility PILLAR	*Relevant authors*
The 'FEELING' – aspirational principles: Compassion Empathy Humility Sensitivity Courage Vulnerability	Chang et al. (2012), Chávez (2022), Gottlieb (2021), Hook & Davis (2019), Hook et al. (2013), Issacson (2014), Jiswari & Arnold (2018), Keselman & Awais (2018), Lee & Haskins (2022), Loue (2022), Mosher et al. (2016), Mosher et al. (2017), Neubauer et al. (2016), Nolan et al. (2021), Tervalon & Murray-García (1998), Yancu & Farmer (2017), Zhu et al. (2021)

Appendix 7

Ethics approval (FHMREC)

[External] FHM-2022-0658-RECR-1 Ethics Approval from FREC

donotreply@infonetica.net <donotreply@infonetica.net>
Wed 02/03/2022 21:11
To: Workman, Siobhan (Postgraduate Researcher) <s.workman1@lancaster.ac.uk>
Cc: Swarbrick, Caroline <c.swarbrick2@lancaster.ac.uk>; Ashmore, Lisa <l.ashmore@lancaster.ac.uk>

1 attachments (110 KB)
Letter.pdf;

This email originated outside the University. Check before clicking links or attachments.

Name: Siobhan Workman

Supervisor: Caroline Swarbrick

Department: Health Research

FHM **REC Reference:** FHM-2022-0658-RECR-1

Title: 'Cultural Humility' in palliative care: a practice amongst nurses to address social stigma towards older sexual and gender minority patients and their family of choice.

Dear Ms Siobhan Workman,

Thank you for submitting your ethics application in REAMS, Lancaster University's online ethics review system for research. The application was recommended for approval by the FHM Research Ethics Committee, and on behalf of the Committee, I can confirm that approval has been granted for this application.

As Principal Investigator/Co-Investigator your responsibilities include:

- ensuring that (where applicable) all the necessary legal and regulatory requirements in order to conduct the research are met, and the necessary licences and approvals have been obtained.

- reporting any ethics-related issues that occur during the course of the research or arising from the research to the Research Ethics Officer at the email address below (e.g. unforeseen ethical issues, complaints about the conduct of the research, adverse reactions such as extreme distress).

- submitting any changes to your application, including in your participant facing materials (see attached amendment guidance).

Please keep a copy of this email for your records. Please contact me if you have any queries or require further information.

Yours sincerely,

Dr Laura Machin
Chair of the Faculty of Health and Medicine Research Ethics Committee
fhmresearchsupport@lancaster.ac.uk

Appendix 8

Substantial amendment (FHMREC)

RE: [External] FHM-2022-0658-SA-1 Ethics approval of amendment

From: donotreply@infonetica.net <donotreply@infonetica.net>
Sent: 15 August 2022 13:48
To: Workman, Siobhan (Postgraduate Researcher) <s.workman1@lancaster.ac.uk>
Cc: Swarbrick, Caroline <c.swarbrick2@lancaster.ac.uk>; Ashmore, Lisa <l.ashmore@lancaster.ac.uk>
Subject: [External] FHM-2022-0658-SA-1 Ethics approval of amendment

This email originated outside the University. Check before clicking links or attachments.
FHM-2022-0658-SA-1 'Cultural Humility' in palliative care: a practice amongst health and social care clinicians to address social stigma towards older sexual and gender minority patients and their family of choice.
Dear Siobhan Workman,
Thank you for submitting your ethics amendment application in REAMS, Lancaster University's online ethics review system for research. The amendments have been approved by the FHM REC.
Yours sincerely,
Faculty Research Ethics Officer on behalf of FHM

This email is confidential and intended solely for the use of the individual to whom it is addressed. Any views or opinions presented are solely those of the author and do not necessarily represent those of St Elizabeth Hospice. If you are not the intended recipient, be advised that you have received this email in error and that any use, dissemination, forwarding, printing, or copying of this email is strictly prohibited. If you have received this email in error, please notify The Hospice on 01473 727776 or reply to this email. Finally, you should check this email and any attachments for viruses. St Elizabeth Hospice accepts no liability for any damage caused by any virus transmitted by this email.

Appendix 9

Site specific approvals

Site One

From: [redacted]
Sent: 05 May 2022 10:05
To: [redacted]
Cc: Siobhan Workman <Siobhan.Workman@[redacted]
Subject: RE: [redacted] Research Log

Thank you [redacted]

[redacted]

From: [redacted]
Sent: 05 May 2022 09:35
To: [redacted]
Cc: Siobhan Workman <Siobhan.Workman[redacted]
Subject: RE: [redacted] Research Log

Hi [redacted]
I have said that I would pass on to nursing colleagues as well as research group and then get back to her
I have now heard from all the research group, as you know, and they are agreeable with it – some comments but nothing major
[redacted] was due to get back to me but hasn't and she is now off
Siobhan was included in the email I sent to the nursing team [redacted] asking them to circulate to nurses
so I have given approval even though no response from the nursing team as yet
[redacted]

[redacted]

Working days: Monday to Friday

Site Two - research team approval and support

13 December 2021

To whom it may concern,

Siobhan Workman PhD Research Proposal:

'Cultural humility in Palliative Care: a practice amongst nurses as it relates to reducing stigma towards older sexual and gender minority patients and their family of choice'.

Please accept this letter as confirmation that having reviewed the draft proposal for the above research study, we can confirm that [redacted] have agreed in principle to support Siobhan with this project.

We have discussed permitting Siobhan to approach nursing staff employed by [redacted] as potential participants, and to assist in obtaining the required documentation to do this through the Research and Development office at [redacted]. We also agree to this project on the understanding that Siobhan does not require access to any patient information.

Please feel free to contact us using the information above if you require any further information.

Yours sincerely,

Site Two – local commission group approval

Outlook

[External] 2022GC03. Cultural Humility in palliative care - permission

From

Date Wed 16/03/2022 14:09

To Workman, Siobhan (Postgraduate Researcher) <s.workman1@lancaster.ac.uk>

Cc

This email originated outside the University. Check before clicking links or attachments.

Dear Siobhan

Re: 2022GC03. Full Study Title: Cultural Humility in palliative care: a practice amongst nurses to reduce social stigma towards older sexual and gender minority patients and their family of choice

This email confirms that has the capacity and capability to deliver the above referenced study. You may now begin your study at

Please keep us advised of the following:

- Amendments to the study and revised paperwork which could affect how the study runs locally.
- Completion date for study locally.

Once your study has completed, we would be grateful if you could forward a copy of the final report, a one page lay summary and any publications associated with the study to

May we take this opportunity to wish you well with your research and we look forward to hearing the outcomes for the study. Please note our local reference number for this study is **2022GC03** and this should be quoted on all correspondence.

Kind regards

E-mail:
Team email:

Site Two – approval following substantial amendment

Outlook

[External] RE: 2022.08.16-SA-1 No objection to Substantial amendment

From

Date Mon 22/08/2022 15:28

To Workman, Siobhan (Postgraduate Researcher) <s.workman1@lancaster.ac.uk>

Cc

This email originated outside the University. Check before clicking links or attachments.

Dear Siobhan,

Re: Study ID 2022GC03 No objection to Substantial amendment

Arrangements to support the below amendment in

Full Study Title: 'Cultural Humility' in palliative care: a practice amongst nurses to reduce social stigma towards older sexual and gender minority patients and their family of choice

Type	Title	Date of Amendment	Date of Ethics Approval	Summary of Amendment
Substantial	SA1	15/08/22	15/08/2022	• Extending recruitment to all health and social care clinicians nvolved in palliative and end-of-life care or with a working interest in the study area. • Addition of new research site (St Helena Hospice, Colchester) • Updated documents: o Participant flyer SA Aug 22 o Consent Form SA Aug 22 o Participant flyer SA Aug 22 o PIS SA Aug 22 o Prompt Sheets SA Aug 22 o Protocol FULL SA Aug 22 o Solicited Diary prompt sheet SA Aug 22

We acknowledge receipt of this amendment for which Faculty of Health and Medicine Lancaster University REC approval is in place and are happy for it to be implemented in

It is a sponsor/researcher responsibility to communicate the changes to sites.

Kind regards

Appendix 10

Recruitment Flyer

Call for Research Participants

Do you have a keen interest in or work in palliative and end-of-life care?

Would you like to be part of a small research group exploring social stigma and the care of sexual and gender minority patients?

If the answer is 'YES' ..... you are invited to take part as a:

- Doctor, nurse, allied healthcare professional (physio/ OT/ paramedic), social worker, counsellor, therapist or chaplain working with [redacted]
- Participant in a collaborative project including group and individual activities with a focus on being educational and transformative in nature.

The project is led by ***Siobhán Workman***:

postgraduate researcher with Lancaster University on the PhD Blended Learning Programme in Palliative Care (Division of Health Research)

To find out more please email:

s.workman1@lancaster.ac.uk

stating '*Participation Interest*'

... "you matter because you are you, and you matter to the end of your life."
- Dame Cecily Saunders

Lancaster University

Appendix 11

Invitation to Participate (covering letter)

Division of Health Research
Faculty of Health and Medicine
Furness College
Lancaster University
Lancaster LA1 4YQ

Date

Dear Recipient,

Research study title:

'Cultural Humility' in palliative care; a practice amongst nurses to reduce social stigma towards older sexual and gender minority patients and their family of choice.

Study ID: FHM-2022-0658-RECR-1

Thank you for your interest in being a part of this study.

Please find attached/ enclosed a pack of items which will be used prior to and at our initial group session.

You are welcome to look through these in advance, but please do not worry if you are not sure what to do with anything. I will explain this when we first meet as a group. If you only want to look at one part of the pack, I recommend the 'Initial Focus Group Prompt Sheet' which has some suggestions/ questions you may wish to think about ahead of our kick-off session.

When we first meet in person, we will hopefully set the timetable for the first phase of sessions (3 in total) and discuss activities to be engaged with away from the group meetings.

I will be advising the date of the kick-off session at least 4 weeks in advance. It is important that we all attend in person (i.e. face to face) so if there are any dates in September which you cannot make due to annual leave etc please let me know in good time. A suitable venue will be organised which is hopefully convenient for everyone.

Yours sincerely,

Your Name
Postgraduate Researcher
s.workman1@lancaster.ac.uk

Appendix 12

Participant Information Sheet & Prompt Sheet

'Cultural Humility' in palliative care: a practice amongst health and social care clinicians to reduce social stigma towards older sexual and gender minority patients and their family of choice.

PARTICIPANT INFORMATION SHEET

My name is Siobhán Workman. I am conducting this research study as a student on the PhD blended learning Palliative Care programme at Lancaster University.

I work in palliative and end-of-life care, and have a keen interest in issues relating to care provision for patients who identify as gay, lesbian, bisexual, or transgender (referred to as sexual and gender minority individuals in the proposed study).

I am a registered nurse working with a local hospice providing community specialist palliative care services in the (DELETED) area.

Why have You been approached?

You are being invited to take part as a research participant.

Before you decide if you wish to be involved, it is important you understand why the research is being done and what participation involves.

Your decision to take part will be on the basis of self-selection. Take time to decide whether you wish to take part.

Please take time to read the following information carefully and discuss it with others if you wish. Ask me anything that is not clear or if you would like further information.

Thank you for reading this.

Siobhán
Date: August 2022

What is the study about?

The purpose of this study is to explore collaboratively the concept and practice of 'cultural humility' amongst health and social care clinicians and its relationship to reducing social stigma in the palliative and end-of-life care for older sexual and gender minority patients and their family of choice.

The study is seeking participation from individuals who are health and social care clinicians (such as doctors, nurses, allied health professionals, social workers, counsellors, therapists or chaplains) working either directly in the provision of palliative care or with an interest in this field.

It is important to highlight it is not a requirement for participants to have been involved in patient care for sexual and gender minority individuals. Participants should aspire for professional practice, which is holistically and therapeutically focused, and person-centred in its underpinning.

Do I have to take part?

- It is up to you to decide whether to take part.

- If you do decide to take part, you will be able to keep a copy of this information sheet and you show your agreement by completing and signing the consent form.

- You can withdraw at any time and you do not have to give a reason. Thereafter you will have 14 days following the first focus group in which to withdraw so that there are no further compromises to the participatory nature of the study.

- You should be aware however, that if you do withdraw after your input (data) has been anonymised and incorporated into themes it might not be possible to withdraw it, although every effort will be made to extract the data up to the point of compiling the final report for thesis submission.

What will I be asked to do if I take part?

- You will be asked to be involved in focus group sessions, reflexive activities including journaling, action research learning activities, aiding with data collection and interpretation.

- It is expected the study will be spread over an 18-month to two-year period with six focus groups being held every two to three months throughout the duration, or more regular if the group reach a consensus to meet sooner.

What special competencies will I need?

- It is not a requirement to be a specialist working with sexual and gender minority individuals, or in palliative/ end-of-life care.

- The purpose of the research is to work collaboratively to plan, act, reflect and evaluate through action research, so it is more important to have an interest in the project's aim and objectives.

- For the most part, you will need to be knowledgeable about your own experiences in nursing, which may be both good and bad, happy and unhappy, successful and unsuccessful.

- You will also need to be willing and able to describe your experiences, through collaboration as a team member engaging in group activities, and individually by keeping a reflective diary during your time as a participant.

How will I benefit from this experience?

- Whilst there are no immediate benefits in taking part in this study, it is hoped the work will have a beneficial impact on your clinical practice and how person-centred care is delivered to marginalised patients in need of palliative and end-of-life care and their family of choice.

- Potential participation benefits may include a chance to gain research experience, knowledge and skills, and the opportunity to use your personal experiences, both good and bad, as a source of help for other.

- It is also hoped that the practice of cultural humility will gain wider exposure and integration as a practice in nursing.

Will my data be identifiable?

The data collected for this research study will be stored securely on university approved cloud platforms and only the researcher conducting this study will have access to this data.

- Audio recordings will be destroyed and/or deleted once the study has been submitted for publication/examined.
- Hard copies of focus group session minutes will be kept in a locked cabinet.
- The files on the computer will be encrypted (no-one other than the researcher will be able to access them) and the computer itself password protected.
- At the end of the study, hard copies of focus group session minutes and participant journals will be kept securely in a locked cabinet for ten years. At the end of this period, they will be destroyed.
- The typed version of discussions will be anonymised by removing any identifying information including your name. Direct quotations from your diary contributions which may be used in the reports or publications from the study will not have your name attached to them. Agreed aliases or pseudonyms will protect your anonymity and maintain confidentiality.
- All your personal data will be confidential and will be kept separately from your research contributions.

- All reasonable steps will be taken to protect the anonymity of participants involved in this research study through the use of aliases or pseudonyms, and appropriate disclosure and deletion/ destruction of personal data.

There are some limits to confidentiality: if what is said in the group sessions or solicited diaries makes me think that you, or someone else, are at significant risk of harm, I will have to break confidentiality and speak to a member of staff about this. If possible, I will tell you if I have to do this.

For further information about how Lancaster University processes personal data for research purposes and your data rights please visit our webpage: www.lancaster.ac.uk/research/data-protection

What will happen to the results?

The results will be analysed, synthesised, and written up as part of my PhD thesis with Lancaster University and may be submitted for publication in an academic or professional journal such as the European Journal of Palliative Care or the Journal of Transcultural Nursing. As a participant you will be consulted about dissemination of the findings.

Are there any risks?

There are no risks expected with participating in this study. The potential physical and/or psychological harm or distress will be the same as any experienced in everyday life. However, if you experience any distress following participation you are encouraged to inform me and contact the resources provided at the end of this sheet. A distress/ disturbance diary will be made available so that you can make a record of your concerns, to be followed up and discussed if appropriate by the group after gaining your permission to share.

Who has reviewed the project?

This study has been reviewed and approved by the Faculty of Health and Medicine Research Ethics Committee at Lancaster University.

Where can I obtain further information about the study if I need it?

If you have any questions about the study, please contact the main researcher:

Main researcher: Siobhán Workman
Email: s.workman1@lancaster.ac.uk
Position: Postgraduate researcher

Project supervisor: Dr. Caroline Swarbrick
Email: c.swarbrick2@lancaster.ac.uk
Position: Senior Lecturer in Ageing

Complaints:

If you wish to make a complaint or raise concerns about any aspect of this study and do not wish to speak directly with the researcher, you can contact:

Dr. Ian Smith
Research Director
Tel: +44 (0) 1524 592 282
email: i.smith@lancaster.ac.uk

Division of Health Research
Furness College
Lancaster University
Lancaster
LA1 4YW

If you wish to speak to someone outside of the Ph.D. Doctorate Programme, you may also contact:

Dr Laura Machin
Chair of FHM (Faculty of Health & Medicine) Research Ethics Committee (REC)
Tel: +44 (0)1524 594 973
Email: l.machin@lancaster.ac.uk

Faculty of Health and Medicine
(Lancaster Medical School)
Lancaster University
Lancaster
LA1 4YG

Thank you for taking the time to read this information sheet.

Resources in case of distress

Should you feel distressed either because of taking part, or in the future, the following resources may be of assistance:

Occupational Health services

For participants from (DELETED):

Wellbeing Zone – online confidential site providing information on stress/ tension reduction and for access to professional advice centres. Details for accessing this service are available in the employee handbook.

Occupational Health team – counselling and support services, and stress management and resilience.

Email: (DELETED)

For participants from (DELETED) and (DELETED)

Employee Assistance Programme - hospice participants have access to this service for practical information, emotional and counselling support.

Additionally, there is an online health and wellbeing portal and a monthly wellbeing newsletter. The people and culture team can also provide additional information regarding appropriate external services.

Occupational health services are available to hospice participants and are provided by (DELETED).

Freedom to Speak Up

(DELETED) guardian – Director of Quality (DELETED)
Email: (DELETED)

(DELETED) champion – (DELETED)
Email: (DELETED)

Confidential helpline: (DELETED)

(DELETED) guardian: (DELETED)
Email: (DELETED)

(DELETED) guardian: (DELETED)
Email: (DELETED)

Prompt Sheet distributed in advance of Focus Group series

Proposed prompt sheets for use at initial Focus Group session

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Initial Focus Group prompt sheet

Suggested questions to kick-start group discussions. Subsequent focus groups will use topic guides compiled by contributions from participants and researcher.

Probing questions:

1) How familiar are you with the practice of cultural humility?

2) What comes to mind when you think about?
   - Palliative and end-of-life care
   - Social stigma
   - Cultural humility
   - Sexual and gender minority patients and family of choice

Follow up questions:

1) How is social stigma perceived as an issue in health and social care?
2) How do you think social stigma relates to providing person-centred care in palliative and end-of-life contexts for marginalized patients?
3) What do you think cultural humility involves?
4) Why do you think cultural humility should matter when providing palliative and end-of-life care, and for sexual and gender minority patients in particular?
5) How do you think you might be able to integrate cultural humility into palliative and end-of-life care?

Exit questions:

Is there anything else you'd like to say about what we have talked about today?

What themes or issues do you feel are important after today's session?

In which direction do you see the study going next?

What did you like about the focus group session and how could it be improved the next time we meet?

Did you feel listened to and how comfortable did you feel sharing your viewpoint?

Has everyone got details of how to get in touch with me?

Appendix 13

Consent Form

Lancaster University

CONSENT FORM

Research study title:

'Cultural Humility' in palliative care: a practice amongst nurses to reduce social stigma towards older sexual and gender minority patients and their family of choice.

Name of researcher: Siobhán Workman

Before you consent to participating in this study, please read the participant information sheet and mark each box below with your initials if you agree, then sign where indicated. You will receive a copy once the researcher has counter-signed.

If you have any questions or queries before signing the consent form, please do not hesitate to contact me.

Participant Identification Number for this study:

		YES/ NO
1	I confirm that I have read the participant information sheet and fully understand what is expected of me within the study	
2	I confirm I have had the opportunity to ask questions and to have them answered	
3	I understand that my contributions to the focus group sessions will be audio recorded and then made into an anonymized written transcript	
4	I understand that audio recordings will be kept until the research project has been examined	
5	I understand that my participation is voluntary and that I have up to 14 days after the focus group to contact the researcher to exercise my right to withdraw and have my data removed and destroyed, where possible. However, if the focus group has already commenced the researcher will be unable to remove your anonymized responses and input from the transcription. Refusal to participate will not affect me in any way.	
6	I understand that once my data has been anonymized and incorporated into themes it might not be possible for it to be withdrawn. If I am involved in focus groups and then withdraw, I understand that it may not be possible to withdraw data.	

Lancaster University

		YES/ NO
7	I understand that the information from my input in the focus groups and my journal will be pooled with other participants' input, anonymized, and may be published. All reasonable steps will be taken to protect the anonymity of the participants involved in this research study.	
8	I consent to information and quotations from my input and journals being used in reports, conferences, and training events.	
9	I understand the researcher will discuss data with their Supervisor as needed.	
10	I understand any information I give will remain confidential and anonymous unless it is thought that there is a risk of harm to myself or others, in which case the researcher will/ may need to share this information with their research Supervisor.	
11	I consent to Lancaster University keeping written transcripts of the focus groups and journals for 10 years after the study has finished.	
12	By participating in focus groups, I understand that any information disclosed within the group sessions remains confidential to the group, and I will not discuss the focus group with or in front of anyone who was not involved unless I have the relevant person's express permission.	
13	I consent to take part in the above study	

(PRINT NAME) ______________________

Signature of Participant ______________________

Date: ______________________

Researcher contact details:

Siobhán Workman
Email: s.workman1@lancaster.ac.uk

Signature of Researcher ______________________

Date: ______________________

Note: when completed: one copy for participant and one copy for researcher's records

Appendix 14

Distress/disturbance diary

Distress/ disturbance diary

Individual participants are asked to keep a diary (without any personal identifiable data) which records difficulties, anxiety or stress encountered during focus group sessions or when engaging with personal reflective activities.

Diaries can be as brief or detailed as the participants wish for.

The table provided below is shown as a written version, but submissions will be welcomed by the researcher in audio or other formats if preferred by the participant.

Diaries will only be shared in group sessions with participants' permission.

How it works:

1. Start with column two: what was the situation, what happened, who was present (do not use names – roles are acceptable), and what was done.

   Describing the experience might be useful (how did you feel, what did you think?)

2. Complete columns three and four if possible. If preferred these can be discussed at the next focus group session.

3. Finally, if it is possible to identify a broad topic/ theme that would help describe (label) the issue, put the description in the first column.

Topic (label)	*Difficulty/ anxiety/ stressor* *(the WHAT?)*	*How did I deal with the issue?* *(the SO WHAT?)*	*What can be done to prevent a repeat of the situation/ issue* *(the NOW WHAT?)*

Appendix 15

Group agreement

Group Agreement

PhD Research Group – GROUND RULES
('group agreement' as referred to in research protocol)

From kick-off session on 2 Nov 2022 – revisited on 1 Feb 2023

- Keeping the meeting environment a 'safe space'
- All discussions are confidential within the group
- Respecting other people's opinions
- For online sessions, using the hand button (monitored by SW)
- Avoid interrupting people when talking

Additionally taken from Ethics protocol, as submitted to FHMREC at Lancaster University

- The researcher (SW) will take care to respect the privacy and needs of all participants.
- Completion of consent forms, signed by both participants and researcher (SW) and copies made available.
- If a participant decides to leave the study, recordings of discussions may include their input.
- Once data has been anonymised and incorporated into the analysis, participants should be aware it may not be possible to extract data relevant to them.

This 'group agreement' will be revisited at each group session, and added to following collective discussion and agreement.

Appendix 16

Sample agenda used for Focus Group sessions

Kick Off session with research participants – 2nd November 2022

Agenda outline:

1. Welcome and Introduction	SW
a. Permission to record	
2. Round table introduction	ALL
3. Background to research – show presentation	SW
4. Ground rules – group discussion	ALL
5. Consent	ALL
6. Confidentiality and pseudonyms	ALL
7. Reflective activities for next session	SW
8. Date for next group session	ALL
a. Online/ in person F2F	

Appendix 17

Template used for Solicited Diary prompts

Solicited diary prompt sheet

Participants are asked to keep an individual diary (in handwritten or digital format) which records thoughts, feelings, behaviours and/ or activities under direction from the researcher following a focus group and prior to the next session.

Participants are encouraged to record other issues not aligned to the predefined themes, considered important to the individual or group, as they relate to the study. Diaries can be as brief or detailed as the participants wish for.

The table provided below is shown as a written version, but submissions will be welcomed by the researcher in audio or other formats if preferred by the participant. Diaries will only be shared in group sessions with participants' permission.

How it is expected to work:

Stage of study: ____________	Activity Type: ____________ Focus Group: session ___ of ___	Date held: ____________	Venue: ____________ In person/ virtual (delete as appropriate)

Study focus and aim:

An exploration of the concept and practice of 'cultural humility' amongst health and social care clinicians and its relationship to reducing social stigma in the palliative and end-of-life care for older sexual and gender minority patients and their family of choice.

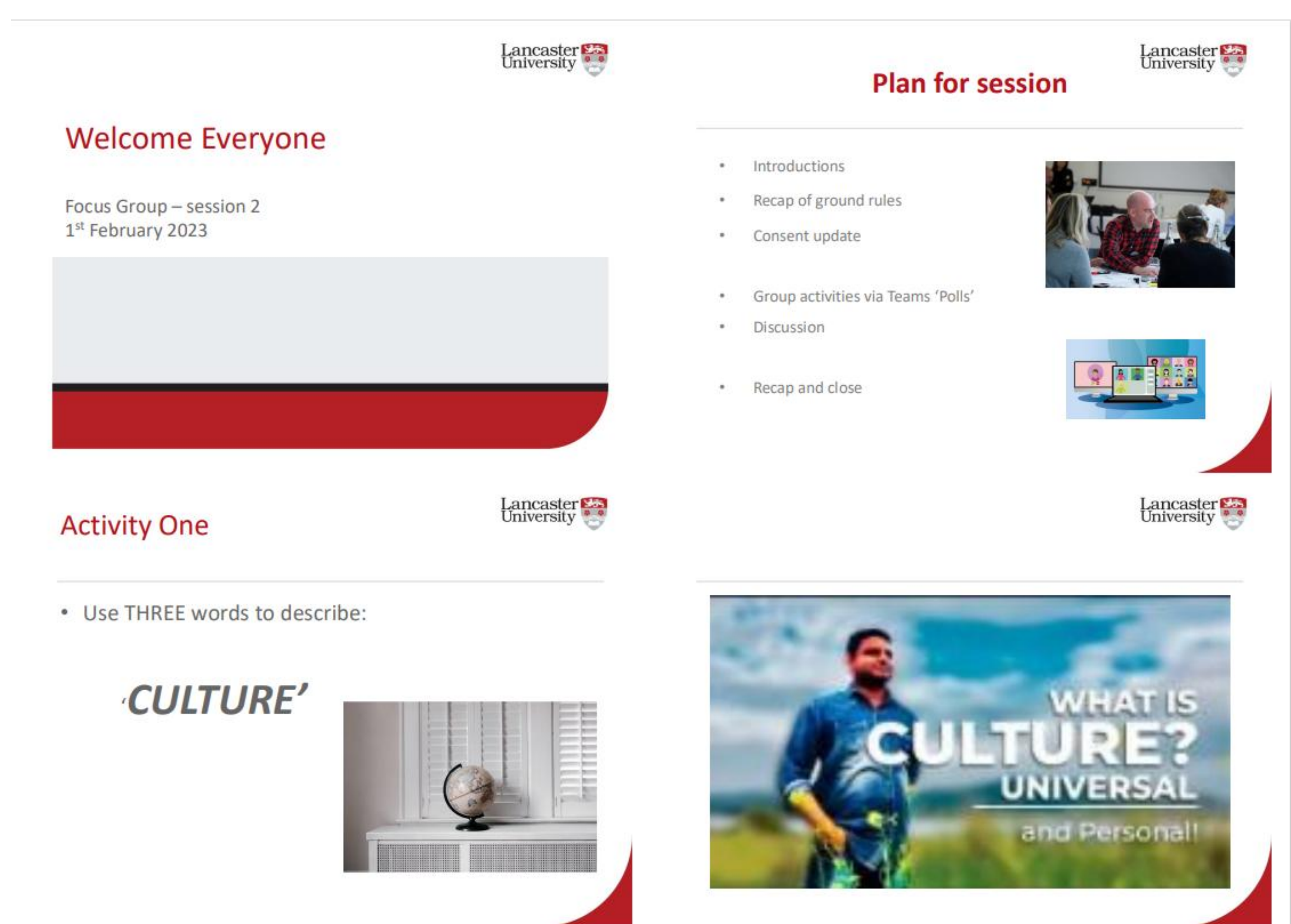
Study objectives:

- consider and discuss current knowledge and awareness of 'cultural humility' as a concept, value, or attitude;
- understand how 'cultural humility' may apply in the context of palliative care;
- examine the impact of social stigma and its relationship to the provision of person-centred care for sexual and gender minority patients using group and individual reflection;
- consider how 'cultural humility' contributes to stigma reduction and its role in fostering therapeutic and respectful patient-provider relationships.

Diary reflection prompts	***A record of thoughts, feelings, behaviours and/ or activities: reflections can be as brief or comprehensive as you wish to engage with***
How did you feel before attending the Focus Group session?	
What went well? And not so well?	
What surprised you and why: was this a negative or positive reaction?	
Did anything distress/ annoy you? Please remember group confidentiality and mutual respect for fellow participants	
How did your contribution add to group activities and/ or discussions?	
What have you learnt from your participation in the group session today?	
How likely are you to continue taking part in the sessions and with completing any required tasks, including this diary?	
What would you like to add to/ include in the next session?	
How appropriate and realistic do you believe the research focus, aim and objectives are in relation to the patient care you are involved with?	

Appendix 18

A selection of sample resources used in Focus Group sessions



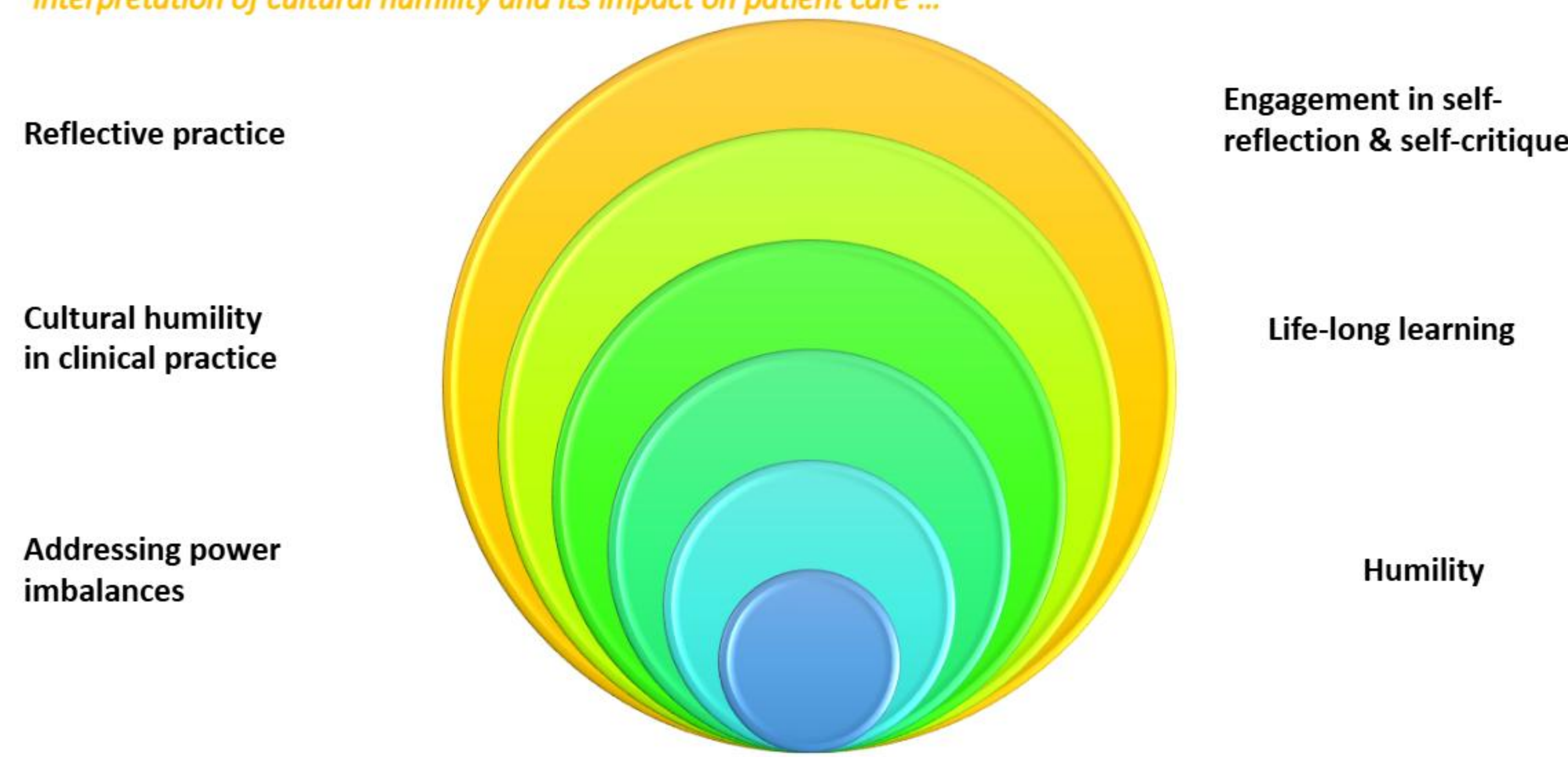
Activity – used in FG 2 (M1 - February 2023)

Did your three words appear?

(….. everyone loves a word search)

Observation	Journey	Evocation	Ever-evolving	Legacy	Civilization	Bonding	Inclusiveness	Celebration
Compassion	Sanskriti - (Hindi for Culture)	Story Telling	Sharing	Folk Dance	Happiness	Together	Horizons	Inheritance
Creative	Essence	Literature	Engaging	Love	Bridge	Environment	People	Oneness
Identity	Community	Exploration	Freedom	Dress	Folk Art	History	Food	Expression
Tradition	Essential	Dignity	Empathy	Authenticity	Knowledge	Mirror	Manifestation	Caring
Family	'Craic' – Gaelic for a good time	Encounter	Sports	Interpretation	Reflection	Appreciation	Heritage	Peace
Passion	Commoning	Two Spirit	Huge	Learned	Tolerance	Integrity	Joie de Vivre	Being

Cultural Humility 'onion' activity used in FG 3 (M2 - May 2023)



Culturally humble CLARE/CLAIRE (useful mnemonic)

Lancaster University

Meet ….

(a play on 'culturally humble care')

- CLARE:
  - **C**ollaboration
  - **L**istening
  - **A**wareness
  - **R**eflexivity
  - **E**mpathy

- CLAIRE:
  - **C**ommunication
  - **L**earning
  - **A**sking
  - **I**nclusivity
  - **R**espect
  - **E**quity

Appendix 19

Reflective exercise sample pre-Focus Group sessions

Reflective activity prior to first reflection/action Focus Group (M1 - February 2023)

For working group 1 – Qtr 1 2023

Reflective Activities prior to next group session:

What do the following mean to:

a) The wider society
b) In health and social care environments
c) For interactions with individuals from marginalised populations
d) You personally

Cultural humility

Culturally humble care

For the last two have a think about whether they are:

1. A concept
2. A behaviour
3. A value/ attitude

And do you think they are inherent within an individual or something to be learnt (i.e. a skill?)

Just record what initially comes to mind, and feel free to ask others for their thoughts/ opinions

Appendix 20

Reflective exercises used during Focus Group series: samples

Reflective activity used prior to Focus Group 5 (M4 - October 2023)

Who do YOU think you ARE?

For our next focus group session, I would like you to take some time to think through a series of questions I have considered, as we continue to explore "Cultural Humility" and its implication for us as practitioners.

There are no right/ wrong answers. But please, be honest. I would be grateful if you could send them to me on completion (either before the session or soon afterwards). They will make important contributions to the overall findings.

(NOTE: nothing will be shared/ discussed without your consent and will be anonymised as per our group agreement and ethical protocol)

There will be the opportunity to discuss these as a group too.

In remembering the features of "CULTURAL HUMILITY" – (see page 3)

Based on your own personal and professional experiences, respond to the following questions:

Describe a scenario in which you (or someone that you know) experienced cultural humility (or lack thereof) in an interpersonal exchange. Consider the cultural context in which this occurred, and reflect on and evaluate your response.

What types of actions or values reveal cultural humility to you?

One way to recognize and develop cultural humility in myself is to...

One time I have witnessed/experienced genuine cultural humility was...

Cultural humility can directly benefit me, my colleagues, and patients, because...

As part of the self-reflection element of cultural humility, take a few minutes to think where you stand on the following:

Self-Identification worksheet (Asnaani, 2023)

IDENTITY FACTOR	How others IDENTIFY ME	How I IDENTIFY
***A**ge and generational influences*		
***D**evelopmental disabilities*		
***D**isabilities (other)*		
***R**eligion and spirituality*		
***E**thnic and racial identity*		
***S**ocioeconomic status/ social class*		
***S**exual orientation*		
***I**ndigenous heritage*		
***N**ational origin*		
***G**ender*		

(Based on the ADDRESSING model by Pamela Hays – 2008)

Appendix 21

Reflective responses received from Clara and Mac (exerts)

Taken from questions posed as shown in Appendix 20

From Clara (with permission to share)

"Just a few thoughts

Scenario
Thinking about different incidents over the years one situation (among many)stands out
I was working in Homerton hospital early noughties
Paul was a young gay chap in his late 30's
He was a heroin addict, and he described his life as ' colourful'he was often non compliant with treatment
He had a fungating rectal tumour which unfortunately had an offensive odour
Both medical and nursing team avoided Paul as much as possible they inferred his symptoms were exacerbated by his lifestyle
Cultural humility was scarce in his care
I felt uncomfortable with my colleagues attitude to Paul and tried to make up for their distance and judgment of him by spending a lot of time with him But on reflection I didn't stand up and confront my colleagues behaviour and biases which I would hope I would do now
The medical team were not comfortable with Paul's sexuality and showed this by overall lack of empathy
I see cultural humility as an acceptance and respect of people for how they perceive themselves
I feel that I need to continually question bias and presumption but also recognise not everyone has a western value system
Cultural humility isn't about judging people based on my own value system but respect for others as individuals with unique values and beliefs
I also appreciate not everyone will agree or possibly accept me or my beliefs/ values
Standing up for the concept of CH may be difficult when faced by outright opposition to respecting people's sexuality

Another incident which illustrates CH was when same sex couple were allowed to stay together in hospice and staff ensured the patient and her partner shared a bed (although a squash) which was their wish and all respected and showed empathy

Self identification

I identify as straight working-class white female
A feminist, basically a n agnostic but tolerant of others religious beliefs
My code has always been do unto others how I would want to be treated
Following our recent focus group I have asked a friend (not health care professional but in social care)how he sees me
He said he would identify me as a mature Caucasian female"

And from Mac (with permission to share)

<u>Reflection</u>

Description

Whilst working on a hospice Inpatient Unit I was supporting a gentleman on a four bedded bay. I had received my handover and knew what I needed to know to look after him e.g. condition, moving and handling guidance etc

During the shift I had provided personal care and administered his medication. During the day I overheard and was included in conversations about this particular gentleman. These conversations centred on a *belief* that this gentleman had been/was a paedophile

Feelings

This was the first time I had experienced comments and concerns about a hospice patient and what they may or may not have been. I had only ever experienced myself and colleagues looking after people with compassion and striving to look after and care for them to a very high standard. This regardless of age, gender, sexual orientation, colour, beliefs…and even if they were rude or ungrateful!

This was difficult to hear and understand. Colleagues that I respected and who had taught me how to look after people with the greatest of care, compassion, dignity and respect. Yet now they were judging and discussing whether they wanted to be 'working in that bay' because of his presence. I struggled with this. I have my own values and moral compass and for me *every* person I look after gets the very best of care from me. As a nurse this is how I should be – zero discrimination or bias

I felt sad and I have to admit I also felt angry. How could they be having these discussions when they were there to care for everyone as I was. Had they not become a nurse or health care assistant for the same reasons as me

Evaluation

From being part of this research project I have been able to look back and reflect on this with perhaps a different understanding. As I know nothing about my patients past life I also know nothing (unless shared) about my colleague's life experiences. With the gentleman on that bay had what was being discussed amongst them, whether true or not, triggered feelings from previous experiences and situations they had been in. Experiences where there were perpetrators and victims

If I ask myself if this impacted on my capacity to care for anyone and everyone, regardless, the answer is yes. It made me even more committed to caring without bias or discrimination and reinforced my existing values and beliefs

Just coming to the end of this reflective piece I have asked myself how I feel about having not challenged my colleagues. During conversations at the time I just nodded and grunted at appropriate points just to show I was listening. With the benefit of hindsight I should have challenged this perhaps and explained how I felt about their judging of this gentleman. Many years later the 'me' now would

Appendix 22

Example of coding data and theme labelling

For the theme – Facing our Vulnerability (initial mind mapping, linking with co-researcher quotes).

Manual coding supported by Microsoft Excel to group into patterns of meaning.

	Uneasy with reflection	Admitting shortfalls (Mac)	
	Experience as a 'minority'		Dorothea experience in Bermuda etc (from M4)
	Fearing perception of self by others	"fearing judgement myself … and being judged on your personal position, … wherever you are in life " (Dorothea - M4)	'Who do YOU think you are" activity - from M4
	'Naval gazing' - (Dorothea)		"where is your safe space to be yourself" (Dorothea - M4)
OUR OWN VULNERABILITIES	Acknowledging assumptions	Being non-judgemental (all co-researchers)	"bringing your own preconceived ideas rather than learning from the individual" (Bianca - M3)
	Becoming other-orientated		
	Lack of courage/ fear	Takes courage to admin/ articulate "what we don't know" - all co-researchers	"fear of saying something wrong or doing something wrong" (Dorothea - M3)
	Being the 'student' of the patient		"being the inferior one" (Mac - M5)

Appendix 23

Summary of cycles and where the chosen themes featured

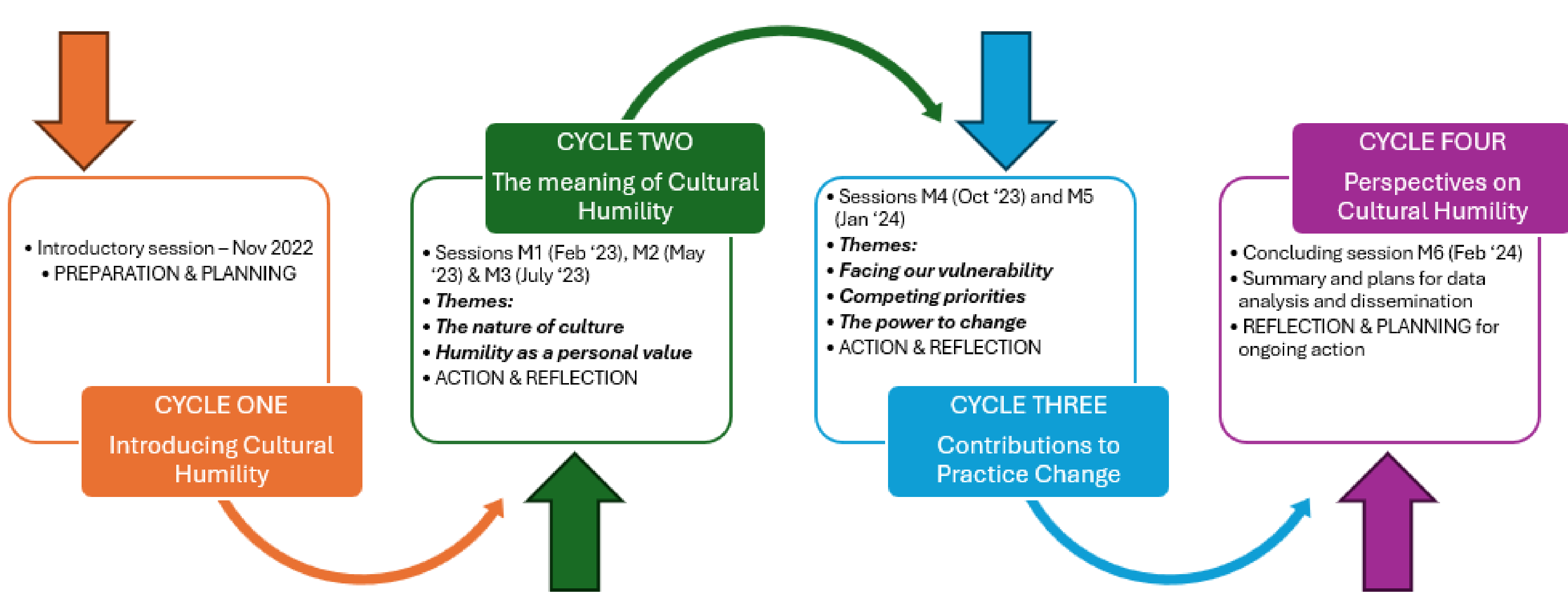


Illustration of where data contributed to themes