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Understanding oral history with people in palliative and supportive care: a constructivist grounded theory study

PhD

July 2023

# Understanding oral history with people in palliative and supportive care: a constructivist grounded theory study

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A thesis submitted in partial fulfilment of the requirements for the degree of Doctor of Philosophy

The University of Sheffield, Health Sciences School,
Division of Nursing and Midwifery

July 2023

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## Abstract

This study develops understanding of how oral history in palliative and supportive care is experienced by patients, family and friends, volunteers and health care professionals, using Constructivist Grounded Theory Methodology.

Thirty-two semi-structured interviews are conducted with 22 research interviewees to consider the motives, experience, and outcomes of all parties, as six recipients of an oral history service move through the process. Constant comparative analysis is used with line-by-line and focused coding to determine emerging theories.

The oral history experience is shaped by the participants' own sense of mortality, their relationship with the volunteer interviewer, referring HCP, family and friends, and the interview setting. Motivations and experiencing legacy are identified as pivotal. The CGT identifies the basic social process of giving voice, which begins and continues through the temporal process with remembering and reflecting, this creates opportunities for autonomy and social interaction with the desired outcome of dignity.

The study is the first to explore the experience of oral history at the end-of-life, from a range of perspectives. The work has implications for setting up and coordinating oral history services in palliative and supportive care and for the wider oral history community in understanding the oral history experience in these settings.

# Acknowledgements

I would like to take this opportunity to thank all the people who have helped me during this study.

Firstly, I would like to thank all the research participants for giving me their time and thoughts, without which this research would not have been possible. I hope that my findings and corresponding theory does their insights justice. I would also like to thank the ethics committee, advisory group and health care professionals who played a part in making this study a possibility and who gave me valuable insight.

I would like to thank my supervisors, Prof. Tony Ryan, Dr. Jane McKeown and Dr. Michelle Winslow, for their ongoing support throughout the PhD. They have been invaluable in steering this work and helping me build confidence in my ideas and writing. I have learnt a lot from them. My fellow PhD students have also been a great source of encouragement and useful information, particularly thanks to Andy, Samar and Sarah.

My friends who have put with me being preoccupied and talking relentlessly about the PhD, including Alex, who suggested it was a good idea to do a PhD in the first place, Sam and Gavin.

My family, my daughters Saskia and Edie, both of whom have grown and learnt so much themselves while I have worked on this doctorate. Whilst they don't currently understand what I've been doing, they have made me so happy and content in life, and I have loved watching them develop and spending time with them.

My mum and dad, for their love and encouragement, and my parents-in-law, for theirs, and for showing so much interest in what I've been doing. Finally, my wife Jo, for her constant support, brilliant advice, being extremely understanding during this process, and all her love.

# Abbreviations

AI – Artificial Intelligence

CD – Compact Disc

CGT – Constructivist Grounded Theory

DBS – Disclosure and Barring Service

ECHO - Extension of Community Healthcare Outcomes

EoL – End of Life

GDPR – General Data Protection Regulation

GVT – Giving Voice Theory

HCP – Health Care Professional

Incomp - Incomprehensible

NLS – National Life Stories

MDT – Multi-disciplinary Team

OH – Oral History

OHinPSC – Oral History in Palliative and Supportive Care

OHA – Oral History Association

OHS – Oral History Society

REC – Research Ethics Committee

PCNF – Person Centred Nursing Framework

# 1. Introduction

This study builds on an unpublished study report for Macmillan Cancer Support: 'How does providing an oral history at the end-of-life influence well-being of the individual and the bereaved?' (Winslow and Smith, 2013) I was the Research Associate on the study, and one of my PhD supervisors, Michelle Winslow, was the Chief Investigator. This study is linked by association and topic, but independent in methodology and analysis. It builds on the work of the pioneering Oral History in Palliative and Supportive Care (OHinPSC) Services Project, which began in 2007 at the Macmillan Unit for Palliative Care, Sheffield. This study took place in another setting, which also has a well-established service. The aim of this study is to develop understanding of how OHinPSC is experienced by participants, their family and friends, service volunteers and healthcare professionals (HCPs).

OHinPSC gives people the opportunity to audio record memories for family and friends, and as a public archived resource. The purpose of this study is not to seek permission to undertake oral history (OH), but to evaluate it. Objectives are to understand the implications for practice in health and social care. This involves asking participants and all involved about the ethical considerations, challenges and benefits of recording an OHinPSC interview. Consideration is also given to the legacy of archived interviews for family and friends, and within the University of Sheffield as an educational resource, including teaching in the School of Nursing and Midwifery.

The study follows a constructivist grounded theory (CGT) approach (Charmaz, 2014). This includes continuous collection and analysis of information via semi-structured interviews in which research interviewees review their participation in OHinPSC. Open-ended repeat interviews following guide questions were recorded with six participants, associated family and friends, volunteer interviewers, and HCPs. Interviews were conducted before, during and after OH was recorded. Coding of interview transcripts and researcher notes identified key concepts which enabled me and research interviewees to co-create a CGT about the experiences of OHinPSC. This thesis will present a new theory in the field of OHinPSC called

the Giving Voice Theory (GVT) which can support practitioners and stakeholders in planning and assessing OHinPSC projects, and conducting OHinPSC interviews.

Patient and public involvement informed the study and is ongoing. Findings will be shared with experts, patients and the public, and contribute towards a working document on ethical implications and procedural duties to inform future policy making.

I start (Chapter 2) by providing background to OH as a medium and understanding its development both in the field of history and as a multidisciplinary method. I then introduce background to patient narrative in health and social care, before charting the development of OH for people in palliative and supportive care. My literature review follows (Chapter 3), in which I outline my methodology for finding literature relevant to understanding OHinPSC and steps I took in refining my search and analysis. I then present my literature review and a narrative synthesis of my findings, including an understanding of personal and organisational motives for taking part, therapeutic outcomes and challenges, narrative identity and its impact on relationships between stakeholders, the implications for sharing OH recordings in legacy and research, and the context of OH within the digital realm. I conclude with discussion of the findings including strengths and limitations of the review, recommendations for further research and sensitizing concepts.

Building on the review findings and sensitizing concepts, I present my study questions and outline my proposal with methodological indications, ontological and epistemological positioning and scientific justification (Chapter 4). I describe the research design based on the research setting, population and ethical considerations (Chapter 5). I explain the methods I used in practice (Chapter 6), and my reflections on the process, including acquiring ethical approval, permission and advice to undertake the research, producing relevant study documentation, recruiting interviewees, decisions made in data sampling, collection and analysis, and overall reflections on the study and my role as researcher.

I set the scene for the study (Chapter 7) by explaining the different settings in which the OHinPSC takes place and introducing pen portraits of all the research interviewees. This serves as an aid to sharing my findings (Chapter 8), in which I share the motives and understanding of interviewees for their involvement in the OHinPSC. I examine the experience of the interview in how participants and volunteers co-construct narrative and in

how this relates to their illness and sense of their own and others mortality. Finally, I review the outcomes for research interviewees with OHinPSC as a legacy for various audiences – how it is and could be heard, shared and received by participants, family and friends, and in the public archive such as for educational and training purposes. Based on the findings I describe the basic social process of the CGT (Chapter 9). I discuss how the GVT was identified and is multifaceted in its purpose. I explain each of the key elements of the theory as a way for understanding the temporal process of OHinPSC.

Finally, I present my discussion (Chapter 10), in which I set out my contribution to knowledge from this study. I review how the CGT relates to other relevant OH and nursing literature based on the process of motives, experience and outcome. I discuss the CGT in relation to other nursing concepts – Person-Centred Care in the experience of OHinPSC and Continuing Bonds in the outcome, with which I also consider the future possibilities of OHinPSC in the digital realm. I evaluate my study using guidelines for its "credibility, originality, resonance and usefulness", as suggested by Charmaz (2014, p.336-338). I detail the strengths and limitations of the study, then present my final recommendations stemming from the study for education, policy and practice and suggest a future research agenda.

My interest in the field originates from my work as a practitioner on the Oral History in Palliative and Supportive Care Services Project at Sheffield Teaching Hospitals NHS Foundation Trust. I have worked on the service for over ten years, in which time I have conducted approximately 250 interviews with patients and coordinated volunteers to conduct interviews and perform archival duties. Several points of interest and ethical considerations have come to light, and this study allows me to investigate similar projects and related research to further understand the experience of OHinPSC. I am a Regional Networker and Trainer for the Oral History Society, offering guidance and training to people embarking on projects in Yorkshire and in the UK. I am interested in the impact of this research for the wider OH and palliative and supportive care communities.

## 2. Background

### 2.1 What is oral history?

OH is the "method of gathering, preserving and interpreting the voices and memories of people, communities, and participants in past events." (Oral History Association, 2018). A recorded audio interview follows a life story or event narrative, generally featuring an interviewer, who is an empathetic listener with open questions, and an interviewee, the dominant storyteller who dictates the interview's pace and tone.

### 2.2 The origins and rise of oral history

Oral testimony for historical purposes can be traced back to community orators in African village traditions (Vansina, 1985) and ancient Greece (Thompson, 1978, p.26). It was "the first kind of history" (p.26) in pre-literate societies. However, oral history as a method coincided with advancements after World War 2, in being able to use better technology in the form of magnetic tape to audio record the voice. The term 'oral history' is attributed to American journalist/biographer Allan Nevins, who opened the first institutional OH programme at Columbia University in 1948 to record the histories of people deemed significant in society, such as politicians and charity donors (Thomson, 1998, p.581). In the UK, an early example of OH was George Ewart Evans, who, in contrast to Nevins, interviewed local people about rural life in Sussex (1956). Magnetic tape recorders continued to develop and become more portable and affordable, leading to an increased interest in recording OH. Guidance bodies were set up in the form of the Oral History Association (OHA) in the USA in 1966 (OHA, 2023) and the Oral History Society (OHS) in the UK in 1973 (OHS, 2018).

Since then, Thomson (2007) notes paradigm shifts:

- The post-war renaissance of memory as a source for *people history*
- The development since the late 1970s of post-positivist approaches to memory and subjectivity
- A transformation in perceptions about the role of the oral historian as interviewer and analyst from the late 1980s
- The digital revolution that began in the late 1990s (p.50)

Whilst the focus of OH during this time became more involved with understanding subjective memory and its value, during the same period there were developments in health and social care about subjectivity in patient narratives (Winslow, Seymour and Clark, 2005).

## 2.3 The patient 'narrative turn' in health and social care

There was a much debated "narrative turn" (Brown *et al.*, 1996; Atkinson, 1997; Riessman and Quinney, 2005) in health and social care towards interest in patient stories (Porter, 1985). It is noted that traditionally, pre 1970s, historical narratives focussed on the study of medicine and scientific breakthroughs rather than patient experience and policy making (Winslow and Smith, 2010). The narrative turn is not solely attributed to the history of medicine and is part of a bigger multidisciplinary shift (Thomson, 2007). The study of narrative has become more entwined with the functions and possibilities of subjective memory and social constructionism (Berger, 1967). In health and social care, personal narratives of health and illness are now significantly regarded (Frank, 1995).

There have been questions raised about ethical ambiguity in the wider production and use of "illness narratives" (Bury, 1982), including lay epidemiology (Davison, Frankel and Smith, 1992) in health and social care. Angela Woods (2011) investigated the limits of narrative in medical humanities and highlighted the implicit dangers: its questionable authentic potency; lack of understanding of other narrative disciplines and the philosophical concept of "narrative selfhood and identity" (p.74), and the potential for harm to participants.

As detailed later in this thesis, several narrative therapies and interventions have come to prominence in health and social care, particularly in palliative care, such as Dignity Therapy (Chochinov *et al.*, 2005), reminiscence (Bornat, 1989), life review (Butler, 1963; Jenko, Gonzalez and Seymour, 2007), and life story work (McKeown, Clarke and Repper, 2006). Digital technology presents a plethora of new opportunities for recording biographies (Smith *et al.*, 2009)**.**

## 2.4 The development of oral history in palliative and supportive care

The act of recording patients' stories for posterity and cathartic benefits is not new (Bingley *et al.*, 2008, p.653). Hospice pioneer Dame Cicely Saunders stressed the importance of listening to patients' stories to address existential and spiritual needs (Saunders, 1960).

The first written mention found of OHinPSC is in the 'News Abroad' section of the Oral History Journal (Lance, 2003), detailing a pilot project at the Australian Capital Territory Hospice in Canberra and knowledge of three other projects in Australia, New Zealand and Britain (p.18). The service at the Te Omango Hospice, New Zealand, has a corresponding published article (Lichter, Mooney and Boyd, 1993) included within the review synthesis. Unfortunately, I was unable to find further research or grey literature relating to the Australian project. The Hospice History Project at the University of Sheffield (Clark, 2006), sowed the seeds for the Oral History in Palliative Care Services Project in Sheffield in 2007 (Winslow and Smith, 2013), included in the review synthesis.

I have not been able to find present international examples of OHinPSC, although there are undoubtedly several instances of patients recording their life stories in palliative and supportive care settings and at the end of life, whether this be in a video, audio or written form. OHinPSC as an academic discipline and method appears to currently be a UK phenomenon, which centres around the Oral History Palliative Care Services project. Several other services, overseen by the project have been piloted, including services in Antrim, Chesterfield, Manchester, North Shields and Winsford (Winslow and Smith, 2019), some of which are still in existence. Another example, not badged as OH but with similar motives, is the Stories for Life Charity: (https://www.storiesforlife.co.uk/) This was set up by journalists rather than oral historians, and the recordings are not professionally archived. Corresponding research relating to this model (Halton-Hernandez *et al.,* 2023) is embargoed until 2024.

## 2.5 Chapter summary

I have introduced this study thesis, given background to the development of OH and its wider remit as a narrative approach in health and social care and pertaining to palliative and supportive care settings. I now move to the development of my literature review, its methodology, consequent synthesis and discussion.

## 3. Literature review

## 3.1 Methodology

A qualitative narrative synthesis has been adopted to enable a systematic approach to the review, to develop theory about understanding OHinPSC, explore relationships in the data, and evaluate the strength of the synthesis (Aveyard, 2016, p.136). Due to scant specific quantitative data, the use of a systematic review with a meta-analysis or meta-ethnography (Barnett-Page and Thomas, 2009), although desirable as robust evidence, was not suitable here. For guidance in conducting and writing my literature review I have referred to 'A post-graduate's guide to doing a literature review in health and social care' (Aveyard, 2016), which outlines several approaches for analysis and synthesis of qualitative and mixed methods research (p.123). Due to scant research relating to the subject, an inductive approach was used to analyse and compare the data and the approach of narrative synthesis was deemed suitable, this also afforded the opportunity to include non-research. I have drawn on advice from supervisors and University of Sheffield video tutorials (2018a).

### 3.1.1 Search strategy

Searches were conducted on Cinahl nursing database, Web of Science Core Collection and ASSIA social science database (December 2016; January 2017). Further searches were undertaken in OH, narrative and healthcare journals using keywords, and additional papers were obtained from a relevant module bibliography, reference lists and supervisor recommendations.

### 3.1.2 Inclusion/exclusion criteria

#### 3.1.2.1 Inclusion criteria

- Research and theoretical papers noted as relating to an OH approach
- Involving people in palliative and supportive care
- English language only
- Predominantly relating to adult (over 18) population

#### 3.1.2.2 Exclusion criteria

- Research and theoretical papers not relating to OH as an approach
- Not involving people in palliative or supportive care
- Not English language

- Predominantly relating to children (under 18) population

The exact inclusion/exclusion criteria was initially left open to ascertain how OH is deemed a narrative approach and in what setting, and to allow an understanding of the wider context of narrative interventions and illness. Due to the abundance of narrative approaches which incorporate aspects of the OH process, the final inclusion were those studies which directly reference OH as an approach with people in palliative and supportive care. This enabled an understanding of the breadth of OH as a discipline and process. Due to lack of resources for translating other languages, only English literature was included in the results.

### 3.1.3 Search terms

The following keywords for biographical approach, location and setting were chosen after general reading on the topic and consultation with my supervisors and the Health Sciences Librarian. I also, when possible, used and referred to MeSH terms (U.S. National Library of Medicine, 2018), to ensure the search terms followed appropriate vocabulary. Due to the cross-disciplinary nature of this review, and particularly the contrast between history and nursing, the process for finding the appropriate vocabulary and syntax is multi-versed.

The word "interview" was also included as a biographical approach but taken out to enable a manageable number of results. The search terms were tried with and without abbreviations and yielded the same results, so the abbreviated version was adopted as below. The original unabbreviated search terms are included (Appendix 1).

> "oral history" or "oral histories" or narrative or biograph* or testimon* or "life story" or "life stories" or "life history" or "life histories" or story or stories or storytelling or "narrative method" or reminiscence
>
> AND
>
> "nursing home" or hospice or hospital or "residential care" or "care home" or "long term care" or "post-acute care" or "long term facility"
>
> AND
>
> palliative or "end of life" or EoL or terminal or death or dying or "life support care" or "patient care"

The terms were searched on the Web of Science Core Collection database as a 'topic' to allow for a manageable number but to avoid missing any without a clear title. On the Cinahl and ASSIA databases the search was extended to anywhere due to the databases' smaller capacities.

### 3.1.4 Database search results

Web of Science Core Collection =677

Cinahl = 669

ASSIA = 173

**Total = 1519**

### 3.1.5 Hand search of journals

On the 16th February 2017 I conducted hand searches on relevant journal websites (Appendix 2). Due to the journal websites not generally having Boolean operator capabilities, my search was condensed to one or two keywords.

### 3.1.6 Search for relevant websites

On the 20th February 2017 I conducted an additional online search for grey literature of the first seven Google pages for: *oral history in palliative care,* and then: *oral history end of life* and *oral history hospice.* Content not already found in the journal and database searches and deemed of interest is included in a table (Appendix 3). The majority relate to practice and guidance, with two research papers found.

### 3.1.7 Results

My method for collecting and illustrating my results adheres to the recommended PRISMA format for systematic reviews (Moher *et al.*, 2009). It differs slightly in that I performed the journal and website hand search after initial exclusion and theming with literature from the database search. This was to allow me to understand the wider context of the literature before deciding on what to search further elsewhere.

*Figure 1: A diagram to illustrate the PRISMA flow*

| Records identified through database search (n = 1519) | Records identified through other sources (n = 21) |
|---|---|

Records after duplicates removed

(n = 1243)

| Records screened on title (n =341) | → | Records excluded on abstract (n = 218) |
|---|---|---|

| Full-text articles assessed for eligibility (n = 123) | → | Full-text articles excluded, with reasons (n = 115) |
|---|---|---|

Studies included in narrative synthesis

(n = 8)

*Figure 2: A table of included empirical studies*

|  | Reference | Title |
|---|---|---|
| 1 | (Lichter, Mooney and Boyd, 1993) | Biography as therapy |
| 2 | (Rickard, 1998) | Oral history – 'more dangerous than therapy?': Interviewees' reflections on recording traumatic or taboo topics |
| 3 | (Taft *et al.*, 2004) | Oral history: validating contributions of elders |
| 4 | (McCarthy, 2010) | "Is oral history good for you?" Taking oral history beyond documentation and into a clinical setting: first steps |
| 5 | (Savundranayagam, Dilley and Basting, 2011) | StoryCorps memory loss initiative: enhancing personhood for storytellers with memory loss |
| 6 | (Ligon *et al.*, 2012) | Oral history: A pragmatic approach to improving life satisfaction of elders |
| 7 | (Winslow and Smith, 2013) | How does providing an oral history at the end-of-life influence well-being of the individual and the bereaved? |
| 8 | (Beasley *et al.*, 2015) | The lived experience of volunteering in a palliative care biography service |

A more detailed table is included (Appendix 6).

### 3.1.8 Data extraction

Due to the majority of research data being qualitative, I created a data extraction form to identify the key details relevant to my research question and then charted reoccurring themes using a suggested guidance form (Aveyard, 2016, p.96). A completed form is included (Appendix 4). Relevant titles and themes evolved as I reread the literature and narrowed the inclusion criteria. I produced a typology of similar biographical methods (Appendix 5) to give clarity to the role of OH within the wider field of patient narrative approaches, and extracted grey literature deemed relevant (Appendix 3).

### 3.1.9 Critical appraisal

Initially I appraised a more general pool of literature using a hierarchy of evidence as suggested by Polit (2004). I adopted the CASP tool (Critical Appraisal Skills Programme, 2018) and referred to evidence review guidelines (Booth, Rees and Beecroft, 2015, p.333-

337). However, due to the lack of published evidence of scientific rigour in the final inclusion, I ranked my studies in accordance with a framework more akin to qualitative data, for evaluating healthcare interventions effectiveness, appropriateness and feasibility (Evans, 2003). Using this framework (p.79), the studies can be viewed as poor to fair evidence, being case studies (Lichter, Mooney and Boyd, 1993; Taft *et al.*, 2004), descriptive studies (McCarthy, 2010), focus groups (Rickard, 1998), before and after studies (Ligon *et al.*, 2012) and semi-structured interviews (Savundranayagam, Dilley and Basting, 2011; Winslow and Smith, 2013; Beasley *et al.*, 2015). More recent studies reflect an increase in evidence, possibly suggesting an expanding field of research.

In my discussion, I also include theoretical papers which do not have empirical research but are deemed as highly relevant in adding depth to the review.

### 3.1.10 Analysis and synthesis

Due to the subjective experience of OHinPSC and the qualitative, theoretical and sometimes anecdotal research, a narrative review was considered the most appropriate approach for analysing and synthesising the data and key concepts. The definition and process for narrative synthesis outlined by Popay et al (2006) was utilised as suggested by Aveyard (2016, p.136) to enable translation of the similarities and differences in the data. Relevant keywords and reoccurring themes were identified in the studies which were tabulated and condensed to generate the following themes for analysis:

- Motivations
- Finding meaning and therapeutic outcomes
- Interrelationships before and after
- Legacy - its meaning and how OH achieves it

To establish the results, articles were analysed, and colour-coded to the above themes noting "reciprocal and refutional translation" (p.136).

### 3.1.11 Methodology summary

In this section I have outlined the strategy, process and primary results of my literature search. I have followed and referenced guidelines for extracting data, critical appraisal, and analysis and synthesis. In the next section I share the review findings in the form of a

narrative review, analysing the key themes I encountered. I then discuss the themes drawing on relevant OH and nursing research, including other biographical methods used in palliative and supportive care. Finally, I produce sensitizing concepts to inform my research question and corresponding methodology. Sensitizing concepts are suggested by Charmaz (2014) as a key component for starting inquiry in constructivist grounded theory to give "…initial but tentative ideas to pursue and questions to raise about their topics" (p.30) These concepts factor in the prior knowledge and interests of the researcher based on their field experience and the reviewed literature.

## 3.2 Narrative review

My rationale for conducting a narrative review is to seek to understand the underlying concepts and contexts of OHinPSC. In doing so, I will create a series of sensitizing concepts which will assist me in developing my research questions to be used as the basis for the study. As part of my analysis I explore the concepts of value and meaning for the narrator and others involved; the narrative process; its impact on identity and relationships; the final legacy; how it is shared and (re)interpreted.

The literature included in this synthesis draws on research identified from four distinct service models: The Oral History in Palliative Care Services Project in the UK, (Winslow, Noble and Hitchlock, 2009; Williams and Park, 2013; Winslow and Smith, 2014; Winslow, 2015) an audio biography service in Australia (Beasley *et al.*, 2015) and New Zealand, (Lichter, Mooney and Boyd, 1993) and two projects in the USA: one using OH as a reminiscence tool in nursing homes, (Taft *et al.*, 2004) and the StoryCorps Memory Loss Initiative, involved in computer assisted oral histories for people with early-stage memory loss (Savunranayagam, Dilley and Basting, 2011).

All the services vary in process and outputs as outlined in a table (Appendix 7). They were deemed relevant projects for this review in that they had research studies attached and facilitate recording the voice for historical purposes of people in palliative and supportive care. Research literature is also included which is assumed to be study-specific but relies on assessing relevant OH methodology (Rickard, 1998; Taft *et al.*, 2004; McCarthy, 2010; Ligon *et al.*, 2012).

The majority of the research is qualitative with the quantitative data exceptions of Ligon *et al.* (2012) measuring baseline life satisfaction scores, McCarthy (2010) using surveys and Savundranayagam, Dilley and Basting (2011) using interviews with yes/no questions.

Review studies come from a range of journal disciplines: palliative and supportive care (Lichter, Mooney and Boyd, 1993; Taft *et al.*, 2004; Winslow and Smith, 2013; Beasley *et al.*, 2015), oral history (Rickard, 1998; McCarthy, 2010), dementia (Savundranayagam, Dilley and Basting, 2011), and intergenerational relationships (Ligon *et al.*, 2012).

In the discussion I draw on relevant OH and nursing research and theory to further examine the commonalities and differences within the themes, and draw comparisons with other biographical approaches.

### 3.2.1 Motivations

The motivations of the interviewee, interviewer, the service and its stakeholders all warrant consideration. The organisational motives for research into OHinPSC include whether it improves the life satisfaction of older people (Ligon *et al.*, 2012); validates their contributions (Taft *et al.*, 2004); influences the well-being of the participant and the bereaved in legacy (Winslow and Smith, 2014); helps the participant find meaning and is therapeutic (Lichter, Mooney and Boyd, 1993; McCarthy, 2010); or investigates the lived experience for interviewees, family members (Savundranayagam, Dilley and Basting, 2011) and volunteers (Beasley *et al.*, 2015).

How participants are recruited varies between being selected with strict variables in study specific research (Taft *et al.*, 2004; Savundranayagam, Dilley and Basting, 2011; Ligon *et al.*, 2012) or based more broadly within service models (Lichter, Mooney and Boyd, 1993; Beasley *et al.*, 2015) in which it is open to all or many users of a service. This review is interested more in how people want to be involved in service models rather than taking part in research exercises.

In the Oral History in Palliative Care Services project model (Winslow and Smith, 2013), the motivation is to create a family record or social history (p.4). OH is recognised as a preferred and sometimes necessary alternative to writing a biography (p.83). There are instances of participants wanting to talk specifically about their illness, with a view to sharing it with people going through the same condition (p.31). In the hospice model studied by Lichter,

Mooney and Boyd (1993), participants were selected as a result of them being "considered to have a need to find meaning in their lives in order to improve their quality of life...whose lack of self-regard is considered to be a key factor leading to apathy and depression" (p.134). The service was latterly extended to patients as a "satisfying way to occupy their time when they become bored or unable to undertake even the lightest of tasks because of weakness." (p.134). Other motivations include setting the record straight (Rickard, 1998), and experiencing an historical event (Taft *et al.*, 2004).

The strongest evidence found for interviewer participation comes from a study on volunteers (Beasley *et al.*, 2015). This found multiple motives, an interest in writing and listening to stories, or gaining a stronger understanding of others' personalities (p.1419). Others wanted to give something back in gratitude for the quality of care they or others received, and offer psychological and emotional support they had found lacking. (p.1420).

### 3.2.2 Finding meaning and therapeutic outcomes

Throughout the literature there is suggestion that OH is a meaningful activity which can improve well-being and quality of life. The differences and similarities between OHinPSC being 'meaningful' and 'good for you' are sometimes indistinguishable, so I review the literature with both themes entwined to try and reach a comprehensive understanding.

Overall, OH was found to be a positive and enjoyable experience for the interviewee, (Lichter, Mooney and Boyd, 1993; Rickard, 1998; Taft *et al.*, 2004; McCarthy, 2010; Savundranayagam, Dilley and Basting, 2011; Ligon *et al.*, 2012; Winslow and Smith, 2013) volunteer interviewers (Taft *et al.*, 2004; Beasley *et al.*, 2015) and family interviewers (Savundranayagam, Dilley and Basting, 2011).

Some studies focused on OH as a way to enhance quality of life (Taft *et al.*, 2004; McCarthy, 2010; Ligon *et al.*, 2012). Ligon et al (2012) argued that over time, OH interviews may contribute to improved quality of life among old people. Qualitative survey analysis by McCarthy (2010) "supports the argument that the OH interview allows for a thorough understanding of how patients define and measure their own quality of life" (p.166). Taft et al (2004) suggested that OH can give validation to the participant and "create a culture to enhance a therapeutic environment" (p.38).

Other studies concentrated on the overall experience of an OH interview (Lichter, Mooney and Boyd, 1993; Savundranayagam, Dilley and Basting, 2011; Winslow and Smith, 2013; Beasley *et al.*, 2015). In these studies, OH was found to foster meaningful conversations for both the interviewer and interviewee (Lichter, Mooney and Boyd, 1993; Savundranayagam, Dilley and Basting, 2011; Winslow and Smith, 2013; Beasley *et al.*, 2015). Winslow and Smith (2013) found that "talking with a non-judgmental, empathetic and interested listener is seen as cathartic by many people, and interviewees do not confuse OH with counselling" (p.4). The study by Beasley et al (2015) found that volunteers gained "a deeper appreciation of existential issues and helped them to be more appreciative of their own lives…" (p.1417).

Savundranayagam, Dilley and Basting (2011) found that OH "encouraged meaningful and collaborative conversations, especially with family" (p.417). McCarthy (2010) found that interviewees had "no feelings of regret, even when the interview brings up difficult memories and reminds them of things they had not thought of in a long time" (p.165). Rickard (1998) was more cautious, arguing "oral history seems to have an important place in straddling the therapeutic and the need for creative affirming expression" (p.42). Compared to formal therapy, OH has "the possibility of both affirming and destabilising a personal narrative." (p.36).

### 3.2.3 Interrelationships
This theme considers the complex patterns of relationships in the formation of the participant's identity and narrative. How is the interviewee approached? What are the topics of conversation and who determines it? How is the recording reinterpreted as a historical record in bereavement and how does this affect well-being and ongoing relationships?

There are several key relationships within an OH service. Perhaps foremost is the relationship between interviewer and interviewee. This review found the interviewer to be one of a number of people: a trained volunteer (Lichter, Mooney and Boyd, 1993; Winslow and Smith, 2013; Beasley *et al.*, 2015), nursing student (Taft *et al.*, 2004; Ligon *et al.*, 2012), family member (Savundranayagam, Dilley and Basting, 2011), paid facilitator or researcher (Rickard, 1998; Savundranayagam, Dilley and Basting, 2011; Winslow and Smith, 2013). The interviewee was generally to be in a hospice or palliative care setting (Lichter, Mooney and

Boyd, 1993; Winslow and Smith, 2013; Beasley *et al.*, 2015), nursing or retirement home (Taft *et al.*, 2004; Ligon *et al.*, 2012), or has a life-threatening illness such as dementia (Savundranayagam, Dilley and Basting, 2011), cancer (McCarthy, 2010) or AIDS (Rickard, 1998).

In the model referred to by Lichter, Mooney and Boyd (1993), the volunteer biographer visits the patient over several sessions, building up a rapport "with discussion gradually turning to the patient's life story" (p.136) and "becomes a trusted friend…whose company they enjoy" (p.137). The process enables interviewees to "tie up some loose ends in their lives and may lead to concluding some parts of 'unfinished business'"(p.136). In this study no issues were encountered with traumatic or upsetting memories, with the interviewee deciding what they chose to talk about and omit (p.137). Other studies (Winslow and Smith, 2013; Beasley *et al.*, 2015) examine an equivalent service model to Lichter, Mooney and Boyd (1993), in which the OH interview is open-ended, allowing the participant to dictate what is said and omitted in the final version, although in the model adopted by Winslow and Smith (2013), the biography is not usually written but summarised for archiving. The study by Winslow and Smith (2013) does not contain interviews with interviewers but with interviewees, their family and HCPs, who all have positive experiences of the services. The successful establishment is viewed by the authors as a result of training volunteers in an understanding of the "practical, emotional and ethical complexities of the work" (p.4). They stress a need for "more research on the ethical challenges in OH recording and to learn what interviews tell us about patient experience" (p.4).

Beasley *et al.* (2015) focused on the experiences of the volunteer biographer, finding the volunteer interviewer had a mutually beneficial relationship with the interviewee. However, challenges emerged with family members (p.1417):

> While some were appreciative, others imposed time limits, became overly reliant on the volunteers and were sometimes offended, hurt, and angered by what was included in the final biography.

As a result, the authors suggested a "need for ongoing support for volunteers to assist them in handling the challenges of volunteering in a palliative care setting" (p.1417). In the study by Savundranayagam, Dilley and Basting (2011), the interviewer was a family member or

facilitator using a question generator. The results reported that participants "shared topics that they had not thought about in years but were not new" (p.420), and felt comfortable regardless of who the interviewer was (p.420). The family members were also comfortable being interviewers. Results showed that "over half learnt something new about the storyteller during the interview" and "approx. one third of family members said they have more meaningful conversations with storytellers as a result of the StoryCorps experience." (p.420). The question generator utilised "theme generated opportunities for reflection and meaningful conversations" (p.421). The study found that the service offered a means for reaffirming personhood in the storyteller and their relationships with family members (p.423).

The use of nursing students as interviewers in studies (Taft *et al.*, 2004; Ligon *et al.*, 2012) could "foster intergenerational interaction" (Ligon *et al.*, 2012, p.147) and spark an interest in history among students (Taft *et al.*, 2004, p.42). Ligon *et al.* (2012) suggested that exploring the inter-generational relationship between interviewee and interviewer could "…influence changes in older adults' life satisfaction and student changes in attitudes toward older adults and the aging process" (p.156). The study viewed the benefits of the OH process as a way to "understand history from individual perspectives" (p.157), "giving voice to those who might otherwise be unheard and… a way to document information that might otherwise be lost" (p.156). OH was seen as having benefits for the "narrator, listeners and society" (p.156). The study by Taft *et al.* (2004) found that using OH methods for reminiscence relating to World War 2 could create a therapeutic environment, and the use of group discussion was utilised to generate conversation among residents (p.43). The student interviewers validated the storyteller's contributions by listening to, and learning from, their stories (p.39). The study suggested implications for nurses working in long-term care, where OH can be used as "a supportive strategy that builds relationships" (p.42).

The relationships between interviewee and HCP, often indirectly as a result of the OH process, have also been studied. The study by Winslow and Smith (2013) found that "health care professionals appreciate it and see it as beneficial as an important complement to clinical care." (p.4). Lichter, Mooney and Boyd (1993) draw on case studies to demonstrate how OH lifted patients' mood and in turn their interactions with HCPs (p.135), whilst noting creating a written biography was a time-consuming process (p.137).

None of the studies identified explore the impact of OH in wider social circles and community. Winslow and Smith (2013) include interviews with bereavement volunteers and bereaved relatives to ascertain their thoughts about the services and to investigate how the recording is listened to in bereavement. These opportunities provide an insight to further relationships which can be developed after the interview and even after the interviewee has died.

### 3.2.4 Legacy

The final section focuses on findings relating to legacy and what is kept, by whom, its reuse and how those involved feel about it. Some studies in the review research legacy in-depth (Rickard, 1998; Savundranayagam, Dilley and Basting, 2011; Winslow and Smith, 2013), some not at all (Ligon *et al.*, 2012; Beasley *et al.*, 2015). Although this section predominantly focuses on the legacy product from the OH process, there is also brief consideration for the legacy of memories of the OH experience over time by Savundragayam *et al.* (2011). Here, people were interviewed at different intervals to see how the interview had impacted on the relationships between participants and family interviewers. They questioned whether there was evidence that the impact was sustained over time (p.417).

Several studies enabled participants to keep an audio recording of the interview (Lichter, Mooney and Boyd, 1993; Taft *et al.*, 2004; Savundranayagam, Dilley and Basting, 2011; Winslow and Smith, 2013), or a written biography with photographs based on the recording (Lichter, Mooney and Boyd, 1993; Savundranayagam, Dilley and Basting, 2011; Beasley *et al.*, 2015). The legacy product in all these studies is denoted as high quality, with audio recordings being produced at broadcast quality (Savundranayagam, Dilley and Basting, 2011, p.418; Winslow and Smith, 2013, p.8), and the written biography being bound with mounted photographs and artwork (Lichter, Mooney and Boyd, 1993, p.135) or additional historical notes (Taft *et al.*, 2004, p.40). Lichter, Mooney and Boyd (1993) found that a written biography, rather than a voice recording, was more accessible and useful for patients, although hearing the voice recording in bereavement also received positive feedback (p.136). The biography was found to give participants "considerate satisfaction…[who]…read and reread them with apparent fascination" (p.136). They often requested several copies for family and friends (p.136), to become a "tangible memorial of the deceased" (p.137).

Winslow and Smith (2013) found that some study participants chose to record messages for family (p.4). Being able to hear the participant's voice was found to be the most important attribute for family and friends in bereavement (p.4). Although no bereaved relatives were interviewed, Lichter, Mooney and Boyd (1993) suggest the biography is discussed by family in bereavement and "talking about the person who has died may be a healing experience." (p.136). The biography can provide insights into the life of the participant and "may enable them to understand past behaviour and…empathise better with the dying person" (p.136). Savundranayagam, Dilley and Basting (2011) recognise the recording can "offer a chance for family members to learn even more about and better understand the storyteller" (p.425). The interviewee with memory loss, and the family member interviewer, valued "the importance of leaving a legacy for future generations…children and grandchildren" (p.425). Approximately 82% of family members suggested they planned to listen to the interview, and several had already listened prior to being interviewed (p.420). Extracts were read (Lichter, Mooney and Boyd, 1993, p.136) and played (Winslow and Smith, 2013, p.10) at the funeral of the deceased.

It is not mentioned by Taft *et al.* (2004) whether oral histories recordings are archived or reused beyond being handed to participants (p.40), however themes in the article correlate with participants' interview topics about World War 2 such as patriotism, self-sufficiency and loss (p.41-42) and thus the study is a wider reused legacy document. The autonomous nature of personal oral histories with World War II as a focus for reminiscence, "provide a rich counterpoint to historical accounts of the war. The combination of historical and personal accounts makes history come alive." (p.42). Whereas in the study by Lichter, Mooney and Boyd (1993), the written biography and tape are handed only to the participant and remain confidential (p.135), two studies have service models in which the participant can give permission for their OH recording to be archived, either in the Library of Congress (Savundranayagam, Dilley and Basting, 2011) or in the University of Sheffield Special Collections Archive (Winslow and Smith, 2013). Both models rely on written consent being signed by participants for future use. Winslow and Smith (2013) found oral histories could be reused as social histories for non-commercial purposes and "interviewees and their families find this an acceptable and satisfactory outcome." (p.4). The StoryCorps model

offered opportunities to contribute to both family and national history (Savundranayagam, Dilley and Basting, 2011, p.425).

In investigating traumatic and taboo topics in interviews, Rickard (1998, p.35) questioned:

> …the difficult decisions facing archivists in accepting and holding sensitive data and the ethical behaviour of the users of archival sources where interviews are made available to a wider public.

One study participant remarked she would have liked to have understood more about the access restrictions of her OH (p.37). Rickard comments on the post-modern increase in "fragmented or contradictory experiences as part of a life story account" with the public realm as "a repository for an increasing range and depth of personal material" (p.40). She suggested that owning an OH recording and listening to it "can be a disarming experience" (p.44), and recommended the interviewer listen to the interview with the interviewee afterwards. For Winslow and Smith (2013), issues with surfacing distressing information were partly addressed by encouraging interviewees to listen to the recording immediately after the interview and allowing them to suggest edits. The interviewer thoroughly explained the archiving process and consent form before and after (p.9).

## 3.3 Discussion

Motivations in OHinPSC include interviewees' and interviewers' personal choices for involvement, and organisational and research reasons for recruitment and service development. The power dynamic in how OH participants are recruited and whether they choose to be involved (often as part a service), or are chosen (often in research exercises), varies accordingly and can empower or appropriate the interviewee in the process (Bornat and Walmsley, 2008). An open-ended process in which the interviewee was encouraged to decide on the interview content was chosen by some models (Lichter, Mooney and Boyd, 1993; Winslow and Smith, 2013), adopting the principles of shared authority (Frisch, 1990) (subsequently this became known as *sharing authority* and that is the term I will use where appropriate later in this thesis). Other models adopted a more rigid approach to questioning and content creation (Taft *et al.*, 2004; Savundranayagam, Dilley and Basting, 2011). The interviewees' and interviewers' motives for participating were based mainly on anecdotal evidence and warrant further research.

The outcome of an intervention being therapeutic is less of importance in OH as in reminiscence and life review (Bornat, 2001, p.223). OH is primarily preserved historical information (Yow, 1994), and arguably any therapeutic benefits are secondary. It is assumed that OH can be psychologically beneficial (Winslow, Noble and Hitchlock, 2009, p.129) but there is no strong evidence (McCarthy, 2010, p.160).

Finding meaning or a therapeutic outcome in OHinPSC is perhaps reliant on the narrative formation and constructed identity, founded through the interrelationships between interviewer and interviewee, their family/carers and HCPs**.**

The role of interviewer could be professional, voluntary or a family/carer. Training and supporting volunteer interviewers in interviewing skills and ethics was viewed as essential (Lichter, Mooney and Boyd, 1993; Planalp *et al.*, 2011; Winslow and Smith, 2013; Beasley *et al.*, 2015). Relationships between interviewer and interviewee could be relationship building and intergenerational (Taft *et al.*, 2004; Ligon *et al.*, 2012), but problematic between interviewer and family/carers (Beasley *et al.*, 2015). The interviewer was in a unique position of having the potential time to spend with the interviewee and support HCPs to improve interactions with patients (Winslow and Smith, 2013), and better understand the person behind the patient (Clarke*,* Hanson and Ross, 2003).

How legacy was presented as either audio or writing, and to whom it is given – participant, family or researcher/archive – raises questions of ownership, how, and when the recording is listened to, and for what purpose. Listening back to recordings has received positive feedback from the bereaved (Winslow and Smith, 2013), but was not without ethical dilemmas. Distressing or uncomplimentary information could surface, questions remain unanswered, and histories omitted (Stewart, 2013; Stewart and Brown, 2017). There was also the risk of people not intended by the participant being able to access an archive version, or stumble upon the recording through family (Rickard, 1998, p.44). Archiving of oral histories with sensitive personal data presented ethical concerns including achieving informed consent and crediting the authors of the material properly, avoiding reuse in an improper or disrespectful way, understanding how the OH was analysed (Bornat, 2013, p.312), and its temporal meaning in interpretation (Rickard, 1998, p.45).

There are opportunities and challenges for OHinPSC in the digital age. OHinPSC archives and services have increasing parallels with online legacy websites, blogs and social media such as Facebook, in which users contribute to a corporate, personal, but shared archive of life stories (Walter *et al.*, 2012). Adopting Creative Commons licensing could be a way for acquiring more transparent informed consent (Dougherty and Simpson, 2012).

The narrative review presents a development in qualitative research methods and the use of increasingly involved methods for collecting data. Whereas earlier studies relied on anecdotal and case studies (Lichter, Mooney and Boyd, 1993; Taft *et al.*, 2004), recent research has applied more rigorous methods, such as before and after studies (Ligon *et al.*, 2012), semi-structured interviewing (Winslow and Smith, 2013; Beasley *et al.*, 2015), and ethnographical and grounded theory approaches (Savundranayagam, Dilley and Basting, 2011). These enabled in-depth collection and analysis of qualitative data, and the ability to understand participants' experience of meaning as it happened and to adapt accordingly.

There is a dearth of evidence and material relating to OHinPSC and a need for further research within several areas as identified within the discussion. The emergence of OH initiatives in the UK, USA, Australia and New Zealand suggests a need for further understanding of the OHinPSC experience. What does, and can, OHinPSC entail? How do those involved benefit, and what are the ethical concerns which require further thought? The impact of having a voice recording of a loved one in bereavement has thus far received little research, and there is scant literature which examines the content of OH interviews in palliative and supportive care.

The literature review and my own experience of coordinating a service identifies with sensitizing concepts in:

- Meaning for participants before, during and after the interview: motivations, experience and legacy.
- How motivations and experiences interact with experience of health and social care and relationships with others.
- How legacy is produced, stored and reused.

## 4. Methodology

This chapter explains the chosen methodology based on the sensitizing concepts which arose from the literature review, my previous experience coordinating an OH service in palliative and supportive care, and as a Research Associate on previous research which contributed to an unpublished study report for Macmillan Cancer Support: 'How does providing an oral history at the end-of-life influence well-being of the individual and the bereaved?' (Winslow and Smith, 2013). I start the chapter by outlining the study questions. To explain the basis for my research design I share my theoretical perspective, and my ontological and epistemological stance. From this positioning I explain my rationale for opting for a qualitative method and using the CGT approach. More detail is given about two of the main components of CGT: constant comparative analysis and reflexivity.

### 4.1 Aims/questions
Drawing on sensitizing concepts realised as result of my review and my experience in the field, I aim to develop further understanding of OHINPSC and question:

- How is OH experienced by participants, families and volunteers in the context of palliative and supportive care?

With the sub-questions:

- What are the implications of OHinPSC for HCPs and health and social care?
- How is dialogical content created within an OH interview in palliative and supportive care and then reused?

### 4.2 Theoretical perspective
For this study I adopt theoretical perspectives based on the ontological question of "what is the form and nature of reality and…what is there that can be known about it?" (Guba *et al.*, 1994, p.108) and the epistemological question interested in "the relationship between the knower… and what can be known" (p.108). I then proceed to outline how the ontological and epistemological positions for the study are interrelated with the chosen CGT approach, and I describe how each theoretical position is suitable for understanding OHinPSC.

## 4.3 Ontology

The ontological perspective questions "what is the nature of the phenomena, or entities, or social world, that I wish to investigate?" (Mason, 2018, p.4). Understanding OHinPSC is foremost a social reality rather than as a phenomenon or entity. It exists based on the social interactions of people with subjective views and the meaning they give to them. The ontological viewpoint for this study is relativist and interpretative, centred on belief that there exist multiple realities and that knowledge is constructed, fluid and subjective (Charmaz, 2014). The interpretative stance "rejects a unilateral focus on an objective social reality in favour of an emphasis on empathetic understanding of social phenomena from the actor or participant's point of view" (Rodwell, 1998, p.15). Interpretation is "capable of producing specific explanations but not of identifying cause" (p.16), and the purpose of its inquiry "showcases the meaning people give to their own situations" (p.17). This is opposed to the positivist approach, traditionally favoured by quantitative, and some qualitative researchers (Glaser, 1967), which seeks objective 'truths'. This viewpoint "assumes that any social phenomenon has real existence, external to the individual; that knowledge is hard and factual; and that humans are shaped by their environment" (Rodwell, 1998, p.14).

In my work coordinating an OH service in palliative care the relativist viewpoint resonated with me, in that different people would give and create their own meanings to the opportunity to record or support someone in recording an OHinPSC. How the OHinPSC service would play out for service participants was dependent on who was interviewing them and what prior conversations they had with HCPs and family about the interview. Also, they were affected by how they felt in the interview moment as a snapshot in time. For service participants who recorded several interviews, the meaning they gave to experiences would change in a temporal manner dependent on their mood and memory that day. This was also the case for family members listening back to interviews, how they heard it varied, especially in bereavement. For some it might be too upsetting, whereas others found it comforting. This experience of OHinPSC assisted in informing my ontological position for the study.

## 4.4 Epistemology

The epistemological position questions "what might represent knowledge or evidence of the entities or social world that I wish to investigate?" (Mason, 2018, p.7). It is the way in which

knowledge is formed and demonstrable. The epistemological perspective coincides with the ontological. If the ontological viewpoint is based on relativism and subjective multiple realities, the epistemological position follows a social constructivist approach, recognising "that every person determines his or her own meanings and constructions of events… all meanings must be encountered as potentially possible and valid" (p.6). This approach follows OH methods as there is a sense of open interpretation for participants actively involved in deciding the research outcomes, and recognition of subjective experience as a powerful medium from which a sense of meaning can be found. Social Constructivism relies "as much as possible on the participants' views of the situation" (Creswell, 2013, p.24-25). These views are not individual but are formed with others.

In this sense, all qualitative interviewing is working towards a socially constructed outcome. Using the social constructivist approach considers the different cultural and social backgrounds of participants when interpreting the meaning they give to an experience, whilst recognising my own bias and meaning of experience as researcher. In turn, a social constructivist approach relies on me being reflexive and open to my own influence on the study, with understanding of the background and prior perceptions I bring to the research.

## 4.5 Sharing authority

The OH interview itself could be interpreted as a social construction in which both interviewer and participant interact to create meaning of the situation with an understood sharing of authority (Shopes, 2003; High, 2009). Whilst Frisch (1990) conceptualised the term 'shared authority' to suggest OH as a democratic process between researcher and participant, the term has since been elaborated on by Shopes (2003) who argues that 'sharing authority' is more applicable to collaborating in OH. The autonomy of the interviewee is sought, but it is recognised that it is not fully possible, or even always desirable for the researcher. The interviewer and narrator have defined roles which do not always serve to work in tandem, "while both parties may need to cede some interpretive authority, neither party needs to relinquish it altogether" (p.108). The possibilities of sharing authority are further explored by High (2009) in which advocacy becomes central in an "ongoing process of dialogue and sharing" (p.13), which "requires the cultivation of trust, the development of collaborative relationships, and shared decision making" (p.13). Following this call to action, Calabria and Bailey (2023) discuss making the sharing of

authority more social action orientated by aligning and comparing participatory action research methodology with recording oral histories in mental health. They argue for "…a shift in academic priorities to fit with community agendas, which must guide participation and frame the research" (p.679).

## 4.6 Scientific justification for qualitative research

Following on from the majority of included review literature being qualitative, I considered the merits and issues of qualitative as opposed to quantitative research, with regards to the study. Whereas quantitative research focuses on value and measuring variable results, qualitative research is more concerned with inter-subjectivity and meaning in experience, "the socially constructed nature of reality, the intimate relationship between the researcher and what is studied, and the situational constraints that shape inquiry" (Denzin and Lincoln, 2000, p.8). The open-ended nature of qualitative research allows for the complexities of OH to be investigated and for me "to connect with (the) research participants and to see the world from their viewpoints" (Strauss and Corbin, 2015, p.5).

A quantitative approach could have been useful for identifying data such as interview take up, time length, hours committed (Savundranayagam, Dilley and Basting, 2011), or measuring life satisfaction levels (Ligon *et al.*, 2012). However, qualitative research was well suited to understanding OH as an approach, able to identify intricacies in meanings and give broader parameters of experience. OH, a form of qualitative research (Shopes, 2011), centres on orality of subjective experience and empowerment of voice. Conducting qualitative research allowed these attributes to remain intact and relevant.

Whereas qualitative research could follow a positivist and post-positivist theoretical paradigm, this study was informed by concepts of social constructivism. This enabled multiple realities to be studied rather than specific cases and allowed for shared meaning and reflexivity in the research process (Rodwell, 1998). The constructivist outcome could be in the form of "interpretive case studies" (Denzin and Lincoln, 2000, p.22), constructed by both researcher and participant throughout the process.

## 4.7 Why grounded theory?

The strategy for collecting and analysing material relies on this dynamism of participant involvement. Consideration was given to an ethnographical approach, interested in cultural

meaning and behaviour in representation (Tedlock, 2000). However, ethnography is "studying a group that shares the same culture" (Creswell, 2013, p.104), which was less apt for researching OHinPSC in which a shared culture is not always apparent. Similarly, phenomenology involves studying the shared experience of several people (Creswell, 2013, p.104), however a unified experience was not visible to the researcher in OHinPSC. A grounded theory approach is concerned with "studying a process…or an interaction involving many people" (Creswell, 2013, p.104). Grounded theory generates theory from experiences and can address the multiple psychological and social processes of OHinPSC such as motivations, narrative, inter-relationships and legacy. It is interested in the multiple perspectives of people and the meaning they give to process rather than seeking to understand cultural experience or phenomena.

Due to the lack of academic OHinSPC knowledge and the breadth of experience for all involved in the process, the grounded theory method presented a suitable way to research experience and gather rich data (Glaser, 1967; Charmaz, 2014). Grounded theory is an advantageous way to conduct research within health and social care environments as it explores interpersonal relationships and behaviour. It is useful in creating concepts with scant prior knowledge of a subject (McCann and Clark, 2003, p.7), and is based on the ideas of symbolic interactionism, with language key to understanding meaning, which constructs social reality (Garfinkel, 1984). Grounded theory is unique as a qualitative method in that "the concepts out of which the theory is constructed are derived from data collected during the research process and not chosen *prior* to beginning the research." (Strauss and Corbin, 2015, p.7). Further to this, the analysis of data is ongoing throughout the research and informs later data collection. These features enable the OH experience to be better understood through the different stages of recruitment, the interview and the final outcome of the recording and how it is received. This enables the research interviewees' temporality of the experience to be studied.

## 4.8 Rationale for constructivist grounded theory

Constructivist grounded theory (Charmaz, 2014) was chosen due to the participatory nature and fluidity of social constructivism for open identification of social and psychological processes, and grounded theory as a systematic and comprehensive procedure for data collection and analysis. This allowed for creativity in data collection and transition in analysis

through emerging theories. These methods enabled the subjective experience and multiple realities encountered in the OH process to be recognised and conceptualised. In constructivist research, the entry point is a natural setting in which the topic is experienced, to allow for the "context embedded nature of constructed realities" (Rodwell, 1998, p.55). Researching within an OH service in a hospice fits this setting. Constructivist research entry requires the researcher has prior knowledge of the topic, to be able to know the setting and create preliminary questions to start data collection. I have extensive experience of OHinPSC and have performed a literature review to develop understanding of the topic and research questions.

Due to the participatory process of social constructivism the research follows an emergent design (p.56) in that it is inductive and relies on what happens in continuum, shaped by the participants as much as the researcher. "Problem-determined boundaries" (p.56), are those determined by participants and inquirer in narrowing or expanding the construction of the question and can shape the scope of enquiry and determine when theoretical saturation is reached, and no more new data is unearthed on a topic.

## 4.9 Constant comparative method

Constructivist grounded theory as an approach for collection and analysis of data involves transcribing and constant comparative coding of interviews to find key concepts which can contribute to emerging theories (Charmaz, 2014). The constant comparative method allows for in-depth analysis and the opportunity to build on findings as they arise. The research questions can be thoroughly analysed with new categories developed which can enlighten the topic and assist in constructing innovative theories (p.18). Interviews are recorded and transcribed, and initial analysis involves line-by-line coding and coding with gerunds to determine participants actions and processes (p.126). Comparisons are then drawn between the coding and journal entries to highlight the difference and common attributes in relation to the research questions. Initial coding informs more focused coding as immersion in the larger data set is possible and coding becomes more conceptual based on emergent theories (p.138). The analytical process is supported by writing memos about key analytical changes and happenings as I move through the process.

In later interviews the interviewee can extrapolate meanings and further discuss their understanding of the OH experience with me. Recruitment for the study ceases either within the time limit, or after a saturation point has been reached in establishing emerging concepts when findings become repetitive. Using the grounded theory approach, all study interviewees have the opportunity in discussion with me to analyse their own thoughts in earlier interviews and to expand on their experience in later interviews. This informs theoretical sampling to further develop categories and more analytical memo writing, which in turn contributes to my theory (p.192-193).

## 4.10 Reflexivity

A key component of CGT is an awareness of reflexivity and an understanding of how it can impact and be entwined within the research. As noted by Rodwell (1998): "Reflexivity and feedback from the environment, combined with other data sources, determine the emerging direction of constructivist activities." (p.7). As already discussed, my career in OHinPSC predates this research and I have preconceptions and my own ideas about OHinPSC based on practice in the field, previous research, conferences, and literature I have read. Further to this I have my own biases, both conscious and unconscious, which I bring to the research including class, cultural and political beliefs, and gender. Whilst I attempt to remain impartial, both in my interviewing and analysis, it is inevitable that some of these biases and preconceived ideas about OHinPSC will have come to the fore. Further to this, I do not have a terminal illness or care for/am currently close to someone that does, and I have never worked as a nurse, so my only shared experience is working on an OHinPSC service and seeing it from one angle as a volunteer/Coordinator. Having previous experience of OHinPSC, is, of course, also a positive, in that I can bring my own knowledge and positionality to the research, but being able to be reflexive throughout the research process enables some transparency on my influence. As suggested by Rodwell (1998, p.31), a reflexive journal was maintained throughout the interviewing and analysis stages of the research, and I discuss this in more detail in my methods (Chapter 6).

In both my career in palliative and supportive care and this research I was aware of the emotional impact on myself and the possibility of compassionate fatigue which warrants attention. Whilst I may have encountered symptoms of this when conducting multiple oral history interviews during my career, I do not feel this occurred during the research, perhaps

because the professional boundaries and time limits were more defined as a researcher, and I was not as closely entwined in the participants life as when recording a life story interview. However, this is a key consideration when undertaking sensitive research with people in a healthcare environment and as noted in the findings of this thesis and my reflexive diary, I was undoubtedly emotionally moved by the interviews and contact with several of the research interviewees.

## 4.11 Chapter summary

In this chapter I have outlined my methodology, discussing adopting a relativist and interpretive ontological position to coincide with an epistemological stance of using a social constructivist approach. I have scientifically justified my reasons for using qualitative research and my rationale for using CGT to evaluate the experience of OHinPSC. In the next chapter I address my research design and how I implement my research using CGT.

## 5.  Research design

This is a qualitative study utilising a CGT approach. To comprehensively understand the OH experience for participants it is necessary to adopt a qualitative approach to be able to explore meaning. The OHinPSC experience for participants encounters different stages before, during, and after the OH interview. Grounded theory enables all stages to be explored, and thus records the temporal experience of participants. Social CGT presents a qualitative approach which encourages participants to be involved in the analysis and to build on theories over multiple interviews.

This study consists of the following methods:

1) A narrative literature review of OHinPSC

2) 1-3 semi-structured qualitative interviews with participants, family and friends, volunteers and HCPs involved in the OH service

3) Qualitative grounded theory analysis beginning after the first interview and involving interviewees discussing and constructing emerging concepts in later interviews.

The literature review has highlighted a lack of relevant academic research but similar services operating in the UK, USA, Australia and New Zealand. This study proposes to develop understanding of OHinPSC and establish awareness of the field.

### 5.1 Data sampling
Grounded theory suggests iterative sampling in which preliminary data collection and analysis occur, which shapes future data collection. This could involve follow-up interviews based on preliminary categories to elucidate further findings and develop more in-depth analysis and coding. I followed this procedure with both theoretical and purposeful sampling. Theoretical sampling is integral to the use of grounded theory (Glaser, 1967; Charmaz, 2014). It enables the possibility to develop further categories and "illuminate and define the boundaries and relevance of categories" (Charmaz, 2014, p.189). There is critical discussion of the crossover and distinctions of purposeful, selective and theoretical sampling in nursing (Coyne, 1997). The sampling was selectively purposeful in that it involved identifying and sourcing rich information for the purpose of addressing research questions

(p.624). This meant determining the appropriate people, timing, setting conducive to understanding OHinPSC within the remit of my study.

To achieve understanding of the range of data from "multiple realities" (Rodwell, 1998, p.56), of participants and researcher, "purposive sampling" (p.56), avoids generalisation and randomisation to focus on selective cases which are deemed to be "information rich" (Patton, 1990, p.169). Several types of purposeful sampling are available such as "extreme", "maximum variation", "typical", "theory –based", "opportunistic" and "politically important cases" (p.182-183).

The strategy for determining the sampling of people to interview was selective in them having direct or indirect experience of the OH process. This meant:

- participants or potential participants
- family members or friends of the participant aware of the recording
- HCPs involved in recruitment or communication about the OH process
- volunteers and staff working on the service

Inclusion in the study also relied on the participant being over the age of 18 and having the physical and mental capacity to participate and give consent. The decision on what constituted capacity is detailed later in Ethical implications (5.9).

Further theoretical sampling was led by "purposeful selection of samples to inform the emerging theory in the study" (Coyne, 1997, p.626). Where possible, two follow-up interviews were conducted to facilitate an aspect of co-construction between the interviewee and researcher, and to build on emerging theories and categories found in analysis. Emergent theories found through constant comparative analysis and coding data informed new sampling until a saturation point was reached.

The second and third interviews were also an opportunity to share preliminary findings with interviewees, receive feedback on their contribution and check they were happy with the process. To allow time for analysis of data I tried to leave 6-8 weeks between interviews, although due to participants being at the end-of-life and having other prior commitments this was not always possible. To allow for this, I conducted follow-up interviews sooner or

relied on fewer interviews. In these instances, I also relied on volunteers' and HCPs' reflections. A triadic approach was adopted in which, for each participant, their referring HCP, interviewing volunteer, and, where possible, relevant family and friends, were interviewed to aim to achieve a full picture of each case study.

## 5.2 Data collection

The data collected for analysis was open-ended and included "interviewing, observing, recording, and analysis of non-verbal communication and artefacts, depending upon what seems most appropriate as the enquiry emerges" (Rodwell, 1998, p.57). The main collection method was conducting face-to-face semi-structured interviews. The use of "intensive interviewing" (Charmaz, 2006, p.25), is the suggested method for collecting data in CGT. Charmaz suggests this type of interviewing "fosters eliciting each participant's interpretation of his or her experience" (p.25). This enables the interviewee to talk about the topics of interest in a non-judgemental and exploratory process (p.26). Using this sensibility, I opted to conduct one-to-one face-to-face interviews rather than phone, computer mediated communication or discussion groups (Opdenakker, 2006; Creswell, 2013). Face-to-face interviews allowed me to also witness any non-verbal communication (Creswell, 2013, p.164). The decision to have face-to-face rather than discussion group interviews ensured that certain interviewees could not dominate the conversation (p.164). Also due to the sensitive nature of the exploration, one-to-one interviews allowed the interviewee to share thoughts anonymously. Conducting one-to-one face-to-face audio recorded interviews drew on my extensive experience of conducting OH interviews and transcribing.

Data collection adhered to the process outlined by Rodwell (1998) which relies on knowledge both "tacit" and "propositional" (p.58). She suggests recording interviews with open guides for developing conversation, "some concepts and connections grow while others diminish.... the guide becomes more and more focused but is never rigidly applied." (p.124). The interviews were semi-structured with around 10 questions (DiCicco-Bloom and Crabtree, 2006, p.316) but open-ended to facilitate an empowering and participatory experience for the interviewee and to explore relevant topics informally but in further depth where relevant. Questions in later interviews related more to emerging theories and thus changed as the research developed. The preliminary research questions informed early

interviews and the conversational guide sheet (Appendix 8). The decision on how many interviews to conduct followed the suggestions of around 10-12 interviews (Charmaz, 2014, p.107) with each interviewee group.

In line with Rodwell (1998), ongoing journals were produced to track research progress and assist in meaning and theory construction. A reflexive journal (p.134) was maintained as a personal log of "underlying assumptions about the problem, the people, the context" (p.134). A methodological journal (p.136) was kept featuring the methods as they unravelled, such as research questions, sampling cases, categories and analytical decisions (p.136). Field notes (p.138) were produced and updated based on non-verbal and verbal data, such as observations and interview transcripts.

Prior to later interviews, as a separate data set, I also gained consent to listen to the OH recordings. Access was not an issue as oral histories for the service were archived and made available for research. The OH offered a rich source of data which had potential for understanding in the moment factors such as voice quality and orality, and interviewer/interviewee dynamic. The OH interview data was used to provide further context and as a source of prompt for specific questions. Field notes on the interviews informed my conversational guide sheet and methodological journal.

## 5.3 Data analysis

"The objective of grounded theory is to develop theory from the data which is encompassed in a core category and related categories and concepts." (McCann and Clark, 2003, p.8). The grounded theory approach "focuses on creating conceptual frameworks or theories through building inductive analysis from the data" (Charmaz, 2014, p.187). The method generates analytic rather than descriptive categories, better suited to researching subjective experience such as the OH process and the benefits and challenges for all involved. The method involves data analysis and creation of categories whilst still in the collection phase which can inform later data collection. The constant comparative method (Glaser, 1967) allows for in-depth analysis and the opportunity to build on findings as they arise. The research questions can be thoroughly analysed with new categories developed which can enlighten the topic and assist in constructing innovative theories. Grounded theory offers the opportunity to research the subject without being tied to a static methodology and

allows for data to influence the next steps in the methodology as an ongoing fluid process (Rodwell, 1998, p.59).

I adhered to the guidelines for coding with Charmaz (2014) as an authority. My initial coding involved "coding with gerunds" and "line-by-line coding" (p.121) of interview transcripts to determine participants actions and processes. I began initial analysis as soon as I had recorded and transcribed the first interviews. Initial codes were, whilst acknowledging a reflexive approach from my viewpoint, based in accordance with what the interviewee stated and described. Constant comparative methods (Glaser, 1967) were then used to draw comparisons between coding of transcripts and journal entries and highlight differences and common attributes in relation to my research questions. Invivo codes were also produced to specify "symbolic markers of participants' speech and meanings" (Charmaz, 2014, p.134). These codes could be:

- Terms everyone 'knows' that flag condensed but significant meanings
- A participant's innovative term that captures meanings or experience
- Insider shorthand terms reflecting a particular group's perspective
- Statements that crystalize participant's actions or concerns (p.134)

Examples of this in the context of the research were terms pertaining to legacy such as 'passed on' and 'leaving something behind' and to mortality with 'passed away' and 'not being forgotten'. This familiar terminology was common in the research interviews, with significant meaning central to the theme of continuation in the research. More metaphorical or symbolic terminology used by research interviewees, which captured the experience included 'when I'm gone' or 'bringing that person back'. These terms based on a locative perspective with the sense of a journey in the moment, whether it be when the participant dies or their voice is listened back to.

Initial coding informed more focused coding (p.138) as immersion in the larger data set was possible and coding became more conceptual based on emergent theories. This back-and-forth process dictated my final analysis and conceptual categories. The analytical process was supported by writing memos (p.162) about key analytical changes and happenings as I moved through the process.

*Figure 3: A table illustrating moving from coding to conceptual category*

| Quote | Line-by-line coding | Focused coding - Quirkos category (see Section 6.21) | Findings section | Theory |
|---|---|---|---|---|
| "I think there is something about I don't know if it's a biological drive we have to leave something" (Volunteer, Jenny, 1) | Leaving something behind, passing on | Continuation | Motives, Legacy | Autonomy in giving voice |
| "I suppose when I'm gone…there will be nothing left about me but I've got it on audio…I'm still going you know what I mean? I'm not – I haven't been forgotten." (Participant Jake, 1) | Dying/mortality, being remembered, remaining | Continuation, Voice, Reflection | Motives, Framing mortality, Legacy (giving) | Reflection in giving voice |
| "Because it's hearing someone's voice it's kind of I don't know it brings that person back a lot quicker…the majority of people have said that they found it comforting." (HCP Holly, 1) | Listening, remembering, remaining, comforting | Continuation, Voice, Memory, Familiarity | Motives, Experience, Legacy (listening back) | Reflection and dignity in giving voice |

## 5.4 Rigor

Standards in "trustworthiness and authenticity" (Rodwell, 1998, p.59), set the quality of the research. Trustworthiness is concerned with the final product whereas authenticity is central to the research process (p.59). The trustworthiness of the product was based on having standards in credibility, transferability, dependability and confirmability (Lincoln, 1985), which need to be addressed. The authenticity of the process involved demonstration of participant empowerment, with a sense of sharing authority (High, 2009; Calabria and Bailey, 2023) and an appreciation of constructions for developing "effective change" (Rodwell, 1998, p.59).

The criteria for reliability and validity of the study followed the guidelines of Charmaz (2014), who suggests ensuring the research has credibility through familiarity with the topic, originality, in that it offers new insights, resonance, in that it portrays the full experience, and usefulness in how the study contributes to practical use and knowledge (p.336-338).

The study also adhered to methods for rigour in grounded theory (Chiovitti and Piran, 2003), which outlines eight methods to further involve research interviewees in the process and recognise the researcher's perspective and scope of research:

(1) let participants guide the inquiry process

(2) check the theoretical construction generated against participants' meanings of the phenomenon

(3) use participants' actual words in the theory

(4) articulate the researcher's personal views and insights about the phenomenon explored

(5) specify the criteria built into the researcher's thinking

(6) specify how and why participants in the study were selected

(7) delineate the scope of the research

(8) describe how the literature relates to each category which emerged in the theory.

Whilst the models of evaluation mentioned above have been a guide for my own self-evaluation throughout the study, I return to this in the discussion (10.8) in which I detail my study with reference to the evaluation guidelines of Charmaz (2014, p.336-338).

## 5.5 Product

Data analysis informed generation of a substantive theory which gives "theoretical interpretation or explanation of a delimited problem" (Charmaz, 2014, p.344). This was presented in a case study report (Rodwell, 1998, p.60) which featured final findings, based on the participants co-construction of meaning, stemming from emerging theories. The hermeneutic circle informs the process of "meaning-making" (p.82) which dictates the results. The results were negotiated with participant ownership and consultation throughout to ensure their empowerment (p.60).

## 5.6 Conducting research with participants receiving palliative care

Whilst some argue the end-of-life is not a time for participation in research, there is evidence that involvement in end-of-life research is valued by participants (Gysels, Evans and Higginson, 2012) and they appreciate the opportunity to contribute to help others (Bloomer *et al.*, 2018). However, there are debatable ethical challenges in conducting research with people receiving palliative care. This research was guided by recent research and subsequent guidance on the support of patients, families and researchers in undertaking fieldwork with palliative patients (Sivell *et al.*, 2015).

There is the increased possibility of people not having the physical or cognitive capability to take part and give informed consent. People may also be depressed, upset or feel vulnerable in a hospice setting. These issues required a sensitive, thoughtful and flexible approach from me as researcher. I have extensive experience of conducting research interviews with people receiving palliative and supportive care and was supported via the opportunity to receive ongoing debriefing and supervision. I received monthly academic supervision, with the opportunity to receive additional supervision during the fieldwork stages of the research. Specific safeguards for people receiving palliative care were adhered to throughout the study, from recruitment to archiving data. Participants had to be able to read and write in English to give informed consent and would be excluded if an HCP had doubts about their physical or psychological ability to take part. A recruitment process (detailed below), in liaison with HCPs, families and volunteers, provided the basis for inclusion of participants. Once the participant was recruited, a consent form (Appendix 11) was signed before each interview to ensure ongoing informed consent throughout the study. The information sheet (Appendix 13-15) stated participants were free to withdraw at any time and that taking part was voluntary and would not affect their healthcare. They could choose to have their data terminated without giving a reason, and this was reiterated verbally before each interview. Due to the possibility of three interviews over a longer time-period, the physical and psychological ability of patients was reviewed by me with HCPs prior to later interviews to check ongoing capabilities.

Recording an OH has the possibility of invoking distressing memories and feelings for the interviewee (Rickard, 1998), and this could potentially happen within a qualitative research interview about the OH experience. The information sheet outlined this potential risk for

interviewees and noted in the event of a participant becoming upset or distressed they would be offered support from the hospice counselling team or Social Worker. Safeguards also needed to be recognised in terms of the credentials of myself as researcher and having an appropriate setting for the interviews (Sivell *et al.*, 2015). I have over 15 years' experience of recording and archiving OH interviews and gaining informed consent in a hospice setting and had an enhanced DBS check prior to starting the study. Interviews for the study were conducted at a place chosen by the interviewee, such as their hospice room, the hospice OH room, or their own home. I adhered to the University of Sheffield Health and Safety lone worker guidelines and checklist (2023) when visiting homes and always left contact details with a supervisor for both me and the address I was visiting. I also detailed the interview times and contacted the supervisor once the interview was completed.

## 5.7 Informed consent

As already mentioned, informed consent is a pertinent issue when conducting research with older or vulnerable people, particularly with those who may have diminished cognitive capabilities (University of Sheffield, 2008). Being able to maintain the autonomy of the participant whilst ensuring best practice in research and following views of HCPs and family and carers can create conflicts of interest (University of Sheffield, 2008). As a result, there is a need to endeavour to research best practice whilst also gaining the cooperation and trust of all involved. There were particular questions to be asked about gaining informed consent from those with early stage or moderate dementia and there are arguments as to whether this is viable (Warner *et al.*, 2008). Although there were no participants in the study with dementia, I was prepared to draw on my extensive experience of working in OHinPSC and adopt a reflexive approach to determining whether participants were able to give informed consent. I would only recruit people with the capacity to consent. Capacity would be assumed even if people had a diagnosis of dementia. Drawing on my experience, if there were any doubts about capacity with reference to the *Mental Capacity Act 2005,* and whether a person with a mental impairment was able to make specific decisions at the time or at a later date, I would liaise with relevant HCPs for advice and assessment. If a person was assessed as not having capacity, then they would not be recruited. If someone was deemed to have lost capacity in a follow-up interview, they would be withdrawn, but, with permission, data gathered up to that point may be used.

## 5.8 Research with participants in bereavement

Although this did not happen due to a lack of recruiting family and friends, plans were in place for if an interviewee became bereaved during the interview process: they would only be interviewed again if they expressed a wish to continue, otherwise I would wait a minimum of four months before contacting them as recommended in a national UK survey of bereaved people (VOICES, 2015). I have extensive experience of liaising with and gaining feedback from bereaved family of OH participants, both informally, and for research purposes.

## 5.9 Ethical implications

This study involved interviewing vulnerable adults including older people, classed as aged over 60 (University of Sheffield, 2008), people in health and social care, and potentially their family, friends and carers. Vulnerable people are those classed as having "care and support needs" (NHS, 2017, p.4). In reference to this as a researcher with unsupervised contact with vulnerable people I undertook an enhanced DBS check. For some vulnerable people asking questions about their life context may invoke painful memories or distress (University of Sheffield, 2008) to counter this I ensured there was emotional support available from the hospice Social Worker or counselling team. Research on the risks of upsetting patients/carers when research interviewing in a palliative care environment (Gysels, Shipman and Higginson, 2008) found researchers should act with caution in asking questions about the patient or carers future, and care should be taken when asking for signed consent: "being physically unable to sign was experienced as upsetting." (p.1). As referenced at the start of Chapter 6, my research required and achieved a favourable opinion from the NHS Social Care Research Ethics Committee to proceed.

## 5.10 Potential burden on participants

To ensure that potential participants were recruited in their own time, a step-by-step recruitment process was followed (see Recruitment, 6.3) in which they received the information sheet from a third party (either the Service User Coordinator, a volunteer or HCP). Participants would only be recruited once they had read the information sheet and had agreed for me to contact them directly. On average, interviews lasted 30-45 minutes each, if the interviewee wished to take a break due to tiredness it could be resumed at a later date. All interviews were transcribed by me, and the key topics were discussed with

the participant in later interviews. Multiple interviews could be a time burden for research interviewees, especially participants and HCPs. The design of the study was not rigid to always having three interviews with each interviewee, although it was desired when possible. I have extensive experience of qualitative interviewing with palliative care patients and liaising with volunteers, families and HCPs in a hospice setting. A flexible approach to interview schedules and an awareness of participant fatigue was adhered to throughout the study.

## 5.11 Confidentiality

I followed ethical guidelines in how I recruited and involved interviewees in the research and all interviews were kept confidential. The information sheet (Appendix 13-15) stressed they were able to withdraw from the interview process at any time and could choose not to answer questions which they found upsetting or awkward. Building on the OH sensibility, they could also have the option to speak for as long as they wanted during the interview and to stipulate what was included in the final interview by way of the consent form (Appendix 11). I utilised my knowledge as an experienced oral historian in palliative and supportive care to recognise the sensitivities involved and try to ensure interviewees found it a valuable and considerate experience. Where necessary I would liaise closely with HCPs and volunteers to ensure interviewees were treated with respect, and that taking part in the study did not have a negative impact on their care and time at the hospice. It was envisaged that bereaved relatives of OH participants could also be interviewed, although this did not occur. This would only have been with those who felt ready for the experience. Although this may often not be for months after a death, research suggests bereaved relatives may prefer to be interviewed in the first few weeks of bereavement (Bentley and O'Connor, 2015).

## 5.12 Conflicts of interest

I have extensive experience of OHinPSC, having coordinated an OH project in palliative and supportive care from 2009-2017. During this period, over 280 project interviews were recorded with patients. The academic supervisors also have experience of OH and life story work in palliative and supportive care. Dr Michelle Winslow is the lead of the OHinPSC Services project, and oversees several other OHinPSC projects in the UK. Dr Jane McKeown has worked extensively in using life story work with people with dementia. The hospice site

for the research provided an OH service which the researcher was not directly involved in, so there were fewer issues of over-familiarity.

## 5.13 Conceptual and methodological statement

My literature review highlighted the limited amount of research, evidence based or otherwise, around OHinPSC and the need for further inquiry into this expanding area. CGT, which to my knowledge has only been used in one study in this area (Savundranayagam, Dilley and Basting, 2011), offers a comprehensive method for collecting, analysing and interpreting the experiences of participation in OHinPSC. This study, which aimed to include participants, family and friends, volunteer interviewers and HCPs, was unique in being based in a hospice setting and recruiting all parties directly involved in the process. It builds on earlier research around the Sheffield model (Winslow and Smith, 2013), which used semi-structured interviewing, by also including follow-up interviews and analysis of emerging theories. The resulting research aims to address some of the current gaps in understanding about the experience of OHinPSC surrounding motivations, meaning-making, interrelationships and legacy. It will provide a unique contribution towards future policy and practice for similar services in health and social care, and for the OH discipline in recognising the ethical implications of recording interviews with people in palliative and supportive care and understanding how OH recordings are received in bereavement.

## 5.14 Scientific justification

There is a dearth of evidence and material relating to OHinPSC and a need for further research within several areas including participant motivations, therapeutic benefit, interrelationships and legacy reuse. The emergence of OH initiatives in the UK, USA, Australia and New Zealand suggests provision is growing but there is little evidence upon which to base the development of OHinPSC. There is a need for further understanding of the OHinPSC experience. What does, and can, the experience entail? How do those involved benefit and what are the ethical concerns which require further thought? The impact of having a voice recording of a loved one in bereavement has thus far received little research and there is scant literature which examines the content of OH interviews in palliative and supportive care. This study contributes further understanding about the experience of OHinPSC and explores the full process from initial motivations to interview experience to listening to the recording in bereavement, research and teaching. This study is

interpretative, in which participants can express their temporal experience of the service over three semi-structured interviews. Emerging concepts and theories will then inform a working document of recommendations which will be shared with experts in the field. Recommendations decided will inform future policy and procedures for services. The study provides training for me as the student researcher in utilising the grounded theory qualitative methodology and builds my experience of conducting semi-structured interviews.

## 5.15 Chapter summary

In this chapter I have outlined my research design and the methods and delivery, and ethical implications involved in this study. I draw on the methods used for data sampling, collection and analysis based on CGT and specific to this study. I discuss how I will use rigor in ongoing evaluation of the research and delineate a final product in the CGT and accompanying recommendations. I discuss the practicalities and best practice in conducting research in a palliative and supportive care setting, and how I have the relevant experience and knowledge, along with declaring any possible conflicts of interest. Finally, I give the conceptual and scientific justification for undertaking the research. In the next chapter I set out the methods and procedures carried out for the research, from being granted ethics approval, to producing study documentation, recruitment and decisions and reflections on data sampling, collection, and detailed analysis. I include relevant information about the study and the research interviewees' involvement and reflect on my skills and application as a researcher and interviewer.

# 6. Methods

In this chapter I explain my methods and how the relevant documentation was agreed on in conjunction with Patient and Public Involvement and through ethics review. I detail the methods I used to carry out the CGT approach which involved co-construction of data via conducting, transcribing and analysing 1-3 semi structured interviews with each research interviewee, keeping reflexive and methodological journals and producing field notes and memos based on emerging concepts and theories. I focus on the data-analysis process involving using coding, and creating key categories in Quirkos software (see Section 6.21), which informed the basic social process of the final CGT. Finally, I reflect on the quality of the research, ethical issues encountered and the overall research process experience.

## 6.1 Ethics approval

Due to the research taking part in a hospice with the possibility that it may include people whose mental capacity was declining, it was required for me to apply for the research to be assessed by the NHS Social Care Research Ethics Committee, both by application and in person as a presentation. A favourable ethical opinion for the research was granted by the NHS Social Care Research Ethics Committee on the 8th March, 2019. Further to this, ethical permission was sought from the research department and healthcare governance at the hospice, and the Service User Coordinator granted permission for me to access and recruit people involved in the service, observe the process and access the corresponding archive.

## 6.2 Research documentation

As part of the ethics application, I included all the research documentation I planned to use:

- Conversational guide sheet (Appendix 8)
- Mini questionnaire (Appendix 10)
- Participant consent form (Appendix 11)
- General information sheet (For GPs/consultants) (Appendix 12)
- Participation information sheet (for patients) (Appendix 13)
- Participation information sheet (for volunteers and HCPs) (Appendix 14)
- Participation information sheet (for family)(Appendix 15)

These were checked, first by my supervisors, then to ensure Patient and Public involvement, they were checked by members of the North Trent Cancer Research Network Consumer Research Panel. Their feedback was invaluable in developing the participant information sheets, consent form, conversational guide sheet and lay summary. They suggested the following:

- Correcting wording for a lay audience, for instance not using or explaining words like 'semi-structured', 'qualitative' and 'redacting'.
- Adding a couple of questions to the conversational guide sheet: 'did you enjoy it?', 'Have you listened to the recording? And 'how did it make you feel?'
- On the lay summary add how participants and their relatives will be informed of the results.

Following this useful feedback, I was then able to update the documentation and submit it along with my proposal to the Social Care REC. All the information sheets and consent forms for the study also adopted appropriate font sizes and vocabulary for research interviewees as suggested by the University of Sheffield (2008).

## 6.3 Recruitment

All interviewees were selected due to being connected to the hospice OH service. To ensure credibility the process for recruitment of interviewees involved the following steps:

1. Potential interviewees were identified in liaison with the Service User Coordinator.
2. An information sheet outlining the research was given to the potential interviewee by a third party (Service User Coordinator, service volunteer, HCP).
3. Once the potential interviewee had read the information they could decide if they were happy for the researcher to contact them.
4. If they chose to proceed the Service User Coordinator contacted the researcher to make available their contact details.
5. The researcher would then visit the potential interviewee to provide more verbal information and ensure they understood the study and implications of their involvement. They would be offered some time to further consider if they wished, before arranging the interview.

6. Assuming they wanted to proceed, an interview was arranged and the recruitment process was complete.

7. Immediately before the interview the interviewee would be asked to sign a consent form and give any stipulations for their contribution to be used for research. It was reiterated, both verbally and on the information sheet, that they could withdraw from the research process at any time.

8. Any follow-up interviews required further consent forms.

Potential interviewees were given as long as they needed to decide whether to take part. This was ideally 1 or 2 days, unless they expressed a wish to proceed sooner or wanted more time to decide. Once a potential interviewee had agreed to take part, a date, time and place was agreed which worked for them. This could be in the hospice, nursing home or in their home. Locations used were:

- The hospice OH room

- The day centre break-off room

- A hospice inpatients private room

- The hospice research room

- Interviewees homes

- A nursing home private room

Precautions were taken to ensure that all locations interviews were conducted in were confidential settings.

## 6.4 Study background

This study took place in a hospice which had an existing OH service for patients and had been running since 2011 with over 400 interviews recorded. The hospice had a day care centre which offered respite for people with terminal illness, and users had relatively good functional and cognitive capacity for a palliative care environment. The hospice also had a large active volunteer team.

The fieldwork lasted from June 2019 to March 2020, during which time I conducted 32 semi-structured interviews, investigating and evaluating the experiences of all involved. I spent approximately 95 days on the field work involving arranging and conducting interviews,

transcribing and coding, maintaining methodological and reflexive journals and writing corresponding memos. I constructed a conversational guide sheet (Appendix 8), and conducted preliminary and follow-up open-ended interviews with all parties to find out how they drew meaning from their experiences and to ascertain their views on the process, its benefits and challenges, and the final legacy outcome. I analysed the interviews and notes using grounded theory constant comparative methods and wrote corresponding memos. As new categories arose, these informed (where relevant) follow-up interviews to ascertain a deeper understanding of emerging theories. Where relevant I also drew on participants' archived oral histories to further explore themes. The PhD schedule is included (Appendix 9).

## 6.5 Data collection

With each interviewee, one to three semi-structured interviews were conducted to follow the process from motivations to interview, to reflections afterwards, and to explore emerging theories from earlier research interviews. The interviews had no specified length, allowing interviewees to dictate the pace and finish. However, in preliminary interviews, once all questions have been answered and topics exhausted, the interview finished. Interviews lasted between 10-60 minutes and were fully transcribed. If an interviewee was unable or did not wish to complete the full cycle, or in the second interview it was felt that all topics had been exhausted, the interviewing would cease. All consented data was kept unless the participant requested its withdrawal. Emerging concepts were shared with interviewees in later interviews. The before and after multiple interview approach enabled understanding of the temporal meaning for interviewees as they were involved in the OH recording process, and the opportunity to construct associated concepts and theories. The three interviews happened within an eight week or longer time frame to allow for a reflexive approach to the study and time for transcribing interviews.

## 6.6 Reflections on data collection

My data collection strategy worked in as much as I was able to recruit enough people and conduct interviews to collect relevant data to reach a saturation point and be in abundance of ideas for my findings, and to discover emerging theories. However, some aspects of the original strategy and the ongoing data collection were not possible. In the recruitment stage, with the Service User Coordinator I was able to recruit participants who had their

own OH produced in various settings such as inpatients, the day centre and in the community. I was also able to get a good cross-section of participants in terms of age and gender. Despite our best efforts unfortunately there were no participants from other cultural backgrounds apart from white British. This was endemic of the hospice setting which largely catered for white British people. It could have been interesting to see how and if a participant with a different cultural or religious background differed in experiencing the service and particularly if they viewed legacy in a different way. This was equally an issue with volunteers and HCPs who were all white British people.

The recruitment worked well in that for each participant I was able to interview their volunteer interviewer and, in most cases, their referring HCP. However, I found it not possible to recruit family and friends of participants, apart from a friend of the participant Sarah. This was largely due to not having any, or very little, contact with family and friends through the service, and when I did, they were already very busy with caring and supporting for the participant. The Coordinator as my first port of call for recruitment also had little to no contact with participants' family and friends, so as a result I realised early on this would be a hard endeavour. Another factor was participants becoming ill or dying during the research process. Two of the participants I was only able to interview once due to them dying shortly afterwards. One of the participants I was only able to interview twice due to him becoming too ill.

## 6.7 Adopting separation in my reflexive stance

A challenge for me in reflecting on these data was to try and make sure I was representing what the research interviewees had discussed with me and not bringing in my own bias based on my past experiences of OHinPSC. There was the risk as I explored emerging theories that I would subconsciously draw on past experiences to aid my findings. Whilst this was inevitable and, in some instances, useful, keeping an awareness of the data I had collected and checking my theories against it continuously meant I was able to keep it rooted in the research data and not my preconceived ideas and experiences.

## 6.8 Inclusion/exclusion criteria

Due to limited funding attached to this doctoral study I was unable to fund translation requirements. As a result, patients without a good level of spoken English were excluded.

In the scenario of a participant losing capacity, they would be withdrawn from the study, but any data which had consent to be used would be retained unless the participant or family requested its termination. However, there were no instances of either an interviewee not having a good level of spoken English or of someone living losing the capacity to take part.

### 6.8.1 Inclusion criteria

People in palliative and supportive care involved in producing an OH.

People who are deemed to have the mental and physical capacity to participate.

English language only.

Adult (over 18) population.

### 6.8.2 Exclusion criteria

People who are deemed under the *Mental Capacity Act 2005* unable to be interviewed or give informed consent.

People who for physical, psychological, or linguistic reasons are unable to participate.

People under 18 years old.

## 6.9 Sample

Due to the nature of CGT the number of interviews and exploratory research was governed by either the timeframe of the study or a sense of reaching theoretical saturation point. I focussed on interviewing those with direct experience of the service. In total, 22 people (13 females/ nine males) were interviewed. These comprised of six participants, nine volunteers, six HCPs and one family/friend of a participant. Attempts were made to interview more people who were family and friends of OH participants but only one person was found who was interested in taking part in the research. I conducted 32 interviews in total: 14 people were interviewed once, six people twice and two people three times.

The demographic questionnaire which all research interviewees completed asked them their age, gender and to describe their ethnicity and religious beliefs. All the research interviewees were white British people. Despite efforts to try and include others, unfortunately there were no interviewees available from other ethnic backgrounds. This

was also probably symptomatic of the setting of the hospice and the service in an affluent, middle class, and largely white British part of a city in the north of England. Participant Sarah, who was also the oldest research interviewee at 93, preferred to identify as English rather than British. In terms of religious beliefs, seven identified as Christians, five as atheists and one as a Buddhist. Nine of the research interviewees identified as Other, of which four were Church of England, two did not specify, one noted they were non-practicing, one as agnostic and one as a humanist.

### 6.9.1 Participant sample

For the study six participants were interviewed, four men and two women, ranging in age from 42 to 93. Their median age was 67.5, and they included the youngest and oldest research interviewees in the study. The four participants aged over 60 identified themselves as Christians, or Other – Church of England, whereas the two youngest interviewees aged 50 and 42, both identified themselves as either atheist or non-practising religious. This could reflect a change in societal attitudes to religion post 1960.

Only two participants, Sarah and James, were able to do all three research interviews to reflect their thoughts before and after recording their OH, and then after listening to their OH recording/s. Participant Jake became increasingly unavailable and had a low mood, choosing to stay in his bed without visitors, although several attempts were made to record a third research interview with him. Whenever contacted he would ask me to try again in a few weeks' time. On speaking to nursing home staff, his condition did not improve. Participant Heather was also due to record a third research interview but became unwell. She wanted to listen to her OH first, however due to the fact that she wanted to fix her computer first (an offer of a CD player, made by both hospice staff and myself, was refused), she was unable to find the time. Plans were still being made for a final research interview when the Covid pandemic started. Participant Ralph was due to record another research interview but unfortunately deteriorated very quickly and died shortly before the interview. Participant Tim died shortly after recording both his first research interview and the first OH interview. The fact that two participants died during the research process, and one's health significantly declined, was perhaps inevitable when conducting grounded theory research with people at the end-of-life. In my previous roles in OHinPSC, this would often happen in between prospective OH interviews with patients. This was also reflected anecdotally by

both the Service User Coordinator, volunteer interviewers and HCPs (as discussed in the Experience section 8.2).

The grounded theory approach of being to record interviews throughout the process – before a participant's OH, soon after their OH, and again, after they had listened to the recordings – was also not always possible. For one interviewee I was only able to get there after they had recorded their first interview. In addition, I was not always able to interview them immediately after the OH interviews due to time and organisational constraints. Not all interviewees had listened to their oral histories, which meant I was not able to gauge all their full feedback. However, I was able to collect useful reviews on the overall process and, alongside the recollections of the volunteers, HCPs and from listening to the oral histories myself and the corresponding notes, reflexive and methodological journal entries, I was still able to build a better understanding of the people and processes involved.

### 6.9.2 Volunteer sample

The volunteers interviewed comprised of one Coordinator, six interviewers and two audio editors. All the volunteers were female apart from one of the interviewers and both audio editors who were male. Their age ranged from 45 (for the Coordinator) to 71 with a median age of 58. The median age minus the Coordinator was 65. The median age of the interviewers was 65.5 and the median age of audio editors was 61. In terms of religious beliefs, two volunteers identified as Christians, two as atheists (including the Coordinator), one as a Buddhist and three as Other, including one interviewer who added she was a Humanist.

The audio editors and Coordinator were only interviewed once whereas four of the Interviewers were interviewed twice. This was to gauge their thoughts before and after interviewing and meeting participants. Interviewer Lucy did not manage to interview a participant due to the participant dying before the OH interview, so was only interviewed once, and interviewer Jack was unavailable to be interviewed a second time for the research. Interviewer June was responsible for interviewing two participants, Jake, and James. The audio editors, who were responsible for editing recordings, had no direct links to the participants, although audio editor Richard remarked on the interview of participant Jake.

### 6.9.3 HCP sample

The HCPs interviewed consisted of two nurses (Staff Nurse and Junior Sister), both based in the day centre, an Assistant Practitioner based in the community working in residential care and nursing homes, two Chaplains (Specialist Palliative Care and Senior) and a Bereavement Counsellor, who all worked regularly at the hospice and often with people on the inpatient's wards. As with the volunteers, the HCPs roles were very gender based: all the nursing staff and the Bereavement Counsellor were female, and both Chaplains male. The nursing staff were also close together in age, with only a five-year age difference, whereas the Chaplains had an 18-year age difference. The median age of the HCPs was 51.5. The median age of the nurses and Assistant Practitioner was 53.5, and the median age of the Chaplains and Bereavement Counsellor was 51.5. In terms of religious beliefs, four of the HCPs identified as Christian or Other – Church of England, one of the nurses as an atheist, and the Bereavement Counsellor as agnostic.

All the HCPs were responsible for referring at least one OH interviewee for the study, with the exceptions of the Senior Chaplain and Bereavement Counsellor. I chose to interview the Senior Chaplain due to his extensive experience of referring people and working alongside the OH service, and the Bereavement Counsellor due to there being a lack of knowledge of how the oral histories were received by bereaved family and friends. Both HCPs gave invaluable contributions on how interviews were reused and listened to by the bereaved.

### 6.9.4 Family and friends sample

I was unable to recruit any family members, but I was able to recruit one friend, Christine, a friend of participant Sarah, who was able to feedback on listening to the Sarah's OH and what the service had meant for both.

### 6.10 Personal data storage

All interviews were recorded using an encrypted high quality digital Marantz recorder to ensure security and that voices were audible. They were immediately transferred and backed up as audio wav files on my University of Sheffield cloud storage, set up by the University of Sheffield Medical IT team to ensure security and confidentiality. All data, including corresponding data, was stored in the cloud and password protected in accordance with the recommendations of the Corporate Information and Computing Services (University of Sheffield, 2018b).

Beyond checking data with participants and sharing connected ideas with my supervisors, I was the only person with access to the data. Personal contact details were kept for arranging interviews with interviewees and for sending thank you letters for their participation. All contact details were secured on a password-protected university laptop computer, and dedicated university storage accessible only by me. All transcribed interviews and corresponding quotations were anonymised, and each interview was assigned a chronological ID number and organised and inputted into an Excel database. Each interviewee was given a pseudonym name to assist in making the findings more accessible and relatable. The corresponding pseudonyms and numbers were the main reference for the data. All manual files, such as consent forms and transcripts, were kept in a locked cupboard at Sykes House, University of Sheffield. To ensure confidentiality of personal data, all transcripts of interviews were assigned an ID number. The ID number and corresponding pseudonym were then used for all subsequent analysis and coding to protect interviewees identities. The study adhered to GDPR and any mention of a third person or establishment by name in an interview was redacted to ensure appliance. With signed consent, the academic supervisors and I had access to interviewees names and addresses. The research team did not access medical records of interviewees.

The anonymised transcripts will be deposited in the University's Online Research Data repository (ORDA) with limited access by request for University of Sheffield staff and students. Interviewees who expressed an interest (on the consent form) in reading more about the study outcome will receive a final summary and, if desired, the full report or connected publications.

## 6.11 Prior experience of interviewing: OH v semi-structured interviewing

As already mentioned, I have extensive experience of conducting open-ended OH interviews with people and of conducting some semi-structured interviews in previous research projects. However, most of my experience was from conducting OH interviews, and, whilst many of the skills I had in this area were transferrable to semi-structured interviewing on this study, there were some key differences I had to be aware of and change. Using a conversational guide sheet with prescribed questions was central to this, whereas no questions beyond prompts are set in most OHinPSC interviews. This meant I was keen to keep to the scripted questions more and felt more uncomfortable in straying from them.

Other factors were that when recording OHinPSC I have learnt to be meticulous in the audio recording and introductions and guiding the listener through the interview, and I found myself still doing this with the research interviews, despite it not mattering as much about the audio quality or making the signposts of the interview starting, pausing and ending. In OH interviews these factors are useful for listeners, however, with the research interviews I was the only person listening back when transcribing the interviews. Also, as an OHinPSC interviewer, I am always keen to keep my own opinions and thoughts of the recordings, especially when they are legacy recordings for family. In CGT interviews however, it was sometimes useful for me to be sharing thoughts and thinking aloud with the interviewee to co-construct ideas and discuss emerging theories. The commonalities and contrast between both styles of interviewing sometimes needed unpicking. One question I found useful to ask in the research interviews which I also always ask in OH interviews is "is there anything else you would like to say?" This is a question I ask at the end of interviews, as it enables the interviewee to pick up on anything they feel has been left out and to have a final think about what they want to say. It feels a good question for ensuring some autonomy for the interviewee and can sometimes provide interesting data or stories.

Sometimes, once I switch off the recorder and end the official OH interview, the interviewee will come out with a profound story or memory, and I will ask them if they would like me to record it and turn the recorder back on. This happened a couple of times with the research interviews, with two of the participants who said something very interesting for the research as soon as we had ended the interview. I was unsure ethically in this situation if I should do the same and see if they minded me turning the recorder back on for them to say it again to be part of the research interview. There was the risk that they might not really want to say it on the recording, which is why they chose to say after, but would agree to out of politeness. However, in both situations I felt that it was because the thought had only come to them after the interview, or they perhaps did not deem their comment that important anyway. As it was it had been made clear to them that I would be writing a reflexive and methodological journals as well, so there was nothing to stop me making a note of any conversations outside of the interview anyway.

## 6.12 Prior knowledge of research interviewees

I had no prior knowledge of any of the OH participants, but I knew some of the HCPs from my previous work in OHinPSC where they had also worked. I had also previously conducted an OH interview with the mother of one of the HCPs. As a result, these research interviews were unavoidably shaped by our prior knowledge of each other and this was encountered in what they chose to talk about, either in mentioning the OHinPSC service I had worked on or in the instance of the HCP whose mother I interviewed, her relaying about her mother's experience of being OH interviewed by me. For these HCPs, there was arguably a more positivist approach to their interviews in that we had already established good working relationships. However, I knew none of them well enough for it to alter our interviews further in terms of what was talked about.

I also had prior contact with some of the volunteers, primarily from training which I had delivered or taken part in, although this arguably did not interfere with the research interviews as the training had occurred several years previously and I had only met them briefly. However, one volunteer I had conducted an OH interview with previously as part of an educational project at Sheffield Teaching Hospitals. As discussed in my findings, the fact she had been an interviewer and interviewee was useful in achieving a more rounded view of OH. The Service User Coordinator is the one research interviewee I knew reasonably well as we had worked together previously in OHinPSC. Whilst she was able to give me an in-depth overview of the service and her experience of OHinPSC in the first and our only research interview, she was not interviewed about any of the corresponding triadic case studies or participants, and thus did not impact on the findings of others beyond her original thoughts.

## 6.13 Interviewees comprehending the project

Another commonality between OH interviewing and the research interviewing was that often interviewees would not fully understand what was being asked of them even though I would read through the information sheet with them to try and make sure they did prior to starting. This was particularly an issue with participants who had their own illness and other worries to attend with. Amongst the participants, three seemed to slip into their oral histories frequently as I was recording research interviews with them, as if they were unsure of the boundary between the research and the service. Perhaps they saw it as an

opportunity to road test their stories or they got confused between both interview scenarios. In some ways them recalling aspects of their oral histories was interesting from a research perspective, and I found myself pondering on whether there were subconscious meanings within their stories which assisted me in understanding their identities and thoughts about the OH process in more detail.

## 6.14 Reflexive journal

I used my reflexive journal as a predominantly private means to express my thoughts about how interviewing and subsequent transcribing and theorising had been shaped. When arranging and conducting interviews I used it to write about my initial thoughts and observations, such as conversations with research interviewees, getting to and from interviews, the interrelationships developed with research interviewees and those around them who were not interviewed but played a role such as family, carers and other HCPs who I did not interview. The journal was a useful way for me to express my feelings based on the observations I made, and to assess my own practice in terms of developing my interpersonal and interviewing skills. Instances included how I, and others, were feeling on certain days in terms of tiredness or other factors, such as what was happening outside of the remit of the study, whether it be the weather, or the ramifications and polarities of the Brexit debate, which I felt was sometimes apparent during the study in how people related.

As I started transcribing, the journal gave me a means to chart how my perception of the interview changed. Once I listened back in detail and heard sections repeated new meanings came to mind in what was said and how research interviewees talked. Certain phrases signalled different interpretations as I listened again, which in turn helped me with developing new categories and developing my theory as I found new meaning in what someone was saying. This was particularly the case when people used metaphors or talked in a more storied or abstract way. Sometimes something said which, at first, seemed not relevant, became a new area of interest which could help me rethink a category. For instance, the way a participant talked in an abstract way about a painting on their wall of a path to the sea, led to a new way of me understanding their views on the end-of-life and legacy. Similarly, with another participant who talked about as a youngster enjoying the lucky dip bag in their local shop, led to me interpreting it as a metaphor for their reflections on life.

On a more practical level, the journal also included entries on professional boundaries within visiting interviewees homes. For one older participant I was aware that there were issues with their front door lock being broken and they were having trouble with mould in the kitchen which they wanted to show me. To what extent I should help became an ethical dilemma. I felt uneasy on leaving them knowing that their front door was unlocked, and anyone could walk in and that they had no one else visiting until the next day, despite being assured by the interviewee that it was fine.

## 6.14 Methodological journal

My methodological journal was particularly useful for noting practical and ethical challenges with recruitment, interviewing and subsequent transcribing and coding. An ethical dilemma I faced in terms of recruitment was in how contact details were passed to me for potential interviewees. Ideally this would have been word of mouth from the Coordinator, volunteer or HCP, although sometimes contact details were sent by email, which I was aware could be at odds with my ethics application.

When interviewing it became clear that my pre-planned questions were not all ideal for the first interview with interviewees, as some referred to the experience and outcome of the interview and some were non-specific as to their timing. Deciding on which questions to ask in the first interview became an important point to keep consistency with other interviewees' early interviews. Added to this, it was not always clear to what extent I should ask other supplement questions. Some interviewees gave short answers to the pre-prepared questions and there was sometimes the feeling I needed to get a longer interview from them and the risk of asking too many extra questions which were not needed. Other times, an extra question asked in one interview, such as asking them what their career was (in the case of volunteers and participants), might yield an interesting answer relevant to the research, but then on asking other interviewees the same question it could come across as not important and be irrelevant to the research. Sometimes it did not feel appropriate to ask further questions like this. Another instance was in asking about family members, particularly in relation to whether they had spoken about them in their OH or planned to give them a copy. Whilst interesting to the research, these sorts of questions could become interrogative or be too personal to enquire further about.

Another issue was when participants were visibly ill, tired or upset during their interviews, knowing when to stop or to let them have a break. One participant had issues coughing, breathing and swallowing water during their interviews, and hence the interviews were relatively short, involving several short breaks. Whilst I made it clear they were able to stop whenever they wanted, they were keen to continue, but I was aware that this could have been from politeness rather than a desire to assist or take part in the study.

The transcribing presented methodological challenges in what I chose to include in terms of repetitions, ums and errs and silences. Whilst I followed professional guidelines as explained in the transcription section below, there were still subjective decisions to be made in terms of what was important to identify in these verbal fillers and non-verbal moments. I discuss the different interpretations of silence within an oral history context in more detail in Section 10.4 (p.201).

## 6.15 Field notes

I created short field notes about the research interviews covering the main topics talked about and any contributing factors such as the setting and how the conversation shaped the interviews. I also created field notes when listening back to the participants oral histories as discussed in the section below. The field notes were a quick way for me to revisit and recap on some of the core elements of both the research and OH interviews.

## 6.16 Memos

Writing memos was a way to distil my thoughts and theories as they arose in research interviews and during the coding and constant comparative analysis. They were a way for me to write down and collect my, and research interviewees', thoughts on potential categories, to assist in developing overarching theories. General topics such as illness, narrating, formatting, service models and continuation became more nuanced as I worked through the process and later memos centred on framing mortality, validating a narrative, existential suffering and digital life span. The memos enabled me to then conduct more focused coding within Quirkos (see Section 6.21), and to start to assess what the key concepts were from the study. Some categories became less important, and others more pertinent, as I revisited my coding and developed a stronger understanding of the overall basic social process which led to my grounded theory.

In the later research interviews, I was able to discuss some of the factors around motivations, experience and legacy in more detail with research interviewees, and these developed categories informed who I would interview later in the process, such as the Bereavement Counsellor and Chaplain regarding legacy and reuse, and follow-up interviews with participants and volunteers who had raised poignant points regarding key concepts in earlier interviews. Writing memos throughout the data collection and analysis was an essential way for me to develop my ideas and theories.

## 6.17 Listening to the oral histories

This was a study to evaluate and better understand the experience of taking part in OHinPSC, involving semi-structured interviews with all involved parties and not a study to examine in detail the actual oral histories audio. However, later in the research process, after conducting the first two interviews with participants, it was useful for me to listen to their corresponding OH interviews to see how they tallied with their motives and experiences, and prior to asking them how they found listening to the oral histories to give context. I found this to be a useful exercise which made me reconsider some of the thoughts and assumptions which research interviewees and I had discussed in the research interviews. By looking in-depth at certain motives and shared experiences there could be a tendency for me to over emote situations and read into comments too much, the oral histories presented a more stable account in some cases. They also gave me a clearer understanding of the co-construction and interviewing styles, and I was able to make notes on whether the interviews had been introduced and ended well by the interviewer, and whether the CDs metadata was labelled correctly, which could help with future training exercises.

The merits and limitations of the reuse of oral history archives both as a primary source and for secondary reanalysis has been discussed in academic literature (Bornat et al., 2003, 2012, Gallwey, 2013). They argue that when revisiting oral histories, key topics can be found to be amiss whilst other topics take on new meaning, due to changes in temporal and ethical dimensions. Whilst this study does not include in-depth research in listening back to the oral histories, I do mention the issues regarding the lack of cataloguing information and missing formatting metadata of interviews (see Section 8.3.5.1, p.174). Gallwey also encountered this when accessing several archives including the Millennium Memory Bank

archive (2013). I discuss the lack of summaries in this study project archive and their importance (see Section 8.5.2, p.153). The significance of comprehensive summaries is also flagged by Gallwey (2013, p.42).

## 6.18 Transcribing

I transcribed all the interviews myself using a transcription pedal and the free Express Scribe software. I also followed the British Library transcription guidelines (2023, p38-49) for the presentation of documents in Microsoft Word. For instance, using italics for my voice and plain text for the interviewees, recommended spacing of 1.5 and commas to denote small pauses, three dots… for longer pauses and [pause] for even longer pauses. When there was a word I was unsure of this was denoted by [sp.] or [ph] for a phonetic approximation of a spelling. When it was not possible to make out what someone said, this was denoted as [incomp] for incomprehensible. This is how I have transcribed oral histories in the past in my work, so I was comfortable with this process and following the guidelines assisted me in being able to read the transcripts.

Due to the constructive grounded theory approach necessitating that I analyse data throughout the study process, I would transcribe interviews immediately or as soon as possible after completion of an interview to allow me to then start coding prior to consequent interviews, particularly if with the same interviewee, in order that I could summarise with them what they talked about in the last interview. This continuous analysis also enabled me to reflect on possible themes and new questions for the next interviews. Transcribing myself rather than paying someone else to do it meant I had the opportunity to listen in detail to the interviews at the first instance. Spending time and giving repetition as I listened to their voice sentence by sentence, I was able to hone in on how they sounded and thus how they felt in that moment which gave me clues and ideas which I missed in the original moment of the interview.

## 6.19 Line-by-line coding

Once transcribed, I went through each interview transcript and started using line-by-line coding (Charmaz, 2006). This involved identifying gerunds (words ending in -ing) to explain actions and processes which appeared from the surface text to explore the meanings of what was said by the interviewees. An example of my line-by-line coding can be viewed in the Appendices (Appendix 16). During this coding I also referred to my reflexive and

methodological journals, and field notes to develop further understanding and ideas about the actions and processes at play within the interviewee dialogue. Once line-by-line coding was completed within a transcript I would review the gerunds and start to think about overarching themes and concepts which I would then make groups of lists and notes from. These notes then informed memos on specific ideas which I encountered over different transcripts, which in turn informed my questioning and topics to investigate in future interviews. For instance, in developing understanding of the different motives of participants and how these were perceived by volunteers and HCPs, I was able to tailor new questions to ask about recording family legacies or social histories in more detail. I was also able to ask more about the understanding and adaptability of OH and its possibilities in the present and the future and how these were interpreted by different research interviewees. In a more straight-forward specific way, I started asking research interviewees more about their career backgrounds, as there seemed interesting parallels with their understanding and uses for OH.

## 6.20 Focused coding

Drawing on my initial line-by-line coding, coding with gerunds, and by writing coinciding memos I was then able to concentrate on the main reoccurring and significant codes and test these again within my data. From this analysis I was able to create new, focused categories within the Quirkos software (see Section 6.21) and to analyse them collectively. This inductive process of generating new focused categories enabled me to start to recognise emerging theories and understand and test the links and boundaries between them using axial coding. Some categories such as motivations and legacy were closely linked and existed in some form throughout the OHinPSC process. The categories which existed temporally from the start of a participant's involvement in OHinPSC to the final outcome when the OH was reused became the basis of my findings and informed the basic social process of my grounded theory (the GVT).

## 6.21 Using Quirkos software

Quirkos is a computer assisted qualitative data analysis tool which allows users to group textual data in different titled coloured bubbles enabling visual connections between groups and categories (see Figure 4). This visual element gave a more accessible way to analysis data allowing me to look at the different categories together and to think about how they

interacted. This was invaluable when managing a large data set from 32 interviews transcripts and the corresponding memos and diary entries. The software gave me a new visual way to interact with the data,

The software was intuitive to use with the function to create subpages of data bubbles, meaning I could focus on categories in isolation or with other linked categories to see how they overlapped. A feature Quirkos did not have which could have been useful was the ability to add multimedia. This would have been useful for adding corresponding interview audio clips to enable me to consider not only what was said but how it was said. The software was also lacking in being able to import and export the transcripts without then needing to reformat the text.

Based on the gerunds discovered, and then the overarching categories which I felt they formed from focused coding, I created groups within the software. Following the concept that there was a clear before, during, and after to the OH process, which the research interviews also followed, when possible, I was able to break this down to motivations, experience and outcomes as the three key areas of the study. However, it was clear that also the motivations were fluid, and changed for many participants throughout the process, and that the experiences were different for each interviewee group throughout the process too.

I uploaded all the transcripts to Quirkos and used the topic headings which I had decided on from the line-by-line coding and subsequent focused coding. I then went through the transcripts again and moved chunks of text into each theme where they fitted. After this I could see which categories had the most text and were the most apparent and which were the outliers. At the same time, I was also able to create more straight-forward groups for text such as for different questions I asked or for different interview settings and illnesses.

At this point I started to group the different categories together to look for possible links between groups and to develop my own understanding. For instance, the differences between narrative, stories and histories, or the connections between mortality, illness and legacy. As I found interesting connections or areas that I wanted to understand more I would then write further memos. Once I had settled on the areas of motivations, experience and outcomes I then went through all the relevant focused categories and re-examined the

transcript text within their new contexts. From this I was able to illustrate the key parameters of each group (see Figure 4).

When creating codes and corresponding themes in Quirkos there was the methodological dilemma of where the boundaries were in terms of what was relevant to the study and its parameters. For instance, the category of *familiarity* was central early on my research, relating to interviewees prior and present knowledge of each other and their environments. Whilst this was an interesting topic to investigate and, in some ways, led to categories such as *understanding, storying* and *adapting*, it became superfluous to the findings later. There was the risk, particularly in the Quirkos software, of creating too many categories and becoming overwhelmed, but in having several it also enabled a more focused way of producing key concepts to inform the overriding categories for my findings.

*Figure 4: A screen grab of categories organised in the Quirkos software*



## 6.22 Diagramming

I used Coggle software throughout my research to create diagrams. In the first instance I used them to map out my preconceptions about OHinPSC and for my narrative literature review, as illustrated in Figure 5:

*Figure 5: A Coggle diagram relating to categories for the narrative review*



Being able to create the diagrams helped me in gathering and positioning my ideas. From the new notes made by coding in Quirkos I again started to create my own spider diagrams around key concepts such as mortality (illustrated in Figure 6), storying and co-constructing to try and understand how all the different parameters connected, particularly in terms of motivations, experience (illustrated in Figure 7), and outcomes. By linking main categories with subcategories, I was conducting axial coding in specifying the dimensions and parameters of each category. At this point I was able to plan my findings and to draw on text from each subcategory to begin to build key concepts.

*Figure 6: A Coggle diagram illustrating subcategories relating to mortality*



*Figure 7: A Coggle diagram illustrating categories relating to the concept of experience*



## 6.23 Developing the CGT

On writing up my findings under the main headings of Motives, Experience and Outcomes, and considering how all the key categories and subcategories within these three areas worked across all research interviewee groups of participants, volunteers, HCPs and family and friends, I was then able to create an overarching theory with key elements which formed the basic social process of the CGT. The GVT became central to my contribution to knowledge from this thesis.

## 6.24 Covid

After I had conducted 32 interviews, the Covid pandemic began. This meant I was unable to continue with the study interviews, despite planning follow-up interviews with several people. This included a follow-up interview with one of the participants, and follow-up

interviews planned with some HCPs and volunteers. These interviews, whilst not essential to the research, could have supported me further in discussing emerging theories and following up on discussions from earlier interviews. HCPs were particularly hard to get follow-up interviews with, even before Covid, due to them being so busy. A final interview with the Coordinator could also have been useful as an anchoring starting and ending point, particularly as she had strong knowledge and experience of the service and would have undoubtedly had illuminating ideas regarding the findings and emerging theories. It was decided with my supervisors that I still had plenty of data to draw on from the 32 interviews and associated documents, and I had reached a saturation point in that several ideas and theories were reoccurring.

## 6.25 Chapter summary

In this chapter I have outlined the methods I used for undertaking this study and my reflections on the process. In the first instance it involved preparing my ethics application, acquiring Patient and Public Involvement and getting ethical approval of my research documentation to proceed with the study. In line with CGT, I conducted both purposeful and theoretical data sampling and carried out data collection using constant comparative analysis, transcribing and line-by-line and focused coding of interviews, categorising and diagramming. I also included reflections on my experience and suitability, interviewees understanding of the study and how external factors such as Covid impacted on the study. In the next chapter (Chapter 7) I discuss the study settings for OHinPSC and give pen portraits of the research interviewees to set the scene for my Findings (Chapter 8).

# 7. Setting the Scene

## 7.1 Settings

The OH service at the study hospice was offered across multiple settings:

- Inpatients

- A day centre

- An external venue run by the hospice

- In the community – in a participant's home

- In the community – In nursing homes

In each setting the OH offer could vary slightly dependent on the type of participant, referring HCP and the time and setting constraints as detailed in section 7.1. Attempts were made to recruit participants for the study from each setting, but unfortunately it was not possible to recruit a participant who recorded an OH from the external venue run by the hospice. However, the volunteers and HCPs interviewed for the study had different views which they shared about the OH offer in each setting. To protect the identity of research interviewees in this study and fulfil the REC requirements, whilst keeping my thesis readable and coherent, pseudonyms have been used for all interviewees, detailed in section 7.2.

## 7.1.1 Inpatients

The hospice had 15 private rooms and two bays with beds for inpatients, and sometimes OH would be offered in within this setting at a patient's bedside as with one of the research participants. It was recognized that there was fewer OH interviews in this setting than in previous years, due to patients being much more ill on inpatient wards. It was suggested in research interviews that this was mainly because pain management could now be managed better at home. Due to the interviews being conducted in private rooms, there was no fixed time constraints, although there was the possibility of interruptions from HCPs. Also, participants were more likely to be closer to the end-of-life and thus interviews could be much shorter due to their illness or the brevity of their situation with more likelihood of them recording a family legacy (as detailed more in the Experience section 8.2). The participant interviewed in this setting (Tim) was referred by a Chaplain (Keith). In line with

being closer to the end-of-life, participants in this setting were more likely to be having conversations with Chaplains.

### 7.1.2 Day centre

The day centre was a comfortable and social environment with other activities on offer. It also had a designated OH interview room which had been soundproofed, although there were still issues with outside noise:

> …there is a room next door and they have their door open and the noise comes through and we've had instances - there was one that I was editing and it was dreadful, the poor chap he was really depressed and he was heartbroken about his diagnosis and his children and he'd had a shit life basically…then he got diagnosed in his forties and he was talking about something really difficult and deep and he said something and there were peals of laughter coming from the corridor and it was so incongruous with what was being said….I just had to take the bit out, because for a family member listening to that it would have just sounded awful, it was terrible, the noise really carries through and it just sounded like people were laughing at what he was saying.

> (Volunteer Jenny, 1)

There was the opportunity to talk and meet with potential participants about the OH process in advance. Keeping continuity with the volunteer interviewer was also straightforward, as most patients were signed up for weekly visits to the day centre for 5-8 weeks. However, the OH slot was usually only for an hour in a week, which did limit the time of each session. One HCP who worked regularly in the day centre suggested that people always choose OH over the other activities and therapies: "What we say is you've got a full day and you choose what you want - they will always choose oral history over everything else." (HCP Judy, 1).

### 7.1.3 External venue run by the hospice

Although none of the study OH case interviews were conducted at the external venue, it was mentioned by several of the volunteers and HCPs. OH was offered as an activity alongside other pursuits or therapies like at the day centre. This could be painting, music workshops and genealogy. The OH offer had been running there for less than a year and this

setting was unique in also offering OH to carers as well as patients. The service was advertised there, and people could book via the website. In this sense it was less structured and more like a 'walk in' service; one volunteer compared it to a "taster session" (Volunteer Kate, 1). Some volunteers mentioned the issue of potential participants not turning up, especially as there was no follow-up reminder to the online booking. Another issue, mentioned by the Coordinator, was that it was not possible to match suitable volunteer interviewers to the participant as there was no prior background knowledge of who would be interviewed. One example given was a man with dementia who came with his carer but thought he was having his hair cut rather than recording his history. Although the interview went reasonably well despite this, if the interviewer had known in advance, they "**might have suggested bringing in some pictures**" (Volunteer Jenny, 1) to use as prompts to help his memory. The automated booking system also meant there was a lack of continuity, and a participant could find they had a different volunteer interviewer on a follow-up interview. Positive points which were raised about the setting included it being comfortable, and recently refurnished, and that due to recruitment being via a booking system rather than HCPs, it meant there was equality of access (Volunteer Jenny, 1).

### 7.1.4 In the community – participants' homes

Interviews happening at a participant's home often happened as a follow-up to people attending the day centre. One of the volunteer editors remarked on the exceptional sound quality of interviews conducted in people's homes:

> …perhaps soft furnishings were just really appropriately placed and that's why the quality was so good because it was like listening to Radio 4 on a DAB radio it was fantastic.
>
> (Volunteer Richard, 1)

However, the other volunteer editor felt there could be more interfering extraneous background sounds: "…there might be traffic going by, there might be the telephone ringing in the background, whatever there can be a lot more…" (Volunteer Simon, 1). Interviews in people's homes also meant that there were fewer time constraints and added autonomy for the participant in terms of how long interviews lasted and how many follow-up interviews

were conducted. As a result, there was also the risk of professional boundaries being blurred when volunteers and HCPs visited them (as discussed in the Experience section 8.2).

## 7.1.5 In the community – nursing homes

OH interviews could also happen in nursing home settings. Again, the setting gave the participant more autonomy in terms of time constraints and the possibility of return visits. Although, as witnessed in the study with the one participant who was interviewed in a nursing home setting, they were perhaps a less comfortable and familiar environment for participants and thus interviews were possibly not as relaxed and informal as in participants' homes. OH Interviews in nursing home settings tended to be referred by HCPs who worked in the community for the hospice.

## 7.2 Pen portraits

### 7.2.1 Participants

*Figure 8: A table showing background information about participants*

| Participant | Age | Sex | Religion | Number of Research Interviews | Number of OH Interviews and Location |
|---|---|---|---|---|---|
| 1. Jake | 62 | M | Other – Church of England | 2 (1 before (ID2) and 1 after (ID6) but before listening to their OH) | 2 (Nursing home) |
| 2. Sarah | 93 | F | Other – Church of England | 3 (1 before (ID4), 1 in between (ID11) and 1 after listening to their OH (ID21)) | 4 (Day centre and home) |
| 3. Ralph | 82 | M | Other – Church of England | 1 (ID12) (after first OH interview) | 3 (Day centre) |
| 4. James | 62 | M | Christianity | 3 (before (ID13), after one (ID17), after listening to their OH (ID30)) | 2 (Home) |
| 5. Heather | 50 | F | Other – non practicing | 2 (before (ID14) and after but before listening to their OH (ID20)) | 2 (Home) |
| 6. Tim | 42 | M | Atheism | 1 (before (ID24)) | 1 (Inpatients) |

### 7.2.1.1 Jake

Jake was 62 and based in a nursing home. He was perceived to be depressed and isolated, spending most of his time in bed in a dark room with the curtains closed. He had lots of friends prior to moving into the nursing home but only got visits from his ex-wife occasionally, and his son when he felt he wanted money. Both his parents had died, and his

brother was murdered when they were younger. He also had a sister who he did not get on with and had lost contact with. He had lived locally all his life, and shared memories of growing up. He was keen to talk about the poverty his family endured and felt this might help his son gain a better understanding of money. He was excited by the prospect that his OH would be archived for posterity and might be used as a social history resource, likening this to the reconstructed butchers display in the local museum based on one he used to visit with his dad as a child. Although he was not classified as palliative, he had been referred to the service by the ECHO (Extension of Community Healthcare Outcomes) scheme via the HCP Lucy as a psychological intervention which she felt might lift his mood. After speaking with him they realised they had friends in common and grew up nearby to each other. He recorded two oral histories and two research interviews – one before his OH and one after but before listening back to it. His mental and physical health deteriorated during the research process, and he was unable to do a third research interview.

### 7.2.1.2 Sarah

Sarah was 93 and at the end of a series of visits to the hospice day centre. She found out about the OH service after it came up in conversation in the hospice art class from a family member of another OH participant. She lived alone in supported accommodation and was unable to walk far and was quite isolated. Her older sister lived nearby but unfortunately died towards the end of the research process. Her sister was her only nearby family and the connections made with the hospice gave her much needed social interaction. She also had three nieces, but they did not live locally so she did not see them often. She had always been interested in local history and on moving to the city the first thing she did was to visit the local library to see what was available. She was particularly keen to talk about the village she grew up in, which had since become a commuter belt and she felt had lost its character. She wanted to record in her OH about how it was, so it was not lost, and had thought about writing it before, so this was a good opportunity to record it. She also talked about her time in the Women's Royal Navy Service during the war. She met her husband before going to war, but he died of polio after they had been married for five months and she had been a widow ever since. She was unable to go to his funeral due to being in hospital herself. She recorded four oral histories with the final one being about her sister during the time her sister had become very ill. She was interviewed three times for the research – once before

starting her oral histories, once after recording two oral histories and once after she had listened to the first three interviews.

### 7.2.1.3 Ralph

Ralph was 82 and visited the day centre. He lived alone and was recently widowed. He was keen to talk about the local area and his life, and requested that his interviewer be a white local man. He felt he had witnessed a lot of change locally and wanted to share his knowledge. He was motivated by the idea that his knowledge may be of use for research in the future and in creating a social record rather than leaving a family record. He had a brother and sister who lived nearby but both have dementia. He also had two older sisters but was not sure that they would be interested. He talked about his work a lot during his interview and much less about relationships and family. On meeting his interviewer Jack, he realised he vaguely knew him as they both frequented the same pubs. He recorded three oral histories at the day centre and one research interview after his first OH. Unfortunately, he died soon after his final OH so was unable to be interviewed again for the research.

### 7.2.1.4 James

James was 62 and based at his home where he lived with his wife. He found out about the OH service from visiting the day centre and reading about it in a leaflet. He had MND and was planning on doing a similar written life story via the MND Association so liked the idea of OH and decided it would be easier and more personal using his voice. He had lost most use of his hands and needed his wife's support in signing the consent forms. He was particularly keen to leave a family legacy for his daughters and grandchildren in the knowledge that he may lose his voice very soon. He was also involved in a voice banking scheme for which he would repeat thousands of words with his voice so he could then use his voice via a computer in the future and so other people with MND could use it too. His parents died when he was very young, and he wished he had a record of them for reference. Prior to having MND. he was self-employed as a carpenter and floor layer. During his oral histories he felt he had to be careful about what he said about his first wife and his estranged son as he did not want to upset anyone. He recorded two oral histories at his home and three research interviews – one before his OH, one after the first OH, and one after he had listened to both his oral histories.

### 7.2.1.5 Heather

Heather was 50 and had been visiting the day centre after taking part in genealogy classes at the hospice. She was fascinated by her family history and primarily saw OH as a means for charting this. She was a fourth-generation market trader, although the family business had all but ended due to the changing times and it not being profitable. She lived with her husband and four children. One of her sons was autistic and there was a lot of dyslexia in her family. She had recently scored very highly in an ADHD test. She found out she had a rare form of cancer the previous year, but had recently been told that it was not terminal, so she was no longer deemed palliative. She was at odds with new technology and disliked her children being on their mobile phones all the time. She would much prefer to talk with them than text. She recorded two oral histories at her home and two research interviews – one before her first OH, and one after she had finished both oral histories but before she had listened to them.

### 7.2.1.6 Tim

Tim was 42 and an inpatient at the hospice. After discussing OH with Keith, the Specialist Care Chaplain, he decided to record an OH for his son, who was six years old, and his wife. He felt this would be a more personable way to do it rather than leaving cards or letters. He was very unsure about what to write or say and was nervous about the interview because of this. He was reassured by the Chaplain and me that the interviewer would guide him. He worked previously as a postman. He recorded one OH and one research interview prior to his OH. Unfortunately, he died soon after his OH interview.

## 7.2.2 Volunteers

*Figure 9: A table showing background information about volunteers*

| Volunteer | OH Team Role | Age | Sex | Religion | Amount of Research Interviews | Connection to participants |
|---|---|---|---|---|---|---|
| 1. Jenny | Coordinator | 45 | F | Atheism | 1 (ID1) | Involved in referrals, communications and archiving for all interviews |
| 2. June | Interviewer 1 | 66 | F | Other | 2 (ID3 and ID16) | Interviewed Jake and James |
| 3. Lucy | Interviewer 2 | 65 | F | Buddhism | 1 (ID5) | None - participant died before planned OH interview |
| 4. Kate | Interviewer 3 | 71 | F | Christianity | 2 (ID7 and ID31) | Interviewed Sarah |
| 5. Jack | Interviewer 4 | 60 | M | Other | 1 (ID9) | Interviewed Ralph |
| 6. Fiona | Interviewer 5 | 65 | F | Atheism | 2 (ID15 and ID22) | Interviewed Heather |
| 7. Karen | Interviewer 6 | 67 | F | Other – Humanist | 2 (ID25 and ID32) | Interviewed Tim |
| 8. Richard | Audio Editor 1 | 63 | M | Atheism | 1 (ID18) | None |
| 9. Simon | Audio Editor 2 | 59 | M | Christianity | 1 (ID29) | None |

The volunteers comprised of seven interviewers and two audio editors. The addition of having audio editors on the team enabled interviews to be edited for the participants and their family and friends. This could mean editing out unwanted background sound, interruptions, coughs or repetitions, or parts of an interview which the participant decided were not suitable for their legacy. Whilst many oral history projects do not to involve making edits to interviews, this was deemed necessary in OHinPSC due to the uniqueness of making a legacy for family and friends.

### 7.2.2.1 Jenny

Jenny was 45 and the Coordinator of the service. Although it could be argued that her role was paid and therefore perhaps should be housed with the HCPs, she could as easily be grouped with the volunteers. Firstly, coordinating the OH service was not her primary role but an extra part of her position as Service User Coordinator, which, at her own admission, required a lot of extra time and effort, so it could be argued she gave an additional voluntary contribution to the service. Secondly, and perhaps more importantly, her role within the service encompassed all the roles of the volunteers, such as interviewing, summarising and editing audio. It was these skills, which she originally developed whilst working on another hospice OH service as a volunteer, that enabled her to coordinate and train other volunteers on the service. She was responsible for setting up the OH service at the hospice and for its development over several years. Her role enabled her to reflect on recruiting and training others, and their approaches and experiences of the service, thus she had further knowledge and understanding of the motivations and backgrounds of volunteers and indeed the other parts of the OH service process.

She was different to the other volunteers in this study in being younger and perhaps representative of a different generation. She was unique amongst the volunteers in being able to demonstrate skill sets in interviewing and supporting people within a therapeutic or caring capacity (she previously worked for a homeless charity), as well as working with digital equipment and files. She often acted as an intermediary when recruiting and liaising with participants and their families, and occasionally would conduct interviews if no volunteers were available or it was a particularly challenging interview. Her responsibilities included preparing the interviews for archiving, producing extracts for events, and making physical copies to give participants and their families. She recorded one research interview

and was the first person to be interviewed. She was also my key contact in recruiting people for the study and helping to try and get a broad cross-section of people and settings.

### 7.2.2.2 June

June was 66 and a volunteer interviewer for the service. She had conducted approximately 20 interviews for the service and had volunteered on the service for over five years. A friend got her involved in volunteering at the hospice and she thought the OH service sounded interesting. Her mother had dementia and she wished she could have had some of her memories recorded. She had also borrowed the equipment and recorded an OH with an elderly aunt. She had also been interviewed herself by me through an NHS educational scheme when she was ill and so felt this was an opportunity to give something back. She had not listened back to her own OH yet. Her interviewing style was to stay off the recording as much as possible as she did not want to steer the participant in the wrong direction and thought it was important that it was their story and not hers. She was a retired primary school teacher and had no prior awareness of OH before joining the service. She conducted OH interviews with two research participants, two with Jake and two with James. She recorded two research interviews, one before conducting the OH interviews with research participants and one afterwards.

### 7.2.2.3 Lucy

Lucy was 65 and a volunteer interviewer for the service. She started volunteering for the hospice by asking people to fill in short surveys in the day centre and then joined the OH service shortly after. She had been working on the service for two years and had conducted interviews with 17 people. She graduated in social anthropology and worked as a qualitative researcher, which she really enjoyed and saw the parallels with OH, which she had some prior knowledge of. After she retired, she volunteered for Samaritans but then her mother became very ill so she had a break and decided she would prefer OH as it was face-to-face rather than on the phone. Also, she wanted to support the hospice because her husband had died there, and she thought they had been wonderful. She had recorded an OH with her father after joining the service. Her interviewing style was 'non-interventionist' and to stay off the recording. She was due to interview a potential participant who died before he could be interviewed. She recorded one research interview.

### 7.2.2.4 Kate

Kate was 71 and a volunteer interviewer for the service. She was introduced to volunteering on the service by a friend and joined two years ago. She had always been interested in history and studied it as part of her degree, and was also very interested in her own family history. She had interviewed eight or nine people. Previously she had worked as an English and French teacher with all ages, and when she retired thought it was a good opportunity to volunteer as she likes hearing people's stories and helping people. She conducted four OH interviews with Sarah. and two research interviews, one after she had recorded two of the OH interviews, and one after she had recorded all four. Her interviewing style was that she sometimes interpolated and talked too, and did not obey the rule of always being silent. She thought having another voice made it seem more natural.

### 7.2.2.5 Jack

Jack was 60 and a volunteer interviewer for the service. He had been volunteering on the service for three years. His wife was being treated for cancer at the hospice and he wanted to give something back. A friend was volunteering on the service, and he thought he would enjoy it as he liked talking with people and local history. He always enjoyed history at school but had not heard of OH prior to joining the service. He had conducted between 30-40 interviews. He was a second-generation owner of a boat business, and found conducting the OH interviews a nice break from his work and a way to relax. His interviewing style was more conversational, and he had been told by the Coordinator that he needed to speak less about himself and not try to fill silences, both of which he now tried to adhere to. However, he felt that there was not a right or wrong way to conduct interviews if the interviewee enjoyed it. He conducted two OH interviews with Ralph, and one research interview prior to interviewing Ralph.

### 7.2.2.6 Fiona

Fiona was 65 and a volunteer interviewer for the service. She had been volunteering on the service for over five years and volunteered as a telephone counsellor before that. She had worked as a Social Worker and was interested in narrative therapy, especially with young people, so liked the idea of recording life stories. Her partner died when he was in his 40s, and she wished she had a voice recording of him. She had conducted approximately 30 interviews for the service. She had some knowledge of OH with older people before joining the service, but not of OH in palliative care. Her interviewing style depended on the

interviewee, but sometimes she was quite conversational and sometimes she held back. She conducted two OH interviews with Heather and two research interviews, one before the first OH with Heather, and one after both interviews with her.

### 7.2.2.7 Karen

Karen was 67 and a volunteer interviewer for the service. She had been volunteering on the service for a few years and had interviewed approximately ten people. She was retired from teaching, and heard about the service from a friend. She previously only knew a little bit about OH. Her father, who had died shortly before she started volunteering, had created his own memoirs, and she wished she had known more about OH as it could have been something they could have done together. She had always been interested in personal and political histories, and during her MA study she looked at the stories of marginalised communities. She had a son with learning difficulties, and she identified as a feminist. Her interviewing style was to try and stay off the recording but also to prompt as needed and to allow for some natural conversation, so it was not like a monologue. She conducted one OH interview with Tim, and two research interviews, one before the OH with Tim, and one afterwards.

### 7.2.2.8 Richard

Richard was 63 and a volunteer audio editor for the service. He had worked on the service for five months. He had a PhD in biochemistry and worked abroad for over a decade, but came back due to his wife's illness, and his becoming her main carer. He felt he was unable to get a job in his field due to his age. His wife died at the hospice two years before, and he wanted to give something back. He wished he had a voice recording of his wife. He already volunteered elsewhere teaching people to use computers, and he made computer music so this seemed a good opportunity as he understood how to work with digital files. He found out about the role after looking on the website but was not familiar with OH before. He had edited approximately seven OH interviews. He enjoyed it but wished there was more of a social component as it could be isolating work. He recorded one research interview.

### 7.2.2.9 Simon

Simon was 59 and a volunteer audio editor for the service. He had retired from working in IT. He saw the post advertised online, and had volunteered on the service for nearly a year. He had recorded his own music so was already skilled in audio editing. He had not heard of

OH prior to joining the service. His father died of cancer, and he would have appreciated an OH of him, so this was an opportunity to give something back. He wanted to be able to work from home volunteering with audio editing so he could be near family, so he was provided with a secure laptop to access the interviews. He recorded one research interview.

## 7.2.3 HCPs

*Figure 10: A table showing background information about HCPs*

| Health Care Professional | Job Title | Age | Sex | Religion | Amount of Research Interviews | Connection to participants |
|---|---|---|---|---|---|---|
| 1. Holly | Assistant Practitioner in Community Team | 51 | F | Other – Church of England | 1 (ID8) | Referred Jake |
| 2. Judy | Staff Nurse in Day Centre | 51 | F | Atheism | 1 (ID10) | Referred Sarah |
| 3. Margaret | Junior Sister in Day Centre | 56 | F | Christianity | 1 (ID19) | Referred Ralph and James |
| 4. Keith | Specialist Palliative Care Chaplain | 43 | M | Christianity | 1 (ID26) | Referred Tim |
| 5. Geoff | Senior Chaplain | 61 | M | Christianity | 1 (ID27) | No |
| 6. Hannah | Bereavement Counsellor | 60 | F | Other – Agnostic | 1 (ID28) | No |

### 7.2.3.1 Holly

Holly was 51 and worked as an Assistant Practitioner in the Community team. Her role involved visiting patients in their own homes and giving general support. She had more time to talk with patients than other nurses and often referred people to the OH service. She loved listening to people's stories but had no prior knowledge of OH. She had to develop her understanding so she knew how to pitch it to potential participants. Her mother was also interviewed for the OH service and enjoyed it very much. Holly had four CDs but had not listened to them yet. She referred Jake to the service after chatting with him for over two

hours and finding out they had friends in common and grew up in the same area. She recorded one research interview.

### 7.2.3.2 Judy
Judy was 51 and worked as a Staff Nurse in the day centre. She originally worked on inpatients at another palliative care unit where the was an OH service so was already aware of OH and an advocate for it, but she had not heard of OH prior to knowing about the service. She viewed OH as being more personable compared to other methods such as memory boxes. She referred Sarah to the service whilst she was visiting the day centre and felt she had some amazing stories to share. She recorded one research interview.

### 7.2.3.3 Margaret
Margaret was 56 and worked as a Junior Sister in the day centre. She first found out about OH working as a Specialist Nurse in the community for 14 years. Once she had developed an understanding of the concept, she realised its importance and benefits for patients. She had recently started working in the day centre and was pleased to be able to continue referring patients to the service. She referred two of the research participants. She referred Ralph to the service because she knew he liked chatting and would enjoy it, and that they could adapt the OH for him to be more of a conversation. She referred James because she felt he would like to feel he was achieving something else separate to living with his MND, and she thought he would enjoy it. She recorded one research interview soon after the participant Ralph had died.

### 7.2.3.4 Keith
Keith was 43 and worked as a Specialist Palliative Care Chaplain. He had worked at the hospice for two months. Previously he had worked in a palliative care unit for 14 years as a Chaplain, where he had come across an OH service. He had a small amount of knowledge of OH prior to being a Chaplain, and described himself as a 'narrative theologian' with a strong interest in stories and belief in their importance for individuals to reconnect with their identities. He referred Tim to the service so he could leave a voice recording for his son, and as a method to help him reflect on his life. He recorded one research interview prior to seeing Tim after his OH interview.

### 7.2.3.5 Geoff

Geoff was 61 and had worked as a Senior Chaplain at the hospice for 13 years. He had no prior knowledge of OH before starting the role. He shared an office with Jenny, the Coordinator, and as well as referring patients to the service would sometimes act as a point of reference when she was on holiday. He sometimes used the OH of participants from bereaved family and friends when planning their funerals so he could get more knowledge of their lives, or even for extracts to be played at funerals. He had referred at least 40 people to the service in the past, but did not refer any of the research participants. He recorded one research interview.

### 7.2.3.6 Hannah

Hannah was 60 and worked as a Bereavement Counsellor in a team of counsellors offering telephone support to bereaved family and friends. She had been in her post two and half years but had worked in mental health counselling for 16 years. She had heard of OH before, because it was suggested to her in a previous job by her supervisor as an idea for a relative in palliative care, although they did not record one. When bereaved family and friends fed back about the OH, the vast majority talked about it being very comforting, although for some it could cause upset if a family member had been missed out. She was an advocate in her work for the model of Continuing Bonds – supporting the bereaved to have methods to continue their relationships with the deceased – and saw OH as a method for this. She recorded one research interview.

## 7.2.4 Family and friends

*Figure 11: A table showing background information about family and friends*

| Family/Friend | Job Title | Age | Sex | Religion | Amount of Research Interviews | Connection to participants |
|---|---|---|---|---|---|---|
| 1.Christine | Chiropodist | 52 | F | Christianity | 1 (ID23) | Chiropodist/Friend of Sarah |

### 7.2.4.1 Christine

Christine was 52 and a Chiropodist for the participant Sarah. She often visited Sarah and had got to know her well for more than five years. She had been given CDs of two of her interviews and enjoyed listening to them in her car, comparing it to listening to an audiobook. She particularly enjoyed hearing her voice and stories about being in the Women's Royal Navy Service. She recorded one research interview.

## 7.3 Chapter summary

In this chapter I have provided background to the various settings in which OHinPSC happened and the research interviewees backgrounds and involvement in the study. This serves as a method of 'setting the scene' for the following chapters outlining the findings and the CGT. In the next chapter, in three sections I present the research interviewees' motives, experiences and outcomes from being involved in the service in their various capacities. I also draw on the research interviewees anecdotes about other people's involvement in the service, when not directly part of the research as a secondary source and I use my reflexive journal and notes to cross reference emerging theories.

The three main research interviewee groups (participants, volunteers and HCPs) all had different reasons for being involved but there was a fair amount of overlap in their motivations and experiences. For the findings it was key to find a way in which I could integrate an understanding of all three groups succinctly. Participants are central to everyone else's involvement – without the participants there would no service – so they are given the most attention throughout the findings. However, by gaining an understanding of the volunteers and HCPs involvement it became possible to reach a collective understanding and to assist in working towards ideas for training and setting up successful services in the future. I conclude my findings by presenting the CGT (Chapter 9) which incorporates the findings into a basic social process from which the experience of OHinPSC can be understood and theorised.

## 8. Findings

### 8.1 Motivations

#### 8.1.1 Background

This section primarily considers the participants motives for taking part in the service, and what the volunteer who interviewed them and the HCP who referred them think were the participants' motives. Sometimes the participants' motives are revealed in their second or third research interview. This is after they have recorded their OH interview/s, and are being asked again and encouraged by me as researcher to go into more depth as to their motives. There is undoubtedly some transference by this point as participants' understanding and my questioning evolves through the process in line with the CGT methodology. The volunteers' motives for joining the service are also reviewed, as are the HCPs for pitching the service to potential participants. Initially this includes the challenges they encountered with understanding the concept of OH both for themselves and when approaching and reflecting on interviewing and conversations with participants. Structurally, motives are understood throughout the process in this section, from initial and ongoing understanding of OH, to storying and selecting a narrative and audience, to personalising a legacy as an ongoing presence for the bereaved and the archive.

#### 8.1.2 Primary motives

All research interviewees were asked about their prior knowledge of OH before being involved in the service and how they thought OH could be utilised. It quickly became clear that most of the research interviewees did not have one clear motivation for their involvement in the service but several, and I have tried where possible to break these down into primary and secondary motives, particularly for the participants taking part in the service. A method for integrating all the groups' motives mentioned above was established after many reiterations of writing this section.

After repeat reviewing of transcripts and my research diaries, I was struck by a theory which was discussed in the second interview with volunteer June who was interviewer for two participants (Jake and James), and a corresponding entry in my reflexive journal. June was unique in that she had previously recorded an OH herself, as part of a scheme, which gave the opportunity for interviewers on the OHinPSC Services project to get training in

interviewing, even though the interviewees like June were not palliative care patients. The fact that she had prior experience of being interviewed and now volunteered as an interviewer meant she had a unique perspective from both sides of the interview scenario. In her second research interview, we reflected on her motivations for being interviewed and she questioned whether she was doing it for herself rather than for family:

> …the one I did for myself I actually thought well I'd quite like to write down all this about what happened when I was little and all these things but I'm not sure if it's for family or whether it was just that I wanted to record it …to have it written down because you do forget things and then you know you're lying in bed at night or something and you think ooh I did that when you know - these things pop in your mind at strange times

> *now you've made me think of it as sort of a triangle in that way I suppose it's either for yourself or it's for family or for the archives or all of them or you know two of them, yeah that's really interesting, a kind of triangle and you can put all the interviews into that*

> and I know it's all going to go into the archive but if you were saying its specifically for that are you going to put a different slant on it?

> (Volunteer June, 2)

June reflected on the interview she conducted with Jake and discussed whether his motives were unclear. This led to us discussing her own experience of being interviewed and her motives for being interviewed. Whether people angle their narrative depending on who they want to hear their OH, or if they are just doing it for themselves, is pertinent to how I discuss some of the motives in this section. After the interview, in my reflexive journal I wrote about her talking about interviewing Jake and questioning his motives:

> She didn't know if it would be shared beyond his son but wondered if he'd want to hear such gruesome tales…It made me think of a triangle of experience between the interviewee - family (listening) – archives (listening) with the interviewer, HCP, Coordinator and Archivist central inside the triangle taking turns to ensure the triangle works.

*(Reflexive Journal, Volunteer June, 2)*

The corresponding triangulation was interpreted like this:

*Figure 12: A diagram illustrating the triangulation of motives and experience in OHinPSC*

Interviewee (participating)

Facilitation:
volunteers/
HCPs

Family and friends (listening)                                    Public archive (listening)

This is based on the OHinPSC Services project model in which the interviewee usually also signs a Recording Agreement for their interview to be archived. Within this model all possible audiences are considered, so interviewees are motivated for intrinsic and extrinsic reasons: themselves, family and friends, or the public archive – or a mixture of the three. The facilitation of the service by the volunteers and HCPs is central to making this possible and understanding the participants motives within this triangulation supports the participant in achieving the desired output from the interview. The volunteers and HCPs understanding of the OH service, and their natural bias as to how to conduct interviews or pitch the service, also shaped the corresponding motives and narrative of the participants, and again, there was a risk of this being misconstrued. There was also my own natural perspective to consider when reviewing the motivations of everyone involved, as a practitioner and past Coordinator on another OHinPSC service, and as researcher on this study. This undoubtedly played a part in my interactions with the research interviewees and the corresponding interviews.

During the first research interview with Jenny, the Coordinator of the OH service who had the most experience of OHinPSC of all the research interviewees, the multiple motives of participants for taking part was discussed.

> ...so I think that's a big motivation for people to actually – part of them to remain behind if you see what I mean...the stories that people tell if people have done something important, if they've played a part in something or other, however small, they like the idea of that being there and remaining. For others I think it's just that people like talking – they like telling their stories, sometimes it's just to pass the time, they might be a bit bored I don't know I get that impression sometimes – it's just something to do...but I think a lot of it yes it's about leaving something behind for relatives and just generally for the future...and I think also to sort of, I don't know, it's almost a consolidation isn't it, it's that sense of this is my life this is what I've done, people are proud of what they've done and it's almost like doing a review of their lives, yes.

> (Volunteer Jenny, 1)

The motivations for the individual (being lonely or bored/passing the time) and as a legacy for both family and the public archive all are mentioned here. The opportunity for life review fits within all these motives. By choosing to record stories about their lives they are also reflecting upon them at different stages – as they plan, discuss them and then listen back. Motivations may change during their OH interview, different topics may be talked about for different audiences, sometimes unknowingly. Motives are conscious, subconscious and temporal.

An interesting point Jenny raised was whether the need for continuation or leaving a mark is inherent in us all. Perhaps this is central to the ambiguity of the motives for recording an OH, whether as a legacy or a recorded conversation with a third party (the interviewer):

> ... I don't know if it's a biological drive we have to leave something. I think maybe that's why people have children on a biological level they are leaving a part of them behind – maybe it's why people create things, people write books or create great works of art because they are actually leaving a mark on the world, I think they say, don't they, we sort of – we finally disappear from the world when the last person

who remembers us dies, so when we die, we still live on in people's memories. But then eventually, as time goes on, the people that will remember us will die and then we will be forgotten – unless we are Shakespeare or Einstein, or whoever – but if you've made a recording, that stays in perpetuity and a lot of patients get really excited by the thought that their recordings will remain forever – they will be in an archive and that people will listen to them in the future and they are really keen...

(Volunteer Jenny, 1)

This is perhaps a major part of the service's appeal - the desire to be remembered or leave a mark is innate in all humans. Considering Jenny's comments and the theoretical triangulation of motives and experience, it is possible to view the different motivating factors of participating in OH as concentric circles for the individual, family and friends and public domain, as illustrated in Figure 13:

*Figure 13: A diagram illustrating the different motives and audiences in OHinPSC*



This illustration can be used as a lens for reviewing the research data in the following findings sections. Here it can assist in understanding the motives for all the research interviewees, whether they view it as an opportunity for the individual to connect and reflect in sharing stories with a third party, perhaps for something to do, because participants are lonely or want to take stock of their life. It could also be for the volunteers, the opportunity to learn new skills and give something back, and for the family or the public as a legacy which the volunteers and HCPs support in happening and producing. A family legacy may improve relations between the HCP and the participant and their family. A public legacy may improve relations between the HCP and participant and help forge a

relationship with the volunteers. In all scenarios there is the opportunity for the individual to self-reflect and to find possible therapeutic benefits. For volunteers and HCPs there is the motive of enjoying hearing the stories of the participants and being able to give something back by supporting the opportunity for conversations and legacies. I now break down what are deemed the three major factors in developing motivations for involvement in OHinPSC:

- Understanding the concept of OHinPSC, partly determined by how they had found about it and how they perceived it as an ambiguous medium and chose to adapt with it.

- Storying in how research interviewees determine the audience/s and identify with themselves psychosocially, to tell and share stories.

- The act of recording the voice: how the research interviewees were motivated by the opportunity to have a voice recording for the future as an opportunity for reflection, personalised legacy as a physical tangible ongoing presence for family and friends, and the public.

### 8.1.3 Understanding

All of the research interviewees were asked about their prior knowledge of OH. The majority had no knowledge of the term prior to their involvement with the service. Only one participant mentioned prior knowledge of the term prior to being offered it:

> …well I was aware of it, I was thinking of doing a similar thing but on paper, so I thought this would be a good opportunity to do it when [hospice name] said it was available
>
> *so you were already hoping to write something down*
>
> yeah I'd got something from the Motor Neurone Disease Association, they do a sort of paper equivalent.

<div align="right">(Participant James, 1)</div>

Two of the volunteers – the Coordinator Jenny, who had previously worked as a volunteer on the OHinPSC Services project, and volunteer June, who, as already mentioned, had been interviewed as part of the same service – had prior knowledge. Three other volunteers (Lucy, Fiona and Karen) had a little prior knowledge of OH, all from their previous work

backgrounds, either in qualitative research (Lucy), as a Social Worker working with narrative therapy (Fiona), or through working as a teacher (Karen). However, none of these three claimed to know specifically about OHinPSC prior to joining the service. Five of the HCPs had some prior knowledge of OHinPSC, mainly via connections to the OHinPSC Services project, by either referring people to the service there (Judy, Margaret) or being aware of the service in the case of the Chaplains (Keith, Geoff). Hannah knew about OHinPSC because a colleague had suggested it for her sister, although it had not been pursued. Keith also had some vague prior knowledge of OH:

> "a little bit…if I describe myself as a theologian I would view myself as a narrative theologian so aware of the importance of story...but the particular bit of the OH would have been new to me and its aims and things so I guess an awareness of narrative and the importance of narrative but not the exactly this sort of aspect of it."

> (HCP Keith, 1)

To summarise, other than some prior knowledge of the original OHinPSC Service project, which I coordinated (volunteers: Jenny, June, HCPs: Judy, Margaret, Keith, Geoff), very little was known overall about the term OH, and it was only previously encountered by those in either academic or research settings (volunteers: Lucy, Fiona, Karen), or having been briefly mentioned externally for recording their own history (James) or for a family member (HCP: Hannah).

### 8.1.3.1 Finding out

The majority of research interviewees, especially those who had did not have prior understanding of OH, found out about the method through conversation. The participants were all offered it verbally by the HCPs. Four of the participants were offered it initially as an activity in the Day Centre (Sarah, Ralph, James, Heather); two were offered it by HCPs (Chaplain Keith on the inpatients wards for Tim, and the Assistant Practitioner from the Community team Holly for the nursing home participant Jake). Two of the HCPs (Holly and Judy) had found out about OH after encountering patients who had been participants and were advocates. The participants had in effect referred the HCPs to the service by giving an understanding of the concept and demonstrating its meaning for the participant and their

family. Another HCP, Margaret, mentioned hearing about it first in MDT meetings as something which could help support people who wanted to leave a legacy or would benefit from it psychosocially. Some of the volunteers also found out about the service and the concept of OH from conversations with past participants or volunteers. Several had previous links with the hospice in other volunteer capacities, or through their own family experiences. One of the volunteers, who worked as an editor, Richard, discovered it from a web advert. Many of the volunteers, including Richard, had witnessed someone close to them die and wished they had a recording of them. These volunteers were more centred on the family legacy potential of the OH service.

### 8.1.3.2 Ambiguity

How the service was understood when the research interviewees found out about it, and how this influenced what was actioned by referring HCPs, participants and volunteers in taking part, was arguably, for some, ambiguous. Two of the HCPs remarked on issues explaining the service:

> ...when I first asked someone if they wanted to be put down for OH I didn't really know that much about it, I'd just seen one of our patients that's on front of a leaflet that's giving his life you know talked about his life and stuff and I thought oh looks good and this patient just says 'well so what does that mean?' I says 'well it means you're putting your life on a disc' and I says instead of writing everything down and it's 'why am I dying now?'  I were like oops [laughs] so I had to then like very quickly build up this big spiel in my head and I just said 'right so OK let me just start again so no you're not dying at this moment in time but wouldn't it be nice for years to come you know when your day comes like when mine comes, if for your family instead of just photographs they've got your voice?' I says and you know some of them that you don't like put a message on there and they'll never know and it sort of turned it round but then I just thought wow you've got to be careful of how you're going to put this across and that were like one of the first experiences but then since then I just choose my wording, I wait while I'm you know I've been there a while and then we'll just be chatting and if they start with stories you know 'oh back in my day it was such' and... 'oh god you'd be great for OH you need to put that on a disc, you really do', so it's more of a story now not the meaning of it type thing but I mean it's

for both I feel. . . so I got over that hurdle where If they ask me if they've died I say its stories. . . it's easier.

*And is there anything which would help you in kind of doing that spiel with people is there anything any kind of support you could be given?*

No I mean I don't think so I think it's just...you've just got to have that confidence to say it because there are a lot of around palliative care there a lot of questions and conversations that people don't want to have.

*So it's just knowing how to word things*

yeah and knowing that person so I think that's what it is its knowing individual and that they're all different.

(HCP Holly, 1)

The issue for HCPs referring people to the service were in the semantics and timings of how the service was offered and perceived. The term OH for many is academic and can be difficult to explain and understand for all involved. The concept of OHinPSC, or at the end-of-life, can suggest the potential participant is about to die. In this scenario the participant leaves a legacy, often for the family, as with participants James and Tim. Both had a firm understanding they were recording a legacy for their families and this was how it was offered to them. For the other participants, the service was offered in a more ambiguous way, in which their life expectancy was not an open, conscious, consideration. The service instead was a variation of a method of sharing stories and legacy making. The way these four participants (Jake, Sarah, Ralph, Heather) approached the interview and constructed their narrative accordingly was different to James and Tim, who were consciously creating family legacies from the start.

The discussion about impending death and personal legacy can be avoided if the service can be viewed as an open conversation or recounting stories – an activity that is on offer in the Day Centre or as something to do to "lift the patient's mood" (HCP Holly, 1), in the nursing home. When OHinPSC happens with more informal motives, without clear knowledge of who will listen to it afterwards, and in what context, there is arguably more risk of

unintentional upset or it being misperceived. In this method, OH is more akin to reminiscence work, or even having a conversation about the past. There is more emphasis on local and social history and less on the personal family record. The audio recording may be more for the public archive or for the individual rather than family or a specific audience.

The concept of who the interview and recording was for was also ambiguous: "Just that they're doing a study on...people reminiscing about the olden days" (Participant Jake, 1). Two of the participants (Jake, Ralph) changed the power dynamic to it being a study or collecting information, suggesting its primary use was for a researcher or the hospice rather than for the participant as a personal legacy:

*Could you just by telling me what your involvement is in the service?*

your service or

*the OH service what's your involvement in it?*

I'm just giving information about [place name] and my life.

(Participant Ralph, 1)

In these cases, the audience may not be known or considered:

*What do you plan to do with your finished OH recording?*

I've never even thought of it

*no so they will give you a CD at the end basically*

yeah well that part has not come up

*yeah but you know I mean obviously it's being archived as well and...*

I will probably give it my sister.

(Participant Ralph, 1)

For some people it was something to do because they were bored or lonely. It might be because they wanted to consolidate what they had done and an opportunity for reflection,

or to have a conversation; for someone to listen to their stories or the chance to leave a mark. The open-ended nature of the offer could be confusing if not fully understood:

> I get the impression from some of the people I interview that they don't really know what they're doing, they don't know what it's for or anything so I think that might be something that could be a little bit better.

> (Volunteer June, 1)

The importance of them reading the leaflet first and for the HCP or volunteer spending time with them before to explain could be a way to counter this:

> I think it's because they don't digest the information and also some of them may not have had all the information it depends who's passing it on to them, if they are just given a leaflet sometimes you just skim leaflets whereas if someone talks to them that's doing it they may - it makes them understand better.

> (Volunteer June, 1)

There was the risk that potential interviewees did not fully understand the process and read the information fully. This could be countered by a comprehensive explanation directly before the interview:

> I think talking to them for 10, 15 minutes before you start recording is very helpful because they are more comfortable, they know what you're doing and they know who it's for because some of them don't understand who it is for, and they keep saying 'is that what you want?' And that's not what it's about and you reassure them.

> (Volunteer June, 1)

In our second interview June reaffirms this theory and questions whether Jake understood the interview was for his benefits rather than for the OH service:

> *and he didn't give you any real idea of what his motives were for doing it then?*

> No, the only thing I could think was he'd been approached to do it, and I think sometimes they think they're doing it for us or the service not for themselves, I've

heard that once or twice people have said oh what - is this alright is this what you

want? And that's not the idea of it so I think that's what he's doing it for more than

anything.

(Volunteer June, 2)

Here the OH interview morphed into an ambiguous co-construction between the

participant, volunteer/s and referring HCP. The collective understanding determined the

thought necessary motives.

### 8.1.3.3 Adapting

In this sense, OHinPSC can be an adaptable medium with a spectrum of uses and thus

reasons for taking part. These may be based in the process for the individual (the

interview/prior engagement), or in the output (the recording: family, public). OH can

produce a range of facets for the individual, family and the public domain. It was offered via

the study hospice service in a variety of ways (drop-in timed allocated interviews, Desert

Island Discs, full life story interviews) on different sites. Whilst with all the methods there

was an understanding it was being recorded, the importance of the legacy differed. For

some, the opportunity for conversation and hearing stories was given equal billing. This was

how it was understood by some participants and volunteers: "I didn't know what you were

really after so all I really mentioned and talked about was my life story, and my accidents

that I used to have…" (Participant Jake, 2). Jake re-appropriated his narrative in the

interview to suit his understanding of OH.

How the service was understood by the volunteers could also be ambiguous and adaptive.

Some of the volunteers preferred the conversational method, benefitting the individual's

wellbeing and talking about local or social history, whereas some were more motivated by

supporting someone record their personal or family legacy:

… I thought wow that would be amazing because that's something local history and

just speaking to people is just something I really enjoy doing… its - the surprise of it

all is and just the human stories is just I love it.

(Volunteer Jack, 1)

Amongst the participants and volunteers there was an interest in history which made the association with OH easier to relate to. The participants who were not recording primarily family legacies found associated histories were key to them. For instance, Jake made several references to the local museum replica of a former butchers he frequented with his father when he was young. He mentioned it in relation to understanding OH, and the idea of living history, and, for him, OH was a way to share his stories as a social history resource. The replica was an example of a past being preserved which was part of his history. In tandem, his narrative centred around stories of growing up locally and living in poverty. Sarah mentioned enjoying reading local history books, and one premise of her OH was to set the records straight about her parents' involvement in the village library where she came from. They were omitted from a book about the village and, she feared, had been forgotten. For her, the village had changed to commuter belt territory rather than the place she knew. Heather was a keen genealogist, and it was this pursuit that motivated her interest to record an OH. Her narrative was thus based on her relatives' histories rather than her own. However, they were based on her strong family connections, with generations of her extended family working together as market traders. For these participants, OH offered an opportunity to discuss and give witness about a key place and time in their life. This was evident in the research interviews and their OHs. During the research interviews, these participants would freely slip into telling their OHs.

Several of the volunteers had been involved in recording their own family OHs or wished that they had one of a relative. These were the ones likely to treat interviews as primarily a legacy exercise. However, one volunteer, Fiona, viewed it more as a therapeutic exercise to unpack feelings. This was an attribute also shared by several HCPs. The volunteers and HCPs put the participant and the family at the forefront for different reasons. OH offered an adaptable vehicle for determining what the participant wanted, as well as what the HCP and volunteer perceived they wanted.

### 8.1.4 Storying
By being recorded and the participants knowing that it was being recorded, the assumption was that this was a historical artefact, and storying was central to the creation. Story was omni-present in everything that happened within the process, from the participant finding out and agreeing to take part via conversations with the HCP, to the interview being

conducted and how it was received by its audience. At each point narratives, both internal and external, were being created. If storying is expression and history is factual evidence, the storying was everything in the process driven by experience and giving meaning, which was not archived, and data driven. Storying was integral to all the interviewees narratives, and it permeates throughout the findings. The evidence for this thesis is built on stories and storying. In this section, storying demonstrates motives which are not strictly about recording a family legacy but are more for the individual or the public realm. The research interviewees refer to storying throughout, and it is implicit in their motives, especially when adapted to something other than a family-focussed legacy recording. I start by outlining how the different approaches to OH connect to the perceived audience whether it be themselves, family or the public realm. I then share the findings on how storying was integral to participants identity and their psychosocial being. I consider the act of storytelling as motivation, and a medium to connect with and learn about other people.

### 8.1.4.1 Selecting an audience

The narrative adopted by each participant was dependent on who they felt their intended audience was, besides the volunteer interviewer. There was evidence of participants being motivated to tell their stories for their own benefit, their families and the public realm. Notably, while all had some remaining family, how the OH was composed tended to relate to how much it was aimed at a specific family member. Participants James and Tim both had specific family members they were recording for: "I...I want to leave something for my family that they can look back on and, grandchildren can find out about different parts of my life" (Participant James, 1)."I want to make something for my son...so that he will know about my life and know, what has gone on in my life and stuff" (Participant Tom, 1). Whilst they were open to the sharing their legacy with the public, their primary motive was to share it with family: "I mean if anybody else wants to listen to it that's fine but specifically for him" (Participant Tom, 1), "I don't mind leaving it... for anybody really" (Participant James, 2).

Participants Jake and Heather both had children in mind for their recordings but had different interpretations of the concept of OH as personal legacy. Both had complicated relationships with their children, and, correspondingly, the idea of recording personal legacy was more complex. As a result. they viewed OH as two-fold: a way of leaving a mark and

remaining and to share stories in the moment. There was a desire from both to pass on stories so they were not lost, and for their children to learn from them. Jake wanted his son to know the truth about his life:

> I'd like my son to hear it...because I don't think he believes half the things I come out with but if he's on tape he's got to know it's true because I wouldn't lie, I wouldn't lie about anything like that no [laughs] oh he'd be surprised about some of the things I used to get up to when I were a young un...not criminal...but fights and oh...[laughs]
>
> (Participant Jake, 1)

The father-son relationship figures heavily in his narrative, both in the research interviews and OH. In the second research interview, his OH becomes an opportunity to understand the meaning of money and social conditions:

> ...if you can get across to people how poor we were then, to what we are now
>
> *yeah and when you say getting across to people do you mean whoever listens to it?*
>
> Whoever listens, I mean there is probably if there is people going to be listening to it they're probably a hell of a lot younger than me and they are going to be well they had hard times.
>
> *Yeah so it's making sure that's passed on to be heard?*
>
> Yeah
>
> (Participant Jake, 2)

This narrative is adapted for passing to his son:

> I can't wait for my son to hear these tapes because what he's got now, and he listens to what we used to have and how poor we were he might thank his lucky stars that he didn't live then or things were like that now because I don't think he would grasp it at all the concept of being poor you know what I mean? So I can't wait for him to hear it yeah.
>
> (Participant Jake, 2)

Heather wanted her children to know her family stories and to be interested in family and the past, rather than engrossed in their phones. There is a tension here in the relationship with her children involving digital technology and what she sees as a meaningless pastime.

*What are your motivations for taking part?*

erm, because I love genealogy, and I love my family's history, and kids today don't really care, I know that's stupid but they don't, I just thought I'd love to get it down on tape, because all my older generation are going, and these stories - there's some right characters in my family [laughs] you know this can't be lost.

(Participant Heather, 2)

For both there is a communication disconnect with their children. Arguably, as a result, their narratives in the interviews become slightly askew. Both participants also relate to the idea of their OH being used as social histories in the public realm. Their narratives are shaped by reminiscence and wanting to leave their mark, but with their children in mind as a secondary audience. For Jake this manifests in the form of grizzly stories of growing up in a deprived area and recalling his brother's and parents' deaths. Heather shares family stories of her ancestors and characters she knew through market trading, but largely avoids talking about herself and her own life throughout the interviews.

Participants Sarah and Ralph were the oldest participants and had the least close family to give a recording to. Their motives were more general: they both enjoyed conversation and liked the opportunity to put it on record. They were motivated by passing on stories from certain times and places when they were happier. For Sarah, this was growing up in her village, and generations-old stories of highway men and smugglers. For Ralph, this was his career and his local knowledge of his home city. Both bemoaned how these settings had changed for the worse, citing new buildings as one-way things were lost. They weren't sure who would listen to their OH or if it would be of interest to others. This changed for Sarah on her final OH interview, which was intended for her sister who was dying. She was motivated to do this interview to talk about how proud she was of her sister.

Compared in this way, the participants can be seen as on a spectrum from recording their OH as personal legacy for a specific audience, to recording a public history. How their own story features in the history can fluctuate, dependent on who their specific audience is:

*Figure 14: Diagrams to illustrate the continuums of interview audience narratives*

Specific

audience            Non-defined audience

Personal legacy            Reminiscence/public history

Own story            Others' stories

For James and Tim, their OHs were to the far left, whereas Jake and Heather were somewhere near the middle, and Sarah and Ralph towards the right (changing on Sarah's final interview for her sister). It is taken that this model will not always be correct, people may choose to record a very personal legacy which isn't targeted at a particular audience, and a public history for a specific audience, but this was not encountered in the study. This model helps to understand people's motives for being involved and perhaps how to guide them as to how to frame their narratives. The two participants who were nearest the middle on this scale (Jake, Heather) also had the most problematic interviews. These were examples of where there was a potential specific audience, but they were tailored to as a by-product of the stories the participants chose to share**,** and there had been a breakdown in communication within their families**.**

Some participants chose to talk about themselves whereas others predominantly shared other people's stories. In this study both females (Sarah, Heather) opted to share less about themselves and more about stories of ancestors and people they knew. All the men (Jake, Ralph, James, Tim) talked mainly about themselves in the research interviews when referring to their motives. Usually when someone was recording a personal legacy for a

specific audience such as family and friends, it was by default their own story they shared, but anywhere else on the scale above it could become about others' stories.

### 8.1.4.2 Identifying and sharing – being a storyteller

The psychosocial attributes of the OH process and how the participants felt in the moment during the interview, and throughout the process, continually reshaped their motives. This section considers what the HCPs and volunteers believed to be its benefits and whether these were apparent to the participants as a motivation to take part. For participants, particularly those who were not recording primarily family legacies, stories were a way for them to forge an identity as open storytellers. Although their reasons for being involved may not have been to solely share stories, taking part in the OH process enabled them to foster and develop them. For the HCPs and the volunteers, hearing the stories was a way to learn more about the participants and to give them autonomy.

Whereas the two participants (James, Tim) who were recording their life story for family recognised the value of the opportunity, they felt more pressure and were unsure about what to say:

> …I'm a bit nervous actually
>
> *OK, so you feel a bit nervous because you're not sure what you'll say*
>
> yeah
>
> *and you want…*
>
> I don't want to be muddled for words and...
>
> *sure*
>
> along those sort of lines, like muddled for words and not really have much to say I want to have lots to say but I don't know what I've got to say, to be honest at the moment, whether they'll be able to coax something out of me I don't know.
>
> (Participant Tim, 1)

The other four participants (Jake, Sarah, Ralph, Heather) were much looser in their narratives and who it was aimed for, with it being a mixture of the self, public and family.

Those who did not clearly mention family as a primary motivation in the first instance all presented stories linked to their identity in a specific period in their lives, using the OH service as an opportunity to reflect and reminisce. The stories all represented change and a moment in time which the participant identified with and had a distinct purpose, and had a clear beginning and end, and perceived heroes and villains – which also created the motivation for the narrative.

For Jake, the onus was on his son, who didn't understand the poverty and hardship he had endured. Sarah criticised the newcomers to the village she grew up in and hated how it had been modernised and changed into a commuter belt. She talked at length about the lady of the manor and several village stories about highway men and smugglers which had been passed down generations. Her husband had died in his early twenties, so the history of the village, before and during her childhood, was a time before trauma in her life, and one around which she felt most control. There was a sense that if she didn't give witness to the time and stories before the village changed it would be lost. Ralph talked about his career and the changes in local history. He was keen "to share knowledge which otherwise might be lost" (Interview 1). He was critical of the Council and how housing and commerce had changed. In line with this he mentioned supporting a local library when it was threatened with closure. There was a strong sense of then and now and us and them. For him the knowledge he wanted to pass on was based on working conditions and opportunities through the time of his career. Heather had a strong interest in genealogy and was keen to talk about her family history and her time spent working as a market trader. Again, there was a strong sense of then vs now, us vs them, younger vs older generations, and specifically her children, who were more tech savvy but less interested in talking and history. In this narrative the enemies were technology and her children's disinterest. The opportunity to preserve reminiscences and the chance others might listen afterwards gave added agency for the participants. However, for all these participants there was a generational disconnect and nostalgia for a specific time and place which was better or misunderstood (See Section 10.5, p.211 for more context about nostalgia in oral histories). There was a desire that these were the stories worth recording and of some benefit for the self and the public realm.

All the volunteers were motivated to be involved in the service because they enjoyed hearing people's stories: "stories, anecdotal evidence is just uniformly splendid" (Volunteer Richard, 1), and some of the volunteer interviewers had experience of storying from their career backgrounds: "I'd always had contacts in my jobs with people, and, I was interested in hearing their stories basically, and I felt I had some ability to draw people out, I like that." (Volunteer Kate, 1). These career backgrounds were either in teaching, social work or qualitative research, all using stories in different ways: "Sitting with someone and saying to them tell me your story is what I did in my early career in a kind of semi-structured form." (Volunteer Lucy, 1). The only male volunteer interviewer was also the only volunteer both from a business background and still working. The other interviewers were from social or teaching backgrounds and retired. His main motivation for being involved was to give back for the care his wife had received at the hospice. He was enthused by hearing stories, but more from a local history angle. There was a sense of altruism and appreciation for learning new stories:

> … from a selfish point of view it gives me a complete different perspective on life on other people older people in particular where I mean I have this sort of thing where people go oh you know 'old people are just old and boring' but you sort of think no, they've seen everything done everything they know everything so [laughs] if you listen to them you will learn something so I actually - just getting out of the office for that hour and doing something completely different to it...
>
> (Volunteer Jack, 1)

Challenging perceptions of older people and giving them the opportunity to record their story was seen as both a legacy and well-being activity:

> …I like hearing people's stories and once they've gone these older people you know…you no longer know what life here was like …the places they'd been you learn a lot yourself don't you?…Or they just like it's nice hearing people who - see their satisfaction at telling their own story.
>
> (Volunteer Kate, 2)

The satisfaction from participants telling their story was central to HCPs' motivations for referring people to the service. The opportunity to give voice to the patient:

> One of the first ones I actually referred… he said 'oh my story aren't that good', and I said 'well why don't you let somebody else judge that?' I said 'because it would be amazing if somebody else could take something from what you are saying', I says you know I says 'don't forget we weren't there, we weren't in wars we get told little things and we can read things in books but to know you've sat with someone that's actually done that' I says 'that's amazing'…so they did it.

> (HCP Judy, 1)

The volunteer editors Richard and Simon were unique in that they listened to the recordings but didn't interview. They both had backgrounds in music technology and the necessary skills for audio editing. It could be argued that their prior interest in music was also connected to stories and creative interpretation. Spending time listening through and making edits meant they heard all the stories on tape, sometimes repeatedly and in detail, such as when editing out a cough. They were both motivated by losing family members and wishing they had their own recordings of loved ones:

> Some individuals have interesting stories so instead of focusing just on the noises, some people's lives are actually quite interesting, a couple of horror stories in there, most people's lives are not very interesting to people other than their friends and their family but that's massively important to them and I would have liked to have had the same thing - I miss the sound of my wife's voice but I have no video you know we have no recordings so that motivates me.

> (Volunteer Richard, 1)

Whether a story is of interest to a wider audience than family and friends is consistent with how the OH is collectively pitched and narrated. The existence of stories which are temporal, conditional and flex to suit the participant and volunteer in the moment may not translate well to a public archive. Sharing stories can be validating and for some of the research interviewees this was deemed as important as the recording. The psychosocial benefits of having company and being able to talk or listen to a third party was motivation

enough. In these situations, the public access and preservation of the recording are secondary drivers and may not have even been considered. Storying is separated from history-making, with less understanding of the purpose of the history - it is instead a vehicle for self- and collective reflection. The participants were supported in this pursuit by the HCPs and volunteers and vice-versa. The volunteers enjoyed listening and learning about people's lives and the HCPs found it a way to build rapport with participants and their families and to know the person behind the patient.

### 8.1.5 Recording the voice and stories

"People hand down oral stories throughout their lives don't they and they never get recorded." (Volunteer Karen, 1). The act of making a recording to be passed on as a legacy and an archival document was a clear apparent motive within the study mentioned by all interviewee groups. In this section I will firstly share the findings in terms of leaving a mark for the future and the impact for the participants to be able to talk and reflect. I will then present the findings in terms of leaving a legacy for family and friends and particularly the opportunity to leave a voice record, the latter being mentioned by several research interviewees as a motive. Finally, I will share the findings in terms of the motivations for sharing an OH for the public realm as a resource to be used by others.

### 8.1.5.1 Talking and listening for the recording – reflecting and enabling

For most research interviewees having a voice recording for the future seemed to be a key motive. However, it was often unclear who it was exactly for, and to what extent it was for family, the wider world or just themselves. For some it seemed the act of talking and having someone listen to them, with the knowledge it was being recorded, was reward enough. Having a specific audience was either not as important or they valued it as much for themselves to listen back to take stock of their life. The importance of it being recorded was unclear. For some a conversation may have been enough but the opportunity to have it recorded was certainly valued by many of the research interviewees. This was echoed by Ralph, who, when asked his motivations, referenced having a conversation with someone about his knowledge of the area:

> *…what were your motivations for taking part?*

> I was asked by one of the staff here.

*…and it appealed to you?*

I just like people that like talking

*…OK so that was your main reason and you've quite an interest in [place name] as well haven't you?*

Well I've lived here 82 years nearly 83 years...born in the city centre so I know the city very well, I lived in this house that I'm in now, since 1964 and that's on the outskirts of [place name], so I've seen a lot of change there and from one side of the road that I'm on there was about three houses now there's about 150 flats and - so you've seen growth expansion whether its quality or not I don't know.

(Participant Ralph, 1)

The referring HCP also suggested having a conversation as his reason for taking part, and, on being asked by Ralph if OH was appropriate for him, mentioned how adaptable it was as a medium:

…he just enjoyed talking really and I said to him you know 'if you have the opportunity to do anything you wanted in relation to talking to people what would you like to do?' And he said, 'I'd like to talk to somebody about [place name], I'd like to talk to somebody about the places in [place name]' he said 'are there any other patients who I can talk to about [place name]?' And I said, 'well I can't promise that but I can refer you to something I can get Jenny to come and talk to you about OH, if I can get her to come up today would that be OK with you?' He said, 'oh yeah' he said 'but I'm not sure it will be - it will work because...they might not see it as OH' I said 'I think they will and they will be able to adapt, to the way it will work.'

(HCP Margaret, 1)

In this sense it could be argued that he was not only requesting a conversation but knowing it would be recorded, an opportunity to reflect and share his knowledge about his home city and the changes he had encountered. How much this was for himself or a wider audience was not clear in our interview, but there was a suggestion that he wanted other people to hear it, perhaps as a social history resource: "I looked at it just in - I have knowledge that if -

if somebody hadn't asked me would have just gone with me, and how many more are there like me?" (Participant Ralph, 1). The motive for being recorded as an act of reflection for the self or others was also mentioned by one of the Chaplains:

> …you've led an interesting life [laughs] but have you thought about recording this? So sometimes for other people and sometimes as much for themselves, it's about them being able to reflect on their life really what is it you know.
>
> (HCP Keith, 1)

It is unclear whether recorded reflection can be seen as life review or simply an opportunity to reminisce with someone about a particular aspect, such as the changes in the places they've lived. The concept of reflecting is linked to participants recounting their own experiences or sharing the experiences of others. Knowing that the interview is being recorded, and not a private conversation between two people, creates of performance between the narrator and the interviewer, performed also for who listens afterwards whether this be family or as a public resource. Thus, reflections may be personal or more social accordingly dependent on target audience. If the participant has opted to have the interview recorded and given clearance for it be archived with an understanding of what that means, it is inevitable a third party audience is being considered. If the recording was strictly an opportunity to record for themselves, there would be no need to sign the Recording Agreement for it to be archived. However, there may be joint motives to do it both for self and others. The acts of self and social reflection, whilst not always singular, are distinct with different motives attached. For self this could mean remembering and taking stock, with social reflection, an opportunity to reminisce and be heard. The role of the interviewer as witness adds another layer. For Ralph, he was keen to be interviewed by someone else who knew [place name] and requested a white male, perhaps someone he could relate with from his own experiences. This was known by the volunteer interviewer in advance:

> All I know is he is called Ralph and Jenny said that he wants it to have a man not a woman interviewing and he wanted someone from [place name] so he could - obviously he is a local [place name] bloke and wanted to talk about [place name] with somebody who knows…

<div align="right">(Volunteer Jack, 1)</div>

A motivation for several of the volunteer interviewers in joining the service was to enable others to be able to reflect and share their experiences, knowing the therapeutic properties of being able to talk openly to a third party. This was given as motive by the Coordinator, Jenny:

> …a lot of the volunteers they come from a background that sort of maybe social work, often from a background where they've listened to people, they've perhaps been a Samaritan a few of the volunteers so I think they're sort of tuned into that you know and I think they just they feel very privileged listening to peoples stories and to help people leave something behind, in that same way really and they just enjoy spending time with people and I think it's the same for me I think I feel for me it's also about preserving the voice and that's what family members say afterwards that actually it's about the persons voice more than anything else - people do come back and say they've heard things that they didn't know, about their relative but mainly they say it's a person's voice.

<div align="right">(Volunteer Jenny, 1)</div>

It was clear that for some participants having the voice recording was a core motive, especially for those recording a family legacy. A less clear motive for some participants was the opportunity to talk, reflect and give meaning to their experiences with the secondary knowledge that it would be recorded and could be listened back to either by themselves or others; the act of being able to give voice and be heard in the present and in the future.

### 8.1.5.2 Personalising – as a form of end-of-life legacy

Being able to produce a voice recording was seen by many of the research interviewees as a personal way to leave a legacy, especially when leaving it for family, as with participants James and Tim. Recording the voice as an alternative to writing was mentioned by both and by other research interviewees. James, who had MND, was unable to write down his life story and was aware his voice would deteriorate, so the OH service offered an opportunity for him to vocalise his life stories:

> …I knew there was a way of leaving history behind, like I say I've had the sheet from the MND Association with a view to filling it in, never got round to it but weren't - [hospice name] said there were this available I thought yeah it might be better in my own words.

> *…so you feel this might be a better way to do it then the MND approach?*

> More personal

> (Participant James, 1)

For Tim, it was more that he wasn't comfortable with writing, a reason mentioned by the Chaplain, Keith who referred him:

> …I'd wondered about things that he might be able to do to leave cards or things for his son as he grew up for significant occasions and he was talking about not being able to...write very well, and I think something just popped into my head about well actually recording your voice and having your voice for your son, might be a good thing and I said 'has anyone talked to you about OH and the OH project here?' And he said 'no' so I told him a little bit about it and I could just see that it really grabbed him as something, as I say whether something for himself or for his son or, I suspect a combination of both, so I said well I would find out what needed to happen next.

> (HCP Keith, 1)

For both these participants, OH was deemed more accessible than writing, whether because they were constricted by their illness, or they did not feel confident in writing. Another factor for some research interviewees was it may be harder or more upsetting to write down personal memories compared to voice recording them. As the Chaplain, Keith pointed out:

> So if anyone for example with this person who was talking about what I would review as legacy questions as to what...what might their children know about them, their sense of missing important future occasions, they were particularly saying that they weren't able to write anything...struggling to write so actually the sense of having their voice recorded, so there was something in this particular incidence of

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someone being able to, have something of them self-recorded for... their children to be able to listen to and to know something about... their father...

(HCP Keith, 1)

If having a voice recording served as a useful alternative to writing, it could also be used in the reverse for those whose voice had deteriorated due to their illness. The volunteer could then transcribe it or write a summary of the conversation to give as the family legacy:

I also did one with someone with multiple sclerosis...originally he wanted someone to write it down as he said it and I said 'well I can't do that' but I said 'I'm prepared to record it and then write it', which is what I did and so he wanted it for his daughter who is nine and...his wife came as well and so that actually was a really nice interview because he couldn't speak very well...but she was able to prompt his memories and it was... memories of them both but I transcribed the first interview that he'd done with someone else and then I knew where we were going and then I gave him that and all the others...that was interesting to do that because... it wasn't that he couldn't remember but he couldn't actually put it into words because his speech was really badly deteriorating...

(Volunteer June, 1)

In this instance, the OH interviewee's wife was also present to support in prompting memories. The transcript successfully became the legacy document based on the audio recording. Having a voice recording was seen as more personal than other legacy items such as photographs and memory boxes. Being able to hear the voice could offer comfort for the bereaved in a more tangible format:

...you can do a memory box and people can write letters and things but it's just not as personal and I think people's feelings don't come out as clearly as they do on the recording so it's that and it because listening to your relatives voice is so I suppose it is so real for them to be able to just pop it on when they're missing their husband/wife whatever it's just so much nicer somehow it's better than yeah you can look at your memory box but somehow it brings them that bit closer and I've heard lots of relatives say that so I think it's the nicest way of doing it.

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For several research interviewees, being able to hear the voice presented an added element to a family legacy which was unique in offering something which would otherwise be lost. As James mentioned, it was better in his own words. A voice recording gives more context and identity to the stories than writing alone, as mentioned by Geoff, the Chaplain:

> There's the voice which is very important for patients and relatives to have their voice and for the grandchildren maybe when they're small to be actually hear the voice hear the story, there's the whole thing about legacy about this was your grandmother this was what your grandfather did so the schooled projects that they get onto what did granddad do they're taking his CDs now and kind of saying well this is what he is doing and those sort of things and actually it gives context into people's life into where they've come from, it helps to root them in who they are and what their families are, now that's a good and sometimes a bad but on the whole it's a good thing.

Hearing the voice in bereavement was mentioned as being comforting by several of the research interviewees, although there were also accounts of it being upsetting for some, especially in early bereavement. The recorded voice became an ongoing physical presence and a method for continuing bonds with the bereaved. Although bereaved relatives and friends were unable to be interviewed for the study, accounts were given by some research interviewees on hearing recordings of their own deceased relatives:

> I think I feel for me it's also about preserving the voice and that's what family members say afterwards that actually it's about the persons voice more than anything else - people do come back and say they've heard things that they didn't know, about their relative but mainly they say it's a person's voice and I think I - over the past few years I found recordings of two of my - well my two grandfathers and the first one I remembered that my father had had a Bolton accent but I didn't realise how Bolton he was and it was like wooo but I also didn't realise how articulate he was as well. My other grandfather I'd completely forgotten what he

sounded like, completely forgotten - I had no recollection of his voice and he died when I was 15 and I found a recording and we are all on it and he had quite a quiet voice and I'm straining to hear his voice and as soon as I'd heard him I though god he sounds just like my uncle [laughs] but it's just - it's getting a person's voice. he came back to me in his voice and that is what people say.

(Volunteer Jenny, 1)

The familiarity of hearing the voice, its accent and articulation, was a powerful way to remember the deceased. One volunteer remarked on finding an old camcorder video of her deceased husband with a short snippet of his voice recorded, and how not having more motivated her to join the service:

*…what were your motives for becoming involved in the service?*

Well you know that obviously my interest from social work but also I lost my partner quite - you know he was quite young in his 40s and, I suppose it's the strength of the voice, you know the importance of the voice, I haven't got that from him really and he had quite a distinctive voice, so that feels quite sad that I haven't got that and the children haven't got that, all we found was an old camcorder, in the house I thought he'd thrown it out but there was no you know just the film and he must have been beckoning one of the children to come so his voice is on that but that's about the only thing I've got so you know I just thought well if he would have done this that would have been really interesting…

*…could I ask you obviously you are under no obligation to answer this at all but how did you feel when you found the camcorder tape, listening back to that?*

Oh yes well it was actually really emotive, you know it actually takes you back to that you know and just thinking but it was also quite helpful you know, and I shared it with the children who are old enough now obviously…and yeah, no it was celebratory really rather than sad so that bit was really good, it wasn't really - I mean the only words were 'come closer to daddy' [laughs] you know that was all it was you know because he was trying to obviously take a film but it was really good.

(Volunteer Fiona, 1)

For other volunteers, wishing they had a voice recording of a family member also served as a motive for joining:

> Of course, we all feel oh my goodness why didn't we do this with our parents…I mean my mother wrote her, memoir so that was fascinating…but I wish we'd got their voices you know – it's hearing the voice I think.

(Volunteer Kate, 1)

### 8.1.5.3 Ongoing presence – for the bereaved and the archive

The power of the voice of the deceased continuing was seen as being unique to OHinPSC by the research interviewees. For the volunteers and HCPs, it was a major motivation for their involvement. For several participants it was also a key motivation, notably with participants James and Tim, who were leaving a family legacy, and also those leaving an archival recording as a social history resource or solely for being preserved. However, due to participants being at the end-of-life it was a more sensitive topic to broach and thus harder to gain an understanding of what it fully meant to them.

The voice as a continuing presence was mentioned by research interviewees in other contexts separate to OH, such as recording people's answer machine messages so the bereaved had a voice recording of the deceased:

> …it's about the voice and just even snippets...can be really important to some people. I've gone over to someone's house and recorded an answer machine message for them because that's all they had and that was so important to them because that was the only thing they'd got of their daughter...so I think, to actually have a quality voice recording we know the importance of that yes.

(Volunteer Jenny, 1)

Participant James, aware of the effect MND could have on his voice, was also involved in voice banking, which would allow him and others with MND to use recordings of his voice in a computer aided system for when they were no longer able to speak:

...I knew about voice banking because of people with my condition, could quite easily lose their voice so...I was aware of it and asked about it and... because I bank my voice, if I'm not going to use it someone else can, so it's available to anybody, plus it means if I do - if my speech does deteriorate, then I keep my own voice, so that will be good… you know you've got 1600 sentences to repeat …you kind of send it off electronically and they sort of tell you it's accepted and then it's there stored for whenever you need it.

(Participant James, 1)

The importance of hearing the voice was also mentioned in another context by Heather, who bemoaned the text generation of her children and valued the importance of hearing their voices:

We've got such silly stories you know and, the kids today they don't care, they just do not...care you know it's like even when I ring my kids and they say 'why don't you text?' 'Well, I want to hear your voice', 'oh are you gay are you daft, are you stupid?' [laughs] 'No I just want to hear your voice' you know…

(Participant Heather, 1)

In both instances, the importance of the voice as a physical presence was apparent. Hearing the voice is a way of continuing a relationship which feels physical and present. Hannah, the Bereavement Counsellor, drew comparisons with photos and music:

I think it's just having…the permanent record of that person's voice and any messages they want to leave…I think to have that - it's keeping that part of the relationship isn't it, we have photographs, some people have maybe little bits of film that they might keep, particularly nowadays we all have a camera we can use, but just to have that voice I would imagine would be very very comforting to lots of people.

*OK just in terms of the you were talking about the Continuing Bonds framework, so I guess the OH kind of fits in, how do you feel that fits in with that kind of framework?*

It kind of it's about the relationship isn't it and that helps the relationship continue…there's always that fear I think for people that they are going to forget their loved one you know and they never - you know they are really not going to, so if they've got something like that like I say photographs, letters but the voice in particular I think would...no music can be really...moving and triggering and comforting and distressing and I would think of the voice in terms of the music really of having a similar impact.

*And in terms of the amount of feedback you've had about the OH service and you know people being upset how often does that happen and…?*

…not very often I think because I would imagine for a lot of people it would be quite positive and it's not necessarily something they're going to bring to therapy.

(HCP Hannah, 1)

Referencing the Continuing Bonds framework, here OH was viewed as a powerful medium to provide an ongoing physical presence in people's lives. In much the same way as music, it can evoke both comforting and distressing feelings for the listener, especially the bereaved when receiving a family legacy. The extent to which the research interviewees were motivated by the idea of OH being an ongoing presence in bereavement, or its use from within the archive and their understanding of how it could affect the listener (particularly family) varied. Clearly for several of the participants they had not completely factored in that it could raise a spectrum of emotions for people listening. The volunteers and HCPs, by contrast, who had more experience of the service, seemed to have a better understanding of how it might be received. However, some were still learning about the multi-faceted possibilities of OHinPSC, as witnessed in the first section of this chapter.

The reuse of OHs as a public resource and the idea that they would be listened to by third parties (the general public rather than family and friends) was an indirect motivation for many of the HCPs and volunteers and some of the participants. It was perhaps only during the research interviews, when they were asked how they felt about their OH being archived and being used as a public resource, that this became apparent to some. The opportunity for their stories to be reused was welcomed and perhaps shaped participants narratives in

further OHs after the initial research interview/OH gave an enhanced understanding of OH: "…I think it's brilliant. I mean if a lot of people did it can you imagine all the people that would be still alive in people's eyes if they've got you on tape." (Participant Jake, 1).

### 8.1.6 Section summary

The motivations of research interviewees are here built on the premise of prior and ongoing knowledge of OH and their individual and collective identity in the process. How stories are chosen and developed and the opportunity for reflection and a physical archival document is recognised and embraced. How participants wished to be remembered by their family as a continuing relationship and how the archive could create the potential for new relationships evolved through the process. There is the understanding that participants take part with several motivations in mind, for themselves, family or the public, and the order and importance or accessibility of each of these is set by their primary motive. There is the risk of confusion between personal and public stories when motivated by both. OH offered an opportunity for self-reflection, family legacy and public witnessing. It was viewed as comforting but with the potential to be upsetting for all involved, particularly the participant and their family. The personalised nature of the voice and its recording was a novel and unique way to preserve and showcase history and could be adapted in numerous ways.

## 8.2 Experience

### 8.2.1 Background

This section focuses on the interview experience and how the participants and the volunteer interviewers found the process. Integral to the experience for all involved is the concept that oral histories are being recorded with the end-of-life in mind. As already covered in the last section, the participants were motivated by both recording family legacies and sharing more general reminiscence. This section considers the connections made by participants during the interview experience – what they remembered and communicated, and how this was shaped by their illness and own sense of mortality. These factors raise questions about what is deemed interesting or not by both participants and volunteers, and how their narratives are constructed in terms of planning, identifying and locating their stories and memories. In some cases what they choose to omit was as interesting as what they included. The relationship between the participant interviewee and volunteer interviewer is examined and how volunteers prompt the participants – whether they approach the interview as a conversation or more akin to a monologue. Some volunteers were able to relate to participants better than others. This section tries to unpack the reasons for this, whether they be generational, social class based, or due to individual preferences.

### 8.2.2 Co-constructing in meaning-making

In this section I look in more detail at the co-construction between the volunteer and participant. How the participants recording non-defined legacies perform as storytellers in contrast to those recording family legacies following a more rigid structure, and how the participants reflect on the process of recalling memories during, and after, the interview. I also look at co-construction as being cross generational – how participants and the volunteer interviewers relate to each other, and how age differences can change the interview dynamic. Finally, I illustrate the different interviewing styles of the volunteers and how they impact on the participants and interviews.

### 8.2.2.1 Performing – being interesting

On asking participant Sarah if there was anyone else, she wanted to hear her OH, she replied: "Well, no they're all dead...you know it - I've outlived them all at the moment I have many mornings like this morning [laughs] no I suppose it's reading scandal isn't it in a way?"

(Participant Sarah, 2). This illustrates the way that all the participants (Jake, Sarah, Ralph, Heather) who were in some way recording a non-defined legacy in which the public audience was apparent beyond family, all performed to some degree for the recording. Throughout the research transcripts, there is a common theme which occurs around narrative being deemed interesting or not interesting. HCPs often refer someone because they feel they have interesting stories to share. Hearing interesting stories, such as local or social history, is also a motive for volunteers. Volunteer Kate remarked on this point with Sarah:

> She did say to me a one point 'I don't think anyone is going to be interested in this', so I thought it was as good and interesting for her, to learn more about her village and about the war and she's told me all sorts of things about the war that aren't necessarily all about her but do tell her story as well.

> (Volunteer Kate, 2)

The act of something being designated for a public archive creates an inherent desire for interesting stories or memories. For participants James and Tim, who were recording family legacies, this was less of a concern: "I suppose up to a point it could be boring for anyone outside of the family…" (James, 2). What is deemed interesting is, of course, subjective, and so there is a risk of participants feeling their stories are not interesting enough or that there will be a lack of interest from volunteer interviewers or their future audience: "People are funny...things you don't think they are interested in they are and things which it would be nice for them to know they couldn't care less."(Participant Sarah, 3). Sarah particularly picks up on the idea of the purpose of the OH and continuously in her three research interviews tries to make sense of what might be interesting to others. In her final interview she concluded: "Well, no I've found it most interesting, because well it's most interesting because you're interested in finding out, what's happened on the other side of the street." (Participant Sarah, 3). Similar statements also came from Jake and Ralph, both of whom were taken with the idea that others would have an interest in their stories: "The way it was put...when I go everything goes with me, I'm leaving something behind for somebody else to research with, it's not a bad idea." (Participant Ralph, 1). All these three participants were living on their own, with suggestions they were lonely. For them, the opportunity to be able

to share something about themselves which was of interest to others was both novel and possibly dignifying. It gave the opportunity to be remembered in the future, when perhaps they didn't feel remembered in the present:

> "I'd just like to be remembered...because once I've gone, I've gone...and that's it in it? Closed a book on me but, if I've got a verbal history of m'life and m'loves and things like that [laughs] it would be brilliant, that I'm on tape yeah."

(Participant Jake, 1)

As storytellers they could decide what was of worth to share with a public audience. For Jake this was the poverty and social conditions he lived in. For Sarah this was the changes to the village she had grown up in, and the stories which had been passed down, and for Ralph this was the knowledge he had acquired through his career and about local history. Heather also performed for the public, but lived with her family so was perhaps less isolated than those mentioned above. However, she felt isolated from her family in terms of being a technophobe, and the fact that the rest of her family communicated by text rather than speaking. For her, the stories worth sharing were of past generations, when her family had all worked together and there had been a much clearer sense of community.

### 8.2.2.2 Reflecting

What the participants remembered before, during and after the interview could be seen as different stages of reflection. Before the interview the participants planned what they would say to varying degrees. For participants James and Tom, recording family legacies came in the form of making notes (James), or conversations with the Chaplain (Tom), to ensure they left fitting legacies for their families. For other participants there was perhaps less planning, but it can be assumed that they all had some forethoughts about what they might talk about. Participants who appeared to plan less tended to talk more about whatever came into their minds during interviews. This was expressed by Jake "...well yeah got a bit upset like but...they were on my mind and that's what they wanted for me to think whatever was on my mind and that's what were on mind at the time..." (Participant Jake, 2).

For Heather there was a lack of personal reflection during her interview, and she chose to tell stories about others rather than herself, as mentioned by her interviewer, Fiona:

Well from what I could gather she's interested in genealogy and doing her family history and so I think she saw it as sort of dovetailing into that really…and maybe that's why it wasn't so reflective because she saw it as just…looking at people and

*reporting back*

people in their situation rather than hers… I think that's what I felt was missing, I sort of thought at the end I really don't know Heather.

(Volunteer Fiona, 2)

Heather picked up on what she could have talked about after the interview with the emphasis being that the interviewer could have prompted her more:

You know and then afterwards you think of other stories that you should have said that you didn't say, and now you've said about my childhood I don't think she ever mentioned my childhood growing up there.

(Participant Heather, 2)

For Jake and Sarah, the OH brought up upsetting memories about family loss from the past. It is perhaps useful for the volunteer to talk through issues like this before the interview with the participant or the HCP to assist in planning who and what should be mentioned. It could also be useful afterwards to check how reflection may have impacted on the participant, both in talking and listening back (as discussed later in the Outcomes section 8.3), then to ascertain whether they need further support or if edits need to be made to the recording before sharing with family.

### 8.2.2.3 Relating

All the participants and most of the volunteer interviewers remarked on how they enjoyed their interview experiences. For the volunteers there were specific reasons why some did not enjoy it which will become clear in this section. The primary reason given by the participants as to why they enjoyed the experience was the opportunity to leave a personal or public legacy. How the participants and volunteers related to each other and got on was revealing on several fronts. Clearly, thought had been put into how the volunteers and participants were matched by the Coordinator, Jenny:

> …I'm not sure how I do it, there's just something when I meet a patient, a volunteer or a number of volunteers come to mind and I don't know why and I just feel - I just have a feel for who will work best with who, and it's even got to the point where I picked one volunteer straight away for a patient and it turns out they knew each other.

> (Volunteer Jenny, 1)

The point of them being well-matched was also picked up by participant Ralph, who interestingly did have several things in common with his volunteer interviewer:

> *…you've enjoyed doing the interview and can you explain why you found it enjoyable?*

> One…the person who was doing the interviewing was convivial pleasant, we had a background what which fitted each other, so it was very easy

> *excellent*

> but I think that was the cleverness of the girl here, knowing who her volunteers were and matching the two together.

> (Participant Ralph, 1)

However, a couple of the volunteer/participant connections were less strong. For Jake, interviewed by June, and Heather, interviewed by Fiona, there was a disconnect. The exact reasons for this can only be assumed and could be for more subjective beyond the remit of this study, however for both there were similar issues. Both interview scenarios were over two sessions which was a positive, suggesting there was some connection for the process to continue. Both scenarios included interviews in which the participant was bed-bound, which created unease for the volunteer. Jake was the only participant based in a nursing home and did both interviews (and the research interviews) from his bed in a room with the curtains closed. June quickly picked up on the setting:

> …when I'd eventually found the place [laughs] I did actually find it was quite a nice nursing home it was bright and airy and all the rooms seemed light until I went into his room which was a lovely sunny day and all the curtains were closed, it was

actually the first time I have ever felt uncomfortable of going into a room to do an interview, it was OK but I did initially feel slightly uncomfortable, I think possibly because it was dark it was the end of a corridor there was nobody about, he was in bed didn't like any of the light from outside to come in and I didn't quite know what I was going to find, but in fact he started to talk and told me things, I did wonder why he was doing it, I didn't know why - he didn't seem to be doing it to give memories to his family.

(Volunteer June, 2)

Fiona remarked on a similar predicament in her first interview conducted at Heather's home:

Well I thought because she was in bed I thought she was poorly so I was - felt as if I was actually putting something on her really, and you know I think I did say you know I'm not sure if that was because it was on the day but I think I did say you know 'I'm happy to come back should you want' but she said 'no we can carry on you know' so…

(Volunteer Fiona, 2)

For Fiona, in her second interview with Heather, conducted on the sofa in the living room, she mentions issues with Heather receiving a mobile phone call: "…on the second one when we were you know in the lounge so, but that was also the time when we got disturbed by the phone a bit." (Volunteer Fiona, 2). These issues with the setting and interruptions were not, on their own, likely to cause disconnect but remain worth noting. Perhaps a more interesting finding was that these were the two interview relationships in which the motives were particularly non-defined, and the participants (Jake and Heather) were younger than the volunteer interviewers as outlined in Figure 15:

*Figure 15: A table to illustrate age differences in different interview scenarios*

| Age differences in different interview scenarios | | |
|---|---|---|
| **Participant** | **Public/undefined legacy** | **Personal/family legacy** |
| Jake | **4 years younger than Vol June** | |
| Sarah | 22 years older than Vol Kate | |
| Ralph | 22 years older than Vol Jack | |
| James | | 4 years younger than Vol June |
| Heather | **15 years younger than Vol Fiona** | |
| participant 6 - Tom | | 25 years younger than Vol Karen |

Both had less clarity in their understanding and motivations (see section 8.1.3). As well as being younger than their volunteer interviewers, Fiona and June, there were issues as to how they related – a distance to the topics covered, how the volunteers received their narrative and approached the interview in their interview style. Both volunteers adopted a hands-off approach in terms of prompting the interviewees, choosing to let the interviewees decide what they talked about. However, as a result, both volunteers seemed dismayed with how the participants Jake and Heather delivered their narratives and what they chose to focus on. Fiona felt indifferent about Heather's career choice:

> …and that's - you know that came out you know, for you or I may be working as a market trader would be hell you know [laughs] its very cold and…you know and unpredictable, she liked that.
>
> (Volunteer Fiona, 2)

June had similar reservations about Jake's background:

> …some of the things he told me about were quite well [laughs] they were quite distressing for him he'd had a rough life, and that I found quite difficult I think it's the

first time I've really thought I'm not sure your family are going to want to know anything about all this, he'd had quite an interesting life I'd say.

(Volunteer June, 2)

Perhaps because of Jake and Heather being younger (although still middle age) than their interviewers, and having non-defined motives, led in some part to the volunteer's detachment and indifference about the interviews. Following this theory, it could be argued that the non-defined legacy interviews in which the interview relationship was strongest, Sarah being interviewed by Kate and Ralph by Jack, were also the interviews with the oldest participants (93 and 82 respectively). When the legacy is not defined and what will be talked about possibly less planned, and when someone is older (over 80), it may be argued that they are more likely to be revered by the volunteer/HCP and thus the interview will be more likely be successful in its construction. There is an acceptance that these participants can reflect on a whole life span, as mentioned here by HCP Margaret who referred Ralph and had developed a strong bond with him:

> …he worked in [place name] as a salesman it was obviously a big interest of his, it meant a lot to him, maybe he was coming toward the end of his life and he was pondering on a lot of things and memories - a lot of memories, he hadn't got a lot of family…

(HCP Margaret, 1)

For Sarah and Ralph, they were not only the oldest participants but also both lived alone and were bereft of company. Despite Ralph being interviewed on both occasions in the day centre, he was keen to do more at home: "The actual interviewer and the interview went that well that we will do it at home if he needs to." (Interview 1). He also suggested he could do further research interviews with me at his home (neither happened due to him dying shortly after his OH interviews):

> *… if you have time, it would be really nice to have a quick chat with you once you've listened to your recordings and you've done all of them and just to see how you feel about it, that's all, but see how you're fixed.*

> Well, I would suggest that conversation would have to take place at home.

> (Participant Ralph, 1)

For both participants Ralph and Sarah, the OH experience was a big success despite their non-defined legacy approach. Tom was the youngest and based on his setting on inpatients, the closest to the end-of-life. His interviewer Karen found the interview challenging due to his young age:

> **…**well, it was a very difficult one because I think that the gentleman was quite a young gentleman actually. I found it particularly difficult because he was about the same age as my son and so I found that very hard…

> (Volunteer Karen, 2)

However, Karen also recognised it as a powerful way to assist him in recording his family legacy: "I felt very privileged to be doing it, that this person was sharing not with me with his family and wanted to talk about his life…" (Interview 2).

### 8.2.2.4 Prompting

It became clear from interviewing the volunteers that they had slightly different interviewing styles, which related to how much they chose to talk and prompt within the interview. At one extreme was Jack, who adopted a much more conversational style. This seemed to suit his interview with Ralph, in which the format of the interview was more akin to a reminiscence session. This approach was established before the interview:

> …he is a local [place name] bloke and wanted to talk about [place name] with somebody who knows. I mean was born and bred in [place name] so hopefully I know some of the bits he knows, and you know so maybe we can reminisce or talk to some degree…

> (Volunteer Jack, 1)

With this interview being for the public archive rather than family, the fact that the interviewer talked more on the recording was less of an issue. For family to hear the voice of a stranger giving their recollections is perhaps not desirable, but clearly the participant

wanted to have a conversation rather than be solely prompted. The Coordinator Jenny had picked up on this dilemma previously with Jack:

> … a couple of times I think Jenny has said 'ooh on that last one'… when I started early off she sort of said - I mean it's the classic thing of the interviewer, you know it's not about you it's about the person you interview and I just thought yeah because it's that there's always an easy trap to fall into especially when you are talking about local about [place name] when you are talking to the people and then go and they are talking about the [place name] thing or something … well you might have an interesting story but it's not relevant to this conversation so I actually - that is pretty enshrined in my head to try not to do that and if I can definitely not do that anymore so yeah that's so I guess I have learnt interviewing techniques which I didn't know about before.

> (Volunteer Jack, 1)

He mentioned how interviewing style had been discussed at a recent volunteer meeting as well:

> …there was a meeting with volunteers a few months ago and…obviously people were talking about their experiences and one thing and another and it was very apparent to me that virtually every person - well not totally - there was a diversity of way that people interviewed…and there was one or two comments that I picked up - I sort of said something and I wasn't exactly shot down but there was a couple of comments I thought oh OK that's obviously [laughs] not - that sort of didn't reverberate well with that person I can sense that although she didn't say that I could sense that so there obviously…there's a myriad of ways that people do it and I think truth be told, I don't think there is a right way or a wrong way to do it...

> (Volunteer Jack, 1)

Other volunteers had different approaches, with June being at the opposite extreme: "I like to speak as little as possible, I think it's their story it's not my story and if you prompt them, you might lead them in the wrong direction…" (Volunteer June, 1). Kate was somewhere in-between in her approach:

well it's the same with all the interviews, you're listening to somebody trying not to interrupt it is a problem and I don't obey the rule of being silent all the time, which we were encouraged to be and I have talked to Jenny about this and she agrees that sometimes it's not relevant but some people are a little bit paralysed when you say nothing [laughs] … obviously you never say 'well I know just what you're talking about because I lived in a similar sort of village.' I do that after the interview, it's very tempting sometimes because you find they are telling you something that you've experienced exactly the same, you have to shut up, and it - obviously we've been told to express everything by you know grimaces, it's quite hard sometimes and I think in a way if somebody is talking, just another voice sometimes makes it feel more natural.

(Volunteer Kate, 1)

In this sense a continuum of interviewing style can be suggested which fits to the different interview formats, as shown in Figure 16:

*Figure 16: A diagram to illustrate the continuum of interviewing styles*

Minimum prompting (June, Fiona, Lucy)    Talking more (Kate, Karen)    Conversational (Jack)

Family legacy/messages (James, Tim)    Both (Jake, Heather)    Public reminiscence (Sarah, Ralph)

If an interview was more for the public archive as a joint reminiscence on local history, as it was for Ralph and Jack, it could work well: "We just clicked" (Participant Ralph, 1). If, as for participants James and Tom, it was predominantly a family legacy, then it was beneficial for the volunteer to speak as little as possible as the participants voice had added importance. Recording messages for family, although not encountered in this study are included in the continuum to illustrate the point. When the interview was in the grey area of being a mixture of both family and public facing, it could help for the volunteer to talk more to give more direction in their prompting. This was mentioned by participant Heather:

*What do you think could be done differently?*

...I don't know maybe if the interviewer had, like prompted questions more

*OK*

like you said we didn't talk about my childhood, and it never even occurred to me, so maybe you know...

*right OK yeah so having a bit of it might have helped you?*

More of a structure

(Participant Heather, 2)

This was also picked up by her interviewer, Fiona who questioned if she could have spoken in the interview more:

...I can't pinpoint the bit that I was disappointed about, I think it was more about - I suppose that I just expected it - otherwise she just went you know a series of snippets of stories, and yeah and maybe I didn't give her the opportunity I don't know

*what to*

you know a bit more reflection you know, encouraging you know 'I guess that must be hard you know durr durr' you know...

(Volunteer Fiona, 2)

Similarly, Jake could have possibly benefited from more prompts and steering of the interview:

...I used to have a lot of accidents, aye when I were a child and some were horrendous and some, damn right silly but that's all I could think of and when she come back to do the second interview I says can I go back in time and tell you about how poor we were and...you know how we used to live and...

(Participant Jake, 2)

Both their volunteer interviewers (June, Fiona) were unsure as to why the participants had chosen to record their oral histories and who they might be for. There was arguably less co-constructing between interviewee and interviewer in the process in comparison to the interviews with the older participants Sarah and Ralph, for whom the OH process had been adapted to suit them by the volunteers and there was less of a grey area as to whether it was for a family audience or the public archive. Both these volunteers (June, Fiona) were from either educational or social work backgrounds which perhaps lent itself to having a more hands-off approach in their interviewing style to give participants more autonomy. June had much better results with this approach in interviewing another participant James recording a family legacy:

> He'd enjoyed the experience and he said you only prompted me just enough [laughs] I was alright because I said I didn't like to - I don't like to say too much I just feel it's not my story it's their story and I'd rather that happened, yeah, they were very nice.

(Volunteer June, 2)

James also mentioned her interviewing approach: "…pushed on certain points which got me in the right direction." (Interview 2). However, as already mentioned this approach worked less well in interviewing Jake for a non-defined legacy. In contrast, volunteer Jack who had the conversational approach, was from a business background and less concerned by the ethical guidelines for interviewing and treated interviews on a case-by-case basis.

It is accepted that the interview is a co-construction between the volunteer and participant and thought is needed in how they are matched. Considerations include age difference, social background and interviewing style. Also, it is important for there to be a clear understanding from both parties as to the reason for the interview, if it is meant solely for family, or for the public archive, or both. Reflecting on the process before, during and after can produce unforeseen memories for the participant and complications for the volunteer, and it is important there is awareness of the possibilities and a support framework for both participant and volunteer.

### 8.2.3 Framing mortality

### 8.2.3.1 Setting linked to mortality

The five different settings for the OH interviews (as set out in the Chapter 7) all represented different stages in how close a participant might be towards the end of their life, as illustrated in Figure 17:

*Figure 17: A diagram to illustrate the OHinPSC settings relating to the end-of-life*

Activity based    Activity based (more ill)    Last opportunity

Hospice external venue    Day Centre    Home/Nursing home    Inpatients

Home based    Institution based

As illustrated and could be expected, people based in nursing homes and inpatients who were institution based tend to be closer to the end-of-life. At the hospice external venue and within the day centre, OH was offered as an activity alongside other pursuits or therapies. It was offered as something to do and a well-being activity alongside painting, music workshops and genealogy in both venues, and craft making and physiotherapy in the day centre. At the hospice external venue, OH was open to anyone with a life-limiting condition and also carers. It was usually the first stop for people before they were involved with other hospice services such as the day centre. As a result, it could mean people had more time and there was less worry about health deteriorating. Volunteer June mentioned there was also less of a pressing need to record an OH as life review and had encountered someone previously using it to help them write a book without being palliative: "we're just a means I feel of giving him the information written down." (Volunteer June, 2). It was also suggested by June that it might be a good way to record the OH earlier as there was less emotion attached. Potential participants using the day centre were identified as being at a point where they were relatively well but starting to become less so. The OH service offered an opportunity for them to reflect, but with less urgency compared to those on inpatients:

> I work in the day centre where patients come for the day…they've still got the
> energy I suppose and the capacity to be able to do things and what most of them

want to do is leave something for their families or a mark in some way or yeah sort of not necessarily a present but sort of a reminder I suppose for some of them and this is the best way of doing it I think and also because they're quite poorly it's made them… reflect a lot more so they are more in the position of thinking actually yes I look back at my life and I want to put it down or have it recorded for my family.

(HCP Judy, 1)

There was also more opportunity for them to have discussions with their families and look at photo albums or diaries which could then be used as prompts:

…quite often you'll find people will come in and say ooh I spent this week looking through my… old diaries or my albums or…it's prompted them to look back and to do more things…and talk to their families more because they will sort of start thinking oh what happened in 1972 well I will have to ask my wife about that so it's prompted some more discussion and memory sharing, at home preparing for it as well for a lot of the patients.

(HCP Judy, 1)

The day centre was viewed as somewhere which improved quality of life for many:

I think often it gives these patients - it opens their minds up coming here, they access lots of different therapies. They know that we will also help with symptom management, and I think that hopefully, well, many do say their quality of life improves.

(HCP Margaret, 1)

People could concentrate on having creative autonomy and social interaction with others. OH in this setting was available within a spectrum of reminiscence activities:

…when people come into the [day centre] and...just going into the activity room its great in there, because you see them all buzzing and concentrating on their own thing and chatting to each other as well and...yeah I spoke to a relative today and I'd been really trying to reach this gentleman who is very closed, and he just felt very

sad since his wife died and...you know I said to him I think your wife would want to know that you are having some sort of quality and not giving up because she's not here, and anyway I will not go into that but basically and it wasn't persuasion I just led him up the path of going into the [day centre] going into therapy room, making some things that in memory of his wife, and he did that and he gave them to his daughters, and his daughters couldn't believe it, that he'd actually made something for them because since his wife had died he had just completely closed off.

(HCP Margaret, 1)

This was echoed by participant Heather, who said, "I love it and you know it has brought me back to life again, given me something to you know...go for and just the meeting of the people…" (Participant Heather, 2).

Whereas the day centre and the hospice external venue offered sociable outlets, research findings suggest that interviews conducted in people's homes, or the nursing home, were sometimes with people who were isolated and possibly lonely. The participant, Jake, in a nursing home who was bed bound and very isolated, was referred by the HCP because of his low mood rather than for palliative care: "…the nurse had referred him to me just said 'well I don't think he's got any palliative needs at the moment, but I feel that you might be able to offer him something psychological'…" (HCP Holly, 1). Several HCPs and volunteers mentioned that people interviewed in their own homes wanted company. One volunteer gave an example of returning to a participant's home who had no intention of being interviewed but wanted someone to chat to:

I talked to one lady and I mean the system is that you're - they are sent their CDs they listen to them and then they decide if they want to do it again…well she did the recording, Jenny sent the CDs, and then rang her up – 'no I haven't got anything to listen to them on, but I'd like her to come again', so the second time I went she'd no intentions of recording anything …she just wanted me to talk to her.

(Volunteer June, 1)

Other volunteers found themselves doing other jobs such as watering plants: "...the one I'm doing now when I interviewed her at home, I quite liked seeing her home setting and I was also able to water her plants..." (Volunteer Kate, 1). Or trying to fix their TV or internet:

> ...you're going to someone's home and she's making you tea and biscuits and then you know she is saying 'ooh I can't get my television to work' [laughs] and... you think ooh well you know what are the boundaries of this that and the other ... but you know she's an elderly lady she needs help so I mean irrespective of the conversation and interview process you know she can't sort - you know she's got the aerial on her tv is bust or something or this is wrong or the internet can't connect up I'm more than happy to look at it so there was that aspect to it...
>
> (Volunteer Jack, 1)

In my reflexive journal I wrote about this after interviewing Sarah for the research and discovering the lock to her front door wasn't working:

> Her front door keylock has become stiff, probably because of the heat. I offer to have a look – the key works fine for me, but perhaps her strength is not as good and she struggles with it and decides to leave it unlocked. I suggest this might not be a good idea and she says she will let her carers know – 'will they come today I ask?' 'No', she says and then tells me she once had a man with a knife in her bedroom. I'm shocked! I'm not sure what to do about this – it's not my job and if she is letting her carers know it's their responsibility, but I feel uneasy with the idea that it will remain unlocked all night. As I think about it walking down the hill afterwards, I console myself that it was unlocked when I got there, and she told me to let myself in so perhaps it's not so unusual.
>
> *(Reflexive Journal, Participant Sarah, 3)*

The home setting risked blurring the professional boundaries. It was a setting in which the volunteer and participant may find themselves developing a stronger rapport, but in which it was viewed unprofessional for the volunteer to then become friends with the participant and make further visits for personal reasons, despite the participant perhaps being lonely and benefitting from their visits. This was encountered by Kate, visiting Sarah:

> Well, what I found frustrating was of course that [name] said 'oh it'd be lovely to go on seeing you'…even though I'd finished, and of course we can't do that when we are still being employed by [study hospice name] but that was a bit frustrating because I thought it would be lovely to pop in and just have a chat, but you can't do that
>
> *So, you felt you got on well with her then?*
>
> Yes, I did, and I thought she needed company, she was an intelligent woman, and she could do with more companionship you know.
>
> (Volunteer Kate, 2)

In contrast, potential participants may be uncomfortable with strangers visiting their homes:

> …I've only had a couple declined but one of them just said 'well it's not for me my stories aren't that good anyway', I said 'you'd be surprised'. 'Well, I don't think I really want strangers coming in my house' 'well that's fine' and we left it there, you know so it's only been a couple and I think it's just the unknown of what it involves and who it is that comes.
>
> (HCP Holly, 1)

However, for others it could be beneficial to be in their own home in which they may have their family at hand to assist: "…I think people feel more relaxed at home." (Volunteer Fiona, 1).

Interviews on the inpatients ward tended to be "…usually more urgent…" (HCP Geoff, 1) and there would often be no opportunity to record a follow-up interview:

> …the day centre obviously people are not as ill as they on the inpatients…and so on inpatients it is quite often a very last-minute thing...and that gives a real sense of urgency and people don't have time to do the follow-up interviews as much, whereas in the day centre it's almost like more of an activity.
>
> (HCP Hannah, 1)

It was recognised that people were more ill compared to five or six years ago in this setting:

> …nowadays we get fewer referrals from the ward because people are more poorly, but I think… five or six years [ago] when people were a bit more well - we tended to get more referrals from people who were just a bit lonely and a bit bored…

> (Volunteer Jenny, 1)

One reason given for this being that people were able to stay at home longer with better pain management:

> …I think people are sicker that are in the inpatient units because we are able to keep them at home for longer and there is more treatment symptom management is better, so they feel more well for longer…

> (HCP Judy, 1)

There was a desire for people at the end-of-life on inpatients to put everything in order and consolidate and leave something behind before it was too late:

> …I think a lot of it yes, it's about leaving something behind for relatives and for just generally for the future...and I think also to sort of I don't know it's almost a consolidation isn't it, it's that sense of this is my life this is what I've done, people are proud of what they've done and it's almost like doing a review of their lives, yes.

> (Volunteer Jenny, 1)

Often people may be taking drugs for pain relief and would only be able to record short interviews due to their voice or mental capacity deteriorating (Volunteer Jenny, 1). This could be in the form of personal messages and birthday cards for family. There was a recognition that some people didn't want to think about the end-of-life until they were coming up to it:

> …it's the people who are an inpatient or who know why they are an inpatient, they know that they are not going to get better and they're running - they're trying to do this quick before…because I think people will probably think well why do I want to talk about my life story I'm going to be around for a long time yet, and I think there's probably some of that in it...because I know from people I've met and gone through

things with that once they come towards the end of their life they start to put everything in order, I had a friend who she made sure she'd got birthday cards written for all her great grandchildren and she made sure there was a box for each one of them but she didn't do that until sort of the last year or so...I suppose we all try to keep things that are memories, you know we save all sorts of stuff and you think oh somebody might be interested in it one day but I don't think purposefully you would say right I'm going to put this in this box for this reason - I don't think people like to...look on the end, not until they're sort of coming up to it.

(Volunteer June, 2)

As illustrated the different settings were framed by the expected mortality of the participant and the urgency and format as to which the OH might take. The length of the interview, what was spoken about and the dynamic between the participant and the volunteer could also be determined by where and at what stage the interview took place.

### 8.2.3.2 Talking about mortality

As already mentioned in the Motivations section (8.1), the mortality of participants is generally not mentioned by HCPs or volunteers when pitching the OH service to potential participants. It can also be assumed that it is not brought into question during and after the interview experience unless the participants choose to talk about it. However, it was clear that most of the participants had their own mortality present in their thoughts, and it was inevitable that it would be referenced in their interviews, whether the interviews were for non-defined or family legacies. How and why mortality was mentioned by each participant in the research interviews was perhaps revealing as to their intentions and experience of the OH process. How these mentions of mortality were managed by the volunteers and HCPs also offered a better understanding of the OH service and whether any training or policy recommendations could be implemented. Another finding in research interviews was that several of the participants mentioned the deaths of other people in their research interviews and oral histories. Jake talked in detail in both his research interview and his OH about his parents and his brother dying:

*…you mentioned before that you found yourself talking about some of the more traumatic experiences and you've named a few there within your family their*

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*traumatic experiences - how it did it feel to you talking about those, were you OK talking about those in the interview?*

well yeah got a bit upset like but...they were on my mind and that's what they wanted me to think whatever was on my mind and that's what were on mind at the time and talking about them from the past, know what I mean? Talking about people from the past years and my dad and my mother, and I reflected on how they died and... how I felt then, how I feel now about it and obviously we are still here like our [brothers name] were only two years younger than me...so he'd have still been here, but he was only 23, so....

(Participant Jake, 2)

The presumption here is that he talked about them because they asked him to talk about 'whatever was on his mind.' The fact that he was bedbound in a nursing home and most probably questioning his own mortality suggested that it was only natural that he would be thinking about others close to him who have died, especially when then asked to share his memories and personal life story, knowing that it would be a legacy for when he's gone. The fact he talked about close family dying as a traumatic experience was met with some unease by the volunteer interviewer:

*And what were the things you talked about? Just a general overview of the topics you talked about over both interviews.*

Well he talked about his early life and we also talked about I think it was a sister - one of his siblings I can't remember whether it was a brother or sister that had died, and somebody else as they were growing up was stabbed and died and it was all things like that he'd been - the family had been involved in and he'd been involved in, so it seemed to be quite a rough life he'd had, with all these incidents and all the things that sort of went wrong in his life.

*Why do you think he chose to talk about those kinds of stories, have you got any thoughts?*

I don't know, whether it was sort of bring them out into the open so somebody could see them, I don't know or to give an idea of what life is like for someone like him...because he told me of accidents he'd had and things like that and it just seemed to be a catalogue of disasters rather than an insight into his life and any happy memories - he didn't seem to have many happy memories.

(Volunteer June, 2)

For June there was a suggestion that Jake had misunderstood the concept of the OH interview and thus had used narrative perhaps not suitable for a family legacy. As already mentioned, Jake's OH interview was not a defined family legacy. He intended for his son to hear it, but he was also keen for the public to hear an archive version. This duality meant he chose to speak what was on his mind rather than a thought out and planned narrative aimed solely at his son. As a result, the mortality of others became central to his narrative. Sarah was similar in talking about the mortality of others, although for her it was stories of people's deaths connected to the village she came from, dating back to before she was born. She talked in detail in her research interview about the lady of the manor, whose funeral everyone in the village attended, and shared the story of a man who wasn't allowed to be buried in the graveyard:

*So, in the interview you talked about your childhood in the village I presume and your family, and you talked about the lady of the manor in the village and how the village has changed is there anything else you talked about?*

well only the sort of things like... well I'm pertaining to the village that, this old resident I mean before my time, but we had had it handed to us, he committed suicide, so he wasn't allowed to be buried in the churchyard, so they buried him just over the wall by the little car parky thing on a bit of grass yeah.

*Oh gosh*

And as children if we were up there and we picked wildflowers and placed them where we thought the grave would have been looking at the lichgate and the wall and sort of assuming it would be just there, and we used to put flowers there.

<div align="right">(Participant Sarah, 2)</div>

As with Jake, Sarah chooses to talk about death in connection to what she remembers and what was current on her mind. Death was entwined in stories connected to key times and places in their lives. Both their oral histories and research interviews were set in localities close to their heart which have attached meaning they were keen to pass on, whether it be stories of poverty and trauma for Jake, or of village rural life in which generation old stories were passed down for Sarah. For both participants death was an inevitability connected to change but also to injustice and they both revelled in the gruesomeness of history:

> *So how do you feel about those stories being heard by other people?*
>
> Well, its history it happened in our village, and I felt nothing to be ashamed of, because highway men were hung on the gibbets as punishment for - so it was only the same as in London where they went outside the you know big prisons for the hangings of murderers and that sort of thing.

<div align="right">(Participant Sarah, 3)</div>

Sarah chose largely to omit another key story which was about her husband dying after they'd only been married for 5 months:

> *How did it feel - was it OK talking about the experience of losing your husband, I mean talking about that in the OH interview, did you feel comfortable talking about it?*
>
> Oh yes because in a way, it sounds stupid really when I say it like this, but you see I was in hospital for several weeks after he died because I was still infectious and for two years, I was at home not working or anything and I didn't go to the funeral I wasn't allowed to, so I have nothing to associate [names] funeral with me because I wasn't there.
>
> *So, in some ways it was quite helpful to…*
>
> Well, I suppose so, but I don't know you know sort of I have no memories that I can say what happened at the funeral or anything

> *Sure, no I don't want you to…*
>
> Oh no I mean it's so long ago now it would be hypocritical to say oh yes, I get terribly upset.
>
> *No absolutely I guess just in the interview situation how you felt talking about all these things which have happened in your life and whether there was - whether you felt comfortable in all the interviews talking*
>
> Oh yes
>
> *Yes*
>
> Because I was glad to talk about my childhood and the village as I knew it as a child.
>
> *So, was it did you find it...you said you found it an enjoyable experience during the interviews would you go as far as saying it was kind of cathartic or therapeutic even?*
>
> Yes, because I felt it's stupid mind, but I felt somebody might be interested to read it and think oh did that happen there?
>
> (Participant Sarah, 3)

Choosing to talk less about her husband's death, and it likely being a turning point in her life at a stage when she was also leaving the village she loved, and the war was starting, may suggest it was too hard for her to talk about it much in her OH interviews. Another key point here is in her last sentence, when she says about people possibly being interested in what happened in her village. She and Jake both expressed a desire to share stories which might be of interest to others. In the knowledge they were sharing non-defined public legacies, they both chose to take on the role of storyteller and opted for stories which were sometimes gruesome and not necessarily personal, or, when they were personal, connected to a sense of meaning they felt was universal. Both their oral histories and research interviews were based very much on social history with elements of good and bad and heroes and villains. Death was both an unavoidable and useful topic for them.

Both female participants (Sarah and Heather) also challenged the common perception of the hospice being a place to die. They had both used the day centre, and with their own

mortality not being in question as much as other participants, it's possible the role of the hospice was slightly different, linked to the quality of life rather than facing one's mortality:

> ...how they say that people are frightened when they say, 'oh go to [hospice name] as if you go there to die, well all of us sort of die eventually but it didn't occur to me that people were frightened of going to [hospice name], because of the fear of dying...which to me is stupid, because they are so kind, they just can't do enough for you.

> (Participant Sarah, 1)

Death was integral to the OH process, both in the settings and conditions for participation, and in the narrative adopted by the participants. It was reflected on and talked about in different ways for those recording non-defined and family legacies. By taking part in the OH process, participants were confronted by their own and others mortality. This could be both a cathartic and upsetting exercise for them.

### 8.2.4 Illness and autonomy

The diseases a participant has is another important factor in understanding how it interacts with and shapes the OH process, especially in terms of how autonomy is left intact or not. In deciding which diseases to mention here, three key disorders were chosen which were mentioned in the research interviews – dementia, MND and cancer. Although none of the participants had dementia it was discussed with several of the volunteers and HCPs and their thoughts were varied and thought-provoking. MND was similar in having a significant impact on the implications surrounding recording an OH. Participant James had MND so this was discussed with someone with first-hand experience of the disease. Participant Heather was also able to give first-hand experience of living with cancer, which offered an insight into a different type of disease, which may not be terminal, and the way it could impact on the OH process.

### 8.2.4.1 Dementia

Several volunteers and HCPs had good experience of interviewing people with dementia. There was an awareness of the different types of dementia and how they might affect the participant:

> …we've worked with people with more straightforward dementia which is
> Alzheimer's or vascular dementia but somebody with say frontal temporal lobal or
> Parkinson dementia type that present in different ways and there are certain
> symptoms that might be difficult for a volunteer to cope with, and you might need to
> take a bit more time…

(Volunteer Jenny, 1)

Whether to refer someone to the service with dementia was debated, some HCPs would
refer people with dementia on a case-by-case basis:

> I mean I've got a guy with dementia...mildish, and I think I feel personally that he
> would be a good candidate for it, my colleagues seem to think that probably, but his
> wife would be there, he's just got lots to tell, lots and lots to tell so I'm still debating
> whether to refer him or not.

(HCP Holly, 1)

Similarly, volunteers were not deterred by interviewing people with dementia but were
aware of several challenges. Interviewees with dementia usually remembered past events
better than current ones and may forget who their interviewer was: "…she remembered the
things from the past quite well, but she didn't remember the immediate things at all so
when I'd met her later, she'd no idea who I was." (Volunteer June, 1).

There was the risk of them forgetting what they had said previously and sharing the same
stories in follow-up interviews: "…I have a feeling that the third interview was practically a
replica of the second one that I'd done so that was another thing that maybe the family had
to just accept." (Volunteer Kate, 1). Another challenge was sharing stories which weren't
appropriate or had the potential to be distressing to family:

> I think if it was somebody who had a reduced mental capacity then…in the instance
> I'm talking about, it was you know it was just a graphic description and I thought …
> that's quite an intimate - to reveal those sorts of things if you want your unborn
> grandchildren to hear them but anyway.

(Volunteer Jenny, 1)

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It was suggested that prompts such as photographs, and music could work well but could be problematic:

> I interviewed a lady who has got dementia, and had her daughter and her carer with her, she brought photographs to prompt her but she didn't know who the people were on the photographs and she was surprised every time her daughter said oh this is such and such, but it was a difficult interview, I had to do most of the talking or her daughter and in fact she didn't really remember very much at all, and in the end it actually upset her daughter, she didn't let her mother see she was upset but it had upset her.

<p align="right">(Volunteer June, 1)</p>

Several research interviewees suggested having family present could be a good idea as they could help with the consent process, remembering and curating which stories were shared and were also then aware that the volunteer interviewer would have tried their best:

> *…so, you didn't feel it made any difference at all his daughter being present?*

> Well, it might have made a little bit of difference…but he was wanting just to return to the same themes…so not much…but at least it was a good thing she was there because she could see - she could witness the problem…really so she might have otherwise have just thought oh gosh this interviewer hasn't delved very deep or something, but she could see for herself that…

> *So, she's part of the co-construction?*

> Yes

> *and so therefore understands why it sounds like it does at the end of it.*

> Exactly yes so that's quite important.

<p align="right">(Volunteer Kate, 2)</p>

However, there was then the risk of participants losing autonomy with family interjecting more. For volunteer interviewers there was perhaps a need for more specialised training in interviewing, such as knowing how to deal with silences, giving participants more time and

avoiding asking closed questions to try and determine dates and facts which might be harder for participants to remember:

> He was obviously an intelligent man but there were some signs of dementia and a lot of things were repeated and something's where I made mistakes like I would ask him a sort of closed question when I should have asked something slightly more open ended, he couldn't answer the closed question so instead of giving him a chance to talk about something vaguely related, I had asked him this, I didn't say anything like what's the date that happened but I might say how long did you work there…and that was a mistake I should have said and after that job can you remember what you went on to do…but as I say I don't always think on my feet.

> (Volunteer Kate, 1)

For the volunteer editors there was the added challenge of whether to edit out the silences and repetitions:

> …people with dementia, there are long pregnant pauses, so I remove those I remove false starts of stories that go nowhere so that it seems in the end more fluid and like a chilled conversation, no stress and remove signs of hesitancy associated with illness or dementia…

> (Volunteer Richard, 1)

Whether the editing was a preference of either the participant or family members was unclear, but as the editors tended to work in isolation with no contact other than with the Coordinator, it can be assumed it was not. How much and what should be edited would perhaps ideally be decided by liaising with the participant, family members and the Coordinator in the hope of where possible keeping the participant's autonomy intact.

### 8.2.4.2 MND

James had MND so was able to give first-hand experience of how this impacted on the OH process for him. Whereas people with dementia had limited mental capacity, people with MND have their physical capacity affected, with a risk of losing their voice and body movement. James was able to be more autonomous in dealing with the prospect of losing his voice (and supporting others with this predicament) by using voice banking, as

mentioned in the Motivations section (8.1). He pointed out in his second interview the advantage of someone with MND recording their OH early on: "a lot of people with MND lose their voice, so the sooner they could do an OH would be an advantage to them." (Participant James, 2). The referring HCP mentioned how he was restricted by being in a wheelchair and having difficulty using his hands:

> …a gentleman who…another one who is a very able bright gentleman, very much can use his mind but very restricted with his MND in the sense of he's in a wheelchair, electric wheelchair, he has difficulty using his hands, if his hands only work with the buttons on the machine if his hands were placed on the buttons, he talked a lot about his family to me, again he was somebody who appeared to have quite an interesting life and I felt that he needed to feel as though he was achieving something else, he was very keen to live his life as fully as possible I felt, for as long as possible and very able to have normal conversations, quite an animated sort of gentleman, could become quite tearful quite easily about some things, particularly when he talked about his family…incredible gentleman, and again I felt that he would probably enjoy talking about whatever he wanted to talk about and he did.
>
> (HCP Margaret, 1)

His OH interviews were deemed a success by the volunteer interviewer and his wife was able to sign the documentation at the end:

> Well, it was a very pleasant interview all the way through, I mean they were very welcoming, his wife was there, and his daughter…, and it was nice and bright in the room…he couldn't write because he couldn't move, I don't think he can move his hands he can just do something with a finger but, yeah that was quite a pleasant morning really.
>
> *Good, and you say his wife and daughter were present while you were interviewing him.*
>
> They were in the house they left us to it and his wife came in at the end to sign things so.
>
> (Volunteer June, 2)

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### 8.2.4.3 Cancer

The most common disease that participants might have on the OH service was cancer. Whereas dementia and MND are both visible diseases in how the mind or body deteriorates, cancer is sometimes less so, and is not necessarily terminal. In this sense cancer may be a journey without the inevitable conclusions of MND or to a degree dementia. Heather had largely recovered from cancer and felt she no longer had a life-limiting disease. She talked repeatedly about her journey with cancer, and shared an illness narrative whenever she was asked about the OH service in both her research interviews, which was perhaps her own way of expressing her autonomy and highlighting she was still in control of her mortality:

> *Great and the OH service as part of that kind of day centre offer how do you – you enjoyed the interviews?*
>
> Yeah and I think it is important to leave something you know touch wood I've had the operation, I've still got a bit of cancer on the liver, that will never ever go but I had a scan in September and my results said no reoccurring cancer…so I'm going to be here forever I keep telling them they're not stopping me nagging them yet. However, I'm not going to be here forever am I... it's - two things are certain in life aren't they birth and death you know that's guaranteed but I'm going to be here for a lot longer.

<div align="right">(Participant Heather, 2)</div>

### 8.2.4.4 Bearing witness

For these three different illnesses a continuum can be illustrated as below (Figure 18), dependent on whether the participants mental or physical capacity are limited and with which they then need family support in bearing witness, either to aid their memory with dementia or to help with writing and administrational tasks as with MND. For someone with cancer who adopts an illness narrative, such as Heather, it could then be that the volunteer interviewer or the intended audience of the recording is the intended witness of their story. In this sense the OH process is a way of bearing witness to someone's stories and memories.

*Figure 18: A diagram to illustrate family involvement dependent on illness*

Dementia                                    MND                                    Cancer

Family present in interview        Some family support with admin        No family support

If participating in recording an OH is a way of giving autonomy to someone at the end-of-life, the psychological support they need dependent on their illness can weaken their autonomy. Talking to a third party and opting to share their experiences of illness can be a way of achieving more autonomy by talking about something they may feel less comfortable speaking to family or friends about. It could also be useful for participants to talk about someone else's mortality (particularly bereavement within their family) and in this way the future audience listening to the OH also bears witness.

### 8.2.5 Section summary

A CGT of the OH interview process is here built on the premise of the experience of the six study participants, their volunteer Interviewers and referring HCPs. Secondary experience of OH interviewing, and connected scenarios are also discussed with the volunteers and HCPs. The various settings define the OH experience, as do the relation to being at the end-of-life, and the participants sense of mortality influence the experience. How the interview is a co-construction between participant and volunteer, how they are matched, how the participant remembers and reflects, what they choose to talk about and how the volunteer prompts them.

The findings suggest that the setting and disease of the participant could be impactful on the process for both non-defined and family legacies in varying ways, and there was a need for understanding and awareness by the volunteers of the participants' predicaments. For participants recording non-defined legacies there was a desire for it to be a dignifying experience in which their stories and memories had worth and were heard by others. For the participants recording family legacies it was important for them to leave appropriate memories for their families in which they considered how they would feel in bereavement.

This could mean making sure family members were suitably included and potentially upsetting memories such as previous relationships were possibly omitted.

The volunteers appeared to approach the interview scenarios differently dependent on the age of the participant in relation to their own age, and how close the participants were to the end-of-life. They shared different methods for interviewing and prompting participants which had strengths and weaknesses for both non-defined and family legacies. Some chose to say as little as possible, which could work well with recording family legacies, and others prompted more or were conversational, which could help with recording more archival social history based oral histories. There was a grey area in between, when participants were recording with both family and the public in mind, but it wasn't clear as to which was the most important. In this scenario, if the volunteer didn't prompt and steer the participant enough, the interview could be become haphazard and unsuitable for family or the public archive.

## 8.3 Outcomes

### 8.3.1 Background

This section examines the views of the research interviewees on the outcomes of the OH process for the participant, family and friends and the public. The findings cover:

- The challenges and opportunities in accessing the archived oral histories by the public.

- The personal outcome of recording one's OH as an opportunity to reflect and leave something behind for perpetuity.

- How, when and why participants and family and friends choose to listen back to the recordings, and the ethical implications in sensitive topics being omitted and included in a recording.

- How the OH can be reused for documenting social history, training, marketing and raising awareness.

- Views on the impact of digital technology on OHinPSC and death and grieving, including the challenges and opportunities presented by new formats, digital legacy websites and social media.

### 8.3.2 Accessing the archive

Future public access to oral histories became a major talking point in the research interviews. For the original OHinPSC model service which I worked on as a Coordinator, and which the study service was based on and linked to, all interviews were summarised and eventually archived in the University Special Collections. To achieve this, interviews were also given keywords so they could be searched more quickly. Volunteers on the original OHinPSC service were responsible for summarising interviews, and partly responsible for preparing them for the University Special Collections. However, volunteers on the study service rarely summarised interviews, and of approx. 300 interviews, most were without summaries.

### 8.3.2.1 Understanding GDPR and clearance forms

Whilst understanding the GDPR and clearance forms was process based, I have chosen to discuss them in this section with reference to how their implementation determined future use of the recordings. The original OHinPSC services project and the study service used the same permission forms, which were modelled on the best-practice standards set by the OHS where examples of the forms can be found (OHS, 2019). Both forms needed to be signed. The Pre-participation Agreement was to ensure GDPR was adhered to, and that participants were aware of the purpose of the service and what would happen to their personal data. The Copyright and Clearance form, which was signed after the interview by both participant and volunteer interviewer, enabled the interview to be archived and used in the future, in non-commercial ways such as research, the internet, publications and broadcast media. On the latter form, participants were able to specify a timeframe before parts of the interview could be made publicly available, as well as if they would prefer for their interview not be used in certain ways (e.g. on the internet). By signing it, participants agreed to hand over the copyright of their voice recording, and for the interview to be archived and used as outlined. Not all volunteers were fully aware of what exactly the forms meant. One volunteer showed ambivalence, commenting on whether there needed to be two forms:

> The pre-consent form I find in a way it's a waste of time because if they didn't want to do it they wouldn't have agreed to it in the first place particularly when you're going to someone's house because they have got to agree to you going to the house, so...I know you have to have the consent but I'm not sure you need two different forms, I think it could all be in one…for someone who is having a struggle with writing to have to fill in two forms is quite a lot and there's a lot to read on it.
>
> (Volunteer June, 2)

What also became clear was that some of the participants were unaware of what they were signing and agreeing to in terms of how the interviews might be used in the future. For several of them, particularly those in the day centre in which the OH was offered as an activity, they didn't realise its possible uses for the future, or that it was even going to be archived:

*…there is an option also when you archive it that you allow it to be used in other*

*ways for research or for exhibitions etc.*

Really?

*But it's totally up to you that but…*

No but that would be - I would love that…

(Participant Heather, 1)

However, for most this was a positive outcome, and they liked the idea of there being more of a chance that their interviews might be heard:

*So, in the consent form it says it might be used for education research...*

Yeah, it doesn't matter what it is used for

*Yeah, your happy for it to be used*

Yeah

*And that's a nice outcome for you*

Well, if it wasn't I wouldn't give it you…simple as that.

(Participant Ralph, 1)

### 8.3.2.2 Referencing

Another issue discussed was how and if interviews would be accessed by the public in the future. Participants were aware that interviews might be lost in obscurity in an archive. My questioning with all research interviewees included 'how do you think your OH should be reused?':

*…How do you think your OH interview and others and clips from them should be reused?*

I don't know what do you think? Are they just going to be put in a box and left?

(Participant Jake, 2)

How to make the interviews more accessible was a major discussion point, particularly within later research interviews. Ralph had some very strong ideas about this, especially as his interview was for the public rather than for family. For him, making sure the interviews were accessed in the future was vital. This informed discussion in later research interviews with others:

> I think...there's no challenge to the person who's giving the information, the challenge will be...how well they can file the information and if they can use good references so a variety of people doing different...research may find it interesting, that I think might be the difficult part.
>
> *So how to tag it so say you for example you talked about [brewery name] maybe how do we know when we get that big archive of interviews that there's that bit about [brewery name]?*
>
> Yep
>
> *And how's that going to be used by everyone else?*
>
> Like in a reference library
>
> *Yep, absolutely OK, yeah that's really interesting.*
>
> So that I think is probably as important as the information we are giving.
>
> *How it is then shared and how it's…*
>
> Well, if you don't make it available and easily found then we're wasting our time.
>
> (Participant Ralph, 1)

His premise that it was a waste of time if the archive wasn't accessible is interesting in that it fits with the fact he was recording his interview as a piece of social history for a public audience. It also suggests that he was less interested in the idea of the process of recording the interview as an end in itself, despite it clearly being a positive experience for him. As our discussion continued, I explained to him how interviews were currently archived with access in mind:

...you need to get somebody doing that - who's got his head screwed on who is worldly wise.

*Yeah, OK so somebody who brings it all together.*

That's right I think that's the important part.

*Yeah OK*

Not what I'm saying because somebody is going to pick that to pieces and say that's worth putting in that's not

*Yeah*

Not that I can understand, but once you've got that...I'm a 20-year-old at university doing a course I find out this information is available, and I don't know how to get it.

*Yeah, absolutely so it's what's done with the interview afterwards in a way so I know that they are summarised, somebody goes through and summarises all the topics in the interview so then it is written down the different things that are talked about.*

Yeah, but then it's got to be dissected and put out.

*Well, what happens is eventually they'll go into the university library and with keywords for each interview.*

Right

*So, for yours it will have [brewery name] as a keyword so then anybody who comes onto that catalogue types in [brewery name] your interview will come up.*

Like in Wikipedia

*Yeah, same kind of thing yeah*

Fine

*…how do you think OH interviews and clips should be used or could be reused?*

I just think you've got to continue building them.

> *Yeah OK*

> And they will develop in their own way not guided by us at the beginning, guided by informed information that people can manipulate and use in a good way.

> (Participant Ralph, 1)

His final point was interesting in that despite him being keen on finding ways to access the interviews, rather than suggesting sharing options he recommended continuing to build almost organically. It is not clear if he meant that the keywords would then dictate how the interviews were used or if he was possibly referring to future technology enabling the interviews to become more accessible.

### 8.3.2.3 Gatekeeping

Another discussion point was around the ethical implications of gatekeeping the archive. If interviews were used in the public domain should the bereaved next-of-kin be notified, and if so, how was the best way to contact them, or the most ethical way to share the oral histories?

> …if we've used the clip publicly which I think we've only planned to once and it didn't happen but it was at our Festival of Light we were going to play a clip of a patient, we contacted the next of kin so the ones that we use in house we don't because they are just internal, but I would to contact the next of kin.

> *And if the next of kin was uncontactable, would you hold off from then using it or - would it depend on...*

> I suppose it would depend on how identifiable it was.

> *Yes*

> Some people have got very distinct voices and stories, other people haven't.

> (Volunteer Jenny, 1)

### 8.3.2.4 Identification

Whether someone was identifiable was another interesting idea in terms of ways to share the oral histories with less risk of upsetting family, as suggested by Heather:

> ...if their names are never used but then somebody did a voiceover actually saying these stories again…because then somebody is not going to go in the museums and go oh my god that's my dad's voice.

<div align="right">(Participant Heather, 2)</div>

Accessing oral histories and making them available in an organised fashion to the public was an exciting option, especially for those participants who were interested in sharing a more public recording. However, it was agreed to be a challenge to achieve effectively. There was a need for a clear understanding of the forms that need be signed by participants and volunteers. A system for referencing the oral histories via summaries, keywords and transcripts was also deemed essential, and the role of gatekeeping, and when necessary, anonymisation, was integral to accessing the oral histories in an ethical way.

### 8.3.3 Reflecting on the voice

Whereas in Motivations, (section 8.1.5) was devoted to recording the voice as a motive for people being involved in the service, here the voice is considered as the finished product, including how it is shared, heard and remains for the participant, their family and friends and the public.

### 8.3.3.1 Remaining (making a recording for the self)

A major motivation for participants was to record an OH as a lasting record, whether it be for family, the public or without any specific audience in mind but knowing it remains. For many participants, recording an OH was an opportunity to articulate the contributions and achievements during their life which they were proud of. It was perhaps presumed or hoped by the participant that someone would listen to it in the future but the act of it being preserved as a tangible continuation was exciting: "I suppose when I've gone...there will be nothing left about me but if I've got in on audio...I'm still going you know what I mean? I'm not - I haven't been forgotten." (Participant Jake, 1). The question of who might listen to an OH in the future when there was not a specific audience in mind is examined later in this section with regards to sharing oral histories with a public audience. However, some oral histories may seem particularly pertinent for public use by the OH service team, particularly if they felt the audience was lacking, as mentioned here by the Coordinator, Jenny:

I always include an extract of [name] even though he died seven or six years ago because I want [name] to continue to be heard, because his family didn't listen to him and they showed no interest in him but it's like for me it's really important that he remains heard and listened to because I will always remember [name] and I know the volunteer who interviewed him will always remember [name] and I want his voice to carry on being there if you see what I mean so I think that's a big motivation for people to actually - part of them to remain behind if you see what I mean - their story, their woes.

(Volunteer Jenny, 1)

### 8.3.3.2 Listening back

The majority of volunteers (other than the editors) hadn't listened to interviews they or others had recorded – once they conducted any interview/s, generally they then took the recorder back to the Coordinator who was then responsible for preparing and delivering copies to the participant. It was also the same for the HCPs who would only hear clips of interviews in retrospect at hospice events or if a participant played them a small section in passing. The one exception was the Senior Chaplain when they were preparing audio for a funeral or occasionally covering for the Coordinator when she was on leave.

Volunteer June, who had her own OH recorded prior to volunteering on the service, had actively chosen not to listen to her OH yet. However, she felt the experience left her feeling she had "…not said this and not said that…" (Interview 1). And she vowed "that one day I will borrow the equipment and I will do it myself and just talk it through." (Interview 1).

Unfortunately, it was not possible to get feedback from all the participants about how they found listening to their OH. This was either due to the participant dying, not being contactable anymore during the research study, or because the participant was still to listen to it. For Heather this was because she didn't have the right technology set up via her computer. The Coordinator pointed out that usually, when participant's do follow-up interviews, they were encouraged to listen to their first recording/s:

With the interviewee if they're doing another recording, we try to encourage them to listen to it before the next recording, so they can remember where they got up to but also quite often they will remember other things that they want to say so they

often come with a few jotted down notes, so I think it's good to keep listening as they go, definitely.

<div align="right">(Volunteer Jenny, 1)</div>

Some participants did listen to their OH and reported back. Sarah reflected on it being an enjoyable and novel experience. Her OH was less for family and more a social history and an opportunity to reflect on stories of where she came from. It was perhaps unsurprising that she found listening to her own voice like listening to her cousin:

*…how did you feel listening to them?*

Sounded like my cousin [laughs] …well I was quite surprised that…. I had so much to say really but I suppose you could sort of sit down maybe and think of other things that happened like we used to have May Day where we had a May Queen and a Maypole in the village and all those sorts of things.

*So did listening to it make you think of other stories to tell?*

Oh yes it really sort of took you back…to the time and all the little petty squabbles in the village because a lot of them were married into each other's family you know…

*…and did you enjoy listening to the interviews?*

Oh yes it was quite enjoyable really.

*Because I know last time when I came you didn't have a CD player which worked so you managed to sort that out.*

Well, I bought myself one.

<div align="right">(Participant Sarah, 3)</div>

For James, listening back to the legacy he had recorded for his family, and knowing he had terminal MND, meant he found it quite an upsetting experience:

I wanted to kind of listen to it on my own so you know...there's parts of it that...made me quite sad, so, found that interesting - didn't think it would get me upset but it did so yeah but life's got its many ups and downs…

*And so was it listening back in the kind of reflection and I mean is there anything else you want to say?*

Just the impact of, things from the past that I'd done, that changed my life so obviously having what I've got now is a really big unforeseen issue, but I'd like to think we coped with it quite well

*Yeah, and were there any other feelings you had from listening to the recordings?*

Not really no…

*…so it made you feel a little bit sad listening to it and obviously some of the things you'd gone through which you have to then listen back to that*

I think most people do go through… stresses and strains in their life…

*…yeah absolutely and you decided you wanted to listen to it on your own first I presume it was for that reason.*

Yeah…and…touching on other aspects of life before I got remarried, I didn't want my wife to get upset over mentioning my previous marriage…so you know she quite understands that side of things so.

*Yeah, and that was something you were thoughtful of before you started the process wasn't it? Did you speak about that in your interview at all?*

Probably not no but

*but it's a part of your life.*

Yeah

*You can't ignore it*

No if you've not gone down that pathway then you wouldn't have ended up where you are and I'm quite pleased with my life so yeah.

*… it feels to me you've gone into it pretty well prepared as you can be…whereas some people, go into it and just talk about what's on their mind at the time and haven't…prepared for it at all.*

Yeah, and so tend to ramble on a bit.

*Yeah, and there's perhaps more room there for upset for saying something which they - or not saying something which they should have you know…and so, it's how you… mitigate that but then also it's a reflection of real life isn't it and that's what people are like in real life so…at what point can you know?...I'm just kind of [laughs] musing with you a bit about it but it's just interesting you saying that about it yeah.*

Yeah, like I never see my son anymore, he sort of…caused a division, on his own so he's got children which I've never really seen so unseen grandchildren…so…

*I mean there's not much you can do about that.*

No I try to keep contact but he just drifted away, so

*…in your interview you mentioned that you've lost contact with him don't you?*

That's right yeah.

*But you don't kind of*

I don't elaborate too much on it…we know what's happened, and my daughter and wife do too so you know.

(Participant James, 3)

For James, despite finding listening back to his OH upsetting, it was also a useful way to confirm he was OK with what he had recorded. There were relationships from his life that he either chose to omit or mention only partially, guided by how he felt they might be received by his family in the future. Our discussion about the process was a useful contribution to the research in understanding how oral histories are representations of life and as such it is often unavoidable they will feature the complexities of life choices and relationships. It can perhaps be assumed that James and Tim were particularly thoughtful about how their oral histories would be received by their families in the future. However,

some participants may need assistance from the volunteer in deciding what to omit and include when remembering past relationships and the effect it can have on family and themselves when listening back in the future. There was a fine balance for the volunteer in finding out in advance whether the participant should be including people within their OH or not. For instance, for a participant with several grandchildren, making sure they are all included by making a note of their names in advance, should this be appropriate. This is a point which I discussed in the final research interview with volunteer Karen who questioned whether it was right to check with participants about including family members to include in their legacy. "…if you start doing that you almost then are interfering with the flow and it doesn't become the persons story does it?" (Volunteer Karen, 2). She was keen to point out this could be an affront to the participant's autonomy. "…the whole point of I think OH and personal stories is that it is your story…for better or for worse." (Volunteer Karen, 2). How the participants planned for their family and friends to listen naturally varied. Jake wanted to give his as a surprise for his son:

> *…what do you plan to do with your finished OH recordings?*
>
> Er dunno pass them to give me son.
>
> *….and is your son already aware of them does he know about them?*
>
> No it's going to be a surprise.
>
> (Participant Jake, 2)

He was also keen that his brother and sister never hear it:

> *You mentioned in the first interview that there's a couple of members of family who'd you prefer not to hear your interview is that right?*
>
> Yeah, brother and sister.
>
> *So, if it did ever get...*
>
> I don't think they'd ever listen to it, it would never come to – because…my brother lives in [place name] and my sister I don't know where she is.
>
> (Participant Jake, 2)

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Heather, after becoming familiar with the concept of making the OH as a family legacy (as discussed in the Experience section 8.2), formed a loose plan to leave it for her children:

*So do you hope they will listen to the recording and get something from it?*

Yeah maybe not in the you know next year or whatever but in time to come it's there if they do want it…

(Participant Heather, 1)

The idea of family legacy was further discussed in her second research interview:

*So what do you see as being the opportunities in recording an OH and sharing one afterwards?*

I suppose just so that I know that the kids have got something, even if they don't want to listen it's still there isn't it?…still there for them to hear if they want.

(Participant Heather, 2)

The dilemma of the planning needed in an interview to avoid future upset whilst making sure the participant retains their autonomy was mentioned by Hannah, who as a Bereavement Counsellor, had a unique insight into how oral histories could affect family members:

Because it's not about saying goodbye it's about changing your relationship…and the hard bit is not having that physical presence isn't it?

*Yeah, OK so in some ways the OH can be very good in that way in terms of having the voice recording…and that presence.*

Oh, I think that's huge…I really do yeah.

*So, it's double edged*

I think it's just that you know there's always going to be something that upsets somebody that you might not think it might you know…and I think but if you take as much information as you can...and just I think it's about awareness of the impact

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that it might have on whoever's going to listen to it, from my perspective that's the important thing because that's where I will be giving that support to that person.

(HCP Hannah, 1)

How a participant's OH is received in bereavement can bring a mixture of emotions. For some it might be upsetting. This could be related to the participant including or omitting something from their stories, or for an unexpected reason which is much harder for the participant and supporting volunteer or HCP to plan for. For the participant, the process can offer an opportunity to be more open about their feelings:

> I think the person who is listening to it, there may be surprises that they either didn't know about or yeah that are new to them, and they might not have seen that side of, the person before, they might not be an emotional person in the sense that...some people find it much more difficult face-to-face to actually share their feelings but sometimes maybe in a situation like this I would imagine that for some people it might be easier to share their emotions and how they feel about some things and some people maybe.

(HCP Margaret, 1)

The only research interview conducted with a family or friend of one of the participants, was Christine, a friend of Sarah. She picked up on the risk of upset for Sarah recalling traumatic memories. In this case, memories had surfaced around Sarah losing her husband, and she questioned whether there needed to be a support network in place for Sarah afterwards:

> I was thinking to myself if she started breaking down and getting a little bit upset you know talking about that kind of that particular incident…and it's a long long time ago so she didn't but I'm guessing other people might be a little bit and she never seems to be a depressed kind of person anyway, she always upbeat, but I do - I was thinking if by the interviewer, if they spotted that somebody was having sort of a little bit of trouble talking about their past like that then they could direct them to another supportive service if they needed to…and I was thinking that as a kind of health and wellbeing point of view that's really important not just you know having somebody

enjoying talking about their life but it could trigger off some kind of health points as well.

(Friend Christine, 1)

Christine enjoyed listening to Sarah's oral histories in her car:

I had them quite a while before I started listening to them and I'd got them they were in the car with me and I just one time I'd got quite a long journey to do and I thought I'll just pop one of these CDs in - absolutely totally hooked then after that and I wanted to listen and then I stopped and had an appointment and then couldn't wait to get back to it to sort of finish off this CD. They were - I think they were only about 40 minutes long each one but really really enjoyed them...

(Friend Christine, 1)

The fact that Christine chose to listen to the OH as she drove, was perhaps due to the recording format being a CD, which many people choose to listen to in their car. With the advent of digital file, cars have become one of the few places people still have a CD player. (Jake and Sarah needed assistance from the hospice in getting a CD player and Heather still hadn't listened to hers due to her Computer CD player not being set up). On Christine listening to the recordings, she was struck be hearing Sarah's voice "...she's got a lovely voice, a lovely accent..." (Friend Christine, 1). And the stories:

...I was totally taken away with it, you know it was like having in an audio book in the car...but these stories were really interesting because I do like that kind of war time story...I mean they won't all be about the kind of thing will they oral histories at all?...it's just fascinating how we used to live, really.

(Friend Christine, 1)

After listening to the oral histories, they became a discussion point when she next visited Sarah. She was keen to point out how comforting it had been for Sarah to recall her memories to the volunteer Kate, and have them listen to, and record, her stories:

I think just the fact that these people are I mean this lady is in her nineties, they're at home all the time there's not a lot happening I guess the days are long and I think it gives them a purpose…and triggers memories as well so you know so good for the mind and soul kind of thing…because everybody likes talking about nice memories don't they?

(Friend Christine, 1)

Although this interview was the only one with family or friends of participants, the research interviews did include several first-hand and secondary accounts of people listening back to oral histories, especially in bereavement. When, where and how they listened varied greatly:

As for family, we've had such a variety. There was one family that I know that they listened to the patient's Desert Island Discs the night that he died - they sat round and listened to it and had a laugh about it because they told me about that and others have still not been able to bring themselves to listen years later, so there is a huge spectrum of that.

(Volunteer Jenny, 1)

HCP Holly, whose mother had recorded an OH, was given a CD of the recording to vet before passing it onto her brothers:

*…do you know when you plan to listen to it? - I obviously wouldn't ask you to do it as part of this it's when you choose to do it.*

No, we've mentioned it, I mentioned it to her because I said 'I don't know if I want to listen' but I know they are all marked one, two, three, four. I said 'you can remember where you've talked about me and you know said horrible things about me, we'll keep that one away.' She says 'I've never said horrible things about anybody', but [name] my youngest son he's quite interested to listen, he just doesn't want to listen to one if she's singing, so yeah in the summer holidays we're going to look at putting one on and just listening to it just me and my son just listen to it and then, feedback to my mum what we thought to what she'd said…because she wants somebody to

listen to it, before anything ever happens to her…she wants to know what people think now, I've got two lots well there's three sets, so obviously there's a set for both my brothers but she doesn't want to give them theirs…until anything happens to her so she wants me to listen first and then give her feedback.

(HCP Holly, 1)

Other volunteers and HCPs gave secondary examples of family finding out about recordings after a participant's death:

We had a letter from one lady that Jenny passed on to me because she talked about me in the letter and it was from the daughter - they didn't know anything about the recording, until she died and they found it…so...

*and do you know how they felt about that?*

They really liked it I mean the letter was really nice and they said it was really nice to hear her voice, from before she got really ill because her voice deteriorated as well so.

(Volunteer June, 1)

There would also be the case for future family generations who are yet to be born, or are too young to understand:

… obviously that recorded disc then obviously stays you know forever so you know so I don't know there's probably situations where there's a person there with a terminal illness that's got grandchildren that's got you know probably two, three, four, five that probably will remember their granddad or grandmother but that's only a vague memory of what they're going to have and I suppose in later life they can say 'oh actually this is a recording of your granddad, he was talking and in fact he mentions you in here.' And so you know that kind of like I suppose that's sort of sound gift goes on and on and on and on forever and ever and for a day so it's obviously it's for posterity.

(Volunteer Jack, 1)

For some family members it could be too hard to listen to the recording or they preferred to wait until after the funeral:

> …I've never had a family say to me 'we wish we'd never heard it.'…Always said 'it's very hard.' Sometimes they say to me they haven't listened to it, but I've never been involved with them to find out when they do listen to it because actually the funeral has gone and all the rest of it that so I'd count [incomp] any evidence about the length of time after death that family listen to them, but sometimes they haven't listened to it for the funeral and…sometimes they've wanted to listen to and each family relative or whatever is - will do it in their own way really.

> (HCP Geoff, 1)

How often people chose to listen to recordings was another consideration. Some listened regularly: "….I know it's a big thing for family and loved ones they - like I said the lady she plays it every morning, so that her mum is still close to her." (HCP Holly, 1). The importance of the voice recording was specified by participant James who was aware of not having had similar from his parents, who both died when he was young:

> The legacy of leaving something behind for my grandchildren, and my wife and daughters too, so the fact that it's in my voice, will be good for them to hear when I'm not around anymore.

> (Participant James, 2)

In general, the presence of the voice was a major positive for family to be able to listen back to:

> I really thinks it is a good service that you're providing because to see the different characters that have given the stories, how much it means to them and then I met a family…they'd been bereaved but their loved one had done this OH and she said 'it's absolutely marvellous.' She said 'it's absolutely wonderful because you're sat with grandkids and were looking at photos like you do' she says 'and then in background we put disc on…so they were talking in the room.' She said it was a bit weird at first,

because you could hear their voice and it were like I think three months after...but she says 'it's really good'.

(HCP Holly, 1)

Many family members had mentioned to volunteers and HCPs about the ongoing presence: "… it were like their loved one was still there." (HCP Holly, 1). Hearing the voice in bereavement felt comforting for most. However, the content of the interview could require more awareness in terms of what was being said and how that might affect bereaved family and friends.

Sometimes family and friends were asked to listen to the recording by the participant when they were still alive to check it was OK. However, when and where bereaved family and friends listened to recordings varied widely, as did their response. Some found great comfort in hearing the voice of the deceased and would listen to it regularly, whereas others were unable to listen, or waited until during or after the funeral. There was a risk that family and friends could find aspects upsetting, such as omissions or surprise revelations, but nonetheless, being given a voice recording was a unique, continuing presence.

### 8.3.4 Reusing oral histories in the public domain

The strength of the story and hearing a voice giving first-hand witness of experience demonstrated how powerful OH could be as a resource within the archive. The possibilities of the archival copy were not fully realised by several research interviewees, but for others with more experience, such as the Coordinator, Jenny, there was more awareness and positivity around it and how it could be used for educational and intergenerational purposes. A key point was raised by volunteer Karen in the final research interview in which she mentioned the power of people histories and of OH as a vehicle for giving voice to people who might be marginalised or even silenced otherwise:

…I think it all enhances our understanding of society of people's lives throughout history, I mean history has been... rewritten or amended all the time as we speak really and I'm not - that could well be as a result of personal histories stories so I think it does, it actually puts a little bit of flesh on the bones of the history you know.

*so you it's almost kind of a political thing to you in that sense that it's a way of giving voice to people?*

Yeah

*And making sure that voice is heard by others would you...*

I do think that it definitely gives voice…especially to the silenced voices in society but I think it also actually just as I say…it's much broader representations so it's perhaps what you're saying but I think sometimes kind of history that you know we receive, is very much on yeah I suppose it is political it's very much on who happens to… who the powerful voices are.

(Volunteer Karen, 2)

In this sense the OHinPSC archive could be viewed as a way of preserving personal histories which might not be heard otherwise, with the possibility of offering an alternative to traditional mainstream histories, of recording ordinary people histories rather than those of the famous or powerful. These personal histories could bring fresh perspectives to general historical discourses.

### 8.3.4.1 Documenting social history

The possibility of using the OHinPSC as a social history resource was identified by several of the research interviewees. To have the recorded voice giving first-hand experience of collective topics such as war and social economic conditions, or more personal experiences relating to professions, local history and identity, were deemed useful for educational, research, creative work and entertainment purposes. It was suggested they could be shared within schools, local history groups, on the radio and for documentaries. For the participants (many of whom did not realise their oral histories might be used as social history at the outset), this was a potentially rewarding outcome. Jake was particularly effusive about his OH being used to document social economic conditions:

I mean can you imagine in future...well I won't be here [incomp] there might not be any poverty anymore...and they listen to that, and they go wow...that's how it used to be, yeah.

For participant Heather it was a way to preserve the stories of characters she worked with on the market: "…he stopped every tram coming into Sheffield, that has got to be put somewhere you know." (Interview 1). Participant James, despite recording more of a family legacy, could see historical relevance in documenting changes that had taken place in his profession:

> Like you were saying about social history, so even in my time doing the job I did things had changed and moved on...so in that respect yeah it would be interesting for other people to listen to things.

Participant Sarah saw it as a way to let people know about the history of her childhood village before it became a commuter town: "to know that life did exist in [place name] long before they arrived." (Interview 1). Sarah's friend Christine, who listened to her OH's, thought they could be useful as an educational resource about the war:

> …just as an educational thing you know and even in like primary schools you know they always do wartime topics don't they different for different years and things yeah so even as a child I'd have enjoyed listening to what Sarah had to say yeah.

The referring HCP said similar:

> *How do you think OH interviews and clips should or could be reused?*

> History definitely, I'm thinking about that lady [Sarah] up at [place name], I don't know where you would pass it on to I've had a couple of nurses that had careers that started you know years and years ago sort of war time onwards and you think the RCN *(Royal College of Nursing)* for example would love that as an archive, it's the history aspect of it…quite amazing for some of them.

The idea of sharing wartime memories as an educational resource was echoed by several other volunteers and HCPs:

> I mean can you imagine you know a class learning about the war, hearing the story of our - we've got two actually who were refugees on the Kindertransport, listening to their actual words, their voices, people from [place name] who came you know on the Kindertransport, how amazing would that be - people studying the war, can listen to the voices.

> (Volunteer Jenny, 1)

It was presumed that having first-hand accounts like these could be of interest to many people if they were easily accessible, helped by having detailed summaries:

> …and I think as you were saying earlier you know there is a lot of history in them, a lot of personal history but also you know people talk about, how things were in the 1930s, how things were you know what happened to their family during the war, and these kinds of things which anybody would find interesting, and if we kept more information about what is contained in there then you know it would be possible to put together you know like the history of the wartime years, you know from the perspective of individuals you know my brother went away to war and I was very lucky that I didn't but I did my National Service and in my National Service we did this and I learnt to do this and that and the other and I think hearing those things from ordinary people, is the best way certainly for young people to learn.

> (Volunteer Simon, 1)

The research interviewees believed unique first-hand experiences shared in oral histories could be a rich historical resource, and most were excited by this prospect. Having detailed summaries could enable oral histories to be identified by topic, and then shared through a variety of mediums with the public.

### 8.3.5 Changing technologies

There was agreement in most research interviews that rapid changes in technology had changed how we communicate with each other and how we prepare for death and grief.

### 8.3.5.1 Formatting

On a basic level the audio format was no longer only on CDs, with some people preferring the audio as a digital file or a memory stick. As already mentioned, this transition had led to CD players being less universal, however, many older people were not familiar with new digital formats. This was clear amongst the participants, who despite primarily asking for CDs, lacked the means to play them:

> …already we are getting people say to me 'I haven't got a CD player anymore can I have my recording on a memory stick?' Which is fine…but, what is going to be the future? Is there going to be some new technology come along that replaces voice recording I don't know are we going to be watching 3D videos? Are we going to be able to capture our memories in some other way? Is it going to be all Black Mirror and we're going to be able to download our memories onto a chip and replay them so we won't need to have any OH because our relatives can have a copy of our chip and we can edit it and… show them what our first day at school looked like through our own eyes I don't know [laughs] going off into a bit of science fiction…

> (Volunteer Jenny, 1)

Another issue with formatting the audio was filling in the correct metadata to identify the audio. An issue I spotted when listening to all the participant's oral histories was that in Windows Media Player the audio was given wrong and inappropriate titles such as 'Sean Yost – Christ the Redeemer Church – Light on Father's Day', 'Patrick Fitzhenry – Defeat Smoking – Cheap Drunk' or 'Jack Jones/John Williams Sings Loves Songs'. Whether this was an issue for people listening back was unknown but by filling in the metadata prior to formatting files it could have been avoided.

The invention of smartphones has meant that people can record memories easily via a camera, video and voice recorder. However, younger generations, particularly, opt to text rather than have voice conversations. This was viewed by some as causing a communication chasm between generations:

> I don't think people talk anymore, you know it's like I've got a stepdaughter…and everything is a text, you know even to her brothers and sisters, and I think just talk, just talk to each other.

(Participant Heather, 1)

Social media and the internet have also changed how we perceive life and death. Certain websites enable people to research their genealogy, and this was part of the hospice offer:

> …then I'm doing genealogy up at [external hospice venue]…so me and my mum we've joined Ancestry [.com] so we're going through it all and I decided to do my mum's dad's side, his mums because we know nothing about that for some reason so I was going through it and it directed me to Findmygrave [.com] and I thought ooh right we'll have a look at that and there was this picture of my great uncle…and I was looking at it and it said - mother and I thought oh I will just have a look and there was a picture of my great great grandma. . . and then it led to my great great granddad a painting of him…so I got it and my husband was saying 'ring your mum ring your mum' but I wanted to show her face-to-face because my mum had never seen her grandparents… and I were like buzzing you know and the kids were like 'oh alright yeah whatever'.

(Participant Heather, 1)

### 8.3.5.2 Digital memorialising

A person's digital footprint can now span beyond birth and death, from the womb, with photos from pregnancy scans, to being mourned after their death on digital platforms. How people are memorialised and remembered digitally means that grieving happens in a much more public and instantaneous way. This was particularly apparent to the Bereavement Counsellor Hannah:

> …I think it does change with generations because, sometimes people find out somebody has died on social media, you know it's very public and it's very quick and you know so it's not like somebody turning up and saying I'm really sorry but I need to inform you it's kind of poof there in your face and you can't take it away [laughs] and that's not the best way to find out that somebody you cared for has died.

(HCP Hannah, 1)

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Funerals can now be broadcast on YouTube and song playlists chosen via the internet. As the Chaplain Geoff pointed out, it wasn't unusual for extracts from someone's OH to be used in a service, although this could require extra thought on the Chaplain's part:

> Sometimes you get conversations when you do the funeral visit to say 'we've got these we daren't listen to them yet, we're waiting for the right time, to do that we don't feel we can do that as yet.

> *That's interesting*

> And another way that sometimes happens is that people say to me 'can we somehow lift this section of the story?' Or something they have left, and 'can we play it at the funeral?', Which is very easy to do because Jenny lifts it for me, puts in the whatever format it is and I then send it to the crematorium and it's then included into the kind of running list of music and stuff like that and then can be played as part of the service…Now I always have to give a health warning about this because actually hearing the voice of the person whose funeral you are at sometimes can be quiet, unusual these days but it's becoming a little more common, because of OH really…but I do give it with a health warning to the relatives when I'm doing the funeral arrangements but also before I play it in the service, I say to the congregation so that it's not a shock, especially when you are in North Chapel at [place name] where the speakers are above the coffin so that whole thing about the person might be speaking, from the coffin or what it seems like can be quite disconcerting and sometimes a bit frightening for people so I would always want to unpack that as quickly as I can but as carefully as I can with the family and with the congregation.

> (HCP Geoff, 1)

The advent of digital legacy platforms was also discussed with the Coordinator Jenny, and compared with the OH service as a form of legacy making:

> I think with the digital legacy stuff I think people tend to do those themselves and I think there is a real benefit to having someone else in the room asking you questions, or even just bouncing of somebody else in the room, rather than just sitting there with your phone, and I still think we produce a much better quality of

recording than an iPhone can, I will always say that, and the archive as well - you know you can drop your iPhone down the loo or in the canal like my brother did and it's gone - everything is gone. I know there is back up facilities and things like that but you know it's - I think what we produce is a lot more tangible because we offer that permanent storage, but I don't know where we will be in ten years' time. I'm excited about changes in the future in terms of technology but I'm also wondering where that leaves us.

*Do you think it's possible that the OH model which we work within can inform digital legacy platforms?*

I suppose it could because I suppose what it tells you is what people want to talk about, the memories that people want to leave behind, we know what people talk about, we know what's important to people and we also know the power of the voice, that's come through a lot…

(Volunteer Jenny, 1)

### 8.3.5.3 Sharing online

Despite the pace of technology being recognised and several factors being considered, there were mixed feelings amongst the research interviewees about oral histories being shared online. Participant Jake voiced concern about family members having access whom he didn't want it shared with:

Err I don't know about being online I don't know…because there's one - there's two of my family, I wouldn't like them to hear...to hear it because we don't speak.

(Participant Jake, 1)

Some research interviewees seemed surprised they weren't already:

*…what about her interview being available online how do you feel about that?*

Well, I'm surprised it's not to be honest once it's in the university I would have thought that would be the next step - everything would be put online and I guess if

they're - I think it would be a good idea…because everything is online anyway now isn't it?

(Friend Christine, 1)

Some volunteers and HCPs were less sure about using oral histories online. This included the Coordinator Jenny:

…somebody suggested why don't we have available clips like the ones I was doing at the showcase online for people to listen to and I'm always a little bit sort of ergh because the thing about having them as clips to listen to is that we can control who listens to them, whereas if they are online, you know they can be downloaded, people can record them, copy them, we don't know where they are going to end up and I'm always a bit nervous about that…They can be altered digitally, I know you can do that because I could do that, we don't want something ending up somewhere or yes, I'm slightly nervous about things going online just generally.

(Volunteer Jenny, 1)

There was a belief that the oral histories might be manipulated in an undesirable way:

*How do you feel about clips being shared online?*

Not sure about online...not sure because it's - I don't like text - I'm a bit old fashioned - I don't like text I like talking to people, and sometimes I think it can be misread...you know when they...

*It's interpreted yeah*

Yeah so, I just think it's I think it each and every to their own but me personally I wouldn't…I just feel that people when it's online then people sort of like clip it and reword it and they do these things don't they so then something nice has just gone pear shaped you know.

(HCP Holly, 1)

In one of the final research interviews I discussed with volunteer Kate the idea of using social history elements of OH interviews online in a podcast which was met with enthusiasm:

> *so, I was thinking maybe a good idea would be to create some kind of podcast - a short podcast where we could have people's stories and they could choose to opt into that when they do the recording and then say a two-minute story would come out of that into - and so it would be shared*

> Yes

> *Straight away pretty much if they were happy to you know*

> Yes

> *And we could be very clear from the outset that we were doing that with it if they wanted because it does feel like a lot of people are doing these as family records but some people are doing them much - I don't know if you've come across this in doing your interviewing but aren't doing it so much as a family record, they're doing it as something to do or they are doing it from a social history angle.*

> Yes

> *They want to talk about…*

> They want this thing to be recorded yes

> *Yeah, so especially in those examples maybe less so the kind of family records but where people are talking just about their stories of [place name] or…*

> Yes exactly

> *…you know*

> well, I would think that's a good idea.

<div align="right">(Volunteer Kate, 2)</div>

New technology and the rise of social media and digital legacy platforms has changed how the public process life and death. The speed at which digital formats are changing, and the ease of sharing audio and video online, has created challenges and opportunities for the conventional model of OHinPSC. Many of the research interviewees felt unsure about how to use digital formats, and sceptical about sharing oral histories at the end-of-life online due to the risk of them being manipulated or shared on social media. However, digital media offered several new avenues for conventional grieving, particularly funerals, where OH clips were increasingly used as part of the service. It was also discussed how OHinPSC might offer an alternative to digital legacy platforms, in that it involves a more human approach with a third party interviewer, as well as more secure archiving. Creating a tailored podcast was discussed as a possibly more ethical method for sharing OH clips digitally.

### 8.3.6 Reusing in health and social care

Another question which all research interviewees were asked was how could OHinPSC be reused in health and social care. Ideas included for training and promotional purposes, as well as raising general awareness of being a hospice patient.

### 8.3.6.1 Training

Clips from interviews could be used to train medical staff to have a better understanding of people at the end-of-life, and used as a tool to grasp the person behind the patient by developing listening and empathy skills:

> Well, I guess in training, we did listen to some in training, snippets, medical training as well, I think that would be…helpful in getting people to be able to have conversations listening to patients, respecting people's lives and finding the pleasure in everybody's life - less seeing them as a patient but as somebody doing a you know a history.
>
> (Volunteer Fiona, 1)

Clips were also already regularly being used to train future OH volunteers or, to inform hospice staff about patients and the service:

> …names obviously should be taken out...identity should be taken out then I think probably educating, us.

*Yeah, OK for educating nurses then*

Because I'm not sure that everybody understands it

*Yeah, OK so that they have a better understanding of the service*

Yeah, I just wonder if you could get permission from one or two, to actually share there - a little bit of their story if they are happy to, different styles different methods, whether that would help some people really understand and sort of capture about OH.

(HCP Margaret, 1)

### 8.3.6.2 Raising awareness

It was also suggested that clips could be useful for other patients to hear first-hand experiences of those with certain diseases such as MND or cancer, particularly when the OH included some kind of illness narrative:

…I think patients experiences as well because some of people's oral histories I imagine would be talking about their treatment and how their disease has progressed so I think in terms of people's feelings about stuff it would definitely be useful, and how their journey has been and could it have been better, because it's obviously the main topic of conversation for our patients is how what treatment they've had how was it what hospital out - what did people say to them that kind of thing, what was good what was bad that kind of thing.

(HCP Judy, 1)

This theory was also echoed by volunteer June after interviewing participant James:

I think it could be reused with people with in a way with MND because they could see little bits of what you still can do you know because he hadn't give up any hope at all, I did feel that with him he was quite positive, and he was doing all he could and somebody who's perhaps just been diagnosed or it might help it might help them to...get some positivity back into their life because I would think it is quite devastating to be told you've got that, and you know you're going to deteriorate but, if someone, is quite a way down the line with it, and he's still talking positively he's

still going on holiday still going to football matches because he still has a [local football team] season ticket and his daughter takes him I think it could possibly be a helpful thing for somebody like that, if they ever get to hear of it so.

(Volunteer June, 2)

One of the volunteer editors also felt clips could be used to help people get used to the idea of being in palliative care:

Whether there's a use in counselling, or not or whether, whether patients in the future would benefit from listening to some of these interviews as well, is that if you're going if you're going into palliative care, listening to people being interviewed that were in the middle of it, so are further down that road than you are…and seeing hearing their attitude I think would be you know…it must be very frightening, when you first go into palliative care, but I think if you - most of these people are positive…now they talk positively, they talk about positive subjects…I don't know whether that would help or not.

(Volunteer Simon, 1)

And for helping potential participants understand the service better before taking part:

…certainly, for training and anonymised for letting other people know - even playing someone a little clip to recruit them - that's the wrong word recruit them but to get them to understand.

*To comprehend the service*

Yes

*That's interesting*

And do it like that…because then they'd know exactly what sort of things…that we were asking them really or wanting them to record.

(Volunteer June, 1)

### 8.3.6.3 Marketing the service and hospice

Quotes from interviews had also been used to promote the service. This was viewed as a good idea:

> ...I'm in business so I'm big into marketing products and getting the product to market, those soundbites of people are fascinating and interesting and I think there's a lot of people...their default position is always 'ooh no I wouldn't want to do an interview, I'm not interested or not capable.' And so there's always that knee jerk reaction that it's easier to say no then to say yes so I think a lot of people instinctively say no…maybe getting those sound bites you could you could make a sort of quite a good marketing case to sort of explain what it is because obviously sounds and pictures are explanatory where if someone's says to you 'how would you like to do an interview about your life?' It's - a lot of people are not sure about that 'why would I?' Or "what have I got to say?'…so those sound bite clips yeah I think they could market the service better.

> (Volunteer Jack, 1)

And also, for marketing the hospice:

> …we've also had quite a few patients who are really quite complimentary about [hospice name], and when that happens, I have sometimes referred patients to our Communications Team and they will perhaps do a video and a social media post.

> *Brilliant so it's been used for promotional...*

> That's right, were hoping to do one on Thursday, we had a patient who did his Desert Island Discs but he actually sang all the tracks [laughs] because he's a crooner, he's a club singer or he was a club singer so on Thursday apparently it's World Music Day or something coming up so our Comms Team are going to interview him and perhaps take one of his songs, because he'll sing - he'll serenade you when you go and see him and put it on social media, so it gets used with things like that and patients enjoy that - they like having their five minutes of fame.

> (Volunteer Jenny, 1)

Several of the research interviewees, and particularly volunteers and HCPs, expressed ways in which OH clips could be used for training staff and volunteers about the service and working in palliative care. It was also suggested that they could be used to raise awareness of the service for potential participants as well as to support people coming to the hospice. Finally, clips could also be used to market the service and hospice to the public and external partners.
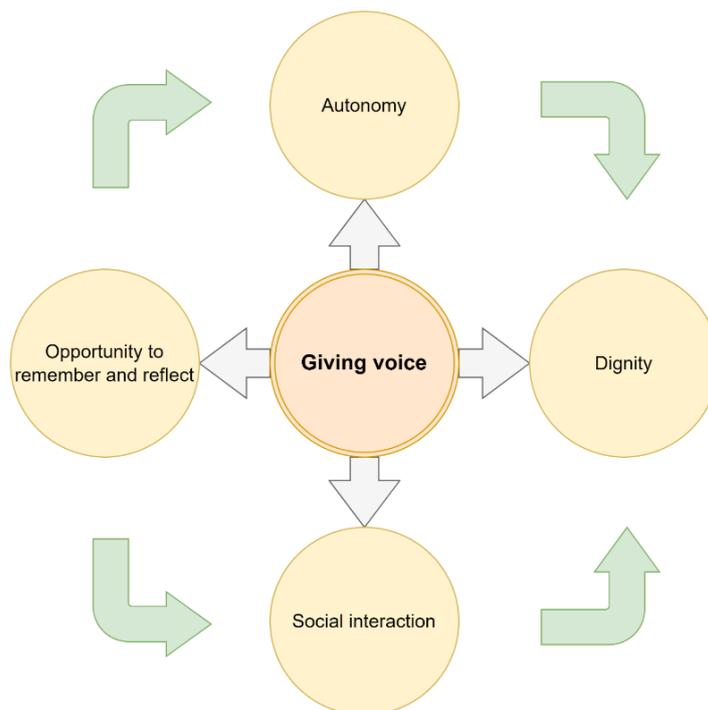
### 8.3.7 Section summary

The outcomes for participants, family and friends and the public were viewed by the research interviewees as being multi-faceted. Participants found comfort in their OH being archived and preserved. On listening back, it could invoke a mixture of emotions, whether that was due to hearing their own voice and memories and reflections on life or deciding what to include – or omit – in the recording. Family and friends varied widely as to when and how they chose to listen to recordings. For many it was an enjoyable experience which enabled them to feel like the deceased's voice and stories remained. There was also the risk of hearing surprise omissions/inclusions which could cause upset, and the need for a support network was mentioned, for both participant and family and friends, should any upsetting topics be raised.

For the public, all the research interviewees agreed that the oral histories could be a rich social history resource via multiple mediums, especially in education. There was a need to find ways to access them within the archive to ensure they could be used in the future, especially as some participants had recorded their oral histories for this specific reason. There were also suggestions for reusing oral histories in health and social care, particularly relating to promoting the hospice and service, delivering associated training, or raising awareness for hospice patients and potential OH participants. Digital technology and the internet were deemed by the research interviewees as presenting both opportunities and challenges for OHinPSC. Whilst there was ambivalence about sharing OH clips online, it was felt that there were ways, such as podcasting and sharing audio at funerals, in which OH could work well within an ethical framework. It was also considered that, although OHinPSC may eventually become superseded by other digital legacy methods, it offered a unique, human, and relatively secure way of archiving OH.

## 9.  Constructivist grounded theory

In the findings chapter I discussed the processes in motives, experiences and outcomes in OHinPSC. Here I focus on the CGT and how the different research interviewee groups and the data generated during the study were involved in identifying a basic social process. I start by diagramming the basic social process of *giving voice* which serves as the medium at the core to other key elements supported by the findings. Giving voice is present throughout whether it be *to* the participant, or *by* the participant to the volunteer and HCP, family and friends or archive and public domain. It is the primary reason for undertaking OHinPSC and the main consequence. It happens before the interview takes place in the planning, during the interview recording and afterwards in disseminating the recording and discussing and reflecting on it. The *opportunity to remember and reflect* can be perceived as the action which enables the service to happen in the first instance. During the process *autonomy* and *social interaction* are both key processes in mirror duality which become apparent, with a desired outcome of *dignity*. Central and integral to these elements is the process of *giving voice* which enables all four elements. I present the Giving Voice Theory (GVT) (Figure 19) as the CGT for this thesis which encompasses the key elements of my research data and the basic social process of OHinPSC.

*Figure 19: A diagram illustrating the basic social process of the Giving Voice Theory (GVT)*



I now give detail of these social processes considering how they figured for each research interviewee group throughout the temporal process of OHinPSC.

## 9.1 Giving voice

The act of *giving voice* happened in both a literal and abstract sense. For participants and their family and friends it was having the voice recording, and for volunteers and HCPs it was being able to support this happening. In an abstract sense *giving voice* meant the act of enabling and supporting the participant to have autonomy. In taking part they were encouraged to share their voice and identity and express themselves whilst planning for the interview. This could lead to them discussing their life and memories with family and friends, other patients and HCPs before the interview. During the interview they could talk within reason, about whatever they wanted, usually with no time limit, and had the opportunity for follow-up interviews. The interviewer was a third party, who probably did not know them prior, or about their medical background.

The physical capacity to give voice also factored. Participant James, who had MND, was unable to speak for long, with coughs and splutters throughout the interview. Other participants could be extremely tired or under the influence of medication which affected their speech. How well the interview was recorded – the microphones used, recording levels

and other background sounds – all shaped the final voice recording. The different settings for OHinPSC had their own acoustics to be aware of. Even in the purpose-made hospice room for OHinPSC, volunteer Jenny mentioned an example of laughter from the corridor which was incongruous with a participant's narrative of an upsetting incident. Some participants and family and friends were pleasantly surprised by the audio quality of the voice. However, if the voice was not well recorded or at its best, it could be upsetting.

The power of the voice was unique to OHinPSC in comparison to other end-of-life legacy services. Being able to hear and remember the voice was extremely important to the bereaved. How and when they listened varied widely, whether it was soon or years after the participant had died, and recordings were listened back to in their home, car, alone or in public spaces such as their funeral. Several research interviewees mentioned the physical power of the voice as an ongoing presence as if the person was in the room. By signing the Recording Agreement form the participant was also giving voice to the archive. That the voice was being preserved was another positive for research interviewees. The voice was an important attribute within the public archive. Having a social history resource with first-hand experience, in a physical form, which could be heard in schools or museums was deemed unique and exciting. Volunteer Jenny gave the example of a past participant who had travelled on the Kindertransport during World War 2, and how interesting it could be to hear that first-hand perspective in schools. For some participants, giving their voice for social history purposes was a key motive. As mentioned by volunteer Karen, it was also a way to give voice to personal narratives to be heard which might normally be missed or silenced in public discourse.

## 9.2 Opportunity to remember and reflect

The *opportunity to remember and reflect* was apparent throughout the temporal process, in terms of both being remembered and recalling and sharing memories. Remembering was central to participant's identities and how they wished to be, and were, perceived by others. In the first instance, the participant was remembered as a person rather than a patient by the referring HCP/volunteer, both through their interest in them as an individual, and providing the opportunity for them to be remembered. For example, when HCP Holly met with participant Jake prior to joining the service, they had friends in common, and both used remembering people as a way to bond. It helped the HCP to know more about the patient's

background and identity, and for the patient to be able to understand, and possibly trust, the HCP more. When asked if they would like to participate, potential participants automatically began to recall memories, both internally and externally with family and friends, or even other patients, in anticipation of the interview. For many this was a positive experience of self-reflection, affirming their identity and possibly giving them something to think about other than their medical care or diagnosis. For others this brought into question their own mortality (Heather) or others' (Jake).

The extent to which each participant prepared what they would reflect on impacted the interview. Participant Jake mentioned he was asked to speak about whatever was on his mind, which is what he did, whereas participant James planned what to say in advance, both in written form and mentally. They were both interviewed by volunteer June, who had an interviewing style of saying as little as possible to uphold the autonomy of the participant. She viewed the service as primarily to create a personal record for family and friends, who wouldn't be interested in listening to her voice. This ambiguity in her understanding meant her approach worked well for participant James, but less so for participant Jake. Volunteers had different interview approaches ranging from minimal prompting to conversational. This impacted on how participants reflected and performed for the volunteer and future audiences such as family and friends or the public. For participant Ralph and volunteer Jack, the interview was more conversational. This worked well and they reflected on memories in common about local history, having several shared experiences. This conversational interviewing style would have been unsuitable for a personal family legacy wherein the minimal approach of volunteer June was ideal.

The act of remembering and reflection, in learning about social history, was also a motive for volunteers for joining the service. In listening and enabling reflection from the participants they interviewed, they could also make a positive impact to the participant's wellbeing. How the volunteer prompted and steered the participant in structuring their memories and stories was successful dependent on their understanding of if it was a recording for family, or a social history. Where the motive was less defined, the volunteer perhaps needed to adapt to both approaches, staying largely off the recording but also prompting or steering when needed. Recording a family legacy added more pressure on the participant in what to include or omit, knowing that family and friends would be listening

back. There was a risk of upset recalling certain life events, such as past relationships or forgetting to mention people or happenings, such as grandchildren's names or an anniversary date.

Some participants' memory capacity might be compromised due to medication, illness or other considerations. Although no participants had dementia, this was discussed by volunteers and HCPs as to when more support might be needed. How the participant performed and identified as a storyteller in their reflection was dependent on who was interviewing them. The co-construction relied on factors such as gender, age and social background, which could determine how they related and the participants' memories were invoked.

For the participant, listening back to check the recording was another powerful period for reflection. Participant James found it quite upsetting. Other participants who listened back (Jake, Sarah, Ralph) found it invoked more remembering, whether thinking they sounded like a deceased family member or reflecting on their life in an encapsulated form. There was the risk that if participants chose not to listen back (Heather), or were unable to due to their illness or dying (Tim), they would include or omit parts of their narrative which might upset others.

The research lacks first-hand experience of family or friends listening to recordings in bereavement, but based on those with secondary experience, having a recording was a unique way for family and friends to remember a participant, and a lasting way for their memories to continue. Remembering and reflection could also happen via publicly archived recordings in educational and research settings, or extracts being played at events and in training.

## 9.3 Autonomy and social interaction

*Autonomy* was shaped by the *social interactions* participants had or lacked during the OHinPSC process and how they chose to identify themselves and with others. In deciding to take part, participants would often refer to family and friends, HCPs or other patients for advice and to help their understanding. Conversely, when participants did not have immediate family and friends or frequent social interaction, visiting the day centre or having more frequent visits from HCPs and volunteers became a motive for taking part in OHinPSC.

For HCPs, spending more time with (potential) participants and finding out about their backgrounds led to stronger links with them and their families, in turn giving them autonomy to make more informed decisions about their care.

The interview co-construction between participant and volunteer was a social interaction and the Coordinator was key in trying to effectively match volunteers to participants. When successful, this gave the participant autonomy to affirm their identity as storyteller. For some this meant sharing stories of other people rather than themselves. Participants recording social histories tended to focus on places or times of change key to their identity. The volunteer had a role in supporting the participant with their autonomy, particularly with participants with MND or Dementia who may require extra support from family or friends in writing or recalling memories. The volunteer's own autonomy also developed in learning new skills in OH interviewing and recording. For volunteers conducting interviews in participants homes, there was the risk of blurring professional boundaries in supporting participants beyond the OH. This became the case with participant Sarah whom volunteer Kate wanted to befriend, knowing that Sarah would enjoy the company. This was not allowed by the Coordinator and thus social interaction was ended.

New opportunities for autonomy arose for participants in listening back and reviewing their recording/s and confirming edits. However, this was at risk when the audio editors made changes to recordings without consulting the participant. The balance as to what edits should be made, such as deleting coughs, interruptions and repetitions, ideally would be in consultation with participants, but the editors worked entirely in isolation. This could have been another opportunity for social interaction.

The voice recording, as an ongoing physical presence, created new potential for autonomy and social interaction for family and friends. They had freedom to listen to the recording when and where they chose. However, there was the risk of hearing it unexpectedly in public spaces, such as funerals, museums or online. The recording could be a social activity for family listening together, or if the participant was still alive, a means to finding out more about them and increased social interaction. Similarly, archived OH extracts heard in public could foster social interaction.

## 9.4 Dignity

*Dignity* was a desired outcome for participants, family and friends, for volunteers in being altruistic and HCPs in composure in their interactions. For HCPs, it was an opportunity to get to know the person behind the patient. HCP Holly, who worked in the community and so had more time to interact with patients, explained that knowing how to pitch OHinPSC sensitively, as a method to record memories, without mentioning mortality, was a dignifying approach for recruiting people. The OHinPSC service standing outside of medical care and interventions was dignifying, giving participants a new sense of autonomy, and space for reflection. Other HCPs who referred patients also took part in dignifying conversations. HCP Keith proposed participant Tim leaving birthday cards as a legacy for his child, but OH was chosen because it didn't require him to write and meant a third party could prompt him during the interview. The anxiety around leaving messages for family at the end-of-life was lifted by being able to verbalise them in a storied manner with external support.

Other participants took part in OHinPSC after visiting the day centre. Set up to create a dignifying experience in itself, it enabled patients to have time to chat with other patients and HCPs and offered creative and therapeutic interventions. OH was viewed by both HCPs and participants as a particularly popular and adaptable intervention in the day centre. Despite not having younger family to give a recording to, participant Ralph, in discussion with HCP Margaret, agreed the OH process could be adapted to be conversational so he could record social history relating to his career and local knowledge with a volunteer from a similar background. The participant lived alone and felt he had a lot to share, so found it a particularly dignifying experience. Similarly, participant Sarah lived alone and enjoyed meeting people at the day centre. Although she finished her allocated visits, she was keen to continue. For her the OH, and coinciding visits to her home for interviews, enabled her to feel her stories, and company, were valued. She could talk for as long as she wanted in the home interviews, and to a volunteer who showed interest. It can also be assumed it was a dignifying experience for the participants (James, Tim) recording family legacies, both were ably guided by their volunteers and achieved positive outcomes.

When participants were well matched with volunteers, it helped ensure a dignifying experience. Volunteers found the experience worthwhile, learning about history while contributing to the participant's well-being. The experience was perhaps less dignifying for

participants Jake and Heather and their respective volunteers. In these interviews, the co-construction lacked understanding and definition as to why it was happening. The participants could have perhaps benefited from more steering by the volunteers, and the volunteers from a clearer understanding of the participant's motives. Both participants had children to pass it on to, but mentioned a communication disconnect with them. Their interview narratives were more ad hoc and shaped by either what was on their mind at that time (Jake), or the stories and histories of others (Heather). Their approaches to the interview/s also tallied with their own sense of mortality. Participant Heather had recently been given an all-clear cancer diagnosis, and no longer identified as palliative. Instead, her narrative focused on her interest in genealogy, sharing stories and memories of extended family and past co-workers. The shift from 'I' to 'they' in her narrative was perhaps unexpected for the volunteer, who became less interested in interviewing. Participant Jake had an estranged relationship with his son and was interested in OH in a social history setting. For this reason, he chose to focus on the poverty of his childhood. He was depressed and isolated and offering a dignifying experience had been a motive for the referring HCP. Participant Jake was not palliative, but his current mental health, and spending much of his time in bed in the dark in a nursing home, perhaps meant he had dwelled on mortality, particularly his deceased brother and parents. As a result, his life story focused on trauma. This was unexpected for the volunteer, and not something she felt his son would want to hear. It is unclear if the interview was a dignifying experience for the participant. While he clearly found the experience of passing on his stories for posterity as social history a dignifying process, he was unsure about how it might come across to his son, and also suggested it might have been better had his son been the interviewer. The volunteer appeared to find the process undignified, commenting on how uncomfortable she felt visiting his dark nursing home room, and the shocking nature of some of the stories, which she could not imagine anyone would want to listen to. She was unclear of Jake's motivations. This could, perhaps, have been a more dignified experience for both had there been greater understanding of Jake's motives and had the volunteer June been more adaptable in steering the interview accordingly. Discussions could have been had between the volunteer interviewers (June, Fiona) and participants Jake and Heather prior and after the interviews about how the recordings might be heard in the future, especially by family or friends. Whilst aware of the participant's autonomy, the volunteers could have noted

what was said or missed during the interviews which might cause upset in the future and discussed this with the participants.

Sharing their families' social histories was potentially dignifying for both participants. It is less clear how these narratives might be received by their families. Participant Jake's son may not have been shocked by the traumatic memories. He may already have known them or wished he could have asked more. Participant Heather's children may feel similarly or be pleased to have a record of their extended family background. For participants James and Tim, who recorded family legacies, their family being able to listen to the voice recordings in the future can be assumed to be dignifying for them. With James having MND, recording his voice whilst still possible gave even more importance as a family record. Participants Sarah and Ralph's recordings were primarily to be archival social histories, and how they are received depends on their future accessibility. Whether it was a dignifying experience for them as legacy works on the assumption they are heard by others, and that others want to hear them. As mentioned by Ralph, this relies on them being well indexed and publicly searchable.

## 9.5 Chapter summary

As outlined, the basic social process of *giving voice* (the GVT) is a way to understand the OHinPSC service, which begins and continues through the temporal process with *remembering and reflection*. This in turn creates opportunities and challenges for *autonomy and social interaction* with a desired outcome of *dignity*. This process can be interpreted for each of the different research interviewee groups in how they support (volunteers/HCPs) and are supported (participants, family and friends) by taking part in the service.

## 10. Discussion

### 10.1 Introduction

I start this discussion chapter with a recap on my original motivations for conducting the research and the aims of the study. I conducted this research after working extensively in the field of OHinPSC for over ten years and witnessing and supporting several OHinPSC services in their organisation. Being able to research OHinPSC for this doctorate offered a way for me to able further evaluate and understand OHinPSC from the perspectives of other involved parties, namely participants, family and friends, HCPs and volunteers. The PhD has given me opportunity to vastly improve my research skills, giving me knowledge and practical application of performing a literature review, choosing an appropriate method in CGT, producing coinciding methodology and analysis, presenting my findings, building a basic social process from my CGT, and finally, writing this discussion.

OH has grown significantly in its stature and development in the UK since the OHS began in the early 1970s as an ethical and best practice body for recording primarily people histories. Since the early 2000s it has expanded even further due to digital advancements making recording equipment affordable and more user friendly. Funding bodies such as the National Lottery Heritage Fund have also invested heavily in community history initiatives.

Since the early 2000s, OHinPSC has become an adaptable model for people in palliative and supportive care to record their life stories and memories with the possibility of them being used as legacy for family and friends and in the public domain, preserved for posterity in a professional archive. The ease of recording the voice and sharing audio files enabled this to be done at small cost, and successful services started to appear in hospice environments. As confirmed in my literature review, whilst OH with older people is not a new phenomenon, to have a service available to people in palliative and supportive care in the UK was unique, with scant prior research. I was involved as a Research Associate in previous unpublished research for Macmillan Cancer Support, which culminated in a report, 'How does providing an oral history at the end-of-life influence well-being of the individual and the bereaved?' (Winslow and Smith, 2013). The research involved interviewing participants, bereavement volunteers, HCPs and family and friends, and found that OHinPSC was beneficial for all

involved. participants found it an enjoyable experience, family and friends valued the voice recording, and HCPs viewed it as beneficial, complementing the patients clinical care.

The above study served as a precursor to this research, and following on from conducting a literature review and analysing the relevant texts based on my own experience of working in OHinPSC, the following sensitizing concepts were established:

- Meaning for participants before, during and after the interview: motivations, experience and legacy.
- How motivations and experiences interact with experience of health and social care and relationships with others.
- How legacy is produced, stored and reused.

Based on these concepts the aims of this study was to question:

- How is OH experienced by participants, family and friends, HCPs and volunteers in the context of palliative and supportive care?

With the sub-questions:

- What are the implications of OHinPSC for HCPs and health and social care?
- How is dialogical content created within an OH interview in palliative and supportive care and then reused?

In this chapter I outline my contribution to knowledge, discuss my findings and GVT in relation to other relevant literature and explore the existing nursing theories and practices of person-centred care and Continuing Bonds (Klass *et al.*, 1996), which I view as of relevance to OHinPSC and the GVT. I then evaluate this study using tools suggested by Charmaz (2014, p.336-338) and finish by discussing strengths, limitations and final recommendations.

## 10.2 Contribution to knowledge

As already detailed in the literature review discussion, this is the first time, to the best of my knowledge, that this research has been done. The research is unique in using CGT as a method to understand the temporal experience from start to finish for all parties involved in

an OHinPSC service. There has been some prior research pertaining to OHinPSC as listed in my literature review and recently, a yet to be published study (Halton-Hernandez *et al.,* 2023). However, this study incorporated a method for follow-up semi-structured interviews, which allowed the research interviewees to reflect and develop their thoughts through the research process, and for me as researcher to ask follow-up questions and explore meaning and theories with them. Based on the findings I developed the Giving Voice Theory (GVT) which helps to understand the social process of OHinPSC. The theory can be used when planning and delivering OH and life story interventions in which there is an audio legacy outcome and potential therapeutic benefit for the participant. The theory could be further tested with projects which fulfil this criteria beyond palliative and supportive care settings, for instance as a tool for recording family histories or within intergenerational interviews.

This study was unique in recruiting participants, family and friends, HCPs, and volunteers. Whereas there have been previous studies with all these groups, as far as I am aware this is the only study which has involved multiple interviews with research interviewees. This study aims to give a more detailed understanding of the social process of OHinPSC. It contributes findings where there is scant research which can be referred to in terms of biographical methods for patients in palliative and supportive care with an audio legacy output. As outlined in my literature review discussion there are several other biographical methods in palliative and supportive care such as life review, reminiscence and Dignity Therapy which have been the focus of a great deal more academic research. OHinPSC, in comparison, is primarily concerned with the historical document rather than biographical methods which are psychotherapeutic interventions. However, based on the findings of this study, there is some evidence of OHinPSC being a therapeutic intervention which is discussed later in this discussion.

OHinPSC is unique in comparison to other biographical methods in that the voice is recorded and preserved for participants, family and friends, and the public archive. Although some biographical methods in palliative and supportive care do include an audio recording, the majority have a written (Vuksanovic *et al.*, 2016) or visual output (Boles and Jones, 2021). Sometimes, as in the case of Dignity Therapy, audio is recorded and then destroyed in favour of the written document as legacy (Chochinov *et al.*, 2005). Other

methods have no physical output (Chiang *et al.*, 2010), and are solely a therapeutic activity which may be to improve wellbeing and quality of life. This study is unique in including the legacy output of the voice recording, and thus the motivations and experience of the research interviewees, which are entwined with an understanding of this output. The voice recording sets OHinPSC aside from other biographical methods, and this research is primarily concerned with how this positions it as a biographical method. I now concentrate on the GVT within the three areas of my findings: motivations, experience and outcomes, and discuss with reference to other relevant research.

## 10.3 Motivations

The act of giving voice was central to the motivations of the participants, volunteers and HCPs and their reasons for involvement in the service corresponded with previous research. For the participants, the motives of creating a family legacy or a social history record, as well as doing it for themselves, either as an opportunity for them to have a conversation or to take stock of their life and memories are all mentioned before, with the same OHinPSC model researched by Winslow and Smith (2013). These three main motives are manifestations of giving voice whether it be for family and friends, the public or the participant. It could be argued that it was immediately dignifying for them all in being asked to and agreeing to take part. There was also evidence of participants taking part for additional social interaction. Taking part in OH because of loneliness, or wanting to be helpful has been identified in research as a motivation for people agreeing to be interviewed (Jones, 1998). According to Jones, these people may be "less in control" and "might find themselves exposing themselves more than they feel comfortable with." (1998, p.51).

The volunteers and HCPs were also central to the theory of giving voice, enabling social interaction and reflection. As in other studies centred on volunteers on a biography service in palliative care (Beasley *et al.*, 2015; Hesse *et al.*, 2019a), this research found that people were motivated to volunteer to hear people's stories, because they had the relevant skills or career backgrounds, and for altruistic reasons, including giving something back for the care that they or family had received. In this sense by volunteering, some volunteers were reflecting on their own past circumstances and opting for social interaction as motives for their involvement. The referring HCPs reasons for their involvement in the service echoed

those given in previous research, which suggested that HCPs appreciate the intervention and see it as an "important complement to clinical care" (Winslow and Smith, 2013, p.4). Previous research suggesting that biography as legacy work in palliative care could lift the patient's mood, help with depression and loneliness and support them in finding meaning (Lichter, Mooney and Boyd, 1993) was also apparent from the HCPs interviewed for this research. Again, enabling social interaction and reflection were central to HCPs reasons for taking part and referring people to the service.

An unexpected finding not mentioned in previous research was that the rationale for some participants doing it as a family legacy, a social history record, or for themselves morphed. As they began to reflect on and understand what was involved in the act of giving voice and how this related to their autonomy in the choices they made, and the social interaction they encountered, their motives changed through the temporal process. This illustrates how OHinPSC contrasts with other biographical methods, such as one suggested in a recent study with strict variables, in which the audio output was only created for family legacy (Cuhls *et al.*, 2021). The OHinPSC model for this research was unique in the interviews being an audio legacy for family and friends, and an archival record for further research and social history purposes, presenting multiple ways of giving voice. The volunteers and HCPs had their own interpretation of participants' specific motivations and their own intentions regarding OHinPSC which fed into the social interaction and shaped the autonomy of the participant. All the research interviewees had varied understanding of OHinPSC and this contributed to their interpretation.

A lack of prior knowledge and understanding of OH found in this study was not new (Rickard, 1998; Winslow and Smith, 2013). Arguably, for some research interviewees it continued to be not entirely clear in terms of the way their OH would be used. There could be confusion as to who was being given voice. Although all can be assumed participants were presented with the OHinPSC information sheet and the process was explained to them, it is possible it was not read or fully understood, and there was the risk of participants entering the OH process without the full picture of how their OH might be used. This was the case with participant Heather, who revealed in the research interview that she did not realise her interview would be available as a social history resource, although this was a positive outcome to her. Where prior conversation with the participant was lacking as to the

service remit, the issue of not having a comprehensive understanding of the possibilities of OHinPSC could shape how participants decided to give voice and reflect. Further to this, in understanding the service as being for the researcher or the hospice rather than for themselves, it could challenge their autonomy and own motives and become a less dignifying process. The risk of OH participants not fully understanding what they are entering into on starting an interview is arguably a common yet under researched occurrence with OH projects in which people are generally happy to help, and sometimes do not feel a need to read and comprehend the legal paperwork.

With the introduction of GDPR in the UK (*Data Protection Act 2018*), OH interviews now require a Pre-participation Agreement to be understood and signed, as well as a Recording Agreement covering copyright and access clearance to be signed after the interview (OHS, 2019). Whilst these are in part to enable participant autonomy, both contain complex text which unless verbally discussed could easily baffle potential participants. It is perhaps not surprising that a comprehensive understanding is not always reached, despite a more accessible information sheet being provided and the best efforts of an interviewer talking through it with them. In this sense it is essential that volunteers and HCPs can give voice as to what is expected by the participant and what the purpose of the service is prior to starting. This is exacerbated further by OH being conducted in a palliative or supportive care environment, in which participants (and HCPs) have other pressing priorities to reflect on and where OH is classed as a social and holistic activity. No corresponding research could be found relating to the issue of OH participants not fully understanding the OH process and the accompanying legal documentation, but a section on the OHS website: "Is your oral history legal and ethical?" (OHS, 2019), is devoted to providing guidelines on this subject. How to further assist in providing understanding of the legal documentation could be an interesting area of future research, which might help other oral historians in explaining information to potential participants and stakeholders.

Some volunteers' understanding of OHinPSC centred on family legacy, and for others it was viewed as more a social history record and this could be at odds with what the participant intended, particularly when their understanding was limited. Whilst the use of volunteers can encourage an adaptable approach to working with people in palliative care (Hesse *et al.*, 2019a), there could be a communication disconnect between volunteer and participant as

to both their motives. This could also be the case for HCPs - how some referred participants to the service was adapted to avoid talking about the end-of-life and legacy and instead making it a storytelling and memory sharing activity which could then suggest the OH recording was for the volunteer or hospice rather than the participant as a family legacy. HCPs knowing how to communicate with patients about the end-of-life is a general research topic within palliative care not specific to OHinPSC (Brighton and Bristowe, 2016), but in discussing a legacy making service it is hard to avoid and guidelines for volunteers and HCPs could be useful to avoid causing upset and distress. This layer of social interaction, whilst aiming to be dignifying for potential participants can also lead to a lack of understanding and autonomy as to the potential of a voice legacy as an act of reflection, especially for family in bereavement.

Understanding that there were multiple and temporal motives in giving voice introduced a new way of thinking about the OH process for me. This came about because uniquely there was a volunteer who had previously had her OHinPSC recorded and so had a strong understanding of both sides of the interview scenario. Understanding that OHinPSC could also be for the self rather than for family or the archive was perhaps the ultimate act of autonomy, in which someone can reflect on their life and give voice and meaning to their memories for their own self-gratification. This idea allowed me to see OHinPSC through a more complete lens (see Figures 12 and 13). For the participants who were not recording a defined family legacy, there could be other motives at play which could change through the process. This was particularly so for the participants who had children to give their voice recording to but for whom it was not their primary motive to record the OH and only on reflection did it become so. By not having a clear understanding as to the legacy potential of the OH and seeing it as more of an activity or a chance to give voice for the public record, their imagined audience was more open, and confusion was created between personal legacy and public reminiscence. This could lead to a less dignifying outcome for the participant and for family receiving the recording if the family legacy was lacking. If they were keen instead to record a public reminiscence, their autonomy could be challenged by their volunteers not understanding why they were not tailoring their OH for their children. This draws on the differences and similarities between OH, life review and reminiscence, having blurred boundaries open to misinterpretation (Bornat, 2001). This study was unique

in being the open-ended OHinPSC model on offer which allowed for different types of reflection.

Whereas predominantly biographical methods at the end-of-life are seen as therapeutic interventions or meaning-making activities to promote dignity (Hesse *et al.*, 2019b), OHinPSC is multifaceted. Whilst there is some literature which argues for OH as a therapeutic pursuit (Taft *et al.*, 2004; McCarthy, 2010), its primary focus is the historical record and thus OHinPSC stands alone from other biographical approaches in palliative and supportive care. Where there is good understanding between all parties (participants, volunteers and HCPs) as to the motives and audience, there is the possibility to enable more autonomy for the participant as to which direction their OH is intended and for whom. However, the wider scope and resulting audio output can also lead to more confusion and unintentional upset for both the participant (Rickard, 1998) and family and friends listening back to the voice recording (Stewart, 2013; Stewart and Brown, 2017).

## 10.4 Experience

Experiencing the OH interview presented new challenges and opportunities encompassed within the GVT. As could be expected prior to starting the study, the findings suggest the setting of the OH interview, disease of the participant and the relationships between all involved influenced the OH experience and act of giving voice. With there being several possible settings in which the OH could happen during the study it was possible to get an understanding as to how it varied. As expected the interviews with participants on inpatients wards tended to be more family legacy based, with participants closer to the end-of-life (Winslow and Smith, 2013). In this situation the autonomy of the participant was given added importance and social interaction was tailored to supporting them in achieving a fitting legacy when they had difficulties expressing their feelings. In this scenario volunteers and HCPs could be skilled in helping participants find their voice and frame their reflections. Whereas those which happened in the day centre, in the community, or in people's homes tended to be with participants with more time and thus some of them were less focused on a family legacy and more on quality of life (Taft *et al.*, 2004; McCarthy, 2010; Ligon *et al.*, 2012). In these instances, social interaction was more akin to having a two-way conversation or enabling discussion.

The disease of the participant shaped their OH experience and how the outcome could be dignifying for them. For those with cancer it could be having the opportunity to reflect on their illness journey (McCarthy, 2010), whereas for those with dementia (as deemed from secondary accounts), it could be a meaningful way to involve family in reflection (Savundranayagam, Dilley and Basting, 2011), and for those with MND an alternative to writing and a method to preserve the voice (Cave and Bloch, 2021).

The co-construction between interviewee and interviewer in the OH experience and understanding of it being a collaboration is widely recognised by oral historians based on the principle of sharing authority (Shope, 2003; High, 2009; Calabria and Bailey, 2023) (see Section 4.5), in which the OH interviewer accepts their positionality will have an unavoidable influence on the OH interview and interviewee. In this sense whilst autonomy is desired it is perceived as inevitable that social interaction will shape the experience.  This concept may not have been known or fully understood by the research interviewees and in the future could be a useful addition to training volunteers and HCPs. However, this dynamic was clear between all the participants, the volunteers interviewing them and the referring HCPs within the study. Where there was a dignifying outcome for the participant it was relative to how much their autonomy was enabled by social interaction provided by the volunteer and HCP.

For the volunteers who interviewed participants in their homes there was an added social layer of attachment in which the dynamic could be more about interviewing within a personal autonomous space and gaining insight into how someone lives. For one volunteer Kate, she felt the participant would appreciate more home visits after the interview due to being older and lonely and wanted to start a friendship with her. However, the Coordinator was clear to point out this was not allowed and raised the issue of keeping personal boundaries with participants. This scenario has been written about extensively in the OH community (Yow, 1997) with the importance of understanding subjective reality and personal perspectives at its core (Passerini, 1979). In this situation the prospect of social interaction becoming severed could lead to an undignified and autonomous outcome for both the participant and volunteer, but on continuing the relationship there could be the risk of making it worse in making stronger social links only to be ended later down the line. There may be an argument for volunteers and participants being able to make friends

outside of the service remit (Zembrzycki, 2013), but the boundaries are blurred by them being in a service facilitating role.

What is new in this research is that participants valued the importance of giving voice in different ways, dependent on whether their OH was for a defined family audience or for a non-defined public audience. For those recording defined family legacies, the act of giving voice was about giving it to their family and friends. Their identity and voice were not forgotten and remembered and reflected on by future generations, giving family support in bereavement once they had gone – this could be a dignifying experience for both parties. Importance was given to making sure they gave a suitable narrative for their family which may omit aspects of their life which might upset them. Omissions in OH interviews and key pauses and silences are important in how people construct their identities and so of interest to oral historians and researchers (Portelli, 1981; Norquay, 1999). Silence can be interpreted as a form of control, in which collective memory shapes the individual's autonomy, as noted by Passerini (1987), when discussing Fiat factory workers in Turin and how they chose to remain silent when confronting the challenging past of the fascist regime. Whereas, more recent OH literature has suggested silence can act as a form of agency for the interviewee, allowing them to decide what is said in the interview and what is kept off the record as discussed by Freund (2013) who suggests an "ethics of silence as constructive rather than destructive" (p.236). The use of silence by interviewees recording defined family legacies and deciding what to omit, fits within this praxis.

In contrast, for the participants recording non-defined oral histories, the experience was more about giving voice in reflecting what was meaningful to them in their life and what knowledge they felt they had to give for a public audience. This could also be a dignifying experience. However, if they had family to give it to but as a secondary motive, they might be less likely to omit aspects which could cause upset and there was less urgency to censor their narratives which in turn could be less dignifying. The interview was more about the opportunity to have a conversation with a third party or to leave memories for a non-specific public audience, promoting social interaction and reflection rather than giving voice in a dignified way for family. In this sense the experience could be more akin to a counselling session or a confessional, an opportunity to set the record straight. As already mentioned in the literature review discussion, OH can be therapeutic for some but is not

therapy (Bornat, 1994) and has unique considerations and connotations to be aware of (Rickard, 1998; Bornat, 2001). For some participants it can be an opportunity to give voice on behalf of a community or to give their side of the story in an account of an event, which might challenge popular histories (Thompson, 2017, p.6). Different motivations and how they were formed based on the participants understanding of OH and as to whether they were recording a defined OH life story for family, sharing an account or a meaning-making exercise for a less predetermined audience meant their narrative and approach changed accordingly. Being able to choose the interview direction enabled autonomy reliant on their social interaction with the volunteer.

An aspect of the OH experience which really moved me was the intersubjectivity between the participant and volunteer interviewer in the case studies and how this shaped the GVT. There were different interview approaches and generational and cultural chasms between both which raised questions about power dynamics, traumatic remembering, and the role of empathy in OH. All these topics have been discussed at length in OH and memory studies research (Bornat, 2010; Abrams, 2016; Thompson, 2017; Radstone, 2020). Within OHinPSC these areas take on unique meaning in which OH is not only recording a historical record but also life review and/or reminiscence with a legacy outcome for the interviewee to share. The co-construction between participant and volunteer, the possibility of traumatic remembering and need for an emphatic listener are further enhanced and thus the crossover between OH and therapeutic intervention more obvious, hence why research on other biographical methods at the end-of-life such as Dignity Therapy and life review are evaluated as therapeutic endeavours. This study has highlighted the adaptable and multi-faceted nature of OHinPSC, which presents a broader and more complex context for understanding the OH interview in how participants and volunteers relate, remember and reflect in palliative and supportive care.

The co-construction of the OHinPSC interview can be more adaptable than conventional OH. Traditionally in OH and particularly life story interviewing there is advice for interviewers to not give their own opinions and where possible to keep their voice off the audio recording and facilitate the narrator by listening (Thompson, 2017, p.323). However, there was evidence in the case study interviews of participants needing more guidance from the volunteer and of a more conversational approach working well when the OH was less a

family legacy and more a public record as with the participant Ralph. Here, it could be argued the OH interview was adapted to suit his autonomy and be more of a recorded reminiscence session in which two people social interacted to share experiences in conversation as a relational and enjoyable experience. Building a sense of rapport and belonging was at the core of the activity, traits discussed in recent research making the link between OH and therapy interviewing (Wiesner, 2021). The OH interview was about the volunteer giving voice too as an aid to supporting the participant.

For the participants in this study who were not recording family legacies and who had a public audience in mind, there was an open performative aspect and a narrative identity adopted in their remembering and social interaction with the interviewer. Arguably, here there was a different type of emotional impact to the interview and psychological effect for the participant, similar to those explored in a study comparing biographic and episodic narrative (Turner *et al.*, 2021). For the two participants who had non-defined motives there was less of a straightforward chronological biographical life story approach and their interviews became more episodic in which the participant could represent themselves through isolated life events and memories which they deemed important in that moment. For these participants the end-of-life was less inevitable in the present moment and thus there was a challenge in the narrative identity they adopted. Participant Jake opted to talk about whatever was on his mind and so let his subconsciousness help determine his narrative identity through an act of free association and this in turn caught the volunteer off guard as emotional and distressing topics from his past surfaced. How the interviewer impacts on the type of narrative given, especially in their questioning whether it biographical or narrative based can shape the outcome (Harding, 2006).

How the OH interviewer should adapt to circumstances which could become traumatic for both the interviewee and interviewer is discussed in research by Jones (1998). He questions when it is appropriate for interviewers to probe interviewees when emotional topics surface and how OH interviewing can then enter the realm of the therapeutic. He suggests there needs to be a "greater awareness of the feelings and motivations of interviewees amongst researchers" (1998, p.55). As within therapy there becomes a need for supervision from someone with therapeutic experience to discuss emotional interviews for both participants

and interviewers. Further supervision for interviewers is suggested in other discussion on unexpected trauma in OH (Vickers, 2019).

In this research, the participants who were recording family legacies exhibited reasoning to their narrative and an acceptance of change, knowing their illness was palliative. With the participants deemed as having non-defined motivations, Jake and Heather, the interviewers could have arguably taken a more active role in steering the interview and could have benefited from a clearer understanding of the participants' motives before the interview and spending time with them to establish these. The GVT could have been enacted more before the interview. The instance of enabling the autonomy of the participant by staying off the recording and not intervening meant a lack of social interaction which could have supported reflection and a more dignified outcome for both participant and volunteer.

## 10.5 Outcomes

The final stage in the process of the GVT is in the outcome of receiving and listening to the voice recording. As expected, when asked in the research interviews some participants had listened back to their recordings and some had not. Those who did found it a dignifying experience, but it raised a mixture of emotions and listening to their own voice and reflecting on their life could be upsetting. Deciding what to include or omit, especially with family in mind has been mentioned in other research (Rickard, 1998; Stewart, 2013). Being able to encapsulate their life story in short interview/s was a challenge for some participants and there was a reflection that as new memories surfaced after the interview they could have recorded more. This is understandable as while the OH interviews undertaken during this study were approx. one-three hours long, interviews conducted for the National Life Stories Department at the British Library can amass to over 15 hours (NLS, 2023). With these interviews taking place in a palliative and supportive care setting with people facing illness, the shorter time could be expected, but further opportunity and time to give voice and reflect through social interaction could have enabled more autonomy and dignity. A major difference between the interviews conducted by the National Life Stories Department and within OHinPSC is the people interviewed. Whereas NLS interviews are often with successful and renowned people such as scientists, artists, authors and architects (NLS, 2022), the interviewees in OHinPSC are people only chosen because of their locality to the service, which is available free of charge to any patients or hospice users, whatever their

background. In this sense, OHinPSC is unique in giving voice to people from a wide range of socioeconomic backgrounds and thus arguably a more representative archival collection of people histories from its surrounding environment.

For family and friends being given a voice recording was additional social interaction which in reflection could raise a mixture of emotions and be comforting, dignifying and distressing. Family and friends could exercise autonomy in listening back in a range of ways and at different times after. As mentioned by the Director of the National Life Stories Department, Mary Stewart in her research exploring family reactions to receiving an OH of the deceased (2013) for some it may be upsetting to hear the voice, especially if the participant's voice was tainted by their illness. For others it might be upsetting to listen to traumatic events the participant went through or about something that happened in their life of which they had no knowledge. Because of this National Life Stories now issue a statement in advance when sending out OH to family members which judging by email feedback from family members had helped:

> In our work here at the British Library we have - sadly - dealt with a number of enquiries from relatives requesting the interviews of a recently deceased family member. A number of families have subsequently contacted the archive, and have reported back a great variety of reactions to listening to the recordings: some have told us that listening to the interview was a great comfort, some have found listening distressing and others have decided to wait some time before they played the recording and heard their relative's voice again. How and when you listen is entirely up to you, but I thought it best to let you know the experiences of others which may help inform this decision.

(Stewart, 2013)

Autonomy and dignity are central to this statement and having a statement like this for OHinPSC for when family members get in contact for voice recordings is advisable. Family and friends finding out more about the deceased from their OH was evident from the interview with Christine, participant Sarah's friend. Although she knew several of the stories already, she was able to find more context and reflection in the OH. An example of similar in the National Life Stories collection can be found in an interview with the daughter of a

rocket scientist Roy Dommett (NLS, 2016). Due to his career being strictly confidential and him not divulging it to family during his lifetime, his daughter was struck from reading the transcript to learn more about the context of his life and to find out his standing as a rocket scientist.

OH involving being interviewed and recorded by a third party enables the participant to remember and reflect in a way, they perhaps would not interact with a family member. This can raise both interesting and sometimes distressing information that family members have not heard before. The OH team liaising with the participant after the interview to check they are OK with their recording and being open with family members on them being given and listening to a voice recording is of importance here to a dignified outcome. Where distressing reflections surface it would also be useful to have a support network – which could be the hospice Social Worker or Chaplain for the participant, and the Bereavement Counsellor for family, as was the case with the OHinPSC study model. Due to a dearth of research relating to how family members receive OH and mainly anecdotal evidence it is hard to know to what extent it can affect family members.

There are challenges to the GVT in how it exists with regards to the internet. I found that amongst the research interviewees there was ambivalence about sharing oral histories online with several not keen on the idea due to worries about how it could be manipulated or shared in unintended ways adding unintended layers of social interaction which could further misshape an autonomous and dignified outcome. This perhaps also related to the age range of research interviewees, all of whom could remember pre-internet times and many of whom were not digitally adept. However, with the advent of digital legacy websites and social media acting as online archive repository of people's memories and stories, OHinPSC is arguably well placed to exist online as a longer form version compared to fast and instantaneous forms of recorded memories. The digital realm is seen to hold challenges and opportunities for OH as noted by Thomson (2007) who foresaw several of the latest trends such as remote interviewing, advanced transcript search tools and even the possibility of AI being able to search multiple collections. However, as noted by Smyth *et al.* (2023) the role of audio and being able to hear the voice, its inflections and emotions which are deemed so important to OH (Portelli, 1981; Karpf, 2014), and which were foreseen as a future search tool (High, 2010; Lambert and Frisch, 2013), is still yet to be made fully

accessibly in digital catalogue form. Instead a multimodal form of working is suggested in which the audio and transcript coexist as OH research matter (Smyth *et al.*, 2023).

A difference between OH and other digital sociological research is the rarity of the interviewee being anonymised (Stewart and Brown, 2017, p.229), thus giving added agency and autonomy to the participant. However, there is the potential of causing distress to family members and friends by finding personal information on the internet about an interviewee in which even the most innocuous information could cause upset (Crossen-White, 2015). This social interaction could be an afront to their reflection and dignity. It is argued that implications about how OH is utilised on the web may even mean a reframing of what is reflected and discussed in interviews and how they are conducted to avoid unintended and unwanted secondary uses (Gluck, 2014). The adaption and commodification of OH on the internet in which short extracts representing a story are favoured instead of full interviews also changes the social interaction in how and by who OH is heard and interpreted (Sheftel and Zembrzycki, 2017). The possibilities of new technology such as AI being able to search multiple online collections also opens OH to further secondary analysis for which it was not first intended, creating interaction and reflection beyond the autonomy of the participant. However, secondary analysis of OH such as searching for people who worked for a certain company or who experienced certain events or even emotions could be an exciting development (Bornat, 2010; Irwin, Bornat and Winterton 2012), and potentially dignifying for family and friends of the deceased participant. These new possibilities may shape how future participants choose to give voice. As noted by Thomson (2007), in the knowledge that OH can be easily accessed and manipulated, interviewees will think differently about recording an interview.

The research interviewees deemed OH to be a useful social history and educational resource and this could be seen as a dignifying outcome. Some research interviews such as with participant Ralph, involved discussion on the risk of OH being archived and then forgotten or only being available to those who knew where and how to access archives which could be a undignified outcome. Here the added social interaction of being able to widely access OH as a historical or educational resource was given importance. Stewart and Brown (2017) mention this potential of life story OH as a resource and stress that contrary to some beliefs

about OH, it is not only nostalgia being recorded but examples of social and family history, which can give rich context for researchers (p.230).

The function of nostalgia in OH has been discussed as a beneficial form of agency to preserve a lost and irretrievable past (Ramsden, 2016; Calabria, 2023). Ramsden (2016) argued the remit for nostalgia was not class specific but a way to construct a collective past and "…an understandable reaction to the rapid economic, social and cultural changes that reshape the ways we relate to those who live around us" (p.96). Similarly, Calabria (2023) found nostalgic accounts of patients and staff at mental hospitals, fostered a sense of belonging at odds with the perceived progressive initiative of 'care in the community' and OH could "create an alternative site of memory for those who considered the institution a place of safety" (p.245). She argued "Understanding nostalgia as an analytical lens allows for an informed evaluation of the present by contrasting individual and collective past lived experiences" (p.247).

Nostalgia was found in this thesis in the case studies where reminiscence was present, and participants gave voice to certain times and places which contributed to a sense of collective identity. However, nostalgia was less present in interviews with the two participants who were recording defined autonomous legacies specifically for a family audience. The differing approach to reflection offers possibilities for researching nostalgia in OHinPSC. Nostalgia can "…give meaning to our lives over time by bringing our past and current sense of identity in line with one another" (Calabria, 2023, p.247).

Whereas traditionally the main outcome of OH research was the transcript, the power of giving voice has become central to OH, as technology has enabled better recordings, easier storage and more accessible ways to edit and listen back to recordings (Shopes, 2012). The significance of hearing the voice is further enhanced in OHinPSC in which the bereaved strongly value hearing the voice of the deceased as a dignifying outcome (Winslow and Smith, 2019). Research interviewees were enthused by the importance of hearing the voice with some comparing the interaction to being in the room with the deceased. The power of the voice recording as a remaining presence has been written about at length (Stewart, 2013; Karpf, 2014). However, the power of giving the voice recording to the bereaved was an aspect of the research which whilst expected, really moved me in terms of how it

affected the bereaved and also the participants in listening back to their own voices. Recording and hearing the voice is what sets OHinPSC apart from other digital legacy methods in palliative and supportive care such as life review or Dignity Therapy. Whilst Dignity Therapy can involve a recorded interview, the voice recording is deleted, with the transcript as the legacy document (Chochinov *et al.*, 2011). As noted by research interviewees such as participant James, being able to give a voice recording offered a more personable and autonomous legacy to writing, for the bereaved.

Several online digital legacy platforms do offer audio and video recording (such as legacyroom.co.uk or mywishes.co.uk) but do not involve a volunteer interviewer providing social interaction for reflection, and comprehensive archiving like the OHinPSC model, with preservation as a dignifying outcome. However, there was a need for more summarising of interviews on the study model to prepare them for archive, and the suggestion that this could be a role for volunteers to also evaluate theirs and other interviewing skills. Online legacy methods could be problematic in terms of archiving as outlined by Kiel in a conference presentation about digital legacy platforms (2016), which found that several platforms had disappeared within years of starting and thus the archived recordings were lost or not passed on to the bereaved. These platforms also generally involved the participant self-recording their memories onto the computer without assistance. A search on the web finds a proliferation of freelance life story services which do involve an interviewer, often run by journalists or oral historians such as A Lasting Tale (https://www.alastingtale.com/) and Life Stories – Spoken Memories (https://www.spokenmemoirs.co.uk/life-stories/), but these are paid services whereas the OHinPSC model is offered for free to patients and thus more dignifying. There is also no guarantee that these services professionally archive recordings or follow an ethical framework such as the OHS guidelines for conducting interviews (OHS, 2019). Adopting the GVT to other digital legacy services like these could help ensure a dignified outcome by presenting the ways in which OHinPSC allows autonomy of the participant and ongoing reflection and social interaction for the listener in posterity.

## 10.6 Person-centred care and OHinPSC

I am curious how the GVT can fit in with other practice theories in the field of OHinPSC and particularly how patients and OH participants can feel empowered by added social

interaction and opportunities for autonomy and reflection. The temporal processes in receiving health and social care and taking part in OHinPSC have similarities in how they can address the psychological needs and narrative identity of the individual. In this section I discuss OHinPSC in relation to person-centred care (PCC) in nursing. I'm drawn to the ideas centred around PCC as they cover similar ground to OHinPSC in terms of the HCP developing better understanding of the person behind the patient and the therapeutic possibilities when taking part in OHinPSC. As already discussed throughout this thesis, biographical methods in palliative and supportive care can be integral to the holistic care of older people and there are several examples of successful projects which have taken place over the past fifty years (Bornat, 1994). The role of biographical methods in assisting PCC are well documented (McCormack and McCance, 2010; Ryan, 2022). There are several parallels between OHinPSC and PCC and maybe OHinPSC can be viewed as a way of delivering PCC.

As outlined by Ryan (2022) in a review of current evidence, PCC has now become integral to nursing practice and policy making. It has been strategized by the World Health Organisation (WHO, 2015) "to shift the management and delivery of health services towards more integrated and person-centred approaches" (p.5), and in the UK PCC has become central to assisting people in healthcare decision-making as outlined in National Institute for Health and Care Excellence guidelines (NICE, 2006; 2017).

Whilst I know other PCC models and related concepts exist (Nolan *et al.*, 2004; Zoffmann, Harder and Kirkevold, 2008), I am particularly interested in the Person-Centred Nursing Framework (PCNF) developed by McCormack and McCance (2010), suggesting a move away from medically inclined health delivery to one that is "relationship focused, collaborative and holistic." (p.21). It argues that caring and being person-centred is about forming therapeutic relationships. The PCNF involves five PCC processes: "working with patients' beliefs and values; shared decision-making; engagement; having sympathetic presence and providing holistic care" (p.89). These five components, whilst referring to nursing, offer similarities with OHinPSC and could be used in a wider framework to assist in planning and delivering OHinPSC as I will now discuss.

OHinPSC offers a unique way to *work with patients' beliefs and values*. Giving voice to the participant in an interview with a non-judgemental third party interviewer, not connected to

their medical care and social network allows them the autonomy to talk about whatever they want and to be able to express and reflect on their own beliefs and values. This opportunity can often go beyond the resources and remit of nursing staff who may have less time for conversation and are often primarily concerned with clinical care. Having an oral historian available can assist in fostering social interaction between HCP and patient. They can find out more about a patient's personhood and sociocultural background which can in turn inadvertently or by design help HCPs know more about the patient and assist the patient in feeling their beliefs and values have been considered during their care.

Biographical approaches enable the person's life experiences, values and beliefs to be better understood as illustrated in a study by Clarke*,* Hanson and Ross (2003), which utilised life storytelling in a nursing home and collected views on the approach from older people, their family carers and practitioners as a method to encourage PCC. They found that the intervention "helped practitioners to see patients as people, to understand individuals more fully and to form closer relationships with their families" (p.698). McCormack and McCance (2010) view biographical methods similar to OHinPSC as being central to this component "to understand what is important to the patient in order to be able to integrate personalised information into a plan of care" (p.91). Where OHinPSC is less helpful is in its separation from clinical care. There is the possibility of it happening almost unnoticed by the HCPs in the setting and it is not normal for it to inform formal healthcare planning for the patient. In the instance of it becoming more integrated into planning it's not clear if patients would choose to take part and be as open in their narrative or whether it would challenge their autonomy more and be treated with suspicion. There could be more instance of them sharing narrative relating to their illness rather than their life history which may not be so suitable as a legacy, particularly for family. However, by having the added element of the voice legacy in OHinPSC, it could be argued that patients' values and beliefs are given added importance and worth, with the knowledge that they will be preserved and the possibility of being heard by others beyond their lifetime as a dignifying outcome.

*Shared decision-making* is viewed as being closely linked to the patients' beliefs and values. In developing a greater understanding of a patient's background and life history HCPs can better assess their needs and involve them more in decision-making. It follows that as discussed OHinPSC and utilising the GVT can assist in developing understanding for HCPs

and thus decision-making. However, OHinPSC being separate to healthcare does not lend itself to shared decision-making. What OHinPSC does do is introduce an outlet for patients to reflect autonomously which can help foster an environment in which patients and HCPs are able to communicate on a more open and equal basis. The power dynamic of the OH interview has been much discussed in literature (Frisch, 1990; Bornat and Walmsley, 2008). Ways to empower the participant in how they choose to tell and share their memories and stories has similarities with the concept of shared decision-making between patient and HCP. Whilst it is accepted that the HCP or oral historian may be the expert in the field, the patient is the expert of their own needs and desires and by forming a mutually beneficial relationship both professional application and patient autonomy can be accounted for. For some patients they may prefer to be guided in the process, whereas for others they may prefer to determine what is talked about in an interview or decided in the health planning. With the latter this can be encouraged within the boundaries of the professional and ethical practice and procedures. This is another way in which patients can be given voice and thus relates to the GVT.

*Engagement* can be viewed as key to connecting *values and beliefs* and *shared decision-making*:

> Having a clear picture of what the patient values about his life and how he makes sense of what is happening to him is needed, which provides a standard against which the practitioner can compare current decisions and behaviours of the patient.

> (McCormack and McCance, 2010, p.98)

OHinPSC is rich in the possibility of engaging with the participant and the GVT suggests a framework to successfully achieve this. To assist a dignifying outcome, an OH interviewer should be a good listener who shows interest in the participants' stories and is able to prompt them to elicit meaning and reflection with some empathy. The added connection afforded by OHinPSC can make a patient feel a sense of belonging within a care environment and assist them and their family in engaging more with HCPs and vice-versa. OHinPSC when successful, can foster relationships between all involved, and develop reflexive dialogue before, during and after the interview which is dignifying and beneficial for both patient and HCP. The expertise of the OH interviewer and HCP to engage with the

patient are here necessary including being able to exhibit related interpersonal skills such as compassion and deep listening. Again, with OHinPSC working effectively alongside clinical care rather than independently there are opportunities to support HCPs in improved engagement with patients. One way to do this could be to play HCPs clips from interviews (with the participant's permission) to assist them in knowing the patient better, another example of giving voice. Another way could be to offer training to HCPs in OH interviewing techniques such as deep listening.

*Having sympathetic presence* is the next component of the PCNF and again relies on excellent interpersonal skills. McCormack and McCance (2010) choose to centre on sympathy rather than empathy, a term frequently used in nursing (and OH) literature. They point out empathy is comprehending someone's experience which cannot always be the case in nursing. Whereas sympathy has the attributes of being affected by someone's experiences despite the issue of it also suggesting a removed status from the plight of others, OHinPSC is reliant on volunteers having a sympathetic presence. Without it, as found in this study there is the risk of disconnect between participant and volunteer which can lead to confusion surrounding motives and narrative and an unsatisfactory outcome as in relation to the GVT. Conversely, too much of a sympathetic presence could take the interview into the arena of therapy beyond the remit of OHinPSC. The balance needed by interviewers suggests understanding this fine line and when recruiting volunteers from a wide range of backgrounds attention needs to be given to having this social skill. As witnessed in this study several of the volunteers were from caring and educational backgrounds which rely on this attribute. Also apparent was the socioeconomic and generational divide between many of the volunteers and participants, as was arguably encountered in two of the research case studies. There is a risk of volunteers thinking they know what's best for a participant or feeling removed from their predicament, resulting in a threat to the participants autonomy and dignity. Delivering training to new volunteers in understanding sympathetic presence in an OHinPSC context which covers the differences and crossover between therapy and OH could be a way to curtail these issues.

*Providing holistic care* in this scenario suggests addressing physical as well as psychological and spiritual needs. Whilst OHinPSC is a unique way to offer an added element of holistic care for patients it could also deter nurses from providing further holistic care and become a

way for them to assume the psychological and spiritual needs are then being covered. Again, the connection between nurse and oral historian comes to the fore in that by working together within a holistic care framework they can establish stronger bonds with patients and their families. As highlighted in this study and the resulting GVT, whilst OHinPSC should not be badged as therapy and assumed as a way to alleviate patients with depression or anxiety, by the added social interaction and providing reflexive narrative it can produce a dignifying outcome for patients. The engagement created by OHinPSC can be a useful accompaniment for HCPs working with patients in understanding more about their identities and needs, but is reliant in a strong triangulation between patient, HCP and oral historian. Whilst remaining separate to a patient's clinical care it can be a staple part of their holistic care and inform HCPs in understanding more about the patients' beliefs and values and thus contribute to shared decision-making, giving the patient agency and an outlet for reflection. Further to this, a narrative review investigating how OH and digital storytelling have been used in public health research and practice (Tsui and Starecheski, 2018), found that OH methods have "substantial potential for supplementing public health activities" to better understand health experiences, engage people, educate HCPs and health service providers and inform public health practice. Whilst this does not implicitly mention PCC the same foundations are evident.

As with the GVT, the PCNF is underpinned by the opportunity for reflection, autonomy, social interaction and a dignifying outcome:

> Life plans are formed through, memory, reflection, imagination and through conversation with others. Through reflection on an individual's values, individual traits and broad ambitions, various options for action are outlined.
>
> (McCormack and McCance, 2010, p.18)

Whilst OHinPSC does not usually involve creating an action plan, this concept of authenticity in the PCNF holds deep parallels, and for those recording family legacies it could be argued that in leaving select memories for the bereaved some decision-making and planning is involved planted by the idea of an authentic self and that which they want to share for the future. OHinPSC goes beyond the remit of PCC in producing the audio recorded legacy which continues in posterity after the embodied self is no more. In this sense the embodiment

continues with the recording. I will now consider the GVT regarding another nursing concept Continuing Bonds (Klass *et al.*, 1996), which suggest a continuation of deceased personhood for bereaved family, friends and the public archive.

## 10.7 The future of OHinPSC in relation to Continuing Bonds

The GVT presents a new method for grieving and remembering in relation to the legacy recording being heard by family and friends in ongoing social interaction and reflection. This has similarities with the Continuing Bonds theory (Klass *et al.*, 1996) which I encountered when I interviewed the Bereavement Counsellor about her thoughts on OHinPSC and she drew links with the concept and how OHinPSC is received in bereavement. The theory challenges previous ideas of grief by suggesting that bereaved individuals keep an ongoing relationship with the deceased rather than detaching themselves. The grief process involves keeping the deceased present in their lives so as not to bury grief and to make it part of their ongoing identity. In this sense, the voice of the deceased as a continuing bond in the life of the bereaved becomes central to the GVT as a potentially dignifying experience. Whilst the Continuing Bonds model clarifies how OHinPSC can help the grieving process by preserving memories and promoting healing, it was theorised before the advent of digital memorialisation and social media which have changed the way we communicate death and dying (Walter, 2015). There are several ethical implications surrounding OHinPSC and receiving a voice record as a continuing bond in common with other digital legacy, some of which have already been discussed in this chapter. I now further discuss the future possibilities for the GVT in relation to Continuing Bonds.

Adopting to the Continuing Bonds model is for many now unavoidable in the digital world. When someone dies who has accounts on the internet, whether they be social media accounts or digital assets such as online banking and email, there is an added layer of identity which is left for the bereaved to manage and account for in their grieving (Walter *et al.*, 2012). Digital legacy and memorialisation have expanded exponentially during the last decade (Yamauchi *et al.*, 2021) and become an important consideration for end-of-life care planning (Hospices UK, 2023) with initiatives such as the Digital Legacy Association (2023) set up to raise awareness and assist in digital assets and legacy planning.

As with OHinPSC, digital legacy platforms offer opportunities and challenges for both public and private grieving, determining new factors relating to giving voice. Digital memorialisation on social media such as Facebook allows for public grieving and a social connectedness unavailable before (Kasket, 2012) as does being able to attend funerals virtually (Walter *et al.*, 2012, p.281) via websites like YouTube. There is a need to better understand intimate private grieving in the digital realm and what has been labelled "backstage grieving" (She *et al.*, 2021). With reference to the GVT, there are different considerations in giving voice as a private personal intervention, via copies given to family and friends, and publicly via the archive copy. However, the opposite is true of the archive copy in OHinPSC, in that the challenge is less that there will be overwhelming public online memorialisation and more the associated challenges in it being accessed and heard in public when stored in an archive which takes more effort and knowledge to be accessed. There is still the risks of family and friends unknowingly hearing the voice record in a museum or online setting but presently these are fewer than public memorialisation on social media. To ensure a balance between accessibility and ethical dissemination, the GVT could be tested in the digital realm as a method for understanding ongoing presence of the deceased.

Giving voice as a private personal continuing bond in the digital landscape presents a challenge in its digital format. As found in this research, people either no longer have a CD player, and CDs are likely to break over time, whereas a digital file relies on some technical knowledge about computer or cloud storage for it not to become lost or corrupted. External hard drives can also break, and cloud storage may come with additional ownership and access permissions which need to be accounted for (The British Library and OHS, 2023, p.18-19). There is a need for ongoing digital preservation of OH as current formats become obsolescent (Boyd, 2010, p.300). Archiving them publicly online could present an alternative. However, listening to a whole OH interview online could present a challenge to many who favour more instant online condensed sound clips (Cohen, 2013, p.161).

A way to introduce more public ethical dissemination of OH voice recordings could be to make excerpts available online as agreed in advance with the participant. This would give the oral histories potentially a much larger audience and global reach (Cohen, 2013, p.155), and would align OHinPSC more with other digital legacy initiatives. However, the findings showed that several research interviewees were suspicious of OHinPSC being shared online.

The ethical dilemmas and possibilities of sharing OH online has been debated by oral historians since the late 1990s (Larson, 2013, p.42). There is the added complexity that with the narrator's identity being key to their narrative, it is common to not anonymise OH interviews (p.38). There has also been debate about what to do if data surfaces from an OH interview on the internet which could be damaging for the interviewee, their family or others (p.47). In one of the final research interviews I discussed with a volunteer the possibility of hosting a podcast with excerpts from recent OHinPSC to share more public facing stories and memories, particularly those with a social history angle with a wider public. This could offer a more controlled method for disseminating OHinPSC online which honoured the participant without inherently promoting public grieving. Some of the participants in the research clearly expressed a desire for their stories to be shared publicly and this would accommodate it in a transparent way which could be agreed in advance, and thus achieve a dignified outcome, involving autonomy and social interaction, as set out in the GVT.

As already discussed, OHinPSC can offer a more personable and secure form of digital legacy compared to generic digital legacy platforms. However, due to the more adaptive use of OHinPSC in the study it meant some research interviewees had a less defined idea as to why they were involved. Participants could have multiple motives and the volunteers and HCPs, their own interpretation of what these were and how the OH should be approached. These situations could produce a very different method of giving voice. The legacy was able to be tailored but the narrative could be misconstrued where there was a mismatch between parties in understandings of motives and approach. Who the intended audience was, whether public or family, and how the recording might affect them in the future as a continuing bond was not always fully considered or agreed by participants, their volunteer interviewer and referring HCP. Also, the differences in participants illness, and those closer to losing mental or physical capabilities or with a greater sense of their mortality meant the continuing bond could be more pertinent.

As we move further into the digital realm and our continuing digital presence and bonds become more inevitable it is unknown how will it shape the practice of OHinPSC. New technology could supersede OH as it is currently practiced or even make OH redundant. The GVT could be used as a benchmark for achieving ethical and mutually beneficial outcomes

for the participant, the bereaved and the archive. It can be assumed with current AI developments that the associated summarising, transcribing and accessing of interviews will become more rapid and fluid, enabling an OH interview to be immediately available and searchable on the internet as soon as the interview finishes. However, it is unclear how data from OH interviews will be reused in the future. OHinPSC offers a rich resource of people histories and reflections at the end-of-life, but in making these histories accessible in the digital realm, what was once considered a democratising way to share archived experience could become a data grab for big companies such as Meta and Google as witnessed with social media (Paasonen, 2018). For instance, the possibilities of AI developments could enable OHInPSC to be easily accessed as data for healthcare providers, insurance companies and other money-making ventures. This would surely be an unintended outcome for participants who wished to share their OH with the wider public and would change the whole notion of giving voice. For bereaved family knowing that the memories of the deceased are being data mined in such a way is surely not a dignifying outcome. When communicating to participants and their families about future possibilities for archival reuse and when they are asked to take part and to sign the Recording Agreement, these factors need to be communicated. Oral historians and archivists need awareness of how publicly available oral histories might be used in the future and to relay this to people involved in OHinPSC. By referring to the GVT they can find ways to consider and communicate this throughout the process. The possibilities of how OH can be reused and socially interacted with in the digital realm are more varied and accessible than ever before but the potential of giving voice to people in an autonomous and dignified way could backfire.

Another element is the capabilities of AI natural language processing and text to speech synthesis to realistically simulate people's voices (Pessanha *et al.*, 2022; Wang *et al.*, 2023). By making people's voices available in the digital realm there is the possibility of them being copied and misused, with fake interviews appearing in the archive or the voice being used in malicious way against bereaved family. The use of a cryptographic digital signature (Bralić *et al.*, 2020) to delineate authentic interviews from fake ones could be a way to counter this. Voice simulation would be another potentially unintended and undignified way of giving voice. We are witnessing the preface of a new digital world. What OHinPSC offers is unique in recording the voices, stories and legacies of a wide range of people. Whether it loses its

democratising scope and original intentions and becomes instead rich data to be mined by corporations remains to be seen. Death and mortality may become less about making continuing bonds apparent and more about managing digital presence, deciding what is private and public and establishing what is authentic and what is fake in the legacy of the deceased. The GVT may become more akin to a keeping voice theory to ensure a dignified outcome for family and the participant. Giving voice to marginalised and under-represented communities has been the mainstay of OH and for OHinPSC, also giving voice to the person at the end-of-life and to their family and friends. To ensure the intentions of the GVT, OHinPSC may become increasingly guarded, and deemed not appropriate to be shared in the digital realm. The differences between people wanting a voice record for family, the public archive, or for themselves as found in this study, should determine the continuing bond and how their OH is then reshared in the digital realm. For those wanting it shared as a publicly available archival resource they should be aware of the yet unknown possibilities.

## 10.8 Evaluation

Throughout this CGT study I have undertaken self-evaluation adhering to the models suggested in my methodology (Chapter 4). Here I further evaluate my research using the framework suggested by Charmaz (2014, p.336-338) to assess the credibility, originality, resonance and usefulness of my study and corresponding findings.

### 10.8.1 Credibility

*Has your research achieved intimate familiarity with the setting or topic?*

This research builds on my own extensive experience and familiarity of OHinPSC and working in situ on a OHinPSC service. The research enabled me to firstly conduct a narrative literature review which strengthened my knowledge further of other OHinPSC initiatives and similar biographical methods in palliative and supportive care. I then identified the sensitizing concepts and foreshadowing questions which instructed my study. Conducting repeat semi-structured interviews throughout the OH process enabled me to achieve in-depth analysis of the settings and topic for participants, volunteers and HCPs. Conducting follow-up interviews enabled me to co-construct and develop theories and understanding with research interviewees. Discounting the family and friends' group, collecting several first-hand accounts of all other parties meant I achieved intimate familiarity with them, having spent approximately 95 days on the fieldwork.

*Are the data sufficient to merit your claims?*

I conducted 32 interviews with 22 people, all of whom fitted the inclusion criteria. My data analysis involved using constant comparative methods, line-by-line and axial coding. I also performed purposeful and then theoretical sampling. This was supplemented by observations in my reflexive and methodological diaries and writing memos to form the basic social process and grounded theory. A sufficient dataset for a grounded theory study was available to present my theories. Despite being limited in only interviewing one family and friend of a participant my research was rich in primary accounts from participants, volunteers and HCPs who also gave secondary accounts of how OHinPSC was received by family and friends. The findings in regard of family and friends also tallies with other research in which more have been interviewed.

*Have you made systematic comparisons between observations and between categories?*

I used constant comparative methods throughout the analysis and a constructivist approach involving the research interviewees in the analysis and findings in follow-up interviews. Structured comparison was continually made in the latter stages of the research process. By line-by-line and thematic coding of transcripts and within Quirkos analysis software with coinciding memo writing, categories and themes were created and negotiated throughout the process. In follow-up interviews with research interviewees, and in writing my findings and discussion with my supervisors, these categories were further developed into my final basic social process and grounded theory.

*Do the categories cover a wide range of empirical observations?*

The categories covered in the research analysis and findings span the OH process from the start of participants being invited to take part, to the outcome of receiving and listening to their OH, taking in the perspectives from all involved parties. Due to the different stages and research interviewees involved, this encompasses a wide range of empirical observations based on the semi-structured interview transcripts and audio, methodological and reflexive diaries and subsequent memos, diagrams, and analysis in Quirkos software. The categories in Quirkos covered the OH service logistics and settings, the conscious experiences for all interviewee groups and the underlying concepts and terms which run through the OH

process. From these categories the final basic social process and grounded theory was constructed.

*Are there strong logical links between the gathered data and your argument and analysis?*

My argument and analysis are formed based on my methodology (Chapter 4), outlined earlier in this thesis. This involved stringent coding of my gathered data being interview transcripts and diaries and writing memos based on emerging themes. The motivations, experience and outcomes for research interviewees was at the core of the data and central to the ongoing analysis and the final grounded theory. As the study progressed, I regularly discussed findings and emerging theories with research interviewees and my supervisors. This enabled me to be consistent and credible in my analysis, and by discussing findings, and reiterating research interviewees' earlier comments in later research interviews, I was able to offer a justified and logical co-constructed argument in my grounded theory.

*Has the research provided enough evidence for your claims to allow the reader to form an independent assessment – and agree with your claims?*

Throughout my findings I provide interview quotes and diary extracts from the research data as evidence to strengthen my claims, which could be used by the reader to form their own assessment. In Setting the scene (Chapter 7), I give background to the research interviewees, and further context is available for the reader from which they can determine how I have reached my categories and theory. Within my final CGT (Chapter 9), in which I outline the basic social process of OHinPSC, I refer to my findings which gives the reader an overview for checking my claims and categories in building an emerging theory.

## 10.8.2 Originality
*Are your categories fresh? Do they offer new insights?*

Due to their being a dearth of research about OHinPSC, it is assumed that to the best of my knowledge my research and corresponding categories offers new insights into the topic. The categories are based on my findings, unique to OHinPSC. Whilst in the limited research on OHinPSC there is some overlap in the themes covered, this is the first study to use grounded theory as a methodology and to understand the experience for all parties throughout the process. Other research about biographical methods at the end-of-life and about OH in

general has also drawn on similar categories such as motivations and legacy but this study is specific to OHinPSC with fresh understanding of the nuances encountered on a OHinPSC service.

*Does your analysis provide a new conceptual rendering of the data?*

In constructing the basic social process of giving voice through reflection, autonomy and social interaction to achieve a dignifying outcome, my analysis provides a new conceptual rendering of the data. This grounded theory is specific to the research and based on the cumulative data I have collected. The theory of giving voice builds on both research specific to OH and other similar biographical methods, which enable participants to leave a legacy but is authentic to the specific topic.

*What is the social and theoretical significance of this work?*

The social significance of this study is in the implications for OHinPSC services and general recording of OH for people within this setting. As outlined in the recommendations later in this chapter, by presenting strengthened understanding of OHinPSC and the GVT, specific training for volunteers and HCPs can be delivered. This would take into account the diversity of participants motivations and outcomes, and the required procedures recommended to achieve a dignifying experience for both participants and their family and friends in the legacy output. The recommendations aim to provide an ethical and adaptable framework which can be used in future planning of OHinPSC.

The theoretical significance of this study builds on previous research relating to OH as legacy and life-story recording to offer new understanding about leaving a voice record for family and friends, and the coinciding motives and interview experience for all involved. The theory of giving voice, a theme synonymous with OH in general, considers the notion not only as a method for giving voice to marginalised or underrepresented communities or 'everyday' people in an autonomous way but also as a legacy document for bereaved family and friends. Research on voice recordings as biographical legacy is of theoretical worth to the wider realm of biographical methods at the end-of-life, and in how producing a voice recording with assistance from volunteers and HCPs can be a reflective, social and dignifying experience.

*How does your grounded theory challenge, extend, or refine current ideas, concepts, and practices?*

As mentioned above, the GVT extends the general perceived notion of OH beyond being a method for offering autonomy to also being a voice legacy for personal and public outcomes within a palliative and supportive care setting. The theory that motives in this setting are both defined, non-defined and temporal, refines the OH research in which motives change through the process shaped by reflection, autonomy and social interaction. This grounded theory also refines current thinking about OH and biographical methods in palliative and supportive care as a meaning-making exercise, which can be therapeutic. Whilst recognising that OHinPSC is not solely a therapeutic intervention, it can provide a social and dignifying experience which enables the participant, volunteer and latterly family and friends to reflect on memories and a voice recording. As discussed earlier in this chapter, OHinPSC and the GVT relates to PCC and the Continuing Bonds theories. This is in reference to the voice record being a unique form of digital legacy which offers a method to understand it as a co-constructed yet autonomous memorialisation with personal and public outcomes.

### 10.8.3 Resonance
*Do the categories portray the fullness of the studied experience?*

The categories were determined after in-depth methodological analysis and theoretical and purposeful sampling. By using constant comparative analysis, categories were revised and further developed, and in writing coinciding memos and creating diagrams to better understand the commonalities between categories I was able to build the basic social process and GVT. By following this methodology, I was able to ensure I covered the full picture of the experience for all research interviewees. In conducting follow-up interviews I was able to share and test emerging theories with interviewees. In my supervision meetings I was able to discuss draft memos, and findings with my supervisors. This enabled me to develop categories further to capture the full experience of OHinPSC and produce my final grounded theory of giving voice.

*Have you revealed both liminal and unstable taken for granted meanings?*

The nature of understanding the OHinPSC experience for this research has involved an understanding the temporality of the process for all the research interviewees in how OH is

understood, produced and received. The research has covered liminality in moving between these stages and encountering how motivations and legacy changes over time. Unstable taken for granted meanings were revealed in how the interviews were conducted and co-constructed by the volunteer and participant involving social interaction, setting and illness and in the outcome in terms of opportunities for reflection and sharing the legacy. This study has also challenged taken for granted meanings about OHinPSC, for example it being a simple activity akin to a normal conversation or it being mistaken to being an outlet for therapy.

*Have you drawn links between larger collectivities or institutions and individual lives, when the data so indicate?*

Drawing on the data, the links between setting for the OH, whether it be the hospice or nursing home and illness and how this impacted on the OHinPSC experience has been covered in the findings (section 8.2). Some interviewees also commented on the stigma around being a patient at a hospice and this data contributed to understanding their identities and motives further. Also, the links between the archive and public outlets for accessing the legacy recording have been accounted for when creating categories and writing up my findings. For instance, the possibilities and challenges for OH in funeral settings, education, on the internet or for marketing and training within the hospice.

*Does your grounded theory make sense to your participants or people who share their circumstances? Does your analysis offer them deeper insights and their lives and worlds?*

The grounded theory and associated terms of reflection, autonomy, social interaction, dignity and ultimately giving voice is embedded in the interview transcripts and as a basic social process the GVT is simple to understand. Whilst giving a fundamental understanding of OHinPSC, the theory enables people to have a deeper insight into the temporal and collective aspects of OHinPSC using key terms which people can understand. Due to the study being cut short by Covid I was unable to further share my grounded theory with the research interviewees. However, in presenting my findings and the GVT at a national OH conference I was able to share it and gained valuable feedback from the audience made up of oral historians.

### 10.8.4 Usefulness

*Does your analysis offer interpretation that people can use in their everyday worlds?*

This research offers useful interpretation which can be used by service providers, oral historians and HCPs when considering or performing OHinPSC. The findings linked to motivations and in particular the challenges when working with people with non-defined motives, who may have multiple reasons for taking part is useful to consider when approaching people in future OHinPSC initiatives. This research offers insights into understanding the interview experience in terms of the kind of narrative, whether it be reminiscence based or a life-story legacy. It considers how this differentiation can impact on both the interviewee and interviewer, when it might be emotional and possibly upsetting relaying traumatic memories. These insights can inform training and guidelines for interviewers in appropriate interviewing approaches, and in aftercare for the interviewee and interviewer, by understanding the therapeutic challenges and opportunities of OHinPSC. The voice recording as legacy is novel to this research and an understanding of how it can be accessed and promote reflection offers useful knowledge which can be used in everyday worlds, especially with reference to digital archives and memorialisation which is becoming increasingly common place as digital life span and capabilities have increased in significance. New similar digital developments could be evaluated using the GVT.

*Do your analytic categories suggest any generic processes?*

The themes of understanding, motivations, autonomy, co-construction, reflection, dignity and legacy are all generic processes which can be found in research relating to other biographical methods in palliative and supportive care and in OH research. These categories are all integral to understanding biographical methodology, and whilst they were generated independently within this research based on the collected data, it was perhaps inevitable they would be encountered. As demonstrated in the basic social process of GVT, they are identifiable throughout the OHinPSC experience from participants being approached to the final OH being accessed and interpreted for personal and public outcomes.

*If so, have you examined these generic processes for tacit implications?*

These generic processes have all been investigated further within the research by using theoretical coding and constant comparative methods to understand their meaning and

uses, and thus subcategories were created as outlined in my findings which get closer to understanding tacit implications. These were then linked to the final basic social process and grounded theory in offering a fuller understanding of OHinPSC.

*Can the analysis spark further research in substantive areas?*

The existing analysis could spark further research in understanding OHinPSC as an adaptable medium and in understanding the breadth of how it can be used a reminiscence and legacy making process, with different formats for recording such as video and other digital applications. The interview dynamic between volunteers, HCPs, family and friends and participants could also be further investigated and the emotional impact both during the interview and afterwards in reflection. How the voice recording is received by family and friends, and ways in which the archive copy can be made more publicly accessible within an ethical framework, is another key area for further research which was not able to be fully researched in this study due to the lack of family and friends interviewed.

*How does your work contribute to knowledge? How does it contribute to making a better world?*

This research contributes to knowledge by sharing first-hand experience of OHinPSC which enhances understanding of the basic social process of OHinPSC in the form of the GVT. As far as I am aware it is the first study specifically about OHinPSC which uses grounded theory to understand the experience of all parties involved in the process. It contributes to knowledge pertaining to biographical methods in palliative and supportive care in which there is a voice legacy, and the findings are useful for further understanding theories linked to narrative medicine and meaning-making within a life review based interview. The research also contributes knowledge to the wider OH community in regard of OH as a form of life review in palliative and supportive care environments and OH as a voice recording for bereaved family and friends, and as a public resource. This knowledge contributes to making a better world by assisting in creating an ethical framework and guidance for future OHinPSC initiatives with the GVT, which can help inform future practitioners, service providers and participants.

### 10.8.5 Evaluation conclusion

In this section I have evaluated my study method and field work using CGT, and the resulting findings and corresponding GVT, using the evaluation framework and questions suggested by Charmaz (2014). I have demonstrated above how I have met the evaluation criteria and thus the quality of the research as a doctoral study. I now outline what I feel are the strengths and limitations of this study and suggest further recommendations for education, policy, practice and future research.

## 10.9 Strengths

The use of grounded theory and the opportunity to co-construct themes and concepts over repeat interviews enables this study to be unique in OHinPSC research and to explore in more detail the experience for participants and other involved parties. It enables the OH process to be followed from start to finish, from when participants first find out about the service to when they and others listen to the final OH recording.

This study includes a wide range of OH interview settings which offer different perspectives of OHinPSC. In liaison with the Service User Coordinator, I was able to interview participants who recorded their OH in the day centre, on inpatients, in a nursing home and in their own homes. The different settings enhanced my findings, and a discovery was the setting was closely linked to the participants mortality and present outlook on life.

The study included participants with a range of illnesses. Interviewing someone with MND presented different motives and experiences to people with cancer or with an illness relating to being older. This gave valuable insight into how OHinPSC can be interpreted and adapted by people with different illnesses. Although no one was interviewed who had dementia, this was also talked about in detail with volunteers and HCPs, who shared their own experiences of OHinPSC with people with dementia. This also supported wider and more intrinsic data about OHinPSC in connection to participants illnesses.

The participants had multiple motives for taking part in OHinPSC and thus I was able to find out more about the experience of recording family and public legacies, and OHinPSC as a therapeutic intervention or reminiscence exercise. Other research studies and OH services catered for only one or two of these outputs, whereas I was able to compare motives and understand primary and secondary factors.

With recruitment help from the Service User Coordinator, I was able to interview participants with a wide age span. The youngest was 42 and the oldest 93. This enabled me to better understand generational aspects of their OH experience and how the volunteers and HCP related to them based on their age.

## 10.10 Limitations

This study only took place in one city and is based on the thoughts of people with a corresponding cultural and socioeconomic background at the hospice. Data from hospices and palliative care units in other locations could have yielded a wider breadth of results. All the research interviewees were white British and mainly either Christian or atheist. Several of them were born or had spent the majority of their life in the city, and their imparted dialogue was based in their socio-geographical background. The study could have benefitted from research interviewees from more diverse cultures, other religions, disabilities and illnesses to find out more about how they experience OHinPSC.

The research interviews were curtailed by the COVID pandemic in March 2020 after 10 months of data collecting and 32 interviews. Ideally, I would have had more time and conducted more interviews. Several were in the planning stage, but it was decided in consultation with my supervisors, that the sample was enough for my study. I had reached a saturation point with several interviewees and managed to speak with all the related volunteers and HCPs I possibly could for the six case study participants. More interviews could have offered the opportunity to further explore the findings and emerging theories with interviewees.

Another aspect was two participants dying during the process. This was unavoidable and can be expected in a hospice setting. Both deaths shaped the following interviews afterwards with their associated volunteer or HCP. After one participant died, their referring HCP had a pre-arranged research interview the next day with me and she spoke of him in a more sensitive and revered way, keen to overt her empathy. She told me he valued and had enjoyed the OH interview/s, but I was unable to ask him myself, as he died shortly after the first interview. This was also the case with the other participant who died. I was due to interview him again shortly after he had recorded his OH to find out about the experience.

As with the other participant, I was only able to interview them in anticipation of their OH interview/s.

The lack of family and friends to interview for the study was a major limitation with only one friend of a participant interviewed and no family. It became clear during the research process that family were less straightforward to access and recruit. The participants were already engaged in both research interviews and oral histories, and it felt intrusive for me to ask them more than in passing whether I might be able to interview one of their family or friends. For the participants recording clear family legacies, there was an added sensitivity, and the only relative I met was the wife of James, who was very busy helping with her husband's care and not interested in being interviewed. Two of the older participants had very few family members, no children, and their main relatives were siblings who were older and had irregular contact. I did not feel I could ask them easily. With more family and friends, it would have been possible to gauge more first-hand accounts of how they felt about the service and how they received and listened to the audio recording. This could have been valuable research in terms of understanding OH as family legacy.

## 10.11 Final recommendations

### 10.11.1 Education

This research has raised significant considerations for future training of volunteers and HCPs as outlined below:

1. The GVT could be provided and explained as a resource for volunteers and HCPs to train them in understanding the wide scope of OHinPSC as a family legacy, public resource and an opportunity to record memories for the self. It is essential they spend time with participants to find out their motives before and during the interview process as they may change. Key to this is making sure participants fully understand the information sheet, Pre-participation and Recording Agreements. Also, that volunteers and HCPs have some understanding of any potential audiences such as family members to make it a beneficial experience for all and minimise any potential upset. Whilst it is important for the participant to have autonomy and be able to decide to choose what they want to record, it is also important they are fully informed of any potential consequences.

2. It is advisable that volunteers summarise interviews, both their own and those by others, to be able to be reflexive in their practice and learn about interviewing technique and recording quality. By listening back to recordings soon after an interview, they can feedback to the participant about any possible inclusions and omissions which might help achieve a more satisfactory recording for the participant. They can also check if there are any GDPR considerations in terms of sensitive data which might cause "substantial damage or distress" to someone (OHS, 2019). It would be useful for all volunteers to be trained in dealing with GDPR as per the course run by the OHS.

3. Whilst all volunteers already take part in a one-day training course in OHinPSC delivered by an OHS trainer prior to starting to volunteer, it is important that they then attend future training events to ensure they are maintaining best practice and can share their experiences with their peers and the Coordinator. Follow-up training meetings did happen for the volunteers interviewed in this research ,which they

found useful. OHinPSC is a complex and wide-ranging field, and it is essential that volunteers understand the legal and ethical framework, interviewing and recording technique and for those conducting interviews to have excellent interpersonal communication skills. Regular training meetings could help ensure that all these criteria are met.

4. Equally, it is important that HCPs have knowledge of the legal and ethical framework of OHinPSC and particularly that they have the skills and knowledge to be able to pitch the service to potential participants. Whilst OHinPSC was viewed as a popular holistic activity and HCPs recognised its therapeutic benefits, it is also important that they understand the legacy and archival potential of OHinPSC and can assist in communicating this when referring participants. Having a consensus of HCPs involved in the referral who attend a short session to build a fuller understanding of OHinPSC, particularly in how to refer people and manage expectations after the interview, could help with this.

## 10.11.2 Policy and practice

This research presents implications for policy and practice in how service providers investing in OH should organise services and best practice guidelines in line with the GVT:

1. As witnessed in this research, key to a successful OHinPSC service is having leadership from someone who is well versed in OH ethics and procedures and can guide volunteers and HCPs in best practice as a main port of call. This person should be multi-skilled in OH and archival procedures, training, volunteer recruitment and management, service promotion, liaising with family and stakeholders and using digital technology. This is a time intensive post, and requires someone who can be available at short notice to assist with ethical concerns and last-minute referrals as they occur.

2. It is an imperative that interviews can be deposited in a professional archive to ensure preservation and accessibility. This means that all interviews should include associated detailed summaries and signed Pre-participation and Recording Agreements by both the participant and a member of the OH service. If possible,

keywords, which can assist with searching the archive, would also be beneficial. Where possible, interviews should be well recorded and in a wav. audio format at a minimum of 16bit 441.khz sample rate to ensure compatibility with the archive. These are requirements as mentioned on the OHS website (2023).

3. An audio copy of the interview in the participants desired format (digital file/CD), along with photocopies of forms signed, should be given to the participant on completing their interview, and, when possible, they should be encouraged to listen back to it to check they are happy with it before depositing with the archive. The opportunity for edits to be made and follow-up interviews should also be offered. The audio editor should act on the wishes of the participant as to what is kept and taken out apart from when there is a need to comply with GDPR, in which case any incidents should be monitored on a case-by-case basis as to the risk attached as suggested by OHS guidelines (OHS, 2019).

4. A support network for participants and volunteers should be in place for if distressing incidents or memories occur to provide counsel after an interview. This could be a Social Worker, Chaplain, or for volunteers, the Coordinator and regular debriefing meetings with other volunteers to be able to talk through any distressing incidents.

### 10.11.3 Future research agenda

This research raised further questions which could be researched in the future, particularly as listed below:

| Topic | Impact |
|---|---|
| Further testing of the GVT<br><br>• within OHinPSC,<br>• in other branches of OH in health and social care, and | This could assist in understanding its scope and boundaries.<br><br>The GVT could be tested particularly as a safeguard for a dignifying outcome as new |

| | |
|---|---|
| • OH which has therapeutic potential and a voice legacy<br>• with other digital legacy models | technologies such as AI become more entwined in OH practice and legacy making. |
| Learning more about how OHinPSC is received by family and friends | This would be beneficial to gain first-hand experiences and to better understand ethical implications. As found via the literature review and this discussion it is an under researched area. Due to recruiting a lack of family and friends in this study, it would be useful to have more context of how OH is valued and listened to in bereavement. |
| Better understanding of how OHinPSC can continue and flourish in the digital realm with regards to digital legacy interventions | This could help to adapt the OHinPSC model in the internet age. There is the risk of it becoming superseded by digital legacy platforms which offer a similar service but OHinPSC, when executed well, can provide a professional and ethical framework which could be adapted to fit future digital initiatives. The GVT lends itself to this purpose. |
| Whilst apparent in this study, the therapeutic potential and possibilities for improving quality of life, could be given more attention in research. | This study offers a basis for understanding OHinPSC, but more detailed research centring on the dialogue within interviews, and measuring and evaluating the effects on participants and volunteers afterwards, could give stronger insights. |

| Exploring the possibilities of making interviews more accessible via the public archive, with keywords. | This could inform research and could benefit the wider OH community. The ethical sensitivities pertained to in OHinPSC could help shape future guidelines in how to make interviews more accessible. As found in the research, there is wide potential for disseminating OHinPSC in the public arena such as in educational and heritage contexts which could be explored. |
| --- | --- |
| Further research on how OHinPSC is organised and received in other settings and with research interviewees from different backgrounds | This would give broader context to an understanding of OHinPSC and perceptions relating to death, dying and legacy. The limitations of this study being conducted in one city within a narrow demographic and hospice setting means there is the potential for much wider understanding of how it can work. |

## 10.12 Conclusion

The aim of this study was to develop an understanding of OHinPSC using CGT as a methodology to conceptualise and theorise the study data. The findings followed the process of motives, which were found to be multiple, conscious, and unconscious; experience, which was shaped by the setting, co-construction of participant and volunteer, narrative identity and sense of mortality, and legacy, how it was received and shared by the participant, family and friends, and in the public archive. The findings were further conceptualised to form a basic social process of the GVT as the model for the CGT. The GVT accounts for the elements of remembering and reflection, autonomy, social interaction, and dignity as temporal factors in providing OHinPSC and to assist successful delivery of an OHinPSC service. The GVT is specific to the field of OH in which it can be tested as a model

for OH with a therapeutic outcome and a voice legacy for the participant. It is also useful in the context of health and social care, understanding how a biographical method in palliative and supportive care with a voice legacy can be implemented in policy and practice. Throughout the research, key categories and concepts were constructed and discussed with research interviewees, although the Covid pandemic meant the final analysis and theory was not discussed in interviews. However, the GVT model has been discussed further at a national OH conference and OH events where it has been well received and which have assisted in its dissemination.

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# 12. Appendices

## Appendix 1: Unabbreviated search terms
4th January 2016:

Interview* taken out

"oral history" or "oral histories" or narrative or biograph* or testimon* or "life story" or "life stories" or "life history" or "life histories" or story or stories or storytelling or "narrative method" or reminiscence

AND

"nursing home" or hospice or hospital or "residential care" or "care home" or "long term care" or "post-acute care" or "long term facility"

AND

"palliative care" or "end of life" or EoL or "terminal illness" or death or dying or "palliative care" nursing" or "palliative medicine" or "palliative therapy" or "palliative treatment" or "terminal care" or "life support care" or "patient care"

## Appendix 2: Hand search of journals

| Journal website | Search terms | Results | Inclusion |
|---|---|---|---|
| Auto/biography studies (Taylor and Francis online) | "oral history" and "palliative care" | 86 | 3 articles 1 editorial |
| Medical Humanities | "oral history" | 198 | 1 editorial, 1 article |
| Memory studies | "oral history" | 54 | 1 article |
| Narrative | "oral history" | 403 | 6 articles |
| OMEGA- Journal of Death and Dying | "oral history" | 40 | 3 articles |
| Oral History Journal | palliative care | 23 | 2 (both work abroad) |
| Oral History Journal | Hospice | 12 | 1 book found |
| Oral History Journal | end of life | 5 | 1 article |
| The Oral History Review | palliative care | 0 | |
| The Oral History Review | Hospice | 2 | 1 article |
| The Oral History Review | end of life | 115 | 3 articles |
| **Total** | | 938 | **19 articles, 4 editorials or commentaries, 1 book** |

## Appendix 3: Search for relevant websites and grey literature

| Description and hyperlink | Relevance |
|---|---|
| Freelance practitioner: Dvora Liberman | Evidence of freelance practice |

| Visiting Angels – how to conduct an oral history interview | Practical information around oral history in a hospice setting |
| --- | --- |
| Academic poster for St. Luke's Hospice oral history project | Relevant research poster |
| Article by Pat Macnee: The Beneficial Effects of Life Story and Legacy Activities | Relevant research article |
| University of Kentucky Libraries Reflections: Hospice of the Bluegrass Oral History Collection | Relevant archive collection |
| Story Corps Legacy | Relevant project |
| StoryCorps phone app | Relevant project |
| Your Story in Utah – tool kit available | Relevant project |

## Appendix 4: Oral history specific data extraction sheet

| Author Year Country | Research question or aim of study | Sample/participants amount Interviewer/interviewee | Method | Intervention/approach | Legacy document | Key themes |
|---|---|---|---|---|---|---|
| (Smith *et al.*, 2009) Canada | What are the lessons learned in producing digital life histories with people with dementia and their caregivers and how do they act as a reminiscence and social stimulus tool for people with cognitive impairment | Based on multimedia biographical work with six participants with AD and six participants with mild cognitive impairment (MCI), work carried out by research staff (7 undergraduate and graduate students) in collaboration with participants and their family carers. | Description of production and screening process – evaluation? Of Participatory design process – can take up to 6 months? | multimedia biography/digital life history (MB) refer to a collection of personal media assets including photographs, film clips, audio narration, and music that are compiled in digital video format to tell the life story. We also often use the term digital life histories interchangeably to refer to MBs averaged 39 minutes in length and were delivered in DVD format p288 | Multimedia DVD Viewed repeatedly by participant | Digital technology, dementia |

| (Stewart, 2013) UK | Do the families listen to all, part or none of the often lengthy recordings and do they hear what they expected? How do the oral histories mesh with the transmission of stories within the family? What are the implications of increased online access both for interviewees' families and for the archivists and librarians | 3 case study reflections from family members about participants' oral history interviews | Secondary research - exploration | Oral history | Archived oral histories | family views. Digital technology (online access) |
|---|---|---|---|---|---|---|

| | who are responsible for archived oral history and its wider dissemination? | | | | | |
|---|---|---|---|---|---|---|
| (Stewart and Brown, 2017) UK | To explore how archived recordings add crucial context to family research and explore how some families have reacted when accessing a relative's audio interview, including how the interview intersects with | East Midlands Oral History Archive -collection of over 20 interviews about the Wharf Street area of Leicester, most of them relating to the 1920s onwards. Recorded in 1980s and 1990s. National Life Stories archive at The British Library – correspondence and interviews with bereaved relatives | Secondary research – exploration of case studies from archived interviews | Oral history | n/a, Archived oral histories | family views about oral histories, family histories, digital technology (online access) |

| | | | | | | |
|---|---|---|---|---|---|---|
| | existing family histories. | | | | | |
| (Taft *et al.*, 2004) USA | Project designed to investigate oral history as an intervention that has the potential to meet mental health needs in old age – part of an ongoing effort to identify intervention that can enhance quality of life in old age. | Student nurses conducted interviews. 12 Nursing home participants (means aged 85.5 years) 14 community participants (means aged 82.4 years) 10 interviews with 4 with husbands and wives together | Naturalistic enquiry Lincoln YS, Guba EG. Naturalistic inquiry. Beverly Hills, Calif: Sage, 1985. – oral history interviews relating to WW2 open ended lasting 45 to 90 minutes recorded, transcribed case reports inductively analysed | Oral history and reminiscence about WW2 | Audio copy for participant (not mentioned if archived) | WW2 as reminisc ence, oral history with old people and veterans |
| (Winslow, Smith and Noble, 2011) UK | Can oral history improve healthcare professionals | Not clear | Unpublished oral presentation | Oral history | Voice recording | Oral history in |

| | understanding of patients in palliative care? | | | | | palliative care |
|---|---|---|---|---|---|---|
| (Winslow, Noble and Hitchlock, 2009) UK | What are the benefits of oral history in palliative care for the patient? | Anecdotal feedback from patients and healthcare professionals | Descriptive article about a service | Oral history | Voice recording | Oral history in palliative care |
| (Winslow and Smith, 2014) UK | How does providing an oral history at the end-of-life influence well-being of the individual and the bereaved? | with patients, family, bereavement group members and healthcare professionals | Unpublished poster abstract and report. semi-structured interviews and Analysis of archival and qualitative interview material | Oral history | Voice recording | Oral history in palliative care |
| (Beasley *et al.*, 2015) Australia | What is the lived experience of volunteering in a palliative care biography service? | 10 volunteers on a service | Thematic analysis of printed transcripts from semi structured interviews | Oral recorded biographical writing – non-specific biographical services | n/a – on service transcripts for patients | volunteers |

## Appendix 5: A typography of relevant narrative approaches in palliative and supportive care

| Approach | Approach type | Definition | Seminal texts/Key authors | Related concepts | Facilitators/ Interviewers | Population / Settings | Method/Interview style | Legacy document | Related disciplines | Countries (where research was found) |
|---|---|---|---|---|---|---|---|---|---|---|
| Oral history | Intervention, activity | 'Oral history is the recording of unique life experience. It captures and preserves the voice of the individual, and participants become involved in the process of producing their own life histories. It provides an opportunity for | Ethical challenges in the oral history of medicine – Winslow and Smith (2010) book chapter.<br><br>Oral history as a social movement: Reminiscence and older people – Bornat J (1989).<br><br>Reminiscence and oral history: | Personhood (Kitwood, 1997)<br><br>Communication enhancement model (Ryan *et al.*, 1995)<br><br>Logotherapy, (Frankl, 1964)<br><br>Milieu therapy (Gunderson *et al.*, 1983) | Oral historians, trained volunteers, trained nurses, students, family members | Older people, people with a terminal illness, people with early-stage memory loss<br><br>nursing homes, long term care, hospices, palliative care, home setting | Open ended one to one or group interviews either following a life story approach or relating to specific event/s i.e., World War 2, getting married | Oral history recording for participant and for research or an archive,<br><br>Summary, transcript<br><br>Interviewee can give consent for use in secondary research, | History, sociology | UK, USA, New Zealand, Australia |

| | | participation across a range of abilities, to people who may not wish to write or who are unable to, but who can vocalise their stories.' (Winslow and Smith, 2014) | parallel universes or shared endeavours? – (Bornat, 2001) | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| Life story work (LSW) | Intervention, activity | Life story work is a broad term used for biographical approaches in health and social care in which a person has the opportunity to record their life experiences. Their story can | Life story work in health and social care: A Systematic Review (McKeown *et al.*, 2006) | Personhood  Person centred care,  relationship centred care | Trained volunteers, students, Nurses, Social Workers | People with dementia, people with learning difficulties older people, fostered children, people with mental health needs. | Ongoing, dynamic process rather than task orientated – can take between 6-12 weeks (one session per week | Commonly recorded in the form of a life story book, digital story or textual information alongside photographs and can form part of | Nursing, social work | UK, Norway, Sweden, USA |

| | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| | | then be used to inform their care and as a method to enhance their autonomy and personhood in a care environment. (McKeown *et al.*, 2006) | | | | nursing homes, long term care, dementia wards | | a memory box with other relevant life memorabilia | | |
| Life review/ life review therapy also Outlook short term life review interventions | Intervention/ therapy | Life review is a structured intervention which is usually one to one and often focuses on the entire life span of an individual. It seeks to distil positive and negative memories into | The Life Review: An Interpretation of reminiscence in the aged (Butler, R.N. 1963) – 1957? Childhood and Society | Erikson's Life stages (ego integrity, generativity) | Social Worker, Clinical Psychologist, Psychiatrist, nurses (Keall *et al.*, 2015) | Older people, people in palliative care or with mental health problems such as depression, | Outlook – 3 weekly sessions lasting between 40-120 minutes each. Short term life review – 2 30–60-minute sessions in one week | Life review legacy outcomes can vary on the exact intervention i.e. LSW, oral history, Dignity Therapy. Life review therapy. | Psychology | Japan, USA, UK, China, Australia, Canada |

| | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| | | an evaluative life story. Life review therapy has been used to treat and to help give patients a more positive outlook based on their past. (Pinquart and Forstmeier, 2012) Dignity therapy can be attributed as a life review intervention as it is accounted as being a manualised intervention with quantitative evaluation (Keall *et al.*, 2015) | (Erikson, Erik H., 1950) | | | | | Could be an audio tape or scrap book see keal 2015 p755-756 | | |

| Dignity therapy | Therapy | Is designed to address psychosocial and existential distress among terminally ill patients. Dignity therapy invites patients to discuss issues that matter most or that they would most want remembered (Chochinov H. *et al.*, 2005). | Dignity Therapy: a novel psychotherapeutic intervention for patients near the end of life (Chochinov H. et al., 2005)<br><br>Dignity Therapy: Final words for final days (Chochinov H., 2012) | Dignity at the end of life – research by Chochinov | DT-trained healthcare professional. | End of life patients, patients with life threatening diseases, old people, people with mild cognitive impairments (Johnston and Narayanasamy, 2016)<br><br>Hospice, palliative care, home setting, hospital | Question protocol of 9 questions given to the patient followed by recorded interview (Martínez *et al.*, 2016) | Generativity document – interviews are audio recorded and then transcribed and edited into a generativity document to be bequeathed to a friend or family member (the audio recording is not kept) | Psychotherapy | Canada, USA, UK, Australia, Spain, Brazil, Sweden |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| Reminiscence/ reminiscence therapy | Activity, intervention and therapy sometimes | Basic reminiscence work in health and social care involves | The Life Review: An Interpretation of reminiscence in | Erikson's Life stages (ego integrity, generativity) | Youth volunteers, senior volunteers, healthcare | Older people, people with dementia, | Often once or twice weekly sessions for 6-10 or more weeks | Community publishing, Booklets, drama | Psychology | UK, USA, France, China, the Philippines, |

| | | freeform autobiographical discussion and storytelling about the past which aims to engage participants and enhance positive feelings (Pinquart and Forstmeier, 2012). It is often used as a group-based intervention (Bornat, 2001). Reminiscence can be intrapersonal – cognitive and individual or interpersonal – communicated | the aged (Butler, R.N. 1963) Childhood and Society (Erikson, Erik H., 1950) | | staff, computer assisted | Nursing homes, hospitals, long term care, palliative care, dementia wards, retirement communities | | | | Germany, Switzerland |
|---|---|---|---|---|---|---|---|---|---|---|

| | | with others in conversation (Lin *et al.*, 2003) | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| Multimedia biographies | Intervention, activity | 'A collection of personal media assets including photographs, film clips, audio narration, and music that are compiled in digital video format to tell the story of a life'(Smith *et al.*, 2009)p288 use of personal rather than archival materials p292 | The Life Review: An Interpretation of reminiscence in the aged (Butler, R.N. 1963)  Childhood and Society  (Erikson, Erik H., 1950) | Reminiscence and life review practice, participatory design (Greenbaum & Kyng, 1991) for producing the MBs | Research staff, family members, | People with Alzheimer's disease and mild cognitive impairment | 60-100 hours over a one-year period | Multimedia biography DVD (av.39mins) | Technology in human services | Canada |

# Appendix 6: Detailed table of included empirical studies (earliest to most recent)

| | Reference/Title | Subject | Country of Research | Research Type | Journal |
|---|---|---|---|---|---|
| 1 | (Lichter, Mooney and Boyd, 1993) Biography as therapy | Oral biography in a hospice | New Zealand | Two case histories, anecdotal feedback | Palliative Medicine |
| 2 | (Rickard, 1998) Oral history – 'more dangerous than therapy?': Interviewees reflections' on recording traumatic or taboo topics | Oral history as a therapeutic outcome | UK | Theoretical based on study – discussion group with 4 past interviewees with traumatic experiences (2 diagnosed with AIDs) | Oral History |
| 3 | (Taft et al., 2004) Oral history: validating contributions of elders | Oral history reminiscence in a nursing home | USA | naturalistic inquiry –open-ended oral history interviews with 12 participants<br><br>Case reports, inductive data analysis | Geriatric Nursing |
| 4 | (McCarthy, 2010)<br><br>"Is oral history good for you?" Taking oral history beyond documentation and into a clinical setting: first steps | Is oral history good for you? | USA | Anonymous survey to quantitatively measure how interviewees felt about telling their story -32 veterans with PSA failure | The Oral History Review |
| 5 | (Savundranayagam, Dilley and Basting, 2011) StoryCorps memory loss initiative: enhancing personhood for storytellers with memory loss | Oral history for people with memory loss | USA | Grounded theory – two follow-up interviews with 42 persons with memory loss and 27 family members – yes/no and open questions, constant comparative analysis | Dementia |

| 6 | (Ligon *et al.*, 2012) Oral history: A pragmatic approach to improving life satisfaction of elders | Oral history for improving quality of life in old people | USA | before and after experimental study, pre-test-post-test design with intervention vs. control group<br><br>to measure baseline life satisfaction LSIA (60 participants) | Journal of Intergenerational Relationships |
| 7 | (Winslow and Smith, 2014) How does providing an oral history at the end-of-life influence well-being of the individual and the bereaved? | Oral history in palliative care | UK | Unpublished report – analysis of 100 interviews from the archive semi structured interviews (32) with 10 patients, 9 bereaved family members, 6 healthcare professionals, 7 bereavement support volunteers, thematic analysis | British Medical Journal Supportive and Palliative care poster and report |
| 8 | (Beasley *et al.*, 2015) The lived experience of volunteering in a palliative care biography service | Oral biography volunteers in a hospice | Australia | Semi-structured interviews (10 volunteers) thematic analysis of transcripts | Palliative and Supportive Care |

## Appendix 7: Table of oral history service projects identified in empirical studies

| Service | Interview setting | Facilitator | Interviewer | Interviewee | Research theoretical framework | Interview time frame | Questions | Legacy |
|---|---|---|---|---|---|---|---|---|
| StoryCorps Memory Loss Initiative, Wisconsin, USA | StoryCorps booth | Trained StoryCorps facilitator | family members/carers | Persons with self-identified early-stage memory loss | Communication Enhancement Model (Ellen Bouchard Ryan *et al.*, 1995) and personhood approach (Kitwood, 1997) | 40 minutes | Question generator | Personal CD and deposited in the National Archives |
| Oral History in Palliative Care | Hospice, Palliative care unit, | Oral history lead and Coordinator | Trained volunteers, | Patients in palliative care or with terminal illness | n/a | No time limit given | Open questioning using life | Personal CD and deposited in the University of |

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| Services Project, UK | critical care wards, home setting | | oral historians | | | | story approach (Robert Atkinson, 1998) | Sheffield Special Archive Collections |
| Oral Biographer Service, New Zealand and Australia | Hospice care | Hospice Medical director? | Trained volunteers from family support team (coordinate with directors) | Hospice patients selected by a psychiatrist considered 'to have a need to find meaning in their lives in order to improve their quality of life' and those whose lack of self-regard is considered a key factor leading to apathy and depression' (Lichter, Mooney and Boyd, 1993) | Logotherapy (Frankl, 1964) | Initial collection of biographical information – when the interviewee is ready recording commences – no time limit given | Open questioning – led by interviewee | Tape and transcript for interviewee/ friends/family  No consent signed. Remains property of the interviewee. No archive copy |
| Recording Memories of WW2 Oral History Project, Wisconsin, USA | Nursing home, in the community | Funding via University of Wisconsin-Eau Claire | Trained faculty and Student nurses | Older adults (average age of 84) | Therapeutic milieu (Gunderson *et al.*, 1983)  Naturalistic Inquiry (Lincoln, 1985) | Between 45-90 minutes | Open ended guide to questioning but specific questions around Pearl Harbour | Personal transcript with added memoirs. Transcript developed into case report for research.  No other archive mentioned |

## Appendix 8: Conversational guide sheet

**Introduction**

- Introduce myself and check they have read the information sheet and are clear about the purpose of the study
- Reiterate they are free to withdraw at any time and that taking part will not impact on their medical care
- Ask them to sign the pre-interview consent form
- Explain the recording process and how long the interview will take
- Check there are no foreseeable interruptions such as background sound or people due to visit
- Perform a sound check with the recording equipment to get the right sound levels
- Start recording and begin the interview with 'thank you for agreeing to take part in the study: Understanding oral history with people in palliative care or supportive care: a qualitative study. The date is… and we are at….'

**Questions**

1. What is your involvement in oral history in palliative and supportive care?
2. Please can you tell me about your experience of the service?
3. What are/were your motivations for taking part (interviewees/interviewers)?
4. Please can you tell me about your experience of the interview (interviewees/interviewers)?
5. Did you find it enjoyable or not? Can you explain why?
6. What do you plan to do with your finished oral history recording (interviewee/family and loved ones)?
7. What do you perceive to be the challenges encountered in recording and sharing the oral history interview?
8. What do you perceive to be the opportunities encountered in oral history recording and sharing the oral history interview?
9. Have you listened to the recording yet? How did it make you feel?
10. When do you plan to listen to the recording (interviewee/family and loved ones)?
11. What were the main topics you talked about in the interview (interviewee/interviewer)?
12. What do you think could be done differently?
13. How do you think oral history interviews/clips should be reused?
14. What are the possibilities for reuse of oral history interviews in health and social care?
15. Is there anything else you would like to say?

- Thank them for taking part and state on the recording the interview has now finished.
- Ask them to fill in the mini questionnaire and explain it will be kept separately to the interview in a secure locked cupboard only accessible by the researcher to ensure confidentiality.
- Provide them with a photocopy of their consent form and refer them to contact details on the information sheet should they wish to contact someone about the study.

| Phase | Oct-Dec 16 | Jan-Mar 17 | Apr-Jun 17 | Jul-Sep 17 | Oct-Dec 17 | Jan-Mar 18 | Apr-Jun 18 | Jul-Sep 18 | Oct-Dec 18 | Jan-Mar 19 | Apr-Jun 19 | Jul-Sep 19 | Oct-Dec 19 | Jan-Mar 20 | Apr-Jun 20 | Jul-Sep 20 |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| Induction and reading | X | X | | | | | | | | | | | | | | |
| Literature review | X | X | X | X | | | | | | | | | | | | |
| Writing up confirmation review report | | | X | X | X | X | X | | | | | | | | | |
| Submit confirmation review | | | | | | | X | | | | | | | | | |
| Confirmation review meeting | | | | | | | X | | | | | | | | | |
| Ethics approval | | | | | | | | X | | | | | | | | |
| DBS check | | | | | | | | X | | | | | | | | |
| Initial research site meetings | | | | | | | | X | | | | | | | | |
| Recruit advisory group | | | | | | | | X | | | | | | | | |
| Research process on site | | | | | | | | | X | X | X | X | | | | |
| Reflexive journal | | | | | | | | | X | X | X | X | | | | |
| Methodological journal | | | | | | | | | X | X | X | X | | | | |
| Preliminary interviews | | | | | | | | | X | X | X | | | | | |
| Field notes and transcribing | | | | | | | | | X | X | X | X | | | | |
| Follow-up interviews | | | | | | | | | | X | X | X | | | | |

| | | | | | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| Grounded theory analysis | | | | | | | | | | ▓ | ▓ | ▓ | | | | |
| Member checks | | | | | | | | | | | | ▓ | | | | |
| Final results | | | | | | | | | | | | ▓ | | | | |
| Write up findings | | | | | | | | | | | | | ▓ | ▓ | ▓ | |
| Submit draft thesis | | | | | | | | | | | | | | | ▓ | |
| Proof read thesis | | | | | | | | | | | | | | | ▓ | |
| Submit thesis | | | | | | | | | | | | | | | | ▓ |
| Viva | | | | | | | | | | | | | | | | ▓ |

The University Of Sheffield.

## Understanding oral history with people in palliative care or supportive care: a qualitative study

## Mini-questionnaire

1. What is your age? …………..years

2. What is your gender?

   ☐ Female        ☐ Male        ☐ I do not wish to disclose this

3. How would you describe your ethnicity?

**Asian or Asian British**

☐ Bangladeshi
☐ Indian
☐ Pakistani
☐ Any other Asian background

**Black or Black British**

☐ African

☐ Caribbean
☐ Any other Black background

**Mixed**

☐ White & Asian
☐ White & Black African
☐ White & Black Caribbean
☐ Any other mixed background

**White**

☐ British

☐ Irish
☐ Any other White background

**Other Ethnic Group**

☐ Chinese
☐ Any other ethnic group
☐ I do not wish to disclose

4. How would you describe your religion or belief?

☐ Atheism
☐ Buddhism
☐ Christianity
☐ Hinduism

☐ Islam
☐ Jainism
☐ Judaism

☐ Sikhism
☐ Other
☐ I do not wish to disclose

**Thank you for completing this questionnaire. Your name will not be used with this information.**

# Appendix 11: Participant consent form



**Understanding oral history with people in palliative care or supportive care: a qualitative study**

**Consent Form**

| *Please sign your initials in the appropriate boxes* | Initials |
|---|---|
| **Taking Part in the Project** | |
| I have read and understood the project information sheet version 2.5 08/03/19 or the project has been fully explained to me. (Please do not proceed with this consent form until you are fully aware of what your participation in the project will mean.) | ☐ |
| I have been given the opportunity to ask questions about the project. | ☐ |
| I agree to take part in the project. I understand that taking part in the project will include being interviewed and being audio recorded. | ☐ |
| I understand that my taking part is voluntary and that I can withdraw from the study at any time. I do not have to give any reasons for why I no longer want to take part and there will be no adverse consequences if I choose to withdraw. | ☐ |
| **How my information will be used during and after the project** | |
| I understand my personal details such as name, phone number, address and email address etc. will not be revealed to people outside the project. | ☐ |
| I understand and agree that my words may be quoted in reports, web pages, and other research publications. I understand that I will not be named in these publications unless I specifically request this. | ☐ |
| I understand that everything I say is confidential unless I divulge something that suggests that I or someone else is at risk of harm. I understand the researcher will discuss this with me before telling anyone else. | ☐ |
| I understand and agree that other authorised researchers will only have access to this anonymised data if they agree to preserve the confidentiality of the information as requested in this form. | ☐ |
| I understand and agree that other authorised researchers may use my anonymised data in reports, web pages, and other research publications. | ☐ |
| I give permission for the anonymised interview transcript/s and demographic information that I provide to be deposited in the University of Sheffield ORDA data repository so it can be used for future research and learning. | ☐ |
| I give permission for my anonymised data to be used in other projects. So that the information I provide can be used legally by researchers. | ☐ |
| I agree to assign the copyright I hold in any materials generated as part of this project to The University of Sheffield. | ☐ |
| I would like a summary of the final research report. (If initialled please write your email or address): | ☐ |

Name of participant  [printed]                                   Signature


Name of Researcher  [printed]                                   Signature



**Project contact details for further information:**
If you have any questions about this research, please contact Sam Smith by email: s.r.smith@sheffield.ac.uk.
Alternatively, if you would like to speak to a different member of the research team, you can contact Dr Tony Ryan on 0114 222 2062 or email t.ryan@sheffield.ac.uk. If you would like to raise a complaint about the study please contact Dr Sharron Hinchcliff, Postgraduate Research Tutor, by email: s.hinchliff@sheffield.ac.uk

## Appendix 12: General information sheet



**Understanding oral history with people in palliative care or supportive care: a qualitative study**

**General information sheet**

**Research team:**
Sam Smith

Supervisors: Tony Ryan, Jane McKeown, Michelle Winslow. School of Nursing and Midwifery, University of Sheffield

**Project purpose:**
The aim of this study is to better understand how people feel about taking part in oral history at St Luke's Hospice. Results will help shape how oral history develops in the future and how hospice teams are trained.

We are recruiting anyone who has experience of creating or being given an oral history recording in palliative and supportive care. We are particularly interested in recruiting interviewees, their family, and friends, and also volunteer interviewers and health care professionals.

The study is part of a PhD being undertaken by Samuel Smith. For the research he is conducting 1-3 face-to-face interviews (approx. 30mins each) with each participant to ask questions about their experience of the service (before and after taking part), and to discuss emerging ideas. The findings will inform his thesis and enable further knowledge and recommendations for practice and policies.

The research is being funded by and organised within the School of Nursing and Midwifery, University of Sheffield and has been reviewed by the Health Research Authority's Social Care REC and received a favourable opinion.

**Contact for further information**
If you have any questions about this research, please email Samuel Smith: s.r.smith@sheffield.ac.uk
Alternatively, if you would like to speak to a different member of the research team, you can contact Dr Tony Ryan on 0114 222 2062 or email t.ryan@sheffield.ac.uk

## Appendix 13: Participant information sheet (for patients)



**Understanding oral history with people in palliative care or supportive care: a qualitative study**

**Information sheet for patients**

**Research team:**
Sam Smith

Supervisors: Tony Ryan, Jane McKeown, Michelle Winslow, School of Nursing and Midwifery, University of Sheffield.

**Introduction:**
You are invited to take part in a research project. Before you decide whether or not you wish to participate, please take time to read the following information carefully and discuss it with others if you wish. Please ask if there is anything that is not clear or if you would like more information. Thank you for reading this.

**Project purpose:**
I am completing this research as part of a PhD I am undertaking at the University of Sheffield. The aim of this study is to better understand how people feel about taking part in oral history at St Luke's Hospice. Results will help shape how oral history develops in the future and how hospice teams are trained. If you agree to participate, I will conduct three face-to-face interviews that will ask about your experience of oral history (before and after taking part), and your thoughts about the process.

**Why have I been asked to take part in the project?**
I am inviting anyone who has experience of oral history at St. Luke's Hospice. So that includes interviewees, their family, and friends and also volunteer interviewers and health care professionals. Taking part is entirely voluntary and it is up to you to decide whether or not to participate. If you do decide to take part, we ask that you keep this information sheet and you will also be asked to sign a consent form. You are free to withdraw at any time; a decision not to take part will not affect your future medical care.

**What will happen to me if I take part?**

If you decide to be involved I will phone or write to you to arrange to talk about the research and, if you wish to go ahead, arrange an interview time and place that suits you. I will ask you a series of questions about your experience of oral history and ask for your views on how recordings are shared. The interview will take approximately 30 – 45 minutes. Two shorter follow up interviews may be conducted with you within 6-12 weeks of the first interview. All interviews will take place at St. Luke's Hospice or, if you prefer, in your home.

**What are the possible disadvantages and risks of taking part?**

Given the research subject matter of oral history in palliative and supportive care, for some people it may invoke difficult memories and opinions, or some may find it distressing to think about their serious illness. Both I and the research team understand this and are experienced in talking to people in this situation. You will not be expected to discuss anything that you don't wish to. I will understand if you want to take a break during the session, or would like to stop the interview altogether or arrange to return at a time that suits you better. I will also be able to put you in touch with sources of support if you wish.

**Will I be recorded, and how will the recorded media be used?**

Your interview/s will be audio recorded and transcribed. The audio interviews will be used only for analysis and will be destroyed on completion of the study. No other use will be made of them without your written permission, and no one outside the project will be allowed access to the original research recordings.

**Will my taking part in this project be kept confidential?**

Your name will be removed from any transcripts and the audio recording. All the information I collect about you during the course of the research will be kept confidential and will only be accessible to members of the research team. Anonymised quotes may be used in publications and reports. When sharing the findings of the study we would never use your name or any other specific identifier. However, your own circumstances are unique to you and as a result there is a *very small risk* that when we present or report our findings they may be attributed to you.

Everything you say is confidential unless you tell us something that indicates that you or someone else is at risk of harm. I would discuss this with you before telling anyone else and if necessary I would consult a senior member of the healthcare team.

St. Luke's Hospice will collect information from you for this research study in accordance with our instructions. St. Luke's Hospice will use your name and contact details to contact you about the research study, and make sure that relevant information about the study is recorded for your care, and to oversee the quality of the study. St. Luke's Hospice will pass these details to the University of

Sheffield. The only people in the University of Sheffield who will have access to information that identifies you will be people who need to contact you about the study or to audit the data collection process. The University of Sheffield will keep identifiable information about you from this study (contact details and consent forms) for 10 years after the study has finished.

**What will happen to the data collected, and the results of the research project?**
I will transcribe and anonymise all the interviews and during the study only the research team (me and my research supervisors: Tony Ryan, Jane McKeown, Michelle Winslow) will have access to the anonymised data for analysis. The project results will be written up in a PhD thesis and may be published in subsequent publications or reports and presented at conferences.

Due to the nature of this research it is possible that other researchers may find the information collected to be useful in answering future research questions. After the study the anonymised transcripts and demographic information (age, gender, ethnicity and religion/belief) will be deposited in the University's Online Research Data repository (ORDA) with limited access by request for University of Sheffield staff and students. There will an 18 month embargo on data access to allow for study findings to be disseminated first. The data will be preserved for a minimum of 10 years.

**Who is the Data Controller?**
The University of Sheffield is the sponsor for this study based in the United Kingdom. We will use information from you in order to undertake this study and will act as the data controller for it. This means that we are responsible for looking after your information and using it properly. The University of Sheffield will keep identifiable information about you for 10 years after the study has finished.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained or you can choose to have your data erased for up to three months after your interview. After that time it will not be possible as data will have been analysed. To safeguard your rights, we will use the minimum personally-identifiable information possible.

You can find out more about how we use your information, including details about how and why the University processes your personal information, how we keep your information secure, and your legal rights (including how to complain if you feel that your personal information has not been handled correctly), in the University's Privacy Notice https://www.sheffield.ac.uk/govern/data-protection/privacy/general.

**What is the legal basis for processing my personal data?**
In order to collect and use your personal information as part of this research, we must have a basis in law to do so. The basis that we are using is that the research is 'a task in the public interest'. This is

because it is producing developments in education and research on behalf of the University of Sheffield.

As we will be collecting some data that is defined in the legislation as more sensitive information about your oral history experience and personal background, we also need to let you know that we are applying an additional condition in law: that the use of your data is 'necessary for scientific or historical research purposes'. This enables us to collect and archive information such as ethnic background, religion and philosophical beliefs, which could be integral to your contribution.

**Who is organising and funding the research?**
The research is being funded by and organised within the School of Nursing and Midwifery, University of Sheffield.

**How will I find out the results?**
Please let me know if you would like to hear about the outcome of the study and you will be emailed or sent the report summary when the study finishes.

**Who has ethically reviewed the research?**
This study was reviewed by the Health Research Authority's Social Care REC and received a favourable opinion.

**What if something goes wrong?**
If you have an issue with the project please raise your concern with the researcher Sam Smith (contact details at the end). If you would like to make a complaint please contact Dr Sharron Hinchcliff, Postgraduate Research Tutor, on 0114 222 2045 or email her at s.hinchliff@sheffield.ac.uk

**Contact for further information**
If you have any questions about this research, please email Sam Smith  s.r.smith@sheffield.ac.uk
Alternatively, if you would like to speak to a different member of the research team, you can contact Dr Tony Ryan on 0114 222 2062 or email t.ryan@sheffield.ac.uk

**Thank you for reading this information. If you decide to participate you will be given a copy of the information sheet and a signed consent form to keep.**

## Appendix 14: Participant information sheet (for volunteers and HCPs)



**Understanding oral history with people in palliative care or supportive care: a qualitative study**

**Information sheet for volunteers and health care professionals**

**Research team:**
Sam Smith

Supervisors: Tony Ryan, Jane McKeown, Michelle Winslow, School of Nursing and Midwifery, University of Sheffield.

**Introduction:**
You are invited to take part in a research project. Before you decide whether or not you wish to participate, please take time to read the following information carefully and discuss it with others if you wish. Please ask if there is anything that is not clear or if you would like more information. Thank you for reading this.

**Project purpose:**
I am completing this research as part of a PhD I am undertaking at the University of Sheffield. The aim of this study is to better understand how people feel about taking part in oral history at St Luke's Hospice. Results will help shape how oral history develops in the future and how hospice teams are trained. If you agree to participate, I will conduct three face-to-face interviews that will ask about your experience of oral history (before and after taking part), and your thoughts about the process.

**Why have I been asked to take part in the project?**
I am inviting anyone who has experience of oral history at St. Luke's Hospice. So that includes interviewees, their family, and friends and also volunteer interviewers and health care professionals. Taking part is entirely voluntary and it is up to you to decide whether or not to participate. If you do decide to take part, we ask that you keep this information sheet and you will also be asked to sign a consent form. You are free to withdraw at any time.

**What will happen to me if I take part?**
If you decide to be involved I will phone or write to you to arrange to talk about the research and, if you wish to go ahead, arrange an interview time and place that suits you. I will ask you a series of

questions about your experience of oral history and ask for your views on how recordings are shared. The interview will take approximately 30 – 45 minutes. Two shorter follow up interviews may be conducted with you within 6-12 weeks of the first interview. All interviews will take place at St. Luke's Hospice or, if you prefer, in your home.

**What are the possible disadvantages and risks of taking part?**
Given the research subject matter of oral history in palliative and supportive care, for some people it may invoke difficult memories and opinions. You will not be expected to discuss anything that you don't wish to. I will understand if you want to take a break during the session, or would like to stop the interview altogether or arrange to return at a time that suits you better. I will also be able to put you in touch with sources of support if you wish.

**Will I be recorded, and how will the recorded media be used?**
Your interview/s will be audio recorded and transcribed. The audio interviews will be used only for analysis and will be destroyed on completion of the study. No other use will be made of them without your written permission, and no one outside the project will be allowed access to the original research recordings.

**Will my taking part in this project be kept confidential?**
Your name will be removed from any transcripts and the audio recording. All the information I collect about you during the course of the research will be kept confidential and will only be accessible to members of the research team. Anonymised quotes may be used in publications and reports. When sharing the findings of the study we would never use your name or any other specific identifier. However, your own circumstances are unique to you and as a result there is a *very small risk* that when we present or report our findings they may be attributed to you.

Everything you say is confidential unless you tell us something that indicates that you or someone else is at risk of harm. I would discuss this with you before telling anyone else and if necessary I would consult a senior member of the healthcare team.

St. Luke's Hospice will collect information from you for this research study in accordance with our instructions. St. Luke's Hospice will use your name and contact details to contact you about the research study, and make sure that relevant information about the study is recorded for your care, and to oversee the quality of the study. St. Luke's Hospice will pass these details to the University of Sheffield. The only people in the University of Sheffield who will have access to information that identifies you will be people who need to contact you about the study or to audit the data collection process. The University of Sheffield will keep identifiable information about you from this study (contact details and consent forms) for 10 years after the study has finished.

**What will happen to the data collected, and the results of the research project?**

I will transcribe and anonymise all the interviews and during the study only the research team (me and my research supervisors: Tony Ryan, Jane McKeown, Michelle Winslow) will have access to the anonymised data for analysis. The project results will be written up in a PhD thesis and may be published in subsequent publications or reports and presented at conferences.

Due to the nature of this research it is possible that other researchers may find the information collected to be useful in answering future research questions. After the study the anonymised transcripts and demographic information (age, gender, ethnicity and religion/belief) will be deposited in the University's Online Research Data repository (ORDA) with limited access by request for University of Sheffield staff and students. There will an 18 month embargo on data access to allow for study findings to be disseminated first. The data will be preserved for a minimum of 10 years.

**Who is the Data Controller?**

The University of Sheffield is the sponsor for this study based in the United Kingdom. We will be using information from you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. The University of Sheffield will keep identifiable information about you for 10 years after the study has finished.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained or you can choose to have your data erased for up to three months after your interview. After that time it will not be possible as data will have been analysed. To safeguard your rights, we will use the minimum personally-identifiable information possible.

You can find out more about how we use your information, including details about how and why the University processes your personal information, how we keep your information secure, and your legal rights (including how to complain if you feel that your personal information has not been handled correctly), in the University's Privacy Notice https://www.sheffield.ac.uk/govern/data-protection/privacy/general.

**What is the legal basis for processing my personal data?**

In order to collect and use your personal information as part of this research, we must have a basis in law to do so. The basis that we are using is that the research is 'a task in the public interest'. This is because it is producing developments in education and research on behalf of the University of Sheffield.

As we will be collecting some data that is defined in the legislation as more sensitive information about your oral history experience and personal background, we also need to let you know that we are applying an additional condition in law: that the use of your data is 'necessary for scientific or historical

research purposes'. This enables us to collect and archive information such as ethnic background, religion and philosophical beliefs which could be integral to your contribution.

**Who is organising and funding the research?**
The research is being funded by and organised within the School of Nursing and Midwifery, University of Sheffield.

**How will I find out the results?**
Please let me know If you would like to know about the outcome of the study and you will be emailed or sent the report summary when the study finishes.

**Who has ethically reviewed the research?**
This study was reviewed by the Health Research Authority's Social Care REC and received a favourable opinion.

**What if something goes wrong?**
If you have an issue with the project please raise your concern with the researcher Sam Smith (contact details at the end). If you would like to make a complaint please contact Dr Sharron Hinchcliff, Postgraduate Research Tutor, on 0114 222 2045 or email her at s.hinchliff@sheffield.ac.uk

**Contact for further information**
If you have any questions about this research, please email Sam Smith  s.r.smith@sheffield.ac.uk
Alternatively, if you would like to speak to a different member of the research team, you can contact Dr Tony Ryan on 0114 222 2062 or email t.ryan@sheffield.ac.uk

**Thank you for reading this information. If you decide to participate you will be given a copy of the information sheet and a signed consent form to keep.**

v.3.5, 08/03/2019.  IRAS ID: 251866

## Appendix 15: Participant information sheet (for family)



**Understanding oral history with people in palliative care or supportive care: a qualitative study**

**Information sheet for family and friends**

**Research team:**
Sam Smith

Supervisors: Tony Ryan, Jane McKeown, Michelle Winslow, School of Nursing and Midwifery, University of Sheffield.

**Introduction:**
You are invited to take part in a research project. Before you decide whether or not you wish to participate, please take time to read the following information carefully and discuss it with others if you wish. Please ask if there is anything that is not clear or if you would like more information. Thank you for reading this.

**Project purpose:**
I am completing this research as part of a PhD I am undertaking at the University of Sheffield. The aim of this study is to better understand how people feel about taking part in oral history at St Luke's Hospice. Results will help shape how oral history develops in the future and how hospice teams are trained. If you agree to participate, I will conduct three face-to-face interviews that will ask about your experience of oral history (before and after taking part), and your thoughts about the process.

**Why have I been asked to take part in the project?**
I am inviting anyone who has experience of oral history at St. Luke's Hospice. So that includes interviewees, their family, and friends and also volunteer interviewers and health care professionals. Taking part is entirely voluntary and it is up to you to decide whether or not to participate. If you do decide to take part, we ask that you keep this information sheet and you will also be asked to sign a consent form. You are free to withdraw at any time. Your involvement with St. Luke's Hospice will not be affected in any way if you choose to not take part or to withdraw.

v.3.5, 08/03/2019.  IRAS ID: 251866

**What will happen to me if I take part?**

If you decide to be involved I will phone or write to you to arrange to talk about the research and, if you wish to go ahead, arrange an interview time and place that suits you. I will ask you a series of questions about your experience of oral history and ask for your views on how recordings are shared. The interview will take approximately 30 – 45 minutes. Two shorter follow up interviews may be conducted with you within 6-12 weeks of the first interview. All interviews will take place at St. Luke's Hospice or, if you prefer, in your home.

**What are the possible disadvantages and risks of taking part?**

Given the research subject matter of oral history in palliative and supportive care, for some people it may invoke difficult memories and opinions, or some may find it distressing to think about the serious illness of a family member or friend. Both I and the research team understand this and are experienced in talking to people in this situation. You will not be expected to discuss anything that you don't wish to. I will understand if you want to take a break during the session, or would like to stop the interview altogether or arrange to return at a time that suits you better. I will also be able to put you in touch with sources of support if you wish.

**Will I be recorded, and how will the recorded media be used?**

Your interview/s will be audio recorded and transcribed. The audio interviews will be used only for analysis and will be destroyed on completion of the study. No other use will be made of them without your written permission, and no one outside the project will be allowed access to the original research recordings.

**Will my taking part in this project be kept confidential?**

Your name will be removed from any transcripts and the audio recording. All the information I collect about you during the course of the research will be kept confidential and will only be accessible to members of the research team. Anonymised quotes may be used in publications and reports. When sharing the findings of the study we would never use your name or any other specific identifier. However, your own circumstances are unique to you and as a result there is a *very small risk* that when we present or report our findings they may be attributed to you.

Everything you say is confidential unless you tell us something that indicates that you or someone else is at risk of harm. I would discuss this with you before telling anyone else and if necessary I would consult a senior member of the healthcare team.

St. Luke's Hospice will collect information from you for this research study in accordance with our instructions. St. Luke's Hospice will use your name and contact details to contact you about the research study, and make sure that relevant information about the study is recorded for your care, and to oversee the quality of the study. St. Luke's Hospice will pass these details to the University of Sheffield. The only people in the University of Sheffield who will have access to information that

identifies you will be people who need to contact you about the study or to audit the data collection process. The University of Sheffield will keep identifiable information about you from this study (contact details and consent forms) for 10 years after the study has finished.

**What will happen to the data collected, and the results of the research project?**
I will transcribe and anonymise all the interviews and during the study only the research team (me and my research supervisors: Tony Ryan, Jane McKeown, Michelle Winslow) will have access to the anonymised data for analysis. The project results will be written up in a PhD thesis and may be published in subsequent publications or reports and presented at conferences.

Due to the nature of this research it is possible that other researchers may find the information collected to be useful in answering future research questions. After the study the anonymised transcripts and demographic information (age, gender, ethnicity and religion/belief) will be deposited in the University's Online Research Data repository (ORDA) with limited access by request for University of Sheffield staff and students. There will an 18 month embargo on data access to allow for study findings to be disseminated first. The data will be preserved for a minimum of 10 years.

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## Appendix 16: Line-by-line coding example

| | |
|---|---|
| | *right OK thank you, did you enjoy the interviews did you enjoy doing the interviewing with the interviews?* |
| *More unsure of own enjoyment*<br><br>*Enjoys communicating*<br><br>*Increasingly anxious*<br><br>*Told upsetting stories*<br><br>*Shock*<br><br>*Sense of duty*<br><br>*No prompting*<br><br>*He already had things to say* | with him I was more apprehensive than I have been before, I quite enjoy talking to people but I was getting a bit anxious about all the things he was telling me because I did wonder if he ought to be telling me all of these things...but of course you have to go along with what - he didn't need a lot of prompting he just had got his idea of what he was saying |
| | *that's interesting, OK so in terms of - because I know you prefer to stay of the recording in your interviewing style* |
| *Prefers to stay off recording style* | yeah |
| | *and did you find you were able to do that, he was happy to talk on his own* |
| *Straight forward for him talking*<br><br>*Just interjecting*<br><br>*But little* | yes, I was it was quite easy to do that with him, he just talked occasionally I would say a few things but not very much |