CAPTURING THE IMPACTS OF END OF LIFE CARE ON THOSE CLOSE TO THE DYING FOR USE IN ECONOMIC EVALUATION

by

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Abstract

This thesis reports work to develop and score (value) a measure to capture the impact of end of life care (EoLC) on those people close to the dying. This work is conducted in response to the need to capture wider impacts of EoLC for economic evaluation where there is lack of appropriate measures.

To develop the measure, twenty seven in-depth interviews were conducted with those who were recently bereaved or close to somebody receiving EoLC. Constant-comparative analysis was used to develop dimensions for the measure. Pictorial tools were used to explore who is close to those at the end-of-life and therefore could legitimately be included within the evaluation of EoLC interventions. The measure was valued using an exploratory deliberative methodology conducted with six focus groups comprising members of the public.

The measure contains six dimensions: *communication with those providing care services, practical support, privacy and space, emotional support, preparing and coping* and *emotional distress*. The *communication* and *practical support* attributes received the greatest weighting in the valuation process. On average, there were eight individuals close to those at EoL.

This work significantly enhances the potential for including close-persons in economic evaluation of interventions at the end of life.

For Mum.

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List of Abbreviations

Best-worst scaling - BWS
Capability approach - CA
Cost-benefit analysis - CBA
Cost-consequence approach – CCA
Cost-effectiveness analysis – CEA
Cost-utility analysis – CUA
Compensating variation – CV
Department of Health – DoH
Discrete choice experiment - DCE
End of life care – EoLC
End of life – EoL
Equivalent variation - EV
Health related quality of life – HRQL
ICECAP-A – ICEpop CAPability measure for Adults
ICECAP-O - ICEpop CAPability measure for Older people
ICECAP-SCM - ICEpop CAPability Supportive Care Measure
Inclusion of the other in the self-scale – IOS Scale
Kaldor-Hicks criterion – KHC
Liverpool Care Pathway - LCP
National Health Service - NHS
National Institute for Health and Care Excellence – NICE
Office for National Statistics – ONS
Palliative care unit – PCU
Personal acquaintance measure - PAM
Potential Pareto improvement - PPI
Quality adjusted life year – QALY
Standard gamble - SG
Time trade off – TTO
Visual analogue scale – VAS
Virtual Tie-Strength Scale – VTS-Scale
Willingness to accept - WTA
Willingness to pay - WTP

Introduction

This thesis reports the development of a measure to capture the experience of those close to the dying for use in the economic evaluation of end of life care. The empirical work develops and values a measure within the capability framework to capture the impacts of end of life care to close-persons. Furthermore, the evaluative scope is explored to determine how many individuals could enter the economic evaluation should close-persons be included.

Chapter one provides the context for the thesis. This chapter outlines the terminology that is used within the thesis. Furthermore, it explores the impacts of bereavement on those close to the dying. Aspects of end of life care that are important are discussed, and end of life care in practice within the UK is outlined. End of life and bereavement are found to have significant impacts on people close to those at the end of life and thus is something that should be taken into account when assessing end of life care interventions.

Chapter two discusses the theoretical frameworks that underpin economic evaluation. The chapter explains how welfare economics, despite its strong theoretical traditions, has received much criticism in its application to health. For pragmatic reasons, the extra-welfarist approach with health as maximand, has become the incumbent method for conducting economic evaluation in the UK. This chapter argues for a broader application of the capability approach, allowing things other than health into the evaluative space. Given its theoretical superiority compared to simply focusing on levels of functioning, this chapter argues for the adoption of the capability approach as the basis for the development of the close-person measure.

Whilst chapter two was concerned with the theoretical underpinnings of economic evaluation, chapter three is focussed on the more practical aspects of economic evaluation, i.e. what is done in practice, and current issues with the way end of life care is currently evaluated. Arguments are made within this chapter for broadening the evaluative scope to include close-persons within economic evaluation and to broaden the evaluative space to include impacts beyond solely health gains. The literature was reviewed and no directly relevant measures exist for the purpose of this research, justifying the approach of developing a new close-person measure.

Chapter four has two key parts; the first describes the methodology and methods used for the development of the close-person measure. The first part of the chapter justifies the qualitative approach that is used for the development of the measure, and outlines the methods used. The second part of the chapter describes the methodology and methods of the aspect of the study concerning the evaluative scope. Pictorial methods for ascertaining close-person networks are discussed and the hierarchical mapping exercise approach chosen as the optimal method for examining the networks surrounding the decedent is described.

Chapter five is concerned with the methodology and methods for the valuation process. Different methods of valuing measures are discussed. This chapter justifies the use of an aspect of deliberation in the valuation process which is more in line with the capability approach than typical methods of valuation used in health economics. The chapter then describes the deliberative methods that were used to value the close-person measure. These involved the use of a budget pie task in combination with rating scales.

Chapter six reports the results related to the development of the close-person measure. The chapter reports that twenty seven interviews were conducted with those who were bereaved or had somebody close to them receiving end of life care. The wording of the attributes and descriptors were altered and updated iteratively in response to emerging data. The final measure contains six attributes with five levels for each attribute, the attributes are: *communication with those providing care services, practical support, privacy and space, emotional support, preparing and coping,* and *emotional distress.*

Chapter seven focusses on research relating to the evaluative scope and how many people in patient’s close network could be included in the economic evaluation of interventions. The chapter reports on the aspects of ‘closeness’ as derived from the qualitative analysis. The chapter then examines the networks of the decedents and suggests possible influences on closeness and network size at the end of life. Furthermore, characteristics of close-persons are examined, including in terms of whether they are limited solely to family members, or those who are geographically close. The findings of this chapter have significance in terms of identifying possible issues with the inclusion of close-persons within economic evaluation.

Chapter eight outlines the results of the deliberative valuation exercise. Weights are derived for the attributes and levels. The results are further examined on a focus group by focus group basis. Subgroup analysis is also used to examine whether different characteristics lead to different weights given to the attributes. An important aspect of the valuation process was the deliberative component. The impact of discussion on the values is therefore explored within this chapter.

Chapter nine summarises and discusses the main findings for the development and valuation of the close person measure, and the networks of those at end of life. The findings are compared to similar areas of research within the literature and the original contributions of this research are outlined. There are a number of strengths and limitations to this research, and chapter nine explores and discusses these. Practical and ethical considerations of including the close-person measure within economic evaluation are discussed along with potential avenues for future research.

CHAPTER 1: THE INFLUENCE OF END OF LIFE ON CLOSE-PERSONS

"How people die remains in the memory of those who live on"

Dame Cicely Saunders [1]

1.1. Defining end of life

1.1.1. End of life and death

As Benjamin Franklin reportedly said, "The only two certainties in life are death and taxes" [2], this thesis, in examining the impact of end of life care on relatives will touch upon both these certainties. It starts with the fundamentals of end of life care and its impact on those close to the dying; it then takes us through the development of a measure to capture the benefits of end of life care to those close to the dying for use in resource allocation to ensure taxpayers' money is used efficiently.

To begin, it is important that basic concepts are discussed to alleviate ambiguity in the terminology used throughout this thesis. The terms end of life (EoL) and end of life care (EoLC) are often used with disregard to their definition; in academic as well as clinical circles, there is very little consensus as to what exactly EoL is. This is understandable given the ambiguity of when the EoL process begins. The rationale of this chapter is threefold. For the purpose of this thesis, it will firstly clarify the definitions of EoL and EoLC. It will then examine the impact of quality of death on the bereaved and demonstrate that 'quality of death' significantly impacts on the well-being of family and loved ones. Given this, the third aim of this chapter is demonstrate that EoLC via its effect on quality of death and care to the family in the dying process and bereavement period can impact upon the wellbeing and experience of the decedent's family and loved ones.

1.1.2. Dying, death, dead and decedents

For clarity, it is important to discuss the differentiation between dying, death and dead with regards to EoLC. Dying refers to the last stage of life which inevitably leads to death [3]. Whilst dying is universally a process, death is used in the literature [4] to describe both the process of dying, and also to describe the event which reflects the transition from being alive to being dead. For the purpose of this thesis, death will be used to describe the latter. Dead less ambiguously refers to the state that follows death which is reflected by the absence of life. ‘Decedents’ is a term often used within the US legal system to denote someone who is dead [5], this thesis will however draw upon its literal translation from Latin which is ‘one who is dying’ to refer to individuals in the dying process or have recently died. The process of dying is varied and each decedent follows a unique path to their death, this path is known as a death trajectory [6].

1.1.3. Death trajectories

Death trajectories as put forward by Glaser and Strauss [6] can fit into one of three broad categories: abrupt/surprise deaths, expected deaths and entry-re-entry deaths. Recent research [7] has built on this seminal work by describing four theoretical death trajectories: sudden death, terminal illness, organ failure and frailty [7]. These death trajectories can be used to broadly describe the experiences of decedents on their path to death. Based on the care that patients and carers receive at the EoL phase, death trajectories have been further classified as ‘*spectacular’* and ‘*subtacular’* [8]. The spectacular death is often sudden and traumatic, and results in high levels of attention from healthcare professionals, unlike the subtacular which is characterised by a slow dying process [8]. EoLC is concerned with care both during the dying process but also with the moment of death and the post death period. In other words, EoLC can be used to improve dying, death and the bereavement period and is therefore applicable regardless of the particular death trajectory.

1.2. The impact of death and dying on the bereaved

It is intuitive to think that the death of a family member or loved one has a negative impact on one's health and wellbeing; this has been repeatedly found to be the case within the literature with much literature identifying negative impacts as a result of bereavement to a loved one [9]–[21]. The impacts of bereavement on bereaved relatives have been shown to be robustly negative. Such is the impact of death on individuals, a number of studies [14], [21] identified the passing of an individual's spouse as the most stressful life event one can experience. The bereavement of a close family member has significant negative impacts to the wellbeing and health of the surviving family members. How long this impact lasts is still under debate with a number of studies suggesting different periods of adjustment; McCrea and Costa report it to take less than two years [17], Lehman *et al.* [15] suggest four years, whilst others suggest that emotional damage is permanent [19]. The seminal paper by Stroebe *et al*. [21] reviewing the health outcomes of bereavement offers the most complete overview of the health impacts of bereavement, in terms of mortality, physical health and psychological health.

1.2.1. Impact of bereavement on mortality

It is not uncommon to hear of people 'dying of a broken heart' whereby somebody dies shortly after a loved one; this is a manifestation of the increased mortality associated with bereavement. Indeed this has been supported by research, with Van den Berg *et al.* [22] finding that those who suffered conjugal (marital) bereavement lose an average of 12% of their residual life expectancy. This increased mortality due to bereavement has been termed 'the widower effect' [23]. The systematic review of Stroebe *et al*. [21] examined a number of studies exploring the impact of bereavement on mortality. The causes of increased risk were found to be varied, for example, psychological distress, increased alcohol consumption, and increased risk of suicide. The vast majority of studies included in the review that addressed this issue found that bereavement was associated with an increased risk of mortality. This was particularly the case in widowers and risks were at their greatest in the period shortly following bereavement [21], although some studies have found that the increased mortality risks can extend beyond the 6 month period [21].

1.2.2. Impact of bereavement on physical health

There is a body of evidence that bereavement can lead to increased physical health problems in the surviving individuals compared to control groups. Examples include increased likelihood of cardiovascular disease [24] and increased bodily pain in the bereaved [25]. The review by Stroebe *et al*. [21] confirms these findings, with a number of studies included within the review finding poorer physical health in the bereavement period. These findings are replicated in recent studies, Song *et al.* [26] found that bereaved parents had significantly worse health related quality of life (HRQL) than non-bereaved parents as measured by the Health Utilities Index. Similarly a further study by Song [27] found that bereaved family members of patients with terminal cancer had lower HRQL as assessed with the EQ-5D than the general population, particularly in terms of 'self-care' and 'usual activities'. This phenomena is however not consistent across all studies, Rebollo *et al.* [19] using the SF-36 found that the bereaved carer's physical functioning was better than they expected.

1.2.3. Impact of bereavement on mental health

Bereavement has been associated with a host of mental health and psychological problems [21]. Mental health issues associated with bereavement include amongst others, grief and depression, anxiety, social-seclusion, insomnia and suicidal tendencies [21]. The nature and scale of mental health issues is highly heterogeneous amongst the bereaved; for some, mental health problems are resolved quickly whilst for others they can be long lasting. It is clear from the extensive evidence in the literature, that mental health is negatively impacted by the death of a loved one [16], [27]–[29].

1.2.4. Impact of bereavement on life satisfaction and well-being

A number of studies in the wellbeing literature have also shown that bereavement leads to large short term negative impacts in life satisfaction for the bereaved, as well as severe mental strain [13]. Indeed, the bereaved are left less happy than those who never married [11]. The negative impact of a child's death on their parents has also been investigated [10], [16]. The impact of the death of a child on the parent, in particular for mothers, was found to be especially severe. Following the loss of a child, parents were significantly more at risk of psychiatric hospitalisation and reduced mental wellbeing, again particularly for mothers [16], [18]. Furthermore it has been found that the death of a child significantly negatively affects the marital wellbeing of the parents [10]. Other factors that have been found to affect the degree of distress a bereaved individual experiences include gender, age of the bereaved, and relationship to the relative.

Blanchflower and Oswald [30] investigated, using longitudinal data, the determinants of wellbeing in the UK and the US. One of the most significant findings in the paper was just how influential non-financial variables are in determining wellbeing. Of particular interest to this thesis, the second main depressant of reported happiness was the variable 'widowed'. Oswald and Powdthavee [18] further explored this issue in a legal context to examine the hedonic damages required to compensate for the distress caused by bereavement, i.e. the amount of compensation required to return a person's utility to the level before being bereaved. Although largely exploratory in terms of methodology, for illustrative purposes they calculated the compensation required to return the bereaved back to their pre-bereavement wellbeing. To illustrate the impact of the distress caused by bereavement, to compensate somebody for the loss of their partner, it was estimated that a person would need to be given between £114,000 and £202,000 in the first year after bereavement to return them to their pre-bereavement wellbeing level. As individuals adapt to their loss [11], [13], [31] the level of compensation required reduces each year.

1.3. Defining a good death

To understand how EoLC may benefit relatives, it is necessary to first explore the different natures of deaths, and in particular, what constitutes a ‘good death’. It is reasonable to assume that if the quality of death differs, then there will be differing impacts on those close to the person who has died. One of the primary purposes of EoLC is to improve the quality of death of decedents. Quality of death is variable, with a plethora of measures having been developed to try to assess the quality of death [32]. To understand how quality of death may vary, it is first important to define what would constitute a ‘good death’.

Throughout the 1990’s, a ‘good death’ and ‘euthanasia’ were often used interchangeably [4]. Since then, the two terms have developed into distinct concepts. The concept of a ‘good death’ has also evolved over the years, but one particular definition however has risen to the fore [4]. Here, a ‘good death’ is defined as:

> *“A decent or good death is one that is: free from avoidable distress and suffering for patients, families , and caregivers; in general accord with patients’ and families’ wishes; and reasonably consistent with clinical cultural and ethical standards”* (p.24) [33].

This definition of a ‘good death’ is vague, and may be less than helpful for clinicians and commissioners when devising strategies for improving quality of death [4], [34]. The definition, similar to that of EoL, however is broad enough to encapsulate the issues involved in providing quality EoLC. Like EoLC, a good death may vary from individual to individual. This ambiguity in terms of what is a good death was confirmed by two studies [4], [34] which analysed the use of the term ‘a good death’. It was found that of the studies examining ‘a good death’, there was strong agreement in the literature that individuals are heterogeneous and so the definition of a good death depends upon the individual questioned. Furthermore, individuals tend to have dynamic preferences over time for what constitutes a good death, i.e. what people may think is a good death earlier in life does not always accord with how they feel when they are older. Although the definitions of a good death vary in the literature, there was a consensus as to 12 elements that the literature deemed to be important for a person to have a good death. The 12 attributes were:

> *"being in control, being comfortable, sense of closure, affirmation/value of the dying person recognised, trust in care providers, recognition of impending death, beliefs and values honoured, burden minimised, relationships optimised, appropriateness of death, and leaving a legacy and family care."* (p.284) [4].

It is unsurprising to find that there is a considerable overlap between these attributes and those that are of importance in EoLC (see 1.6). Given the unique views of each individual, it is important that EoLC is flexible to incorporate individual's EoL preferences into the EoL pathway to help meet that individual's expectations of a good death.

1.4. Defining end of life care (EoLC)

1.4.1 What is EoLC?

Intuitively, EoLC would appear straight forward, and if you were to stop somebody in the street and ask them, 'what is end of life care?' most would probably be able to provide you with some sort of description. If you pressed them further for more information on EoLC, e.g. in terms of when it would start/end and what is involved, it is likely that the information given would be inconsistent among individuals. This is because EoLC is notoriously difficult to define and there is very little consensus on the 'optimal' definition of EoLC. In fact, it may be the case that there is no such thing as an optimal definition, and the definition may rightly vary by perspective. Palliative care, terminal care and supportive care have long since been used to describe care towards the EoL with EoLC being used as a synonym for one or the other. Over the last 15 years however, EoLC has come to the fore as a distinctive type of care [35].

O'Connor [35] performed a literature review for the UK's National Health Service (NHS) End of Life Care Programme to explore and summarise the different definitions of EoLC being used within academic literature. O'Connor [35] found a plethora of definitions of EoLC; these definitions largely depended on the research area with definitions varying substantially. For example Cherny *et al.* [36] from an oncology standpoint define EoLC as:

> *'…palliative care when death is imminent'* (p.1335) [36].

In contrast, Shipman *et al.* [37] define EoLC from a generalist standpoint as:

> *'…care provided by health or social care professionals other than those whose remit was specialist palliative care. We proposed that 'end of life care' encompassed care provided within the last year(s) of life to anyone with an advanced progressive disease that was likely to shorten their life'* (p.3) [37].

O'Connor [35] found many definitions in the literature with eight primary definitions being used depending on the research focus. There is a clear dearth of consensus between these different definitions. Despite O'Connor's literature review being targeted for the NHS EoLC programme, O'Connor incidentally overlooked the definition of EoLC that is now utilised by the Department of Health. Given the UK-centric focus of this thesis and the broad EoL settings and perspectives that it is applicable to, the definition of EoLC must be both suitably broad, and applicable within the UK's health care setting. One such definition is the definition utilised in the Department of Health's (DoH) [38] EoLC strategy document taken from The National Council for Palliative Care's [39] 'Commissioning end of life care' report which states that EoLC:

> *'Helps all those with advanced, progressive, incurable illness to live as well as possible until they die. It enables the supportive and palliative care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support.'* (p.4) [38]

The definition recognises the importance of family needs in regards to end of life care as well as the needs of the person with advanced illness. It is the preferred definition of the DoH and therefore most pertinent to this study focusing on close-persons within the UK.

1.4.2. When does EoLC begin?

There is no obvious way to define the start of ‘the end of life’, and many different methods for identifying the EoL period have been utilised within the literature. Lorenz *et al.* [40] investigated the scope for ‘end of life’ in respect to EoLC and found six different methods for defining ‘end of life’ as used within the literature. As with the definition of EoLC, there is great variation in how the EoL period is defined. Below are the six methods that Lorenz *et al.* [40] identified as the main methods of defining ‘end of life’.

1. End of life as ‘active dying’
2. End of life as ‘patient readiness’
3. Defining end of life by ‘severity of illness’
4. Defining end of life by ‘prognosis’
5. Defining end of life via ‘multivariable prognostic models’
6. End of life as reported by ‘clinical judgment’

Despite the variety of methods used in the literature, none have had substantial validation [40]. Given the wide range of death trajectories, it is unsurprising that none of the above definitions works for all patients. It is perhaps appropriate that the definition of EoL varies with the individual it is being attributed to. This appears to be the thinking of the Department of Health [38] in the UK; in line with their definition of ‘end of life care’; they use a broader and more comprehensive definition to describe the beginning of ‘end of life care’:

> *‘The definition of the beginning of end of life care is variable according to the individual person and professional perspectives. In some cases it may be the person who first recognises its beginning. In other cases the principal factor may be the judgment of the health/social care professional/team responsible for the care of the person…For some it may be at the time of diagnosis…for others it will be at a point where there is a deterioration in a chronic illness…Alternatively…it could be an elderly person who is becoming increasingly frail and recognises that they need increased help...’* (p.47) [38].

There is no obvious ‘correct’ way to define the start of the EoLC process, those suggestions as identified are perhaps too specific, whereas the definition used by the Department of Health [38] despite being somewhat lengthy is suitably broad enough to encapsulate a breadth of different health care scenarios.

1.5. The prevalence of EoLC

1.5.1 The ageing population

With the improvement of medical technologies and rising global gross domestic product, humans are living longer than ever before. In the UK this is reflected by life expectancy of a new born baby in the UK being at the highest level since records began [41]. According to the Office of National Statistics [41] (ONS) a new born boy in the UK can expect to live for 78.1 years, whilst a new born girl can expect to live for 82.1 years. As a result, the UK’s population has seen a consistent rise in terms of number, and in terms of the age of the population [41]. In the years between 1985 and 2010, the UK saw an increase in the number of those aged 65 or above increase by over 20% to 10.3 million, whilst the number of those over 85 years old rose by more than double to over 1.4 million individuals. Simultaneously there has been a fall in the proportion of young people with those under 16 years old now just making up just 19% of the population. As a consequence of this rise, in 2010, over 17% of the population were 65 years or older [42]. This increasing ageing of our population is expected to continue over the coming decades, with over 85 year olds predicted to account for over 5% of the population by 2035, with a concurrent decrease in the proportion (a decrease from 65% to 59%) of those aged between 16 to 64 years old [42].

1.5.2 The rising demand for EoLC

As the population continues to age and the proportion of those aged 65 years and above increases, there will be an increase in the demand for EoLC [43]. Despite an ageing population, due to medical advancements the number of deaths in the UK fell by 8% between the years 1974 and 2004. This trend however is expected to cease, and then be followed by a consistent increase in deaths per year [43]. In 2010 455,000 people died; of these, 66% were 75 years or older [44]. The number of deaths in England and Wales is expected to rise by a staggering 16.5% between 2012 and 2030 with 86.7% of deaths occurring in those aged 65 years and over, whilst individuals aged 85 years or above will account for over 43% of deaths [43]. Until recently, EoLC had received comparatively little attention; this because health interventions were typically focussed on preventing illness and premature deaths [45]. As a result of medical advancements, the disease burden has shifted away from infectious diseases towards chronic diseases [45] with an increasing proportion of individuals dying from conditions for which death is foreseeable in advance. Medical developments have been increasingly successful and life expectancy has continued to increase, the number who die will in turn increase. As a result there has been an increased recognition that more attention needs to be paid to this area of health care, not least due to the financial burden of EoLC.

1.5.3. EoLC in global terms

EoLC is not just a growing problem within the UK but is an increasing issue worldwide. Globally in 2002 an estimated 56 million people died worldwide [46]. The nature of deaths tends to differ between high income countries and low income countries. In high income countries 70% of deaths are in those aged over 70 years. In contrast 40% of those who die in low income countries are under the age of 15 years, whilst only 20% are over the age of 70 years. Likewise the typical causes of death differ between high and low income countries. Predominately within high income countries, the majority of deaths are due to chronic disease, e.g. diabetes, cancers, heart disease. In contrast, in low income countries the predominant causes of death are related to infectious diseases e.g. malaria, HIV/AIDS, diarrhoea [46], [47]. It is therefore likely that the EoLC issues vary depending on the country. This thesis is set within the context of the UK, and so the remainder of the thesis focusses on the EoLC issues relevant to the UK.

1.6. What is good EoLC?

1.6.1 What factors are considered important in EoLC?

There is clearly an increasing need and scope for EoLC. EoLC itself is a multifaceted and complex intervention. To understand what EoLC involves, a number of studies have examined the factors that are considered important at the EoL in respect to EoLC [33], [34], [48]–[50].

There have been a number of taxonomies of quality EoLC and what quality EoLC involves. Heyland *et al.* [49] provided the most complete list of components of care that quality EoLC should incorporate based on the academic literature as well as empirical qualitative research. They also sought to identify which of these elements were the most important component of quality EoLC. These elements were initially identified within the literature and then more were added based on a further literature review and discussions with an End of Life Research Working Group. Further to this, 12 interviews with 'eligible' seriously ill patients in hospital were then conducted to identify any elements they may have overlooked. Through their taxonomy, they identified 28 elements of EoLC*;* these 28 elements can be split roughly into five different dimensions of EoLC. These domains and examples of components are shown in the table below [49]:

Table 1: Domains identified as being important elements of end of life care

Domains	Example Elements identified as important in EoLC
Medical and nursing care	*- To have trust and confidence in the doctors looking after you* *- Not to be kept alive on life support when there is little hope for a meaningful recovery.* *- To have the relief of symptoms*

Communication and decision making	*- To receive help to make difficult treatment decisions.* *– Information about your disease is communicated to you by your doctor in an honest manner.* *– That your doctor is available to discuss your illness and answer your questions in a way that you understand.*
Social relationships and support	*- To not be a physical or emotional burden on your family* *- To be able to contribute to others.* *- To have an opportunity to strengthen or maintain relationships with people who are important to you*
Meaningful existence	*- To complete things and prepare for life's end (life review, resolving conflicts)*
Advance planning of care	*- Upon discharge from hospital, to have an adequate plan of care and health services available to look after you at home.*

Adapted and developed from information in [49] (p.3-5)

To establish which of the 28 elements were the most (and least) important, the elements were rated in terms of importance by the patients and relatives of the decedents in the study. The study found that three elements were more commonly scored as 'extremely important' than any other attributes in the list. The attributes that were cited as being most important were: *'to have trust and confidence in the doctors looking after you', 'not to be kept alive on life support when there is little hope for a meaningful recovery' and 'that information about your disease be communicated with you by your doctor in an honest manner* [49]. Interestingly the study also explored which factors of EoLC were the least important relative to the others investigated in the study. The three interventions that were rated as the least important were, *'to have the same nurses looking after you', 'to receive help making difficult treatment decisions' and 'to be able to contribute to others'* [49]. It should however be noted that this does not mean these attributes are not important, just less important than the others. It should be borne in mind that EoLC patients are not a homogenous group, deaths and preferences are largely unique, and there is no one rule that fits all. Good EoLC ideally should be flexible and account for different preferences and different trajectories. This work is however useful to give us an idea as to what attributes in EoLC are valued by those in the EoL process; bringing this back to a UK perspective, these attributes are to some extent reflected by National Audit Office's description of high quality EoLC:

> "*Good end of life care includes treating people as individuals, with dignity and respect; ensuring that their pain and other symptoms are well controlled; in familiar surroundings and in the company of close family and friends. In addition to meeting the needs of the patient, good quality end of life care should also take into account the needs of carers."* (p.16) [51]

The definition does however seem to omit the importance of communication as discussed by Heyland *et al.* [49].

1.6.2. Current issues with EoLC in the UK

Now it is known which elements of EoLC are most important to the dying, it is necessary to examine some of the current issues with EoLC in the UK. Although the purpose of this thesis is not to 'improve' EoLC, it is however appropriate to have some awareness of the state of care in the UK, and to have a brief understanding of current issues highlighted in recent reports. Of late, as reflected by the Department of Health's [38] End of Life Strategy document EoLC is becoming an increasing priority within the health and social care settings.

The Healthcare Commission [52] investigated issues with the provision of EoLC and found that there were a number of shortcomings. There is evidence of lack of basic comfort, support and privacy for the patient and the family, as well as a deficiency in supporting patient's cultural, psychological and religious needs. The Healthcare Commission [52] also reported that there were still issues in the communication of EoLC between doctors and patient with the discussion of moving from 'cure' to 'care' not being adequately addressed. This breakdown in communication often results in painful life extending interventions, leading to late referrals to palliative care teams, which in turn produces a diminished quality of life at EoL for patients. Similarly the National Audit Office [51] found EoL services were not being adequately implemented leading to those approaching the EoL being unnecessarily admitted to hospital. Furthermore those at the EoL were found frequently to not receive the dignity and respect that should be expected in EoLC; the quality of EoLC provision was lower than patients expected, with a failure to draw up care plans for those entering the EoL process. For example, in one primary care trust (PCT) it was recorded that 40% of those who died in hospitals did not need to be treated within the hospital [51].

1.7. EoLC pathways

1.7.1. EoLC pathways in the UK - improving quality of death?

The EoLC strategy [38] initiated a series of programmes and strategies to promote high quality care for all using a pathway framework to improve the care of patients and their relatives. To formalise the EoLC process, care pathways have been utilised to aid decision making in EoLC. The Department of Health [53] previously recommended that all hospitals should have the Liverpool Care Pathway (LCP) or an equivalent in place to help optimise EoLC. Care pathways are not end-of life documents, nor tools. Instead they are as defined as:

> ‘*a complex intervention for the mutual decision making and organisation of predictable care for a well-defined group of patients during a well-defined period…’* (p.1) [54].

Characteristics include:

> *‘…an explicit statement of the goals and key elements of care based on evidence, best practice, and patient expectations; the facilitations of the communication and coordination or roles, and sequencing the activities of the multidisciplinary care team, patients and their relatives; the documentation, monitoring, and evaluation of variances and outcomes; and the identification of relevant resources’* (p.1) [54].

The LCP for dying patients was perhaps the most pioneering of EoL pathways. This pathway was advocated by the Department of Health [53] and was designed to incorporate the lessons learned within successful hospice care into a more general health care setting [55]. The LCP as defined by Ellershaw *et al.* is:

> *'…an integrated care pathway that supports clinicians in making important decisions about care for the dying. Importantly, use of the document is reinforced through continuous education and training for doctors, nurses and other health professionals'* (p.1) [55].

It is from this pathway that many EoLC pathways have since been adapted. The purpose of these EoL pathways is to take the dying individual on an 'ideal' journey through the EoL period [56].

1.7.2. The NHS EoLC programme

The NHS End of Life Care Programme utilises the EoLC pathway as outlined by the Department of Health [38]. It identified 6 steps in the EoLC pathway to ensure that optimal care is given towards the EoL which have been recommended to help improve health care professionals caring for the dying and bereaved. These steps are:

Step 1. Discussion as the end of life approaches

Step 2. Assessment, care planning and review

Step 3. Co-ordination of care for individual patients

Step 4. Delivery of high quality services in different settings

Step 5. Care in the last days of life

Step 6. Care after death.

The death trajectory of the person impacts upon the step of the EoLC pathway that a decedent starts on. For example, a foreseeable death would start at step one, whereas a sudden death may start at step 6. Alongside the 6 steps, the Department of Health recommends that supportive and spiritual care, in conjunction with information, should be provided to all patients and families [38]. The EoLC pathway is designed to enable flexible care giving, to tailor the care to the preferences of the patient approaching end of life.

1.7.3. Do end of life pathways improve quality of death?

Chan and Webster [57] conducted a Cochrane review assessing the evidence for the efficacy of EoL pathways. To be eligible for the review the studies had to be one of the following: randomly controlled trial; quasi-experimental study; or controlled before or after study. However, as there were no studies of these types, the review concluded that recommendations for the use of EoLC pathways in caring were inappropriate due to the lack of an evidence base. Watts [56] however posits that given the extremely complex intervention that EoLC represents, a systematic review using such criteria giving weight only to controlled studies is perhaps inappropriate and the qualitative literature may well be a more suitable avenue for examining whether EoLC pathways are successful. There have been a number of qualitative studies that have investigated the effectiveness of EoLC pathways, in particular the LCP.

Evidence in the qualitative literature suggests that EoLC pathways can lead to an improvement in EoLC [55]. Qualitative studies [58]–[63] found positive impacts for EoLC pathways in terms of treatment of those at end of life. The qualitative literature suggests that EoLC pathways can improve EoLC in a number of ways. Firstly, the confidence of the nurses and doctors in delivering EoLC to patients who are approaching death [58], [63] has been shown to improve as a result of the LCP. Furthermore, the streamlined documentation that accompanied the LCP was found to be time saving, freeing up time for other care. Veerbeek *et al.* [62] investigated the perceived level of care by relatives of families on the LCP compared to those who were not on the pathway. The study found that those who were cared for on the LCP received better quality care compared to those who were not on the LCP as perceived by the relatives of the patient.

The 2009 national audit into the care of the dying [64] found that with the introduction of the LCP, high levels of patient care were possible, particularly in terms of patient comfort. It found that for 90% of patients, pain management medication was prescribed prior to the event which would cause pain symptoms; similarly, 92% of patients had their medications reviewed with non-essential medications being removed. Consequently, the vast majority of patients' four hourly assessments in the last 24 hours of their lives reported the patient as being 'comfortable'. The audit found that although there had been improvements in communication with the relatives/carers in terms of communicating that the patient had entered the dying phase and discussing their planned care, there was still room for improvement. Given the importance of communication in EoLC [48], [49], this is an important area for future improvement. Looking specifically at EoLC for patients with dementia, the evaluation of the introduction of the Gold Standards Framework (GSF) and LCP for people with dementia in Greater Manchester reported several benefits. Similar to the 2009 audit [64], it found that staff felt the GSF/LCP gave staff the confidence and tools to relieve pain and discomfort appropriately. The report found those dementia patients that indicated a preferred place of care/death had their needs met indicating a successful application of the LCP. Economic benefits were also indicated with potential reduction of unnecessary and unscheduled admissions into the acute hospital setting. Furthermore, the report found that when open and honest discussions took place on sensitive EoLC issues between staff and carers/families, the experience of EoLC was improved for all parties [64].

As shown by Chan and Webster [57] there is currently a dearth of controlled studies examining the impact of EoLC pathways; given their implicitly complex nature this is unsurprising. On the other hand, there is a growing body of qualitative studies and audit reports that indicate that the introduction and development of EoLC pathways can have positive impacts on the EoLC of patients nearing the end of their lives. Although there is no single conceptualisation of a 'good death' with individuals having their own unique perspective, the evidence to date suggests the implementation of EoLC pathways can facilitate the move towards a 'good death' [56].

In 2013, the LCP came under increasing scrutiny following a spate of incidents where it was improperly implemented and this was picked up extensively within the media. An independent commission was launched to review how the LCP was being used within the UK, the report that resulted from this enquiry is known as the Neuberger Report [65]. The report found that there was much evidence that when used appropriately, patients died a peaceful and dignified death. The LCP in itself is clearly not a bad thing, and the issues of concern related to the LCP commonly being used as a tick box exercise, rather than as a set of alerts and guidelines for good practice as it was intended. In response to the LCP scrutiny, the NHS commissioned a review of complaints about EoLC by relatives of those who had recently died [66]. The complaints by relatives fell into six broad categories:

- Awareness of approaching end of life.
- Communication and being caring
- Symptom management
- The environment
- Concerns around clinical care
- Fundamental medical and nursing care

The review of the complaints called for the replacement of the LCP through 2014 by patient specific EoL plans supported by condition specific good practice guidance [66].

1.8. The influence of EoLC on family/loved ones

1.8.1. The influence of pre-death EoLC on family/loved ones

There is much literature examining the impact of death on family and loved ones, with death clearly having a negative impact on those close to the person who died. In terms of the effect of EoLC on those close to a decedent, there is a body of evidence emerging that indicates that good EoLC has a positive impact that benefits those close to the person who died.

Cameron and Parkes [67] were amongst the first to investigate the effects of EoLC on the family following bereavement. They aimed to evaluate the impact on the surviving family members of care services for EoL patients provided by a palliative care unit (PCU) compared to a matched group of surviving family members in different wards of the same hospital. There were clear benefits to be seen in the surviving relatives of PCU patients as they reported significantly fewer psychological symptoms and less grief that than those whose relatives died elsewhere. Notably, the control group, as well as exhibiting psychological symptoms and persistent grief, were more likely to show feelings of anger and irritability compared to the control group. The difference in those reporting feelings of anger/irritability in surviving relatives during the bereavement period between the PCU group and the control group was striking; just 1 in 20 PCU patients' relatives reported such feelings compared to 17 in 20 in the non-PCU patients' relatives. This study was one of the first to demonstrate that EoLC, specifically palliative care, can positively impact the lives of relatives after bereavement. Similarly, Ransford and Smith [68] found that relatives whose family member received hospice care reported to have significantly lower levels of depression in comparison to those whose relative died within hospital care.

Schulz *et al.* [69] investigated how dementia patients' deaths impacted upon their unpaid carer. The study found that the death of the patient led to a surge in depression levels. On the whole carers showed resilience by adapting to the death and returning to the same depression levels they had before the patient died. However, those carers whose relatives had been institutionalised did not show the same recovery from depressive symptoms. This suggests that the relief from providing daily care alone did not account for the carers' recovery from bereavement. EoLC aimed at avoiding unnecessary institutionalisation may therefore lead to a lower societal impact of death. Based on observational findings that those who die a ‘good death’ impose less stress on their family, Christakis and Iwashyna [70] posited that the nature of EoLC may be associated with the mortality risk of the surviving spouse. To test this theory, they hypothesised that when a decedent died within hospice care, their spouse would be less likely to fall ill and die during the bereavement period. Propensity score matching was used to match 30,838 couples where the decedent was using hospice care to 30,838 couples where the decedent was not using hospice care. The study found that widows whose husbands had died in a hospice care setting were statistically significantly (at the 0.05 level) less likely to die in the 18 months following their husbands death. Husbands whose wives died in a hospice setting were also less likely to die in the following 18 months than those who did not use a hospice; this however was not statistically significant. The authors believe the underlying mechanism by which reduction in mortality risk occurs is due to a reduction of stress on the bereaved spouse. This would suggest that EoLC, in this case hospice care, positively affects not just patients, but also the spouses of patients.

It is clear that EoLC can impact upon the quality of death of an individual, and this in turn impacts the wellbeing of family and loved ones. Importantly, quality EoLC should also include care for those close to the deceased in the period following bereavement; this theoretically should provide further benefits to the family of the individual who has just died. It is therefore important that these benefits are taken into account when assessing EoL interventions.

1.8.2. The Influence of EoLC post death on families/loved ones

Given that optimal EoLC should continue into the bereavement period, it is important to briefly examine whether post bereavement EoLC has positive impacts on the family members and loved ones of the deceased. Stroebe’s [21] review examined the literature on the efficacy of psychological bereavement interventions (medical interventions were ignored due to the lack of research of such interventions in the bereaved). Psychological bereavement interventions can be broadly classified into three preventative categories, primary interventions, secondary interventions and tertiary interventions. Primary interventions are those interventions that are open and available to all bereaved individuals regardless of whether they are requested. Secondary interventions are interventions that have been designed for the bereaved individuals who through screening have been designated as high risk (of negative health outcomes) individuals. Finally tertiary interventions are designed for individuals who are exhibiting symptoms of severe bereavement-related health disorders, for example depression or post traumatic disorders [21].

The evidence on the efficacy of psychological interventions varies according to the intervention and level of intervention e.g. primary versus tertiary. Twenty primary studies were identified in the Stroebe *et al.* [21] review. Of those conducted prior to 2001, most interventions were found not to be effective. In the four studies conducted post 2001, more positive results were found suggesting positive benefits of psychological interventions in the bereavement period, this was particularly the case for females and those with mental health issues prior to bereavement. Ten studies examining the efficacy of secondary interventions were examined in the review [21]. Secondary interventions were found to be more effective than primary interventions, although in some cases the benefits of the intervention were found to be modest and temporary. The evidence suggests that those who were suffering the most as a result of bereavement gained the most from interventions. Finally, nine studies examining the efficacy of tertiary interventions were examined. The evidence overwhelmingly found tertiary bereavement interventions to have positive and lasting effects on the negative health outcomes of bereavement e.g. anxiety, depression and stress disorders [21].

1.9. Conclusion

This chapter has introduced the terminology that will be used throughout this thesis and introduced the concepts of EoL and EoLC. There is much evidence regarding the negative impact of EoL on those close to the dying. The death of a family member/loved one can have a significant impact in terms of health and wellbeing for the families and loved ones of the decedent. Furthermore it is clear from the literature that EoLC both directly to the decedent before death and to the bereaved after death can lead to improved outcomes. There is however, a lack of agreed outcome for assessing the impact of bereavement on those close to the dying, and a range of methods have been used. It is clear that there are important benefits from EoLC received by those close to the dying that are above and beyond those received by the decedent. Given the increasing demand for EoLC as the population ages there will need to be decisions made about how best to spend the money allocated to EoLC. To achieve this, in addition to measuring and valuing benefits of EoLC to the decedents, it will also be important to determine and how best to capture the impacts of EoLC on those close to the dying. The question of how economists make such decisions and the various frameworks that they can use in their analysis is the area to which this thesis now turns.

CHAPTER 2: WELFARISM, EXTRA-WELFARISM AND THE CAPABILITY APPROACH IN HEALTHCARE

With the continual advances and development in health related technologies and the consequent rise in lifespan there is a progressive increase in demand for healthcare as the population ages. In an ideal world with unlimited resources all demand for care could be met. Unfortunately, resources are not unlimited; in fact, they are scarce and highly demanded. As a result important decisions have to be made to determine how best to use the limited resources available. To comprehend how such decisions are made in practice, it is important to understand the theoretical basis for how decisions are made. The theoretical economic frameworks that underpin these resource allocation decisions will be outlined within this chapter. The chapter will also include the shift towards the notion of extra-welfarism and the recent resurgence of interest in the capability approach.

2.1. Normative analysis and the rise of extra-welfarism

2.1.1. Positive and normative economics

Positive economics is concerned with explanation and prediction. It uses objectively measurable economic variables of a given event [71], for example the impact of a change in interest rate on the consumer price index. This type of economics does not require any value judgements and tends to be used to examine economic phenomena and relationships. Positive economics is useful for analysing what is going on in the world [72]. Normative economics on the other hand refers to the branch of economics that utilises value judgements to examine what should be done [73], rather than, what is done. This provides a useful framework for examining how scarce resources should be used. Welfare economics utilises this normative branch of economics typically with an explicit ethical framework to examine the desirability of certain policies and interventions [74].

Normative economics provides an analytical framework to examine the costs and consequences of competing use of resources. The role of economists is to remain impartial to the different options available and present evidence on the relative merits of each competing use [75]. Although impartiality in presenting the evidence is sought, normative value judgements do have to be made. Normative judgements are made at every step of the analysis when deciding exactly how costs and consequences will be measured. The purpose of the following section is to outline the value judgements that underpin the principles used in economic evaluation.

2.1.2. Welfare economics and welfarism

The term ‘welfare economics’ can be defined as the ‘*systematic analysis of the social desirability of any set of arrangements, for example a state of the world or allocation of resources, solely in terms of the utility obtained by individuals”* (p.120) [75]. Welfare economics has a long tradition both within economics generally, and within health [76]. The primary purpose of welfare economics is to provide a framework using a set of value judgements to get to a set of states of the world between which the decision maker can then choose [75].

Neo-classical welfare economics is a long established stream of economics that is built upon explicit normative principles and contains four key tenets which characterise the welfare economics approach [77]:

1. The utility principle – individuals rationally seek to maximise their own welfare.
2. Individual sovereignty – individuals are the best and only judge of their utility function. Welfare economics has individualism as its fundamental principle. What this means is that when making decisions, the only person’s view that is important is the view of those

individuals who are affected. The impact of any decisions will therefore be based on how individuals see their utility impacted by these decisions, i.e. whether they see it making them better/worse/equally off. The implication of this tenet is that social welfare can be assessed by summing the individual utilities of the members of the society. Following from this, any judgements by external parties e.g. policy makers and health care professionals are irrelevant to the decision making process [75].

3. Consequentialism – utility is derived only from the outcomes of event/processes. This tenet is based in consumer choice theory whereby utility can only be obtained through the consumption of goods and services. This tenet does not allow for utility to be obtained through ‘process’, it is only focussed on the outcomes of the consumption. This can extend to altruism whereby utility is generated to a person as a result of another individual’s consumption which they care about.
4. Welfarism – the goodness of any given state can be assessed via the utility obtained by the individuals in that state. The purpose of welfare economics is to devise a set of rules which essentially allow the ordering of the states of the world [77].

These four tenets provide the basis for the neo-classical framework of welfare economics. Despite the jargon, the framework is very simple. Essentially when given a decision, individuals consume in a way that they judge will maximise their utility. The consequent state of the world can then be assessed via the utility of the individual(s) in this state. A challenge that arises out of this framework is presenting a basis for defending the aggregation of individual preferences. There will be situations where there are trade-offs of utility between different individuals. There is no objective way of handling these trade-offs. To resolve this issue the welfarist approach has adopted the Pareto principle as the fundamental rule for judgement in welfare economics [75].

2.1.3. The Pareto principle

As value judgements need to be made when assessing different states of the world, it is logical that the most preferable value judgement would be one that is the weakest; by weak it is meant that it is the least controversial value judgement [75]. The weakest of value judgements within welfare economics is known as the Pareto principle [78]. A Pareto improvement is a change that leads to somebody being better off without making anybody worse off and is therefore a useful criterion for assessing decisions around changes in the state of the world [75]. Pareto improvements can be split into two depending on the strength of the value judgement it requires. If a change in the state of the world leads to an increase in the utility of all parties then this is referred to as a weak Pareto improvement [79]. It is referred to as weak due to the weak value judgement required. The second type of Pareto improvement is known as a strong Pareto improvement. In this instance a change in the world leads to one party becoming better off whilst no other person is worse off [80]. This gives a framework for assessing whether a change in the state of the world is socially optimal. If a policy satisfies the Pareto principle then that policy ought to be introduced. This method of allocation requires few value judgements and is therefore uncontroversial. It is still classed as a value judgement given the resulting distribution of goods may have impacts upon equity (for example making the rich, richer). Thus, a Pareto improvement is not concerned with who is better off, nor is it concerned with the relative improvements to each side, but only that nobody is worse off [81]. Pareto optimality is reached when an increase in utility of one person can only come about as a result of a decrease in utility to another person [82].

The advantage of weak value judgements and limited informational requirements associated with the Pareto principle are also its key drawback. Using the Pareto principle, it is not possible to rank all the states of the world where somebody is made worse off as a result of somebody being made better off, and thus it is not possible to rate non-Pareto optimal points against Pareto optimal points.

Unfortunately, given the difficult nature of policy making, and the opportunity costs of allocating resources to one setting or another, successfully satisfying the Pareto criterion in reality is a rarity [83]. This is therefore an issue, and consequently the concept of 'potential Pareto improvements' (PPI) were devised to allow for situations where one person's utility increases and another decreases [84].

Potential Pareto improvement

The concept of PPI is based upon the work done by Kaldor [85] and Hicks [86] and is commonly referred to the Kaldor-Hicks criterion (KHC). The KHC stipulates that societal improvement occurs if a policy can improve one group so much so that they can fully compensate the group that was made worse off (returning them to their original utility) and still be better off themselves. The compensation does not need to be paid, the fact that it could be paid demonstrates that there has been a societal increase in welfare. Both Kaldor and Hicks sought to overcome this issue of where one individual's utility was increased at the expense of another by introducing the possibility to exchange money between the parties [75]. By adding the possibility of money exchange to the scenario, it allows the analysis of situations where some individuals are made worse off. Given this, welfare economics has generally adopted the KHC to establish whether or not a policy leads to an improved state of the world. This is known as a PPI. In welfare economics, if the KHC is satisfied then it is deemed that the change is an improvement for society. In this form of economics, non-utility information is entirely irrelevant as is the identity of those who create or receive utility [72]. This is the basis of cost-benefit analyses in economics [84]; if the benefits outweigh the costs, then there is a net benefit, and the intervention is deemed to be welfare improving to society.

Given the impossibility of observing and comparing utility values between different individuals which is central to the welfarist approach; welfarism has adopted monetary units as a proxy for the utility of individuals. Welfarism in practice therefore relies on using monetary compensation to assess the impact of interventions. This draws directly on the work of Kaldor [85] and Hicks [86]. Hicks developed two different methods for assessing changes in utility through the medium of money, these are: compensating variation (CV) and equivalent variation (EV). CV uses an ex-post approach that seeks to determine the monetary compensation required to return an individual to their initial level of utility following a change in the state of the world. EV in contrast is an ex-ante approach which seeks to determine the amount of money that is anticipated to return an individual to their current level of utility following a change in the state of the world [75]. CV and EV can therefore be used as proxies for utility and represent monetary values which are both observable and comparable [75].

2.1.4. Criticisms of welfarism in regards to healthcare

2.1.4.1 Theoretical criticisms

The theoretical basis of welfare economics has suffered criticisms when related to the unique nature of health care [87]. In his seminal paper, Kenneth Arrow [76] outlined the unique nature of health care markets and the market failures that results from it. Consequently, the use of markets to determine the funding of healthcare is rarely seen. Given this, it is questionable whether a paradigm based upon consumer theory should be used to allocate resources in a non-market setting [75]. Thus, one of welfare economics purported strengths, that it is has strong theoretical foundations in microeconomic theory, may also be one of its weaknesses in the health care context given the rejection of markets within healthcare.

In terms of its theoretical grounding there have been arguments that the traditional welfare economics framework is too narrow for the purpose of health. This relates to the consequentialism tenet whereby utility is gained only through consumption [88] and the nature of welfarism where utility is of primary importance. The concern is that in the decision making context, things other than individual utility may be important in terms of allocating resources [75]. The tenets of welfare economics and the welfarist approach therefore limit the possibility of incorporating these other factors of importance. This criticism is compounded by the notion within welfare economics that individuals have utility as their maximand [89]. This does not allow for individuals to sacrifice the opportunity to maximise their own utility in order to contribute to a common good [90]. Furthermore as highlighted by Mooney [89], individuals cannot maximise their utility as they are inadequately informed to do so. The most significant problem with the welfarist approach therefore relates to the fundamental issue of having utility as the basis for capturing wellbeing as highlighted in Sen's critique of welfarism. Sen [91] set out two key arguments against utility as the maximand. He terms these two issues: condition neglect and valuation neglect. Condition neglect is based upon the ability of individuals to adapt to their condition and reassess their expectations accordingly. As a result, an individual may be in a poor state of health yet have a high level of utility as they have adapted to their condition [91]. Measuring health benefits in utility terms in this situation is therefore problematic. The second issue is valuation neglect. Valuation neglect refers to the fact that *"valuation is not the same thing as desiring, and the strength of desire is influenced by considerations of realism in one's circumstances"* (p.149) [92]. Individuals, due to their circumstances, may fail to desire adequately so that their assessment of their own utility is affected by their own characteristics as individuals.

2.1.4.2. Practical problems

There are a number of issues with using monetary units as a proxy for utility. First and foremost is the challenge stemming from the diminishing marginal utility from increased income. Economic theory states that as individuals become wealthier, the benefit provided by each extra unit of income diminishes. Consequently the richer you are, the smaller the benefit of each extra pound. In terms of using money as a proxy for utility this is therefore problematic as the willingness to pay (WTP) for changes in utility will be greater for the rich than the poor [75]. Similarly, greater compensation will be required for the rich to undergo a decrease in utility. Thus, ability to pay can impact upon the WTP for technologies [93]. As a result, it is necessary to adjust for the ability to pay to get a closer approximation of utility changes for different parties. This however is rarely done in practice and equal weight is usually given to people regardless of their income [75]. This issue is further compounded by the nature of health and people's inability to accurately state their WTP. WTP methods have been found to be under-sensitive to the magnitude of changes to the state of the world, both in terms of the quantity of change (scope effects) and also nesting effects involving a change embedded within a larger change [94]–[98]. A further limitation of the approach is that individuals place more weight on specific interventions they are asked about in contrast to those not mentioned [94]. If an individual is asked about a specific intervention in isolation they will state they are willing to pay more for it than when considered alongside a range of other interventions [94]. Out of these criticisms of welfarism a new school of thought emerged under the name of 'extra-welfarism'.

2.1.5 Extra-welfarism

In welfarism, individual utility is all important; however the past two decades in health economics have seen the rise of extra-welfarism and the opening of the evaluative space to non-utility information [74]. Extra-welfarism, by definition, implies that something is added to welfarism; extra-welfarism seeks to open up the evaluative space to include information other than individual utility for measuring benefits. Although there had been previous comments within the literature pertaining to the use of criteria other than utility, it was Amartya Sen [99] who shaped the future of economic evaluation through his robust critique of welfarism. Sen attacked the principal tenet of welfarism by recognising the limitations of using individual utility as the evaluative space [72] and the need to widen the evaluative space. Sen stressed the importance of the quality of utility as well as individual's capabilities (opposed to simply utility derived from goods), thus implying that the evaluative space should be widened to capture both functionings and capabilities. Furthermore he stressed the severe equity issues surrounding Pareto efficiency, thus further necessitating the broadening of the evaluative space [99]. Over the past two decades, extra-welfarism has gained momentum and continually evolved. It is now generally agreed, as outlined by Brouwer *et al.* [72], that extra-welfarism relaxes the assumptions of welfarism in four principal ways. Firstly, it allows outcomes other than utility to be included in the evaluation, for example it could include things such as health, social isolation and more [100]. Secondly, it allows the sources of valuation to be others than those affected. Thirdly, it permits outcomes to be weighted by means that are not necessarily preference-based. Finally extra-welfarism allows comparisons of wellbeing to be made among individuals [72].

2.1.6. Extra-welfarism as health maximisation – 'narrow' extra-welfarism

Despite the potential to broaden the evaluative space in extra-welfarism to include all sorts of outcomes, in practice it has very much become the norm for extra-welfarism to be interpreted as health maximisation [101], Coast [102] refers to this as a 'narrow' interpretation of extra-welfarism. Although principles of health maximisation can be tracked back to the late 1960s [101], narrow extra-welfarism in its current form can largely be attributed to the work of Culyer [100]. Culyer focussed on the one particular characteristic of healthcare that he felt was particularly pertinent, i.e. health. If there is a need for healthcare, it is due to a deprivation in health and healthcare is therefore needed to reduce this deprivation. Although Culyer may not have intended to replace utility solely with health, this has been the implication. Morris *et al.* [75] posit that health maximisation may have arisen as a "*pragmatic response to the methodological challenges in economic evaluation"* (p. 236), as the theoretical basis of extra-welfarism does not specifically justify health as the sole maximand. Instead this appears to have become the norm through practice rather than theoretical validity [75]. In many ways this approach falls into a theoretical void and has subsequently endured criticism [103].

2.2. The capability approach (CA)

2.2.1. Background to the capability approach

In recent years there has been renewed interest in a more complete application of the capability approach (CA) in health economics. The CA is based within development economics and was devised primarily through the work of Sen [90], [104], [105] and Dreze and Sen [106] on the analysis of famine and food shortages. Prior to the work of Sen, famines were generally attributed to a lack of food; Sen's work found that famines occurred in regions where there were not food shortages. Dreze and Sen's work explored this issue and built a model (known as the entitlement model) which demonstrated that rather than food shortages *per se* being the cause of famines, it was primarily social factors that inhibited the members of society from converting their assets, labour and wages into sufficient bundles of food [90], [104]–[106] which led to endemic famine [107]. The implications of this work were that social factors such as food exportation, the distribution of food across the population and hoarding were primarily the determinants of famine.

In the context of welfare economics, out of Dreze and Sen's famine analysis [106] an issue of great importance to the fundamental principles of welfare economics was raised. Sen's analysis highlighted the issues of focussing simply on either commodities or just utility. For the former, his analysis showed that concentrating on the commodities i.e. on the levels of food produced was fundamentally flawed as inadequate food production was not the primary cause of famines. Of particular interest to welfare economics was the finding that focussing solely on individual's assessment of wellbeing (or utility) was just as insufficient as focusing solely on the commodities. Sen found periods of famine and starvation are not reflected in the self-reported wellbeing of those 'suffering' the famine. His analysis found that individuals, and in particular women, reported very little impact on their wellbeing despite suffering starvation. Furthermore, Sen's analysis found that social factors such as lack of information and expectations of people could have significant impacts upon their values. These two points have profound implications for welfarism. That individuals were clearly disadvantaged (i.e. suffering starvation) yet that this did not show up in the assessment of utility, represents a major issue with the welfarist approach.

It was from this analysis of famine that the CA emerged. The term capability refers to the ability of an individual to be able to do or be something, Smith *et al.* [107] refer to this as the '*real practical possibility'* of a person being able to do a given thing. The capability of a person is impacted by the individual's initial endowments, the conditions around the individual (both social and material) and also the choices of the individual. The capabilities of an individual depend not only on the past capabilities of an individual but also on their past choices in pursuit of certain capabilities. By defining the capability of an individual as important Sen provides an important distinction from the norm which is a focus on functionings. Functionings refer to the things that people do or are, i.e. it is what the individual actually achieves, and contrast with capabilities which refer to what people are able do. Sen [108] eloquently highlights this using an example of two men, both whom share the same functioning level of nourishment. One is affluent and chooses to fast for religious regions, the other however lives in poverty and is forced to starve. Using a functioning based measure of nourishment the functioning levels are equal, however when using capabilities, it is clear they have very different capability sets: the impoverished man clearly is worse off than the affluent faster. Extra-welfarism as used in health economics has typically focussed on the functionings of individuals, in particular the functioning of health attributes. Functionings, as important as they may be, fail to capture the intrinsic value attached to having the choice to function.

2.2.2. Criticisms of the capability approach

Two key criticisms are often aimed at the capability approach. The first key argument relates to the difficulties associated with operationalising the approach [109], [110]. The CA suffers from being underspecified and has consequently been criticised in relation to its incompleteness and thus the difficulty of application. This is a known concern with the CA, with Sen purposely not specifying a specific set of capabilities. Sen instead suggests context specific capability sets [111] (as discussed in 2.2.3) in order for the CA to maintain its richness. Despite the difficulties of operationalising the approach, recent years have seen the successful development of the approach within the health economics context (see 3.5) suggesting that this challenge can be met. Second, there is an argument that the use of the CA may restrict individuals' freedoms as it involves society making judgments about what is best for people, which may conflict with what individuals themselves desire [110]. Consider the example of smoking to demonstrate this. For an individual who values and enjoys the act of smoking, if society deems that smoking should not be allowed in public, then the individual's freedom to live a good life will be limited [110]. The issue here is one of conflicting freedoms. The freedom for the individual to live a good life may conflict with another individual's freedom to live a good life (i.e. to be able to have a smoke free environment). Sen's writings suggest that, in such situations, it should be recognised that freedoms may conflict, and decisions about which freedoms are more important should be made using public reasoning in a democratic way [108], [110].

Despite criticism, the CA has seen much interest in recent years in terms of operationalising and using the approach in practice [112]. It is important therefore to consider what capabilities are important when developing a measure.

2.2.3. What capabilities are important?

Sen's work provided a strong rebuttal to standard welfare economics and with the development of the CA he opened a new avenue for assessing the state of the world. As useful a critique of welfarism as Sen's work is, he does not specify a set of capabilities which society should focus on with the suggestion that the identification of a suitable capability set should be left to deliberation and established through democratic processes. Nussbaum [113] however has sought to address this lack of specification by developing a set of 10 central human capabilities that she believes society should ensure all citizens have a sufficient level of. These capabilities are: ‘life/longevity’ – the ability to live to the end of a normal human life; ‘bodily health’ – being able to have good health; ‘bodily integrity’ – being able to move freely; ‘senses, imagination and thought’ – being able to use senses; imagination and thought; ‘emotions’ – being able to have attachments to things other than ourselves; ‘practical reason’ – being able to form the conception of good and critical reflection; ‘affiliation with others’ – being able to live with/toward others and show concern; ‘other species’ – being able to live with and have concern for other species and the world; ‘play’ – being able to play and enjoy; ‘control’ – being able to participate in politics and being able to have property [114]. Sen [111] argues against having a pre-determined list of capabilities and that the appropriate specification will be dependent on the context of their use and argues that a predetermined list reduces the richness of the CA.

2.2.4. Capabilities and health

Although Sen does not specify a list of capabilities, in his work he does however reference a health based capability, the capability to avoid premature mortality and morbidity [91]. In Nussbaum’s list of central human capabilities health also features prominently with the bodily health, bodily integrity and life/longevity. In addition to this, health can be seen as a capability conversion factor. If somebody is in poor health then it can limit the ability of individuals to convert their resources into capabilities [115]. Health capabilities are therefore clearly important however its use has been varied with it being conceptualised as functioning, capability and also as a conversion factor.

2.2.5. Beyond health gains in the EoLC context

The ‘narrow’ extra-welfarist perspective implicitly implies that the goal of care is to maximise health, this may be inappropriate for use in EoLC [102]. As can be seen by the definition of EoLC, this is not necessarily the purpose of EoLC. EoL as defined by the National Council for Palliative Care *‘Helps all those with advanced, progressive, incurable illness to live as well as possible until they die. It enables* *the supportive and palliative care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support.'* (p.4) [39]. Thus, it can be argued that EoLC should be evaluated within this context, i.e. with the goal of EoLC in mind. As a result, a 'broader' extra-welfarist framework which allows for other outcomes to be included might represent a superior method for evaluating EoL technologies. This would allow the focus of the economic evaluation to be relevant to the goals of EoLC, and using the CA, include facets where individual choice is intrinsically important. For example, EoLC could be evaluated in terms of the capabilities that allow the patient and close-persons to have a good experience of EoLC [102]. By focussing simply on the health of the patient, important aspects of EoLC may be omitted from economic evaluation. Likewise focussing solely on functionings may omit potentially important aspects of EoLC. Coast [102] uses the example of two individuals, the first living in an area where there is hospice provision, the second where there is no hospice. The first may choose not to use the hospice, whilst the second would have used the hospice had they had the choice. Using functionings both have the same level as neither use the hospice, however the CA would deem the second person to be worse off as they did not have the capability to have hospice care [102]. Thus there are issues with using the 'narrow' extra-welfarist health maximisation approach. A broader extra-welfarist approach using capabilities can therefore be argued to offer a superior method of evaluating EoLC [102].

2.3. Conclusion

This chapter has set out the theoretical frameworks that underpin the methods of economic evaluation in health care. Welfare economics with its strong theoretical traditions has been found to be inadequate within the health care context due to the unique nature of health, as ably demonstrated by Sen's critique. The extra-welfarist approach with health as maximand, for pragmatic reasons, has become the incumbent method for conducting economic evaluation but only represents a partial application of the CA. The CA allows for things instead of utility and health to enter into the evaluative space. Given its theoretical superiority compared to simply focusing on functionings, it is within this theoretical framework that the close-person measure will be created. There are, however, questions about what forms of analysis and what measures might be used in such approaches, and chapter three moves on to consider these issues.

CHAPTER 3: ECONOMIC EVALUATION IN HEALTH CARE AND EOLC

3.1. Introduction

Chapter two introduced the theoretical frameworks that underpin the perspectives often taken within economic evaluation and the renewed interest with using the CA within economic evaluation. The purpose of this chapter is to discuss the importance of economic evaluation, and to examine how in practice economic evaluation is conducted within the UK, and potential issues with the current methodology used in relation to EoLC. Normative arguments are put forward for the inclusion of close-persons within the economic evaluation of EoLC. To finish, the literature is reviewed to examine whether there are any measures that could be used to achieve the goal of this thesis.

3.1.1. Priority setting and efficiency

Economics is inherently concerned with the optimal use of scarce resources [116]. Given a limited budget and competing alternatives, it is important that resources are used in an optimal manner. To inform decision makers, the economic analysis of the costs and benefits of competing options is used to aid decision makers in regards to how to allocate scarce resources optimally [87]. Efficiency is a key concept which aids decision makers in how to best allocate resources [117]. There are two key types of efficiency: technical efficiency and allocative efficiency. Technical efficiency refers to how best to achieve an objective with the given resources. This could be maintaining a given output for the least input, or alternatively maximising the output given a certain amount of resources [117]. Allocative efficiency on the other hand is concerned with whether or not something should be done, or how much of something should be done [117]. Allocative efficiency is achieved when it is not possible to improve overall benefits by reallocating resources between different programmes [117].

3.1.2. Economic evaluation in health care

Providing information on the effectiveness of an intervention alone is of little help to decision makers in determining whether that intervention should be adopted in practice. It is of much more use for decision makers to have information on both the costs (including opportunity costs) and the benefits of interventions to evaluate their cost-effectiveness [118]. This comparison of both the costs and consequences of alternative treatments is known as economic evaluation [87], [119]. Economic evaluation is used in health care to determine the cost-effectiveness of interventions to inform decision making. In terms of the costing side of economic evaluation, methods for establishing cost are relatively consistent between the different methods of evaluation; generally the differences of costing are in terms of the perspective being used. For example the cost of an intervention will potentially differ depending on whether an NHS or a societal perspective is used. The following section briefly outlines the different methods of economic evaluation, particularly in terms of the outcomes that are frequently utilised within healthcare. An overview of the advantages and disadvantages of the different methods is presented in Table 2.

3.1.3. Cost-consequence analysis

Of the different types of economic evaluation, a cost-consequence analysis (CCA) is the simplest [118]. The theoretical underpinnings lie within the broader extra-welfarist framework [120] insofar as outcomes other than utility or health can enter the economic evaluation. CCAs report the incremental costs and benefits in a disaggregated manner [121]. The outcomes of the intervention are usually presented as a list of consequences of the intervention. The benefit of using a disaggregated approach such as this is that it allows all consequences to be presented to the decision maker and thus to be included in the evaluation. This opens up the evaluative space to all types of outcome and allows non-health benefits to be included in the decision making process. Generally speaking, the disadvantage of such an approach is the lack of explicit insight generated by the cost-consequence analysis in terms of aiding decision makers to make decisions between alternative interventions [121]. That is, it does not give an explicit answer as to which option is more cost-effective, thus placing the burden on the decision maker.

The aim of the CCA is to provide the information about all the costs and consequences of a given intervention in the most transparent manner possible. The decision maker must then develop their own system for weighting the benefits of any given intervention and establish whether they believe the consequences are worth the costs [122]. It relies fundamentally on the decision maker to synthesise and interpret the information presented in an appropriate manner with little objective framework to inform the decision maker [118]. Thus there is no straightforward decision rule in establishing the cost-effectiveness of interventions.

3.1.4. Cost-effectiveness analysis

Cost-effectiveness analysis (CEA) has its theoretical underpinnings in extra-welfarism with health outcomes typically being the primary outcome. CEA is useful for examining the technical efficiency of competing interventions [123], i.e. for comparing the relative efficiency of two interventions that both seek to solve the same problem. CEA are typically focussed on comparing two alternative interventions for a similar problem. The primary goal of the CEA is to determine which of similar interventions can get the most benefit for the lowest cost per unit [123]. As with the CCA all the costs for each intervention are valued in their monetary units. The benefits of each intervention however will be specific to the intervention and measured in natural units (e.g. depression free days) relevant to the interventions [121]. For example if there was a cost-effectiveness analysis of two competing obesity prevention interventions, it would be reasonable to measure the benefits in terms of obesity cases prevented. Combining this information with the cost of each intervention results in a cost per obesity case prevented which can then be compared between interventions.

Unlike with CCA, it is possible to quantify the relative cost-effectiveness of two different interventions. The most straightforward decision is when either the costs of the interventions are equal, or the benefits are equal. If costs for the two interventions are equal then the CEA decision rule would be to select the intervention that provides the most benefit. Likewise if benefits are equal, then the most cost-effective approach would be the one that costs the least (also known as a cost minimisation analysis). When costs and benefits differ across the interventions, a more complex approach is used. Incremental cost-effectiveness ratios (ICER) compare interventions based on the difference of costs and the differences in outcomes. This ratio can then be used to assess the efficiency of each intervention [124]. Using the obesity intervention example by calculating the cost per 1% decrease in body fat in both interventions, it is possible to determine which intervention can reduce % body fat for the lowest cost. CEA is therefore a useful tool for addressing technical efficiency issues, i.e. for comparing two competing interventions with the same natural unit of outcome [123], but are limited in terms of addressing allocative efficiency questions (e.g. assessing cost-effectiveness for different interventions in different disease groups).

3.1.5. Cost-utility analysis

The cost-utility analysis (CUA) builds upon the standard cost-effectiveness analysis by including preferences and capturing the benefits of health interventions in a metric that can be compared across disease areas and different interventions. The metric of choice is known as a quality adjusted life year (QALY) [118]. QALYs adjust the length of time in a given health state according to the quality of the health state [121]. In essence QALYs capture both changes in quantity and quality of life of interventions and uses a metric that can be compared across disease groups. In terms of quality of life, QALYs are weighted using utility values [118]. Utility values in terms of economic evaluation are cardinal values that reflect the preference for health states and are anchored on a scale from 0 to 1 where 0 represents a health state equal to death, and 1 represents full health; health states worse than death (negative) are possible. The utility values can then be multiplied by the length of time spent in that health state (in years) to generate QALYs. For example if you were in a health state with an associated utility value of 0.25 for 10 years you would have (0.25 x 10) 2.5 QALYs. Using QALYs to measure the benefits of interventions alongside cost information it is possible to calculate the cost per QALY gained.

By using such a metric, it is feasible to compare the benefits of interventions across different disease groups. Similar to the CEA, it is possible to then compare the difference in costs and the difference in QALYs for the intervention to get a cost-effectiveness ratio. Within CUA, the cost-effectiveness ratio is presented in the form of cost per QALY gained. This provides a method for comparing not just between similar interventions but also between disease groups. Given the possibility of two different interventions, the one with the lower cost per QALY will be preferred. Cost-utility analysis is a useful tool for addressing technical efficiency issues as well as allocative efficiency within the healthcare sector where health maximisation is the goal.

3.1.6. Cost-benefit analysis

Cost-benefit analysis (CBA) based on the KHC (see 2.1 for more details) has its roots firmly in welfarism and seeks to value both the costs and benefits of interventions in a simple monetary unit [121] and therefore allows for the analysis of allocative efficiency questions. Across society CBA is used frequently within other areas of economics to evaluate policies e.g. environmental economics [125]. Cost-benefit analysis in healthcare requires the monetary valuations of both the costs and the benefits that an intervention accrues. For example if an intervention for a disease reduces risk by 10% then a monetary valuation of this risk is required. Likewise, the costs of the intervention are also calculated in monetary units. The costs and benefits are then compared to derive the net benefit/loss to determine its cost-effectiveness.

The monetary costs and benefits to society of the intervention are compared to calculate the net benefit/loss of the intervention. If the intervention results in a net benefit then it can be said that that the intervention is cost-effective as the benefits of the interventions outweigh the costs [121], i.e. it leads to an increase in societal welfare. Likewise, if there is a net loss then the cost of the intervention outweighs benefits and the intervention is deemed cost ineffective. This method of evaluation allows the analysis of both technical and allocative efficiency questions within healthcare, but also broader allocative efficiency questions outside the healthcare sector. For example it allows the comparison of a health care intervention with an environmental intervention.

Table 2: Advantages and disadvantages of the methods of economic evaluation

Type of Evaluation	Benefits	Drawbacks
Cost-Consequence Analysis (see 3.1.3)	Relatively straightforward to conduct. Broadens evaluative space allowing all benefits of interventions to be presented to the decision maker. Possible to collect all benefits. Allows for equity considerations	Shifts burden of analysis away from the researcher and onto the decision maker. Implicitly relies on the decision maker to be able to objectively synthesise such information.
Cost-Effectiveness Analysis (see 3.1.4)	Allows technical efficiency questions to be addressed, i.e. it is good for comparing similar interventions with a single unambiguous outcome. Easy for lay persons to understand.	Does not help answer allocative efficiency questions. Generally a very narrow health focussed evaluative space with just one indicator of health being included in the evaluation Ignores wider benefits to society. Does not incorporate societal preferences for health states. Does not account for changes in quantity and quality of life.

Cost-Utility Analysis (see 3.1.5)	Allows technical efficiency questions to be addressed. It can answer allocative efficiency questions within the healthcare budget. Takes into account both the quality and quantity of life.	Focusses only on health benefits. Cannot be used to address wider allocative efficiency issues. Excludes wider non-health benefits of interventions. Debate around the validity of the underlying QALY assumptions. Equity issues.
Cost-Benefit Analysis (see 3.1.6)	Strong theoretical background in welfare economics. Can answer allocative and technical efficiency questions within the healthcare budget as well as between different sectors. Can incorporate all costs and benefits to society e.g. non-health benefits.	People do not like to place monetary value on health. Issues with stated preference techniques e.g. scope effect and nesting affect. Equity issues. Issue in regards how far wide societal impact should be collected.

Table adapted from information in: [94], [121], [123]

3.2. Economic evaluation: guidance

Globally, a large number of countries publish guidelines for economic evaluation [126]. In general there is a preference for the use of CEA and CUA over CBA. There is also significant variation in terms of the perspectives that are advised within the guidance [126]. Given this research is being conducted in England; the focus will be on economic evaluation within the UK context.

In England and Wales, the National Institute for Health and Care Excellence is responsible for advising the NHS amongst other things as to whether new health technologies should be adopted [127]. In particular, NICE provides the NHS with guidance as to the relative cost-effectiveness of new interventions. NICE through its guide to the methods of technology appraisal provides a 'reference case' to guide researchers in regards to the methodological rigour that NICE desires when evidence is submitted for technology appraisal [127]. The reference case outlines the methods that NICE require for collecting and presenting evidence on the cost-effectiveness of new interventions and health technologies.

To assess cost-effectiveness, the NICE reference case [127]–[129] advocates the use of cost-utility analyses to allow for cross disease comparison. To allow for such comparisons, generally, cost per QALY thresholds are calculated. Although it has not been explicitly stated, the cost per QALY threshold used by NICE is widely thought to lie between £20,000-£30,000 per QALY [130]. Interventions which have a cost per QALY less than £20,000 are generally thought to be cost-effective, interventions over £30,000 per QALY are generally considered to be cost-ineffective whilst interventions that lie within the threshold are considered taking into account other characteristics of the intervention e.g. innovation. To measure the benefits of health technologies and interventions to calculate QALYs, the NICE reference case recommends that the benefits of interventions are measured using generic preference based measures of health related quality of life (HRQL), specifically the EuroQol-5D (EQ-5D) within NHS settings for the calculation of QALYs [127].

3.2.1. The NICE reference case – supplementary advice

In 2010, the Department of Health [131] announced their plans to introduce value based pricing to the United Kingdom. The Department of Health in their response to the consultation on value based pricing explicitly acknowledged that the QALY measure in its current form *'may not capture all aspects of the value society gains from new treatments'.* It goes on to say that there is *'justification for the explicit recognition of the wider societal benefits provided by treatments – which is a key part of the VBP mode*l'…The Government is proposing to calculate '*QALY weights to reflect the value society places on giving health benefits to patients suffering particular types of condition, and to* *products with particular characteristics….These weights can be applied to 'standard' QALYs provided by the treatment to give a measure of 'weighted' QALYs which reflects the broader value of the product's benefits.'* (p.24) [132].

Therefore, it seems that the Department of Health is not currently satisfied with the QALY as a simple outcome measure. This shift in policy has already had an impact on some EoL interventions. In terms of EoLC, there has been a policy change in terms of life extending interventions. NICE [133] sought the public's views on EoLC, and whether more weight should be given to interventions providing proven survival benefits in patients nearing the end of their life, 63% of those who responded to the consultation backed the proposal. Following this, NICE [134] established that the Appraisal Committee would consider *'the impact of giving greater weight to QALYs achieved in the later stages of terminal diseases'.*

The Supplementary Advice for Health Technology Appraisal [134] gives further advice on appraising health technologies aimed at the EoL. The advice allows for treatments to exceed the upper £30,000 per QALY threshold normally considered to be the upper limit of cost-effectiveness. For EOLC intervention to be considered, it must satisfy the following conditions:

- *The treatment is indicated for patients with a short life expectancy, normally less than 24 months and;*
- *There is sufficient evidence to indicate that the treatment offers an extension to life, normally of at least an additional 3 months, compared to current NHS treatment, and;*
- *No alternative treatment with comparable benefits is available through the NHS, and;*
- *The treatment is licensed or otherwise indicated for small patient populations* (p.2) [134].

If these criteria are met, then the appraisal committee will consider giving greater weight to QALYs achieved at the EoL on the following assumption:

> '*the extended survival period is experienced at the full quality of life anticipated for a healthy individual of the same age'* (p.2) [134].

3.2.2. Issues with the NICE reference case for EoLC using quality adjusted life years (QALYs)

NICE has clearly acknowledged that the EoL area is ‘special’, however it places its emphasis on life extending technology and fails to acknowledge the benefits of improved quality of life at the EoL and the benefits that high quality EoLC can bring to the loved ones of those who die. NICE [134] discusses the potential for giving weight to QALYs for life extending treatment, but not for EoL palliative care. Pinto-Prades *et al.* [135] investigated whether this is in accord with social preferences. The paper used online surveys to explore whether extra weighting is preferred for life extending treatments or palliative care. Contrary to NICE’s statement, they found that those sampled not only wanted extra weighting for EoLC generally, but they preferred to give extra weight to palliative care than life extending care. Similar findings are presented by Shah *et al.* [136] who investigated whether there was public support for NICE’s supplementary advice prioritising life extension. Of significance was the finding that there was substantial preference for quality of life improvement over life extending treatments [136], whilst there was some evidence of support for giving priority to patients with shorter remaining life expectancy. NICE [134] state that it is *‘technically more accurate…to include only the QALYs gained through extension of life and not the QALYs gained through improved quality of life during any extended ‘progression free’ period’* (p.16). The results found by Pinto-Prades *et al*. [136] and Shah *et al*. [136] refute this claim, and imply that interventions that improve quality of life should be given more weight than life extending drugs, contrary to NICE guidance. The evidence however is mixed. Pennington *et al.* found that people placed a higher value on life-extension QALYs versus quality of life QALY gains [137] whilst others [138], [139] have found no evidence for an EoL premium.

3.2.3. Problems with QALYs in EoLC

There are also other issues with QALYs in the context of EoLC. It can be argued that the inherent nature of QALY thresholds disadvantage quality of life improving interventions in those who are at the EoL [140]. The NICE reference case recommends that CUA is used to assess the relative effectiveness of competing interventions, with QALYs as the primary outcome measure. EoLC however is often focussed on improving the quality of life at the EoL, and the quality of death. Furthermore EoLC is often directed at the family members as well as the decedent. Any health gains from EoLC for decedents are likely to be short lived; this therefore means that it is difficult for EoLC to have any meaningful impact on the QALYs received by the decedent and the potential for health gain is inevitably lowered. To illustrate, if a new fantastic EoLC intervention were to impact upon the last 30 days of someone's life, taking them from a health state equal to death to perfect health for the final month of their life, the largest health gain that could be derived would be 1 quality adjusted life month (QALM), i.e. 0.08 QALYs. Thus using a standard QALY framework, unless interventions are very cheap (less than £2400 per person) they will not be cost-effective. On the one hand EoLC is seen to be cost-ineffective and therefore "not worthwhile" due to the limitation of incorporating the time spent in a health state into the cost-effectiveness equation, yet society expresses a desire for good EoLC [33], [45], [141]. This implies that QALYs accrued during the EoL period do not provide a fair reflection of the benefits of EoLC. Bryce *et al.* [140] used a time trade-off task to examine the value people place on EoLC. They hypothesised that *'society's valuation of EoLC, measured as the amount of perfect health traded for better EoLC, would exceed the amount of time spent in EoLC'* (p.424) [140]. The implication of this hypothesis is that if participants in the study were willing to trade off more than one month in perfect health of their lives for improved EoLC in the final 30 days of their life then it supports the argument that EoLC is important and the conventional QALY framework underestimates the true value of EoLC. The study found that the median amount of perfect health to be traded for improved EoLC in the final 30 days of life was 8.3 months. The implication of this is that the last month of life could be 'valued' over eight times as much as the rest of life. This demonstrates that the standard framework may underestimate the societal value of EoLC.

There are several reasons for why this cost-ineffectiveness paradox arises as discussed in the two sections below. This thesis aims to address the first issue briefly discussed below, i.e. to incorporate the impact of EoL on those close to the dying into economic evaluation, and to do this using a broader evaluative space. Other criticisms are briefly outlined in section 3.2.3.2; however the resolution of these issues lies beyond the scope of this thesis.

3.2.3.1 Close-person benefits of EoLC

One of the reasons why high levels of EoL spending may arise is due to the extensive wider societal benefits of EoLC. As Saunders [1] eloquently said *'how people die remains in the memory of those who live on'*, and the nature of the decedents' EoL appears to affect those who were close to them beyond the time of death. As discussed in sections 1.2 and 1.8, EoL and bereavement can significantly affect the families of the deceased [10], [11], [16], [18], [19], [21], [22], [24]–[31] and good EoLC can improve their experiences [21], [67]–[70], [142]. By omitting these benefits, benefits that are directly obtained from the intervention are excluded. This is especially the case where EoL interventions are delivered as a package to both the decedent and the family members [142]. Haycox notes *'without standard, comparable evaluations to identify the costs and benefits associated with different treatment pathways on the quality of life of both patient and family we lack the basic information that is required to optimize resource allocation in palliative care…it is necessary to incorporate the impact of palliative care and bereavement support on the quality of life experienced by families'* (p.49-50) [142]. Economic evaluations have a tendency to only focus on the patient, in the case of EoLC, the benefits that accrue due to EoLC typically cease in economic evaluations when the decedent dies. Philipson *et al.* [143] discuss this in terms of the social value of EoLC. Essentially, the social benefits of EoLC exceed the private value of the same care. The benefit of a person's final days of life being extended and the benefits of a good death lead to greater social benefits than the private benefits to the patient. Therefore current methods of evaluating cost-effectiveness are overlooking these wider benefits to families and loved ones. The purpose of this thesis is to address this issue by providing a method to capture the benefits of EoLC to those close to the dying for use in economic evaluation.

3.2.3.2. Other criticisms of QALYs in relation to EoLC

Several other criticisms have been put forward in relation to the use of the QALY in EoLC of which some have been contested [144]. Detailed assessment of these criticisms is outside the scope of this thesis, and so, they are only briefly outlined here.

The first criticism relates to one of the underlying assumptions of the QALY. Chochinov [145], Normand [146] and Bryce [140] discuss this in terms of 'the relative value of time. An assumption of the QALY is that the time in a health state 'can be valued regardless of context', and that these time periods can be added. It would seem however that this may not be the case. As put by Normand *et al.* [146] '*we can look at the quality of life in a given period, and score it on a scale from 0-1, but the value put on any given time period could also be different...This undermines the use of QALY metrics across all health care settings and issues. In adding up QALYs, we are already assuming that we can add up benefits to different individuals which violates some theorems of welfare economics.'* '*…An even more serious issue than this however is the fact that time periods cannot be added up at different points in time for individuals'* (p.29) [146]. Bryce *et al.* [140] have shown that people are willing to trade off over 8 months of life to improve EoLC in the last 30 days of life. This indicates that the additive time issue may exist in those approaching the EoL.

Further criticisms touted by Philipson *et al.* include the concept of 'hope' [143]. Philipson *et al.* theorised that 'hope' can lead to an increased WTP for a medical intervention. People prefer quick accidental deaths; there seems to be a disutility associated with no hope. A suggestion in the literature is that good EoLC could be seen as societal insurance against a bad death [143], with the risk averse in society being willing to pay more than expected to ensure that they are given high quality EoLC. Individuals are effectively willing to trade off current consumption of healthcare for improved healthcare at the EoL.

The implications of the criticisms outlined are that the traditional QALY analysis of interventions designed at the EoL are flawed and inadequately value the benefits of EoLC. A whole thesis could be dedicated to further exploring these issues. The purpose of this thesis however is to account for the first issue raised, i.e. to develop a method for capturing close-person benefits of EoLC. The other issues with EoLC and economic evaluation remain a challenge beyond the scope of this thesis.

3.3. Normative arguments for the inclusion of close-person benefits of EoLC in economic evaluation

Economic evaluations using the extra-welfarist evaluative space typically only consider the direct patient benefits of health interventions from a health care perspective and when relevant to carers [127]. This section argues that wider benefits, particularly in terms of EoLC should be included within economic evaluation. Apart from methodological difficulties, it is hard to comprehend why wider benefits should be excluded from economic evaluation.

This is particularly pertinent within EoLC, when the benefits of care are so short lived for the patient, yet could continue for years for those close to the dying person. Within EoLC, the family members are often the co-recipients of EoLC and their experiences should therefore be included within an evaluation of such an intervention [142]. Furthermore there is existing literature that shows that EoLC can impact on the outcomes of those close to the decedent [21], [67]–[70]. As discussed by Davidson and Levin [147], most economic analyses neglect to include the costs and benefits of relatives. Given this, it is quite a surprise to find that many countries' guidelines on cost-effectiveness indicate that the wider societal impacts should be included in economic analyses [148]–[151].

There is precedent within health economics to consider the impacts of individuals other than the patient within economic evaluation. This in particular has been the case within the carer literature with NICE recommending that direct health benefits where relevant should be captured [127]. There is a growing body of literature that suggests that costs and benefits to those other than the patient should be included within economic evaluation [152]–[157]. A considerable body of research has been conducted exploring the inclusion of carer impacts into economic evaluation [152], [154], [155], [157]–[161]. Of particular note, there are two outcome measures that have been designed and valued for use within economic evaluation of informal care [157], [159]. These measures are the Carer Experience Scale (CES) [159] and the CarerQol [157]. Both measures seek to describe and value the impact of informal care on the caregiver and have recently been validated [162]. The CarerQol has been designed to capture care-related quality of life and has been valued with the general public within the Netherlands [160]. Likewise, the CES is designed to measure care related quality of life within the UK. Both measures can be used within economic evaluation to provide additional information to standard methods. For example the measures could be used alongside the QALY, or as a principal outcome within a CCA, especially where an intervention is targeted at informal carers. In the case of EoLC, although some bereaved individuals will be carers, many will not be carers and thus the dimensions of the CES and the CarerQol may not be relevant to the close family members and close friends. There has been very little effort to include the impact on close-persons beyond 'the carer' in economic evaluation. More generally within health care, Bobinac *et al*. [163], [164] investigated the wider effects of poor health, finding significant wider family effects in addition to carer effects and arguing for the inclusion of both within economic evaluation from a wider perspective. Although this applies to interventions more generally, it may be particularly pertinent to

EoLC where the relatives are often a co-recipient and beneficiary of EoLC [142]. Thus there are strong arguments for the inclusion of those close to the dying in the economic evaluation of EoLC.

There however are some who disagree with the inclusion of others within the health care context. Hughes [165] argues that including family benefits would lead to severe equity issues, the implication being that it is unfair to favour patients who have friends or relatives over those who do not. This argument at the outset seems to make sense; however, economic evaluations are typically conducted using group level data, and it would be unlikely for somebody to be denied treatment due to them not having a relative whilst an identical patient with a family member receives treatment. Hughes [165] also raises the point that if societal impact is included, it may not particularly help EoLC's cause in terms of economic evaluation. It could be argued that greater family benefits could be derived for treatment for non-EoLC patients than for EoLC interventions, for example, someone may benefit more from a relative being saved from a premature death or prolonged disability than a relative receiving better care at the EoL. This may, or may not be true, but there is little logic in saying potentially significant benefits of EoLC should be ignored because it is not being done elsewhere. Inappropriate methodological practices elsewhere should not be a justification for performing methodologically flawed evaluations within EoLC. There are important benefits being accrued as a result of EoLC by those close to the decedent, potentially more than to the patient and it is important that these are included in evaluations.

3.4. Evaluative scope

3.4.1. Evaluative scope: who should come into the evaluation

As discussed above, the Department of Health [132] endorses the inclusion of wider benefits into the evaluation of interventions. In terms of EoLC, interventions are typically complex and often target both the family and the patient and there are therefore important benefits to both the patients and their close-persons. In terms of evaluating interventions, the patient should clearly be included, and, this thesis argues, so should those who are close to the individual and are likely to be affected by the EoLC and death of the patient. In terms of evaluating EoLC, as both the decedent and the people close to them can be jointly the recipients of EoLC, it is useful to attribute them 'identities' for use in economic evaluation, Al-Janabi refers to this as 'evaluation identity' [166]. It would seem logical to give the dying patient a 'decedent' identity and the close-persons a 'close-person' identity to ensure that the benefits of EoLC and to whom they are received are captured for use in economic evaluation.

3.4.2. Who is 'close' to those at the end of life

In terms of inclusion of impacts within economic evaluation, assigning the 'decedent' identity is straightforward. It is the person whose life is ending. When considering who else should enter into the evaluation, assigning a 'close-person' identity to an individual is less clear. Is it just carers, or partners, parents, family or households? It is argued here that benefits to individuals who are close to the decedent and therefore are significantly affected by the death of the decedent should be captured. It is important therefore that this extends to all those who are close to the individual, and is not simply limited to the immediate carer or next of kin. Within the social and personal relationship literature there has been research on definitions of intimacy and closeness. Self-disclosure has been the most frequently cited aspect of intimacy and closeness, along with to lesser extents: help, support and shared interests [167]. Davidson and Levin [147] provide a definition for 'relatives' whilst seeking to incorporate wider social benefits of health technologies in economic evaluation more generally. Their definition reads '*a person who is likely to be affected by another person's disease or disability, but is not necessarily related to the person by blood (the term significant others is sometimes used…)'* (p.26) [147]. In order to be able to capture impacts upon 'close-persons' within economic evaluation, it is important to know who, and how many people, are close to those at the end of life. Looking at the close-person networks of people more generally, for older people, Antonucci [168] found that on average those aged over 50 years had 8.9 individuals within their close-person networks. Similarly they found that on average young adults in the US and Japan had eight individuals within their close-person map, whilst middle aged individuals had nine [169], [170].

3.5. Methods for measuring capability in economic evaluation

As discussed in section 2.2, the CA is a theoretical approach which incorporates broader outcomes than the typical 'narrow' extra-welfarism that has been adopted in practice. The methods for measuring HRQL using functionings for use in economic evaluation are well established and are described elsewhere [119]. The resurgence of interest in the CA has led to new developments in terms of its application within economic evaluation. Although there were concerns within health economics as to whether it would be possible to operationalise the CA [171], recent years have shown the possibilities with the development of the approach in a number of settings [172]–[178]. A thorough overview of the growth of the CA in practice can be found in Coast *et al.* [179], and Smith *et al.* [107]. Current developments and existing methods are briefly outlined here.

3.5.1. OCAP

One of the first CA measures created was the OCAP. Anand *et al.* [173] utilised the British Household Panel Survey (BHPS) and identified questions that gave information on the functionings and capabilities of individuals related to the list of central human capabilities as specified by Nussbaum [114]. Through this methodology, Anand *et al.* developed what is now known as OCAP. OCAP utilises over 60 questions of the BHPS to act as indicators of capability. These indicators have been shown to be strong predictors of wellbeing. Having over 60 questions is not, however, particularly useful in terms of use in economic evaluation; as a result, Lorgelly *et al.* [176] through qualitative and quantitative research reduced and refined [107] the questions to develop a summary measure of capabilities for use in economic evaluation. This refined version contained 18 questions and consequently took on the name OCAP-18. To establish the summary level of capability equal weights between capability questions were used. This measure was found to be strongly correlated with the EQ-5D. The non-preference based nature of this measure however makes it of limited use for informing policy makers in terms of economic evaluation i.e. the weightings may not necessarily reflect the values placed on each capability by society (see 4.1). A third iteration (OxCAP-MH) of the instruments has been developed for use in mental health research [180]. The measure is adapted directly from the OCAP-18 with many questions remaining the same within the two measures [180].

3.5.2. ICEPOP capability index measures (ICECAP-O/A)

More recently this issue has been tackled with a number of measures being created that have been valued to reflect the weights society places on the capabilities making them amenable to economic evaluation (see 4.1). The ICECAP-O and the ICECAP-A represent the first attempts to use the CA in a manner that can be used to inform economic evaluations. The ICECAP-O [174] is designed to assess generic quality of life in older people via a capability framework, whilst the ICECAP-A [175] is designed for use more generally in the adult population. The attributes for ICECAP-O were initially identified through qualitative work by Grewal *et al.* [174]. These attributes are: attachment, role, enjoyment, security and control. They have since been valued by Coast *et al.* [181] using best-worst scaling (BWS) choice experiments to estimate weightings for the attributes. This measure is anchored on a scale from zero to one whereby zero represents no capabilities and one represents an individual with full capabilities and is now being used in a number of studies e.g. Ratcliffe *et al*. [182]. Similarly, attributes for the ICECAP-A have been developed which include: stability, attachment, achievement, autonomy and enjoyment. The ICECAP-A has also been valued using BWS methods [183] and a tariff of weights/values now exists for use in the UK population. Recently the ICECAP instruments have been recommended for use within the evaluation of social care interventions [184]

3.5.3. The adult social care outcomes toolkit (ASCOT)

The ASCOT measure [185] is a measure of social care-related quality of life which has been designed to capture the aspects of quality of life that are the focus of social care support. The measure is a preference based measure and has demonstrated construct validity [186]. The measure features eight attributes related to social care. These attributes include *personal cleanliness and comfort, food and drink, control over daily life, personal safety, accommodation cleanliness and comfort, social participation and involvement, occupation and dignity* [186]. ASCOT has been valued using time trade-off and BWS allowing the calculation of a social care QALY [187] and in addition to the ICECAP instruments is also recommended by NICE for inclusion within the economic evaluation of social care interventions [184].

3.5.4. ICEPOP capability index measures – supportive care measure (ICECAP-SCM)

A third iteration of the ICECAP instruments has been created that focusses on the capabilities of those at the EoL, this is the ICECAP Supportive Care Measure (ICECAP-SCM) [177]. Given the EoL nature of the ICECAP-SCM it is of particular relevance to this piece of research as the new measure is to be used alongside the ICECAP-SCM. The ICECAP-SCM has 7 dimensions: 'Autonomy' – having a say, 'love' – being with people who care about you, 'emotional suffering' – experiencing worry or distress, 'physical suffering' – experiencing pain or physical discomfort, 'dignity' – being yourself, clean, privacy and respect, and 'preparation' – having financial affairs in order/funeral arrangements/saying goodbye [177]. Like the other ICECAP measures this measure was developed using qualitative interviews and constant comparative analysis to obtain the attributes for the measure and to develop meaningful wording. Values are currently in the process of being estimated and the validity of the measure is being assessed.

3.6. Challenges with operationalising the capability approach

It can be argued that the use of the CA is theoretically preferable to focussing simply on functionings and in particular the extra-welfarist's typical use of health as the maximand. Operationalising the CA for use in economic evaluation is relatively new, and consequently far less developed than 'narrow' extra-welfarism as health maximisation using functionings. Despite the evolution of the CA and the rise of new measures designed specifically to be amenable for economic evaluation, there still remains a number of challenges to overcome with the CA.

Despite the progression of the CA, there is still no consensus on the techniques for valuing capability measures. As mentioned above, BWS methods have been used in existing measures to elicit values (see chapter 5 for more on valuation techniques). Recently however, there have been arguments put forward for using a more deliberative approach to obtain values in line with the CA [102]. In terms of the studies to date, there is debate as to whether capability instruments should be anchored in the same way as the 'narrow' extra-welfarist preference-based measures (i.e. anchored at death equal to zero) or whether the instruments should be anchored at zero capabilities at zero [107]. There are further issues in terms of how capabilities should be assessed within economic evaluation. For example should the goal of the health care system be to maximise capabilities for individuals or should it be to ensure that all citizens meet some minimum capability threshold [188], [189]. One of the biggest issues that the CA faces is the issue of fitting the CA into the current framework of economic evaluation. Linked to this is the issue of how decision makers will see the CA. Often with the CA there is little mention of health within the measure and as a result decision makers may be wary unless there is sufficient evidence that the capability measure can capture the benefits of health interventions [74]. Coast *et al.* argue that health is only important in terms of its ability to allow people to function and this should be borne in mind when criticising the CA from this perspective [74].

3.7. Recommended measures for economic evaluation

There are three primary measures that are recommended for use within economic evaluation. *Within the health care setting* the EQ-5D [190] is recommended by NICE [191]. For economic evaluations *outside the health care setting*, the ICECAP-O [174] and ASCOT [185] measures have also been recommended by NICE [184]. The domains of these three measures are outlined in Table 3. The EQ-5D is a health focussed measure and therefore it is unsurprising to note that there is little overlap in terms of dimensions between the EQ-5D and the two capability measures. There is also little overlap between the two capability measures apart from control; this in part may be due to their respective purposes. The ICECAP-O is a measure of capability in older people. The ASCOT measure on the other hand was developed to measure the social-care related quality of life of individuals.

Table 3: NICE recommended measures for use in economic evaluation

Measure:	EQ-5D	ICECAP-O	ASCOT
Domains	Mobility		
	Self-care		Personal cleanliness and comfort
	Usual activity	Role	Occupation
	Pain/discomfort		
	Anxiety/depression		
		Attachment	
		Security	
		Enjoyment	
		Control	Control over daily life
			Food and drink
			Personal Safety
			Social participation and involvement
			Dignity

N.b. domains on the same line represent conceptual overlap.

Earlier in the thesis (section 1.7) the key complaints that relatives had with their experience of EoLC [66] were discussed. The six key themes were:

- Awareness of approaching EoL.
- Communication and being caring
- Symptom management

- The environment
- Concerns around clinical care
- Fundamental medical and nursing care

These key complaints are suggestive of important facets of the experience of EoLC to those close to the dying. Comparing the themes of the complaints to the dimensions of the three recommended measures, it is clear that the measures are incongruent with issues that people feel are important at EoL. For example, a key complaint of relatives in regards to EoLC was communication. If an intervention improved communication, none of the aforementioned measures would be likely to capture this impact.

Given that the three measures outlined above seem to be unsuitable for measuring the experience of those close to the dying, there is scope to develop a measure to capture the close-person's experience of EoL. Before developing a measure using the broader capability based evaluative space, it is necessary to examine the literature to see if there are any suitable measures already in existence.

3.8. Reviewing potential measures of EoLC for close-persons:

A review of the literature is important to ensure that there are no suitable measures already developed that are being used to capture benefits of EoLC to those who are close to the dying. The purpose of this review therefore was to see what measures (if any) have been designed for use to capture the impacts of EoLC on close-persons, and to examine their use in economic evaluation. To ensure best practice, where possible, this review followed the guidelines outlined in the PRISMA statement [192] which provide a 27 point checklist for best practice in systematic reviewing.

3.8.2. Purpose of the review

3.8.2.1. Primary objective of the review:

To find whether there are any measures designed to capture the impact upon **close-persons** of the dying process and bereavement.

3.8.2.2. Secondary objectives of the review:

If such measures exist, the secondary objective is to examine whether they have been designed for use in economic evaluations of EoLC technologies.

3.8.2.3 Rationale of the review and what is already known

As outlined in chapter one, there is evidence that EoL and EoLC can impact those close to the person who has died and lead to better outcomes in the bereaved. In terms of measures used at EoL, a recent systematic review of the literature by Hudson *et al.* [193] investigated the instruments related to family caregivers of palliative patients. Numerous measures (62) were discovered within the review. A closer look at the review shows that just five of the studies picked were used to assess the impact of care on the quality of life of those caregivers. The other measures were focussed on other issues such as: satisfaction with care, burden, carer needs or on specific consequences such as depression or anxiety. Of the five that were interested in broader quality of life/experience, just four were designed specifically for that purpose. However, this review focussed only on caregivers. What is not known is if there are any measures that have been developed for close-persons who may not be caregivers, and if so, whether these are designed for use in economic evaluation.

3.8.2.4. Summary of the review methods

The key steps of the review are briefly outlined here; further details of the methods of the review can be found in Appendix one. The PICOS criteria as advocated by the PRISMA checklist [192] were followed and adapted to add in extra eligibility criteria relevant to this study. The review sought to identify papers that developed or used measures with those close to the dying. To be included, the measures specifically had to be designed for use with those other than solely the patient or caregiver. Papers published in the past 40 years in OVID Medline, Embase, and Psycinfo were considered for the review. In addition, a forward backward citations search was conducted to identify other potentially eligible papers. The screening process comprised three stages: title screening, abstract screening and full paper screening. The forward-backward citation search was conducted on the papers that passed through the full paper screening. From the eligible papers, data were extracted using data extraction forms to capture the key details.

3.8.3. Results of the review of EoLC measures for close-persons

In total, ten papers containing six measures passed through the full screening process and were included within the review. The vast majority of papers that were excluded were focussed solely on either the patient or solely the caregiver. For example, one excluded measure was the Quality of Life in Threatening Illness – Family Carer version (QOLLTI-F), developed by Cohen *et al.* [194]. This measure appeared to have a similar purpose to this research, however, it is limited by its design which was concerned with the quality of life for carers of people with cancer and as such the items within the measure reflect that. For example, one of the 16 items is focussed on 'Feelings re: being a carer'. This question is not applicable to someone who is a close-person but not a carer *per se*. Furthermore along with many other measures excluded within this review, it is focussed on the caring experience, in contrast to the EoL experience for the decedent's close-person.

As shown in Table 4, the measures reviewed were the FAMCARE [195], FAMCARE – 2 [196], FAMCARE – 6 [197], CANHELP [198], CANHELP – Lite [199], and the SAT-FAM-IPC [200]. All six of the measures are oriented around attempting to capture the satisfaction with the EoL (or palliative) care for family members. Although closely linked to the research within this thesis, the fundamental goal of the measures differs. The existing measures are all focussed on capturing the family's satisfaction with the quality of EoLC, whilst this thesis is interested in capturing what is important for those with a close-person at the EoL. The most widely validated of the measures is the original FAMCARE measure. None of the measures in existence included within the review have been developed with economic evaluation in mind. This is reflected by the number of items contained within each of the measures. Five of the six measures contain between 17 and 38 items making them impractical from a feasibility perspective [201] in economic evaluation. Furthermore this also restricts the ease of valuation using standard methods of valuation [202]. The FAMCARE-6 however contains just six items each with a five point Likert scale ranging from very satisfied to very unsatisfied and is therefore both practical and amenable for valuation. The FAMCARE-6 items are: *Answers from health professionals; Information given about side effects; Speed with which symptoms are treated; Availability of doctors to the family; Time required to make a diagnosis; and Availability of the doctor to the patient* [203]. The measure however was developed for use with oncology patients *within the clinical setting* [197] to assess family satisfaction of care, and therefore may exclude other important facets of the bereavement experience outside the clinical setting. For example referring back to the definition of EoLC in section 1.4, End of life care "*…enables the supportive and palliative care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support.*" (p.4) [38]. The FAMCARE-6 may therefore fail to pick up impacts on the latter aspects of EoLC, especially those which occurred outside the clinical setting such as practical support at home or spirituality. As a result, it would be inappropriate to use this measure for the purpose of this thesis.

Table 4: Measures identified

Instrument Name	Measure Development Reference (*first key reference if none exists)	Purpose of Measure	Associated Validity/Feasibility or Reliability Studies	Number of Dimensions/Items	Designed for use in Economic Evaluation?
FAMCARE	* [195]	To measure family satisfaction with advanced cancer care	[195], [204]–[207]	20	No
FAMCARE – 2	* [196]	To measure family satisfaction with advanced cancer care	[196]	17	No
FAMCARE – 6	[197]	To measure family satisfaction with advanced cancer care – shorter version for computer administration	n/a	6	No
CANHELP **(family version)**	[198]	To measure family satisfaction with end of life care	[198]	38	No
CANHELP – Lite **(family version)**	[199]	To measure family satisfaction with end of life care	[199]	21	No
SAT-FAM-IPC	[200]	To measure family satisfaction with hospital based palliative care	[200]	34	No

3.8.4. Conclusion of the review of close-person end of life measures

This review found that there are very few measures for use at EoL that are focussed on those other than patient or caregivers. Of the measures that are included within this review, all were focussed on capturing family satisfaction with care opposed to the experience of those close to the dying and as such may not capture important aspects of the bereavement experience. Furthermore, they are limited by being focussed on the family alone, and in the case of the FAMCARE-6, the measure's focus on only the clinical setting. The conclusion of this review is that there are no measures currently in existence that are designed for use within economic evaluation that will fully capture the impacts of EoLC and bereavement on those close to the dying.

3.9. Chapter summary

This chapter has focussed on the application of economic evaluation, specifically in relation to EoLC and has discussed the different methods of economic evaluation. The NICE reference case and supplementary guidance for EoLC was examined, a number of issues with the QALY framework were highlighted. Arguments were made for widening the evaluative scope to include close-persons within economic evaluation, and furthermore, to broaden the evaluative scope to include impacts beyond solely health gains. The literature was reviewed for possible measures to capture the impact of EoLC for use in economic evaluation. None of the existing measures were focussed on the bereavement of the close-person, and were limited in terms of their use for economic evaluation. Given the impacts of EoLC on close-persons outlined in chapter 1, and the lack of measures developed to capture the experience of those close to the dying, there is scope to develop a measure to capture the bereavement experience of those close to the dying. The purpose of the remainder of this thesis is to develop a measure designed to capture the impact of bereavement on those close to the dying for use in economic evaluation.

CHAPTER 4: METHODOLOGY AND METHODS: DEVELOPING THE CLOSE-PERSON MEASURE AND EXPLORING WHO IS IMPACTED BY END OF LIFE

The first three chapters of this thesis have established that there is a need for a measure to capture the impacts of EoLC on those close to the dying. The broader extra-welfarist approach was described and found to be an ideal framework for evaluating EoLC and impacts to close-persons. The purpose of this chapter is to outline the methodology and methods used to develop the close-person measure and examine who should be included in the evaluative space. This chapter first discusses the different properties of measures that can be used in economic evaluation and how this influences the properties of the close-person measure. The chapter then outlines the methodology surrounding measure development for use in economic evaluation more generally. The methods used for the development of the close-person measure are then discussed. This includes all stages of the measure development from recruitment through to analysis. Following this, the methodology and methods used to examine what makes somebody close, and thus to investigate the evaluative scope of EoLC, are outlined.

4.1. Outcome measures in health care research

4.1.1. Nature of measures for use in economic evaluation

Patient reported outcome measures (PROMs) are measures used to assess outcomes in healthcare [208]. Typically, PROMs define health status in terms of a number of dimensions of health, with a number of levels associated with the severity of the dimension [202]. Since the Darzi [209] 'High Quality Care for All’ report which recommended that the impact of interventions should be captured through the use of PROMs as well as the release of guidelines on their use by the Department of Health [210] there has been a surge in use to measure outcomes within healthcare. The scoring of PROMs typically are either preference-based or non-preference based. Both types of measure have their uses in a wide range of contexts. Their use in relation to economic evaluation is discussed here.

Preference-based measures tend to be standardised instruments that feature two key components in their design: a descriptive system, and a valuation of response profiles/items and levels [202]. First, preference-based measures have a descriptive state classification system (SCS). The descriptive system features questions on different dimensions of health or life with severity levels for each dimension. The recipient of the measure will answer the questions within the measure which then gives them a profile. The 'preference' within preference-based measures refers to the desirability of a given profile. Values and utilities are both types of preference but differ due to their elicitation method [211]. The second part therefore involves the valuation of the states defined by the measure to generate tariff values. Tariff values are usually elicited from the general public and extrapolated to give weighted values for various profiles given by the measure. The tariff values can then be applied to any state defined by the measure to give an associated value e.g. the EQ-5D [212].

Within the health care context, there are a plethora of non-preference based measures (NPBM) in existence. PROMs have been frequently used within studies to examine the efficacy and effectiveness of health care interventions [201]. Some have tried to use NPBMs in economic evaluation; such practice however has received criticism within the health economics literature [201]. Non-preference based measures do not have tariff values associated with them and typically weight all items and response choices equally. This convenient but arbitrary method of valuing health state measures is a severe issue for health economists. This is problematic as this may not be how individuals value these items in terms of their relative impact. For example people may value certain dimensions of health more than others, likewise, they may also have non-linear preferences for the different levels within a dimension. Williams suggests that using NPBMs with arbitrary intervals is such an issue that *"the positive or negative changes in…scores…can be unambiguously rated as improvements or deteriorations in health state if properly valued"* [213]. Thus the results of an economic evaluation using a measure weighted using equal intervals may result in results quite different to those that have been valued. Likewise some NPBMs adopt a psychometric approach to scoring which utilises numerical assessment to reflect an individual's health status. These measures again have received criticism for not reflecting the values that people may put on certain health states [211].

The purpose of the close-person measure is to capture the benefits of EoLC to close-persons for use in economic evaluation. As a result it is important that the measure is amenable to economic evaluation, and so a measure which is both practical, and can be valued is preferable. To facilitate the valuation process, there are two main requirements for measures to be more easily valued. First, the measure should only have one item per dimension. PBMs typically contain between a total of five and nine dimensions [202], and it has been found that people can value seven (plus or minus two) dimensions of health at any one time [214]. This aligns with Brazier's [215] checklist for judging the merits of preference based measures of health. For the measure to be deemed practical, it needs to be acceptable for the target population. It therefore needs to be quick and easy to complete to ensure good response and completion rates. A short questionnaire with few dimensions is therefore preferable in terms of practicality and amenability to economic evaluation. Whilst keeping the measure practical, it is also necessary that the measure has content validity. Content validity refers to the degree to which the items of a measure are appropriate for the health dimensions being measured [216]. When developing a preference based measure for use in economic evaluation there will inevitably be a trade-off between completeness and practicality as it is inconceivable to capture every item in detail within one measure [215]. Thus the dimensions within the measure need to be broad whilst keeping the measure short enough to ensure practicality.

4.1.2. Generic versus condition-specific measures for economic evaluation

PROMs can be further split into two categories, these are: condition-specific measures and generic measures. Condition-specific measures are measures that are designed specifically for certain aspects of health e.g. to measure outcomes for a specific health condition. Generic measures on the other hand are designed for use across disease groups [201], [217]. Both generic and condition-specific measures have their advantages and disadvantages. Condition-specific measures, being designed for certain disease areas, tend to have the advantage of superior content validity and increased sensitivity to smaller changes than generic measures [217]. In contrast, generic measures applied across disease groups are less likely to pick up smaller changes in health and are therefore likely to be less sensitive. Generic measures, although less sensitive to smaller changes have the advantage of being able to account for co-morbidities that are not captured in condition-specific measures [201]. A further advantage of generic measures is that they have the ability to compare changes in health status across different disease groups; this is a key consideration in terms of its value for economic evaluation. The ability to compare the outcomes between different disease areas offers a great advantage over condition-specific measures in terms of evaluating health technologies in the wider health care context and is therefore beneficial for economic evaluation. Generic measures widen the possibilities in terms of the scope of evaluation.

The purpose of the close-person measure is to capture the benefits of EoLC to those close to the decedent. There are many death trajectories caused by a plethora of conditions. There is no one disease that requires EoLC; death can, of course, be the result of a wide range of illnesses, diseases and ailments. Given the wide range of trajectories towards death, the measure needs to be able to capture the impacts of EoL across these trajectories and in a wide range of settings. A generic measure which can be used in a wide range of EoL settings and across disease groups is therefore preferable. As a result the measure should be generic in terms of its use across EoL settings, however, it retains some of the properties of condition-specific measures in terms of its focus on the EoL context.

4.2. Methods for attribute development

Identifying conceptual attributes

The first step to developing a measure is devising the questions for the measure itself [218]. This is not straightforward, and '*no amount of statistical manipulation after the fact can compensate for poorly chosen questions*' (p.17) [218]. It is therefore imperative that the questions within the measure are designed with much thought and care. There are a number of different methods that can be used to obtain conceptual attributes [218].

The majority of existing generic PBMs use a 'top down' approach to develop dimensions. The most frequently used generic preference based measures including the EQ-5D, Health Utilities Index and Short Form-6D all used this 'top down' approach [202]. The 'top down' approach refers to measures derived from existing literature, using expert opinion, or measures based on existing instruments or scales. This is also a common strategy in the development of attributes for use in discrete choice experiments [219]–[222]. Streiner and Norman [218] argue that this may be an unwise method for proceeding with measure development. Adapting previous scales may be problematic as terminology changes over time and existing scales may be outdated. Furthermore, that a new measure is being sought is itself an indicator that the current measures are inadequate at capturing what the investigator is seeking [218]. In addition to this there may not be sufficient relevant literature for attribute development [223]; if literature is limited then it may lead to the omission of potentially important attributes. A review of condition-specific measures by Brazier *et al.* [224] found that, of 22 measures identified, 12 were derived from existing non-preference based measures, and seven used other top down approaches e.g. taking dimensions from existing literature/expert opinion [202]. Only three did not use a top down approach. The review also concluded that the majority of the papers’ methodology for measure development was poorly described. Given Streiner and Norman’s [218] statement about the importance of devising questions, this lack of transparency in many cases of measure development is of concern.

The ‘bottom up’ approach, in contrast, uses the view of the ‘relevant population’ themselves to develop the descriptive system. This method uses the input of those whose health and lives are affected to develop the attributes which are relevant. This is usually done through qualitative research which is used to generate the content for the dimensions of the measures. Although historically this has been infrequently done within the field of health economics, bottom up instrument development has been growing in recent years with the Food and Drug Administration [225] requiring that measures are developed with the input of patient groups [202]. Recent years have seen a rise in the number of measures being developed in this manner within health economics e.g. ICECAP-O [174], ICECAP-A [175], ICECAP-SCM [177], CES [159] and the CHU-9D [226]. By using the patient/target group to develop the dimensions of the measure, it is likely that the measure will have pertinent language and terminology as well as increased content validity in comparison to top down measures. Furthermore, the measure may be likely to be responsive to change as it will be seeking to capture things that the target group feel are important [226]. As a result the use of qualitative work in attribute development often leads to ‘richer attributes’ than through alternative methods and reduces the potential for misspecification [223]. As acknowledged by Sofaer [227], qualitative research methods correctly used can enhance the development of quality measures.

Given the lack of measures aiming to capture the close-person experience of the decedent’s EoL, there is little scope for using the top down approach. Furthermore, given the issues as discussed by Streiner and Norman [218] in regards to developing measures from the literature, there is little incentive to use this approach. The possibility of adapting an existing measure also does not sit comfortably with this specific measure development task. It would be inappropriate to try and adapt a quality of death measure or a HRQL measure for such a unique experience. Furthermore, it is desirable to optimise content validity and create a measure that is meaningful to those completing it. After some deliberation, it was decided that a bottom up approach would be most likely to produce a measure that succinctly captures the benefits of EoLC to those close to the decedent. The bottom up methodology using qualitative methods is most pertinent to attribute development and highly recommended for the development of attributes [202], [223], [227]–[229]. As a result, the following section focusses on the development of the close-person measure from a qualitative perspective.

4.3. Qualitative methods for attribute development – theory/guidelines

To develop a measure, the conceptual attributes which make up the dimensions first need to be obtained. The bottom-up approach was used, thus, qualitative research was required to generate the attributes. There is a lack of guidance on how attributes should be developed for use in outcome measures for economic evaluation. However two recent papers [202], [223] within health economics have developed recommendations for developing attributes using qualitative methods. These are complemented by more general qualitative methods guidelines for PROM attribute development [230]. The methods used here drew upon these papers.

Stevens and Palfreyman [202] helpfully outline the five key stages of research design where critical decisions must be made when developing a measure with a bottom-up approach.

The 5 stages outlined are:

1. Identify who to interview.
2. Decide upon the data collection method.
3. Design interview/focus group.
4. Conduct analysis of data.

5. Develop the descriptive system [202].

4.3.1 Stage 1: Whom to interview - participants

The first stage of measure development using qualitative research methods requires the identification of who should be the participants of the research [202]. It is important when using the bottom up method of qualitative research to make sure the most relevant individuals are included in the measure development. This is to enhance the content validity of the measure ensuring that all attributes are relevant to the target population [230]. Purposive sampling [231] should be used to try to include as diverse a range of experiences as possible. In terms of choosing whom to interview, unlike quantitative studies, representative populations are less important. What is of more importance in this scenario is that representative experiences are included. Thus the variety in experiences is the goal of purposive sampling rather than that of achieving a representative population [230].

4.3.2 Stage 2: Data collection method

The second stage of measure development requires the researcher to decide on the methods of data collection. The two main methods for data collection in qualitative research are focus groups, and in-depth interviews [223]. In-depth interviews require a relatively small number of participants and are usually held on a one-to-one basis with the researcher interviewing the individual in private. Focus groups are held with a group of people and a discussion is led by the researcher around the topic of interest [231]. Both methods have their advantages and disadvantages. Focus groups have the advantage of allowing participants to feed off each other’s ideas; however it also has the disadvantage of creating an environment where people may feel uncomfortable about sharing their experiences. In-depth interviews can also be uncomfortable [202], however if the topic of discussion is a sensitive area, it allows the individual to discuss the topic in the relative privacy of just the researcher. Stevens and Palfreyman [202] argue that in the case of designing a generic measure, interviews may be more suitable than focus groups. The logic is that for a generic measure it is likely that the participants of the study will have had a widely varying experience and therefore the focus group will be of less value than in a condition-specific measure where everybody has had similar experiences. Coast *et al.* surmise that *"the choice of exact data collection method may ultimately be determined by practical considerations including the sensitivity of the topic"* (p738) [223]. Both methods have their merits and the choice is dependent on each specific study and it is clear that there needs to be a level of pragmatism with no method being 'right' or 'wrong'.

Identifying saturation

Unlike quantitative research, the sample sizes used within qualitative studies are usually much smaller than those in quantitative studies. What is more important in qualitative research is that saturation is reached. This occurs when concepts and sub concepts cannot be further developed with additional data collection and analysis [230]. As data collection continues, there is less additional benefit to that same theme emerging in future interviews in terms of developing the framework [231]. It is therefore necessary to ensure the sample size is large enough to capture the range of issues but be balanced with not being too big to ensure that the data from interviews becomes superfluous and unnecessary [232]. Following the principles of qualitative research, recruitment should continue until data saturation is reached [233]. Strauss and Corbin [234] argue that saturation is not a single point but a 'matter of degree' as there will always be potential for something new to come up, and saturation should therefore be thought of as the point where additional research becomes counterproductive and does not significantly impact the overall findings. Mason [232] conducted a systematic review of the sample sizes of 560 PhD theses using qualitative interviews, the most frequent sample sizes were 20 and 30 (followed by 40 and then 10) with a median of 28 participants. The review found that a significantly high proportion of studies had multiples of 10 for their sample size. This suggests that researchers may have failed to keep the concept of saturation in mind when deciding on whether to continue with interviews, instead working to a predetermined quota and suggesting an insufficient grounding in the concept of saturation [232].

There are some guidelines as to sample sizes required to achieve saturation depending on the qualitative study type. Pertinent to this study is Creswell's recommendation for grounded theory studies. When using grounded theory, Creswell recommends a study size between 20 and 30 participants for saturation to be reached [235]. These guidelines fit nicely with the study of Guest *et al.* [236] which aimed to provide an evidence based foundation for researchers to build upon. The study of Guest *et al.* [236] conducted 60 interviews and systematically documented the degree of saturation as the analysis continued; analysis was conducted iteratively. After analysing the 60 interviews, the study found 36 high frequency codes. After just six interviews, 34 of these 36 codes were present. After 12 interviews, 35 of the 36 codes were present. The study found that within six interviews the basic meta-themes had been identified. After 12 interviews they felt saturation had occurred with just 1 code emerging over the following 48 interviews. Thus there was a clear diminishing marginal return to the interviews. This would fit with Strauss and Corbin's [234] definition of saturation whereby saturation occurs where additional research becomes counterproductive and does not significantly impact the overall findings. It should be noted that this is just one study and the heterogeneity of the participants, the skill of the interviewer and the complexity of the research focus will affect the numbers required [223].

4.3.3. Stage 3: Interview design

The next key consideration when creating a new measure using a bottom up approach is the design of the interview or focus group. Interviews can generally be split into three broad categories, structured interviews, semi-structured interviews and unstructured interviews [237].

Structured interviews are typically used to garner quantitative data and follow a strict set of questions with no allowance for deviation. Typically each question would be read aloud by the interviewer with no movement away from the interview protocol. This is an excellent method for collecting standardised data for use in quantitative research, however for measure development it is of limited use. Although the distinction is made between semi-structured and unstructured interviews, in reality, the distinction is rather artificial and a combination of the two strategies is frequently used [231], [237]. Unstructured interviews by definition have no structure to them and have no set path. This in reality is unlikely to happen with interviews that are classed as unstructured actually having some structure and occurring in the form of a conversation with a purpose. Although useful for generating lots of data, the unstructured interview has the disadvantage of not focussing on the topics of interest and may consequently lead to an abundance of redundant data which does not contribute to the research. Semi-structured interviews sit somewhere in the middle and often provide the primary data for qualitative research projects [237]. Semi-structured interviews usually are interviews that are based upon a certain set of prepared open ended questions that make up a topic guide [231], [237]. The topic guide can then be used to steer the interview over the topics of interest to the researcher [237]. Probing and prompting can then be used to further explore the topics of interest.

The setting of the interview is important as the environment and those present may impact upon the willingness of the participant to discuss their experience [231]. It is recommended that interviews take place in an environment in which the participant feels comfortable which is also quiet to avoid disturbance of the interview process [231].

4.3.4 Stage 4: Analysis

Stage four of creating a new measure involves the analysis of data. The method of analysis is important. Data from qualitative research is typically recorded and transcribed to form a record reporting exactly what was said during the interview. There are a number of methods for analysing qualitative data. Examples include: narrative analysis, whereby data are analysed as a story;

discourse analysis, a method of analysing spoken interaction, and grounded theory, whereby themes are generated from the data to understand some phenomena [231]. In grounded theory, transcripts are analysed by assigning codes to different sections of text from which larger themes can be developed [231]. An important aspect of grounded theory is constant comparison. Constant comparison refers to the process of comparing new findings to existing codes when analysing the data and refining the coding structure in response [238].

In relation to the development of attributes, there is some guidance within the qualitative literature as to the method of analysis for the development of attributes. Lasch *et al.* [230] and Coast *et al.* [223] advocate the techniques and procedures of Strauss and Corbin (constant comparative analysis) to develop a mutually exclusive comprehensive list of attributes. Such methods are inductive, thus, there are no pre-conceived theories reducing the chance of bias, with attributes being generated from the data. It has been noted that using codes based upon relevant literature can be useful, however this can also inhibit the creation of new ideas [234]. Strauss and Corbin [234] provide flexible advice on how data should be analysed within this approach. They suggest that coding of the qualitative data can be split into three levels: open coding, axial coding and selective coding. The coding process begins with open coding which is the most micro-level and relates to coding on a line by line basis breaking large sections of text down into small packets of data. Axial coding refers to the process of rearranging and organising the data after open coding by making connections and comparing the categories formed during the open coding process. The final stage of the coding process is selective coding, this refers to the process of identifying the core categories (dimensions) and refining the theory [234].

4.3.5 Stage 5: Development of the descriptive system

The final stage of measure development entails the creation of the descriptive system of the measure. Once the analysis has been completed a number of dimensions should have been identified. It is important that the descriptive system is practical and amenable to valuation and should therefore have no more than nine dimensions [202]. The levels for each dimension are typically in the form of severity or frequency, and the choice may well vary on the nature of the dimension. The constant comparative analysis should lead to a number of conceptual attributes which then form the dimensions of the measure. The initial wording of the conceptual attributes however may change to accommodate the target population for the measure. Coast *et al.* [223] highlight the importance of ensuring that measures are meaningful to respondents. This is one particular aspect where qualitative research has a great strength over quantitative research; it provides the opportunity to get feedback from lay persons on the meaning of the dimensions and the way they are worded. This ensures that the meaning is as desired and avoids terminology that is common to researchers but not to the general public [223]. Coast *et al.* [223] stress the importance of this phase in their experience of measure development. The conceptual attributes initially developed are often meaningful to the researcher however not to the target population. The attributes therefore need to be converted into lay language and interviews used to further test the meaning of the dimensions with the target population [223]. This process should also include the generation of levels for the measure using the interviews to get feedback on what works best for the target population. The two stages of measure development (i.e. obtaining the conceptual attributes and developing meaningful wording) can be seen as two distinct stages [223].

4.4. Identifying close-person networks

As outlined in Chapters 2 and 3, economic evaluation has typically focussed solely on the patient benefits of interventions from the health care perspective. The Department of Health [132] however has endorsed the inclusion of wider benefits of interventions into economic evaluation. This is especially pertinent to EoLC where interventions often extend to those close to the dying [142] and benefits can be received by those other than the patient [21], [67]–[70]. It is straightforward to decide that the patient should be included within economic evaluation. What is less clear is who else should be included within economic evaluation, and how many individuals this may entail. This gives the opportunity for some novel research to be conducted within the interview process to ascertain who is close to those at EoL, how close they are, and to ascertain the scale of the close-person networks at the EoL. To understand the close-person networks around those at the EoL, it is important to understand what makes people ‘close’. Once ‘closeness’ is understood, the networks around those at EoL can be examined to explore what may impact upon closeness. It is useful to obtain an understanding of the close-person networks around those at the EoL as this will facilitate the identification of who may be affected in addition to the decedent and thus should be included in economic evaluation.

4.4.1. Tools that could be used to assess closeness

4.4.1.1. Dyadic tools

Within the social psychology and communication studies literature there has been much research surrounding concepts such as friendship, closeness and intimacy [239]. Relationships have long been studied and within the past 30 years there has been increasing research effort and specialisation in understanding relationships. There is a body of literature within the personality and social psychology field which examines relationships and intimacy. Aron *et al.* [239] discusses a conceptual framework where in a close relationship, the other is, to some extent part of the self. That is, for somebody to be close, one is including the other in the self. In Aron *et al*’s self-expansion model they put forward that, in the context of a close relationship, resources, perspectives and identities of the other are included in the self [239]. By including the resources of the others as one’s own, the implication is that outcomes that are inflicted upon the other will to some extent be experienced by the self. Therefore any harms that are experienced by the other will impact upon the self, likewise any rewards to the other will be rewarding to the self. The implication of this is that within close relationships there is interdependence [240] between the two individuals. With this theory in mind, Aron [241] developed a dyadic measure called the Inclusion of the Other in the Self scale (IOS Scale) to assess the closeness of two individuals. This measure uses seven pairs of circles with differing degrees of overlap with one circle in the pair representing the self, and the second circle, the other. The scale asks individuals to choose a pair of circles which best represents their relationship. The measure is scored from one where there is no overlap to seven where there is nearly a complete overlap between the two circles. This measure has been frequently used within the social psychology literature to examine interpersonal relationships between individuals and has been used to assess closeness between individuals [240].

Building upon the ‘other as the self’ literature, Starzyk *et al.* [242] developed the concept of ‘personal acquaintance’ as assessed by the personal acquaintance measure (PAM). The PAM is an 18 item measure containing six subscales which were found to be dimensions of acquaintance: duration of acquaintance, frequency of interaction, knowledge of goals, physical intimacy, self-disclosure and social network familiarity. The answers for the 18 items are then scored to derive sub scale values as well as a total personal acquaintance score. This measure has demonstrated convergent validity with other relationship measures, as well as sensitivity to known differences in groups. Both the PAM and IOS Scale, although used to assess closeness of inter-personal relations, only do so between the dyad, the self and the other. This research seeks to understand the size of the network and the relative closeness of individuals to those at EoL. Given that many of the decedents will already be deceased, measures such as the previous two are inappropriate as it is unfeasible to identify, and administer such a measure with all possible participants within every decedent’s network.

4.4.1.2. Strength of tie indicators

There is a body of research within the mathematical sociology and social network literature that has focussed extensively on interpersonal ties and the notion of the strength of these social ties. Much of the research based upon social ties is derived from the seminal work on weak social ties by Granovetter [243]. The strength of tie between two individuals has been expressed as a combination of the amount of time spent together, the level of emotional intensity, and reciprocal services which characterise the tie [243]. Over the last thirty years, much research within the social network literature has examined indicators and predictors of social tie strength [244]. Marsden and Campbell [245] found that indicators of tie strength such as frequency of interaction are affected by contextual factors. Petroczi [244] assessed the social tie strength literature and found there were no continuous, quantitative methods for assessing the strength of social ties. In response to this Petroczi [244] developed a measure of strength of social ties called the Virtual Tie-Strength Scale (VTS-scale). The VTS-scale consists of 11 questions and was designed to be used with virtual communities however is also applicable for offline use. This measure like the IOS Scale and the PAM was again limited for this research for the same reasons.

4.4.1.3 Pictorial tools

Within the field of family therapy, family diagrams as pioneered by Bowen [246] have been used to record the facts and function across multiple generations of a family, these include information such as issues with health, and achievements [247]. Out of the family diagram literature genograms were developed [247], [248]. Genograms and family diagrams have often been synonymous however genograms have a different purpose. Whilst family diagrams aim to visually record the facts and functioning of multiple generational families, the genograms as introduced to the literature by Guerin and Pendagast [249] allow for the introduction of broader contextual information such as gender, ethnicity and societal influences. In recent years, other methods have been developed to obtain a greater understanding of the relationships and flow of resources within such networks.

The Pictor method [250] has been developed and used within qualitative analysis to explore the network of people involved in collaborative work surrounding someone receiving care. Closely aligned to the Pictor method are ecological maps (ecomaps). Ecomaps are useful for analysing the different forms of support within a network [250]. Ecomaps are a method that was developed in the 1970s and has been used to examine social networks of individuals and the nature of the bonds within their network [251]. Ecomaps have been used within the social work and nursing literature to explore social relationships, particularly in terms of support for carers [252], [253].

Ecomaps are visual representations of relationships that exist between members of a social group, providing evidence of the size, structure and function of the network [254]. Ecomaps typically have been used to explore not just relationships within social networks but also to investigate other links such as support between individuals within the network. Early *et al.* [255] used an adaptation of the ecomapping process to identify the relationships and needs of those people at EoL and those providing support. Ray and Street [252] used ecomaps to examine different avenues of support for carers of those with motor neurone disease. McCormick *et al.* [256] demonstrated how ecomaps can be used to present factual information on the relationships within a family's network. The ecomaps process has typically relied on getting the carer to draw a circle that represents themselves in the middle of a large piece of paper. The researcher then asks the carer to draw the relevant people/institutions surrounding the individual e.g. in the case of support for carers it may be a nurse or even church [250]. Lines can then be used to indicate the nature of relationships, for example a thicker line may be used show a stronger relationship. Jagged marks across a line can be used to represent conflict. Other lines or arrows can also be used to show other features such as flow of support or resources [251]. To date, most uses of ecomapping have focussed on the support networks surrounding carers [250].

A less complex visual tool with strong similarities to the ecomap which may be suited to the purpose of this research is the sociogram. The sociogram was first introduced by Moreno in 1934 [257] to examine choices within a group. Sociograms are a pictorial tool that have been used to visually represent or map the structure of relationships between individuals [258]. Sociograms have historically been predominately used within educational settings to examine classroom dynamics [259]. They have also been utilised in various other settings including within information systems research [260], as a tool within focus group analysis [258] and in environmental research [261].

Similar in style to the sociogram used by Northway [262], Antonnucci [263] developed the 'hierarchical mapping' method (also referred to as 'mapping' from here-on) which allows the size of close-person networks to be assessed. The mapping task involves the use of three concentric circles to represent the relative levels of closeness that people have in relation to the individual in the centre [264]. Typically within this style of task, individuals are asked to put the principal in the centre and then put the names of those who are closest to them within the inner circle, those who are less close but still important in the second circle and, within the outer circle, those who are still important and close but have not already been mentioned within the two inner rings. This method of eliciting social networks in terms of closeness has been found to be simple, efficient and comprehensible to the general public [265]. The method allows for individuals to describe the social networks according to their own feelings of closeness without influencing their choices, reducing potential bias. The method has been used and adapted within numerous studies to examine a range of different issues. For example it has been used in studies exploring network size of individuals [168]; examining the negative effects of social relations [266]; examining the dynamics of intergenerational relationships [267]; and assessing the composition of social support networks [268].

4.4.2. Benefits of pictorial methods

Visual tools used within qualitative studies, have been found to help generate rapport as part of the interviewing process [269] and when used in conjunction with text can give deeper insights into sociological research [251]. A number of other benefits of using visual tools have been discussed within the literature. The key strength of such tools include their ability to present potentially complex factual information in a straightforward manner [256]. In the study by Rempel *et al.* [253] which explored the use of ecomaps with family caregivers, they found that they led to improved understanding of social networks for caregiving, and also helped facilitate rapport between the researcher and the participant [253]. Pictorial methods have been found to provide a rich source of data for analysis whilst simultaneously giving participants an opportunity to reflect on their situation which would not be so easily afforded by standard interviewing practices. It also has the benefit that it provides a basis for further questioning about the nature of relationships [252]. Pictorial tools provide data that enhance the understanding of the contextual situation around the participant and provide visual triggers for both the participant and the researcher within the interview [252].

4.5. Conduct of qualitative work to develop the measure

The primary aim of the qualitative work was to develop a measure to capture the impacts of EoLC on those close to the dying. The purpose of this section is to outline the methods used to develop the close-person measure.

4.5.1. Sampling

The individuals of interest for the purpose of this study were those who either had loved ones/relatives in EoLC, or were recently bereaved. Given the difficulty in identifying such people with little guidance within the literature on how best to access such a sensitive group of potential participants, several different methods of recruitment were utilised to improve the chances of successful recruitment into the study. There were two primary recruitment streams, the first was through the University of Birmingham, and the second was through the Marie Curie Hospice, West Midlands. Recruitment through the University of Birmingham was chosen due to the broad spectrum of staff and students at the university in respect to their age and professions. In addition to this, there is no specific death trajectory associated with those close to members of the university. In contrast, the Marie Curie Hospice, West Midlands was chosen to capture older participants who are less likely to be in the working population. As part of both recruitment streams, snowball sampling [270] was conducted with recruited participants to try access a wider range of participants giving the opportunity to explore how perceptions of care vary within close-person networks.

Recruitment through the University of Birmingham: To try to capture a variety of experiences and socio-demographics at the University of Birmingham, three primary recruitment strategies were used. First, an advertisement was placed within a number of University of Birmingham newsletters to both staff and students to recruit eligible participants. Second, advertisements inviting participants into the study were placed around campus (see Appendix two). The third sampling method used was snowball sampling. At the end of each interview, participants were given a spare information sheet and asked to pass the information sheet onto anybody they thought might be interested in participating in the study. All three methods of recruitment required individuals to contact the author about inclusion within the study. Upon contact, further information and a screening questionnaire (age/gender/ethnicity/relation to the decedent) was given to the participants and after completion an interview time and date was set up.

Recruitment through the Marie Curie Hospice, West Midlands: The second stream of recruitment was through collaboration with the Marie Curie Hospice, West Midlands. The research nurse at the hospice identified potential participants meeting the inclusion criteria and made initial contact with potential participants to introduce the study and to determine whether they may be interested in participating. Once identified, the research nurse gave them information sheets and obtained informal agreement for participation in the study. Potential participants were then contacted to set up an interview date and obtain consent. Once the participant had been recruited into the study, a time and date was arranged for the interview to be conducted. Again, snowball sampling was conducted with the participants as described above.

4.5.2. Ethical Issues, eligibility and conduct

To recruit participants in the study, it was essential that ethical approval was obtained. Given the two different streams of recruitment, two separate applications for ethics approval were made, one through the University, and one through the NHS. Both the University ethics [ERN_12-1338] and NHS ethics [13/WA/0333] approvals (see Appendix four) were obtained allowing the recruitment in the study. There were a number of important ethical considerations for the research.

One of the key difficulties with recruitment related to the ethical issues surrounding such a population group. Given the sensitivity of the topic, there were a number of necessary considerations when recruiting. For ethical reasons, as discussed in the literature [271] and recommended by the EconEndLife advisory group, it was decided that participants should not be recruited within six months of being bereaved. Likewise, it was desirable that participants could still remember the details of their bereavement, and so the participants had to have been bereaved within two years of recruitment. All participants received an information sheet outlining what participation entailed (see Appendix three) at least a week prior to the interview. To participate in the study, informed consent was sought for all participants prior to the interview. It was stressed during this process that the participants could stop the interview and withdraw from the study should they wish. During the interview process many chose to momentarily pause to shed tears; however none chose to stop the interview.

To try to make the participants as comfortable as possible, interviews were arranged to take place in an environment of their choice, this included at the university, at the hospice, or at the participants homes. When conducted at the university or the hospice, private rooms were booked to ensure privacy and to avoid distractions. This gave the participant the opportunity to talk privately in an environment in which they felt comfortable without interruption. The majority of participants chose to be interviewed at the university; however two did choose to be interviewed at their home, whilst three were interviewed at the Marie Curie Hospice.

There were several risks associated with conducting this research, the greatest being the potential to cause emotional distress to participants. As a result, two training courses were attended to prepare the author to be able to deal with difficult situations, and emotional participants. At the end of each interview, details of bereavement support options were given to participants to signpost them towards information and support, should they require it following the interview. There was also a secondary risk to the interviewer that the experiences of the participants might cause emotional harm. To reduce the chances of this, regular debriefs took place following the interviews at the start of the process; later on these continued as and when the researcher felt they were required. To protect the researcher when interviewing participants in non-institutional premises, a lone-worker protocol (see Appendix three) was used to minimise the risk of harm coming to the researcher.

An important consideration when conducting the research related to confidentiality. Confidentiality was strictly enforced throughout the study. Upon the completion of the consent form, the participant was issued a participant ID code, from this point onward during the research, only their ID code was used to identify the individual. The digital audio-recordings are kept on a secured network that only the researcher and supervision team have access to. Upon the completion of the study, all records will be kept for 10 years (in keeping with University policy) before being destroyed. Any names/places mentioned have been changed to ensure their identity is kept confidential. Similarly, the copies of the consent forms are kept in a separate locked filing cabinet that only the research team has access to. The processes that were put in place should ensure the confidentiality of all those who have participated within the study.

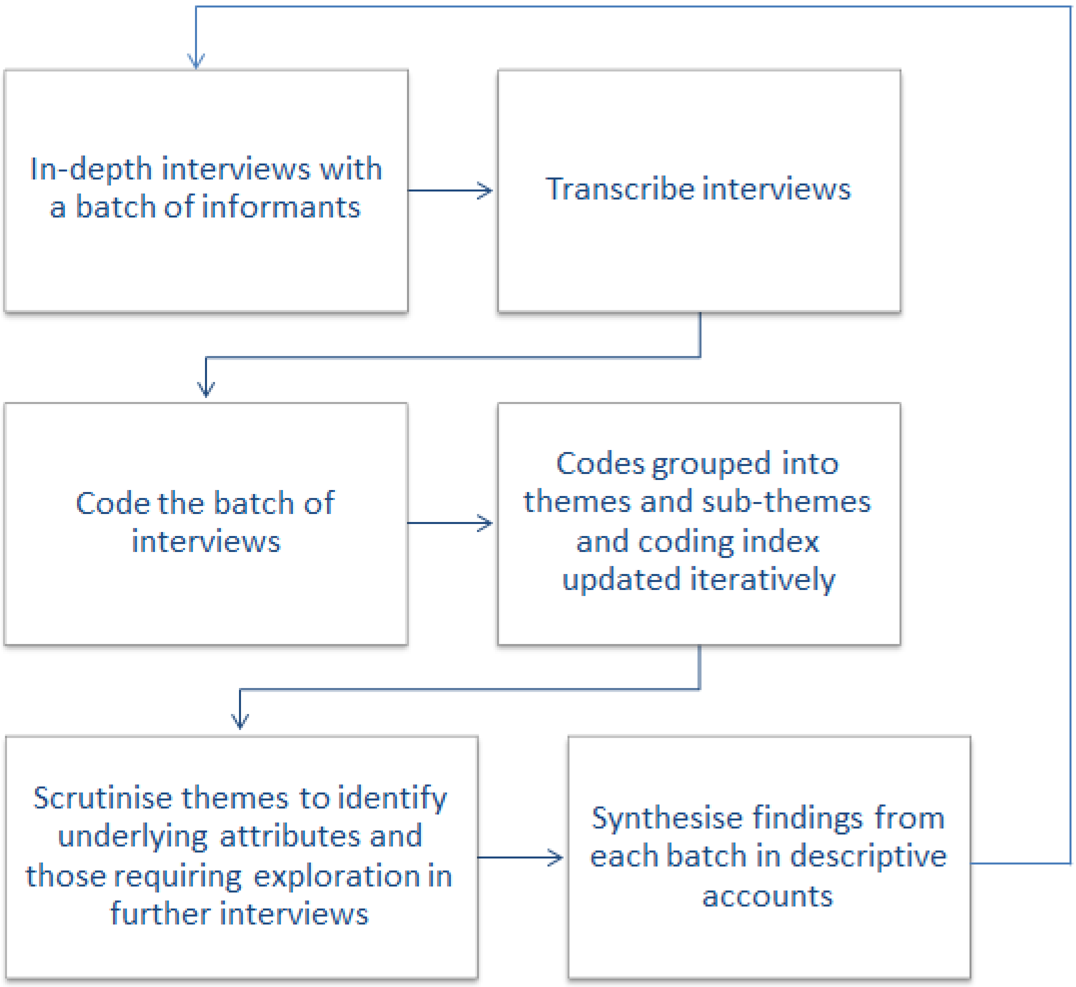
4.5.3. Interview design

Given the extremely sensitive nature of this research and the wide range of different death trajectories, face to face semi-structured interviews were chosen to collect data. Interviews took place with individuals who were either bereaved or had a close-person receiving EoLC. Open ended questions were used to encourage individuals to discuss their experiences of the EoL of their close-person whilst limiting the influence of the interviewer. The interviews followed a broad topic guide (see Appendix five) with responsive questioning and probing being used to obtain an in-depth understanding of the topics discussed. There was flexibility within the interview guide to allow for the exploration of any topics that the interviewee proposed. The interview schedule changed iteratively as new attributes and ideas developed. Initially, interviews began with general questions about the participant and their decedent to build rapport and ease the participant into the interview. The sub-objective exploring the evaluative scope and contextual issues (see 4.6) were then discussed. The latter half of the interview focussed on the participant's own experiences of EoLC and what they felt was good and bad about their experience, and the things that have helped them cope. The interviews were recorded using a digital tape-recorder to aid the interview process and provide a data-rich source for analysis.

4.5.4. Constant comparative analysis

Constant comparative analytic methods, as recommended within the literature [202], [223], were used to analyse the data. The digital recordings were transcribed to form interview transcripts for each interview. These transcripts were then analysed using constant comparative analysis [233] on an ongoing basis. Interviews were conducted and iteratively analysed in batches that numbered between three and six. This was a pragmatic decision and depended on the dates that participants had been booked in to be interviewed. The steps of the analysis process are outlined in Figure 1.

Figure 1: Constant-comparative analysis process



The analysis started off with a general reading through of the transcript, and then a more thorough read with open codes being applied to sections, paragraphs or sentences as they emerged from the data. Having coded the first transcript, further transcripts were coded with this transcript in mind with new codes being added as new categories arose. To ensure a high quality of analysis with qualitative data, repeated systematic searching of the data was required until no new themes emerged or developed [272]. To ensure consistency in the interpretation and application of the codes, newly coded sections were compared to other similarly coded sections [234] and descriptive accounts were created to synthesise the data [231]. Following open coding of transcripts within each batch, axial coding took place. This involved grouping and comparing codes with other similar codes to create sub-themes. The over-arching themes were developed through selective coding, that is by identifying the core themes and relating all sub-themes to these primary themes. At the end of the process, the selective coding process resulted in primary themes, with the axial codes effectively becoming sub-themes of the measure which were in turn developed from the open codes. All themes were therefore created directly from the data. From the analysis of the interviews, to help ensure rigour, a coding structure was formed (see Appendix six) which was edited, and changed iteratively as new codes were assigned and the analysis progressed. Through this process, themes and sub-themes were developed that were to become the basis for the attributes and descriptors of the measure. To further enhance rigour in the process, alongside the development of a coding structure, in-depth descriptive accounts which systematically analysed the data were created for each batch of interviews. Supervision meetings took place with academic supervisors every three weeks. These supervision meetings included discussing, updating and checking the coding structure along with in-depth discussions of the descriptive accounts to ensure that data was being analysed in a systematic and rigorous way.

At every stage of the analysis, when examining the themes, the question ‘why is this important?’ was asked to examine the underlying attributes behind the themes. Things that on the surface appeared to be very different often had the same underlying attribute, and it was through this process that the underlying attributes of the measure were identified and developed. For example, in early transcripts, pain to the decedent, lack of care/attention to the patient, and loss of dignity were treated as separate codes. Through the analysis when asking ‘why is this important’, it became apparent that the underlying impact was emotional distress for the close-person related to the condition and care of the person, which then developed as an attribute. Likewise, on occasion, data that were initially coded together within a larger theme were later divided to form distinct attributes.

4.5.5. Developing meaningful wording

It was important to check that the conceptual attributes covered all areas of importance, and to generate meaningful language that would be understood by the eventual users of the measure. The final batches of interviews therefore turned their focus onto checking the coverage of the attributes that had been developed from the themes and testing the wording for meaningfulness. This occurred as part of the overall iterative process. In the latter part of the interviews, once participants had discussed their own experiences, they were given a list of the conceptual attributes and descriptors. They were then asked to identify what, if anything they felt should be on that list that was not already there. This was to check that saturation was indeed reached and to try to capture any remaining attributes or subthemes. Participants were then asked to go through the list of attributes and descriptors and discuss each in reference to their own situation. This allowed the researcher to assess whether the participants understood each attribute as intended. It also gave the respondents a chance to reflect on the descriptors and give suggestions to things they felt would have been helpful which were not already listed. As the interviews continued, wording for the attributes and their descriptors was changed, and developed based upon these interviews. The participants were questioned about the meaning of these concepts and wording introduced by the participants was incorporated into the topic guide and explored. Later interviews focussed on establishing and fine tuning the description of the attributes and levels to be used within the measure. The final batch of interviews presented the participants with the full set of attributes worded as capabilities, complete with levels for each attribute; the participants were then asked for their views on the terminology and levels to establish that the measure was meaningful.

4.6. Conduct of hierarchical mapping

The interview process featured a novel research method to explore who is close to those at EoL and thus might enter the economic evaluation with a ‘close-person’ identity. The first part of the interview was therefore used to build upon the existing literature and investigate what a 'close-person' is, and who is close to those at EoL. To explore this, qualitative analysis in conjunction with a pictorial tool was utilised to examine the diversity and scale of the networks. As part of the interview process, participants were asked what 'close' meant to them, and the characteristics of close-persons were explored. In conjunction with examining what 'close' meant to participants, information on the close-person networks was sought. By using a pictorial tool it was possible to develop a picture of the people who are likely to be impacted by bereavement and should therefore be considered for inclusion within economic evaluation. For this purpose, the method chosen to capture the scope, and scale of closeness within the networks, in a quick and visually appealing manner, was the hierarchical mapping technique. This method meant that a visual network of those who are close to those at EoL was obtained without collecting superfluous information.

4.6.1. The mapping task

The primary objective of the hierarchical mapping task was to map the relative closeness of the different individuals within the decedent's close-person network. A map with concentric rings was therefore developed (see Appendix seven) with each ring representing a different degree of closeness as first detailed by Antonucci [263]. The mapping process used within the interviews can be broken down into eight simple stages. These were as follows:

1. It was explained to the participants that something that the research was interested in was the networks around those at the EoL. The participants were asked whether they were happy to participate in a task examining these networks. The close-person being interviewed was asked to think about their close-person (whom the interview was focussed on) and who was either currently receiving EoLC or had recently died.

2. The A3 piece of paper that provided the basis for the mapping task was then introduced. In line with by Antonucci's [263] recommendations, the map included concentric circles

moving out from the centre, with the circles representing different degrees of closeness to the person.

3. The task was then explained to the participants. They were asked to imagine that their decedent was in the centre of the piece of paper. It was explained that the concentric circles represented the different degrees of closeness from the decedent, with the inner ring representing extremely close, the second ring very close, and the outer ring quite close.

4. The close-person was then asked to write onto, arrow shaped post it notes (one per note where possible), the name and relationship to the decedent of each person that they would describe as being close to the decedent.

5. The close-person was then instructed to place each post it note onto the map with the distance from the tip of the arrow to the centre representing the closeness of that individual to the decedent. The post it notes did not have to be placed exactly on a line and could be moved to show small differences in closeness.

6. Once all the close-persons had been added to the map, the individual was given time to reflect on their choices and rearrange the arrows accordingly, until they were happy with their final decision.

7. The map was then discussed with the participant, providing the opportunity to ask questions about the impacts of EoLC on the different members of the network.

8. The maps were then scanned into a computer and anonymised. The maps were then used in conjunction with the interview transcripts to provide a snapshot of who was close to the decedent, and how close those individuals were.

4.6.2. Close-person network analysis

Constant comparative methods as outlined within section 4.5.4 were also used to analyse the interview transcripts to determine what closeness meant to the participants and who may be close. As with the attribute development, the transcripts were coded and themes were developed in relation to things that make people ‘close’. Factors that participants mentioned that concerned impact on closeness were also examined and probed when required. From this it was possible to ascertain factors that facilitated closeness between individuals. In addition to the constant comparative methods as previously described, the hierarchical maps were analysed alongside the interview transcripts. To examine the scope of the networks at the EoL the number of ‘close-persons’ included within the hierarchical maps of the decedents were recorded. Descriptive statistics were calculated to examine how many individuals were close to those at the EoL. In addition to this, the hierarchical maps were compared and contrasted, and the reported network size and closeness were examined to give an indication as to the extent of close-person networks surrounding those close to EoL. The nature (e.g. relative or friend etc.) of those close to the dying was explored. Any cases which appeared to be unusual or in any way ‘deviant’ [273] were analysed in further detail to examine why this was the case.

In addition to examining what makes somebody ‘close’ and how many are close to those at the EoL, factors that may impact upon closeness and thus the size of network towards the EoL were investigated. To do this, the largest networks (those with ten or more ‘close-persons’ and the smallest networks (those with five or less participants) were examined and compared/contrasted to each other. By comparing the smallest and the largest networks, it helped to elucidate the factors that potentially affect closeness and the sizes of network at the EoL. Network size was also investigated according to the death trajectory of the decedents, the age and ethnicity of the participant, and the relationship of the participant to the decedent.

4.7. Conclusion

This chapter has described the methodology and methods for the development of the close-person measure, and for the exploration of the evaluative scope. The first half of the chapter focussed on the general methodology relating to measure development and identifying social networks. The second half of the chapter describes the methods that were employed within the study. A bottom up approach was chosen to develop the measure and semi-structured interviews were chosen as the method for data collection with constant comparative methods being used to analyse the data. To examine the evaluative scope hierarchical mapping in conjunction with the interviews were used to explore who may enter the evaluation and how networks may be impacted at EoL.

CHAPTER 5 METHODOLOGY AND METHODS: DELIBERATIVE VALUATION

5.1 Introduction

As discussed in Chapter 4, the primary purpose of this study is to develop a measure to capture the impacts of EoLC to those close to the dying for use in economic evaluation. As a result it is desirable for the measure to be amenable to the economic evaluation process. As previously outlined, measures that have been valued are desirable for use within economic evaluation. Thus it is important that the close-person measure is valued to provide meaning to the relative levels and dimensions of the measure. As the measure is being developed within the capability framework, an opportunity to explore a new novel methodology that more closely aligns with the capability literature is explored within this chapter. The purpose of this chapter is to introduce a new method of valuation within health economics and then describe how the valuation was conducted within this study. This chapter will therefore first explore how measures within the health economics literature have been valued to date. The chapter will then refer back to the guidance on how valuation should be conducted within the capability literature and issues with how current capability measures are being valued. The literature on deliberation, discourse and debate, and its impact on decision making and it’s applicability to the valuation process will then be discussed. The second half of the chapter will then focus on the methods that are used to conduct the valuation. Thus, the chapter will outline the methodology of valuation within the capability literature and then detail the specific methods used within this study.

5.2 Methodology

5.2.1 Valuing measures

The close-person measure is designed to be used within the economic evaluation process of EoL interventions. For this to be the case, the measure has to first be meaningful to close-persons of those at EoL. Secondly to provide use within economic evaluation, it is necessary that a value set for the measure exists [181]. The primary reason that valuation is necessary is that the health care budget is limited and therefore important decisions need to be made about how best to allocate resources. Given this, it is important that the budgets are spent optimally and should therefore be allocated to interventions that provide the largest improvements to the most important capability sets. If the measure is not valued, and either arbitrary weights or equal weights are placed on each capability, then, this is likely to be a poor representation of their relative importance to society.

Within the health economics literature there is very limited guidance on how measures of capability should be valued with no definitive methods for value elicitation existing [181]. In the capability literature there are few capability measures that have been valued. The majority of capability measures therefore do not have value sets associated with them. Rather, in the wider capability literature there is often a focus on using natural units or arbitrary weights [180] which as previously stated is limited in use where budgets are finite and trade-offs have to be made between competing alternatives. To value a measure for use in economic evaluation it is required that the states of a measure are valued on an interval or ratio scale to allow comparability [274].

5.2.2 Valuing health states within the health economics literature

Within the wider health economics literature, a number of different methods have been utilised to value the states as specified by measures. This section will outline the different methods that are frequently used to derive values for measures within health economics.

Traditional methods of health state valuation

Traditionally, health economics has relied primarily on utility as the basis for preference-based measures of HRQL or well-being [201]. Using this methodology, for each state defined by the measure, a utility value is calculated. This value is typically on an interval scale from zero to one where zero equates to a state equal to death, whilst one represents perfect health. States worse than death are possible and these are represented by negative utility scores [201]. A number of methods have been used to generate such scores. The oldest and most well established are direct valuation methods, these include the visual analogue scale (VAS), the standard gamble (SG), and the time trade off (TTO) [201].

Visual Analogue Scale (VAS)

The VAS is the simplest of the methods for valuing a given state and was developed through psychometric theory [275]. The VAS process involves giving the participant a simple line with zero at one end of the scale representing death (or an alternative), and one at the other end representing full health. The participant is then asked to put a given health state onto the line where they believe the state lies in accordance to their preferences [276]. Respondents then place each state onto the line with the differences between each state representing their perceived difference in the quality of that state. From this values can be obtained for the different states of the measure. As there is no trade-off and uncertainty involved in this technique, the outcomes are technically ‘values’ as opposed to ‘utilities’ if economic theory is adhered to [211]. These values however have frequently been used within the literature as utility values.

Standard Gamble (SG)

A more complex approach to deriving the value for a given status as defined by a measure is the standard gamble [277]. The SG approach is the classical way of obtaining preferences within economics and is consistent with economic theory. It has been used extensively within economics for establishing preferences [275]. This approach is much more complex than that of the VAS. The SG gives individuals a choice between two different options. Individuals are asked to choose between a state with certainty, or another better state (normally perfect health) with a particular probability of death [275]. In essence the individual is asked to choose the certain option, or take the gamble of full health with a chance of death. The parameters of the gamble are then changed iteratively until a point of indifference between the gamble and the certain state is achieved. The value can then be determined by one minus the probability of death in the gamble. So if the point of indifference occurred when there was a 0.3 risk of death when gambling for full health, the associated value would be 0.7.

Time Trade-off (TTO)

The TTO was developed specifically for use in health care by Torrance *et al.* [278]. In terms of complexity, the TTO represents a compromise between the simple VAS and the cognitively challenging SG. This approach, like the SG, requires respondents to make a trade-off between two different options; however it lacks the element of uncertainty [211]. Therefore in terms of the degree of its economic grounding, it lies between the VAS and the SG. The TTO exercise involves presenting the individual with two different options. They are asked whether they would prefer to either be in a given state for a set number of years, or live for a shorter period in full health. The period is then changed until the point of indifference is reached and from this the value is derived. This method effectively finds the proportion of time the individual is willing to trade-off to achieve perfect health; this is then used to obtain the value. For example a person who is indifferent to 10 years in the given state and seven years of perfect health will have a value of 0.7 for the health state.

Health economics has primarily relied upon the use of the TTO and SG for valuing measures [275]. The most common measure for use in economic evaluation as recommended by NICE [127], [129] is the EQ-5D; this instrument was valued in the UK using the TTO methodology [212]. The SF-6D and the HUI 2/3 on the other hand have been valued using SG methodology [201]. These methods rely on individuals manipulating probabilities or trading-off life. As a result there are issues with these methods [279]. As all three of the direct valuation techniques are seeking to obtain a 'utility' value, it therefore is an issue that all three methods provide different results for the same health state [276] with the VAS generally giving the lowest values, SG the highest values and the TTO values somewhere in between [275]. This is due to a number of things including the impact of uncertainty, risk averseness of individuals and the complexity of the different tasks [201]. In recent years there has been an increased interest within health economics of exploring alternative methods for valuation.

5.2.3 Discrete choice experiments

The past decade has seen an increase in the use of discrete choice experiments for the valuation of measures including, for example, the Carer Experience Scale (CES) [280], CarerQol-7D [281], ICECAP-O [181] and ICECAP-A [183]. Discrete choice experiments [228] are able to provide inferences about HRQL or utility. Like the TTO, and SG, DCEs rely largely on the assumptions of economic rationality and utility maximisation [282].The DCE is a quantitative technique that allows the elicitation of individual's preferences and has been used in a wide range of scenarios within applied economic research [282]. The DCE method involves getting participants to choose between sets of hypothetical scenarios. Each alternative has a number of attributes and individuals are asked to make a choice between attributes. Recent years have seen an adoption of best-worst scaling (BWS) [283] which is a type of DCE where individuals are asked the cognitively simpler question of which item they think is the best and which is the worst in a given scenario [183].

5.2.4 Valuing capability measures in practice

There is no definitive method for how values for capability measures should be obtained [181]. In terms of the process of valuation within the capability framework, Sen rejects the use of either choices or desires to value capabilities [171] as he feels that the CA should not rely exclusively on mental states [181]. In his 2005 paper [111], Sen refers to the need for valuational scrutiny for making social judgements. However as discussed by Coast *et al.* [181], Sen offers no clear methodology for the valuation process. He does however hint towards the use of '*processes of public reasoning and democracy*' (p.106) [115] and says: '*…It is of course crucial to ask, in any evaluative exercise of this kind, how the weights are to be selected. This judgemental exercise can be resolved only through reasoned evaluation. For a particular person, who is making his or her own judgments, the selection of weights will require reflection, rather than any interpersonal agreement (or consensus).*' (p.78) [108]. More recently when discussing valuation processes, Sen has advocated that methods of valuation should include the '*discipline of public reasoning*' (p.94) [284].

The few papers that have valued capability measures have used two main techniques. The most simple approach that has been used relies on the researcher giving each attribute/capability weights and providing a justification as to why they have chosen such weights e.g. the Human Development Index. This however is a very simplistic method and has been criticised subsequently [112]. The second primary method that has been used is discrete choice experiments and best-worst scaling, as in all the existing ICECAP measures. The ICECAP measures, which to date include the ICECAP-O [174], the ICECAP-A [175], and the ICECAP-SCM [174], are perhaps the most comprehensive of the capability measures that have been created to date, between them covering the capabilities of the general population, older people as well as those who are receiving supportive care. ICECAP-O [181] and ICECAP-A [183] have published value sets whilst ongoing work is currently valuing the ICECAP-SCM. The ICECAP measures have successfully been valued (ICECAP-SCM ongoing) using techniques based upon best-worst scaling. BWS is a method of preference elicitation that was adapted from discrete choice experiments and first used in the early 1990s [285]. Discrete choice experiments are a method that allows the calculation of values for the attributes and the levels of the attributes. The BWS process is a type of discrete choice experiment that involves asking respondents to pick the best and worst options from different attribute levels and through these choices they reveal their values [181], [283]. The BWS process involves presenting the participants with a scenario containing a number of attribute levels and asks them to select which level they feel is the best level, and which level is the worst level. With an experimental design, statistical methods can then be used to calculate weights for the attributes and levels of the measure. This process has the advantage over traditional discrete choice experiments in that they only require an assumption of ordinality [286], making the BWS method of valuation cognitively easier than the traditional DCE methodology [181]and potentially the TTO and SG.

5.2.5 Choosing a valuation method

Although the BWS methodology appears to have been successful within the existing ICECAP studies in generating values, it has not met Sen's criterion of public involvement and reasoned debate [108], [284]. Given the complexity of the method and the indirect way in which values are generated it would be difficult to use the method in a setting where discourse is required. This thesis therefore seeks an alternative methodological route, exploring a novel option that includes an element of public reasoning and debate as discussed by Sen [108], [284] and as suggested elsewhere for valuing capabilities in the EoL context [102].

The simplest option that appears in the literature entails the researcher assigning weights arbitrarily to the different attributes of the measure is overly simplistic and is hardly justifiable. The BWS methods which have been utilised throughout the ICECAP measures is a more viable choice however there remains doubts as to how closely aligned with the CA it is as outlined by Sen. To reiterate Sen's comments on how capabilities should be valued, he says that capabilities should involve processes of public reasoning and democracy [284]. Coast [102] suggests that in light of this, a more deliberative approach may be appropriate for seeking values within the capability framework. This thesis provides an ideal opportunity to explore a methodology more in line with Sen's guidance and to give members of the general public the opportunity to debate and discuss values prior to deciding on their weighting. Thus the notion of including debate and deliberation within the valuation will be explored.

5.3 Deliberative valuation

5.3.1 Deliberation

Sen advocates the use of public reasoning and discussion within the valuation process [108], [284]. There is much literature on the impact and relevance of deliberation on decision making [287]–[292]; deliberation referring to careful consideration and discussion. There is extensive literature looking at the impact of deliberation on decision making in various different areas of the literature, ranging from political [289], legal [293], and environmental economic literature [294], [295], and consequently, deliberation has been strongly advocated to address some of the psychological issues with individual decision making. The concept of deliberative polling was first developed by Fishkin [296] in an attempt to develop a process which addressed the psychological issues associated with decision making, specifically the failure of individuals to have stable, non-random opinions [296].

5.3.2 Why include deliberation in the valuation process

Although well established in legal and political literature, less attention has been paid to deliberation in terms of values within the field of health economics. As outlined in section 5.2, most preference elicitation techniques rely on one-off tasks that involve the individual completing a task where they envision life in that health state and provide a response accordingly [297]. Within health economics there has been debate as to whether it should be patients valuing the health states or members of the general population. Generally, the consensus is that states should be valued via the general public; this is largely because it is the general public who are funding the health care system [121]. When comparing patient values with general population values, there are significant discrepancies between the values obtained [298]. In particular, the general population tends to give lower values than those given by patients. This could result from a variety of factors, for example Sen's physical condition neglect whereby individual's adapt to the health state [91], and/or due to individuals having a poor understanding of the health state that they are valuing. Underlying the preference elicitation techniques is the axiom of completeness whereby it is assumed that individuals can accurately express their preferences for a good. There is a great deal of debate surrounding the degree to which this axiom holds in practice [299]–[301] with the suggestion that individuals are poor at valuing all but the most familiar questions. As outlined by Culyer and Lomas [302], deliberation helps aid thoughts and judgements, and results in better thinking. There is extensive literature addressing how deliberation can impact on the preferences of individuals, not just in terms of elicitation, but also in terms of preference construction [299], [301], [303], [304]. It is hypothesised that deliberation and reflection allows individuals to 'try' a value, before deciding on what they want to finally settle upon [305].

5.3.3 Impact of deliberation in health economic valuation studies

The impact of deliberation within the valuation process is a very under developed area of literature within health economics. McTaggart-Cowan [297] conducted a systematic review of studies that used informed members of the generation population within the valuation process. Just 14 studies were reported to have used methods that used information to explain the health states to the individual. Just two [301], [306] of these studies used the opportunity to reflect and deliberate on the health state descriptions. The review demonstrated that there is a dearth of studies seeking to inform the general population when deriving values for health states. Furthermore, of the studies that were included in the review, the majority found that informing respondents had a significant impact upon the valuations given. This casts doubts on the current procedures of valuation that rely on solitary individual's choices and current values may not accurately represent the general population's values. This could result in resources being misallocated [297]. These findings are echoed more recently by

Robinson and Bryan [305] who identified four studies that explored the impact of deliberation on valuation. Two of these [306], [307] found that the deliberation and discussion led to individuals changing their responses, with validity significantly increasing following group discussion [307] thus supporting the theory that deliberation may contribute to preference construction as well as elicitation. The other two studies identified however did not demonstrate any significant differences [308], [301]. In addition to these studies, Robinson and Bryan [305] further explored this area using deliberation with the person trade-off technique. Robinson and Bryan [305] found that, following deliberation, 74% of participants modified their valuations following the deliberation which significantly impacted the aggregate valuations [305].

The evidence on the degree of impact of deliberation is therefore mixed. Given this lack of clarity, there is an opportunity to add to this under-researched area by including an aspect of deliberation within the valuation process.

5.3.4 Elicitation tasks

Within the deliberative procedure there is a requirement for a task to elicit values for the measure. There are numerous potential tasks that could be used to achieve the goal. There is a long history of deriving weights in a number of disciplines, e.g. medicine, economics, business sciences, marketing, and engineering, but, little consensus regarding how best to calculate weights [309]. There now exists a number of applications and methods of elicitation of weights within both academic and commercial literature [309]. Such methods include: single vote, multiple vote, ranking, constant-sum measurement (budget pie), simple trade-off, scoring and rating, Likert scale, visual analogue scale, Delphi methods, discrete choice experiments, weighted paired comparisons, constant sum paired comparison, constrained rating, measure of value, analytical hierarchy process, conjoint analysis, time trade off, standard gamble, willingness to pay, qualitative discriminant process, aggregated scores and priority search [310]. It is important to identify a method of elicitation that achieves the goals of this task, that is, a method which for our purposes, allows:

- The elicitation of values for the attributes.
- Deliberation and discussion of answers.
- Opportunity to change answers post discussion and reflection.

Of the list of possible methods outlined above, many are based upon established methods of economics, psychology and political science [310], some of which were previously discussed in 5.2.4. There is a tension between theoretical validity and the acceptability of methods. Methods that are seen to have theoretical validity may be difficult to complete and even harder to discuss in a deliberative scenario. They may also not align with people's value systems [310]. It is therefore important that a pragmatic balance is found between validity and acceptability, and that the task is amenable to discussion and deliberation.

When choosing an elicitation method, there are a number of considerations. First a decision needs to be made about whether the elicitation process requires constrained choices or unconstrained choices. Constrained choices refers to the degree to which the choice incorporates issues of scarcity and opportunity cost into the choice [311]. Thus, constrained methods force individuals to trade-off between two or more choices, and inherently involve the notion of sacrifice. Unconstrained choices on the other hand are useful where attributes are completely independent and do not require the trade-off [310]. In the case of developing weights for this measure, constrained choice is preferred as it aligns with the decision making process that occurs when allocating resources. A second consideration relates to whether strength of preference can be determined. Strength of preference is determined via methods that elicit the intensity of preference opposed to just an ordinal ranking of options [311]. By using a method that includes constrained choice with cardinal results, individuals will be forced to trade between the attributes giving us their relative strength of preference for each attribute.

Constant-sum measurement (budget pie)

A method that uses both a constrained choice, and elicits the strength of preference for different options, is the constant-sum measurement (also known as ‘budget pie’ and ‘allocation of points’) [310]. In such a task, participants are given a limited budget of tokens to allocate between different options. Participants then allocate their tokens as they wish to the different options, which can then be aggregated to calculate values [310]. Participants allocate their tokens according to their preferences; they therefore may choose to allocate all their tokens to one option, split them evenly, or allocate them unevenly among the attributes [312]. Variants of this method have successfully elicited societal preferences for efficiency and equity within healthcare [138], [312]–[315] and have been found to have advantages compared to alternatives in addition to its simplicity and intuitive appeal [311]. The budget pie task is perceived to be ideal for allowing the elicitation of the strength of preference for different attributes relative to each other, has shown good reliability [313], and should be amenable to discourse and debate.

5.4 Deliberative valuation methods applied in this study

Deliberative valuation is a novel technique within health economics, and provides the opportunity to conduct an exploratory exercise to develop a preliminary set of weights and to build upon the current literature regarding the impact of deliberation on valuation. To ascertain values, it has been suggested that the key principle is to use methods that are only as precise and complex as needed for the decision at hand [310]. As outlined in 5.3 there are many methods that could be used. The aim for this exploratory work is to choose a method that allows involves a constrained choice, allows respondents to indicate the relative importance of each attribute, is comprehensible enough to be acceptable, and simple enough to facilitate discussion in the deliberative aspect of the task. After careful consideration, it was decided that the budget pie task best met each of the requirements. As well as being cognitively simple and therefore acceptable, the budget pie task is amenable to reflection and discussion and thus is a suitable method for use in the deliberative process.

The budget pie task was chosen to derive weights for the attributes. There however may be differences between each attribute in terms how the levels are distributed, and consequently, there may not be equal decrements between levels. To ascertain the differences within the levels of the attributes, a scaling task as outlined by Peacock *et al.* [316] was used to determine the relative decrements of the levels within the attributes. This scaling task required participants to place the levels on a scale of relative importance between 0-100. The top state was fixed at 100, and the bottom state at zero; individuals were then required to place the interim levels onto the scale depending on how large they felt the relevant decrements were between levels. The responses from participants were then aggregated by calculating the mean score for each level within each attribute to derive the intermediate decrements for the attributes [316].

5.4.1 Valuation ethical considerations

University ethics approval for the deliberative valuation task was obtained by the research team prior to recruitment as part of a broader study on decision making in end of life care. Informed consent from all participants was required for inclusion within the research. To ensure all participants were informed, information sheets were sent out with all initial invitations to the study, and then with all subsequent invitations to participate in the research and at the point of data collection. The information sheet contained information on what the research was about, why they were invited, their obligations and right to withdraw and on the confidentiality arrangements of the study. It also provided contact information for members of the research team in case they required more information and a contact number of senior member of staff independent from the research team should they have any complaints. Informed consent was then obtained prior to the focus groups, in line with university practice, two copies of the consent form were completed, one for the participant to complete and one for the research team's records.

5.4.2 Study design

As with the development of the measure, a decision needed to be made about the format of the data collection. Given this is a relatively unexplored area it allowed a great deal of flexibility over the methods chosen. Focus groups offer individuals within the group the opportunity to reflect on their own decisions and through debate and discourse within the group allows the potential to draw upon the experiences of other participants. Within the larger EconEndLife project [317] of which this research comprises one element, the opportunity to include a valuation task within focus groups arose providing the ideal opportunity to explore the deliberative valuation process. The focus groups were scheduled to last up to two hours, of which an hour was dedicated to conducting the deliberative valuation task. All focus groups had at least three facilitators in attendance. One member of staff led the focus group, another made notes to facilitate transcription, and a third helped out generally with any issues within the focus group, for example, to support any participants who were distressed and to provide refreshments. The start and end parts of the focus group focussed on areas related to EoLC and decision making, and were outside the scope of this thesis whilst the middle element was focussed on the deliberative valuation task.

5.4.3 Sampling

Sampling was dictated by the needs of the wider EconEndLife project. The focus groups were focussed on EoLC, and given the importance of socio-economic status upon health, expectations, and access to health care, participants were recruited into the study to reflect a spread of socio-economic status. The recruitment process was tailored to ensure that areas with different service provisions were included. The West Midlands has a multitude of areas with a spectrum of socio-economic classes. Six areas to represent the different socio-economic classes and hospice service provision were recruited from, to form focus groups. For pragmatic reasons, each focus group took place within each area. Within each area, up to 400 invitations to participate in the study were sent out, however, previous research within the EconEndLife team found that recruitment rate varies depending on upon the socio-economic status of that region [290], and as a result, extra invitations were sent out to more socio-economically deprived areas. A short screening questionnaire was included with the invitation to enable to purposively sample, with the aim of including participants covering a range of experiences regarding EoLC, i.e. some who have experienced bereavement, some who have not. To achieve this, the screening questionnaire asked whether the individual had been bereaved within the last two years, and at what date. Those bereaved within six months were excluded to meet ethical approval. Individuals who were eligible and responded were then contacted and invited to participate in the focus group.

5.4.4 Deliberative valuation task

As this is primarily exploratory work, there was interest not only in the values, but in the differences between pre-deliberation and post-deliberation values, and so, the task designed to allow this issue to be explored. The valuation of the measure therefore took place in a two-step process. The first part of the valuation task was to establish the differences between the levels of each attribute. This was done for one attribute at a time. Before any deliberation over the attribute took place, individuals were asked to value the intermediate levels of the measure with respect to the top and the bottom levels. Values for these top and bottom values were given with full capability given the value 100 and no capability the value zero. Individuals were then asked to put the other levels onto the scale to best reflect the importance of each level relative to each other level. An example of the task can be seen in Appendix eight along with the other elements of the workbook that was relevant to this thesis.

Participants in the study were first asked to do this task on their own and to note their answers. They were then given the opportunity to reflect on their decision and discuss their choices with other members of the focus groups. After a period of discussion, individuals were then given the choice to keep their original answer or change it in light of the discussion. This process was repeated for each attribute.

The second phase of the deliberative valuation process was focussed on valuing the attributes. By valuing the levels of each attribute in the first phase, it was anticipated that the participants would already be familiar with the attributes. To value the attributes, the budget pie method was used. In practice this entailed a task which gave individuals 100 tokens (enough to permit sufficient discrimination as recommended by Mullen [310]) to allocate between the different attributes according to how important they felt each attribute was relative to the others. Individuals could therefore allocate the tokens as they desired, this could be completely to one attribute if they felt that was the only attribute of importance, or equally to all attributes if they felt they were equally important, or unequally across the attributes. Once all members of the focus group had completed their allocations of the tokens, including time to reflect on their decision, one member of the research team facilitated a discussion between the participants on their allocation of tokens between the attributes and the reasons why they have made the decisions they had. This gave the participants the opportunity to draw on the experiences of other members of the focus group and to challenge their original preconceptions. After a period of discussion, individuals were then given the opportunity to change their allocations as a result of the deliberative process, again giving pre-deliberation and post-deliberation values for comparison. This task is shown in Appendix eight, task 2.

5.4.5 Analysis

Descriptive statistics were used to examine the values given by the task. The first part of the analysis was to analyse the results of the levels task. This included aggregating the values given for each level for each attribute. If the levels were equally distributed, there would have been equal decrements of 0.25 between each level. Confidence Intervals (95%) based on the t-distribution (due to the small sample size) were calculated for the values given to each level to examine whether there was deviation from what would be expected if there were even decrements. The levels were also examined on a focus group by focus group basis to assess whether patterns of distribution were consistent across the focus groups.

The second part of the analysis involved examining the results of the attribute valuation exercise. The values given to each attribute were aggregated and examined. Confidence intervals (95%) were calculated for each attribute and differences were tested for statistical significance using the t-distribution. The analysis divided the sample up into sub-groups to examine whether different characteristics led to different values. Attribute weighting was examined according to age, gender and bereavement status, and any differences were tested for significance using t-tests.

To develop weights for the states given by the measure, the attribute weights were multiplied with the results of the levels task and divided by 100 to give a value for each state of the measure on a 0-1 scale. This results in values for the states of the measure that lie between zero as the worst state and one as the best state possible.

Although deliberation was likely to start from the moment they begin talking about EoLC, this work examined whether the impact of discussion and discourse for each specific task led to participants changing their answers. Weights were therefore calculated for answers given before discussion and after discussion. The analysis also examined how many people changed their answers and whether they did so in a significant manner.

5.6 Summary

This section has focussed on the methodology and methods surrounding the valuation of the measure. There are precedents within health economics on how measures are valued, however these standard approaches to valuation based on welfare economics have fundamental drawbacks for use within a capability framework which extends beyond health. More recently within the capability literature there has been a shift towards using BWS to elicit values, however there is still debate as to the extent that this method fits with Sen's interpretation of the CA. This gave the present research the opportunity to explore a new and relatively unexplored area of the literature within health economics that focusses on the use of deliberation and is more closely aligned with the desire for public participation and democracy within the CA valuation process. Focus groups were used to provide the platform for deliberation amongst members of the general public. Within the focus groups, a valuation task in the guise of budget pie was used to elicit values for the measure giving information on the values assigned to attributes, both before and after deliberation. This provided the opportunity to explore the impact of deliberation on values within this scenario. The last two chapters of this thesis have outlined the underlying methodologies and the specific methods used within this research. The thesis now turns to the presentation of the results obtained.

CHAPTER 6: DEVELOPMENT OF ATTRIBUTES FOR THE CLOSE-PERSON MEASURE

This chapter reports on the findings of the in-depth qualitative interviews in relation to the development of the close-person measure. The underlying themes that arose in the interviews are discussed and are brought together to form the attributes of the measure. The purpose of the measure is to capture the impact of EoLC to the close-persons and as a result the attributes that are developed for the measure will reflect that. That is, the measure is concerned primarily with the experience of the close-persons, whilst other measures such as the ICECAP-SCM are focussed on the experience of the patient. As the measure is being created within the capability paradigm, the attributes are also designed within this framework.

This chapter is the result of the analysis of the interviews within each batch and then across each batch of interviews as specified by the constant comparative methods. Due to word count limitations, the quotes and examples given within this chapter for each attribute are just a representation of the complete collection. This chapter begins by outlining the nature of the participants and the conduct of the interviews. The chapter then discusses the themes that emerged from the interviews and focusses on the attribute development for the close-person measure. Finally the chapter summarises the main findings of this aspect of the research.

6.1. Recruitment

The advertisements were first circulated within several newsletters at the University of Birmingham targeted at staff and students during the final week of May 2013. The first round of newsletters led to six respondents. Of these, four participated in the study, one of whom participated at a later date due to ineligibility (through recent bereavement) when initially responding to the newsletter. Two of these respondents did not participate, one for undisclosed reasons, and the other for logistical reasons (living several hundred miles away). Advertisements within newsletters continued to be sent until the final newsletter in the final week of March 2014. The most common reason for individuals who expressed interest not being included in the study was due to it being over two years since being bereaved; several participants also chose to withdraw prior to interview for undisclosed reasons (i.e. did not respond to the invite to interview). One participant was recruited via a respondent into the study (snowball sample). No participants were recruited via the posters. The Marie Curie Hospice, West Midlands, facilitated the recruitment of four participants between May 2014 and July 2014. Overall, the first interview took place on 17 June 2013 and continued till final interview on the 8 July 2014 at the University of Birmingham. The majority of participants were female with just five males participating in the study. There was a plethora of conditions suffered by the decedents of the participants with a wide range of death trajectories and disease types being included in the study. These included the whole range of trajectories from subtacular deaths e.g. slow decline following admission to hospital, to sudden spectacular deaths e.g. from a heart attack as shown in Table 5.

6.2. Setting and conduct

All interviews were conducted by Alastair Canaway in a number of different locations subject to the participant’s preferences. Twenty two interviews took place at the University of Birmingham, three at the Marie Curie Hospice, West Midlands, and two at the participants’ home. Table 5 shows the demographics of the participants. The interviews took place in batches of typically four, and the analysis was conducted iteratively with a gap between each batch of interviews. Pragmatism was needed in terms of how the interviews were grouped into batches and thus the size of batch varied to some extent. The interviews took place in seven batches of interviews, the first five batches focussed on developing the conceptual attributes whilst the final two batches sought to check the attributes for meaningfulness and fine tune the wording of the measure.

6.3. Presenting the findings

The remainder of this chapter sets out the findings of the interviews in relation to the development of the close-person measure. Selected quotes from the transcripts are used to highlight the findings and are included verbatim. For sections where text is excluded, ellipses (…) are used to represent the missing text. The exception to this are words which add nothing to the meaning of the sentence such as ‘errm’, ‘you know’ and ‘ahh’. These are deleted without the use of ellipses. Square brackets are used on occasion to add clarity or context to the quotes, for example, they may be used within a quote to clarify what the participant was referring to. Any names and places are anonymised or changed to protect the participant’s anonymity.

Table 5: Descriptive characteristics of participants (n=27)

Participant ID	Participant's Age Range (years)	Participant’s Gender	Participant's Ethnicity	Months Since Bereavement	Relation of decedent to participant	Decedent's terminal condition	Decedent's age group (years)	Recruitment Method
CDX1	40-49	Female	White British	18-24	Father	Pancreatic Cancer	60-79	Via Newsletter
CDX4	40-49	Female	Indian	18-24	Sibling	Lymphoma	40-59	Forwarded Newsletter (external)
CDX5	40-49	Female	White British	6-12; 18-24	Mother and Father	Alzheimer’s, Heart Failure + COPD	60-79, 80+	Via Newsletter
CDX6	50-59	Female	Mixed	18-24	Friend	Oesophageal Cancer	40-59	Via Newsletter
CDX7	50-59	Female	White British	18-24	Mother	COPD and Alzheimer’s/Dementia	80+	Via Newsletter
CDX8	30-39	Male	White British	18-24	Father	Sudden Death - Heart attack	60-79	Via Newsletter
CDX9	20-29	Male	White British	6-12, 12-18	Father in law, and Grandmother	Cancer, Stroke	60-69, 80+	Via Newsletter
CDX10	30-39	Female	White British	18-24	Father	Death following elective heart surgery complications	Not-specified	Via Newsletter
CDX13	30-39	Female	Greek	Pre-bereaved	Mother	Motor Neurone Disease	60-79	Via Newsletter
CDX14	50-59	Female	White British	Pre-bereaved	Mother	TIA/Dementia	80+	Via Newsletter
CDX15	50-59	Female	White British	18-24 (both)	Friends x 2	Death/decline following extended period in hospital	80+, 80+	Via Newsletter
CDX16	40-49	Male	White British	6-12	Father	CHD - Death following heart surgery complications	80+	Via Newsletter
CDX17	20-29	Female	White British	6-12	Grandmother	Pneumonia	80+	Via Newsletter
CDX18	60-69	Female	White British	6-12	Mother	Pneumonia	80+	Snowball
CDX19	60-69	Female	White British	6-12	Father	Lung Cancer	80+	Via Newsletter
CDX20	40-49	Female	White British	6-12	Mother	Cancer - Colon/Liver	60-79	Via Newsletter
CDX21	50-59	Female	White British	6-12	Father	Undiagnosed - chest complaint	80+	Via Newsletter
CDX22	20-29	Female	Mixed Race	18-24	Grandmother	Heart Disease	Not-specified	Via Newsletter
CDX23	30-39	Female	White British	18-24	Grandmother	Post-fall infections in hospital	80+	Via Newsletter
CDX24	20-29	Female	White British	18-24	Grandfather	Lymphoma	60-79	Via Newsletter
CDX25	20-29	Female	White British	18-24	Father	Cancer - back/spine	60-79	Via Newsletter
CDX26	70-79	Female	White British	Pre-bereaved	Spouse	Multiple System Atrophy	60-79	Marie Curie Hospice
CDX27	40-49	Female	White British	Pre-bereaved	Mother	COPD	60-79	Marie Curie Hospice
CDX28	20-29	Male	White British	12-18	Grandmother	Parkinson's Disease	80+	Via Newsletter
CDX29	50-59	Male	White British	Pre-bereaved	Mother	Sarcoidosis (inflammatory cells clumping around body)	60-79	Marie Curie Hospice
CDX30	70-79	Female	White British	Pre-bereaved	Husband	Mesothelioma (cancer of the lining of the lung)	Not-specified	Marie Curie Hospice
CDX31	20-29	Female	White British	18-24	Mother	Viral Pneumonia + sudden heart attack	Not-specified	Via Newsletter

6.4 Attribute development

A number of primary themes emerged from the interviews during the constant comparative analysis. These themes included: ‘communication’, ‘support, ‘privacy and space’, ‘preparation/coping’, ‘pain and discomfort’, and ‘respect and dignity’. After the first two batches of analysis, all six themes had been touched upon at some stage and the themes were further developed through the analytic process. In this section, the themes will be discussed and sub-themes explored. For each theme, the development of the themes into attributes and the reasons for their inclusion within the measure is discussed. The attributes have been tailored to fit into the capability framework.

6.4.1 Communication

A strong theme to emerge from the initial qualitative interviews was the importance of good communication. The interviews included a broad set of death trajectories in a number of different contexts, for example, slow declining deaths, such as in the case of CDX5, to more sudden deaths, such as CDX10 whose father died in a short space of time following elective surgery. It appears that communication is an important concept that is applicable to a broad spectrum of death trajectories and disease groups. There were a number of aspects to communication. To begin are the themes relating to communication between the health care services and the patient network.

CDX5 best highlighted the general importance of communication in EoLC for family members. When asked what good EoLC entailed she responded:

> CDX5: *but what I feel end of life care should be is firstly: communication with family and telling you what’s going on and telling you what can be done*

Similarly when asked what could be improved, CDX7 responded:

> CDX7*: so actually more communication, God it’s always the same isn’t it, communication every time…With staff.*

This was reflected in a large proportion of the interviews where communication arose as an important issue. Within the general overarching umbrella of communication there was a strong desire amongst participants for information on the decedent's health, prognosis and care plans, and more generally the need for clear communication between the patient network and the health care services.

> CDX1: *I think the doctors need to be more frank. There's an awful lot of 'pussy footing about' you know, there's an awful lot…they used terms like 'oo there's err something we don't like there, there's a mass there' but they didn't say, this is cancerous and they didn't really explain the consequence or the meaning of palliative care...*
>
> CDX16: *It's about communication but also with the relatives in that situation, informing them about what's happening...*

There was a strong desire amongst many of the participants for information not only on the current status of their close-person but also on their diagnosis and prognosis. Lack of diagnosis and prognostic information creates uncertainty which people are intrinsically averse to; this is reflected in the participant's desire for information.

> CDX5: *communication with family and telling you what's going on and telling you what can be done and what…to help people….and more importantly that followed up, somebody almost on hand there all the time that you can go to*
>
> CDX7: *neither of them gave any indication that she was getting towards the end so you get in this limbo state of, I don't know if you're actually thinking this but somewhere in your head you're thinking 'ooo she might come out again, what happens if she comes out, she can't live at home*
>
> CDX9*: It would have been I think, much easier for Jane if there'd been a bit more information I think coming from them about what was happening*
>
> CDX10: *we were talking to the nurses all the time because it was one on one care but they won't give you a prognosis and that's we were missing…we had nearly 2 weeks of going to the hospital twice a day and for a good week we still thought there was a fair chance he was going to come round…it was just horrendous*

The lack of information and poor communication during the EoL period led to some of the participants further suffering in the bereavement period due to a lack of understanding of what occurred.

> CDX10: *…dad's death was compounded by us not understanding what had happened and why things had gone on.*
>
> CDX5: *I think it's be good to have some answers to questions when you, to try and come to terms with it – to understand what's happened, I think that's a lot of it.*

For the close-person network to be communicated with in a clear and informative manner, it seems necessary that they have access to the appropriate staff. This was repeatedly reported to be an issue in the experiences of participants. Lack of contact with staff led to poor communication with the close-person network.

> CDX7*: no, nobody talked, nobody said anything clearly*
>
> CDX7: *trying to find people sometimes is a nightmare, trying to find people to talk to, of any sort of seniority that knows the… you know how ill she is or what's going on*
>
> CDX5: *the doctors aren't there at visiting time obviously*
>
> CDX19: *you know, you couldn't find people, you couldn't find people to give you an update on the status and you couldn't find anybody to say 'well can he go home now?'*

There was one very different experience, however, where the dying person died in a hospice and the close-person valued the approach to communication.

> *CDX6: …the staff weren't intrusive but they were approachable*

Also important in terms of communication is the need to have the patient network's views heard and respected. A number of participants raised this issue as something that they would have valued. It is important for close-persons that not only are they communicated with, but that it is a two way process with their views being sought and respected.

> A: *And that's something you'd have liked?*
> CDX16: *Yeah, definitely, just to sort of say 'look, we're going to do this, what's your thoughts?'…it would have been nice to have had that option really*.

> CDX5: *My mum was quite disturbed at some point and I said…can you please get a doctor to administer this medication…'yes we'll call them'…nothing. Then it was getting onto in during the middle of the night and my mum was still in distress and nothing had been done*

A secondary theme emerged concerning communication within the health care system itself. Some participants referred to issues with communication within the health care system and the inadequate care that followed. One participant described how a breakdown in communication with the staff involved with the care of her father led to increased emotional distress for her.

> CDX1: *And then the nurses…failed to report to whoever was on duty the next day so at 11 o'clock the following day we had somebody rock up to give my dad his medicines, and it's just like 'he's died', and it's just things like that where there's like a breakdown in the system but it just twists the knife at the wrong moment*

Similarly, another participant described extensively how poor communication between the different departments within the hospital led to substandard EoLC for her mother and as a result a very negative EoL outcome and emotional distress for the participant.

> CDX5: *I don't know if it was lack of communication between the staff but anyway, they got in touch with the doctor, and she just said, the doctor just said to treat her for the chest infection and that she doesn't need any drugs.*

The lack of communication between the hospital staff led to a lack of EoLC for CDX5's mother.

> CDX5: *…and that medication, apart from a little bit of morphine helped her sleep which I'm grateful for wasn't there…things that I was promised just by the normal nursing staff weren't administered but no end of life palliative care person came to see mum or us at all in that time…I think it was communication in the hospital, nobody contacted the right people to be there to look at my mum*

This lack of communication between the health care staff led to increased pain for this participant's decedent.

> CDX5: *That communication wasn't there when we were told she was dying and I knew she was dying, there was just nothing, she was just left, and she was in pain, I think if you're not*

> *in pain that's fine but she was definitely uncomfortable and her body was in pain and she couldn't breathe properly, it was just horrible to watch*

This reflects the feelings of other participants wherein a lack of communication and poor data transfer within the health care services led to substandard care.

> CDX20: *a lot of these systems are not working effectively, they probably work as a standalone service but when you try and put them all together they fail*
>
> CDX24: *Another time would be when he's been given medication, one time he was given a certain medication that worked for him, it really did work for him, but it wasn't put on his drugs chart…so when my mum spoke to a doctor about how he was on this medication and it really did help, she couldn't find any record of it.*

Communication attribute development

There were two distinct sub-themes relating to communication –'communication with the patient network' and 'communication within the health care service'. This issue of communication within the healthcare service is clearly important however it is important for a different reason to that of communication with the close-person network. Communication within the health service is important to ensure that optimal care is received for the patient, and in doing so, emotional distress is reduced as a result. In contrast there was an intrinsic value to the communication with the patient network theme. As a result, for the measure, the communication within the patient network will be used as the basis for an attribute. Communication within health care services in contrast is not the underlying attribute and will therefore be captured within the 'emotional distress' attribute discussed in 6.4.5. Framing the conceptual attribute of good communication with the patient network within the capability context, the attribute developed is as follows: 'being able to have good communication with services providing care to the dying'. There were several sub-themes within the good communication with the patient network theme, for example, the need for people to have information on prognosis and diagnosis and having their views heard and respected. These sub themes have formed the basis for the descriptors for the attribute.

6.4.2 Practical support

A second theme which emerged from the interviews revolved around support. This came in two strands, practical support and emotional support. These are two very different things and as a result are dealt with separately.

Practical support tended to be more important for those with close-persons suffering a prolonged death trajectory. For those participants that had experienced their relative suffering a slow and steady decline it is unsurprising to find that there is a greater need for support with the care of their decedent. Several participants identified the need for help with care of their close-person to aid normality in their own lives.

> CDX1: *the Macmillan nurses…they arranged that they would come in and give care overnight and also come in for certain parts of the day to allow my mum to go out and do shopping and do normal things…and that was actually quite helpful*
>
> CDX5: *So there's something missing really…if you're diagnosed with cancer and you're told that somebody's going to die in three months' time, there might be a package there, there might be some support there…but [for] different illnesses and diseases it's not there*
>
> CDX9: *for my father in law…[there was] absolutely no support outside the hospital, no social support at all within the community so everything…fell on his daughter…on my wife, and the mother to look after him and whenever he was in hospital that meant almost 24 hour vigils really*

Some participants felt care was provided but highlighted that it did not always live up to their expectations and was frequently disjointed, and was consequently inadequate.

> CDX19 *…So we had an occupation therapist, we had social care, we had IRIS team, I don't know who they were, we had district nurses, we had twilight nurses, we had the stinking GP, we had ALPEN Best who were contracted out carers…let's say all of these services just talk with each other and then one person, a representative talks to us and we talk to him, end of...can't we simplify all of this*
>
> CDX20: *…there wasn't enough help she was using a commode and quite often I'd ring the bell for a commode and it would be left to me really to get her onto the commode and back off again and back into bed by the time anyone came*

> CDX21: *I'd got the doctors in one place, my father's social worker in another place and then the care providers were a third body and none of them seemed to be particularly joined up and sort of speaking to each other*

Practical support was not just confined to the support with the caring of the patient but also to the practicalities into the bereavement period. This support does not necessarily have to come through services at the hospital. One of the participants felt that they needed support with sorting out the post-bereavement dealings. She got the support she needed through the undertaker.

> CDX10: *In the end we got the support from the undertaker...you just need a friendly face who knows what they're doing just to help guide you….reassure you and guide, particularly for us because it was the first time that we'd been in that situation where we had to arrange the death of a close family member.*

Another source of practical support for some participants was their employers; being given the required time off work to deal with the EoL and flexibility within their working situation was something that was appreciated by some participants.

> CDX16: *I had the usual statutory week's compassionate leave which was helpful in terms of dealing with the house and ringing various people up etc etc. So that was helpful but then the funeral was probably a week or so after that but they still gave me the day obviously for the funeral to deal with that.*
>
> CDX10: *so that second week I worked from home but he had the cardiac arrests and there was no way I could concentrate on work so I had that week as compassionate leave and then I got a sick note for the other two weeks before I went back to work but yeah they were very understanding*

Practical support attribute development

This theme started initially as a theme focussed on support more generally however it became clear at quite an early stage of the analysis that support was split into two distinct themes: practical support and emotional support, both of which are important and have formed attributes. This theme focussed on the issue of practical support. This is support that helps the close-person in a practical nature, whether it is in terms of helping them with caring for their close-person allowing some normality to their lives or in a broader sense of being supported via other means to deal with the bereavement. This is something that is clearly important to participants and not always provided satisfactorily. It is included in the measure as it is important that the measure captures the benefits of support. Practical support is something that is particularly pertinent to those dealing with subtacular death trajectories, however, it is relevant to all trajectories in terms of support with the bereavement processes. To allow for the fact that not everybody will want practical support, and putting this attribute into the capability framework, the attribute that has been developed is 'being able to get all the practical support'. This allows for the possibility that people may not require or desire support. The descriptors for the measure are derived from the sub themes of this attribute which include practical support with care of the dying, practical support from employers and also practical support with dealing with post bereavement affairs.

6.4.3 Emotional support

Dealing with the EoL of a close-person is often a difficult and emotional time for those who are close to the decedent. Given this emotionally charged period, a number of the participants discussed the importance of emotional support at this difficult period of their lives. As a result, emotional support quickly emerged as an attribute. This theme emerged initially within the general support theme and was then separated from practical support to form a separate attribute.

Just one participant received professional support (CDX31) for their emotions i.e. used professional pre-bereavement or bereavement services. Some participants did, however, feel that, had the bereavement services been more proactive in contacting them, it could have improved their experience.

> CDX1: *like we've gone to the GP…it'd almost be nice if somebody just rocked up and sort of went 'do you want to have a chat?' and just sort of see, and that doesn't happen at all.*
>
> CDX10: *I've never been able to persuade her but if access to support from the hospital was easier [we] might have followed through. If the hospital had said that we want to come and*

> *talk about your experience to learn or whatever and improve processes…then she might have moved into, well let me see how it might help you as an individual*

In contrast to professional support, a large number of participants discussed the importance of emotional support from their own close-person network, whether this be family, close friends or colleagues.

> CDX1: *because I'm single, I'm an only child and, as I say, I'm supporting my mum as well, so if I didn't have close friends there wouldn't be anybody at all. And they've been very good you know, sort of helped me through quite, quite a bit really*
>
> CDX10: *…we've got each other…we probably talked about [the death] for a good 6 months constantly which people might not think was healthy but it was what we needed to do as part of the healing process.*
>
> CDX16: *…immediate family you couldn't really manage without them.*

One participant discussed how she felt that the lack of a mutual suffering member in her close-person network made her feel isolated as she was the only individual within her close-person network who knew the decedent. This indicates that it may be important to have emotional support from individuals who are also going through the same process.

> CDX6: *…but we didn't have mutual friends so when she died I found it quite isolating because although her family knew obviously all about me and I knew all about them, there wasn't that closeness that I could go and knock on their door or talk it through with them.*

Similarly, one of the participants felt that her brother who lived alone far away from the rest of the family suffered a lot more than herself and her daughter as a result of not having that support network around him.

> CDX18: *oh well obviously because we were able to talk about her, I mean my brother is down in C and he doesn't talk about it, he is a retired schoolteacher, never married, so that tells you everything you need to know. I actually feel he probably suffered more because he is on his own and retired…but I think he probably suffered a bit more than we did.*

Emotional support was not just confined to the support of friends, family and the close-person network. Some of the participants felt that they derived a great deal of emotional support from their religious beliefs which helped them through the bereavement experience.

> CDX15: *…you just think they are going somewhere better or you're hoping they are going somewhere better. Well you know, if they're out of that body then they are not in pain and free, I mean both had been married, you know for long periods with both husbands predeceased them, you know I tend to imagine that they have joined up again, naïvely perhaps.*
>
> CDX16*: I think this whole thing that happened to me, my faith, because I'm a Roman Catholic, has really helped me through the whole thing, in that sense I know that my Dad is now with my Mum or whatever you wish to call it…it's that knowing that death isn't the final thing.*
>
> CDX17*: …we had already asked that she had had her last rites and things, so I think that gave us a bit of comfort that a priest had been in to see her.*

Emotional support attribute development

There was a feeling amongst a large number of participants that their EoL and bereavement experience had been improved through the capability to have emotional support. Some of the participants felt that others in the decedent's close-person network had suffered more as a result due to the lack of support network. There were a number of avenues from which emotional support was derived, primarily through the participant's own close-person networks and through the religious beliefs of some of the participants. The underlying attribute for these themes is the emotional support that having a close-person network and religious beliefs provide. Close-person networks and religious beliefs can be seen as important support through the emotionally challenging experience of bereavement. The attribute developed from the emotional support theme therefore focusses on the capability to get all the emotional support the person needs. Descriptors for this attribute are developed from the subthemes and include emotional support from the close-person network, as well as through professional services and religion where applicable.

6.4.4 Privacy and space at end of life

Many participants when discussing their experiences of EoLC referred to the environment at EoL. This was something that clearly had an impact on the experience of a number of the participants. There were a number of aspects to this and it appeared to be applicable to a wide range of death trajectories and across in a range of settings. For a number of participants there was something fundamentally important about the death setting.

Many participants expressed their desire for privacy at EoL and felt that this was important for them.

> CDX1:…*And also it gave us privacy as well…you don't really [want] to sort of be on display when you're, when somebody you care about is disappearing out the world, you know.*
>
> CDX1:…*for families, it's just stupid things like, as I say, privacy'*
>
> CDX16:*Well he was in a room in intensive care at the last few days which was good for us, that helped, was a bit more private, we could be with him privately, the door was closed nobody else there, just us, that was nice…but the privacy aspect at the end was very good.*

One participant chose to have her father die on an open ward rather than the private room. This was not due to privacy being unimportant but due to the worry that he may be forgotten about if put in a private room. Despite not opting for privacy, the participant felt it was important to have that choice thus justifying the capability approach.

> CDX21*…So we were actually offered a private room but my mother was quite insistent and I quite agreed with her that she did not want him put in a room and forgotten and left to die on his own and….so we kept him on the ward.*
>
> CDX21*: … [it was] nice to be offered it as well because you know, I'm sure there are other people if you like that maybe weren't dying but would appreciate a bit of privacy and not being on the ward…it was nice because it kind of wasn't necessary for the patient, the offer a private room really was just for mum and I.*

Not only was privacy desired but several participants discussed the ambience of the place where EoLC was received. There was a preference for the setting to be peaceful at EoL. One participant discussed the ward where her father was prior to his death and how terrible it would have been to die there.

> CDX1: *but he died where he wanted to be which was in his own bed with the people that he loved around him and not in a hospital with as I say unfortunately screaming…people who had obviously got major dementia, mental problems, and shouldn't have been there…I think it was important to him and it was important to my mum and myself…'*

> CDX10*: …we asked if dad could be moved to a side room because there was a patient the other side of the curtain who'd had heart transplant and hearing us just sat the other side of the curtain crying, you know it was just a bad environment for everybody.*

One participant felt that the hospice where her close friend died made the experience better for her, herself, as there was nowhere else she would have wanted her to die.

> CDX6*:… it was better than seeing her in a hospital, because it's a, it was a lovely place for her to be and you feel that if she had to be anywhere, we knew she couldn't be at home, then it made it easier to think that she was going to spend her last days somewhere beautiful…'*

The place of death was something that was discussed with a number of participants with some wishing the death had taken place in a different location and other stating their own thoughts on the place of death.

> *CDX7: …she was always moaning about why am I in this police station', or airport….'why aren't I at home?' so home, home in bed, no, home looking at the garden, something set up at home*
>
> CDX8: …*the idea of being in say a hospital, I mean with…if it say was for me, that would just be horrible, just seeing other people suffering as well and you're there kind of just counting the time down…especially if you're in a hospital or somewhere like that*

Many desired EoLC to be provided somewhere other than the hospital, however, this was not true for all participants. In these instances it would seem that care outside the hospital may not fit all the decedent's needs and the hospital setting was preferable in these cases.

> CDX16: *I'd rather it be dealt with in a hospital environment because if we'd taken him home in that situation it just complicates issues, it causes stress and anxiety and all the support agencies that need to be involved….*
>
> CDX17: *I suppose, ideally in her head she would have just gone to sleep at home…she was hooked up to all sorts of things to make a comfortable and I think she probably would have been in pain if she was at home so it was best to be in hospital.*
>
> CDX18: …*but I think probably it was probably best just to leave her there, I don't think she'd have got any better care, I mean at home she probably wouldn't have been so comfortable because she would not have had the hospital amenities*

As well as desiring the optimal environment for their close-persons to die in, many participants expressed the desire for the option of being with their close-person at the EoL.

> CDX16: *You know, I think nobody should be alone when they die, it's very important that someone should be there at that moment.*

One participant felt she needed to be there however her brother chose not to be, this indicates that it is important to have the capability of being there at the EoL, but that not all will choose to be there.

> CDX5: *I'm personally glad I was there, my brother didn't want to be there, he couldn't bring himself to come to the hospital when he knew what was happening and he said that and I said 'that's fine'. But I needed to be there to almost have closure to piece it together to understand what was happening*

Some of the participant's biggest regrets involved not being there at the time of death.

> CDX6: *… it was all tied in with not being here, and feeling that I wasn't here….maybe a bit of guilt.*
>
> CDX7: *Erm, there's no getting away from it is there, it's just… [cries] oh God I didn't think I felt bad about her being on her own*
>
> CDX7*: …the biggest biggest thing is that I still think about her lying there on her own...I'd have stayed...not that we're sort of family but I would have stayed.*

Privacy and space attribute development

The end of a close-person's life is obviously a very important event; the setting surrounding the EoL of that person appears to be an important factor for close-persons. There is clearly an underlying importance to the close-person network relating to the nature and setting of the death. As a result this will form an attribute of the measure. This was an attribute that was mentioned across a range of different death trajectories. This is perhaps unsurprising as the end result of all death trajectories is a place of death, if this place is important to close-persons then all trajectories will be affected by this issue. This again is a broad attribute incorporating a number of the sub themes. From the interviews, there seems to be a desire amongst the participants to have the capability for their loved one to die in the most suitable location which in most instances entails a peaceful environment which offers privacy and space for the close-persons to be with their decedent. Several of the participants' biggest regrets appeared to relate to their not being present at the EoL and this reinforces how important an issue this is. The attribute is therefore based on the capability to have privacy and space with the person who is dying; the descriptors include the subthemes relating to a sense of peacefulness, pleasantness in the death setting and the capability to be there at the EoL.

6.4.5 Emotional distress resulting from the quality of care of their loved one

One of the themes brought up repeatedly when asking about the experiences and issues with end life care related to the level of care received by their dying person. This was often one of the most emotive areas to discuss, with several participants crying when recounting their experience. There were three primary issues that were raised by close-persons, and through the analysis, these were grouped together to form this larger theme. First there were issues with excess pain/discomfort, second there were issues with the loss of respect and dignity of their close-person, and finally there were issues with attentiveness and perceived neglect. These issues were primarily found in those whose close-person had a slow death trajectory and where formal EoLC was not administered. Given that interviews were conducted with individuals who were close to the decedents it is natural that there will be empathy between the decedent and the close-person. Seeing the decedent receiving poor quality care can therefore cause emotional distress to the close-persons not just at the time it occurs, but continuing into the bereavement period, as the bereaved reflect on the last days of their close-person and the condition that they were in.

A number of participants discussed the feeling that good EoLC should control pain and discomfort for the patient. For one participant who felt that her mother was not treated like an EoL patient should be, the pain and discomfort was so bad that the death initially felt like a relief as she was no longer suffering having being treated so poorly in hospital.

> CDX5: *And my mum was clearly in pain and discomfort and she died 9 hours later…and that medication, apart from a little bit of morphine helped her sleep which I'm grateful for wasn't there… [we] felt it was a release for my mum and she wasn't in any pain or discomfort and she didn't have to be treated like that anymore…*

Several participants discussed the impact of pain and discomfort on their experience. Some felt that their experience was tougher due to the discomfort experienced by their close-persons and this led to a reduction in the quality time they could spend with their decedent at EoL.

> CDX1:...*there were a few things that didn't quite match up…like he had to go on anti-nausea medicine and they took a little bit of time to sort that out so he had a couple of days where he was just throwing up constantly and it was very unpleasant for him and all concerned.*
>
> CDX15: *…we would have seen, and been able to spend quality time with them rather than rushing around trying to do all the jobs that you felt might have been done by the hospital nurses.*

The unnecessary pain that one of the participant's close-person had to endure still leaves her feeling angry nearly two years on. When thinking back to her granddad, it is the very end of his life that she focusses on.

> CDX24*:It makes me really angry…it's really bad because I only focus on the last couple of weeks of his life and I don't think he was treated very well in that time and I know how much pain he was in, so they're not good thoughts…'.*

This was then confounded by the fact that the health care workers forgot to administer the pain relief numerous times which led to unnecessary suffering.

> CDX24:*…there was so many times where the staff just forgot, or didn't have time, or came an hour later to give him his pain relief.*

The unnecessary suffering that her granddad endured clearly has had a significant impact on CDX24 in the bereavement period. In contrast, others who felt their close-person was not in pain felt that their experience was made easier as a result.

> CDX6*: …I think that'd have made it more difficult if we'd thought she was suffering again.*

Another facet relating to the quality of care that was commented upon frequently and impacted upon participants experiences was that of dignity and respect. Several participants referred to dignity and respect within their interviews.

> CDX5*: …there's no respect given, there was no respect given for my mum*
>
> CDX9*: …I suppose it's being well looked after, you know making sure your needs, you know being served, making sure that that's done in a dignified and respectful manner*
>
> CDX16: *…as I say I mean I think it's just keeping somebody pain-free and clean and showing them respect regardless of whether they are suffering dementia or anything like that.*

When asked about the EoLC their close-persons received, a number of participants referred to the loss of dignity that their decedent received.

> CDX10: *so it did feel really undignified for two weeks because…at one point he just had a tiny towel protecting his modesty…so everyone's walking past seeing that*
>
> CDX15: *yes, because they were losing their dignity by the hour and could do nothing about it, they were helpless*
>
> CDX19*: …all of these people he didn't know, his worst nightmare really, going into hospital which he never wanted, having to have his arsed wipe by his daughters, who would want that…but you know the loss of dignity is a terrible thing*
>
> *CDX20: … they were unhelpful; they treated her like a naughty child really*

Some of the participants felt that this loss of dignity was what made the whole experience painful and difficult for the close-person network.

> CDX19: *…awful for him, awful to go like that…we knew from the way he was about his life that he wouldn't have wanted a death like that…and that was what made it painful*
>
> CDX9: *So you were responsible for feeding them, you were responsible for cleaning, you were responsible for taking to the toilet and you know for a daughter to take her an elderly dad to the toilet and to tidy and clean up after him…that's unbelievably difficult*

One of the issues raised by some of the participants relates to neglect and the attentiveness of staff.

> CDX15: *And she was horribly horribly neglected…if she wanted to go to the toilet it would take ages for anybody to come and take her to the toilet…they said they are just too busy at the moment, so she was just left, and, she deteriorated very very slowly…*

> CDX20: *And in terms of end of life care, I think the one to one aspect of it and making sure somebody, they have their very basic needs met at all times in a kind and considerate way…*

To a lesser extent than CDX15, CDX17 was not satisfied with the level of attention paid to her decedent.

> CDX17: …*they are only small things, like my grandma could not see very well, food tended to be put in front of her and then sort of left, and she could not necessarily see it…*
>
> CDX17:…*there was also one day we went in…the top of my mum's bed sheets were wet, she had obviously spilt something, and they hadn't noticed and we had to tell them and they were obviously…and another day at they had been taking blood and the plaster was just left on the side which wasn't bad for her but I was uncomfortable with that.*

It is interesting to note that the participant felt that the lack of attentiveness was something that did not impact the health of her close-person; however it did impact on her experience of EoLC and should therefore be captured by the measure.

> CDX17*: …there were just little things, obviously didn't really impact her health but was slightly shit to me.*

Emotional distress attribute development

The quality of care given to the decedents clearly had an impact upon the close-person's experience of EoLC and bereavement. When developing this conceptual attribute it is important to keep in mind that of interest to this study are the impacts of the care upon the close-persons, and not those for the patient. However, as seen in this theme, due to the empathetic and emotional ties between the close-persons and the decedents, the quality of care can cause emotional distress to close-persons. The close-person measure is being designed to capture all the impacts of EoLC on the close-persons. Therefore it is essential that impact on the close-person's experience that results from the quality of care is captured for the measure. Poor care that results in high levels of pain, or a loss of dignity, or neglect will therefore cause emotional distress to the close-person network due to natural levels of empathy between the close-persons. To avoid the potential issue of double counting, it is essential that the attribute is focussed on the impact of the quality of care on the close-person – not the patient. The attribute is therefore based upon the freedom from emotional distress related to the quality of care of their close-person. The descriptors for this attribute are derived from the subthemes that relate to the emotional distress caused by seeing a loved one in excessive pain and discomfort, losing dignity and being neglected.

6.4.6 Preparation and coping

The final primary theme arising from the interviews related to the capability to prepare and accept the death of the decedent. This was mentioned by several participants in different contexts. This ranged from the impact upon discussions about death with the close-person prior to death and associated preparations as well as the impact on the close-persons of post bereavement dealings having being sorted. If individuals can prepare for the death of their decedent it appears to facilitate their ability to come to terms with the death in the bereavement period. Similarly, if post-bereavement dealings are in place then this reduces the burden on the close-person network during the bereavement period.

One of the participants talked at length about how they had discussed her father's death and prepared for it accordingly.

> CDX5: *…he left a detailed plan and written notes of what he wanted from hymns to what type of funeral he wanted, he left me a list of names and telephone numbers for that day to ring, I didn't even have to go through his address book…he'd made a will and he'd put little bits of who he wanted what to go to who and what was happening with the house…and I think he did that for me because…he knew it would fall upon me so he did plans to make it easier for me.*

This participant felt that it helped her and the close-person network in the bereavement period knowing that things had been done according to her father's wishes.

> CDX5: *I think that's important, very important to some people, very important to my dad. And it helped me and it helped us knowing what he wanted to happen to his things, to his home, to his money*

Likewise, a number of the participants discussed the importance of having a will in place and how that helped them in the immediate aftermath of the bereavement period. Some felt that this helped their experience of EoL.

> CDX10: *…he did have a will….And that was an act of love for me, the fact that they'd done that because getting it wrong would have been terrible and I'd never have known if I'd get it wrong but I'd always live with thinking 'have I got it wrong'*
>
> CDX10: *… it'd have been terrible if I hadn't have known*
>
> CDX1: *…he had made a will so that…was very useful and to be honest it was very straight forward.*
>
> CDX16: *Oh that [if a will was not in place] would have caused further problems because he was again one of these people with different accounts in different places and you know, shares, and bits and bobs, would make life much more difficult I think, even though I'm the sole heir, executer or whatever you want to call me, so there'd be no challenge to that but I think…it just complicates things if there wasn't a will*

Demonstrating the importance to some close persons of having made preparations, one of the participants had the experience where preparations had not been made and the will was not in place which made the process more difficult.

> CDX9: *because a will hadn't been signed and although he'd told…his wife about his funeral wishes, the rest of the family weren't privy to that and you know it caused all sorts of really really horrible things to happen afterwards*
>
> CDX9: *… just shocking….and…arguments about the funeral and what should happen at the funeral and how much money to spend at the funeral and all like ridiculously trivial things*

Preparation and coping attribute development

Several participants discussed how being prepared and having post-bereavement dealings in places improved their experience of the bereavement process. Out of all the themes this was the least strong theme with few individuals discussing it. For some participants however, being able to prepare for the death and having the post-bereavement dealings in place did significantly improve their experience of EoLC and bereavement. Furthermore for one participant, not having post-bereavement dealings in place led to severe negative consequences to the close-person network in the bereavement period. This is something that should therefore be captured and included within the measure. Consequently, the underlying attribute of preparation and the acceptance of EoL is included in the measure. Based within the capability paradigm this attribute is founded on the capability to prepare for and cope with the death of the close-persons. The descriptors for this attribute are based upon the sub-themes concerning the capability for people to be able to prepare for the death of their loved one and having their affairs in order.

6.4.7 Assigning levels to the attributes – frequency vs quantity

An issue to consider was to how best to phrase the levels of the attributes, specifically in terms of whether they should be phrased in terms of time, e.g. 'all the time', 'most of the time', or in terms of quantity e.g. 'all that is needed', 'most that is needed'. To improve the readability of the measure and to facilitate acceptability it is thought to be desirable to have the levels for each attribute in the same format. However, in this instance, this clearly was not going to be feasible given the nature of attributes. Four of the six attributes were felt to be a lot more amenable to quantities given the way respondents talked about them, for example:

> CDX10: *He was also **quite** organised with his affairs…*
>
> CDX25: *…and there wasn't really **any** support there…*
>
> CDX16: *…but **no** support was offered at that point…*
>
> CDX24: *It makes me **really** angry…*
>
> CDX5: …*there was **no** respect given to my mum…*

On the contrary were the communication and privacy and space attributes. Communication with those providing care services felt more natural when phrased using time, opposed to having a quantity of communication. This was reflected by the fact that participants regularly discussed communication in reference to time.

> CDX5: *And communication* ***a lot of the time*** *to be told what's going on and what's going to happen*
>
> CDX4: *I mean every time we went to the hospital I mean obviously if we needed to speak to the doctors they were available* ***at all times***

Consequently the communication attribute was developed with time being the basis of the levels. There was much discussion surrounding whether privacy and space should be in the frequency format or quantity format, and there was no clear preference in the data. The decision to opt for a temporal format came down to the desire to keep the measure within the capability framework. This in part is as a result of one of the descriptors for the privacy and space attribute that was developed through the constant comparative analysis which reads *'being able to have time with the person in private'*. Given this temporal descriptor, it follows that the levels are in a temporal format to improve readability. The levels of the other four attributes however were more suited to being described as quantities. To facilitate the acceptability of the measure the two temporal attributes were placed together at the start of the measure which were then followed by the four quantity attributes. This means that there is only one change in the format of the levels whilst completing the measure opposed to changing multiple times between frequencies and quantities as the measure is completed.

6.4.8 The close-person measure – checking the attributes and understanding

Through the interview process conceptual attributes were developed, and through the iterative process, terminology used by the participants was used to inform the wording of the measure. The previous section was focussed on the elicitation of the underlying attributes from the primary themes. The sub-themes for the conceptual attributes were developed and explored through the interview process to develop descriptors for the attributes that would be used within the measure to clarify the attributes to facilitate meaningfulness. This was based on previous experience within the research team which had found this to be a useful way of clarifying attributes for respondents and facilitating understanding and correct interpretation [177]. In the final batch of interviews, the latter half of each interview was spent exploring whether participants were interpreting the attributes as intended, i.e. whether the wording of the measure was meaningful to the participants, and also checking the coverage of the attributes to ensure that there was nothing missing that people felt should be included. Advice from participants was also sought to make fine adjustments to the wording of the attributes and descriptors to make it as clear as possible to the reader whilst retaining the properties of the underlying attribute.

6.4.8.1 Communication with those providing care services

When discussing the communication attribute, the respondents did not appear to have any difficulty in understanding the concept that the attribute was interested in, that is, the capability to have good communication with those providing care services and being able to get information about the condition of their decedent.

> CDX27:...*the question is asking me how I am experiencing being able to access accurate information about mum's care….*
>
> *CDX28:…just about how people communicated to you*
>
> CDX23:…*so communication with those providing services… and I think some of the aspects that you've alluded to here with regard to that person should have access to that information…to be able to have a say…because often they didn't, or they didn't feel comfortable to say because of the position or the authority of the doctor and the structure to ask questions*

CDX28 however felt that it was slightly unclear and that there was a potential to add some examples of possible care services to clarify who is indicated by care services.

> CDX28*: …you could have expressed that a bit clearer…what 'communication with those providing care services', like, who do you mean by providing care services….like when I read that I thought do you mean carers, that's very different to do you mean hospital staff, do you mean doctors, it's a very, nurses, it's a very broad phrase, those providing care services, and you know, you said how do you interpret it, some 'e.gs' might help*

This informed the measure, and in light of this suggestion, the questionnaire was updated to include examples within the description of the attribute. This issue was addressed for CDX23 and CDX31's interview and they felt that the wording was clear.

> A*: And is there any of that top bit that you don't understand, or any wording that you think is unclear?*
> CDX23*: No, no, to me that seems fine.*

To test for understanding, when asked to discuss the attribute in the context of her experience CDX4 clearly had a good grasp of what was being asked responding to the question in a meaningful manner. She felt that although communication was generally good in her case, it would have been beneficial if she had been able to have a bit more say in how the care was administered. Thus the attribute was interpreted as desired with no obvious misunderstandings.

> CDX4: *I think for the first one, although there was some good communication, I think particularly in the last few days, I think the bit about the second part about having to have a say in the care, that might have actually helped a little bit, or helped me to feel a bit more involved. Because although the consultants were telling me about how X was and what they felt would be better for him, I think that would've been important just before.*

Similarly CDX23 and CDX31 when asked where they felt their experience lay on the scale, demonstrated that the attribute and question were being understood as intended. They both described the difficulty they had in having communication with doctors and getting the information that they required.

> CDX23: *I think D* [being able to have good communication a little of the time] *….I just feel that a lot of the time, the doctors in particular didn't have the time to talk to us and they weren't present on the ward at the visiting times and they weren't present outside the visiting times so we couldn't have access to the people who had the information …*
>
> CDX31: *it would have been nice if they'd been able to have that communication throughout the day really. So for me it was 'a little of the time', apart from the bed manager at the very end, there was very little, the communication that came my way was all passed, second, third hand*

CDX23 felt that the wording of the levels was clear, and that five levels was an appropriate number.

> CDX23*: No…it seems fine.*
> A*: And the five levels, do you think that's too many, or is that enough….?*
> CDX23*: No I think that's fair, you've got your sort of top end then your sort of mid-point which is a bit bland then you've got the other end of the spectrum as well.*

The communication attribute and levels were clearly understandable to participants and they demonstrated a good understanding of the issues that were addressed in the dimension. The only suggestion was to add a few examples to clarify who may be classified as a care service provider. This was noted and added to the descriptive system for the final interviews.

6.4.8.2 Practical support

For the practical support attribute, there appeared to be good understanding of the attribute. For the communication attribute CDX28 had wanted some examples added, the practical support attribute however featured some examples of the possible services. As result there were no issues reported when testing the meaningfulness of the practical support attribute for this participant.

He felt that he was able to get the support from work if he needed it; however he chose not to have the time off again interpreting the descriptors correctly.

> CDX28*:…practical support from employees such as time off when needed, I mean I didn't take work off by my own choice, but I think if I did…take time off [the employers] would have understood.*

Likewise when asked what the attribute meant to CDX27, she referred to the examples of practical support given by the descriptors. CDX31 suffered quite a sudden bereavement and as a result the avenues of practical support that were relevant to her were different. She however was successfully able to apply the relevant descriptors to her situation, notably in relation to support (or lack of) from employers.

> CDX27: *Yeah, I would interpret that, as it says, district nurses, Marie Curie, GP, overnight support*
>
> CDX31:*…for us it was more dealing with things after she'd died because it was so quick, so we didn't really need practical support and help with the care of the person because that*

> *obviously followed on, practical support from the employers, I mean I've mentioned already, I was given the five days compassionate leave which allowed me to deal with the funeral but I wasn't able to have time off to go back to X to help my dad with preparing the funeral…*

To further check for understanding participants were asked to respond to the question. In response to this, participants appeared to understand the attribute as intended. There was no evidence of participants misunderstanding the question.

> CDX27: *That one* [selects B]*…I'm able to get most of the practical support that is needed, we don't access any of it really but we know that it's there and we know that…*
>
> CDX31: *….probably, 'somewhat able' to get practical support in that we did get bits where necessary but you were fighting for it all the way rather than being given it. We could get it but we weren't given it if that makes sense.*
>
> CDX4: *Practical support okay…actually think that all of those are quite important, I mean in terms of trying to get help, mostly help, I suppose help from social services didn't come into it because he was actually in the hospital at the time. I did get some time off, I think the time I got off from my employer had passed was after X had passed rather than just before whereas I think I'd have preferred it if I had some time before as well.*

In relation to the number of levels within the measure, she felt that five was appropriate.

> CDX23: *Yeah, same with the others, so that's fine…*

At this stage it was clear that the attribute was being interpreted as intended, and the wording of the levels were clear to the respondents. Of particular interest was the degree to which the participants felt that the descriptors included with the attributes were useful. The descriptors clearly helped the individuals understand the different aspects of the attribute that of interest and thus justify their inclusion within the measure.

6.4.8.3 Privacy and space

In terms of the privacy and space attribute, the participants again all understood the attribute and did not offer any suggestions for changes. In regards to the meaningfulness all participants demonstrated through their answers to questioning that they understood what the attribute was about.

> CDX23: *I think it's just the environment where that person is within during those last you know stages…*

CDX27 clearly understood the issues that the attribute was getting at and talked extensively about her need for time to spend with her mother in private, demonstrating an understanding of the attribute. When asked about privacy and space she describes her experience of being frustrated by always having her mother's appointed carer there when she wanted time with her in private.

> CDX27:*…every time I went to mums she'd* [her mother's appointed carer] *come round which really drove me mad because I wasn't getting any time at all to be on my own with mum and we had a bit of a falling out and then we spoke about it…I need to get time on my own with mum, since then it's been wonderful, it's been great.*

CDX27 felt that this was an easy question to answer and again elaborates on how important it is to her to have privacy and space with her mother at this late stage of her life.

> CDX27: *…because I can't miss that opportunity to spend time with her so I don't have a problem saying I really need to be on my own in mum whereas before I might have thought, maybe I should go in a minute, maybe I'll come down when I think she's doing her dinner or, whilst now I'm like 'I want to spend some time with my mum'…*

CDX4 also demonstrated understanding with this question focussing on the environmental aspect of the privacy and space attribute. She felt that the setting at the EoL was peaceful. There was no sign of her misinterpreting the attribute.

> CDX4: *I think with the third one we were there when X passed away and I think in terms of the peaceful location, before he actually had gone back into intensive care he was in a room of his own, that was a peaceful environment…*

CDX23 demonstrated an understanding of the levels by choosing the option that was in accordance with what she had been discussing.

> CDX23:*…so we had, I would say B, we had privacy most of the time but it wasn't through our request or through the dignity of my grandparents it was more because they kept getting these infections and they didn't want them getting out.*

There were no signs of misunderstanding with any of the participants. To the interviewer it seemed that the descriptors facilitated the understanding as they frequently referred to aspects of the sub-themes given as descriptors when deciding on how it applied to their situation. There were no suggestions as to other things that should be included in this attribute, nor any evidence of misunderstanding.

6.4.8.4 Emotional support

The term 'emotional support' was easily understood by the participants with no evidence of people misinterpreting the attribute.

When asked whether he understood what was meant by the emotional support attribute, CDX28 and CDX27 clearly understood the concept of emotional support and what it was asking them.

> A: *So do you understand what I'm asking with emotional support…*
> CDX28: *Yeah…friends, family, colleagues being able to support one another, charities in this case…*
> CDX27: *I think that it's asking me…what it is…it is asking whether they are aware of it, and can they access it…*

CDX23 appreciated that it could be through both family members, and also more professional services such as charities and religion.

> CDX23:*…emotional support through your family, and then the more technical services if you like, or organised services and religion and things like that.*

CDX27 demonstrated a good understanding of the attribute by discussing the emotional support that she had access to. In the spirit of the attribute, she got emotional support through colleagues who were also nurses, and felt that her job as a nurse helped her reflect on her situation.

> CDX27:*…obviously I work with nurses and I work with people that look after mum so I'm in it every day…*

CDX4 again understood the question and discussed extensively the emotional support that was available to her and the issues that she had with it. She felt she got some support through her friends and family and she felt that the support from some of her wider relatives was especially helpful.

> CDX4: *Emotional Support…okay, there was some support through family and friends, I think some of it has actually been through slightly wider family, so…like one of my aunts, she was, she was going to come and visit X and then she wasn't going to, but then my husband had actually phoned her on the Wednesday to say 'look, please go', and I think she'd actually come more for me because she knew with the amount of stress I was actually under, and just the fact herself, that aunt of mine and another aunt, I think afterwards when they were actually ringing me to see how I felt, that was, I felt was very supportive…*

She felt that she did not receive any emotional support through religion, charity, nor employers.

> CDX4: *Emotional support through other services and religion… no I don't think so…. Emotional support through employers….no I don't think I've had that, no, not through the employers.*

CDX23 felt that there were no aspects of the emotional support attribute that was difficult to understand.

> A: *And is there anything in there that you don't understand.*
> CDX23: *No, no from a question point of view that's fine*

When asked to complete the question in terms of her views on the emotional support she received, CDX23 clearly understood the question. She felt that that the support she received was mostly due to her close-person network, she did however receive some emotional support from Macmillan nurses and clearly comprehended the topics of interest in the attribute.

> CDX23*:…Mostly from family, you know it was mostly inward focussed, although with grandpa, we did have the Macmillan nurses come round and talk to us, just because it was sort of cancer related so they, you know, they talked to mum mostly, not us, but there was a bit of support there from I suppose you'd call it a charity…*

When pushed to give an answer on the emotional support she feels she had, she clearly understands the question and gives a coherent response accordingly.

> CDX23:...*B, because most of the support was heavily weighted on the family friend's side but I guess if we looked for it and actively sought it we could find the additional support.*

All of the participants demonstrated understanding of the attribute and didn't give any recommendations on alterations to the wording.

6.4.8.5 Preparing and coping

The preparing and coping attribute is focussed on the capability for individuals to prepare for the person's death and in turn cope with the experience. The participants did not appear to struggle with answering the question related to the preparing and coping attribute, and discussed their experiences accordingly.

CDX4 felt she was not prepared for her brother's death due to the speed of it.

> CDX4*: …being prepared and coping…being prepared for the person's death, I think because things happened so quickly I don't think I was prepared for X's death.

CDX4 understood the 'being prepared aspect' of the attribute, however was unsure whose 'affairs' the attribute was interested in. This was clarified within the questionnaire for following interviews and there were no further misunderstandings with other participants.

> CDX4*: …having affairs in order…are we, is that looking at my affairs?*
>
> *A: No more to do with the wills and things that you have to deal with afterwards*

Once explained that it was her brother's affairs she did not have any further issues with the wording and answered it coherently explaining that she was very glad her brother had a will and that she had no regrets over how she dealt with her bereavement.

> CDX4*: Right right, yeah, I suppose yeah, he'd made a will which I wasn't aware of at the time but I was very very very glad that he had made the will….No I don't think, I don't have any regrets in a sense, I think what I did at the time, I felt I did to my 100%*

The changed wording however created its own ambiguities and momentarily confused CDX23. Specifically, the term 'close-persons' caused confusion.

> *A: And is there anything unclear in there?*
> CDX23*: I had to read the second point twice…having your 'close-persons' post bereavement affairs and funeral arrangements…I think it's 'close-person'.*

In light of this, the wording was again changed from the conceptual 'close-person' into lay terminology. Furthermore, CDX4 discussed the burden of being the executor of the will, and felt that there was a need for some practical support in dealing with the processes of the will. As a result of this desire for support with the post-bereavement dealings, an extra descriptor was added to the practical support attribute for subsequent interviews.

> *CDX4: And I think the third one as well in terms of dealing with his affairs after he passed away…this was the first time I'd had the role as an executor of his will so it was quite a learning curve for me but I think what would have helped is if there'd actually been somebody to actually take you through the process with what needed to be done…that'd be very helpful.*

CDX23 relates the attribute to emotional wellbeing and the emotional preparedness for the inevitable outcome that results at the EoL.

> CDX23: *I think here we're looking at the sort of emotional wellbeing, and almost emotional preparedness for you know what is an inevitable outcome so that's what's being alluded to here*

CDX28 felt that as a grandson, having the affairs in order was less applicable; he did however feel that the arrangements afterwards were very well done, he also expressed being free from guilt and regrets and thus interpreted the attribute as intended.

> CDX28: *Well the first two aren't so much applicable because…well the memorial events…that was perfectly done so it was a celebration, but being free from guilt and regrets, generally yeah I'd say so.*

CDX23 also discussed the preparation she made for her father's death. She felt her preparation mostly involved speaking to her family and felt the hospital did little to facilitate that, as a result she felt she was only somewhat able to prepare for her grandparent's death.

> CDX23: *I think probably C…we talked outside of the hospital as a family and we prepared ourselves for what was coming but there wasn't anything that the hospital did to help us*

As an aside, CD23 felt that something that should be considered in EoL situations which is related to the need for the close-persons to prepare for death is the need for the patient to prepare for their own death

> CDX23: *But I think there's something in there for preparing the actual person for this as well because granddad in particular was afraid…he did not want to die, he was petrified, and nobody talked to him at all.*

This was not included in the latest iteration of the measure as the measure is focussed on the close-person, not the patient. Other measures such as the ICECAP-SCM are designed to pick up the impact of preparation on patients at EoL.

Based on the comments of CDX4, the descriptor referring to the post-bereavement affairs was edited to make it clear that it is the dealing with the affairs of the decedent that is of interest. Furthermore based on the comment that she desired practical support with the bereavement processes, this was added to the descriptors within the practical support attribute. Based on CDX23's dislike for the term 'close-person' within the descriptor suggested by CDX4, this was changed into a lay term.

6.4.8.6 Emotional distress

The emotional distress attribute is focussed on the emotional distress experienced by the close-person as a result of the condition of their relative, this includes things like the impact of seeing them in pain/discomfort, due to the loss of dignity/respect of their close-person, or as a result of seeing their close-person not get the care and attention they need.

CDX4 clearly interpreted the question as intended and discussed her experience with reference to the descriptors given within the attribute. She went through each bullet point and discussed her experience in relation to the descriptor and did not demonstrate any difficulty in understanding what the question was asking. CDX4 did not feel that he was in any excessive pain, and was not neglected. In addition she felt that they managed to maintain a lot of dignity for her decedent and as a result felt that this was not an issue in her case.

> CDX4: *being free from excess emotional distress…right, I think for the last one… being free from emotional distress caused by excessive pain to the dying person. I think it was hard to know how much pain he was actually going through, and I know when the consultant had said that when they switched off the support if they felt he was becoming quite distressed or*

> *in pain they would obviously up the pain relief and things like that but before then I didn't, I couldn't tell how much pain he was actually in…excessive loss of dignity to X…I think we, we managed a lot of the dignity for him.*
>
> CDX4: *So I think in terms of his dignity, I tried my hardest to maintain that…free from emotional distress caused by any neglect to the dying person…I don't feel there was any neglect to X because obviously he was being cared for in the hospital so no.*

CDX28 felt that the question being asked was clear.

> CDX28:…*this one is fine as well, number 6.*

When developing the wording for this attribute, one of the concerns was that participants would think that the measure is interested in the decedent's emotional distress rather than the close-person's distress resulting from the decedent's condition. With the wording of the measure including 'emotional distress to yourself', this was not an issue in practice. CDX28 clearly grasped that we were interested on the emotional distress to him rather than that experienced by the patient. Rather than the death causing him distress he explains that the thing which was distressing was seeing his grandmother in such a terrible state prior to her death.

> CDX28 ...*I would say that towards the end of her life…it could have got worse so that's why I'm glad she died and there was a cut-off point rather than going on for another 5 months and just getting worse if that makes sense. I would say I'm somewhat able, because it was quite hard going and seeing her in a terrible state rather than seeing that she was dead.*

This was reflected by CDX23 who felt that the end stage of life is an emotionally stressful experience for those close to the dying.

> CDX23: *I think it's sort of, the past two questions are more about the emotional support and preparing but I think in some ways it is visually and emotionally very stressful to see the person going through these stages.*

When asked about this attribute she particularly found seeing the condition of her grandparents in hospital to be very distressing.

> CDX23:…*they were both on catheters and things like that, and you know the occasional one would leak or not be connected properly and that was horrible to see, and I mean I don't know if you can ever be free from that, it is very distressing to go through*

Both CDX27 and CDX23 felt that the top option for this attribute was an unrealistic expectation, and that some degree of emotional distress is inevitable.

> CDX27: [Reading under breath]…*you can't be free emotional distress,* [speaking out loud] *that's a really unrealistic expectation…*
>
> CDX23:*…I don't know whether you could be free from that at any point…I just think it's the free word really, sort of resonates for me, because I don't know if you could ever be free of the distress in that situation.*

CDX23 was asked how she felt both at the time of her bereavement, and how she rated herself on the attribute nearly a year on. In terms of the number of levels for the attribute, it was interesting to note that the middle level was not selected and the range of levels allowed for a notable improvement over time, indicating that the measure may well be sensitive to change.

> CDX23: *At the time I think it would be D…I think probably B now, looking back at it, I'm…you know, almost that intense period of stress and anguish sort of dissipates into a lifetime of other stuff, so it's not so raw…*

There was a feeling from the participants that within this attribute that the top level is unlikely ever to be experienced, i.e. it is unlikely to be fully free from emotional distress. To improve aesthetics of the measure, and to keep the levels consistent, it was decided that the top level would remain to keep the levels consistent in number with the other attributes, improving the readability of the measure, and also the ease of valuation.

6.4.9. Attribute coverage

To check whether the attributes covered all the areas of importance, individuals were given the chance to give feedback on whether they thought anything was missing within the attributes, or whether there was anything that could be added to the descriptors to clarify the wording.

As mentioned in the previous section, CDX4 felt that on the whole the coverage was very good, however she desired a descriptor for support with the bereavement processes which she previously stated she desired.

> CDX4: *Just…I can't think of anything…no…I suppose, I…in relation to the support, I suppose maybe some support for the carer…sure…and that would be obviously from the hospital itself as well…*
> CDX4: *…and I suppose if there was somebody, whether it'd be from palliative care or wherever just to say this is what the process will be once he passes away and this is what will need to be done…I think that sort of support would have been really useful.*

Other than that descriptor to be added to the practical support attribute, CDX4 did not feel that there was anything else that should or could be added to the measure.

> CDX4: *No…no, no I think that's it…*

CDX23 had one suggestion when asked whether there was anything missing from the measure, or whether there is anything that should be added. She felt that a descriptor within practical support should be added/edited to include practical support with financial affairs before EoL.

> CDX23:*…no…I think…the only other thing that I suppose it would be related to this one* [pointing to practical support] *is almost that within that practical support it's about the financial as well because we didn't really know what to do with regard to grandma and grandpa's money and financial affairs*

The wording of one of the descriptors of the practical support attribute was edited to factor in this minor change.

CDX28' felt there was not anything that should be added, and felt the themes within the attributes were very good.

> CDX28*: So we've had this clarification of what's wrong with her, we talked about her dignity prior to death…so those are the things…no I don't…I think that's perfect.*
>
> CDX28*: The themes that were touched on were very, very good.*

As referred to above, his only suggestion was that examples were added to the communication descriptor to clarify health care services.

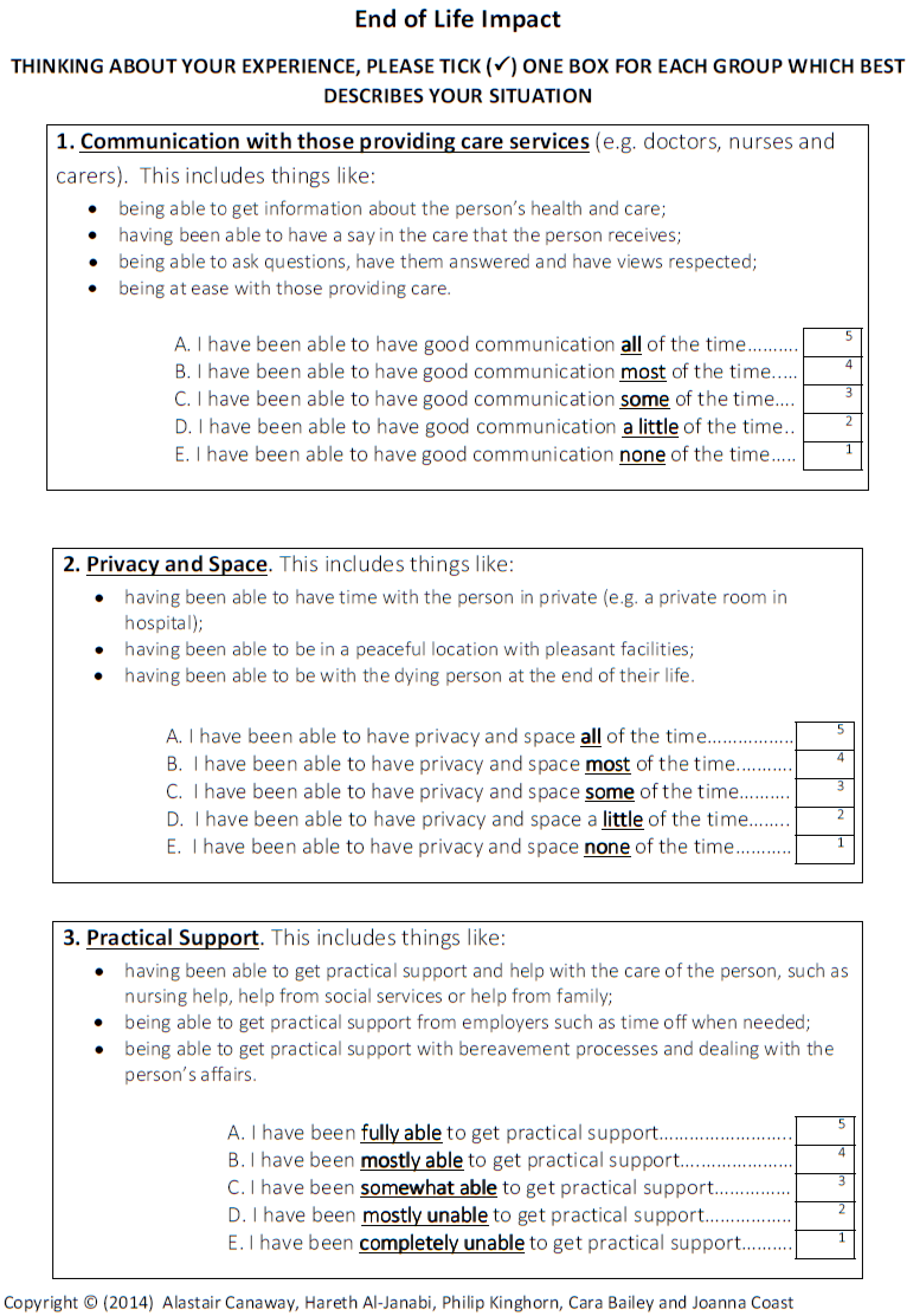
> CDX28*: The first one I think needs to be a bit clearer…but that kind of ties into the second one…like I think it's an e.g., like e.g. carers, hospital staff et cetera*.

Other than that he felt that the measure was '*perfect'*.

6.5. Summary

This chapter has described the development of the close-person measure. Constant comparative methods of analysis were used to analyse and develop attributes for the close-person measure. The wording of the attributes and descriptors were altered and updated iteratively in response to emerging data. During the process of checking and testing the wording of the measure with participants, there were a number of alterations to the wording of the measure. The attributes were found to be meaningful to the respondents and the measure appeared to cover all aspects the participants felt were important. The chapter finishes with the completion of the final measure. The final measure contains six attributes with five levels for each attribute, the attributes are: *communication with those providing care services, practical support, privacy and space, emotional support, preparing and coping and emotional distress*. The finalised version of the measure can be found in Figure 2.

Figure 2: The close-person measure



End of Life Impact

THINKING ABOUT YOUR EXPERIENCE, PLEASE TICK (✓) ONE BOX FOR EACH GROUP WHICH BEST DESCRIBES YOUR SITUATION

1. Communication with those providing care services (e.g. doctors, nurses and carers). This includes things like:

- being able to get information about the person's health and care;
- having been able to have a say in the care that the person receives;
- being able to ask questions, have them answered and have views respected;
- being at ease with those providing care.

A. I have been able to have good communication **all** of the time.......... ☐ 5
B. I have been able to have good communication **most** of the time..... ☐ 4
C. I have been able to have good communication **some** of the time.... ☐ 3
D. I have been able to have good communication **a little** of the time.. ☐ 2
E. I have been able to have good communication **none** of the time..... ☐ 1

2. Privacy and Space. This includes things like:

- having been able to have time with the person in private (e.g. a private room in hospital);
- having been able to be in a peaceful location with pleasant facilities;
- having been able to be with the dying person at the end of their life.

A. I have been able to have privacy and space **all** of the time................. ☐ 5
B. I have been able to have privacy and space **most** of the time........... ☐ 4
C. I have been able to have privacy and space **some** of the time.......... ☐ 3
D. I have been able to have privacy and space a **little** of the time........ ☐ 2
E. I have been able to have privacy and space **none** of the time........... ☐ 1

3. Practical Support. This includes things like:

- having been able to get practical support and help with the care of the person, such as nursing help, help from social services or help from family;
- being able to get practical support from employers such as time off when needed;
- being able to get practical support with bereavement processes and dealing with the person's affairs.

A. I have been **fully able** to get practical support.......................... ☐ 5
B. I have been **mostly able** to get practical support...................... ☐ 4
C. I have been **somewhat able** to get practical support............... ☐ 3
D. I have been **mostly unable** to get practical support................. ☐ 2
E. I have been **completely unable** to get practical support.......... ☐ 1

4. Emotional Support. This includes things like:

- being able to get emotional support through family, friends or colleagues;
- being able to get emotional support through other services including charities and religion if applicable.

A. I have been **fully able** to get emotional support...................... ☐ 5
B. I have been **mostly able** to get emotional support.................. ☐ 4
C. I have been **somewhat able** to get emotional support............ ☐ 3
D. I have been **mostly unable** to get emotional support.............. ☐ 2
E. I have been **completely unable** to get emotional support....... ☐ 1

5. Preparing and Coping. This includes things like:

- being prepared for the person's death;
- having the person's post-bereavement affairs and funeral arrangements in order;
- being free from guilt and regrets.

A. I have been **fully able** to prepare for and cope with, the person's death................ ☐ 5
B. I have been **mostly able** to prepare for, and cope with, the person's death........... ☐ 4
C. I have been **somewhat able** to prepare for, and cope with, the person's death..... ☐ 3
D. I have been **mostly unable** to prepare for, and cope with, the person's death....... ☐ 2
E. I have been **completely unable** to prepare for, and cope with, the person's death ☐ 1

6. Emotional Distress to you, related to the condition of the person. This includes things like being free from emotional distress resulting from:

- seeing the person in pain and discomfort;
- seeing the loss of dignity, or a lack of respect given to the person;
- seeing a lack of care and attention given to the person.

A. I have been **fully able** to be free from emotional distress................. ☐ 5
B. I have been **mostly able** to be free from emotional distress............... ☐ 4
C. I have been **somewhat able** to be free from emotional distress........ ☐ 3
D. I have been **mostly unable** to be free from emotional distress......... ☐ 2
E. I have been **completely unable** to be free from emotional distress... ☐ 1

Thank you for your help with this research

CHAPTER 7: DEFINING A ‘CLOSE-PERSON’ AND EXPLORING THE CLOSE-PERSON NETWORKS OF THOSE AT THE END OF LIFE

7.1 Introduction

Chapter 2 presented normative reasons for the inclusion of impacts upon those close to the dying for use in the economic evaluation of EoLC. Following this, Chapter 6 developed the descriptive system for a measure to capture benefits of EoLC through the analysis of qualitative interviews with those who felt they were close to somebody at the EoL or that were recently bereaved. It is unclear which close-persons should enter into the evaluative space, and what exactly constitutes a ‘close-person’; relatives are often close, but it could be argued that friends can be just as close, possibly closer, and may therefore be impacted by the EoL as much as family may be. Deciding who should enter into the economic evaluation and be assigned a ‘close-person’ identity is therefore not necessarily straightforward. Typically within economic evaluation ‘close-persons’ have been limited to the primary carer e.g. [318]. There is, however, no reason why impacts should be limited just to carers [319] and chapter 2 argues for the wider inclusion of benefits to those close to the dying. If the impacts upon close-persons are to be included within economic evaluation there are some important considerations that need to be addressed.

It is important to understand what makes people ‘close’. Understanding what makes somebody close will inform how different EoL trajectories might impact on who enters the evaluation. If the benefits of EoLC to close-persons are to be included within economic evaluation, then it is necessary to understand the characteristics of those who are close to those at the EoL, and how many people may be impacted by the EoL and thus enter the evaluative space with a close-person identity. The close-person network exercise when combined with the interview transcripts enabled the examination of the influences on the size of networks at the EoL.

This chapter investigates the following questions:

- What makes somebody close?
- Who and how many people appear to be close to those at EoL?
- What influences closeness and network size towards the EoL?

Understanding factors influencing the size of close-person networks and closeness at the EoL elucidates the implications of including those close to the dying within the economic evaluation of EoLC.

7.1.1 Characteristics of the decedents' close-person networks

Table 6 summarises the characteristics of the decedents whose participants completed the close-person mapping task. In total 24 decedent's close-person networks were examined within the interview process. The task was not conducted with four participants due to time limitations arising from the focus on the measure development. The decedents within the close-person mapping task included a broad range of death trajectories from sudden death to deaths after a long period of slow decline. The decedents for whom the close-person maps were completed included nine mothers, seven fathers, four grandmothers, one grandfather, one friend, one sibling and one spouse. There were no cases of reporting on the death of a child. It is unsurprising to find that the age of the decedents reported tended to be relatively old with only two decedents being aged between 40-59 years, 10 between 60-79 years, and nine being aged over 80 years; three did not specify the age of their decedent. Given that the three decedents whose age was not reported were either a parent or grandparent to the participants, it is reasonable to assume they were unlikely to have been younger than 40 at the time they died.

Table 6: Decedent close-person networks

Participant ID	Relation of decedent to participant	Decedent's terminal condition	Decedent's age group	Number of people within decedent's network	Relation of Closest person	Number of specified non-relatives?	Number within inner ring of map	Where they placed themselves
CDX1	Father	Pancreatic Cancer	60-79	7	Spouse	1	5	Inner ring - closest (equal)
CDX4	Sibling	Lymphoma	40-59	6	Sister	0	4	Inner ring - closest
CDX5	Mother	Alzheimer's	60-79	8	Spouse	0	3	Inner ring -second closest
CDX5	Father	Heart Failure (with COPD)	80+	7	Daughter	0	2	Inner ring - closest
CDX6	Friend	Oesophageal Cancer	40-59	20	Multiple - Friends and Family	2	7	Inner ring - closest
CDX7	Mother	COPD and Alzheimer's/Dementia	80+	3	Spouse	0	1	Second ring – second closest
CDX8	Father	Sudden Death - Heart attack	60-79	6	House Keeper	2	2	Second ring – fifth closest
CDX10	Father	Death following elective heart surgery complications	Unknown	74	Multiple - all family	0	9	Inner ring – equal closest
CDX13	Mother	Motor Neurone Disease	60-79	9	Multiple - Sister, Daughter and 2 Friends	3	9	Inner ring – equal closest
CDX14	Mother	TIA/Dementia	80+	4	Brother	0	1	Second ring – second closest
CDX16	Father	CHD - Death following heart surgery complications	80+	10	Son	3	5	Inner ring - closest
CDX17	Grandmother	Pneumonia	80+	8	Daughter	1	3	Inner ring – second closest (equal)
CDX18	Mother	Pneumonia	80+	5	Granddaughter	2	3	Inner ring – second closest
CDX20	Mother	Cancer - Colon/Liver	60-79	12	Daughter	2	3	Inner ring – closest
CDX21	Father	Undiagnosed - chest complaint	80+	8	Multiple - Daughter and Spouse	1	3	Inner ring – equal closest
CDX22	Grandmother	Heart Disease	Unknown	10	Daughters	0	4	Inner ring – third closest
CDX23	Grandmother	Post-fall infections in hospital	80+	10	Spouse	0	2	Second ring – third equal closest
CDX24	Grandfather	Lymphoma	60-79	7	Multiple - Granddaughter and Spouse	0	5	Inner ring – third equal closest
CDX25	Father	Cancer - back/spine	60-79	7	Multiple - Daughter and Spouse	0	5	Inner ring – equal closest
CDX26	Spouse	Multiple System Atrophy	60-79	5	Spouse	0	2	Inner ring – equal closest
CDX27	Mother	COPD	60-79	8	Multiple - Daughter and Carer (Daughter in law)	2	2	Inner ring – equal closest
CDX28	Grandmother	Parkinson's Disease	80+	8	Spouse	0	2	Second ring – third equal closest
CDX29	Mother	Sarcoidosis	60-79	15	Multiple - Son and Brother	0	7	Inner ring – equal closest
CDX31	Mother	Viral Pneumonia + sudden heart attack	Unknown	8	Spouse	1	5	Inner ring – second closest

7.1.2 Task completion

None of the participants appeared to struggle to complete the close-person network task, nor did they seem to struggle with identifying who were the members of the close-person network. There was, however, a desire from many participants to put multiple people on the same post-it note, especially for those with particularly large networks where large groups of friends were included. The task once explained was easily completed by the participants. Many participants chose to rearrange the networks after discussion and reflection. The task worked well as part of the interview giving the participants a break from the more emotive discussion of EoLC.

7.2 What is a close-person?

Participants spoke about a number of factors that they felt made people ‘close’. A number of themes arose from the interviews which formed the aspects of a close-person. This section outlines the characteristics of ‘close-persons’ as elicited from the participants.

7.2.1 Reciprocated relationship/emotional connection

One of the key aspects which appeared to enable people to be described as close, related to the reciprocated emotional ties between individuals. That is where people felt that they had an emotional connection which is also felt by the other person. This attribute of a close-person therefore appears to be focussed on the relationship and connection between the individuals on an emotional level.

Many participants discussed the emotional relationship that is required for two individuals to be close. CDX1 expressed this in terms of ‘friendship bonds’, and felt it is that relationship between the two individuals that defines being close. CDX16 echoed this notion, referring to the emotional connection that exists between individuals and the two-way nature of such a relationship. A number of participants referred to this reciprocal emotional connection.

> CDX20: …*somebody that you care about greatly, and they care about you greatly*…
>
> CDX21: *so it's sort of somebody that cares about what happens to you and you care about what happens to them…*
>
> CDX15: *Just people who are there for you and you are there for them, a reciprocal symbiotic relationship…*

One participant separated the connection into two parts, a biological connection, and emotional connection. They appeared to feel that, when combined, the biological and emotional connection provides a very strong bond between the two individuals.

> CDX16*: I think it's just a connection to that person, to actually know that as a person you sort of have a biological connection to them but also an emotional connection to them…and that's a very strong bond really…*

CDX5 refers to the emotional connection using the term 'love' to signify those who are close, and felt they are the people that she wants most in her life.

> CDX5: *You see close to me, probably I feel are the people that I love the most and I want to be in my life the most, they're what I would call my close people.*

It is clear from the participants that there is a strong feeling that for somebody to be close, it is a two-way process, whereby there is emotional attachment from each party towards the other. For somebody to be close it appears there is a need for a reciprocated relationship between the two individuals.

7.2.2 Shared experiences

Many participants discussed how a key feature of someone being close was due to them having shared experiences together, and being there to support each other through such experiences. This can be seen as a contributory factor for developing closeness. By sharing experiences together the individuals become closer.

> CDX8:*…I suppose it's sort of shared experiences maybe, yeah.*

There appear to be two subtle aspects to this, the first being a shared present, and the second being a shared past, both of which facilitate closeness. Several participants discussed how sharing experiences in the present facilitates closeness

> CDX25: *Somebody that understands the situation, and somebody that's got shared experience and shared understanding of what's going on.*
>
> CDX15*: well somebody with whom you share experiences…*

When describing what makes somebody close, one of the participants explained how 'sharing experiences' had made her feel close to a friend who had died. She described how the shared experiences of their pasts had helped form the close relationship that she had with her decedent.

> CDX6: *well with this friend it was…we'd grown up together and we'd shared such a lot that she became like a part of who I was*

7.2.3 Trust and reliance

When discussing the characteristics of a close-person, many participants referred to the ability to trust and depend on the person as a defining characteristic of a close-person. This was one of the strongest themes that emerged. Many participants appeared to feel that being able to trust and rely on the other person was a key facet to being close.

A number of participants referred explicitly to trust as a major aspect of being close. CDX5 felt that trust was the most important thing that led to someone being a close-person.

> CDX5:*…but I also feel that trust is probably the biggest thing that makes that person (or persons) fall into the close-person profile. Trust is a very important thing… Along with love*

> *and respect I think it would be what makes people around you fall into the 'close-person' category.*

She felt that trust, when augmented by respect, led to love and a good relationship.

> CDX5: *Trust and respect generates love and all of these three things especially when reciprocated to make a two way thing makes a good relationship – whether partner, family member or friend.*

This requirement for trust was echoed by many of the other participants who also felt that trust was an essential part of being close to somebody.

> CDX9: *…I mean trustworthiness…that's important for me, somebody you can trust… the people closest to me are the people who I really trust.*
>
> CDX21:*…you can trust them that if you know phone up and go 'I've got a problem', they'll offer you some support*
>
> CDX22:*…being able to talk with them and trust them and knowing that you can tell them anything and they can tell you anything.*

Linked closely to trust is reliance. Many participants felt that, not only is a close-person somebody you trust, but also somebody that you can rely on should you need their help or support.

> CDX7: *somebody who, you can trust, they won't judge you, without judgement, totally rely on. That's all I can think*
>
> CDX10: *It's somebody that you don't feel concerned about asking to do something for you, if they're not a close friend you think 'can I ask them, is it a bit cheeky?' whereas when it's a close friend it's just 'could you help me with this, could you pick the kids up for me'*
>
> CDX16: *You know you can rely on someone, they're at the end of a phone wherever they might be.*
>
> CDX21:*…you can rely on that person…*

One of the participants felt that loyalty also played a part in being close.

> CDX9:*…someone who's kind of loyal*

Linked inherently to trust, one of the participants felt that respect played a strong role in the close-person definition. She draws on her own experiences of who she would class as being close to her.

She gives the example of how she no longer sees her sister as close as she lost respect for her whilst her mother was approaching the end of her life.

> CDX5: *perhaps that's what close-person is as well, that you would love and respect somebody because you can love somebody but not always respect them, perhaps people on the outskirts of your family perhaps like my sister, I lost respect for my sister when she wasn't in touch with my mum and my dad when I felt they needed her so we don't keep in touch as much now….so my dad and my mum were the link and…that link's broken yep, so it would come through that but now I've lost that respect for her.*

7.2.4 Open and non-judgemental

Another key theme that arose through the interview process was the need for a close-person to be someone with whom the person could communicate freely and not worry about them being judged for what they may say. Many participants felt that for someone to be close, they should be able to talk about anything and feel comfortable doing that. There are two sub-themes to this aspect of closeness: honesty and openness. Some participants appeared to feel that people who are close are those that they can talk to honestly without being judged.

> CDX6: *when it's people that you're comfortable with, you don't have that same kind of reluctance to be yourself or let yourself go a little bit.*
>
> CDX25: *Somebody that you can talk to honestly, and openly, you know about anything.*

Closely linked to honesty, some felt that people who are close are those who you can talk to about anything.

> CDX21: *Ooo they'll tell you anything and you'll tell them anything…*
>
> CDX22: *I think to me it's somebody that you can talk to about like, most things*
>
> CDX24: *Well I guess it's somebody that you can talk to about anything good or bad, that you know will always be there if there's anything wrong…*

This was expressed by others in terms of close people being those who you can talk with openly to get help with any problems or issues that you may have elsewhere in life.

> CDX18:… *yeah somebody [you] get on with…and you can talk to, and if you've got a problem you can take it to them, and they have a problem they can take it to you, I think that's probably it.*
>
> CDX14:…*you can't just say to anybody, 'I don't really get on with my mum', that… And things like 'I hope she doesn't last too much longer'…but it's people you can have those sorts of discussions with, somebody can ring up …sometimes you just need to share that with somebody and have someone say 'oh that is terrible', sympathise without telling you what you should do about it or whatever.*

7.2.5 Comfort and security

The final theme within the qualitative analysis was the notion of security and comfort. Three of the participants felt that the people who are close to them are the people with whom they feel comfortable and secure.

> CDX6:…*it's that sort of security and comfort, and maybe that's because I'm getting older that I want things to be familiar and I want to feel, confident…*
>
> CDX15: *just people that you're comfortable with and spend time with*
>
> *CDX17: … somebody that knows you really well…a close-person is someone that you can sit in a room with in silence and you don't feel you have to talk to them. That's what I think…it's someone that if you are upset and you didn't want to talk about the, they would know you were upset anyway without saying anything.*

7.2.6 Defining a close-person

The key themes mentioned through the interview process were: a reciprocated relationship, shared experiences, trust and reliance, being open and non-judgemental, and comfort and security. All five of these themes are factors that can impact upon closeness; however it is unlikely that all need to be met for somebody to be close. When examining what may impact upon the size of networks, these factors will be useful to consider in understanding why certain conditions or experiences may lead to individuals having smaller or larger networks at the EoL. If a situation or condition negatively affects the factors described above, then it is likely that there will be fewer close-persons.

7.2.7 Beyond immediate family?

Typically, within the health economic literature, benefits of interventions are limited to the patient, and sometimes also the immediate caregiver. The close-person mapping and interview process gave a good opportunity to explore who is actually close to people at EoL and in turn who is likely to be impacted by EoL, and therefore potentially eligible for inclusion within economic evaluation. Fifteen out of the 24 close-person maps contained individuals who were described as being close to the person at EoL who were not relatives. These individuals included friends, paid carers, and even a housekeeper. In two of the close-person maps, non-relatives were found to be the closest or equal closest individuals. In the case of CDX8, the housekeeper was found to be the closest person (and most upset and therefore potentially the most significant close-person in terms of inclusion within economic evaluation) to CDX8's decedent who was then followed by a friend of CDX8's decedent. CDX6 felt she was just as close to her decedent as the immediate family members.

As reflected by the close-person maps, during the interviews when exploring the close-person concept, a number of individuals expressed the view that close-persons were not necessarily limited to relatives. In fact there were no instances of anybody explicitly saying that close-persons should be restricted to family. On the contrary some participants felt that a close-person could extend beyond immediate family.

> CDX20: *I don't think it has to be defined by family or blood, I think people who have made great impacts in your life and you've made great impacts in theirs*

CDX1 felt that the close-person definition can extend beyond just being relatives, and significantly that relatives may not be close. The implication of this is that, if wider benefits are limited simply to relatives, then there may actually be impacts on 'closer' individuals that are not being captured. This is because the benefits to those who are close but are not relatives will be excluded.

> *CDX1: I wouldn't necessarily say it is about relatives because as you know you can have estranged relatives and close friends but I think the key thing is it's somebody who has a…I'm going to say it myself….a close-personal relationship*

In line with the close-person definition derived earlier, she felt that it is an emotional connection rather than a family tie per se that makes them close.

> *CDX1:…I think it's emotional bonds rather than family bonds if that makes sense, quite often the two are the same but not necessarily.*

This can be further explored by examining the networks of the decedents. Over half the close-person maps contained friends of the decedent whom the participants felt were close. When combined with the data above, it is clear that being a family member is not a requisite for being a 'close-person'. Therefore there are strong arguments for including non-family close-persons within the economic evaluation of interventions. Given the definition of a close-person as explored in section 7.2.6 this is not a surprising finding. The aspects of a close-person allow for those other than family to be classified as close and as a result may include non-relatives within the close-person network.

7.2.8 Is geographical closeness required to be a close-person?

It could be hypothesised that to be close to somebody, you need to be physically close in terms of geographical location. This was something that was explored with, and discussed by, some participants. Different opinions were put forward as to whether geographic proximity was a requisite for closeness.

Two participants felt that geographic location was important in terms of closeness. Both CDX1 and CDX22 felt that geographical closeness was important in having a close relationship. CDX1 felt that it is difficult to be close to somebody who does not live nearby.

> CDX1:…*my personal view of the world is that it's quite difficult to be close to somebody that you're a long way away from or relatively long way away, I mean it's all relative*

CDX22 felt that although it is possible to be close to somebody living in a different country, she personally felt that it was more difficult to be close if you live further away. Consequently she felt she had a stronger bond with those living geographically close to her who she sees on a regular basis. Similarly CDX1 felt that you tend to be close to those people that you see regularly.

> CDX22:*…I'm close to my cousin and she lived in Belgium, and I'm…I think it does have an impact, it's harder to be closer when they're living somewhere else because obviously all my friends who live locally, I'm really glad…I see them all the time so we've got a stronger bond.*
>
> *CDX1:…usually you're close to people by default that you see a lot regardless of the relationship you tend to be, you know, I'm quite close to my friends or whatever who I see quite frequently*

Although CDX1 and CDX22 felt that geographical distance hinders closeness, they both conceded that geographical closeness is important but may not be a necessity for closeness.

> CDX22*:…but I don't think it's impossible to be close to somebody living in a different country*
>
> *CDX1: So I think that it has to be mainly geographical but perhaps I'm willing to concede I might be being unkind.*

Looking back at the definition of a close-person as developed previously this would make sense logically as there is a greater opportunity to develop those emotional ties, and grow to trust and rely on those people seen on a regular basis. CDX1 uses the example of her dad's brother who lives a distance away and therefore is not as close as the sisters were to her father.

> *CDX1:…my dad's brother who lives down in E which isn't a million miles away but at their age it is quite a long way away and…I'm perhaps being unfair but I don't think he'd have been as close to my dad as say his sisters who saw him more frequently, and that might be me being unfair about him.*

In contrast, a number of other participants felt that geographical proximity was not important in determining closeness.

> CDX16*:…like immediate family like my cousins because I'm the only one, I'm probably closer to my cousins than other people might be close to cousins like the brothers and sisters you didn't have, even though some are in America I feel very close to them, definitely.*
>
> *CDX25:…my sister, she's moved up to Scotland and so her and the family are living up there now, and we talk a couple of times every day so it's…we're incredibly close still.*

> CDX20: *I have a wish that we* [sister] *were geographically much closer because I think we would both benefit from that but in terms of my feelings towards her and her feelings towards me; they are not lessened by distance.*
>
> *CDX25:…you don't need to be physically close…*

The underlying reason why participants felt that close-person relationships could be maintained over long distances appeared to relate to the ability of technology to aid communication across large distances. Despite some participants having close-persons in distant places, they maintained their close-person relationships via technology.

> *CDX13…I think the beauty of our time is technology so I can see her through the PlayStation now, we've got a nice big screen in our living room and it's like we're in the same room, she sits there and we show her the kids and we don't have to put the Skype phone down or carry around a laptop so it's really easy and I think that distance, even without her disease it's really helped us keep in touch all the time, I feel like whenever I want to have a cup of tea with my mum I just turn on the TV and she's there, so I think in that sense we've been really really lucky, I don't know if that would have happened about ten years* [ago].
>
> CDX16:*…you just pick up the phone…or Skype or everything else.*
>
> CDX25:*…you know you can communicate in so many ways now, and just talking on the phone even, you can have a heart to heart, you can still have that connection.*

It appears that geographical location can play a part in the degree of closeness. Being geographically more distant reduces the likelihood of sharing experiences and communicating regularly, thus reducing the likelihood of becoming close. The advancement of technology, however, appears to have ameliorated this to an extent and allows people to remain close despite distance. The most obvious example of this was CDX13 whose mother is currently suffering from motor neurone disease abroad. CDX13 however felt she was still extremely close to her mother and listed herself as equal closest in the networks at EoL task. It would therefore appear that although geographical closeness facilitates closeness, it is not vital given the capabilities of modern technology.

7.3 Who/how many are close to those at end of life?

Family members appear to play an important role in the close-person networks for those at EoL with every single close-person map featuring somebody related to the decedent. Although the close-person maps predominately contain family members, fourteen of the close-person maps do however contain non-family members; these were typically friends of the decedents; however there was also a carer included within one of the close-person maps (CDX18), and a house keeper in another (CDX8). For 12 out of the 24 close-person maps, the participant felt that they were the closest or equal closest person to the decedent. The descriptive statistics of the network maps is shown in Table 7.

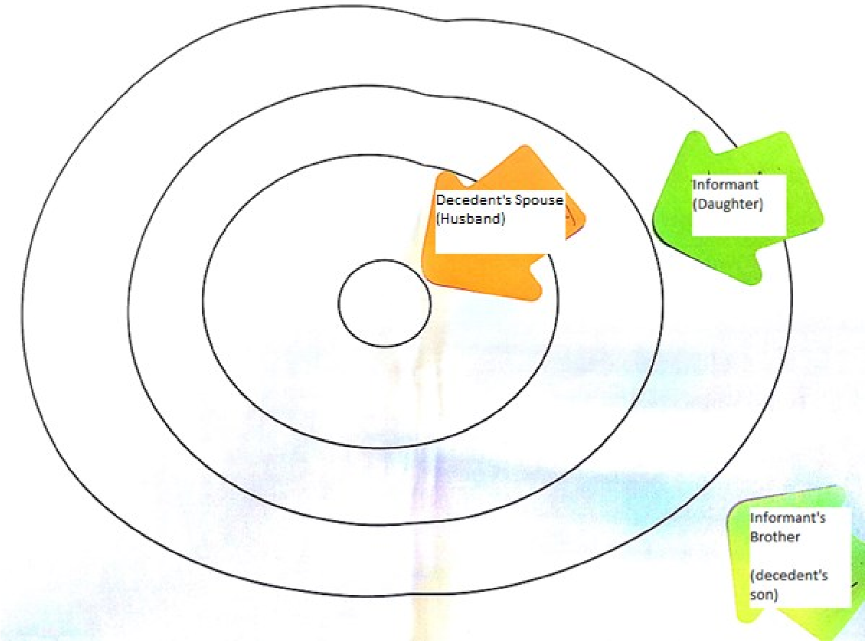
Table 7: Network size descriptive statistics

Extent of Close-person map Network		Number within Inner-ring
Median	8	3
Minimum	3	1
Maximum	74	9
Mean	11	3.9
Standard Deviation	13.9	2.3
Skewness	4.4	0.9
Mode	8	2

The relationship of the closest individual in each case was examined. For nine out of the 24 close-person maps, more than one individual was listed as being the closest person; these were typically different members of the same family, with the exception of CDX6 who included herself (as a friend) to be the same closeness as other family members. For the other 14 close-person maps, six of the closest people were the decedent’s spouse, five of them were the decedent’s children, two of them were the decedent’s siblings, one was a granddaughter and one was the decedent’s housekeeper. Thus the majority of the closest people to the decedents were immediate family members with one notable exception (CDX8). An examination of the close-person maps revealed that CDX8’s close-person map contrasted significantly to all the other close-person maps and is discussed accordingly.

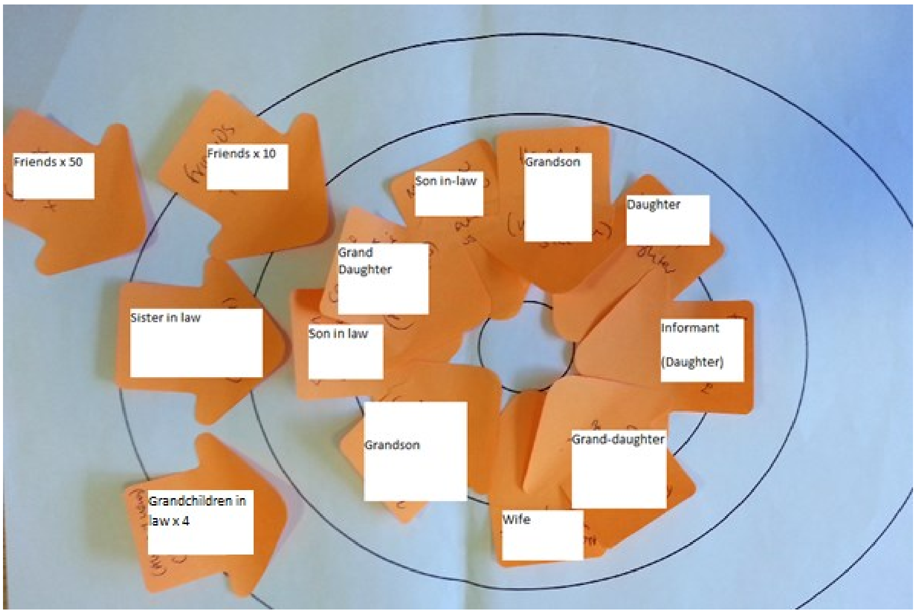
There was a wide variety in terms of the size of the close-person maps. The smallest close-person map was that of CDX7 with just three individuals as shown below.

Figure 3: CDX7's decedent's network



At the opposite end of the spectrum was CDX10 who included 74 different individuals within her father's close-person map. The close-person map containing 74 individuals was very much the outlier with the next largest estimated to contain 20 individuals. The median network size is eight, whilst the mean is 11. This is reflected by the fact that the majority of the close-person maps contained fewer than 10 individuals. One of the main reasons for the large difference in size of close-person maps is that some individuals listed large groups of other friends, e.g. CDX10 included 'other friends x 50' as shown below.

Figure 4: CDX10's decedent's network

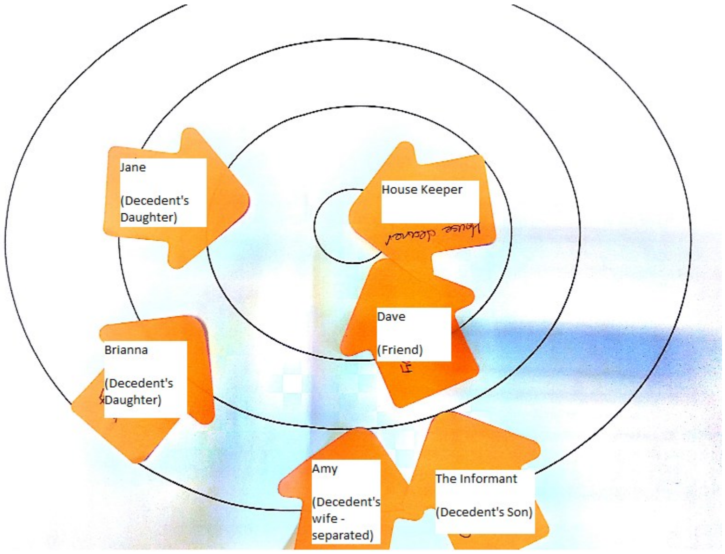


It is of interest to examine those who were closest to the decedent, i.e. those who were included within the inner ring of the close-person map exercise, to determine who were the closest to those at the EoL. When focussing on the inner-ring as shown in the table, there were on average three (median) individuals who were extremely close to the decedent. The range for this was far smaller with a maximum of nine individuals being listed as extremely close and a minimum of one. Just five of the close-person maps featured non-relatives within the inner circle of the close-person map. On all but one of the close-person maps, the closest individuals were relatives; however two of the close-person maps had friends as being equal closest whilst one had the housekeeper as the closest.

Deviant case analysis: CDX8

All but one of the close-person maps had at least one family member as being either the closest person or equal closest. The anomaly to this pattern however was the case of CDX8 which warranted further investigation to understand why this may be the case.

Figure 5: CDX8's father's network



CDX8's close-person map is very different to all others. The closest individual in CDX8's close-person map is the house keeper; this is then followed by a friend labelled as 'Dave' (name changed). Less close, there are the decedent's two daughters, the participant (decedent's son) and the decedent's wife (separated). Unlike every other close-person map where a family member was listed as being the closest or equal closest individual, the two closest in this case were not family members. A closer look at the interview transcript reveals why this may be the case. CDX8's father had become estranged from the rest of the family. This was partly due to the fact that his parents had separated which culminated in his father emigrating to Portugal several years ago.

> CDX8: *…because him and my mum were…he had these kind of ideas, these great ideas he had, and the last one basically was that he went out and he lived in Portugal and I think that was for the last sort of 3 or 4 years that he was alive, possibly a bit longer, yeah actually it would have been about 5 or 6…*

CDX8 had a complex relationship with his father. Initially, as a child, he got on with his dad, however as CDX8 grew older, he realised that his dad had not treated people well which led to a distancing between them.

> CDX8: *…when I was a kid we did a lot of things together but I think there was always that thing where I liked my mum better I think and it was kind of a bit of relief when he wasn't around sometimes when he was off out at work then basically, as you get older, you start*

> *hearing about things that he'd done, you know, just sort of stupid things in terms of money and how he'd treated people*

It appears that in recent years CDX8's father had become less close to his family and in turn had developed close-person relationships elsewhere, in particular with his house keeper and also a friend.

> CDX8:*…he had a house cleaner that he was quite friendly with and she said…there were a couple of people that he talked to but he pretty much stayed to himself.*

CDX8 was of the view that his father's housekeeper was most affected by the death of his father.

> CDX8:*…she was really upset because she was an ex-pat and was living out there and … I don't know if he felt sorry for her a bit, because he gave a lot of work for her to do and she kind of mothered him a little bit….*

A friend of CDX8's father was also badly affected by the decedent's death.

> CDX8:*…there was one person…was really upset and it was like 'Um okay', just one of those weird little things where you think he didn't seem to get close to people but other people seemed to be really badly affected by it.*

This case of CDX8 demonstrates succinctly why when expanding the evaluative space to include close-persons the focus should not be solely on family members. In this instance, the decedent had become estranged from his family and as a result the closest individuals to him were not family members. If only family members were considered within the close-person network then the persons most impacted would not have been included within the evaluation.

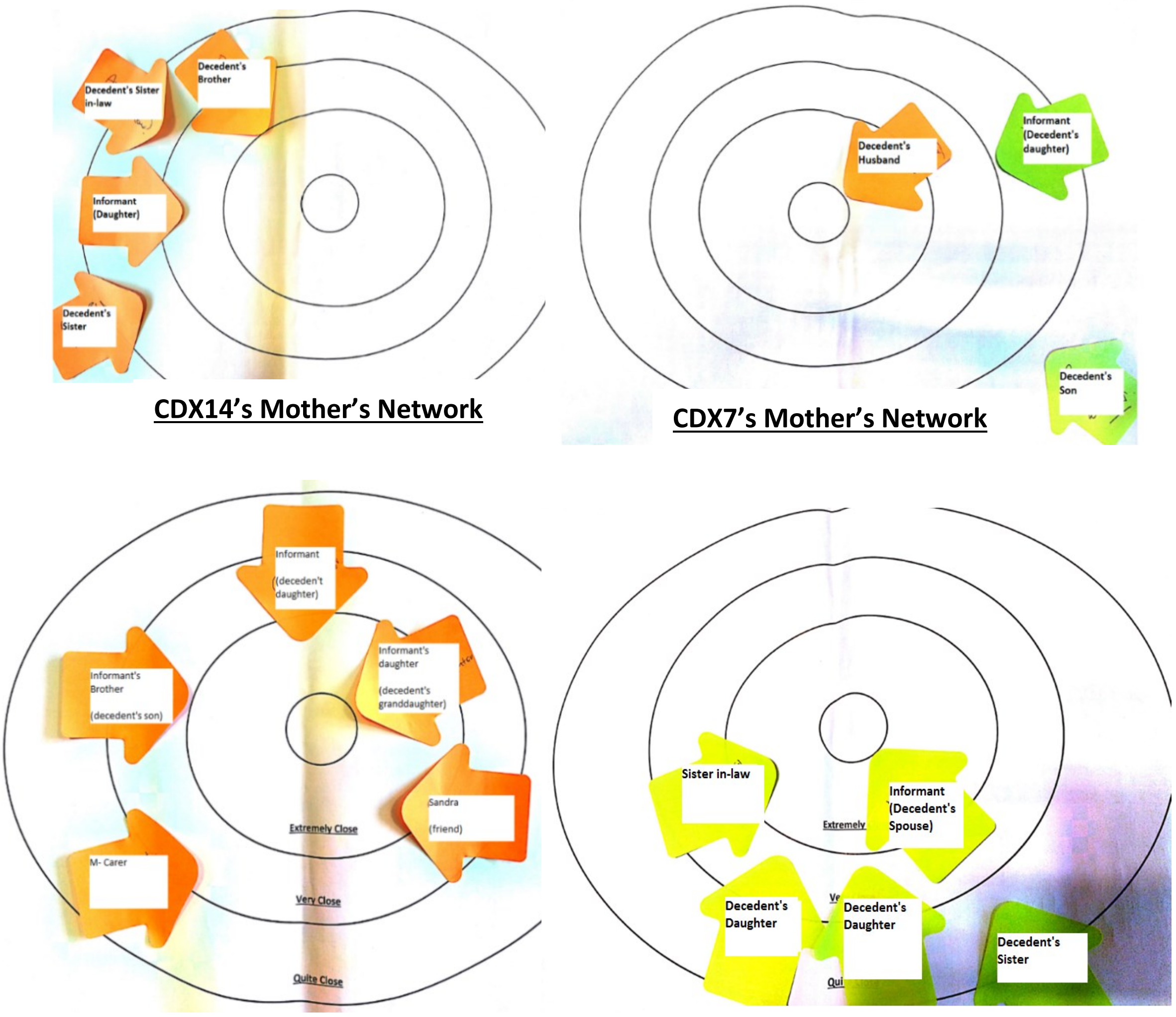
7.4 Influences on the size of the networks and closeness at end of life

Networks are not fixed throughout life and may change as life progresses; this may particularly be the case towards the EoL where illnesses and co-morbidities may impact the size and nature of networks. Within this study there was a large variation in the sizes of close-person networks at the EoL with the smallest being three and the largest being over 70. To investigate what may influence the size of networks at EoL, the close-person maps were examined in conjunction with the qualitative interviews. The participants whose decedents had the smallest number of close-person networks (5 or less) were examined and compared to explore what may influence the size of network towards the EoL. Likewise those with the largest networks (10+) were also examined to elucidate the factors that may impact upon close-person network size at the EoL.

7.4.1 Factors that may reduce closeness and network size

Four close-person networks had 5 people or fewer within them (CDX7, CDX14, CDX18 and CDX26). The close-person network belonging to the decedent of CDX7 was the smallest featuring just three people. CDX14's decedent's network is next which contained just four persons, whilst the decedents of CDX18 and CDX26 both had networks containing five close-persons.

Figure 6: Networks fewer than five



CDX14's Mother's Network

CDX7's Mother's Network

CDX18's Mother's Network

CDX26's Husband's Network

7.4.1.1 Impact of disease

The nature of disease as experienced by some of the decedents led to a distancing towards the EoL and potentially impacted upon the size of network. If a disease reduces the closeness of relationships, it is likely that a smaller network will result. CDX7's decedent had the smallest of the close-person networks with just three close-persons being listed. An investigation of the interview transcript reveals why this may be the case. It appears the nature of her mother's disease seemed to impact upon the relationships around her. In particular, CDX7 discusses the impact that her mother's disease (Alzheimer's) had on their relationship. CDX7 had a complicated relationship with her mother which appeared to worsen with her illness. CDX7 describes how her mother's illness changed her mother's personality making her angry and hard to please.

> CDX7:*…when she began to get ill she became even more angry, she was angry that was it, she became even more angry and nobody could do anything right for her.*

She felt that it was probably due to frustration that she became like this as she became increasingly aggressive and violent.

> CDX7:*…she got slightly aggressive and slightly violent, scratching, hitting, frustrated, she must have been frustrated which must have been partly to do with the dementia and being chronically ill.*

This led to a change in CDX7's relationship with her mother as she felt she had to withdraw emotionally with an eventual change in their relationship such that CDX7 was scared of her mother.

> CDX7:*…so my relationship with her changed because I pulled back a lot because I could not….if I got too close to her, she'd either hurt me, not physically or although she might have had a go, I just got tired of being hurt by it.*
>
> *CDX7…She was always angry, negative, constantly negative, and then when it really was getting close to the end, I mean, say the last year, she started to frighten me, I just used to sit behind my dad. Plus she'd always frightened me in my life to a degree but it got worse because she was kind of out of control, you couldn't reason with her.*

The condition of CDX7's mother clearly impacted upon the closeness between CDX7 and her mother. Given such an illness it would be likely that other close-person relationships may also suffer.

Similarly, the disease burden of CDX14's decedent appears to have reduced the closeness of their relationship. CDX14's mother is receiving care in a nursing home and also suffers from dementia. The nature of the disease as well as the death of her father has led to a change in their relationship over a period of time.

> CDX14: *I suppose it has in…sort of over gradual period because dad did so much for her and when he died it made a huge difference to myself and my brother…Sorry, I should mention she's getting dementia and that's another thing that seems to have got lot worse quite recently.*

As a result, CDX14 finds visiting her mother to be quite a difficult process, in part due to her mother's lack of communicational skills.

> CDX14*: So yeah it became as I say quite stressful, when she was living at home, going to visit her in the care home, was quite honestly a bit of a chore, she is not a great conversationalist. But it's… I suppose I was brought up with a sense of duty and that's why have gone to visit her so, and obvious I do care about her and I miss her if I don't go to see her but it's not an easy relationship.*

The lack of ability to communicate has also led to the distancing of one of the decedent's previously close-persons. The participant's aunt used to be close to the decedent however she was no longer considered close due to the fact that she could no longer communicate with or see the decedent.

> CDX14*: I'd say auntie J is a bit difficult because she is close to her sister but she can't travel so can't see her…they don't talk on the phone…I'll leave her out of it*

Given that the disease led to such a distancing between the participant and her mother, it is unsurprising that her network is small. Both CDX7 and CDX14 describe cases where the condition of their decedent has placed strain on their relationships with the participants and this may contribute to the person at the EoL having a smaller close-person network. This can be further investigated by comparing the experience of CDX5's mother who also suffered from Alzheimer's with CDX7 whose mother suffered from the same condition. CDX5's mother had a wider close-person network, although it should be noted it consisted entirely of family members.

As with CDX7, the nature of the disease (Alzheimer's) led to a distancing between the two of them as they could no longer communicate effectively between each other.

> CDX5: *…they were very close, I don't know, I'll put her as very close, but that's something that's very sad…because when my mum stopped speaking and couldn't speak to my auntie, that gap became wider there.*

The next closest individuals were the participant's brother and sister. Her sister was put as less close than her brother and CDX5 felt that she didn't engage as much as she could have towards the end of their mother's life. It would appear that the decline of communication skills may in part be related to smaller close-person networks. CDX5 felt that her mother's Alzheimer's in the eight years before she died changed her relationship with her; this was due to the nature of the disease which caused a distancing between them.

> CDX5:*…yeah I was always closer to my mum and then my mum was diagnosed with Alzheimer's 8 years before she died and then that relationship then obviously changed because she became more distant.*
>
> CDX5: *…So, even though my mum was my friend growing up and then obviously the disease I felt distanced us.*

Given that the disease led to such a distancing in such an initially close relationship as that between the participant and her mother, it is unsurprising to find there were no friends within the close-person network. The participant felt that her mother had died four years before the actual date of her death due to the disease and as a result it would be unsurprising that the decedent did not have any close friends remaining at the point of death.

> CDX5:*…It's not that we're glad that she died but it's a sad process that you lose them well before they're actually gone so it's like a distance…but I used to think years ago that it was nature's way of preparing me for losing my mum because I was so close to my mum so I felt that I was blessed with that gradual good bye rather than the…a sudden goodbye.*
>
> CDX5:*…I've come to terms more with mum's death because I felt she went 6 years ago even though it's not only 2.*

Going back to the aspects of what makes somebody close; it appears that conditions that inhibit the features of a close-person (see 7.2) may lead to individuals having a small close-person network. For example, if somebody suffers a condition that inhibits their ability to communicate then fundamental aspects of what makes somebody close will be inhibited. The result of such disease groups will be a smaller close-person network.

7.4.1.2 Size of family

When comparing the close-person networks of the decedents with the four smallest networks, one thing that was common to all was the fact that all appeared to have small families. CDX7 lists just three family members in the case of her mother's death. Likewise CDX14 only named four members of family; she did however refer to one other member of the family but no longer classified them as being close. CDX18 had five close-persons on the close-person map of which only three were family members. When discussing the close-person map she explained that her family is small.

> *CDX18:…We are a very relation-short family*

CDX18 however did feel that her mother did have lots of other friends who could potentially have been added to the close-person map but chose just to add just the closest ones.

> CDX18:*…she had masses of friends but S I think is probably her sort of main friend…*

The fact that CDX18 has got two non-family members on the close-person map shows that the reasons for the limited close-person map are possibly quite different to those of CDX7 and CDX14. Although CDX7 and CDX14 also feature small families, the lack of communication skills, in part due to Alzheimer's/dementia may be the key as to why their networks were the smallest.

CDX26's decedent who had five people in their close-person map is different again. CDX26's decedent's close-person map is made up entirely of relatives; this appears to be due to the fact that she considers her and her husband to be relatively private individuals.

> CDX26: *Yes we've always been quite private people, so we've never gathered a lot of friends or anything…*

It appears the primary cause of the small close-person network for CDX26 is the relatively small family network in conjunction with a lack of desire to have many friends.

7.4.1.3 Small networks – conclusions

Based on the analysis of the close-person maps and contextual information from the interviews of those with relatively small networks, it is possible to generate some hypotheses about what things may influence the size of networks. The nature of the illnesses/conditions, specifically those which lead to the loss of ability to communicate freely, appears to be likely to lead to smaller close-person networks. Having a small or estranged family is also likely to result in having a small close-person network. The two smallest networks as seen in the cases of CDX7 and CDX14 combine having a small family with a condition which limits the communication skills of the decedent. Looking back at the definition of a close-person in 7.2.6 this is intuitive as conditions that lead to reduced communication will hinder the ability to have a reciprocated caring relationship in which individuals can talk openly and freely. Similarly, having a small family reduces the number of people with whom individuals are likely to have shared experiences with and thus they have fewer close-persons. The quite small network given by CDX18 appears to be due to a very small family and not related to the condition of her mother. The network of CDX26 is in part limited by the relatively small family network, however the decedent chooses not to have any close friends, and thus the desire for non-family social bonds is also a contributory factor in this instance. Given this, it can be expected that the largest close-person networks belong to decedents whose condition does not affect their ability to communicate (until the very late stages), those with large and tight knit families, and those with a desire (and ability) to have close friends outside of their family.

7.4.2 Large close-person networks

The examination of the smallest close-person networks suggested that conditions that reduce the ability to communicate for an extended period, along with a small family and lack of desire for wider social bonds may restrict the close-person networks that are reported. To further investigate this, the largest close-person maps were investigated in terms of whether there was any further evidence to support these hypotheses. In some of the close-person maps, participants often put ‘other friends’ or similar, for the purpose of examining the larger networks, the focus in this part of the analysis is on named/specified individuals and generic notes such as ‘other friends’ where a number was not specified were counted as two. The reasoning for this was that, if the individuals were particularly close then they would have been specified rather than put into a larger unspecified category.

Using these criteria, six of the participants reported close-person maps with over 10 close-persons. These individuals were the decedents related to CDX6, CDX10, CDX16, CDX22, CDX23 and CDX29. Their close-person networks are shown in figure 2 overleaf.

7.4.2.1 Impact of death trajectory

To explore whether the condition of the decedents prior to death may impact upon the close-person network size, the nature of deaths of the decedents can be examined. Examining the cause of death in all of the large networks, it appears that all the decedents are/were mentally aware until relatively near to the end of their lives, and thus retained the ability to communicate.

The three participants, CDX6, CDX10 and CDX16 all had a close-person who suffered an unexpected and quick death. CDX6’s close friend died as a result of having inoperable oesophageal cancer. She was initially having throat problems but was told it was a symptom of her long term depression/anxiety.

> CDX6:…*And then she just sent me a text saying the news is not good but I think it'll be okay, this was on the Tuesday, and by Friday night…her brother phoned me up and said that she was in intensive care and she wasn't expected to survive the night.*

She then was suspected to have had a stroke and lost her voice. She was then moved to a hospice and died 3 weeks later. Likewise, CDX10's father's death was also unexpected. Having suffered a heart attack and successfully recovered it was found that heart surgery was required. Her father chose to have this surgery electively with only a 4% risk of death associated with the surgery.

> CDX10:…*he made a good recovery from that but the upshot from that was they decided that he needed to have triple heart bypass and a mitral valve repair or replacement so he had that surgery electively but not until 12 months after that heart attack…*

The surgery however did not go to plan and he suffered from multiple cardiovascular arrests which led to 2 weeks in intensive care before the discovery that he had suffered from catastrophic brain damage and care was consequently withdrawn. Likewise CDX16's father died following complications after undergoing heart bypass surgery. Following heart surgery CDX16's father developed sepsis and died as a result approximately a month after the surgery.

> CDX16: *And that was following complications following heart bypass surgery*.
>
> CDX16:…*The doctor sort of thought the chest was the problem, but was admitted to hospital with chest pains, and it was discovered he had significant coronary heart disease. He was taken to X where they started surgery but they…about a month after he passed away due to complications, sepsis etc.*

As a result, the decedents of CDX6, CDX10 and CDX16 were all mentally aware up until the final weeks of their life and thus may have been able to communicate and maintain their social networks. Similarly but to a lesser extent, CDX22 and CDX23's decedents were mentally aware until relatively near the end of their lives. In the case of CDX22, her grandmother had heart disease and fluid on the lungs. Up until the final month of her life, CDX22 felt that her grandmother was mentally aware and able to communicate.

> CDX22: *Heart disease, she went in with fluid on her lungs basically and she was due to have a pacemaker fitted because she couldn't lie flat basically they couldn't do an operation on her*

> *and the idea was that they'd clear the fluid out of her lungs before but she just deteriorated….got worse and worse from that so it never got to a point where they could actually do the operation, and they got to a point when that wouldn't be effective anymore…*
>
> A: *…was she sort of there mentally?*
> CDX22: *I would think…I think for the last month I wouldn't really say she was because she wasn't really making much sense…*

Similarly CDX23's grandmother had a fall whilst visiting hospital and then picked up a series of infections and passed away shortly afterwards. Again there were not any issues related to her ability to communicate prior to this.

> *CDX23 …went to the XY because of that just to get all her sugars balanced out and things, and whilst she was at the XY she had a fall and broke her thigh bone, and after that point, it was a couple of months after that so this was the sort of late December, January and she never came out the hospital after that, they tried to operate on it after a month and a half, and she just deteriorated and passed away*.

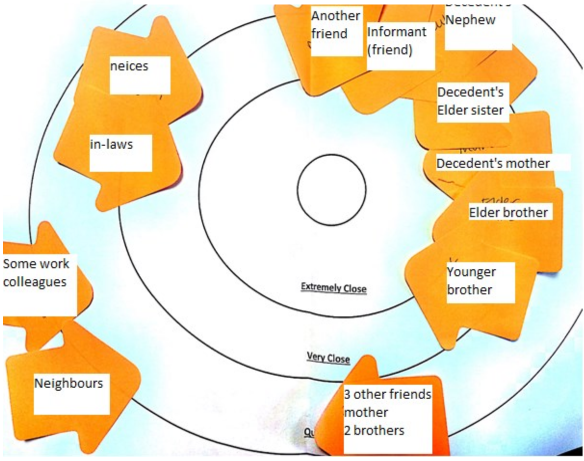
Finally CDX29 differed from the other five participants in that his decedent was still alive. However, as with the other four participants who reported large close-person maps, his close-person was not suffering from any disease that may limit the ability to communicate with those close to them.

> CDX29:*…she developed another leg ulcer on the other leg, so she ended up in a position where she had ulcers on both of her legs…the poor lady was really really suffering and her GP came up with the idea of coming into the Marie Curie for some pain relief and pain management, which is fantastic, so mum was admitted here 9 weeks ago.*

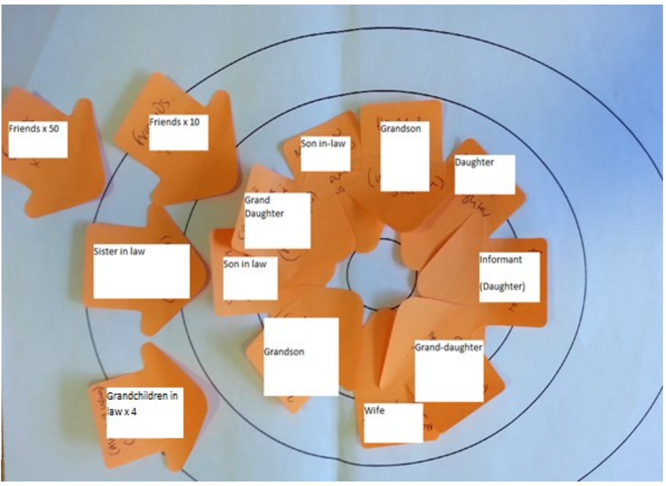
All of the participants who reported the largest close-person maps had a decedent who did not lose mental capacity until relatively near death, and therefore was not inhibited in terms of the ability to have close-person relationships. This relates back to the definition of a close-person that was previously explored (see 7.2). One key aspect of a close-person revolved around them being able to communicate freely in an open and non-judgemental manner. Many participants felt that for someone to be close, they needed to be able to talk to about anything and feel comfortable doing that. It is therefore likely that those who have conditions such as Alzheimer's and dementia which impact upon the ability to communicate and therefore impact upon friendships will have smaller close-person networks than those who can communicate freely.

Figure 7: Networks of ten or greater

CDX6’s close friend’s network

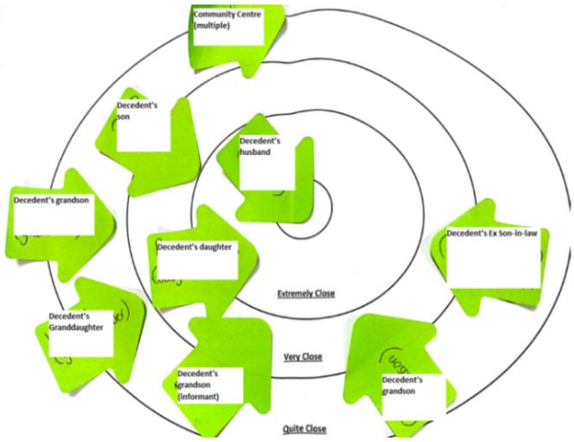


CDX10’s father’s network

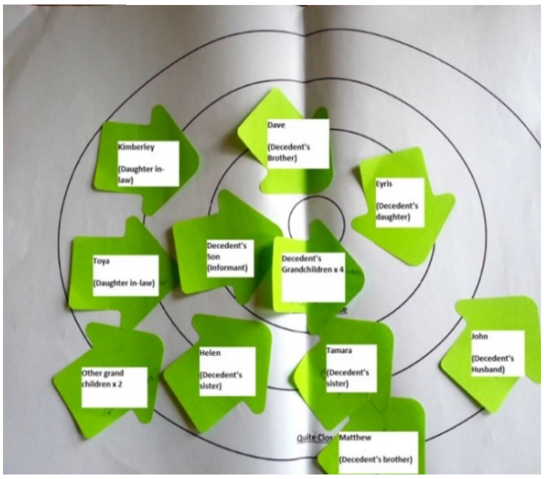


CDX22’s grandmother’s network

CDX23’s granddaughter’s network



CDX29’s mother’s network



CDX16’s father’s network

7.4.2.2 Size of family

The second key feature of the smallest close-person networks was that they tended to have smaller families, thus it is expected that those with large close-person networks will contain a large number of family members. This is the case with all six of the largest networks; all six of the largest networks featured a large number of family members. CDX6's included seven family members including as well more general 'in-laws'. CDX10's decedent had the biggest close-person networks of all. Of these however there were nine who were felt to be extremely close; these were all family members, two of whom were in-laws. Also included in the close-person map were five other relatives who were felt to be close. In total there were 14 family members included within the close-person map. CDX22's decedent's close-person map had a total of 10 individuals; of these, nine individuals were family members with one friend also being included within the close-person map. CDX23's grandmother's close-person map contained eight family members and then a general 'community centre' post it note representing the many friends that they had at the local community centre. Of the eight named individuals, all were family members at one stage; however one is no longer technically family due to remarriage (labelled ex-son in law). Of the 10 individuals within CDX16's decedent's network, seven were family members, of whom two were in-laws. Finally, CDX29's close-person map contains 15 individuals. Again this close-person map is heavily populated with family members. All 15 members of the close-person map are family members, of whom two are in-laws.

As indicated by the examination of those with the smallest networks, it was predicted that those with larger families would in turn have larger close-person maps. This was found to be the case with the six largest close-person maps all containing numerous family members. Of the six largest close-person maps, the fewest family members in any one close-person map was seven. This is two more than the largest (including friends) of the four smallest close-person maps.

7.4.2.3. Large networks versus small networks - conclusions

There were large differences in the size of the close-person networks reported by the participants. Possible reasons for what may influence the size of the networks were investigated. Those with the smallest networks were first compared between each other to search for similarities and differences which may lead to different network sizes. The influences identified were then compared to those with the largest networks. Based on the examination of those with the smallest networks in conjunction with what it is that makes somebody close, it was hypothesised that those decedents who were compos mentis and had large families would be more likely to have larger close-person networks. This appeared to be the case with the six decedents with the largest networks all suffering a relatively quick death, and thus reducing the opportunity for people to become less close as was seen with the smaller networks. Furthermore, the six largest networks all included a large number of family members.

7.4.3 Other influences

7.4.3.1 Impact of who is completing the close-person map

The nature of the participant who is completing the close-person mapping exercise may impact upon the size of the network presented by the participant. A number of factors may influence how people complete the close-person mapping task. Whether an individual is a family member or a friend may impact upon the network given by the participant. It may be that family members are more aware of other family members and less so of the decedent’s friends and as such include more family members in the task. In turn, it may be that a friend is more likely to include friends within the close-person mapping task. Just one participant completed the close-person mapping exercise as a friend opposed to family member. Although it is difficult to draw conclusions from just the one participant, it is of interest to see how the close-person map of the friend differed to those typically done by the family. The first thing to note when observing the close-person map of CDX6 is the number of different people that were placed on the close-person map. This could be interpreted two ways, it could be that she was so close to the person that she knew all the people who were close to the decedent; conversely, it may be that due to her lack of knowledge of others in the network she listed all the individuals she could think of.

Another issue to consider is the relative closeness of the person completing the close-person map. It may be the case that the degree of closeness of the participant may impact the size of the close-person network given for the decedent. For example those who are closest to the decedent may have the best knowledge of the decedent's close-person network, whilst those who more distant may have a limited knowledge. For exactly half of the close-person maps, the participant felt that they were either the closest individual, or the equal closest. There did not appear to be any significant patterns in the size of the networks when comparing those who felt they were the closest with those who felt they were not. Looking at the close-person maps of those with the largest and smallest networks, they both feature participants who felt they were the closest and those who were not.

The networks given by the two participants whereby one was recruited via snowball sampling can be compared to further examine this. Both CDX17 and CDX18 described the network of the same decedent shown in Figure 8. The decedent was the grandmother of CDX17, and the mother of CDX18. The two maps have many similarities. The four specified individuals in the map made by CDX17 also featured within the map made by CDX18. These included both the participants, the decedent's son, and the decedent's carer. There were however differences. CDX18 named a specific friend (labelled 'Sandra') as a close person whilst CDX17 simply used a generic 'friends' label which was placed further out, and CDX17 also included an 'extended family' label which CDX18 did not use. Interestingly, both CDX17 and CDX18, whilst describing themselves as extremely close, both felt the other was the person closest to the decedent.

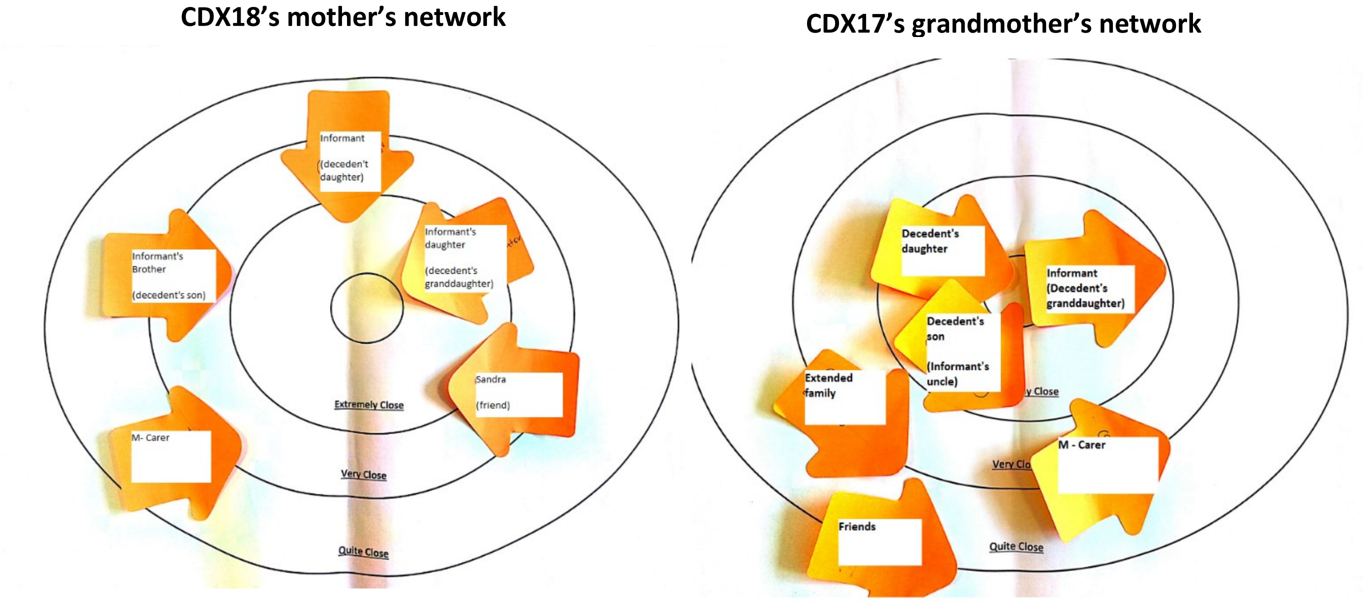


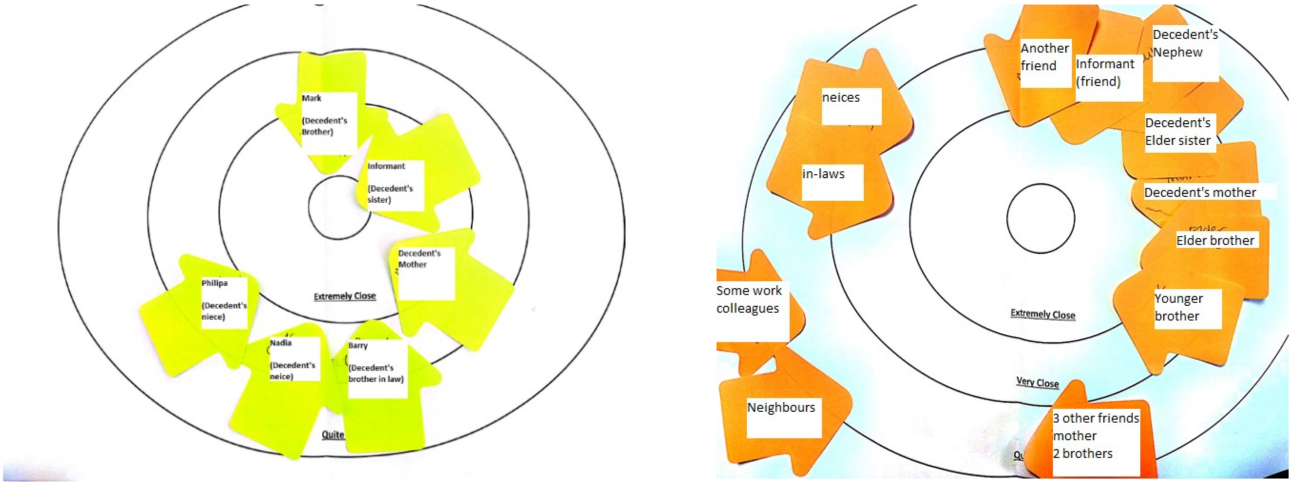
Figure 8: Snowball sample decedent's network

7.4.3.2 Networks by ethnicity

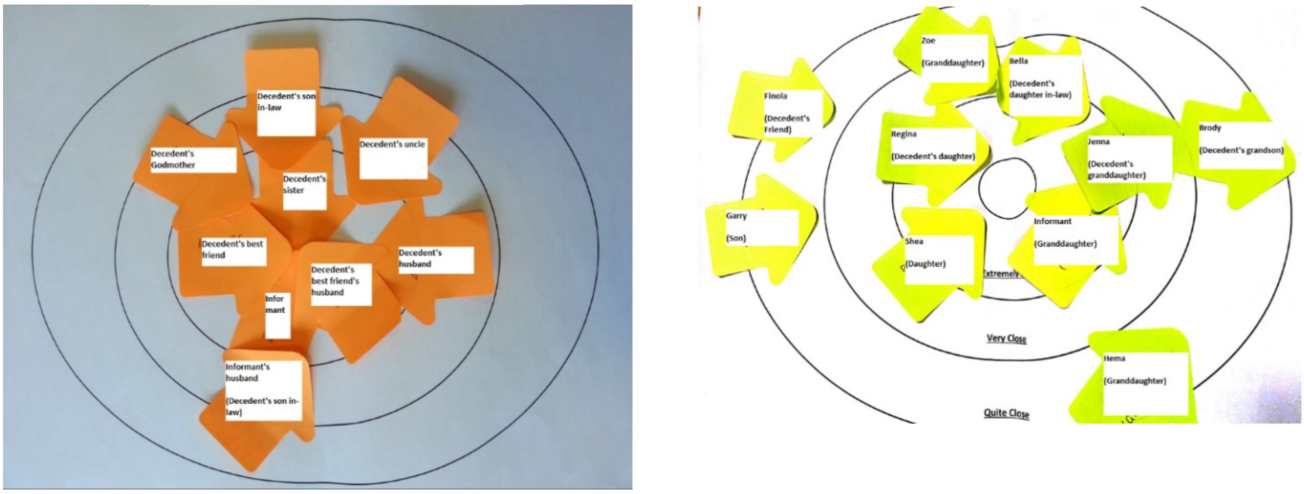
Within the sample, there were four participants who did not describe themselves as being White British, these were CDX4, CDX6, CDX13 and CDX22. When compared to the close-person maps of the White-British participants, there did not appear to be anything significantly different. The exception to this was the close-person map of CDX6. The close-person map of CDX6 was quite different to the makeup of all other close-person maps. The network was large, but less specific than the other close-person maps. Rather than being due to the ethnicity of CDX6, it is suspected that this may be due to the relation of CDX6 to the decedent. Unlike all the other participants who completed the close-person mapping exercise which were family members, CDX6 was a friend to the decedent as discussed above. These differences may be a result of not knowing the family network as well as the participants who are family members of the decedent. The large size of the network however may be explained as alluded to previously by the nature of the decedent's death. It was quite a quick death at a relatively young age and as a result that may be the primary influence of the size of the network

Figure 9: Non white-British networks

CDX4 Brother's Network **CDX6 Friend's Network**



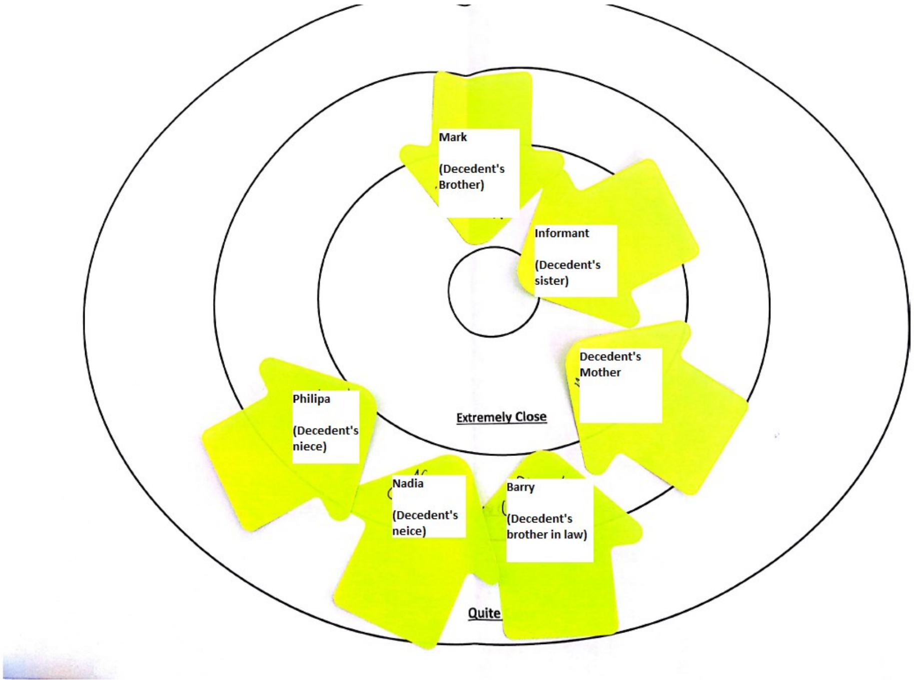
CDX13 Mother's Network **CDX22 Grandmother's**



7.4.3.3 Networks by age of decedent

In the previous section it was suggested that a possible reason for the network of CDX6's decedent being so large was due to the age of the decedent as she was relatively young. The only other decedent who fell into the age 40-59 years age group was CDX4's brother who also died at a relatively young age. As can be seen from the close-person map below the close-person map of CDX4's brother differs significantly to that of the other young decedent (CDX6). The network of CDX4 contains just 6 individuals, all of whom are family members. When looking at the oldest decedents it is noted that three out of the four decedents with the smallest networks were in the oldest 80+ years category which may imply that older people are likely to have smaller networks. However it should be noted that two of the largest networks also feature decedents who were aged 80+ years. It therefore appears that age is only an important factor in terms of the impact of age-related conditions such as dementia on the close-person network. Furthermore as decedents age, it is likely that those who are close to them of a similar age e.g. spouse or siblings may die and as such reduce the size of their close-person network. The fact that two of the largest networks were in in the oldest category however shows that this is not always the case.

Figure 10: CDX4's decedent's network



7.5. Summary

This chapter has investigated the notion of a close-person, specifically in the context of EoLC. Close-person networks of the decedents were explored and possible influences on the size of the networks were examined. A number of factors were felt by the participants to facilitate closeness. These included: a reciprocated relationship, shared experiences, trust and reliance, openness, and comfort and security. It was felt by the majority of participants that the notion of a close-person can extend beyond the immediate family and include others e.g. friends. Furthermore many participants expressed the view that geographical proximity was not an essential condition for closeness. When adopting the broader extra-welfarist perspective this has important implications for who may enter into the economic evaluation and highlights the importance of looking wider than the immediate carer or next of kin. There was wide variation in terms of the size of networks. Factors that appeared to impact upon closeness and network size were examined; the two main factors were the impact of disease and also the size of family. Those with a decedent who did not suffer cognitive problems and had many family members had larger close-person networks. Those who suffered from cognitive issues such as dementia were likely to have smaller networks with few friends. Thus it is likely that those with the cognitive issues and a small family will be those with the smallest close-person networks. Conversely, those who retain mental capacity leading up to death with a large family network are likely to have the largest close-person networks.

CHAPTER 8: DELIBERATIVE VALUATION RESULTS

Chapter 5 described the development of a measure to capture the impacts of EoLC to close-persons. The purpose of this chapter is to outline the results of the weighting of the close-person measure. This chapter is focussed on the results of the deliberative valuation task that was conducted with focus groups consisting of members of the general public. The deliberative valuation process utilised a two-step approach. The first part of the process involved participants placing the level descriptors on a rating scale, whilst the second part of the process required the focus group participants to weight the attributes against each other using a budget pie task. This chapter sets out the results of the valuation process. The results of the attribute levels task and the attribute weighting exercise are presented. These are examined in further detail by exploring the results within each individual focus groups, and then also by examining the weights given according to the characteristics of the participants. This chapter concludes by examining the impact of discussion on the results of the valuation process.

8.1. The focus groups

In total, 38 participants were recruited into the study in seven focus groups which took place between 30 June and 30 July 2014. Each focus group lasted for two hours, with half of that time allotted to the completion of this valuation task. The characteristics of the individuals are shown in Table 8 below. The majority of the participants were aged over 45 years, with just five individuals participating who were younger than this. The largest age category was the 65+ years age category which contained 22 of the 38 participants. The age group with the fewest participants was the 30-44 year old age category which contained just one participant. The majority of the participants were women (24), in contrast to just 14 males. The ethnicity of the participants was predominately White

British (35 participants), with just three of the participants being from other ethnic backgrounds. The majority of the participants reported to be in a good health state (22), whilst 13 felt that their health was fairly good. Only one of the participants felt that their health state was not good. Two of the individuals chose not to report their health status. Of the 38 participants, 26 were not recently bereaved, whilst 10 individuals were. Two individuals chose not to report their bereavement status.

Table 8: Participant characteristics

Demographics		Number of participants
Age:	18-29	4
	30-44	1
	45-64	11
	65+	22
Gender	Female	24
	Male	14
Ethnicity	White British	35
	White non-British	1
	Asian	1
	Black	1
	Mixed Race	0
	Other	0
Health Status	Good	22
	Fairly Good	13
	Not Good	1
	Missing	2
Bereavement Status	Not bereaved	26
	Bereaved	10
	Missing	2

In terms of the number of individuals within each focus group, there were large differences in the number who attended each focus group. The smallest focus group was focus group B where just one individual turned up on the day. The most that attended any one focus group was focus group E where nine individuals participated. Between three and seven individuals participated within the other focus groups as shown in Table 9 below. The numbers within each group will be borne in mind when analysing the responses on a focus group by focus group basis. Given there was only one attendee at focus group B, their finding were excluded when comparing the results of the focus groups.

Table 9: Number in each focus group

Focus Group ID:	**Number in Group**
A	3
B	1
C	6
D	6
D2	6
E	9
E2	7

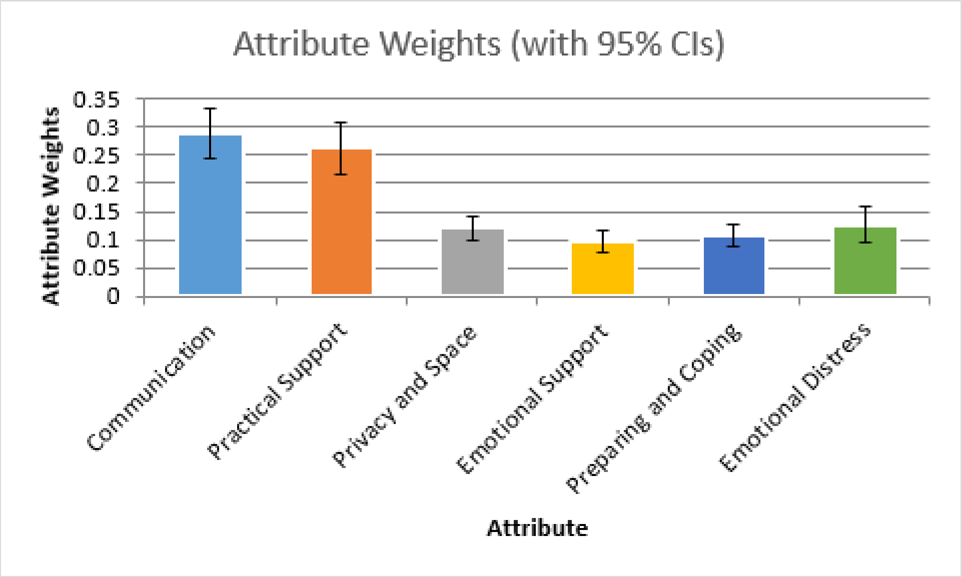
8.2. Weighting the attributes

A key aspect of the valuation process involved the weighting of the attributes. This was done via a budget pie task whereby participants were given a limited sum of tokens and were given the task of weighting the attributes according to how important they felt each attribute was for those close to somebody at the EoL. Table 10 below and Figure 11 show the post-discussion weights given to each attribute and associated confidence intervals (CI) rescaled onto a zero to one scale. The attribute that was given the most weight by the participants was the communication attribute at 0.287 (95% CI 0.331, 0.243) followed by the practical support attribute which was weighted with 0.262 (95% CI 0.307, 0.217). Both these two attributes received a statistically significant greater weight than any of the other four attributes. In fact, combined, communication and practical support received greater weighting than the other four attributes combined. The attribute which received the next greatest weighting was the emotional distress attribute at 0.126 (95% CI 0.158, 0.094), this was closely followed by privacy and space which received 0.12 (95% 0.143, 0.098). The attribute receiving the second least weighting was the preparing and coping attribute at 0.109 (95% CI 0.129, 0.088) and finally the attribute receiving the least amount of weighting was the attribute relating to emotional support which received just 0.096 (95% CI 0.117, 0.076).

Table 10: Attribute weights (95% confidence intervals)

Attribute	Weighting (95% Confidence Intervals)
Communication	0.287 (0.243, 0.331)
Practical Support	0.262 (0.307, 0.217)
Privacy and Space	0.120 (0.143, 0.098)
Emotional Support	0.096 (0.117, 0.076)
Preparing and Coping	0.108 (0.129, 0.088)
Emotional Distress	0.126 (0.158, 0.094)

Figure 11: Attribute weights (95% confidence intervals)

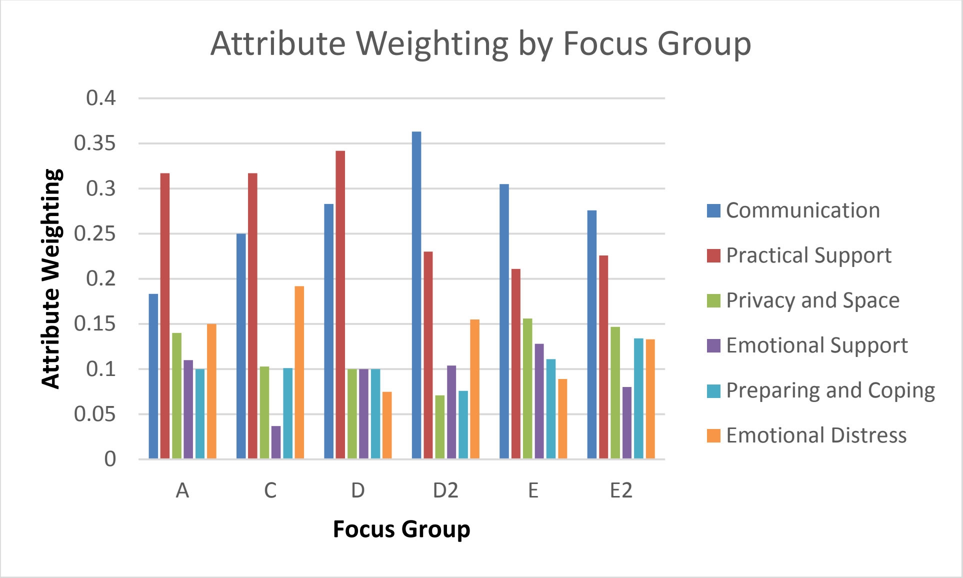


The data can be split into the respective focus groups to examine whether the weights given above are consistent across the focus groups. In agreement with the overall findings, across all focus groups communication was given either the greatest weight (three focus groups), or the second greatest weight (three focus groups). Likewise, the practical support attribute was given the second greatest weight closely behind the communication attribute; it was given either the greatest weight (three focus groups) or the second greatest weight (three groups) within the focus groups. There was no one attribute that was consistently given the lowest weighting. The emotional support, preparing and coping, privacy and space, and emotional distress attributes were all given least weight in at least one focus group. There is clearly a divide between the six attributes, with communication and practical support being given a significantly greater weight than any of the other attributes. Although communication is given a slightly greater weight in aggregate than practical support, three of the focus groups weighted practical support higher indicating there is little between the two attributes. There also appears to be little to separate the four attributes with the least weight. Participants were able to not give attributes any weight if they felt they were not important. The four attributes with the least weight did all receive a significant weighting indicating that although they may not be as important as communication and practical support, they are still important aspects of EoL for a close-person.

Table 11: Attribute weights by focus groups

Focus Group	Communication	Practical Support	Privacy and Space	Emotional Support	Preparing and Coping	Emotional Distress
A	0.183	0.317	0.140	0.110	0.100	0.150
C	0.250	0.317	0.103	0.037	0.101	0.192
D	0.283	0.342	0.100	0.100	0.100	0.075
D2	0.363	0.230	0.071	0.104	0.076	0.155
E	0.305	0.211	0.156	0.128	0.111	0.089
E2	0.276	0.226	0.147	0.080	0.134	0.133

Figure 12: Attribute weighting by focus group



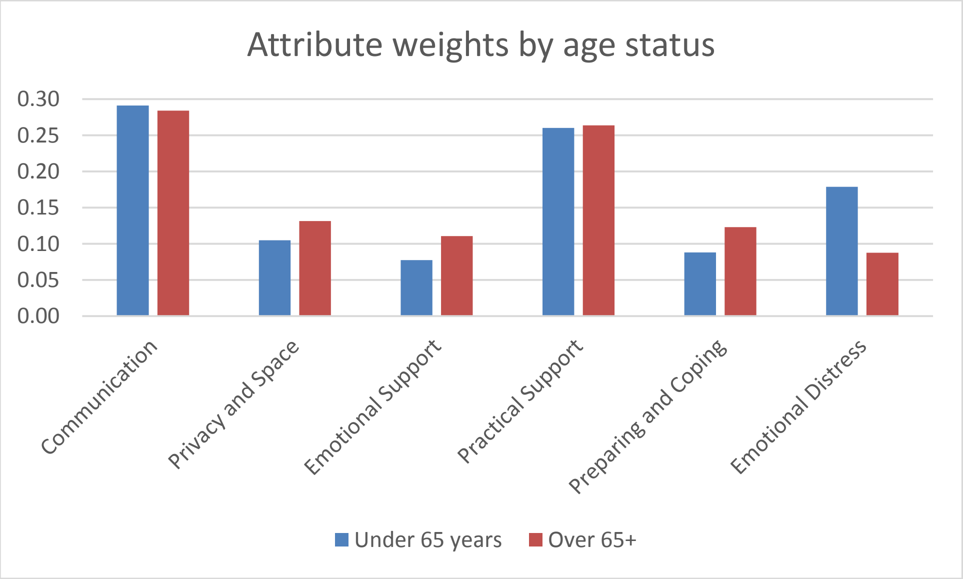
8.2.1 Attribute weights by age group

The weights were examined based upon the age groups of the participants. The participants were split into two groups, those under the age of 65 years, and those over the age of 65 years. The attribute weights for both age ranges are shown in Table 12, and Figure 13 respectively. For both age ranges, as found with the overall results, communication received the highest weighting for both age groups. Practical support again received significant weighting and was the second greatest weighted attribute. There appears to be substantial difference between the age groups in terms of the weighting given to the emotional distress attribute. The older age group appeared to give emotional distress less weighting than those who were under 65 years. All six attributes were tested for significant differences between the age groups. The only significant difference was within the emotional distress attribute where there was a significant difference between the two groups (p=0.0035). This indicates that there is a significant difference between how those under the age of 65 years and those over the age of 65 years weigh the emotional distress attribute. Those under the age of 65 years are significantly more likely to give the emotional distress attribute more weighting than those over the age of 65 years.

Table 12: Attribute weights by age group

Age of Participants	Number of participants	Communication	Privacy and Space	Emotional Support	Practical Support	Preparing and Coping	Emotional Distress
<65 years	16	0.291	0.105	0.077	0.260	0.088	0.179
65+	22	0.284	0.131	0.110	0.264	0.123	0.088
Associated p-value (95% significance)	N/A	p = 0.8718	p = 0.2440	p = 0.1129	p = 0.9378	p = 0.0888	p = 0.0035

Figure 13: Attribute weights by age status



8.2.2 Gender and weighting

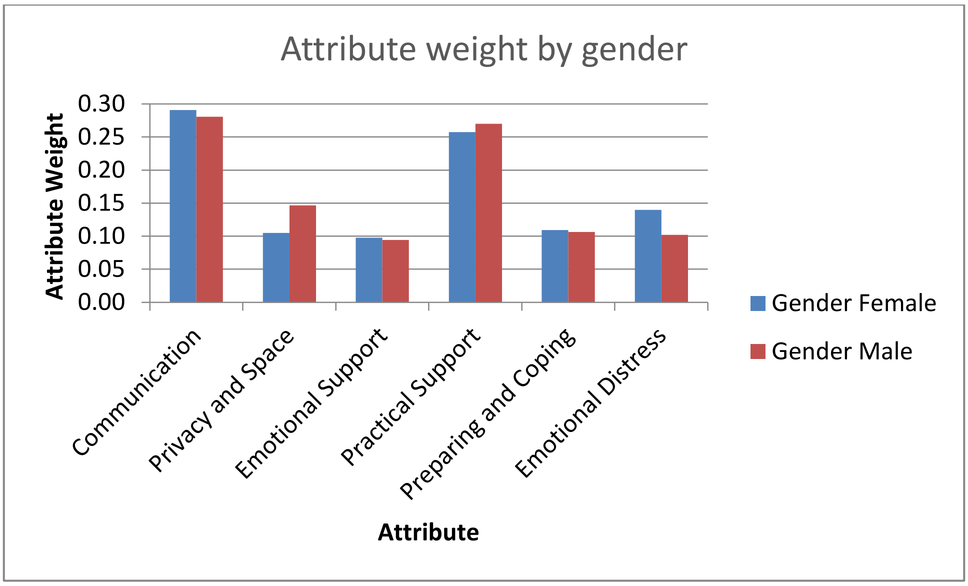
As shown in Table 13 below and graphically in Figure 14, the weightings given by the males and females within the study were very similar. Both the males and females on average weighted the communication attribute as the most important; this was closely followed by the practical support attribute. The other four attributes were then quite evenly weighted. There was some variation within the privacy and space attribute where the men weighed it on average 0.04 higher than women, and also in the emotional distress attribute where women placed extra weight in comparison to men. These differences were however insignificant at the 0.05 level, with the associated p-value for the privacy and space attribute being 0.07, and emotional support's being 0.25

indicating no significant difference. With the relatively small sample, this is unsurprising and is something that may warrant further investigation with a larger sample to see whether these differences become significant in a larger study.

Table 13: Attribute weight by gender

		Communication	Privacy and Space	Emotional Support	Practical Support	Preparing and Coping	Emotional Distress
Gender	**Female**	0.291	0.105	0.098	0.258	0.109	0.140
	Male	0.281	0.146	0.094	0.270	0.106	0.102
Associated p-value (95% sig level)		p = 0.824	p = 0.071	p = 0.872	p = 0.791	p = 0.903	p = 0.260

Figure 14: Attribute weight by gender



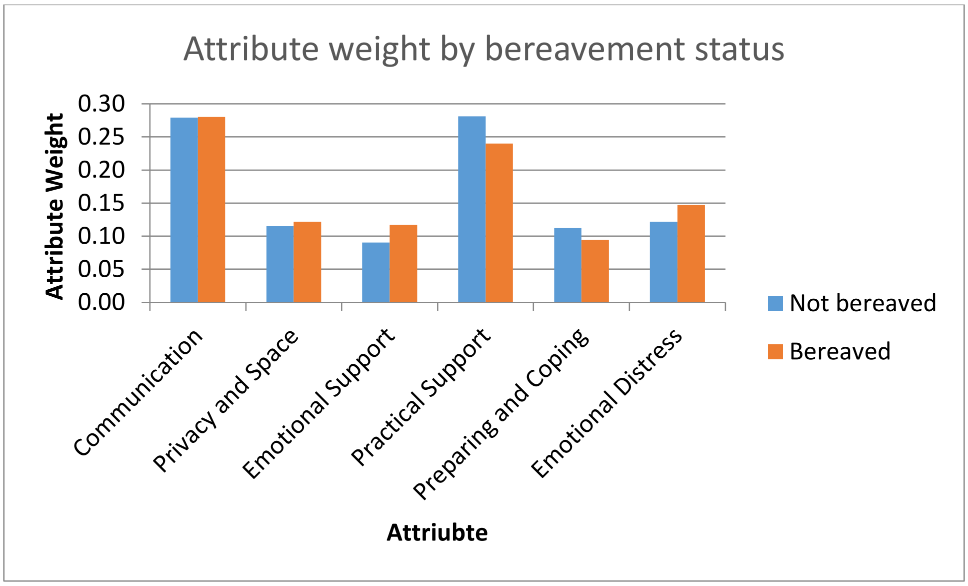
8.2.3 Bereavement status and weighting

Ten participants reported being bereaved, 26 were not bereaved, whilst two individuals did not report on their bereavement status. Table 14 and Figure 15 give the values for those who reported themselves to be bereaved and those who reported themselves to not be bereaved. As is demonstrated visually within Figure 15, the values of the bereaved given to the attributes were very closely matched with those who were not bereaved. The only notable difference in Figure 15 is within the practical support attribute whereby those who were not bereaved gave the practical support attribute greater weight on average than the bereaved. This difference between the two groups in the reported weights for the practical support attribute was tested for statistical significance. The difference was found to be statistically insignificant (p=0.423) indicating no statistically significant difference between the non-bereaved and bereaved participants weight for practical support.

Table 14: Attribute weight by bereavement status

		Communication	Privacy and Space	Emotional Support	Practical Support	Preparing and Coping	Emotional Distress
Bereavement Status	**Not bereaved**	0.279	0.115	0.090	0.281	0.112	0.122
	bereaved	0.280	0.122	0.117	0.240	0.094	0.147
Associated p-value (95% sig level)		p = 0.988	p = 0.791	p = 0.273	p = 0.423	p = 0.394	p = 0.508

Figure 15: Attribute weight by bereavement status



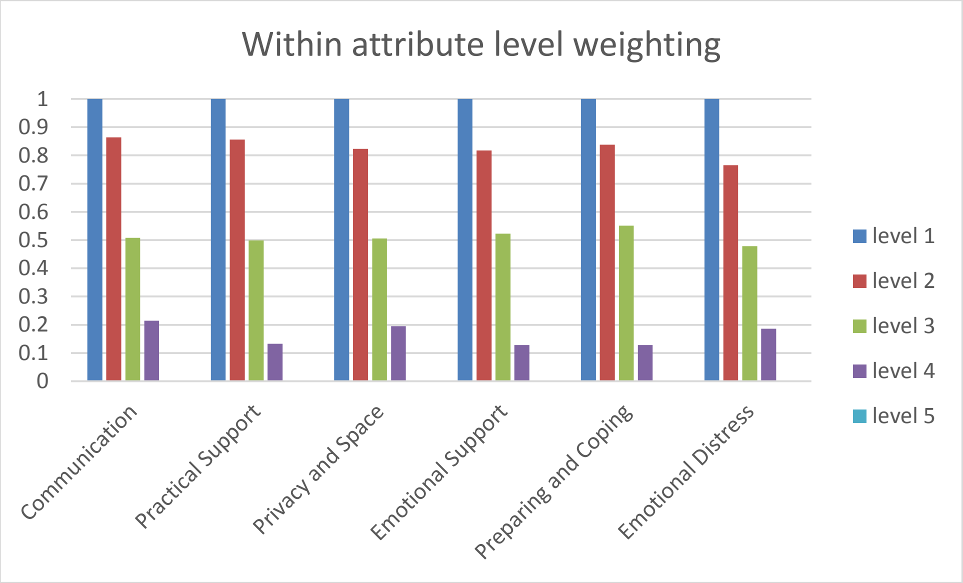
8.3. Weighting the attribute levels

In addition to valuing the attributes, it was required that participants think about the levels within the attribute and decide how good or bad each level was and mark the scale accordingly to show the relative increments between levels within the attribute. Values for each level of the attributes and associated 95% confidence intervals are shown in Table 15. The values of the best levels were anchored at one, with the worst level for each attribute anchored at zero. If the decrements were to be equal between levels as is common in outcome measures that have not been valued (see 4.1.1 for further details), it would be expected that the value assigned to each level would decrease in decrements of 0.25 as the states deteriorate with each level. Thus if there were even decrements it would be expected that level two is at 0.75, level three at 0.5 and level four at 0.25 respectively. Upon examination of the distribution of the levels of the attributes, in general there was a pattern common to all the attributes. Generally the top two levels were relatively closely spaced indicating a relatively small decrement between the 'best' level of each attribute and the second best. There were then larger decrements between the second and third level, and third and fourth levels. In general the fourth level was relatively low indicating a relatively small difference between the bottom two levels of the measure for the attributes.

Table 15: Comparing the levels across attributes (95% confidence intervals)

Attribute	level 1	level 2	level 3	level 4	level 5
Communication	1	0.864 (0.821, 0.906)	0.508 (0.432, 0.584)	0.215 (0.143, 0.286)	0
Practical Support	1	0.857 (0.812, 0.9)	0.499 (0.438, 0.56)	0.133 (0.08, 0.186)	0
Privacy and Space	1	0.82 (0.778, 0.869)	0.51 (0.449, 0.561)	0.19 (0.146, 0.244)	0
Emotional Support	1	0.817 (0.769, 0.865)	0.522 (0.46, 0.586)	0.128 (0.099, 0.156)	0
Preparing and Coping	1	0.838 (0.799, 0.876)	0.551 (0.49, 0.611)	0.128 (0.088, 0.169)	0
Emotional Distress	1	0.766 (0.713, 0.818)	0.479 (0.426, 0.532)	0.187 (0.135, 0.238)	0

Figure 16: Within attribute level weighting

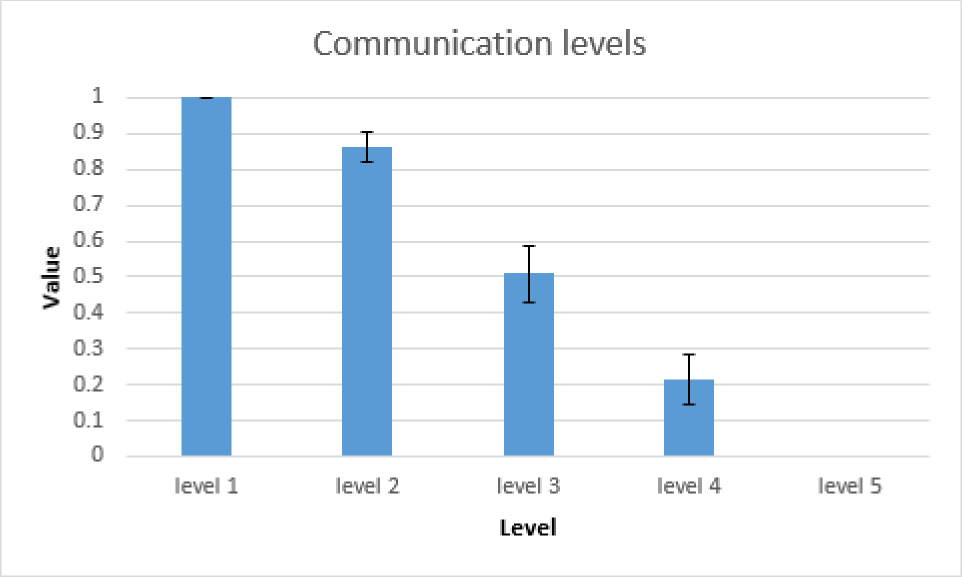


The rest of this section examines in closer detail how the levels for each attribute were valued. This includes examining the weighting of the levels not only in aggregate, but also by focus group. Figures are included alongside tables to help interpret the data.

8.3.1 Communication

Within the communication attribute there is a relatively small decrement between the top level and second level which lies at 0.864 (95% CI 0.821, 0.906) indicating that there is relatively little difference between the top level and the second level. Thus level two is significantly different from what would be expected had the levels been valued with equal decrements (i.e. 0.75). Between the second level and the third level at 0.508 (95% CI 0.432, 0.584) there was a large decrement (0.356) indicating a relatively large drop between the two levels. This is then followed by another relatively large decrement between the third and fourth level (0.293), followed by a smaller decrement between the fourth and fifth levels.

Figure 17: Communication levels (95% confidence intervals)

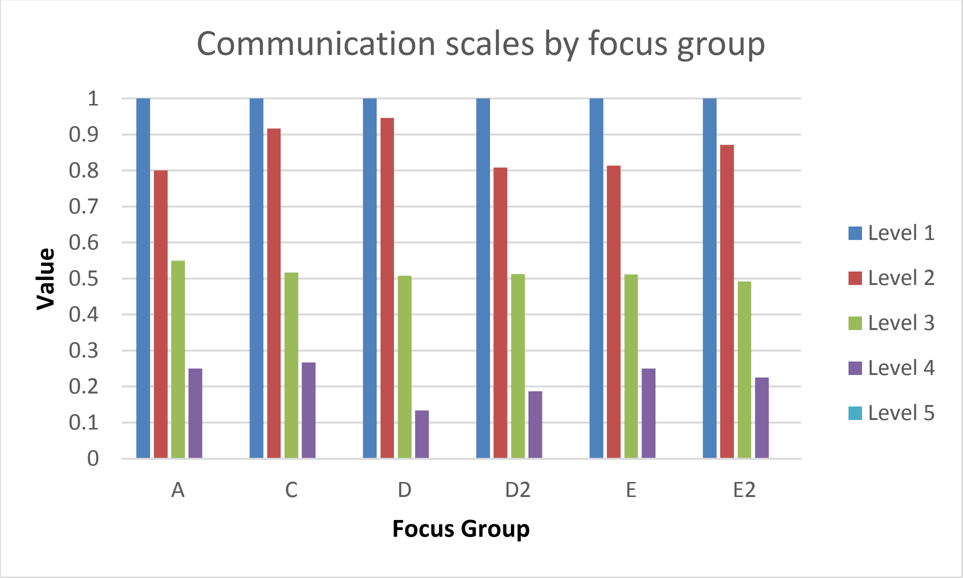


To further examine this, the values for the levels for each focus group were examined separately to see whether this was a common pattern amongst all the focus groups, or just an effect of aggregation. The values for each level by focus groups are shown in Table 16 and Figure 18 respectively. There was some variation between the focus groups in terms of the values given to each level of the attribute. Despite these differences, in all six of the focus groups the pattern as shown in Figure 17 above was similar for the communication attribute. All focus groups had a relatively small decrement between the top level and the next best level, and then larger decrements between the middle levels. The decrement between the top level and the second level is relatively small in each focus group, this can be interpreted as that having ‘good communication **most** of the time’ is not much worse than having ‘good communication **all** of the time’. In contrast the decrements between levels two, three and four are much greater indicating that there are bigger differences between these levels.

Table 16: Average level score by focus group: communication

		Attribute Level (to 3 decimal places)				
Focus Group ID:	**Number in Group**	**Level 1**	**Level 2**	**Level 3**	**Level 4**	**Level 5**
A	3	1	0.800	0.550	0.250	0
C	6	1	0.917	0.517	0.267	0
D	6	1	0.946	0.508	0.133	0
D2	6	1	0.808	0.513	0.188	0
E	9	1	0.814	0.511	0.250	0
E2	7	1	0.871	0.492	0.225	0

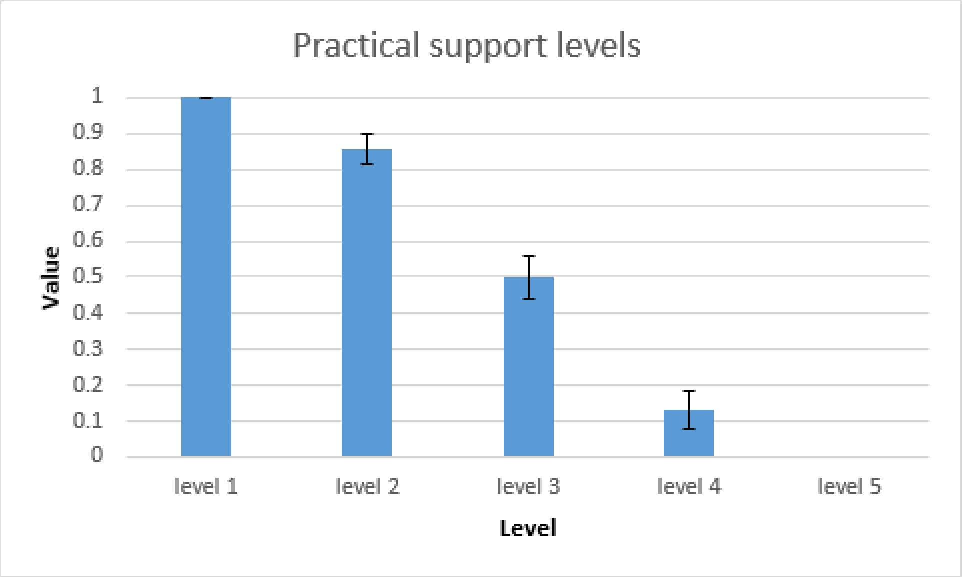
Figure 18: Communication by focus group



8.3.2 Practical support

The aggregated scores for the practical support attribute followed a very similar pattern to that of the communication attribute. Again there was a departure from an even distribution of values. Similar to the communication attribute the second highest level was just 0.144 below the fixed top level at 0.857 (95% CI 0.812, 0.9) and significantly higher than 0.75 which would be expected if evenly spread. The implication of this is that there is a relatively small difference between being **fully** able to get practical support and **mostly** able. This however is then followed by a large decrease between levels two and three (0.357). This is then followed by another large decrement of 0.364 to level four. The value for level four is relatively low at 0.133 and statistically significantly less than the 0.25 that would be expected if decrements were evenly spread across levels. There are large decrements between being **mostly** able to get practical support and being **somewhat** able to get support, and then a large decrement down to being **mostly** unable to get practical support. Unlike the communication attribute, the level four value is particularly low, which implies that there is not a great difference between being **mostly unable** to get practical support and being **completely unable** to get practical support. The bottom two levels are particularly close which similar to the top two levels implies that being **mostly unable** to get practical support and being **completely unable** are closer together than the intermediate levels.

Figure 19: Practical support levels (95% confidence intervals)

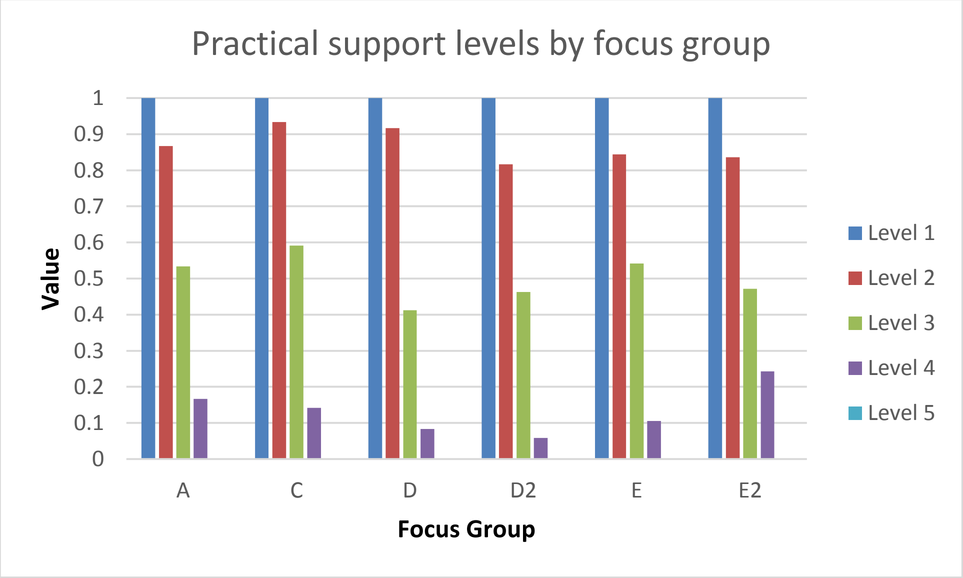


On a focus group by focus group basis, on the whole, a similar pattern remained as seen in Table 17 and Figure 20. This pattern involved level two being relatively high, level four being relatively low, with larger decrements between levels two and three, and levels three and four. Focus group E2 gave the level four a relatively high value in comparison to the other focus groups; it should however be noted that this is still lower than would be expected if the levels were valued with even decrements of 0.25.

Table 17: Practical Support levels by focus group

		Attribute Level				
Focus Group ID:	**Number in Group**	**Level 1**	**Level 2**	**Level 3**	**Level 4**	**Level 5**
A	3	1	0.867	0.533	0.167	0
C	6	1	0.933	0.592	0.142	0
D	6	1	0.917	0.413	0.083	0
D2	6	1	0.817	0.463	0.058	0
E	9	1	0.844	0.542	0.106	0
E2	7	1	0.836	0.471	0.243	0

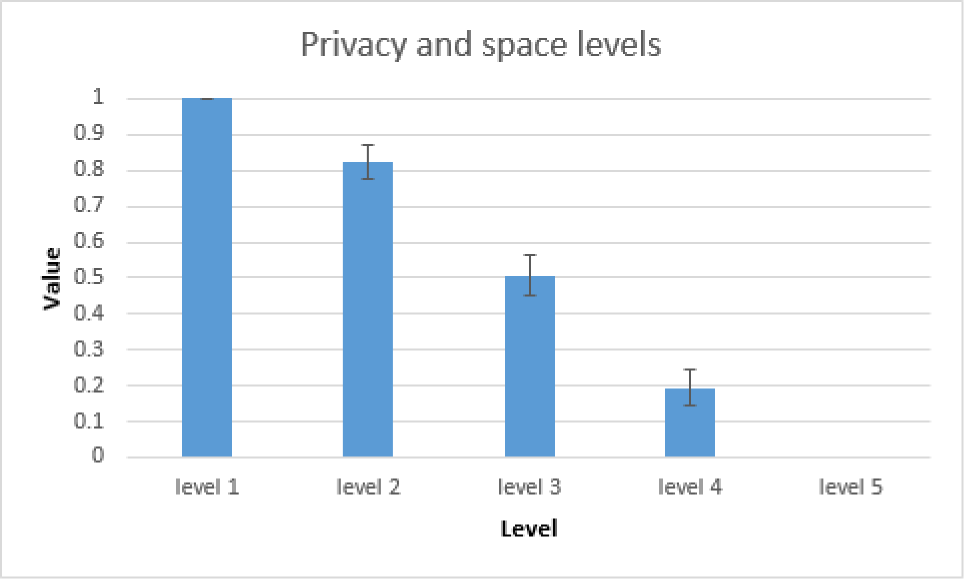
Figure 20: Practical support levels by focus group



8.3.3 Privacy and space

The levels given for privacy and space again follow a familiar pattern to the communication attribute and to a lesser extent the practical support attribute. Level two again is statistically higher at 0.82 (95% CI 0.778, 0.869) than would be expected if the values were evenly split across the levels, likewise the bottom level is significantly lower at 0.19 (95% CI 0.146, 0.244) than would be expected if evenly split. This implies that there is a smaller difference between being able to have ‘privacy and space **all** the time’, and ‘privacy and space **most** of the time’ than the intermediate levels which feature a larger gap between levels. The second worst level is again relatively low implying that there is less difference between having a privacy and space a **little** of the time, and **none** of the time, in comparison to the intermediary levels. These differences are however less pronounced than in the case of the practical support attribute.

Figure 21: Privacy and space levels (95% Confidence Intervals)

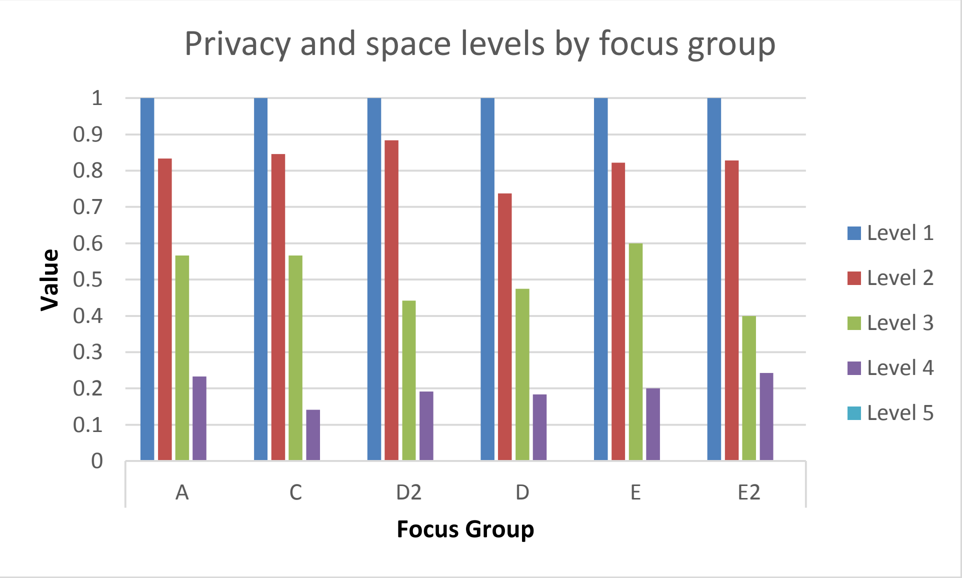


To further investigate this, the results from each focus group were explored as shown in Table 18. There appeared to be less consistency between the different focus groups, however a familiar pattern emerged. The pattern that was present in the previous attributes prevails with five of the six focus groups placing the second level above the 0.75 mark and all of the focus groups placing the level four value below 0.25. Again it appears that the focus group participants felt there was less difference between the top two and the bottom two levels than between the intermediary levels. Level four is again statistically significantly less than the expected 0.25 and this is seen in each focus group. This again implies that having privacy and space a **little** of the time is only slightly better than having privacy and space **none** of the time.

Table 18: Privacy and space levels by focus group

		Attribute Level				
Focus Group ID:	**Number in Group**	**Level 1**	**Level 2**	**Level 3**	**Level 4**	**Level 5**
A	3	1	0.833	0.567	0.233	0
C	6	1	0.846	0.567	0.142	0
D	6	1	0.883	0.442	0.192	0
D2	6	1	0.738	0.475	0.183	0
E	9	1	0.822	0.600	0.200	0
E2	7	1	0.829	0.400	0.243	0

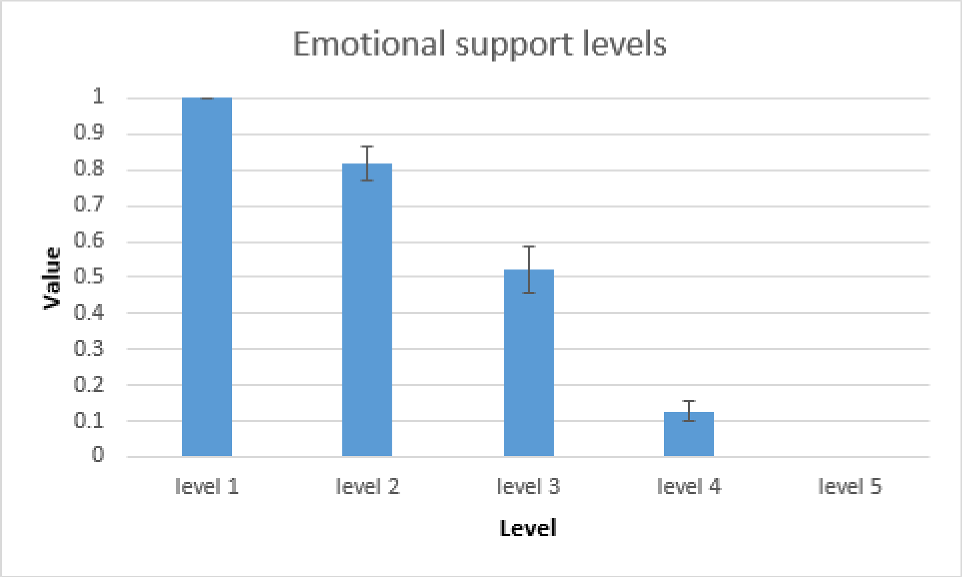
Figure 22: Privacy and space levels by focus group



8.3.4 Emotional support

The levels given for the emotional support attribute again follow a similar pattern to the aforementioned attributes. Although the level two value at 0.817 (95% CI 0.769, 0.865) is lower than the previous attributes, it is still significantly higher than would be expected if the decrements were evenly spread across the levels. As with the previous attributes there is then a large drop to the level three value at 0.522 (95% CI 0.46, 0.586). In a more extreme fashion than in the previous attributes, level four is particularly low at 0.128 (95% CI 0.099, 0.156) and significantly lower than the 0.25 that might be expected if levels were valued in equal decrements. Thus there is a large (0.395) decrement and significant difference between 'being **somewhat able** to get emotional support', and 'being **mostly unable** to get practical support'. In turn, there is relatively little difference between the bottom two levels compared to the intermediate levels. Thus the difference between 'being **mostly** unable to get practical support' and 'being **completely** unable to get practical support' is relatively small.

Figure 23: Emotional support levels (95% confidence intervals)

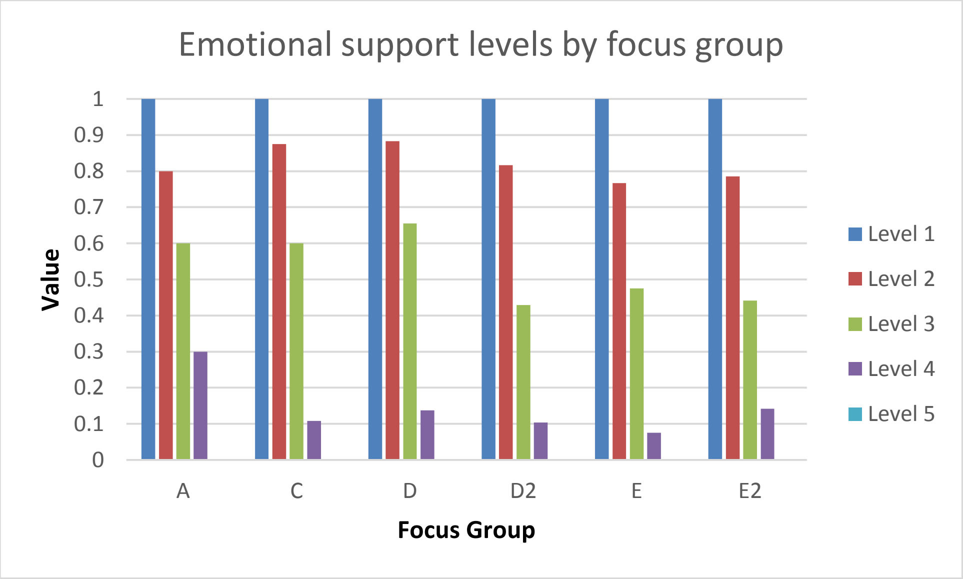


As can be seen from Table 19 and Figure 24 where the levels are broken down by focus group this in general was the case for all focus groups. All focus groups reported level two to be above 0.7, and all but one reported the lowest value to be below 0.25. The exception to this was focus group A which reported level four to be 0.3, above what would be expected, and significantly higher than all the other focus groups. This may have been impacted by the relatively few people within this focus group (three). Across all of the focus groups, level two was higher than would be expected and this implies there is relatively little difference between being fully able to get emotional support, and mostly being able to get emotional support. Likewise, for all focus groups there was a significant decrement between levels three and four of at least 0.3 in all cases indicating that there is a larger difference between these two levels. The relatively low value given to the level ‘mostly unable to get emotional support’ indicates that there is relatively small difference between this and the ‘completely unable to get emotional support’ level.

Table 19: Emotional support by focus group

		Attribute Level				
Focus Group ID:	**Number in Group**	**Level 1**	**Level 2**	**Level 3**	**Level 4**	**Level 5**
A	3	1	0.800	0.600	0.300	0
C	6	1	0.875	0.600	0.108	0
D	6	1	0.883	0.655	0.138	0
D2	6	1	0.817	0.429	0.104	0
E	9	1	0.767	0.475	0.075	0
E2	7	1	0.786	0.442	0.142	0

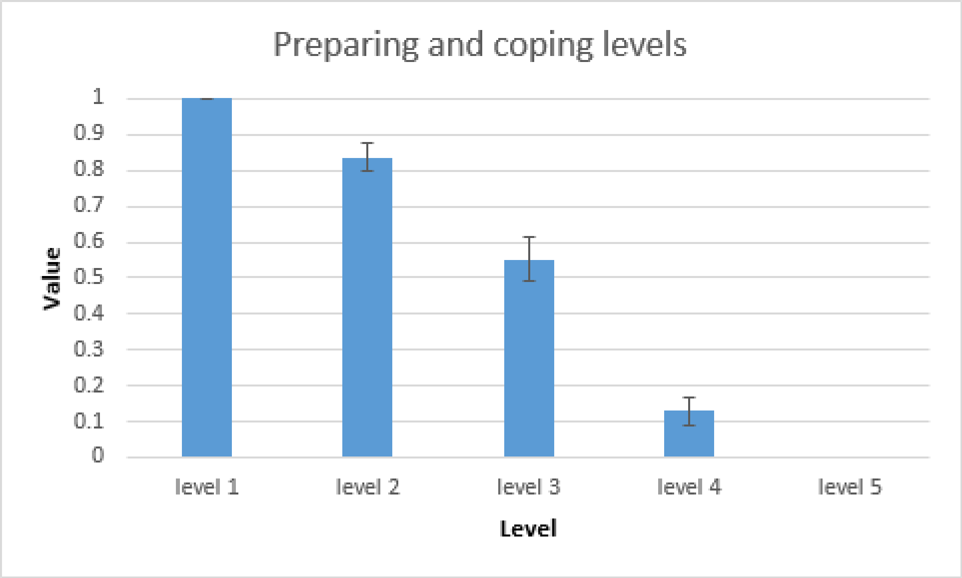
Figure 24: Emotional support levels by focus group



8.3.5 Preparing and coping

When examining the levels for the preparing and coping attribute, they follow a familiar pattern to the previous attributes. Again, the second level at 0.838 (95% CI 0.799, 0.876) is significantly higher than would be expected, again indicating a relatively small gap between the top two levels of the attribute. The middle level of the attribute, 0.551 (95% CI 0.49, 0.611) is greater than in the previous attributes, however it is not statistically significantly higher than might be expected if the levels were valued with equal decrements. Between levels three and four there is a large decrease of 0.423. This very large decrease indicates that there is a large difference between 'being **somewhat able** to prepare for, and cope with the person's death' and '**mostly unable** to prepare for, and cope with the person's death'. Level four at 0.128 (95% CI 0.088, 0.169) was again significantly lower than what would be expected if the values for the levels were equally distributed, indicating that the difference between being mostly unable, and completely unable was relatively small.

Figure 25: Preparing and coping levels (95% confidence intervals)



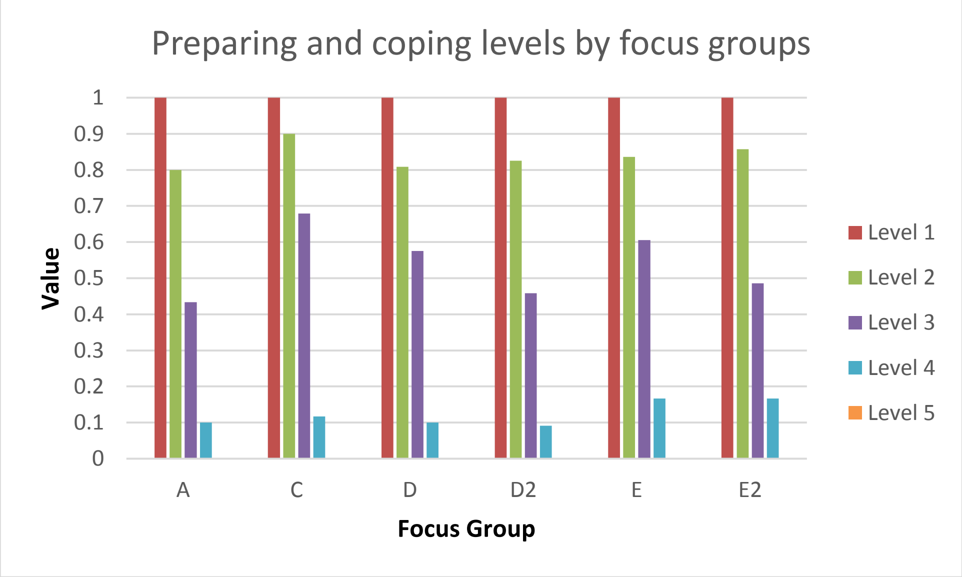
Investigating whether this was true across focus groups, Table 20 and Figure 26 show the values for each level on average for each focus group. Again, the top level is higher than 0.75 which would be expected if there were even decrements between levels. All of the focus groups reported significantly low values for level four, with the highest value being just 0.167. The top two levels again remained relatively close together indicating there is only a relatively small decrement from the top level. Likewise there is a relatively small decrement between the two lowest levels indicating that there is only a relatively small difference between the two worst levels for the preparing and coping attribute.

Table 20: Preparing and coping levels by focus group

		Attribute Level				
Focus Group ID:	**Number in Group**	**Level 1**	**Level 2**	**Level 3**	**Level 4**	**Level 5**
A	3	1	0.800	0.433	0.100	0
C	6	1	0.900	0.679	0.117	0
D	6	1	0.808	0.575	0.100	0
D2	6	1	0.825	0.458	0.092	0

E	9	1	0.836	0.606	0.167	0
E2	7	1	0.857	0.486	0.167	0

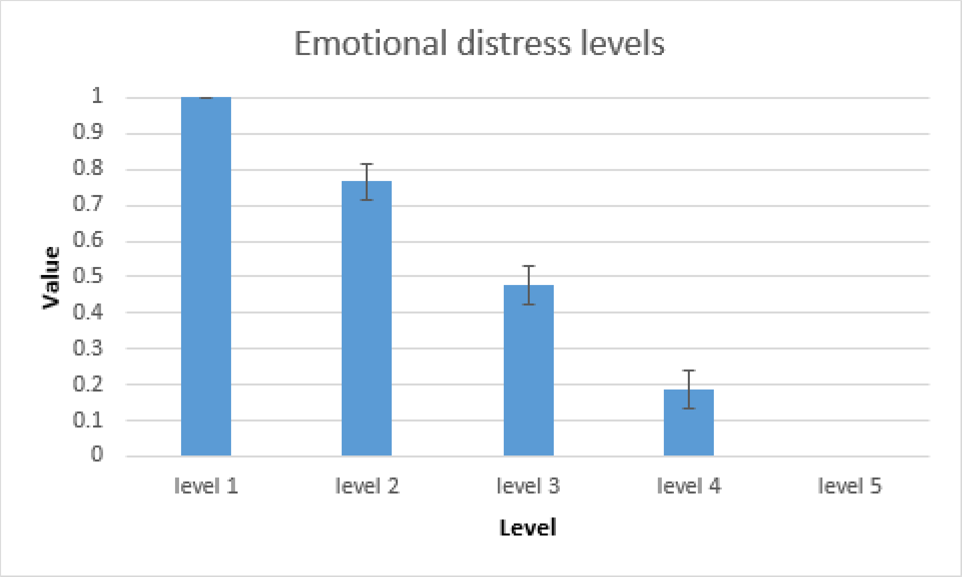
Figure 26: Preparing and coping levels by focus group



8.3.6 Emotional distress

The final attribute relates to emotional distress to the close-person as a result of the condition of the decedent. Unlike all the other attributes, the second level of the emotional distress attribute at 0.766 (95% CI 0.713, 0.818) was not significantly different to what would be expected if the levels were valued with equal decrements. Likewise level three also fits with what might be expected if the levels were distributed equally. There is, however, then a larger gap than would be expected to level four at 0.187 (0.135, 0.238) which is significantly lower than would be expected the decrements were spread evenly across the levels.

Figure 27: Emotional distress levels (95% confidence intervals)



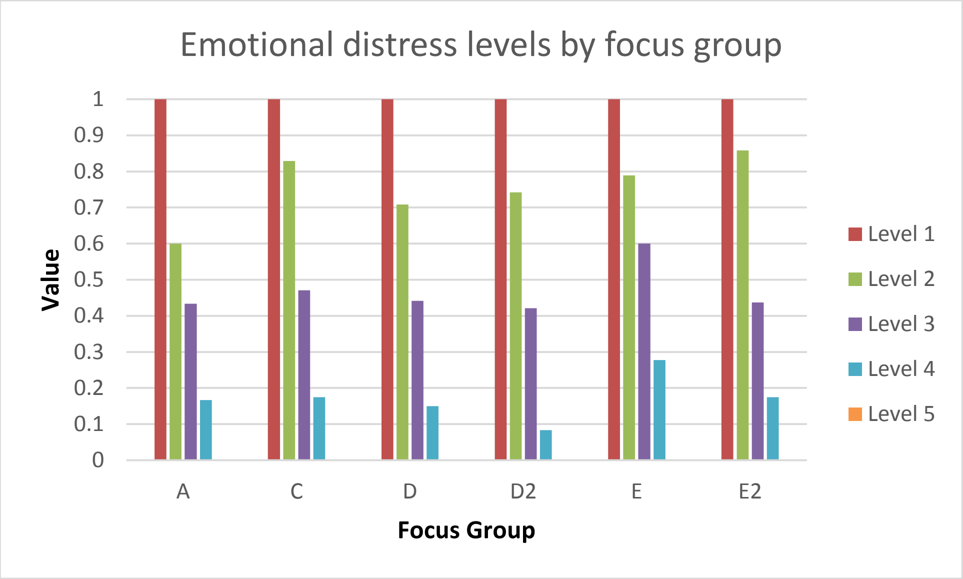
As shown in Table 21, the pattern detected in the previous attributes is much less well defined than in the previous attributes. For level two there was significant variation between the values given the level. Notably for level two, one of the focus groups valued level two at just 0.6. It should however be noted that this was focus group A with the fewest participants. For level three, all but one of the focus groups placed the level at below 0.5, this being focus group E. Six of the eight focus groups rated level four below 0.25 and thus lower than would have been expected. For this attribute, focus group E, which is the largest of the focus groups with 9 attendees, appears to be different. For level three all other focus groups rated level three relatively low, whilst focus group E has a relatively high score. Similarly, for level four, focus group E rates the level to be much higher than the other focus groups.

Table 21: Emotional distress levels by focus group

		Attribute Level				
Focus Group ID:	**Number in Group**	**Level 1**	**Level 2**	**Level 3**	**Level 4**	**Level 5**
A	3	1	0.600	0.433	0.167	0
C	6	1	0.829	0.471	0.175	0

D	6	1	0.708	0.442	0.150	0
D2	6	1	0.742	0.421	0.083	0
E	9	1	0.789	0.600	0.278	0
E2	7	1	0.858	0.4375	0.175	0

Figure 28: Emotional distress levels by focus group



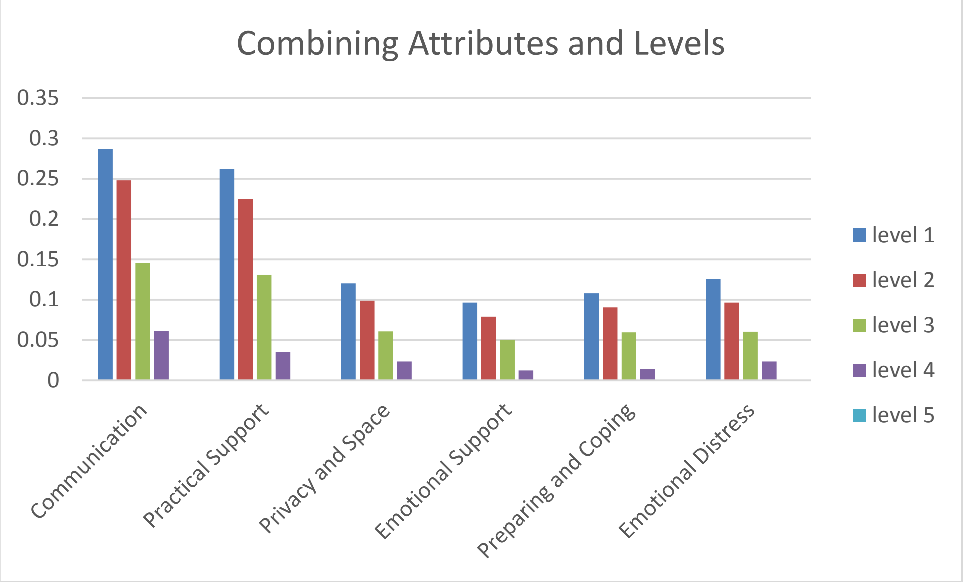
8.4 Combining levels and attribute weights

The values obtained via the scaling task and the attribute weighting task were combined (attribute weight x level value) to derive values for the states defined by the measure. These values can be found in Table 22 below and are represented graphically in Figure 29, giving the weight for each level of each attribute accordingly. As can be seen succinctly in Figure 29, as a result of the greater weighting given to the communication and practical support attributes, more weight is given to these attributes in the combined analysis. Likewise for the four attributes which were assigned less weight within the focus group, less weight is given to these attributes respectively. Given that the communication attribute and the practical support attribute received over double the weighting of the next highest weighting there are interesting implications in terms of decrements between levels that result from these weights. As a result of the heavy weighting given to communication and practical support, in combination with the large decrements between levels two and three, and levels three and four, the difference in weights between these levels is high. For example, the decrement between level two and three in the communication attribute is greater than the decrement in going from level one to level five of the emotional support attribute. Likewise the decrement between levels three and four of the practical support attribute equates to that of the decrement associated with moving from level one of the emotional support attribute to level five. These findings have significant implications for priorities in improving the close-person experience of EoL which will be discussed in section 9.2.3.

Table 22: The close-person measure weights (to four decimal places)

Attribute	**level 1**	**level 2**	**level 3**	**level 4**	**level 5**
Communication	0.2871	0.2479	0.1458	0.0616	0.0000
Practical Support	0.2621	0.2245	0.1309	0.0348	0.0000
Privacy and Space	0.1202	0.0990	0.0607	0.0234	0.0000
Emotional Support	0.0965	0.0788	0.0504	0.0123	0.0000
Preparing and Coping	0.1081	0.0905	0.0595	0.0139	0.0000
Emotional Distress	0.1260	0.0965	0.0604	0.0235	0.0000

Figure 29: The close-person measure weights



8.5 Impact of the deliberative component

The results presented so far throughout this chapter have been the post-discussion results. This section briefly outlines what the impacts of discussion were. It should be noted, that these results are not strictly the impact of deliberation but a result of the discussion of the initial answers to each task. Deliberation itself started from the moment that the participants began discussing EoLC which was prior to the valuation task and this may have impacted upon individual's answers. Upon the completion of each task, the participants were given the opportunity to discuss their initial answers with the group, and then given the opportunity to change should they so wish. The number of individuals who chose to change their answers for each of the levels task is shown below in Table 23. For any given attribute, no more than five (13% of sample) changed their answers; this was for the communication attribute, and the practical support attribute. For three of the other attributes, two individuals changed their weighting. The only level where discussion did not lead to any changes in the levels task was for the preparing and coping attribute. For the attribute weighting task, four individuals (10.5%) chose to change their responses in light of discussion and debate about individuals' answers.

Table 23: Number who changed post-discussion

	Communication	Practical Support	Emotional Support	Privacy and Space	Preparing and Coping	Emotional Distress
Number that changed	5	5	2	2	0	2

To examine the impact of the discussion, changes in the weights that occurred were examined. Although a relatively large proportion of the sample chose to change their answers (13% for some attributes), the changes had very little impact upon the resulting weights as shown in Table 24. The largest impacts of discussion were to the emotional support attribute which saw a decrease in weight of 0.004. In terms of the overall weight this is a very small impact, and all other changes were smaller than this. Thus, discussion of their answers and the opportunity to reflect led to some participants changing their responses; however these were relatively minor changes when aggregated. It should however be noted that prior to the second task (the attribute weighting), the participants had already had the opportunity to discuss and debate each of the attributes within the first task. As a result of this, by the time of the second task, the participants had already had the opportunity to think upon, and discuss, the merits of each attribute and how important they felt them to be. Thus, without the earlier deliberation there may have been more changes within the attribute weighting task.

Table 24: Impact of discussion on weights (to four decimal places)

Impacts of discussion on weights					
Attribute	**level 1**	**level 2**	**level 3**	**level 4**	**level 5**
Communication	0.0013	0.0023	-0.001	0.0003	0
Practical Support	0	0.0007	-0.0028	-0.0029	0
Privacy and Space	-0.0026	-0.0018	-0.0020	-0.0005	0
Emotional Support	-0.004	-0.0043	-0.0028	-0.0005	0
Preparing and Coping	0	0	0	0	0
Emotional Distress	0.0039	0.0030	-0.0010	-0.0036	0

8.6 Summary

This chapter has focussed upon the analysis of the deliberative valuation task. Thirty eight individuals were recruited into the study through seven focus groups. The participants were given two tasks that allowed for the calculation of overall values of the close-person measure. In this chapter, the weighting of the levels for each attribute were examined, along with the weights given to each attribute. These two were combined to develop values for each level of attribute of the close-person measure. The *communication* attribute and *practical support* attributes received the greatest weighting, together receiving more weight than the other four attributes combined. Differences in the weighting of attributes between different age groups, genders, and bereavement status were examined. The only significant difference in attribute weighting came with the lower weight given to *emotional distress* of those over the age 65 compared to those less than 65 years. Those over the age of 65 years were more likely to give the *emotional distress* attribute less weight than those under the age of 65 years. The impact of discussion and the opportunity to change their answers as a result of discussion was also explored. The opportunity to change answers did not have a significant effect on the weighting given to each attribute.

CHAPTER 9: DISCUSSION

This chapter will discuss the key findings of the entire study and provide recommendations for application and future research. Each aspect of the empirical work is discussed in relation to the findings, and in relation to other literature. Discussions have come under criticism for emphasising the strengths of studies and underplaying the limitations, especially in terms of generalisability [320]. For each aspect of the empirical work, respective limitations will be discussed alongside strengths. Considerations for using the measure in practice are outlined and implications of using the measure are discussed. The chapter finishes by highlighting certain areas of possible future research that remain.

9.1. Summary of findings

There is evidence that bereavement often has significant negative impacts on those close to the decedent [10], [11], [16], [18], [19], [21], [22], [24]–[31]. The purpose of EoLC is to allow the patient and close-persons to have a good experience of death/bereavement, and thus it should be evaluated in such a manner [102]. Given this, a broader extra-welfarist perspective which allows outcomes other than health was adopted for this thesis. Specifically, the research was situated within the capability approach developed by Sen *et al.* as interpreted within the ICECAP programme of work. In light of the dearth of current measures, the primary aim of the empirical work was to develop and value a measure to capture the impacts of EoLC on close-persons that could be used within economic evaluation. To understand the implications of including those close to people at end of life within economic evaluation, a task was included to explore who, and how many are close to those at EoL, and thus may be included within the economic evaluation of EoLC.

9.1.1. Development of a measure to capture close-person impacts

The empirical work can be broadly separated into two parts, the first qualitative, the second quantitative. The first part was focussed on the development of the close-person measure and examining who was close to the decedents at the EoL. The second phase involved the valuation of the measure through a novel technique based upon the notion of deliberation. To develop the close-person measure, a bottom up approach was adopted. This involved the recruitment of 27 individuals who were bereaved or were close to somebody receiving EoLC. In-depth interviews were conducted and constant comparative methods of analysis were used to develop conceptual attributes for the measure. Wording for the measure was derived from the terms used within the interviews and a self-complete questionnaire based upon the attributes derived was developed and checked for understanding. The finalised attributes of the measure at the end of the development process were: ‘communication with those providing care services’, ‘practical support’, ‘privacy and space’, ‘emotional support’, ‘preparing and coping’, and ‘emotional distress’. The finalised measure therefore contains six attributes; for each there are five levels.

9.1.2. Exploration of the evaluative scope

As a sub-task within the interview process, the notion of a close-person was explored and hierarchical maps were used to examine the networks around those at EoL. The average close-person network size was eight (median). One of the key findings of this task was that many participants felt that close-persons can extend beyond the immediate family; this has implications for including wider benefits within economic evaluation. The analysis suggested that those who do not retain their mental capacity and those who have smaller families will have smaller close-person networks at the EoL. The implications of this in relation to including close-person impacts in economic evaluation will be discussed in 9.2.

9.1.3. Valuation of the close-person measure

The quantitative aspect of this research was focussed on valuing the measure. The capability approach has seen calls for the inclusion of deliberation and public reasoning within valuation processes [102], [108], [284]. This research sought to include an aspect of public reasoning and deliberation within the valuation process, and consequently a novel exploratory method was employed. A valuation task was devised that would be amenable to discussion and gave individuals the opportunity to debate and change their answers accordingly. The valuation task comprised two parts, a budget pie task to weight the attributes, and rating scales to value the levels within each attribute. The task was placed within a workbook which was then completed by 38 individuals within seven focus groups across the West Midlands. Of the six attributes, the ‘communication’ attribute and the ‘practical support’ attributes were given the most weight; between them, they received over 50% of the weighting. Attribute weights were examined between the different focus groups, as well as between different age groups, genders and bereavement statuses. Those aged under 65 years weighted the emotional distress more highly than those aged over 65 years. Some participants chose to change their answers following deliberation and discussion, however this had minimal effect on the overall weights. As well as exploring a novel method of valuation, there now exists a preliminary set of weights for the close-person measure.

As a result of the development and valuation of the measure, there now exists a method for measuring and valuing the impacts of EoLC for those close to the dying. The purpose of the rest of this chapter is to discuss: how the measure fits into the existing framework for economic evaluation, the strengths and limitations of the methods used within the thesis, the implications for use of the measure in practice, and areas for future research.

9.2 Discussion of the main findings of the thesis

Chapters 4 and 6 of this thesis have described the development of attributes for a measure to capture the impact of EoLC to close-persons for use in economic evaluation within the capability paradigm. The need for the measure arose due to issues with the current methods of economic evaluation. EoLC is typically evaluated like any other health intervention with measures of HRQL being used to measure the effectiveness of interventions [127]. Given the broader goals of EoLC, this is argued to be an inappropriate framework for assessing EoLC [102]. Things other than health gain may be an important outcome of EoLC, and the current framework fails to capture these. The second issue with current methods relates to the focus solely on the patient or caregiver. EoLC interventions are often directed at not only the patient, but in conjunction with those close to the decedent [142]. By failing to capture the impacts of EoLC on those close to the decedent, important benefits are potentially being omitted within economic evaluation. This research enhanced the possibility of using broader approaches to evaluation by developing a measure that can capture the impact of end of life care for those close to the dying person.

9.2.1. Broadening the evaluative space – the attributes of the close-person measure

The developed measure contains six broad attributes covering issues that the participants felt were important to themselves when their close-person was going through the EoL process and in the period immediately following bereavement. These attributes were: *communication, practical support, privacy and space, emotional support, preparing and coping,* and *emotional distress related to the condition of their close-person*. One of the benefits of broader extra-welfarism is that it opens up the evaluative space to include non-health benefits. This section compares the dimensions of the close-person measure to those of existing measures and with the findings of the snapshot of complaints into the Liverpool Care Pathway [66].

9.2.1.2. Comparison with NICE-recommended measures

Table 25 lists the dimensions of the three measures recommended by NICE in addition to the close-person measure. As can be seen from Table 25, a number of these important aspects of EoLC would not be captured by focusing simply on health, as tends to be the case in economic evaluation. This is highlighted by the contrasting domains in the close-person measure and the EQ-5D. There is little overlap between the dimensions of the EQ-5D and the close-person measure, and relevant/important close-person impacts may therefore be excluded within economic evaluation when using the EQ-5D. For example, if an EoL intervention were to lead to improved communication between the health care services and the close-person network, the close-person measure would capture this, yet the EQ-5D would not. Likewise, when comparing the dimensions of the close-person measure to the generic capability instruments (ICECAP-O and ASCOT in Table 25) there are again few similarities indicating that they too would not capture important aspects of EoLC. Given the close-person measure has been designed specifically for use within the context of EoLC whilst the other measures are generic, this is unsurprising.

Table 25: Comparing the dimensions of NICE recommended measures with the Close-Person Measure

Measure:	**Close-Person Measure**	**EQ-5D**	**ICECAP-O**	**ASCOT**
Dimensions	Communication Practical Support Privacy and Space Emotional Support Preparing and Coping Emotional Distress	Mobility Self-care Usual activity Pain/discomfort Anxiety/depression	Attachment Security Role Enjoyment Control	Personal cleanliness and comfort Control over daily life Food and drink Personal Safety Social participation and involvement Occupation Dignity

Using the methodology recommended by NICE [127] important impacts of EoLC to the close-persons are potentially being omitted within economic evaluation.

9.2.1.3. Comparison with measures of family impact

There are no measures directly comparable to the measure developed in this thesis, i.e. a measure to capture the bereavement experience of close-persons. It is however possible to compare it to other measures related to the experience of EoLC. Two measures frequently used within the literature are the FAMCARE-2 [203] which is a scale of family satisfaction of care developed with the carers of patients with advanced cancers (can be used with non-cancer populations) and the QOLLTI-F [194] which is a measure designed to measure the quality of life of those caring for somebody at EoL. The QOLLTI-F and the FAMCARE-2 contain 16 and 17 items respectively and would therefore be challenging to value for use in economic evaluation. Furthermore, the measure developed within this thesis focusses on those close to the decedent and is conceptually broader than that of the QOLLTI-F which focusses on the impact on the carer and the FAMCARE-2 which focusses on satisfaction. Given the link between satisfaction with care, impact of EoL on quality of life for carers, and impact of EoLC on the close-person network, it is unsurprising that there are overlaps between the three different measures. For example the FAMCARE-2 includes questions regarding information, dignity, practical assistance, and emotional support amongst others [203]. Likewise the QOLLTI-F includes items such as emotional wellbeing, privacy and place [194]. This overlap is unsurprising as all three measures are focussed on a similar area however each with different purposes and therefore different items. This is positive in terms of indicating that there is content validity in respect to the attributes of the close-person measure.

9.2.1.4. Comparison with themes from the NHS snapshot of complaints

In June 2013, the Neuberger report [65] reviewed the Liverpool Care Pathway (LCP). Alongside this report, a review of the complaints with EoLC was published giving a snapshot of the issues with EoLC within hospitals [66]. The review analysed 255 complaints from bereaved relatives about the care that their relative received in hospital. The attributes developed in this paper are strongly linked to the themes that arose through the analysis of the complaints. Six primary themes arose through the analysis of the complaints, these were: *awareness of approaching end of life*, *communication and being caring, symptom management, the environment, concerns around clinical care, and fundamental medical and nursing care.* There is a strong overlap between the attributes developed within the measure and those related to the complaints. The ‘awareness of approaching EoL’ theme is linked to the attribute around ‘preparing and coping’; if people are not aware that their close-person is approaching EoL then they do not have the opportunity to prepare. The theme revolving round ‘communication’ is clearly similar to the ‘communication’ attribute developed within the measure. The ‘environment’ theme relates strongly to the’ privacy and space’ attribute of the close-person measure. ‘Symptom management’ and ‘fundamental care’ themes can be linked to the ‘emotional distress’ attribute; if care is poor then the impact of this is likely to be emotional distress to the close-person. The two attributes of the measure that are less prominent in the complaints review are the two attributes relating to support, i.e. ‘practical support’ and ‘emotional support’. It is hypothesised that the reason why these themes are unlikely to be picked up within the report is that their importance is more likely to be relevant outside of the hospital setting. For example ‘practical support’ is likely to be particularly important to those whose decedent is receiving care at home, whilst ‘emotional support’ is likely to be (or at least expected to be) provided by avenues outside of the hospital. The overlaps between the close-person measure, and the complaints and other close-person EoL measure suggest a degree of content/face validity. This however needs to be further examined as discussed in section 9.5.3. Reassuringly it indicates that the measure is designed to capture areas that are clearly of importance to those close to the dying as established by the report [65].

9.2.1.5. Impact of death trajectory

As described in 1.1.3 there are a number of different death trajectories, these include sudden death, terminal illness, organ failure and frailty [7]. Examples of all four of the above death trajectories were seen within the study. Of particular note to the dimensions of the close-person measure are deaths that fall into the ‘sudden death’ trajectory. Although EoLC is typically associated with a period of illness prior to death, it is possible that the measure could be used for any death trajectory, including sudden deaths. An implication of the measure is that those who have a decedent who dies from a sudden death will have a lack of capability within the ‘communication’, ‘privacy and space’ and ‘preparing and coping’ attributes, whilst the other three attributes are also likely to be restricted. The implication of this is that individuals who have somebody close to them who suffers a sudden death are likely to have a lower capability for a good experience of EoL/bereavement. Framing this within the wider bereavement literature, the evidence is equivocal in terms of the impact of type of death upon outcomes such as complicated grief/depression. The seminal review of Stroebe *et al.* [21] on the health outcomes of bereavement found some evidence that traumatic deaths may lead to worse outcomes, whilst sudden death was likely to have more effects on those who are vulnerable, and less prepared. The final point about those being less prepared is captured directly by the close-person measure through the preparing and coping dimension. An implication of this is that the close-person ‘experience’ as rated by the measure has less potential for improvement for those with sudden deaths than those with a protracted death.

9.2.2. Examining who, and how many, are close to those at end of life

There have been increasing calls for people other than patients to be included within economic evaluation [102]. This has typically been further explored within the carer literature [152]–[157], whilst others [163], [164] have found good reason to include the impacts on family members. As outlined in chapters one, two, and three, EoLC is a context where other people are impacted, and therefore arguments have been made for the inclusion of these others within economic evaluation. If those who are close to those at EoL are to be included within economic evaluation then it is important to know who, and how many people are likely to be included. Furthermore it is helpful to understand what factors may impact the sizes of network.

9.2.2.1. 'Close-persons'

In conjunction with the measure development task, the qualitative interviews were used as an opportunity to explore who was close to the decedents at the EoL to inform who could or should enter into the economic evaluation. It should be noted that this was a positive approach, that is, it examined who was close to those at EoL, as opposed to a normative approach, which would be examining who 'should' be included within economic evaluation. To get participants thinking about who was close to the decedent, the notion of a close-person was explored. Through qualitative analysis, there appeared to be several aspects which facilitated closeness between individuals, these were: *a reciprocated relationship*, *shared experiences*, *trust and reliance*, *being open and non-judgemental*, and having *comfort and security*. Not all of the aspects of the close-person need to be fulfilled to be close, however each may facilitate being close. There are strong overlaps between the aspects of closeness found in this study with those within the literature on intimacy and social ties. The most comprehensive study examining closeness was conducted by Parks and Floyd [167]. Parks and Floyd [167] critiqued the existing definitions of 'intimacy' and 'closeness', and examined the meaning of these words with college students in the United States (US). They found that the main characterisations came through self-disclosure, which relates to the open and non-judgemental facet of closeness found within this research. Other aspects within Parks and Floyd's study included: help and support, shared interests, comfort and ease of interaction; trust, acceptance, understanding, respect, frequency of interaction and length of duration of friendship (p.93) [167]. These results closely fit with the facilitators of closeness found within this research. Despite being from very different population groups (US college students and UK adults), the defining characteristics of being close are very similar to those previously reported. These aspects of closeness could in future be used to develop a measure of closeness. This could be useful in terms of 'screening' people to decide if they should fall into the evaluative scope. Developing the facilitators of closeness was important for the mapping exercise to understand why certain situations or death trajectories may impact the close-person networks at EoL.

9.2.2.2. Evaluative scope – beyond the patient, carer and family

When considering incorporating close-persons into economic evaluation, one of the most important findings within chapter seven relates to the scope of those who may be close and thus included within economic evaluation. In over 60% of the hierarchical maps, individuals who were not family members were included, and when discussed, some explicitly felt that the definition should extend beyond immediate family members. It can be seen that being family increases the opportunity for closeness; however it is not required. The case of CDX8 highlights the importance of looking beyond the family; in this instance the two closest individuals were not related to the decedent. By considering only the carer or family impacts [163], [164] then the two closest individuals would have been excluded from the evaluation. Likewise, although not unanimous, the majority of participants who discussed geographical proximity in relation to closeness did not feel that it was necessary to be geographically close to maintain a close relationship. In fact some described their close-relationships with individuals who do not even live in the same country. These findings have two important implications for including close-persons within economic evaluation. First, if close-persons are to be included then it may be necessary to look beyond just family members. Second, when considering who may be close and therefore suitable for inclusion in economic evaluation, it may be necessary to consider those who are not geographically close.

9.2.2.3. Evaluative scope – how many are close at end of life?

Hierarchical maps alongside the interview were used to examine how many are close to those at the EoL, and the factors that may impact upon the aspects of closeness at EoL. For the majority of the participants, the closest individuals were family members (spouse, child, sibling and grandchild). There was a significant range in terms of the sizes of the close-person networks. The mean number of close-persons put on the decedent's maps was 11, the median was eight. On average four individuals were placed within the inner circle. These findings are very similar to what has been found using the technique previously. Antonucci and Akiyama [168] found that on average those aged over 50 years had 8.9 individuals within their network. Similarly more recently Antonucci *et al.* [170] have conducted the hierarchical mapping exercise with young adults, and middle-aged adults in both the US and Japan. They found that on average, young adults had eight individuals within their close-person map, whilst middle-aged individuals had nine. This fits closely with the results with the decedents in the hierarchical mapping exercise used within this research. The mean is higher than that seen by the research conducted by Antonucci *et al.*, however this is likely to be skewed by the one participant who reported 74 close-persons. The median of eight may therefore be a better reflection of the size of networks. When comparing how many were included within the inner circle, the mean of 3.9 (median of four) is very similar to the findings as reported by Antonucci *et al.* who found that on average 3.65 individuals were placed within the inner circle [266]. Despite the subjects of the hierarchical mapping tasks being at the EoL within this study, it appears the size of close-person networks is not dissimilar to those found in the adult populations of Japan and the US.

9.2.2.4. Influences on social network size

Close-person networks are not necessarily fixed and may change through life; this especially may be the case towards the EoL when illnesses and co-morbidities are prevalent. Factors affecting network size were examined and hypotheses as to potential impacts were generated. To examine the impacts on networks, the smallest and the largest networks were examined to identify similarities, and differences. Likewise other influences were examined e.g. the age of decedent, the identity of who was completing the measure, and ethnicity. There were two primary factors that were identified that appeared to play a role in determining the size of networks at the EoL for the decedent, these are: condition type, and size of family. Having a condition that resulted in the loss of mental capacity appeared to reduce closeness between the decedent and those close to them. Referring to the things that facilitate closeness as discussed in 9.2.2.1, this is logical. If a person loses mental capacity then they are likely to lose many of the things that facilitate closeness e.g. being unable to talk openly and freely. The result of a reduction in closeness is a smaller network. Although set within a different context, this resonates with the literature on the impact of mental health problems and social networks. In the review of the literature by Albert *et al*. [321] on social networks in patients with severe mental illness they assess the evidence on the impact of mental illness on social networks. The evidence overwhelmingly suggests that those suffering from mental illness have substantially smaller networks than the general population [321]. Although the context is different within the case of EoLC, and the type of cognitive impairment is likely to be different e.g. dementia compared to schizophrenia, the reasons are similar. Those with cognitive impairments of any type are less likely to be able meet the criteria that facilitate a close-person relationship (i.e. *a reciprocated relationship*, *shared experiences*, *trust and reliance*, *open and non-judgemental*, and *comfort and security).*The second key determinant of network size appeared to relate to the size of the decedent's family. Although being a family member is not requisite to being close, those with larger families tended to have larger close-person networks. Again looking at the facilitators of closeness, being a family member increases the likelihood that some of these aspects will be met. For example, you are likely to have known your family members for a significant portion of your life and thus have had the opportunity to share experiences, gain trust/reliance and discuss issues. Those who have a small family and suffer from a condition that leads to decreased mental capacity are therefore likely to have the smallest networks.

9.2.3. Valuing the measure

For a measure to be of value within economic evaluation, it is necessary that there is full comparability of the states defined by the measure [274]. To achieve this, it was necessary to value the measure placing the states on an interval scale. Within health economics there exist multiple methods for valuing measures as discussed in section 5.2. The capability measures to date tend to have been either valued using arbitrary weights [180], and thus are likely failing to reflect how people value each attribute, or using best-worst scaling methods [181], [183]. Given the close-person measure operates within broader extra-welfarism and the CA, it was seen as an opportunity to value the measure using an approach closer to the recommendations within the capability literature. Specifically, this relates to Sen's comments on establishing weights [108], [284]. Sen calls for methods of weighting that allow for reasoned evaluation and reflection [108], and the inclusion of the discipline of public reasoning [284]. It was with this in mind that the exploratory methods for valuing the close-person measure were chosen.

9.2.3.1. Weighing the levels

Chapter 8 sets out the results of the valuation task. The valuation task was split into two discrete sections. The first part of the valuation process involved examining each individual attribute separately and scoring the levels of the attribute using a rating scale. An interesting pattern emerged when examining the results of the levels valuing task. In general there appeared to be a trend for the top two levels to be relatively close together with larger decrements between the interim levels, and the fourth level being relatively near the bottom of the scale. This pattern was relatively consistent through all of the different attributes and warrants further discussion. The implications is that there is little difference between the highest level and the second level, whilst drops from the second level and third levels lead to greater decrements with a relatively small difference in value between the bottom two levels. In some respects, the patterns of level distribution are not dissimilar to patterns within existing measures. For example, despite only having four levels per attribute, the ICECAP-O [181] and ICECAP-A [183] which were valued using the best-worst scaling methodology found that there was relatively little difference between the top two levels. This phenomenon is also seen in the EQ-5D where there is small decrement between the top two levels of each attribute before a large decrement to the other levels. In contrast to our findings however, the bottom half of the ICECAP-O and ICECAP-A measures tend to have large decrements [181], [183]. This was not the case within this study. Although there were large increments between the interim levels, there were no such decreases between the bottom two levels, with the second worst level being relatively close to the bottom level. This may not only be due to the wording of the levels but also to the number of the levels. The two ICECAP instruments have four levels for each attribute whilst the EQ-5D-3L has three. The close-person measure in contrast has five levels and thus may explain this difference. In addition to having a different number of levels to other measures, the valuation of the four different measures have used very different methods for valuing the states. The two ICECAP measures utilised best-worst scaling [181], [183] whilst the UK EQ-5D tariffs are based upon values elicited using TTO [212]. This study used an altogether different method for eliciting values based within the context of requiring a method amenable to deliberation.

Given the pattern of levels across the attributes, it is important to consider why this pattern may have occurred. One possibility is that the participants have some sort of threshold at which point they feel the level of care becomes no longer acceptable. It may be that the majority feel that being on the second level (most) is still acceptable, but that by level three, care no longer is acceptable, and as a result there is a large decrement between these levels. For others this threshold appeared to lie between levels three and four. As a result, when aggregated, there are large decrements between the intermediate levels. Alternatively it may just be an artefact of the wording of the levels. The top level of attributes are typically *‘all’* of ‘*fully’*, the next levels always refer to ‘*most’* or ‘*mostly’*, whilst the middle levels are ‘*somewhat’*, or ‘*some’*. Given the wording, people may feel that there is very little difference between having *all* of something, and *most* of something but is a big difference between having something *most* of the time, and only *some* of the time. Similarly they may feel that there is a big difference between having something *some* of the time, and only a *little* of the time. A more cynical view might be that the pattern of the levels arose due to the repetitive nature of the task with individuals just repeating the distribution as they went through each attribute rather than engaging with each attribute individually. This view however appears to be countered by the focus group by focus group analysis. This pattern was consistent in all of the focus groups, and therefore there appears to be an underlying cause for this for this distribution.

9.2.3.2. Weighting the attributes

The budget pie task led to the elicitation of weights for the attributes. The weights derived for each attribute were as follows: Communication (0.287), practical support (0.262), privacy and space (0.120), emotional support (0.096), preparing and coping (0.108), and emotional distress (0.126). All attributes as discussed in 9.2.1 were found to be important aspects of EoLC, and it is therefore unsurprising that all attributes received a significant amount of weight. The communication attribute and practical support attributes were rated as the two most important aspects of the close-person measure and received over half the weighting between them. As no other measures have been developed and valued within this context there is little literature upon which to compare the weightings found within this research. Communication was given the greatest weight of all attributes. This was closely followed by practical support. The other four attributes were relatively evenly weighted. The fact that communication was weighted the most highly is an interesting finding itself. Communication is not a health based outcome and again justifies the broadening of the evaluative space to include non-health impacts of EoLC. By focussing solely on health outcomes, the most important factor of EoLC for close-persons would not be included within economic evaluation. All six attributes received a significant weighting indicating that they all were important facets of the close-person experience of EoL.

The distribution of weight across the attributes was relatively consistent with communication and practical support being weighted the greatest or second greatest within all focus groups. There was a clear preference for these two attributes and they received a statistically significant greater weighting than each of the other four attributes. Sub-group differences were examined. When examining the attributes by age (over 65 years compared to less than 65 years), the weightings were very similar in five of the six attributes. The one anomaly however was within the emotional distress attribute. Those under the age of 65 years were significantly more likely to give weight to the emotional distress attribute than those over the age of 65. The implication of this is that those that fell into the younger age group were more concerned with being free from emotional distress related to the condition of the decedent. In contrast those over the age of 65 years gave less weight to the emotional distress attribute but slightly (not statistically significant) more to the preparing and coping, emotional support, practical support, and privacy and space attributes. One explanation is that it could be due to differing levels of experience in terms of dealing with bereavement. Those aged over 65 years are more likely to have been bereaved more times than those under the age of 65 years. It could be hypothesised that this may be due to a form of condition neglect [91] within the older age group. It may be that those who have experienced bereavement multiple times and have been exposed to distressing situations, particularly in relation to emotional distress, have adapted and reassessed their expectations accordingly. This however appears to not be the case when the subgroup analysis of the bereaved versus non-bereaved is considered. Although not significant, the bereaved trended towards giving emotional distress more weight than the non-bereaved, thus signalling that the condition neglect hypothesis for the difference is unlikely to be supported in this group and setting. This remains something that should be further explored in future research.

9.2.3.3. Combining attributes and weights

The attribute weights elicited through the budget pie task were combined with results of the levels task to develop overall weights for the measure. Thus the rating scale levels were multiplied by the weight for the appropriate attribute to derive values for each level of each attribute. As shown in section 8.4, this allows a total score to be calculated on a scale of zero to one. The communication attributes and practical support attributes received the greatest weights, and when combined with the results of the level scaling task, the values have interesting implications. It appears that the greatest impacts to close-persons can be achieved by moving individuals up through the interim levels of the communication and practical support attributes. For example, the increment associated with moving from the third level to the second level of the communication attribute is greater than that of moving from the bottom level of the emotional support attribute to the top level. This is not uncommon with outcome measures, for example with the EQ-5D, a move from the worst level of the '*mobility'* dimension to the second level is associated with a greater increment than a move from the worst *'usual activities'* level to the best *'usual activities'* level [212]. In the decision maker's context, the implication of this is that for close-persons, the greatest improvements for the experience of EoLC for close-persons can be made by focussing interventions that target those receiving poor levels of communication and practical support.

9.2.3.4. Incorporating deliberation into the valuation process

A key aspect of the valuation process was to try an exploratory methodology in line with the CA that drew upon the concept of deliberation and thus included an aspect of reflection [108], and public reasoning [284] as advocated by the CA [102]. Previous research is mixed in terms of the impact of deliberation on the results of valuation exercises. The key benefits of deliberation are outlined in section 5.3; it is posited that deliberation leads to more stable, less random opinions. Within the health economics literature, there have been few attempts to include the concept of deliberation within the valuation process. The evidence is mixed as to the extent to which deliberation impacts upon values elicited. Of the few studies that have included an aspect of deliberation, three [305]–[307], found that deliberation significantly impacted results, whilst two other studies did not demonstrate any significant changes [301], [308]. Given the limited literature upon this subject, this work is an important addition to the field. Within this study, participants had the opportunity to change their weightings following discussion with the rest of the group. Although a proportion of individuals changed their answers when given the opportunity, the changes detected within this study were insignificant and did not significantly impact the resulting values. The results would therefore side with the findings of Stein *et al.* [301] and Cabasés *et al.* [308]. There however is an important caveat to bear in mind when drawing conclusions regarding the impact of deliberation within this study. Due to the nature of the valuation task as part of the focus groups, by the time the participants got to the stage of weighting the attributes, they had systematically been through and discussed each attribute whilst conducting the levels task. As a result, the participants would have already thought about, reflected upon, and discussed the attributes prior to the weighting task. The results of deliberation presented for the attribute weights may therefore not be a fair reflection of the true impact of deliberation. There is also the fact that the time set aside for the valuation within the focus groups was limited to approximately one hour in duration, this contrasts to other contexts where deliberation often takes place over several days [322].

9.3. Strengths and limitations of the studies

9.3.1. Reflections on the measure development process

There were a number of strengths and limitations associated with the development of the close-person measure. As discussed in chapter 3, there was a lack of measures that could be used to capture the impacts of EoLC for use in economic evaluation. This research has addressed this gap within the literature and developed a measure that can be used to capture the impact for close-persons within the EoLC context. In terms of the measure development methodology, a strength to the development procedure lies within the qualitative approach that was used to develop the attributes. Recent years have seen renewed calls for measures to be developed with a bottom up framework [202], [223], [225], and a number of measures in recent years have been developed in this fashion [174], [175], [177], [323]. Qualitative research has been found to enhance the development of quality measures [227] and should improve the content validity of the measure leading to richer attributes [223]. The use of a bottom up methodology is therefore a key strength of the measure development process.

The philosophical framework within which the measure has been developed takes an alternative view to the typical frameworks used within health economics. This research adopted the broader extra-welfarist perspective and developed the measure within the capability paradigm. This is argued to be a strength of this piece of work. As evidenced by the attributes of the measure, a narrow extra-welfarist perspective limiting the impacts assessed for close-persons of EoLC to any health based dimensions would fail to capture many important aspects of the EoLC experience for the close-person. Thus, important aspects of EoLC would be omitted within economic evaluation. Broadening the evaluative space to incorporate non-health dimensions allows for these to be captured. The measure was developed within the capability paradigm with dimensions focussing on the capabilities rather than functionings of the close-persons. This may be particularly important for certain aspects of the measure. To elucidate, the privacy and space attribute provides a good example. Many participants discussed their preference for privacy and space. One of the participants (CDX21) described how they were offered a private room, but chose not to accept it. Despite not accepting the private room, they stated that they valued having the choice of the private room available to them. By simply measuring the functioning, their level of functioning would be the same as somebody who was forced to be in an open ward. However, using the CA it is clear they are better off than the person forced to use an open ward who may have desired privacy. The participant had the capability for privacy and thus using the capability framework has a higher level of well-being than the individual who did not. The CA therefore appears to be a useful framework for analysis within this context. This thesis is unique in developing a measure to capture the benefits of EoLC to those close to people at the EoL for use in economic evaluation. Furthermore the measure has been developed within the capability paradigm adding to an emerging area of research around the development of capability instruments for use in economic evaluation. It is foreseen that the measure could be used alongside the ICECAP-SCM to capture the benefits of EoLC for all those impacted.

9.3.1.1. In-depth interview self-reflection

The measure was developed using in-depth interviews. There are concerns within the literature about the degree to which the position and views of the interviewer can affect the data [231]. A position of ‘empathic neutrality’ has been suggested whereby the research accepts that there is likely be some influence but tries to remain neutral by remaining non-judgmental, open and sensitive to the views of the participant. In light of this, the notion of self-reflexivity which is referred to as a *‘confessional account of methodology or as examining one’s own personal, possibly unconscious reactions’* [324] is required to examine how I, the researcher, may have influenced the findings of the research. There are two primary mechanisms by which I may have impacted the findings; first, as somebody who is relatively new to qualitative research, my lack of experience in interviewing may have impacted upon the data collected. Secondly, my experiences, underlying beliefs and opinions may have impacted upon the interview process, and consequent analysis.

Given my lack of experience, to help minimise the impact of this on the qualitative research I attended a course at the University of Essex on ‘the art of qualitative interviewing’ along with the University of Birmingham’s week long Qualitative Research Methods course. The Essex based course was a two day intensive and highly interactive course which gave a grounding in the skills of interviewing as well as instruction on how to deal with various difficult situations e.g. interviewing on a sensitive issue which was particularly relevant to this context. This was particularly so given the emotive nature of the interview topic. The course run by the University of Birmingham complemented this and also provided the basis for the skills required to analyse the data generated by the interview. There however is only so much that can be gained from courses, and it was through the interviewing process and analysis itself that I felt my qualitative skills developed. At the start of the early interviews, there was often feeling of nerves, and an urge to fill periods of silence. As the interview process progressed and experience was gained, nerves dissipated, and it felt easier to generate and maintain rapport. Furthermore, silences within the interviews felt less uncomfortable, and time was therefore given for participants to think and respond. The implication of this is that the data collected within the initial interviews may be less rich and have less depth than those of later interviews as my interviewing skills improved. Given the sensitive nature of the interviews, I received frequent debriefs following the interviews in the early stages. As I gained confidence in interviewing, and became comfortable with the topic area, debriefs were fewer and farther between as they became less necessary.

The second interviewer/analysis aspect that may influence the findings of the study relates to my role within the interviews and analysis, with the potential for my own personal experiences to impact upon the findings. This was particularly relevant given my own experience of a bereavement with the death of my mother at the beginning of 2013. To reduce the likelihood of this being a factor, steps were taken at each stage to reduce the chances of this. To reduce the likelihood of interviewer bias, the interviews were largely interviewee led where possible with open-ended questions allowing the participants to discuss the issues that were relevant to them [231]. In addition to open-ended questions, a broad topic guide was used to ensure that that all topics of interest were covered within the interview. Care was taken to ensure my own experience of bereavement was not disclosed to the participants in the interviews. Early rounds of the interview data were presented and discussed within supervision meetings to ensure appropriate interviewing techniques were being used. The open-ended nature of questioning is largely reflected by the fact that the interview transcripts tend to have short questions followed by long answers. In terms of analysing and coding the interviews, a coding structure containing themes and sub-themes (Appendix six) was developed and evolved iteratively as new themes and sub-themes emerged allowing the systematic analysis of the data. The coding structure and codes were discussed and checked by the academic supervisors at regular intervals in supervision meetings. After each batch of interviews, a descriptive account [231] was constructed to systematically analyse each batch of interviews. These descriptive accounts were discussed and checked by the academic supervisors. The presence of a coding structure, descriptive accounts and regular supervision meetings should have led to reduced personal bias.

9.3.1.2. Recruitment

In regards to the processes of the measure development, some key limitations lie within the recruitment strategies for the research. To be recruited into the study, participants had to self-select themselves into the study. This may be problematic if people who volunteer to be in the study systematically have different views on what is important at EoL to those who would not volunteer to be interviewed. If those who would not volunteer to be in the study have a specific preference in regards to EoLC, then this may not be included within the measure. Consequently there is scope for a bias resulting from self-selection [231]. This however can be seen to be an ethical constraint as it would be unethical to force individuals to be interviewed for the study. It was planned that the recruitment into the study would be purposive with the aim of including as diverse a range of experiences as possible. Recruitment however, was relatively ‘slow’, and choice over who participated within the study was therefore more limited than desired. Although the primary aim of capturing a diverse range of experiences was successfully achieved, linked inherently to the self-selection issue, there is a potential for a gender bias to exist due to the scarcity of men who volunteered to be part of the study. Just 19% of the sample was made up of males, and consequently there may be things particularly relevant to males that were less likely to be captured through the research. It is hypothesised that this may be due to women being more comfortable to discuss and share their experiences than men. A number of the participants commented after the interview that they felt the interview had been ‘therapeutic’ and it had been good to talk to somebody independent about their experience. Likewise, several participants mentioned that they wanted to participate to help improve EoLC. Given women tend to be more altruistic and volunteer time than men [325], it may be that they were more willing to give up their time to help with the study than men. The reason for such a large proportion in the study may therefore be as a result of women having more reason e.g. as a form of counselling, and being more willing to volunteer to help others have an improved experience of bereavement.

The majority of participants were recruited through the University of Birmingham and therefore caution should be taken with generalising the findings. Several different recruitment strategies were used, and the target population proved difficult to recruit. Given the target population were either bereaved or had somebody close them receiving EoLC it is unsurprising that people may not want to discuss their experiences given the emotive nature of the topic. To recruit the 27 participants into the study numerous newsletters and posters were required over an extended period of time. Four of the participants were recruited through the Marie Curie Hospice, West Midlands. It is worth stressing the degree of effort that was required to get the necessary approvals for recruitment at the hospice. Given the hospice is a combination of NHS staff and non-NHS facilities, it led to a degree of confusion amongst the different organisations as to what approvals were required which culminated in much waiting. In the end, both NHS ethics and R&D approval were obtained, in conjunction with the hospice's internal appraisal process. Considerable time was spent by the research nurse at the hospice and myself to recruit the four hospice participants. This included me spending days in the hospice to make myself available for people to ask questions about the study if they so wished. It was reported back from the research nurse that many people were put off from participating due to the wording of the information sheet, particularly the word 'dying'. Many of the close-persons at the hospice did not consider their close-person to be dying as such, and therefore chose not to participate. This is something that should be borne in mind in future studies trying to access this population.

One of the most disappointing aspects of recruitment was the lack of recruitment via snowball sampling. Snowball sampling was intended to be used to examine how perceptions of care and importance varied within clusters. However, only one participant was recruited via this method and analysis of this issue was not possible as a result. It seems that the main reason for the lack of recruitment via this method may be due to the sensitivity and privacy of this topic area. Death and bereavement is somewhat of a taboo topic; for example, a recent survey by Dying Matters Coalition [326] found that 83% of the public believe that people in Britain are not comfortable talking about dying and death. If people are uncomfortable talking about death and bereavement then this may result in people being reluctant to recruit others into the study. The consequence of this may be the lack of participants recruited via snowball sampling.

9.3.2. Reflections on the close-person mapping exercise

One of the many criticisms of the way EoLC is evaluated, as discussed in section 3.2, is the omission of impacts on those close to the dying [142]. If those who are close to the decedent are to be included, it is important to know who and how many should/might be included. Typically when wider impacts are considered, these are limited to either the carer [157], [159], or in some cases family members [163], [164]. Arguments were made in 3.3 to extend this to close-persons. In the context of EoLC, there is a paucity of research about how many people are close to the person at EoL. A key strength of the close-person task is taking a first exploratory step to address this issue and to consider who is close to those at EoL. This work is novel in using a tool from the social network literature and applying it within the health economics context to explore who may enter the evaluative space. Through the hierarchical mapping task it appears that, if decedents' close-persons are to be included within the economic evaluation of EoLC interventions, it can be expected that between 8-11 people may be included; these may include non-family members and individuals who are not geographically close. The practical implications are discussed in section 9.4.

As part of the interviewing process, the hierarchical mapping tool itself proved to be a strength. The mapping task gave participants the opportunity to reflect and deliberate upon their answers, with participants often changing the positions of individuals within the network as they reflected. As well as allowing the participants to reflect upon those close to the decedent, it also provided a basis for the interviewer to ask further questions and probe in regards to specific aspects of the networks. This resonates with previous research within the qualitative literature [252] which found pictorial tools to be a useful asset within the interviewing process. I would advocate the use of such tools within future research to facilitate the interviewing process, particularly in regards to examining inter-personal relationships and networks.

One the most important influences, and thus limitations of the mapping task, as outlined within 7.4.3 relates to the impact of the identity of the person who completed the close-person mapping task. The type of person who completes the mapping task may impact upon the results of the network analysis. For the decedent that had two participants (one recruited via snowball sampling) conduct the mapping task, there were many similarities with the network given. There however were a few differences in terms of detail suggesting that the identity of who competes the task is important. There was only one ‘friend’ who completed the close-person task. The close-person map belonging to the friend did appear to contrast quite significantly to the other maps. It is not possible to draw any strong conclusions from this one participant; however, it is worth examining this within the wider literature.

Within the wider social network literature, one of the key criticisms relates to the accuracy of the networks as specified by the respondents [327]. Given the focal individual within the interview process is the decedent, and either near the EoL, or dead it was not possible to get these individuals to report on their networks, thus the close-person acted as a proxy respondent for them. In relation to the constituents of a close-person network, there has been work examining the agreement between network ties and the principal themselves. Shulman [328] examined whether ties were reciprocated between individuals, and those they named as being within their network (limited to six). Just 36.2% reciprocated by naming the person that had named them [328]. This gives the cause for concern about the accuracy of the close people acting on behalf of the decedent. In contrast, Stanford and Marmot [329] found moderately high levels of correlation between the principal and the closest individual's assessment of those nominated for inclusion. Antonucci and Israel [330] examined this phenomenon as part of a study examining the congruence of support networks identified by a principal and their social ties. Although there was only limited agreement when focussed on avenues of support, the congruence between the close-persons and the principals was high. They found approximately 84% agreement when both the principal and the other tie were asked about network membership. Of particular note was the degree that this was impacted by the identity of the tie. Overall agreement was found to be the highest with spouses (89%), and high with other family members (81%), however relatively low amongst friends (55%) [330]. The implication of this is that the close-person networks as given by friends should be interpreted with caution. In addition to this, Antonucci and Israel [330] also examined how the degree of closeness affected congruence in response, the closer the respondent was according to the hierarchical mapping task as completed by the principal, the greater the congruence. If the mapping task is to be used to identify who to include within economic evaluation then the implication of this is that the person's spouse is the preferable choice of proxy, followed by the closest family member. The accuracy of measurement is therefore a limiting factor and there remains a need for further investigation into the accuracy and reliability of network data [331]. Had the snowball sampling proved successful, this would have enabled the possibility to test the stability of the perceptions of the close-person networks.

An issue that is pertinent to the examination of close-person networks relates to decedents that do not have any close-persons. Given the participants recruited into the study were recruited on the basis that they reported themselves to be close, it is clear that all decedents in question will have at least one person close to them. It is well documented within the UK that loneliness and social isolation is a prevalent issue in the elderly, with an Age UK [332] poll finding that 10% of people aged over 65 years described themselves as often or always lonely. This is elucidated by the finding that within a sample of 182 councils in the UK, for the years between 2000 to 2004 a total of 11,004 funerals were carried out by local authorities for people who passed away alone without any friends or family [333]. Decedents who fall into this category are therefore likely to have smaller networks and are less likely to be captured within our sample. Furthermore, those who do not have *anybody* who are close to them will not be included within the study. Given these limitations, in conjunction with the potential biases through recruitment as discussed previously, caution should be taken when generalising the results.

9.3.3. Reflections on the deliberative valuation task

A key strength of the research lies within the fact that the method of valuation, by including reflection and deliberation, is more closely aligned with the methods of valuation as hinted towards by Sen within the capability literature [108], [284]. This study has shown that values can be elicited whilst incorporating an element of discussion and deliberation. Despite the results not being significantly impacted by specific discussion of the individual task, it was felt that the budget pie task was successful with participants engaging and discussing their experiences freely within the focus groups. The budget pie task used to value the attributes was a departure from typical economic methods of deriving values. When choosing methods, a compromise is required between the theoretical validity and the acceptability of methods [310]. Given that the measure was designed within the capability framework and an aspect of deliberation was sought, to value the measure it was required that the method of valuation was amenable to discussion and debate amongst the focus groups. Methods were therefore chosen as a compromise between the theoretical validity and the ability of the task to facilitate discussion and debate of the results. Thus, a limitation of attempting to value the measure using deliberative techniques is that the methods used have less grounding within economic theory. As discussed in section 9.5.4 further research is required to assess the validity of the weights.

Within the levels task there may be an issue with ordering bias. This is less applicable to the attribute weighting given the task used a budget pie, and thus there was no ordering *per se*. The level task however, was applied in a consistent order in each of the focus groups and thus may be subject to ordering bias [334]. For example if participants lose interest through the task then the later questions may suffer accordingly. Likewise, if participants do not understand what they are doing initially then the quality of the answers in the early questions may suffer. Furthermore the answers to one question may impact the answers to the next question. In terms of aiding understanding of the first questions, two example questions were included prior to the actual questions. It was reported back from focus groups that the levels scaling task was somewhat tedious, and there is therefore potential bias in terms of participants paying less attention towards the end of the task. The fact that participants gave and discussed their answers with the rest of the group for each task however may have maintained their concentration.

As advocated widely within health economics [121] it was decided (section 5.3.2) that the measure should be weighted with members of the general public. To participate within the study, participants had to return a screening questionnaire, and thus self-select into the study. Given this, a limitation to the valuation exercise lies within the lack of representativeness of the sample. Of the 38 people who participated within the valuation exercise over half the sample constituted people aged over 65 years. Given that there were significant differences between the weightings of those over 65s and under 65s this may have impacted the aggregated results. Care should therefore be taken in generalising the results. Further, a greater number of women than men volunteered to participate in this study. This may be for the same reasons as discussed in section 9.3.1. No significant gender differences were however found. Thirty five of the 38 respondents reported themselves to be white British, and again there may be cultural differences in how individuals weight the attributes. Given the non-representative sample, the values should be treated with caution until further exploration has taken place.

An issue to consider relates to the method of calculating the values within the valuation process. Within this study, values given by each participant were aggregated to develop values for the measure. Aggregating values is not uncommon and mean values have often been used to calculate values [301], [305], [306]. There are, however, theoretical arguments regarding aggregating individuals' values. It can be argued that aggregating values across individuals is impermissible, whilst on the other hand, such societal choices have to be made, and therefore values should be aggregated [310]. Like the decision over what elicitation method to use, there is a trade-off between theoretical grounding and pragmatism. The method of aggregation gave participants equal weight in terms of weighting the measure, and thus, it avoids inter-respondent inequity that may arise through other valuation methods [310].

The valuation method used was unable to take into account possible interactions between the attributes. Although this is relatively common within health economics practice e.g. ICECAP-O [181], ICECAP-A [183], it has been criticised [335]. This study aimed to use exploratory techniques incorporating aspects of deliberation and reflection into the valuation process. There has been recent interest in using extensive BWS exercises to value the ICECAP-SCM [183]. To attempt to incorporate interactions terms within this study would not have been feasible for two primary reasons, the costs, and the logistics of including a deliberative aspect.

9.4. Practical implications for including a close-person measure within economic evaluation at end of life

The purpose of this piece of research was to develop a measure to capture the impacts of EoLC on close-persons for use in economic evaluation. Given this, it is important to consider the implications for including the measure in this way.

9.4.1. What type of economic evaluation?

The two methods of economic evaluation where the measure is most applicable at present are the cost-effectiveness analysis (CEA) and cost-consequence analysis (CCA); this due to the rejection of the QALY methodology in chapter 3, and the lack of monetary valuation of the measure.

9.4.1.1. Allocative efficiency versus technical efficiency

Economic evaluation is typically concerned with either allocative efficiency problems, or technical efficiency [123]. It is foreseen that the close-person measure could be used for aiding both types of efficiency problem, but, primarily the latter.

In terms of allocative efficiency problems there are limitations. The measure itself could not be used as a “standalone” measure as it is clearly not relevant to the non-EoLC context nor encompasses impacts on patients; however it could be used to provide additional information for the decision maker using a cost-consequence analysis (CCA). The CCA reports all the outcomes of interventions in a disaggregated manner [121] and provides the full list of costs and consequences for the decision maker. The decision maker must use their own system for weighting the benefits to decide whether they believe an intervention to be cost-effective [122]. The close-person measure could therefore be used to capture the bereavement experience for those close to the dying. It would then be the decision maker’s decision as to how much weight they would place on the close-person’s experience in relation to the other benefits. Although, CCA has been criticised for not providing a clear framework for decision makers [118], it remains true to the spirit of economic evaluation in terms of providing the decision maker with as much information as possible in relation to the costs and outcomes of interventions [336].

Given the context specific nature of the measure, i.e. EoLC, it is anticipated that the measure will have its greatest use in terms of addressing technical efficiency issues. In terms of technical efficiency, the measure could be used both within a CCA, and cost-effectiveness analysis (CEA). Prior to this research there was no *valued* measure for capturing the experience of those close to the dying; now this measure can be included to capture the impact on close-persons. It could, as above be part of a cost-consequence approach. A more technical use of the close-person measure would be to use it in the CEA of interventions/policies aimed at those close to the dying. The close-person measure could then be used to assess the relative benefits to the close-person of interventions compared to the usual 'care'.

For example, given a £10,000 budget to improve the outcomes for those close to somebody at the EoL, a decision maker has three intervention options (with the an assumption of equal number of people treated):

1. **Proactive communication with family**: Cost: £10,000. Outcome: Compared to control group, intervention improves 'communication' from 'some of the time' to 'most of the time'.

2. **Improved facilities for close-persons:** Cost: £10,000. Outcome: 'Privacy and space' improves from 'some of the time to 'all of the time' in intervention group compared to the control group.

3. **Bereavement Support pack:** Cost: £10,000. Outcome: 'Emotional support' in intervention group goes from 'somewhat able' to 'fully able' compared to the control group.

Using a measure which has not been valued and simply sums the scores would lead to the following order of priority. The intervention targeting communication would be given the lowest score (improvement of 1 point) whilst the improvement of facilities and the bereavement support pack would be joint top (improvement of 2 points). The fact that a value set exists for the measure leads to drastically different conclusions when the value weights are applied. The gain in intervention one is associated with an improvement in the close-person score of 0.1. In contrast intervention 2 provides a gain of 0.06, whilst intervention three leads to a gain of 0.046. Thus it is clear the communication intervention should be prioritised as it provides nearly exactly the same benefits as the other two interventions combined.

9.4.2. When should close-persons be given the measure?

An interesting issue with the close-person measure relates to how and when the measure should be administered. The most obvious use of the measure as given in the example above is to examine technical efficiency questions in relation to the impacts on close-persons of an intervention versus control group. As discussed in section 1.4, ‘end of life care’ as defined, can continue into the bereavement period for those close to the dying [39]. Certain aspects of the measure are designed to account for this, for example, support with bereavement processes. Thus a decision needs to be made about the time point at which the measure should be administered. Typically to reduce the chance of recall bias [337], outcome measures are interested in ‘today’ e.g. EQ-5D [212], CHU-9D [323] or ‘at the moment’ e.g. ICECAP-O [174], ICECAP-A [175], ICECAP-SCM [177]. This measure however is interested in the EoL/bereavement experience as a whole for the close-persons and thus, focussing on short time periods is unlikely to be desirable, and may lead to misleading findings. For example, communication about the condition of the decedent is clearly very important as part of the bereavement experience, however if the measure is administered two weeks after bereavement, using ‘at the moment’ will be irrelevant in terms of the communication they received, and thus not a reflection on their experience.

A further consideration as to when the measure should be administered relates to the ethics of conducting research at such a sensitive period of time. Typically in regards to EoLC research, as with this study, for ethical reasons, six months are left from bereavement before conducting research with the bereaved relatives [338]. A concern is that over time participants may be less able to recall their experience accurately [339]. Given the intensity of bereavement, some studies show that bereaved close-persons have been found to be able to reliably report as proxies in retrospective studies [340], [341]. There however remains doubts as to the extent of the reliability in retrospective studies with Gomes *et al.* [342] finding that although many events remain vivid in the bereavement period, some events get repressed. Ideally, a pragmatic balance is needed between being administered soon after the bereavement period to reduce recall bias, but at a point where it will not cause unnecessary emotional distress. This is unlikely to be the same for everybody and more research is required to examine at what point this is, and how to determine it.

9.4.3. Who should be given the measure?

The findings of chapter 7 found that the individuals within this sample on average had eight (median) people within their close-person network, of which four of these were extremely close. This research has focussed on the positive aspect of who is close and thus may be impacted by bereavement. Technically speaking, within a full economic evaluation taking a societal perspective, all costs and consequence to all the parties who are impacted should be collected. However in practice this may be difficult, in terms of both time, and resources, especially for those with larger networks. For the measure to be used in practice a more practical approach may be necessary. The hierarchical mapping task [263] proved to be a quick and easy tool for assessing the networks around the decedent. A pragmatic solution could be to get the next of kin/closest person to complete the hierarchical mapping task and then focus on the experience of those within the inner circle of the hierarchical maps, i.e. those who are extremely close. Those who are closest are most likely to be the most greatly affected by the experience, and therefore capturing their experiences will capture the greatest impacts to the close-persons.

9.4.4. Equity Considerations

If efficiency is the sole concern then there is no need to worry about who receives the benefits. There may however be concern relating to equity as well as efficiency [343]. The first equity issue relates to the inclusion of close-persons. A criticism of the close-person measure may be that those with large networks of close-persons will be given more weight within economic evaluation. Thus those who have no close-persons will be discriminated against. Although convincing at the individual level, this argument falls down if interventions are analysed at a group level. That is, there would never be an instance of one patient without close-persons not getting treatment whilst another identical patient who does have a close-person network receives it due to having a larger network. What it does however mean, which may be raised as a concern, is that interventions that have an aspect that benefits the close-persons as well as the patient will be preferred to an identical intervention that benefits only the patient. Whether this is equitable or not is a normative judgment.

A second equity consideration that is of importance relates to the finding that close-person network size may be impacted by the death trajectory of the decedent (Chapter 7), in particular, that those with reduced mental capacity are likely to have smaller close-person networks. If close-persons are to be included within economic evaluation, then there is potentially an issue whereby interventions targeting disease areas where mental capacity is compromised will receive less weighting when close-persons are included within the economic evaluation. Conversely, it also means that if an intervention prevents the loss of mental capacity then these will receive a greater weight as there will be more close-persons at EoL. Likewise, given the heavy weighting of the practical support attribute, inclusion of close-persons will provide a greater weighting for improvements for conditions for which are particularly burdensome for the close-persons.

9.5. Future research

There remain a number of issues that should be explored in future research. These include how to prioritise between close-persons and the decedent within economic evaluation, further exploration in regards to the evaluative scope, and testing of the psychometric properties of the close-person measure particularly in relation to its validity and reliability.

9.5.1. Weighting between people

If the measure is to be used as an analytical tool within cost-effectiveness analysis, there are some important normative decisions needed as to how to weight the measure between people. This specifically includes the weighting between: A. different close-persons, and B. weighting between close-persons and the patient. To begin, there needs to be clarity over weighting between different close-persons. There are a number of options that could be considered. From a theoretical standpoint, the measure should aim to capture the experience of all the affected people, and from this position, thought can be given as to how impacts should or should not be weighted. In each individual case there is likely to be a different number of close-persons with a different degree of closeness. There are different methods for potentially including these scores within economic evaluation, and there is no ‘correct’ way to go about how we may choose to use the close-person scores. For capturing the close-person benefits, arguments could be made for giving equal weight to each close-person within the evaluation. Pragmatically, this is the easiest method to incorporate the measure and would simply require aggregation of the close-person scores, and averaging across the close-person sample. This may however lead to a dilution effect for those with many close-persons who are not extremely close whereby they are less affected and resultantly their experience dilutes what may be a severe impact on those closest. An alternative approach would be to get the closest person/next of kin to complete a hierarchical map and weighting the responses of the people according to their position on the map, but further research would be needed to determine their weights.

Further research should also investigate the public's preferences for allocating resources for EoLC between the patient and the decedent. It is likely that many interventions will provide benefits to both the patient and the close-person. It is anticipated that the close-person measure will be used alongside other measures that are focussed on the patient. The obvious choice of measure to be used alongside the close-person measure is the ICECAP-SCM [177] which is also based within the capability framework and captures the impact of EoLC on the patient. When both measures are included within an economic evaluation of an EoL intervention there may then be difficulties in deciding how to weigh the benefits between the two parties. For example, an intervention may improve the circumstances of the patient according to the ICECAP-SCM but worsen the experience of the close-persons. Research therefore is needed to examine how the benefits to each party should be weighted in relation to each other. For example it may be that people feel the resources should be split evenly between the decedent and the close-person, or favouring one party or the other. By eliciting such a weighting it would then inform when there are differential benefits to different parties. Until such a weighting exercise has been conducted and validated, it is advised that a cost-consequence methodology as discussed previously is used, rather than trying to merge the benefits to both parties into one end-point.

9.5.2. Evaluative scope

This work suggests a number of avenues for further research in relation to the evaluative scope. The first would be to examine how the close-person network changes in a longitudinal study through the death trajectory. This could examine how different death trajectories impact the close-person network, and in what ways. Second, further research is needed to examine the accuracy of close-persons reporting of the networks of those at the EoL. This could be achieved by comparing close-persons hierarchical maps with that as reported by a decedent as they move towards the EoL. Finally, as discussed previously, there were limitations with the recruitment of the close-persons within this study, and there are issues therefore with the generalizability of the findings. Further research with different recruitment strategies could examine the networks at the EoL to add to the limited literature within health economics.

9.5.3. Psychometric properties of the close-person measure

Regarding the measure itself, the next step should be to explore the psychometric properties of the close-person measure. Specifically, further research should focus on assessing the practicality, reliability, and validity of the measure [344]. Practicality refers to whether the measure is acceptable to the person completing the measure; this typically would involve testing how long it takes for participants to complete the measure [215]. Future research could therefore time the respondents to see how long they take to complete the measure to assess its practicality for inclusion within economic evaluation. Reliability refers to the ability of a measure to produce results that are consistent over repeated measurements of an unchanged population. A test-retest study could be used to examine the rate of agreement between responses to the measure and thus explore reliability of the measure [345]. Finally, the validity of the measure needs to be explored. The terms 'validity' is very much an umbrella term covering many different sub-types of validity. Here, briefly, some of the most common types of validity that need to be established are discussed. These include: content validity, face validity, criterion validity, and convergent validity [215]. Content validity refers to the extent that the items within an instrument are relevant to what is being measured [215]. Closely related, face validity refers to whether the items are sensible and appropriate for what is trying to be achieved [215]. Give the bottom up methodology used within this study there should be high levels of content validity and face validity as the items of the measure were developed through the experiences of the types of people who will be using the measure. Further research however should be used to examine this further. A study using 'thinkaloud' methodology is a possible route for exploring this with those close to the dying, as has recently been conducted with the ICECAP-SCM [346]. Criterion validity and convergent validity are closely related. Criterion validity refers to the ability of a measure to correlate against what would be the criterion or 'gold standard' measure for the area examined. Convergent validity relates to the degree to which a measure correlates with another measure of the same concept [215]. In the absence of a gold standard, to assess the degree to which this measure has convergent validity it is therefore necessary to include the measure within a study alongside other measures relating to the experience of bereavement e.g. CANHELP and FAMCARE-2 [196], [199]. The correlations between the measures can then be assessed to determine the validity of the measure. Although not formally done within this study, the overlaps between the different measures as discussed in section 9.2 suggest that the measure may have convergent validity.

9.5.4. Deliberative valuation

A novel aspect of this research was to include an aspect of deliberation in the valuation. Studies to date [301], [305]–[308] have been equivocal in relation to the impact of deliberation in the valuation process. This research was also equivocal, and it was clear that it was difficult to separate out general deliberation and the impact of deliberation on each specific task. This is an area that requires further exploration. Future research seeking to use this methodology should attempt to isolate, and assess the impacts of deliberation. This could be achieved by getting all participants to complete the workbook in isolation prior to the focus groups. Then the participants could then be given a new workbook which should be completed following deliberation and discussion within the focus group. By doing this, the impact of deliberation will be more effectively isolated than through the methods used within this study.

A second element requiring further investigation relates to the sample used within the deliberative process. The sample was recruited through the general population and therefore comprised those within a representative population who were sufficiently engaged to take part. Those who are willing to take part however may not be representative of the general population. Care should therefore be taken when generalising the findings. Further research should test whether the preliminary values elicited within the project hold up to scrutiny in the wider population. Something that would be of particular interest for the valuation literature would be to compare the values derived from the deliberative process to those derived using a BWS methodology (given this method has been used in other capability focussed research).

9.5.5. Economic evaluation in other settings

If wider benefits are to be included within economic evaluation of EoLC, it can be argued that wider impacts should also be captured more generally within economic evaluation. Future research should therefore seek to address this issue by disentangling, and capturing the wider benefits of interventions [163], [164] more generally. Again as with the findings in this thesis, this will have implications in interpreting how the results of interventions are assessed when comparing interventions where close-persons are included [152] and those where they are not. Likewise there will be equity implications of incorporating close-persons more generally, and this is an issue that needs to be addressed in future work.

9.6. Conclusion

There are strong arguments for including the impacts of EoLC on close-persons within economic evaluation. Typically a narrow extra-welfarist perspective is used and benefits of EoLC are limited solely to health benefits for the patient. For close-persons there are components of EoLC that are important which extend beyond simple health gains. A broad extra-welfarist approach is more appropriate to capture impacts of EoLC on close-persons.

The research within this thesis has made innovative contributions in a number of areas: First it has developed and valued a measure that is concerned with the EoL/bereavement experience of those close to the dying. Rigorous qualitative methods were used to develop the measure through in-depth interviews with those close to the decedent. The six resulting attributes: (*communication with those providing care services, practical support, privacy and space, emotional support, preparing and coping* and *emotional distress*) can therefore be expected to be important aspects to capture in economic evaluation.

Second, as well as broadening the evaluative space, this research sought to broaden the evaluative scope by including ‘close-persons’. The notion of a close-person was explored and the networks of decedents were explored using hierarchical mapping for the first time. This aspect of the research suggested that those other than immediate family may also be eligible for inclusion within economic evaluation. Those who have conditions which negatively affect mental capacity were found to have smaller networks, as were those with small families. On average four individuals were labelled as being extremely close whilst eight was the median number for the entire close-person network. For the first time therefore, there is an indication of the number off close-persons who could or should be included in the economic evaluation of EoLC.

Finally, a novel method was used to value the attributes of the measure, through a deliberative process. Preliminary values based on deliberative valuation were derived for the measure and the communication and practical support attributes were given the greatest weighting. The impact of discussion within this study had a limited impact upon the values elicited.

Overall, this research has made a substantial contribution to the literature by developing and valuing a measure that can be used to capture the experiences of those close to somebody at the EoL, and by defining the scope of the evaluation that should be conducted.

Appendices

Appendix one: systematic review methods

Appendix one provides further information for those interested in the methods used to review the potential measures that could be used to assess the bereavement experience of those close to the dying.

Eligibility Criteria and Justification

The PICOS methodology that is recommended via the CRD and via the PRISMA checklist [192] is not ideal for the purpose of this review given the lack of comparators or specific interventions. Despite this, the criteria was stuck to as closely as possible with additions to the PICOS criteria where necessary. Below the PICOS considerations are presented followed by extra criteria relevant to this specific study.

Participants (P): The population of interest are those close to people who are terminally ill or are recently bereaved. The proposed measure was interested in capturing the benefits of end of life care to close-persons, therefore the inclusion criteria were restricted to measures that are focussed on the same population as this thesis.

Intervention (I) – There was no one intervention that this review was interested in.

Comparator (C) – As this interview is not focussed on an intervention per se there were no relevant comparators.

Outcome (O) – The measure used must have been designed to capture the impact of end of life on close-persons. The purpose of this measure is to capture benefits of end of life care on close-persons, therefore the relevant outcome of studies is the impact on close-persons.

Study Design (S) – The study must either be:

- A. A measure development study
- B. A measure validity/feasibility/reliability study

This review is interested in studies that have either developed a relevant measure or have assessed its validity. Systematic reviews and methodological discussions amongst others were therefore excluded from the study.

Extra eligibility criteria (E)

- Only papers that are focussed on the period around the patient’s death were to be considered. This is because this research is focussed on developing a measure that is used around the end of life period to assess the impact of end of life care for use in economic evaluation.

- The measure must have been designed to extend beyond solely caregivers, i.e. it should be designed for use with all those who are close to the decedent. The measure proposed in this thesis is designed to capture the impact of end of life care to close-persons. The impact of end of life extends beyond the caregiver, and so the review will exclude measures which are designed solely for caregivers.

The purpose of this review is to ensure that the research is not repeating something that has already been done. These extra eligibility criteria were designed to ascertain whether there are any measures with the same premise as this thesis.

Information Sources:
There were three databases that were targeted for this review, these were: OVID Medline, Embase, Psycinfo. Publications from 1974 onwards (within the last 40 years) were considered for the review. A forward backward citations search will be conducted for any eligible papers.

Search strategy: The titles, keywords and abstracts were searched using the following search strategy. The first column is focussed on the target population, the second column on the period that of interest, the third column represents the possible outcomes that may be used within the studies, and the final column is the thing of interest, i.e. a measure.

Search strategy:

Family OR Relative OR Close-person OR Loved One OR Wife OR Husband OR Father OR Mother OR Son OR Child OR Sibling OR Daughter OR Spouse OR Partner OR Carer OR	AND	End of life Care OR Terminal care OR palliative care OR End of life OR Bereavement OR Bereaved OR Bereft Or Limited Life OR Hospice Care	AND	Capability OR HRQL OR HRQoL OR QoL OR Health related quality of life OR Quality of life OR Utility OR Well-being OR Wellbeing OR Happiness	AND	Measure OR Instrument OR Scale OR Questionnaire OR Index OR Outcome OR Tool

Caregiver						

Screening
The screening process consisted of three stages.

1. Title Screening
2. Abstract Screening
3. Full Paper Screening

Title Screening: If papers were clearly irrelevant then excluded, otherwise proceed to abstract screening. This stage was used to remove papers which are clearly off topic. The number excluded at this stage was recorded.

Abstract Screening: Papers which made it through title screening then had their abstracts screened to assess if they were relevant. If they clearly did not meet all of the eligibility criteria then they did not move forward to full paper screening. Those papers that remained moved forward to full paper screening; the number excluded will be noted.

Full paper screening: If they conform to the eligibility criteria, the papers will then be categorised according to whether it's: A. a measure development study, B. a measure validity study. The number of papers excluded at this stage was noted. Of the remaining papers, a forward backward citation search was conducted to identify any other relevant papers.

In the instance that papers fit into more than one category, e.g. if they are both a development study and a validity study, they were to be coded accordingly. For example if they both developed a measure and tested its validity then it would be coded 'AB' and included when examining both the measure development (A) papers, and the validity (B) papers

Data Extraction:
To extract the properties of interest within this review, two data extraction forms were created, one for each code. I.e. a form was created to capture the key aspects depending of the type of study.

Screening and study selection
The results of the screening and paper selection are shown in Figure 30 below. 861 papers were initially identified. After the screening process and the forward backward search there remained 10 papers that made it through to the reviewing process and were examined as discussed in 3.8.3.

Screening and study selection chart:

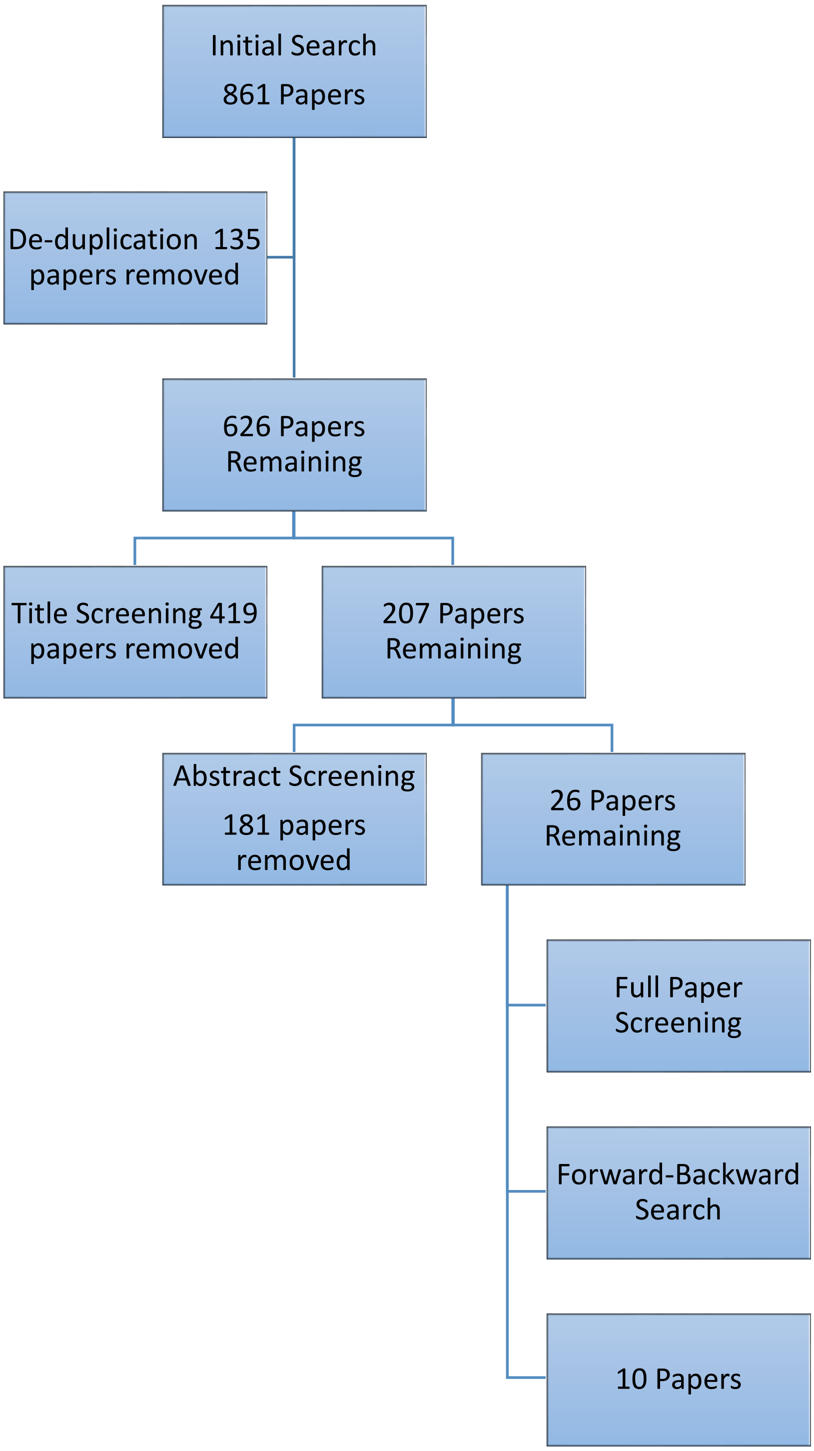
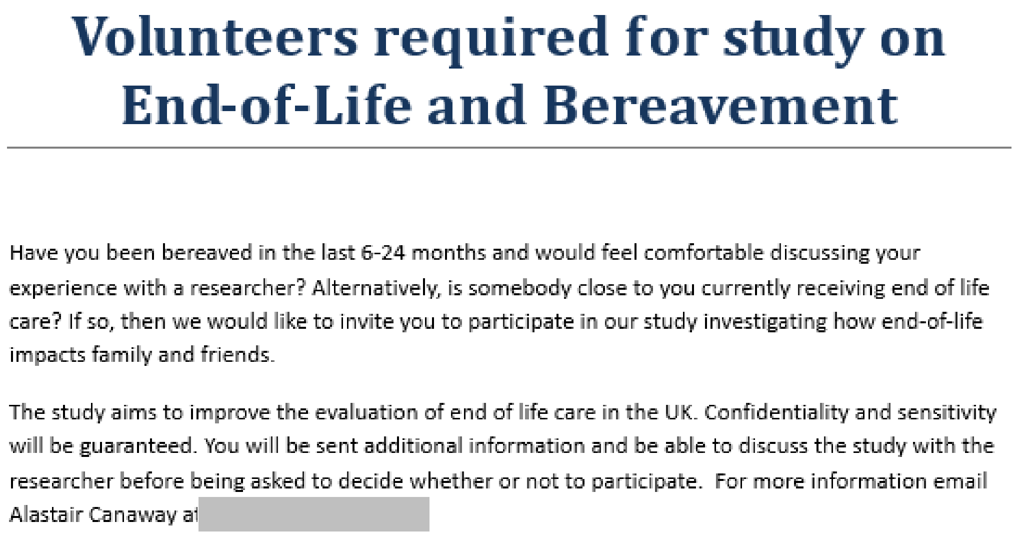


Figure 30: Paper assessment process

Appendix two: recruitment material – University of Birmingham

Advert circulated through multiple newsletters at the University of Birmingham



Volunteers required for study on End-of-Life and Bereavement

Have you been bereaved in the last 6-24 months and would feel comfortable discussing your experience with a researcher? Alternatively, is somebody close to you currently receiving end of life care? If so, then we would like to invite you to participate in our study investigating how end-of-life impacts family and friends.

The study aims to improve the evaluation of end of life care in the UK. Confidentiality and sensitivity will be guaranteed. You will be sent additional information and be able to discuss the study with the researcher before being asked to decide whether or not to participate. For more information email Alastair Canaway at [redacted]

Poster put up around campus at the University of Birmingham

Volunteers required for study on Bereavement and End-of-Life

Have you been bereaved in the last 6-24 months. Alternatively, is somebody close to you currently receiving end of life care? Would you feel comfortable discussing your experience with a researcher investigating the impact of end of life on family and friends?

If so, then we would like to invite you to participate in our study.

The study aims to improve the evaluation of end of life care in the UK. Confidentiality and sensitivity will be guaranteed. You will be sent additional information and be able to discuss the study with the researcher before being asked to decide whether or not to participate. For more information email Alastair Canaway at [redacted]

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End of Life Study

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UNIVERSITY OF BIRMINGHAM

End of Life Care Study – Close-person Information Sheet

Information about the research

We would like you to participate in a study to help develop the way that end of life care is evaluated. The research is being conducted by members of the **Health Economics Unit** at the **University of Birmingham**. The purpose of this leaflet is to help you decide whether you would like to participate in this study. Section 1 of this information sheet briefly outlines the study and what will be asked of you. Section 2 provides more detailed information about the study. Section 3 will inform you of how the information you give will be recorded and managed. If you choose to take part, this information sheet will also be briefly explained to you at the start of the interview.

Section 1 – Overview

Purpose:

The purpose of this study is to develop a measure to capture the benefits of end of life care to those close to a person who is dying or has recently died. To do this we need to find out what is important about end of life care to people who are close to those who are/were receiving end of life care.

Am I eligible?

We would like you to participate in this study if you are **either recently bereaved (between 6 months and 2 years ago) or you are close to somebody who is currently receiving end of life care**. In total, we hope that approximately 30 people will participate in this stage of the research.

Do I have to take part?

There is no obligation for you to participate in this study, however your help would be very much appreciated and will hopefully lead to improved measurement of the benefits of end of life care in the future. Before consenting to participate in the study, this information sheet will be explained to you and you can ask any questions that you may have. You are free to withdraw from the interview and the research, without the need to provide a reason. Upon withdrawal you have the option of asking for the data you have given to be destroyed. If you withdraw during the interview we will ask you then whether you want to withdraw from the research as a whole and have your data destroyed. If you decide to withdraw from the research after the interview, please ensure to notify us within a week of the interview; the data you have provided will then be destroyed. If you notify us after this time period it is possible the data may already have been analysed and used to inform future interviews.

Section 2 – Detailed Information

What will I have to do?

We would like to interview you face-to-face to find out about your experiences with end of life care. To begin, you will be asked questions about those close to you and how the health of those close to you affects your health. We will then discuss end of life care and in particular what you think is important about end-of-life and why different aspects of end of life care may be important. It is expected that the interviews will last between 30 minutes and 1 hour, however this may vary depending on how the interview progresses. The interviews will be digitally tape recorded so we can record what was said accurately. Any quotes or information from your interview will be fully anonymised in the event that it is reported in the results.

What are the benefits of taking part?

Your participation in the study will help us to develop a measure to capture the wider benefits of end of life care. Hopefully in the future this will result in more weight being given to the importance of end of life care. The work will also form part of a doctoral thesis.

Are there any disadvantages to participating?

End of life care is a sensitive topic and it is possible that you may find some of the questions upsetting or difficult to answer. The interviewer will try to ensure you are at ease; you may stop the interview at any point for any reason whatsoever.

Section 3 – Further Information

Will my details be kept confidential?

Great care will be taken to keep your identity confidential. You will be assigned a participant code when you sign the consent form; from this point your name will not be referred to in any transcripts, results or publications that arise from this study. Furthermore any places/names you mention in the interviews will also be anonymised.

What will happen to the recordings of the interview?

The interviews will be transcribed into written text and fully anonymised. The audio recordings will be kept on a secure network at the University of Birmingham, to which access is restricted to just the research team.

Will I get to see the results?

Yes, as a participant of the study we will provide you with the results of the study upon request.

What will happen to the results of this study?

The findings of this study will be written up as part of a doctoral thesis and the key findings will be presented at conferences and published through peer reviewed journals. It is anticipated that a measure will be developed with the help of these interviews which will help improve the measuring of the benefits of end of life care.

Who is organising and funding the research?

The research is being organised by the University of Birmingham and is being funded by the European Research Council.

Has this study been reviewed?

Yes, the study has been reviewed and approved by the University of Birmingham’s Science, Technology, Engineering and Mathematics Ethical Review Committee.

What if I have a complaint?

[redacted]

Further Support

If following the interview process you find that there are issues that have been raised that you require support with we recommend you get in touch with CRUSE Bereavement Care (08444 779400 or email: helpline@cruse.org.uk).

Contact Details

To participate in this study, please contact Alastair Canaway at:

[redacted]

Appendix three – information for ethical approval

UNIVERSITY OF
BIRMINGHAM

Information sheet – Marie Curie Hospice version

in collaboration with

Marie Curie
Cancer Care
Devoted to Life

End of Life Care Study – Close-person Information Sheet

Information about the research

We would like to invite you to participate in a study to help develop the way that end of life care is evaluated. We understand that this may be a difficult period of time for yourself, if you feel you need any support in dealing with your situation then further information can be found on page 4 of this information booklet. We would like to thank you for considering this study.

The research is being conducted by a researcher for a PhD as part of a wider project conducted by the **Health Economics Unit** at the **University of Birmingham** in conjunction with **Marie Curie Hospice, West Midlands**. The purpose of this leaflet is to help you decide whether you would like to participate in this study. Section 1 of this information sheet briefly outlines the study and what will be asked of you. Section 2 provides more detailed information about the study. Section 3 will inform you of how any information you give will be recorded and managed. This information sheet will also be briefly explained to you at the start of the interview.

Section 1 – Overview

Purpose:

The purpose of this study is to develop a measure to capture the impacts of end of life care to those close to a person who is dying or has recently died. To do this we need to find out what is important about end of life care to people who are close to those who are/were receiving end of life care.

Why me?

We would like you to participate in this study as you have informed us that you are **either recently bereaved or you are close to somebody who is currently receiving end of life care**. In total, we hope that approximately 30 people will participate in this stage of the research.

Do I have to take part?

There is no obligation for you to participate in this study, however your help would be very much appreciated and will hopefully lead to improved measurement of the benefits of end of life care in the future. Before consenting to participate in the study, this information sheet will be explained to you and you can ask any questions that you may have. If you do choose to participate in this study, **you are free to withdraw from the study at any point** without needing to inform us why you wish to withdraw. Withdrawal from the study after the interview can be done by contacting Alastair Canaway (see end of information sheet for contact details).

Section 2 – Detailed Information

What will I have to do?

We would like to interview you to find out about your experiences with end of life care. To begin, you will be asked questions about those close to you and how the health of those close to you affects your health. We will then discuss end of life care and in particular what you think is important about end-of-life and why different aspects of end of life care may be important. It is expected that the interviews will last between 30 minutes and 1 hour, however this may vary depending on how the interview progresses. The interviews will be digitally tape recorded so we can record what was said accurately. Any quotes or information from your interview will be fully anonymised in the event that it is reported in the results.

What are the benefits of taking part?

Your participation in the study will help us to develop a measure to capture the wider benefits of end of life care. Hopefully in the future this will result in more importance being given to the impacts of end of life care. This research will also form part of a (PhD) research degree.

Are there any disadvantages to participating?

End of life care is a sensitive topic and it is possible that you may find some of the questions upsetting or difficult to answer. The interviewer will try to ensure you are at ease; you may stop the interview and withdraw from the study at any point for any reason whatsoever.

Section 3 – Further Information

Will my details be kept confidential?

Great care will be taken to keep your identity confidential. You will be assigned a participant code when you sign the consent form; from this point your name will not be referred to in any transcripts, results or publications that arise from this study. Furthermore any places/names you mention in the interviews will also be anonymised. The only times in which confidentiality may be broken is in the instance of: a. an allegation of malpractice/abuse or b. risk to self/others. In such an event, it is statutory requirement to break confidentiality and report the disclosure to the requisite authorities.

What will happen to the recordings of the interview?

The interviews will be transcribed into written text and fully anonymised. The audio recordings themselves will be kept on a secure server at the University of Birmingham, to which access is limited to just Alastair Canaway (the researcher) and his three academic supervisors.

Will I get to see the results?

Yes, as a participant of the study we will provide you with the results of the study upon request.

What will happen to the results of this study?

The findings of this study will be written up as part of a doctoral thesis and the key findings will be presented to people working in this area at conferences and published through peer reviewed journals. It is anticipated that a measure will be developed with the help of these interviews which will help improve the measuring of the benefits of end of life care.

Who is organising and funding the research?

The research is being organised by the University of Birmingham and is being funded by a European Research Council grant to improve the measurement of end of life care.

Has this study been reviewed?

Yes, the study has been reviewed and approved by an NHS Research Ethics Committee

What if I have a complaint?

[redacted]

Further Support

If following the interview process you find that there are issues that have been raised that you require support with we recommend you contact the Marie Curie Family Support Team in the hospice itself (alternatively you can call 0121 703 3600 or email westmidlands.hospice@mariecurie.org.uk) or contact CRUSE Bereavement Care (08444 779400 or email: helpline@cruse.org.uk) who also offer pre-bereavement support.

Contact Details

[redacted]

UNIVERSITY OF
BIRMINGHAM

in collaboration with

Marie Curie
Cancer Care

Close Person Study – Consent Form

[redacted]

Questionnaire

Study ID Number_______

These questions are to help provide context to our study, if you feel at all uncomfortable answering a question please leave it blank.

Gender:

Male ☐

Female ☐

Age:

………………**years**

How would you describe your ethnicity?

……

How do you know the person who is currently receiving end of life care or has recently died?

……

If bereaved, approximately how long is it since the person close to you passed away? (tick one)

6 months to 1 year ☐

1 year to 18 months ☐

18 months to 2 years ☐

N/A ☐

Lone researcher protocol

[redacted]

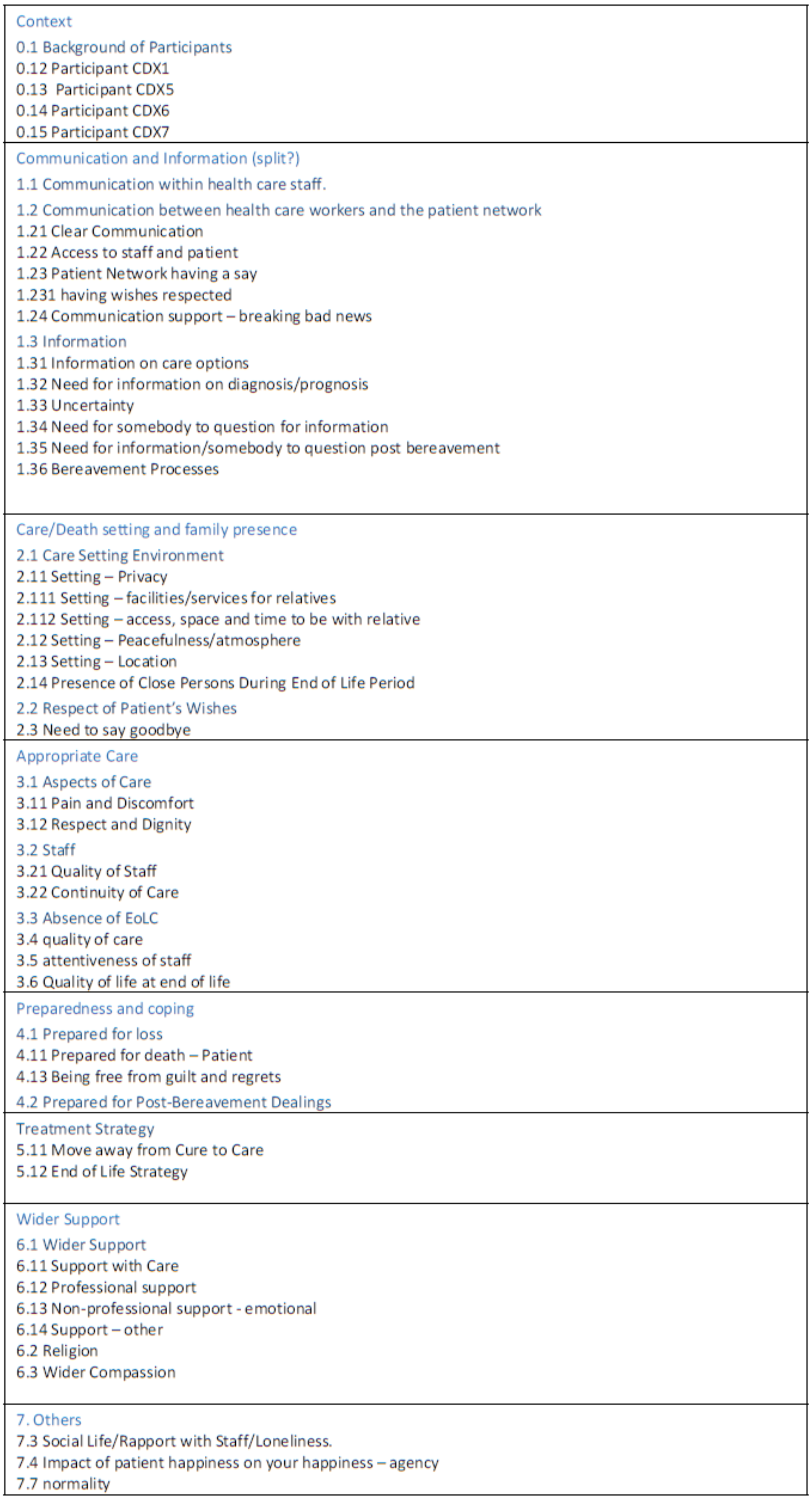
Appendix four - ethics and R&D approvals

[redacted]

Appendix five – interview schedule

Version 2 (March 2013) **CHECKLIST**	• INTRODUCTION/PURPOSE • INFORMAL • CONFIDENTIALITY AND ETHICS • RIGHT TO WITHDRAW • TAPE RECORDED • CONSENT FORM
Warm up questions: What is a 'close' person to them	Warm up Q's Okay, try to think of people that you would class as 'being close to you'. What sort of things come to mind when you think of someone who is close to you? **Probe** Could you tell me about those who are close to you? **Probes**: What makes them close to you? Which of these do you feel most attached to? **Probe**: Why are they the closest?
Who comes into Evaluative Space/Effect of their Close Person's health/care on them	I'd like to find out a little more about you and your relationship to the person who's receiving/received EoLC (relative/close person). • What is/was your relationship to X • How would you describe your relationship with X (**probes/prompts** – is/was it always been this way etc, how close are/were you etc) • Who else is/was close to them? • Of all the different people, who is the closest? – **why**?
	• Has/did their illness change your relationship with them? • How do you feel about the close person's health? -**What emotions does it evoke**? • Does this impact upon your life – **probe and prompt** e.g. how often do you think about it? - In what ways does it affect your life? • If deceased: how did their death impact you – **probe – how long for? Does it still affect you? How does it affect you?**
Eliciting conceptual attributes	- Thinking about end of life and end of life care (in reference to the person they know) **(N.B. In-Depth Probing on their specific issues)** • What does end of life care mean to you? • What end of life care does/did your close person receive? • How has their end of life care (of close person) affected you **Probe/bottom out** • When you think of the end of life care your 'close' person receives/received, what aspects of the care are important to you? - Which aspects of the care are most important to you? **Why?** • How does/has the end of life experience affect you? • What could be done that would improve your experience of your close person's end of life (care)? - As a close person, thinking about the end of life experience, what would improve it for you • How would this affect you? **Always ask <u>why</u>**
Close the Interview	• Reiterate information sheet/bereavement support etc. • Thank them • STOP TAPE RECORDER!

Appendix six – example of coding index



Context
0.1 Background of Participants
0.12 Participant CDX1
0.13 Participant CDX5
0.14 Participant CDX6
0.15 Participant CDX7

Communication and Information (split?)
1.1 Communication within health care staff.
1.2 Communication between health care workers and the patient network
1.21 Clear Communication
1.22 Access to staff and patient
1.23 Patient Network having a say
1.231 having wishes respected
1.24 Communication support – breaking bad news
1.3 Information
1.31 Information on care options
1.32 Need for information on diagnosis/prognosis
1.33 Uncertainty
1.34 Need for somebody to question for information
1.35 Need for information/somebody to question post bereavement
1.36 Bereavement Processes

Care/Death setting and family presence
2.1 Care Setting Environment
2.11 Setting – Privacy
2.111 Setting – facilities/services for relatives
2.112 Setting – access, space and time to be with relative
2.12 Setting – Peacefulness/atmosphere
2.13 Setting – Location
2.14 Presence of Close Persons During End of Life Period
2.2 Respect of Patient's Wishes
2.3 Need to say goodbye

Appropriate Care
3.1 Aspects of Care
3.11 Pain and Discomfort
3.12 Respect and Dignity
3.2 Staff
3.21 Quality of Staff
3.22 Continuity of Care
3.3 Absence of EoLC
3.4 quality of care
3.5 attentiveness of staff
3.6 Quality of life at end of life

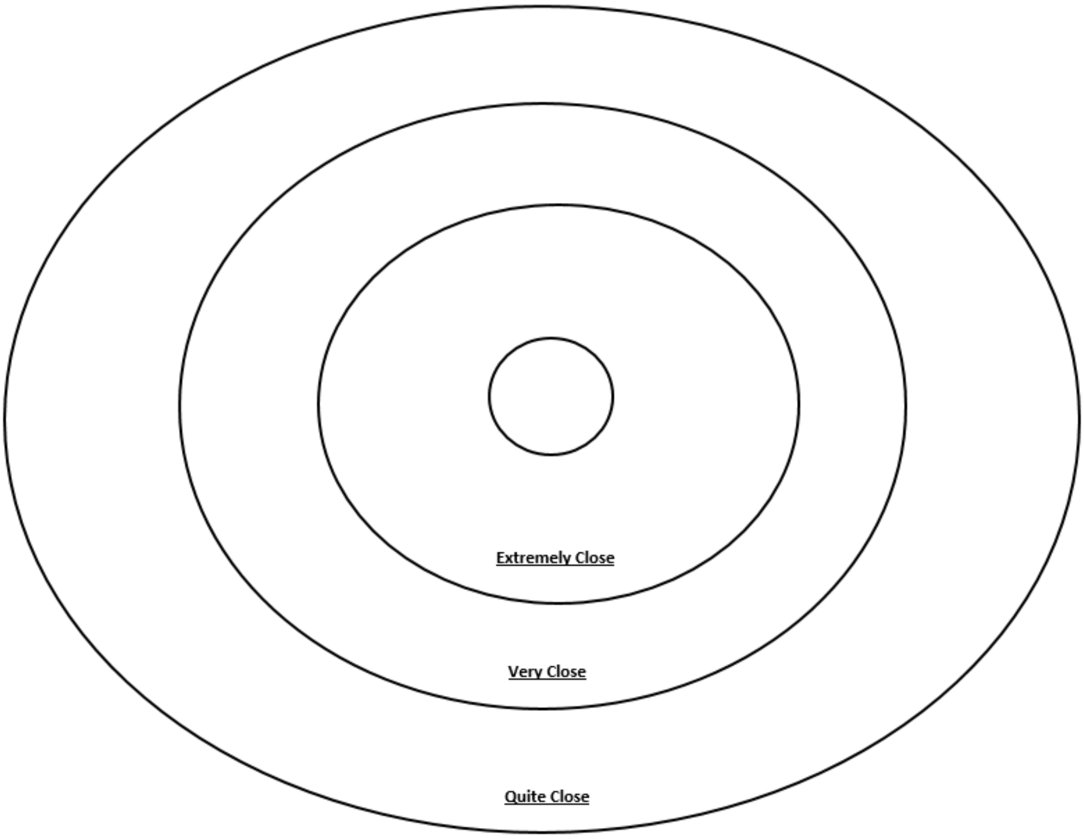
Preparedness and coping
4.1 Prepared for loss
4.11 Prepared for death – Patient
4.13 Being free from guilt and regrets
4.2 Prepared for Post-Bereavement Dealings

Treatment Strategy
5.11 Move away from Cure to Care
5.12 End of Life Strategy

Wider Support
6.1 Wider Support
6.11 Support with Care
6.12 Professional support
6.13 Non-professional support - emotional
6.14 Support – other
6.2 Religion
6.3 Wider Compassion

7. Others
7.3 Social Life/Rapport with Staff/Loneliness.
7.4 Impact of patient happiness on your happiness – agency
7.7 normality

Appendix seven – hierarchical map



Appendix eight – the deliberative valuation workbook

Econ
End
Life

End of Life Care Project:

Exploring Decision-Making relating to End of Life Care

Focus Group Workbook

Facilitators:

Jo Coast
Phil Kinghorn
Cara Bailey
Alastair Canaway
Cathy Campbell

School of Health & Population Sciences, University of Birmingham

Welcome

Welcome to our focus group on decision making relating to end of life care.

We are interested in finding out what **you** think about how decisions about end of life care should be made. Topics we will cover will include

- how important different aspects of end of life care are to the family and friends of a person who is dying,
- how important it is to provide care to the family and friends of a person who is dying,
- and the principles that decision-makers should consider when choosing which types of end of life care to fund.

This is a new area and there are no right or wrong answers. The goal of today's focus group is simply to get **your** thoughts on these topics.

Meeting Plan:

We will be discussing all of the issues as a group but will also ask you to do some tasks on your own, first, before we discuss them.

The workbook contains these tasks. After each task and the discussion of that task, we will ask you to write your own ideas in the workbook. We will tell you when to do this. Don't worry if your thoughts and ideas are different from the group's. What matters is that we hear your views.

Please feel free to express your ideas - *you are the experts here and your voice matters*!

TASK 1

How important are different aspects of end of life care to the family and friends of a person who is dying?

This task is about the family and friends who are close to a person who is dying.

We have found out that there are some aspects of end of life care that seem to be particularly important to family and friends. These have been used to develop a measure that we can use with these people to find out which aspects of care have been good and which have been less good. Each aspect of care is asked about in one question. For each question the family member or friend is asked to pick one of five levels to show what their experience has been like.

To be able to use the measure, however, we need to know how good or bad people think it is for family and friends to experience the different levels. This is where we need your help.

In this task, each question focusses on one aspect of end of life care.

- The top level is always the best
- The bottom level is always the worst.

We would like you to fit the other three levels somewhere in between the best level and the worst level according to how good you think each level is. On the next page is an example to help explain what we mean by this. We will then try a practice example in a different area before going on to do the tasks.

Example

On the opposite page is a scale that shows the possible values from the best to the worst level on a question that asks about how important it is to be happy. You can think of this scale as being like a thermometer, going from zero degrees (freezing) to 100 degrees (boiling).

The best level is 'completely happy'. This is given the label A and it is drawn on the scale at 100.

The worst level is 'completely unhappy'. This is given the label E and it is drawn on the scale at 0

The three levels we would want you to tell us about are given the labels B, C and D. Here, B is 'mostly happy', C is 'neither happy nor unhappy' and D is 'mostly unhappy'

We would ask you to put each of these levels on to the 'thermometer' according to how important you think it is to be at that level or, in other words, how valuable it is.

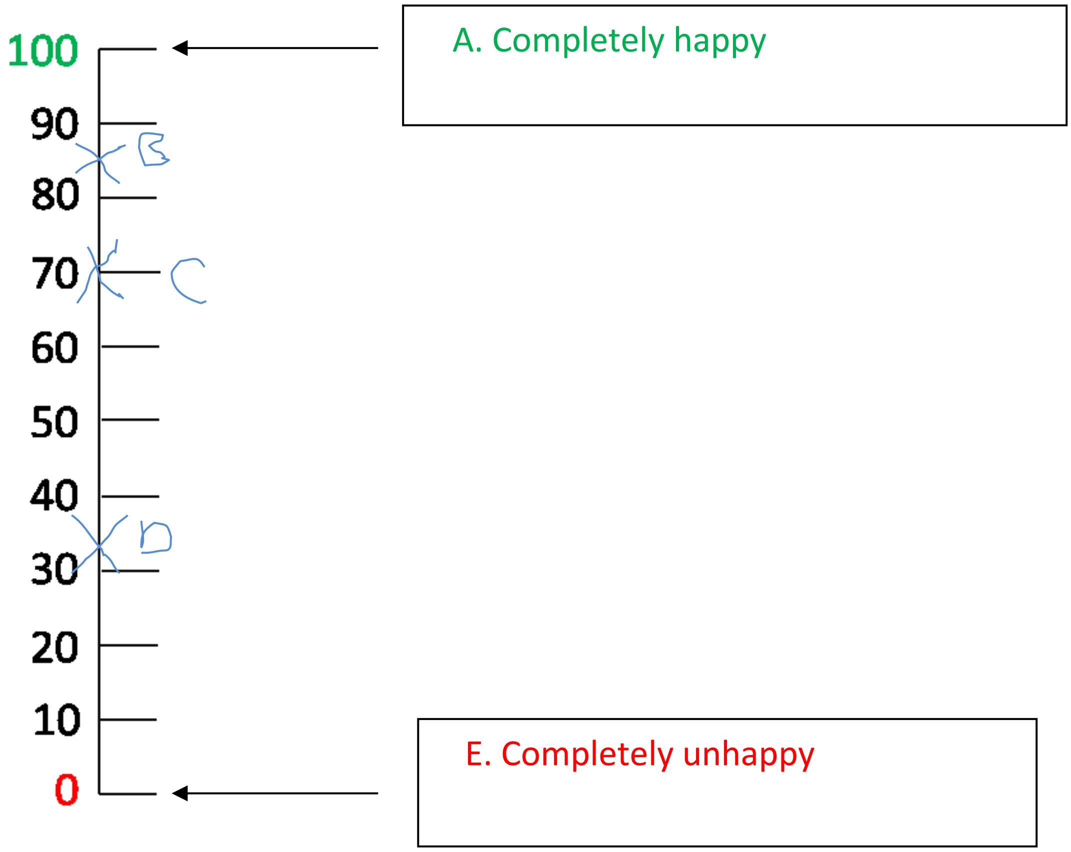
If you thought a level was good (for example, being 'mostly happy'), you would put it near the top end of the scale. If you thought the level was bad (for example, being 'mostly unhappy' you would want to put it nearer the bottom end of the scale.

Where exactly you choose to put each level should depend on how good or bad you think that level is.

It doesn't matter whether you start by putting in level B or level D or level C – the main thing is that you are happy with the points that you end up with.

Example task: happiness

Here, the person completing the questions felt that there was a small but equal difference between the top three levels A, B and C. However they felt that there was a large difference between levels C and D, and also a large difference between level D and the worst level E. This is shown by the large gap between those levels. After group discussion, the participant decided to change their answer…this is noted at the foot of the page.



The missing levels are:
B. Mostly happy
C. Neither happy nor unhappy
D. Mostly unhappy

Please show with crosses where you want to put 'B', 'C' and 'D' on the scale.

After the group discussion, would you:

Keep original answer ☐

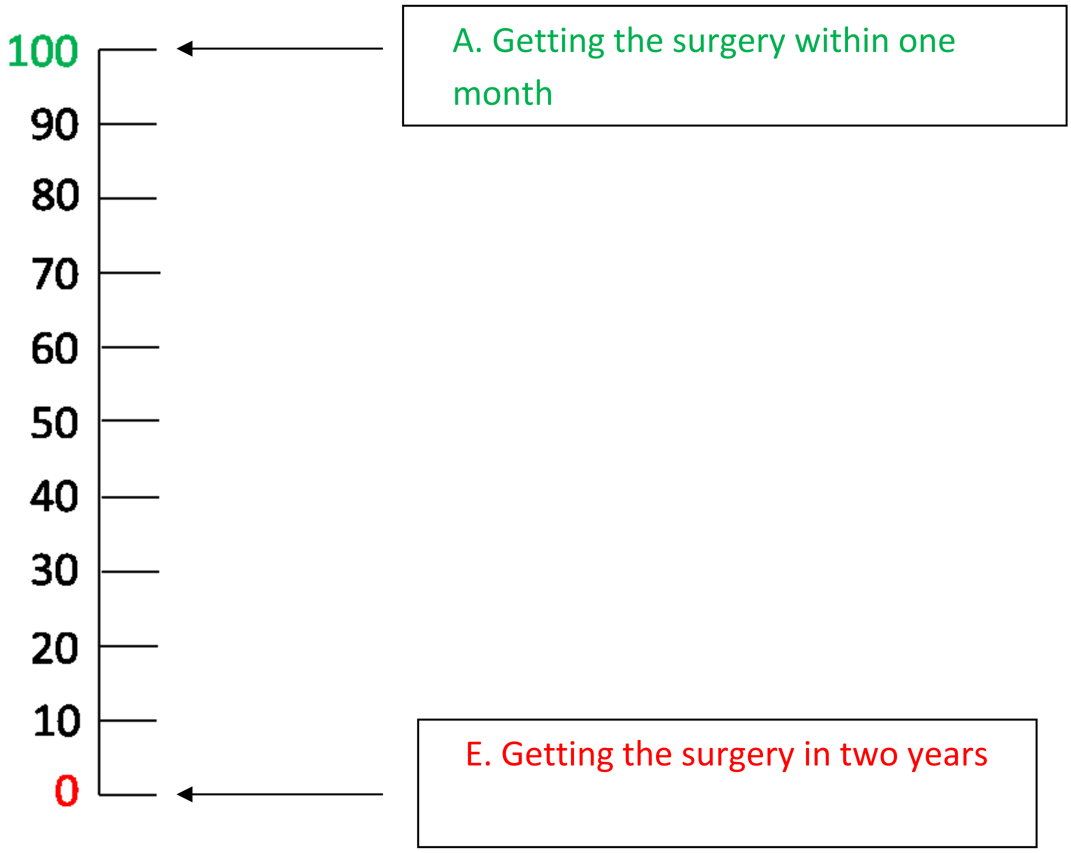
Change answer ☑

please note your changes: B = 90; C = 80; D = 50

Practice task: Hospital waiting times

This question is about your view of the importance of having short waiting times when having elective surgery. It includes things like:

- Hip and knee replacements,
- Cataract surgery,
- Tonsillectomy.



The missing levels are:
B. Being able to get an appointment in six months
C. Being able to get an appointment in one year
D. Being able to get an appointment in eighteen months

Please show with crosses where you want to put ‘B’, ‘C’ and ‘D’ on the scale.

After the group discussion, would you:

Keep original answer ☐

Change answer ☐

please note your changes: B = ...; C = ...; D = ...

Reminder: This task is about aspects of end of life care that are particularly important to family and friends of the person who is dying.

Here we are just interested in the family and friends who are close to a person who is dying. The benefits to the person who is dying will be looked at separately.

We need to know how good or bad people think it is for family and friends to experience different levels of each aspect of end of life care.

In all there are six parts to this task.

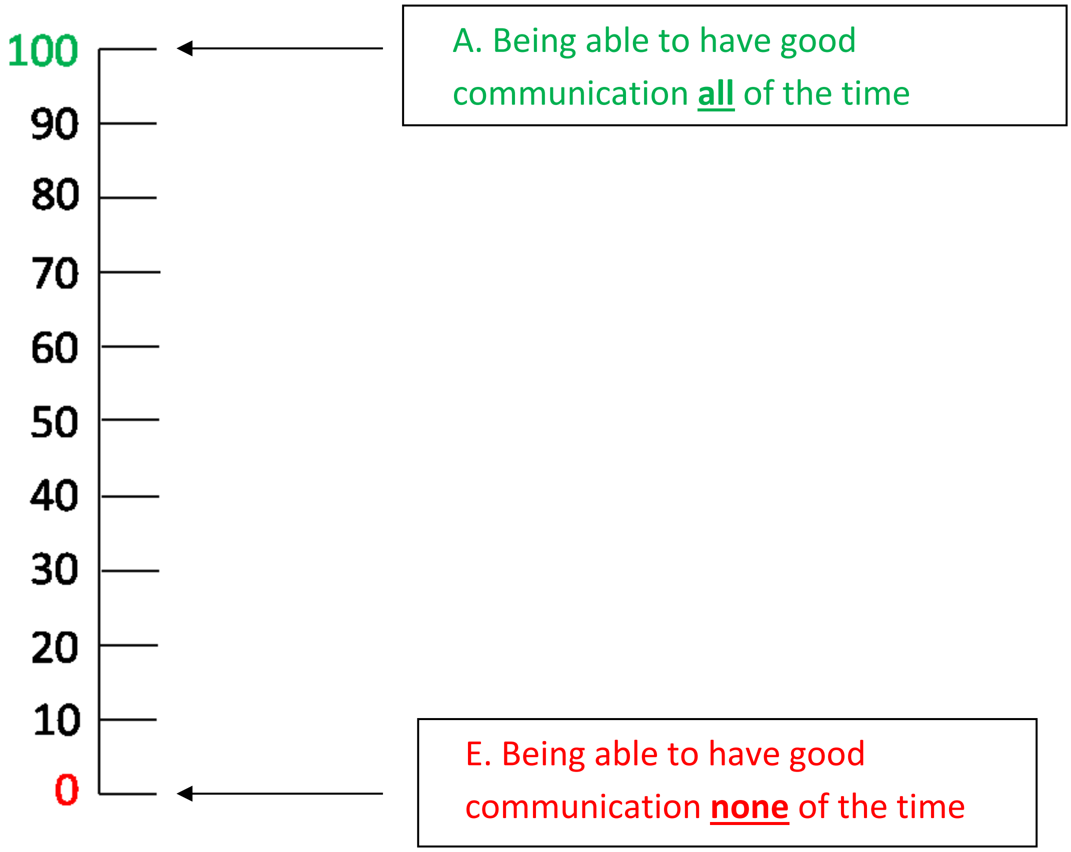
Your own experiences: when you are answering these questions please do think about any personal experiences that have influenced your views.

After each task we will discuss what people thought in the group. Again, please feel free to talk about your own experiences, if you feel comfortable doing so.

Task 1A: Good communication

This question is about your view of the importance for family and friends of being able to have good communication with those providing care services (e.g. doctors, nurses and carers). This includes things like:

- being able to get information about the person's health and care,
- being able to have a say in the care that the person receives
- being able to ask questions, have them answered and have views respected.
- being able to have rapport with those providing care



A. Being able to have good communication **all** of the time

E. Being able to have good communication **none** of the time

The missing levels are:
B. Being able to have good communication **most** of the time
C. Being able to have good communication **some** of the time
D. Being able to have good communication **a little** of the time

Please show with crosses where you want to put 'B', 'C' and 'D' on the scale.

After the group discussion, would you:

Keep original answer ☐

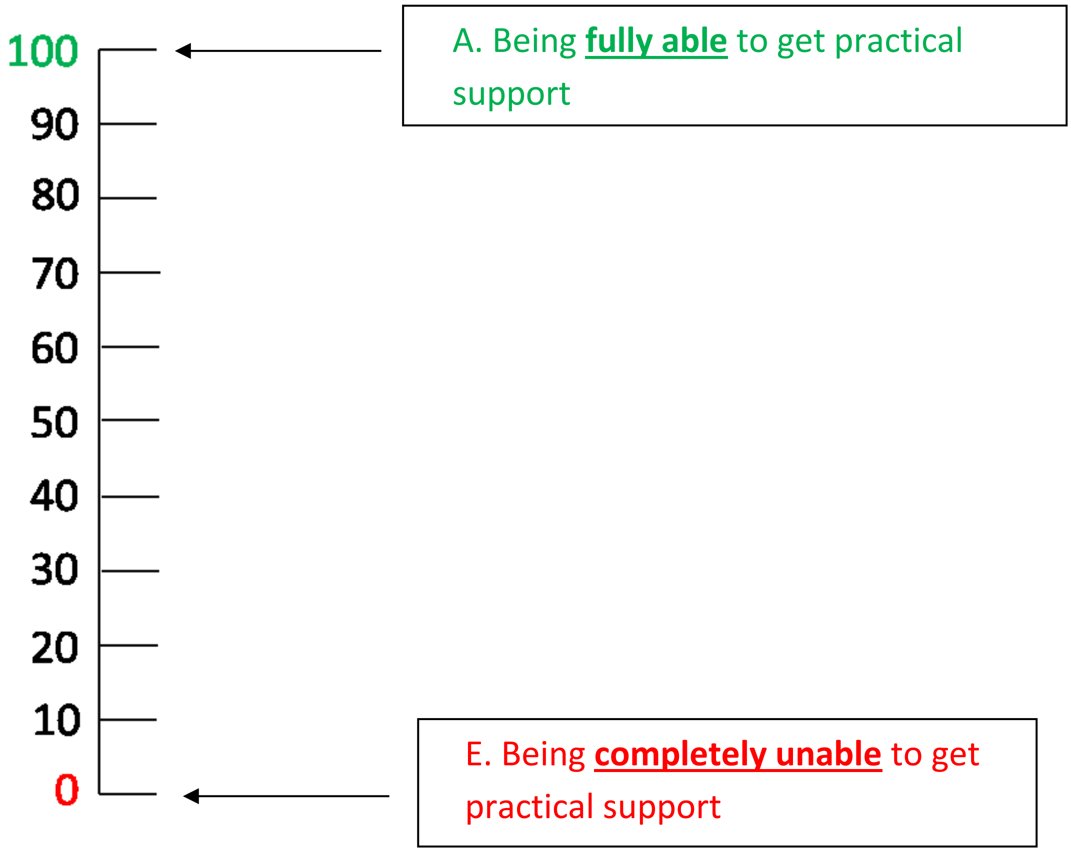
Change answer ☐

please note your changes: B = ……; C = ……; D = ……

Task 1B: Practical support

This question is about your view of the importance of the practical support that the family and friends of people who are dying are able to get. This includes things like:

- being able to get practical support and help with the care of the person, such as nursing help, help from social services or help from family.
- being able to get practical support from employers such as time off when needed,
- being able to get practical support with bereavement processes and dealing with the dying person's affairs.



A. Being **fully able** to get practical support

E. Being **completely unable** to get practical support

The missing levels are:
B. Being **mostly able** to get practical support
C. Being **somewhat able** to get practical support
D. Being **mostly unable** to get practical support

Please show with crosses where you want to put 'B', 'C' and 'D' on the scale.

After the group discussion, would you:

Keep original answer ☐

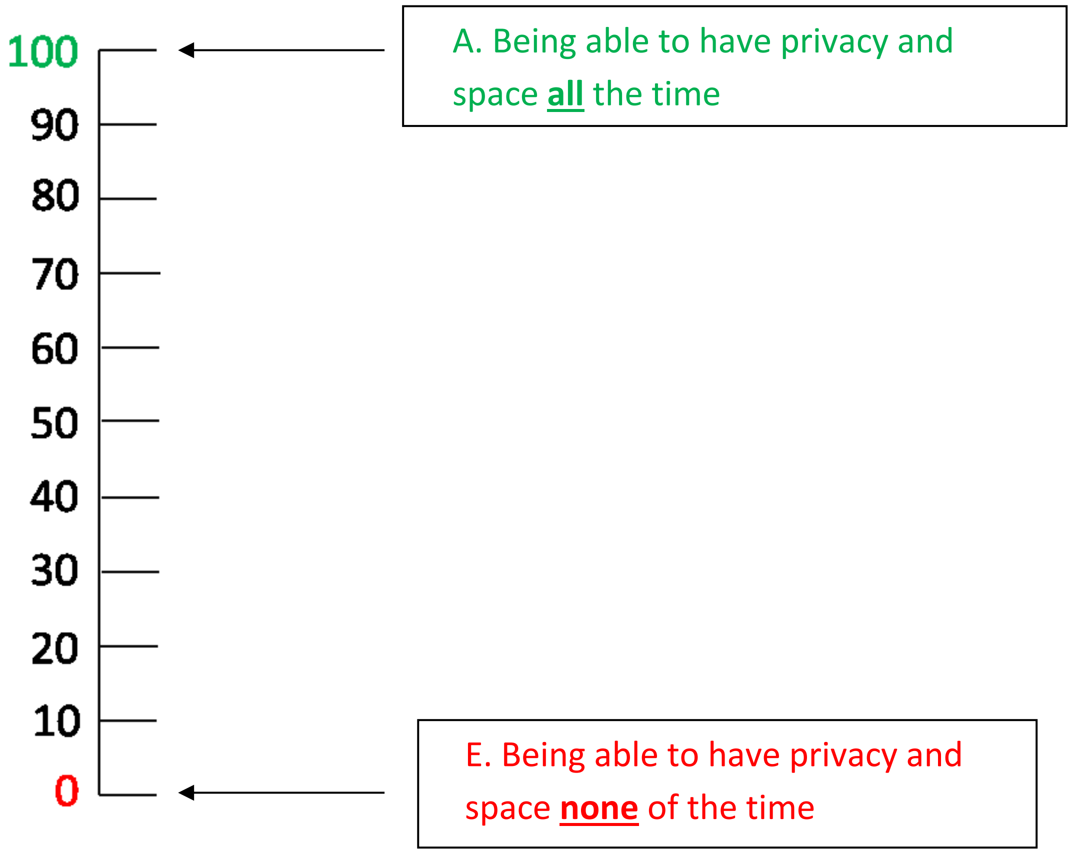
Change answer ☐

please note your changes: B = ...; C = ...; D = ...

Task 1C: Privacy and space

This question is about your view of the importance for family and friends of being able to have privacy and space to be with the person who is dying. It includes things like:

- being able to have time together in private,
- being able to be in a peaceful location with pleasant facilities.



A. Being able to have privacy and space **all** the time

E. Being able to have privacy and space **none** of the time

The missing levels are:
B. Being able to have privacy and space **most** of the time
C. Being able to have privacy and space **some** of the time
D. Being able to have privacy and space a **little** of the time

Please show with crosses where you want to put 'B', 'C' and 'D' on the scale.

After the group discussion, would you:

Keep original answer ☐

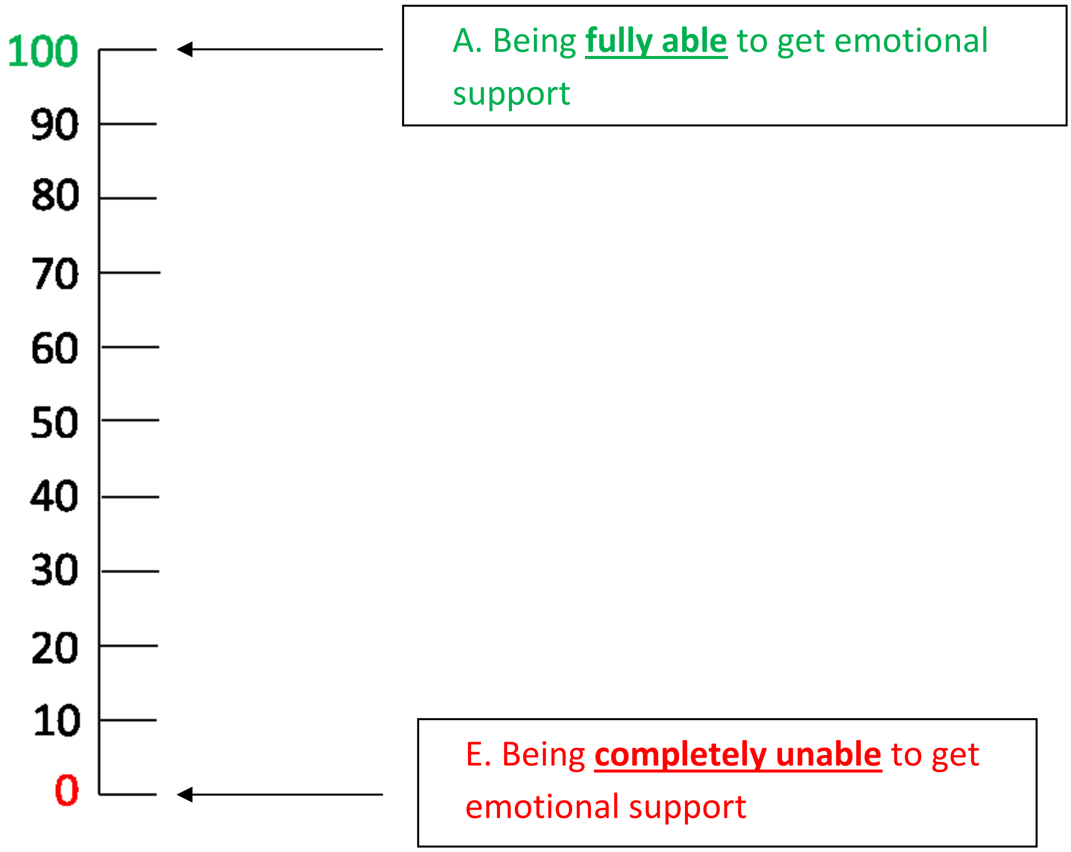
Change answer ☐

please note your changes: B = ...; C = ...; D = ...

Task 1D: Emotional support

This question is about your view of the importance of the emotional support that the family and friends of people who are dying are able to get. This includes things like:

- being able to get emotional support through family, friends or colleagues,
- being able to get emotional support through other services including charities and religion if applicable.



A. Being **fully able** to get emotional support

E. Being **completely unable** to get emotional support

The missing levels are:
B. Being **mostly able** to get emotional support
C. Being **somewhat able** to get emotional support
D. Being **mostly unable** to get emotional support

Please show with crosses where you want to put ‘B’, ‘C’ and ‘D’ on the scale.

After the group discussion, would you:

Keep original answer ☐

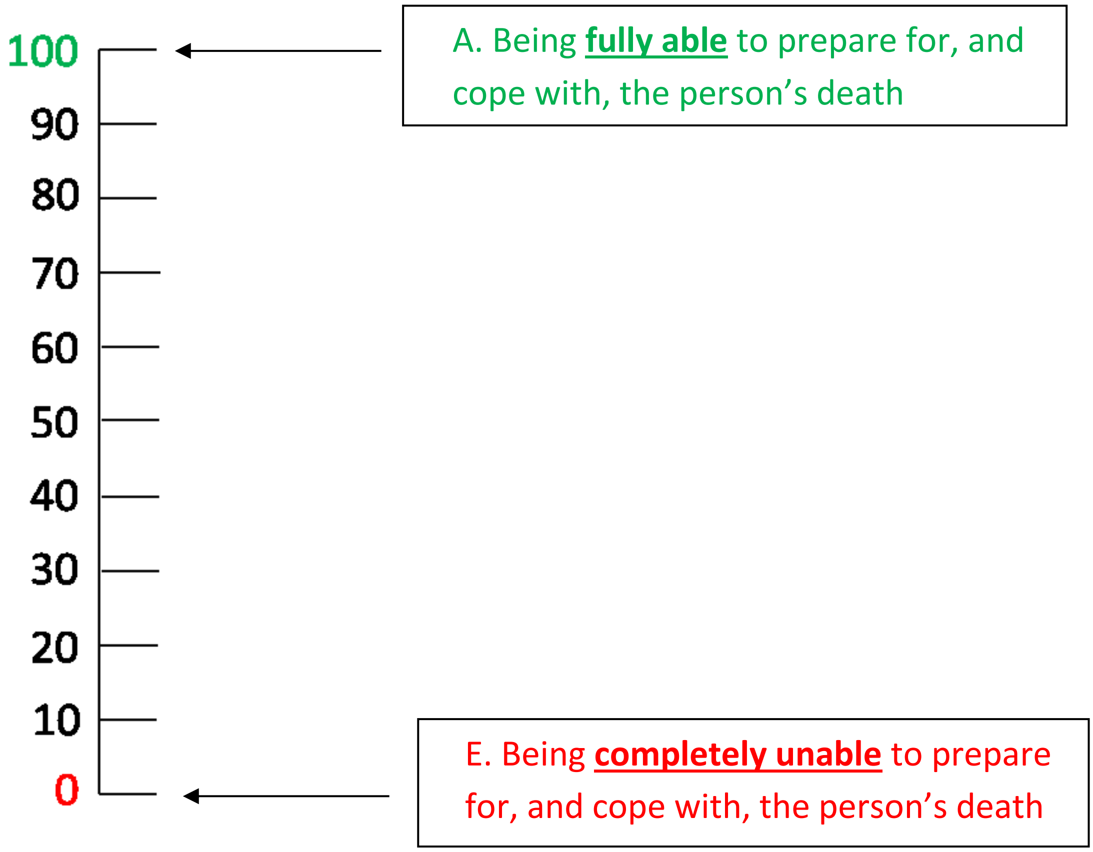
Change answer ☐

please note your changes: B = ……; C = ……; D = ……

Task 1E: Being prepared and coping

This question is about your view of the importance for family and friends of <u>being able to prepare for, and cope with, the death of the loved one</u>. This includes things like:

- being prepared for the person's death,
- having your dying person's post-bereavement affairs and funeral arrangements in order,
- being free from guilt and regrets.



A. Being **<u>fully able</u>** to prepare for, and cope with, the person's death

E. Being **<u>completely unable</u>** to prepare for, and cope with, the person's death

The missing levels are:
B. Being **<u>mostly able</u>** to prepare for, and cope with, with the person's death
C. Being **<u>somewhat able</u>** to prepare for, and cope with, the person's death
D. Being **<u>mostly unable</u>** to prepare for, and cope with, the person's death

Please show with crosses where you want to put 'B', 'C' and 'D' on the scale.

After the group discussion, would you:

Keep original answer ☐

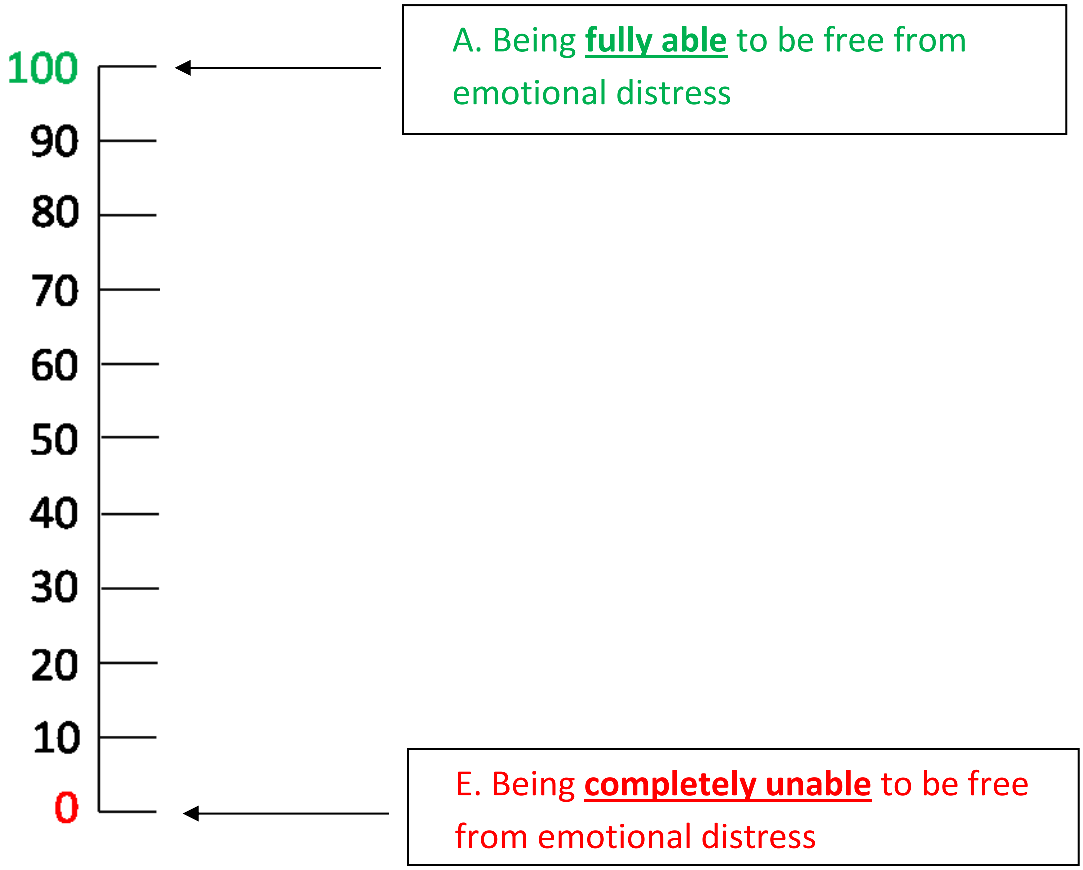
Change answer ☐

please note your changes: B = ...; C = ...; D = ...

Task 1F: Emotional Distress

This question is about your view of the importance for family and friends of being able to be free from emotional distress related to the condition of the dying person. This includes things like being free from emotional distress resulting from:

- seeing the dying person in pain and discomfort
- seeing the loss of dignity, or a lack of respect given to the dying person
- seeing a lack of care and attention given to the dying person.



A. Being **fully able** to be free from emotional distress

E. Being **completely unable** to be free from emotional distress

The missing levels are:
B. Being **mostly able** to be free from emotional distress
C. Being **somewhat able** to be free from emotional distress
D. Being **mostly unable** to be free from emotional distress

Please show with crosses where you want to put 'B', 'C' and 'D' on the scale.

After the group discussion, would you:

Keep original answer ☐

Change answer ☐

please note your changes: B = ...; C = ...; D = ...

TASK 2

How important are different aspects of end of life care to the family and friends of a person who is dying?

In the last task we thought about each aspect of care separately. Now, we want to think about all of them together. If we think about all six of these different aspects, we might not think that they are all equally important to family and friends. Some might be more important than others. That is what we want you to think about now.

We are interested in finding out how important you think each aspect is for family and friends over the whole period of a person dying.

Imagine you have 100 tokens.

We would like you to split these tokens up between the different aspects. We would like you to do this according to how important **you** think each aspect is. You can split them up however you like. For example:

- You may want to split your tokens equally across all six aspects.
- You may want to give them all to one aspect.
- You may want to split them across five aspects and leave one out.
- You may want to give more tokens to some aspects and less to others.

Any of these is OK – we are interested in **your** views and so the choice is up to you.

The key thing to remember is that how you split up the tokens should depend on how important you think the different aspects are. You need to use all 100 tokens.

Once you decide on how many tokens to give to each aspect, write this number on to the appropriate bit of the circle.

You have a pot of 100 tokens that you can move around to help you in making your choice if you want to.

Reminder: the different aspects of care for family and friends are:

1. Communication with those providing care services (e.g. doctors, nurses and carers). This includes things like:

- being able to get information about the person's health and care;
- being able to have a say in the care that the person receives;
- being able to ask questions, have them answered and have views respected;
- being able to have rapport with those providing care.

2. **Practical Support**. This includes things like:

- being able to get practical support and help with the care of the person, such as nursing help, help from social services or help from family;
- being able to get practical support from employers such as time off when needed;
- being able to get practical support with bereavement processes and dealing with the person's affairs.

3. Privacy and Space. This includes things like:

- being able to have time with the person in private;
- being able to be in a peaceful location with pleasant facilities.

4. Emotional Support. This includes things like:

- being able to get emotional support through family, friends or colleagues;
- being able to get emotional support through other services including charities and religion if applicable.

5. Preparing and Coping. This includes things like:

- being prepared for the person's death;
- having your person's post-bereavement affairs and funeral arrangements in order,
- being free from guilt and regrets.

6. **Emotional Distress**, related to the condition of the person. This includes things like being free from emotional distress resulting from:

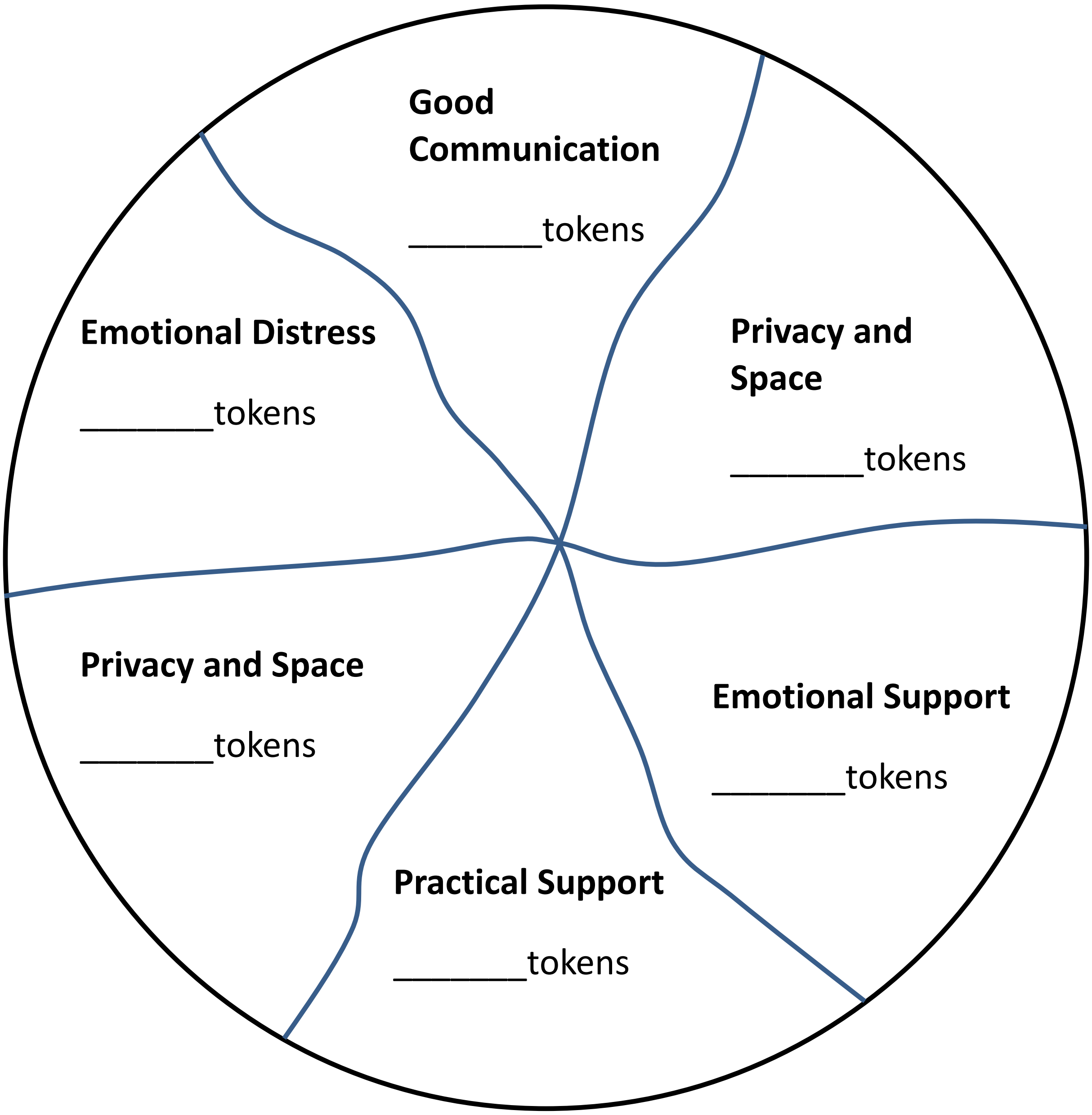
- seeing the person in pain and discomfort;
- seeing the loss of dignity, or a lack of respect given to the person;
- seeing a lack of care and attention given to the person.

Remember: here we are just interested in the family and friends who are close to a person who is dying. The benefits to the person who is dying will be looked at separately.

Task 2A: Deciding on the importance of aspects of end of life care for friends and family

Please now split up your 100 tokens between these different aspects of end of life care. We would like you to do this according to how important you think each aspect is.

Remember to use all of your 100 tokens.



Good Communication

________tokens

Emotional Distress

________tokens

Privacy and Space

________tokens

Privacy and Space

________tokens

Emotional Support

________tokens

Practical Support

________tokens

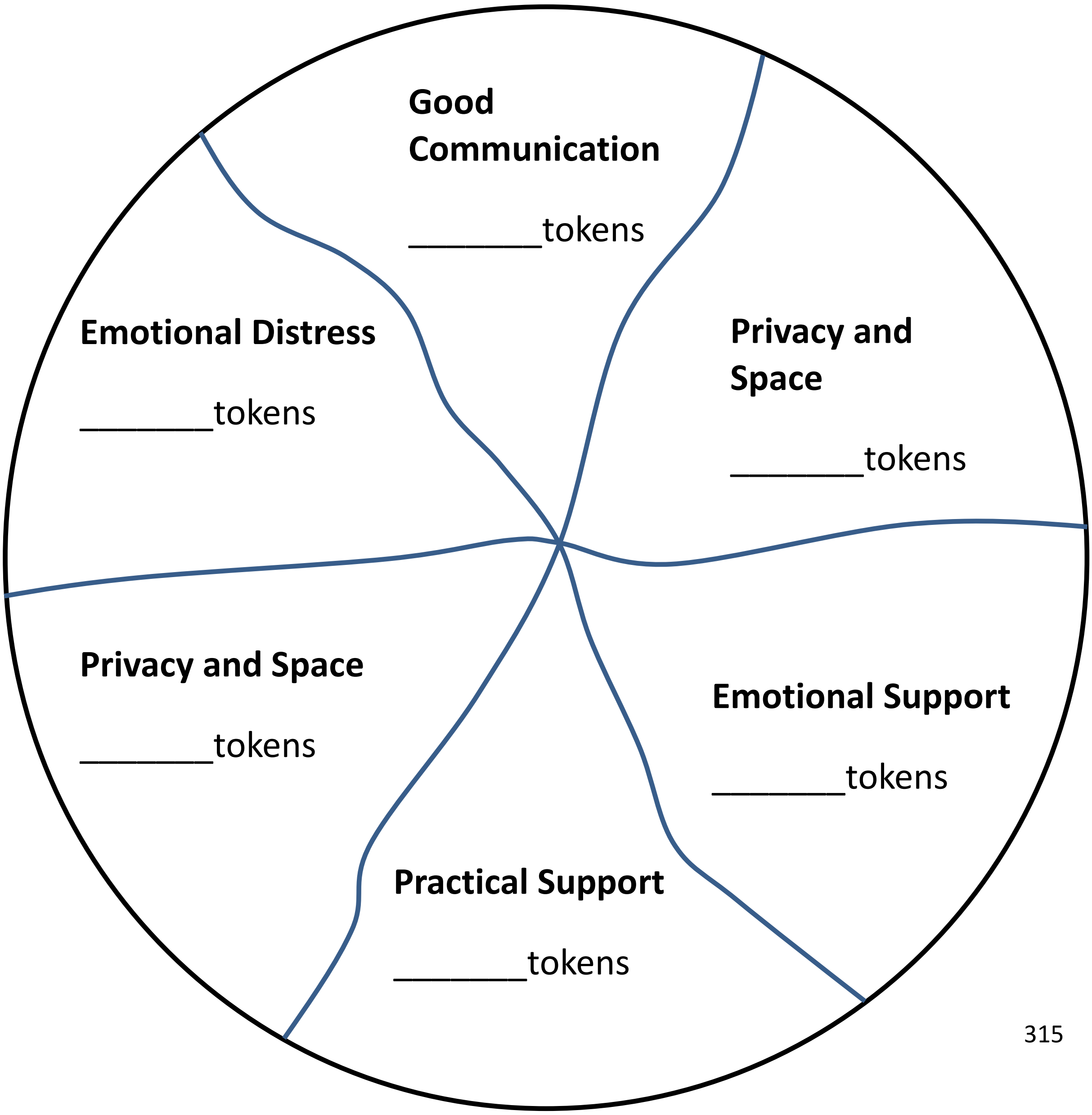
Task 2B: Deciding on the importance of aspects of end of life care for friends and family (after discussion)

Now we have discussed this as a group, do you want to change how you have split up your tokens?

Yes ☐ No ☐

If you answered 'Yes' please show on the circle below how you would now want to split up your tokens, remembering that this is according to how important you think each aspect is. The definitions are given again opposite for you to look at.

Remember to use all of your 100 tokens.



Reminder: the different aspects of care for family and friends are:

1. Communication with those providing care services (e.g. doctors, nurses and carers). This includes things like:

- being able to get information about the person's health and care;
- being able to have a say in the care that the person receives;
- being able to ask questions, have them answered and have views respected;
- being able to have rapport with those providing care.

2. Practical Support. This includes things like:

- being able to get practical support and help with the care of the person, such as nursing help, help from social services or help from family;
- being able to get practical support from employers such as time off when needed;
- being able to get practical support with bereavement processes and dealing with the person's affairs.

3. Privacy and Space. This includes things like:

- being able to have time with the person in private;
- being able to be in a peaceful location with pleasant facilities.

4. Emotional Support. This includes things like:

- being able to get emotional support through family, friends or colleagues;
- being able to get emotional support through other services including charities and religion if applicable.

5. Preparing and Coping. This includes things like:

- being prepared for the person's death;
- having your person's post-bereavement affairs and funeral arrangements in order,
- being free from guilt and regrets.

6. **Emotional Distress**, related to the condition of the person. This includes things like being free from emotional distress resulting from:

- seeing the person in pain and discomfort;
- seeing the loss of dignity, or a lack of respect given to the person;
- seeing a lack of care and attention given to the person.

Remember: here we are just interested in the family and friends who are close to a person who is dying. The benefits to the person who is dying will be looked at separately.

TASK 3

How important is it for policy makers to take account of impacts to the family and friends of a person who is dying?

Now we want to think about how important it is for those who are providing end of life care to think about family and friends as well as about the person who is dying.

We could think about this in terms of simple things such as:

- having nice areas available for relatives
- the doctor or nurse having time to spend explaining things to relatives

We could also think about more complex things such as:

- respite care, which is where the person at the end of life is looked after by others, for example in a hospice, to give family carers a break.
- bereavement services to help the close-person come to terms with the death of their loved one.
- impacts for family and friends may also come from services for the patient.

We would like you to think first about whether you think that policy makers should take account of the impacts to family and friends.

Then, if you think it is important to take account of these benefits, how much importance do you think they should have.

Here we would like you to do a similar thing to the last task. This time, however, we are just asking you to split your 100 tokens between care for persons who are at the end of life and care for family and friends.

Task 3A: Taking account of impacts to family and friends

Do you think it is important it is for policy makers to take account of the impacts to family and friends?

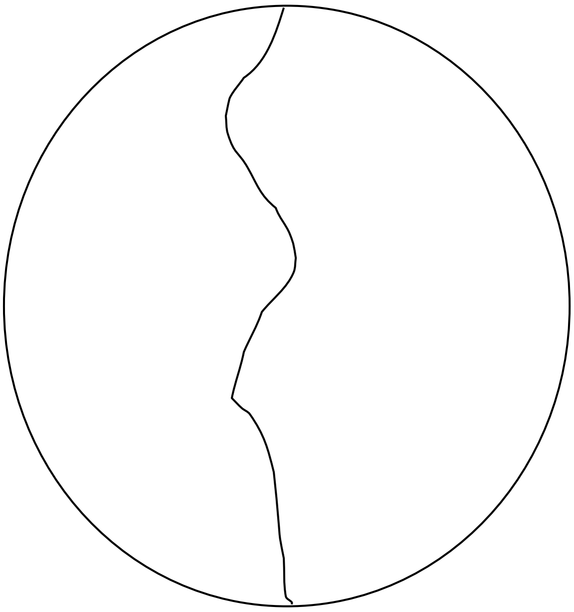
Yes ☐ No ☐

If you answered 'Yes': please think about how important it is for policy makers to take account of the impacts to family and friends, and say how much importance you would want to give to family and friends.

Please split your 100 tokens between people at the end of life and family and friends of these people.

If you answered 'No': please write 0 into the box for 'family and friends' and 100 into the box for 'people at the end of life'.

I would give
__________ tokens
to family and friends



I would give
__________ tokens to
people at the end of

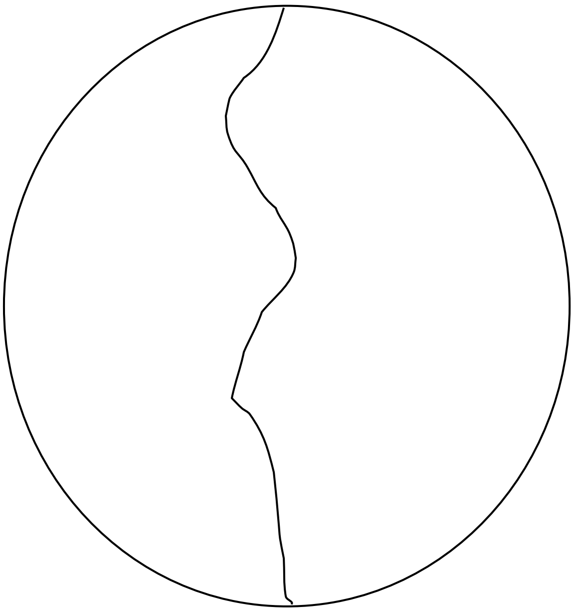
Task 3B: Taking account of impacts to family and friends (after discussion)

Now we have discussed this as a group, do you want to change how you have split up your tokens?

Yes ☐ No ☐

If you answered 'Yes': please split your 100 tokens between people at the end of life and family and friends of these people. .

I would give
___________ tokens
to family and friends



I would give
___________ tokens to
people at the end of

TASK 4

What principles should policy makers use when deciding how to use resources for end of life care?

Now we want to think more about how policy makers should make decisions about end of life care given the limited budgets available.

As we talk, you may want to use this space to write down any additional comments.

Can you help us further with our research?

We would like to thank you for taking part in this research. Your contribution to this group meeting has been very important.

We would like to talk again with some people who have taken part in the group meeting. This is so that we can find out how you felt about taking part and if you felt you were able to speak freely and to give your own opinions. We would also like to know whether you think this type of meeting will be useful for people making decisions about end of life care. **Again, if you take part, all the information collected will be confidential.**

We would be very grateful if you would speak with us again. If you agree to help us it will take less than an hour of your time and we will arrange to meet with you when and wherever it is most convenient.

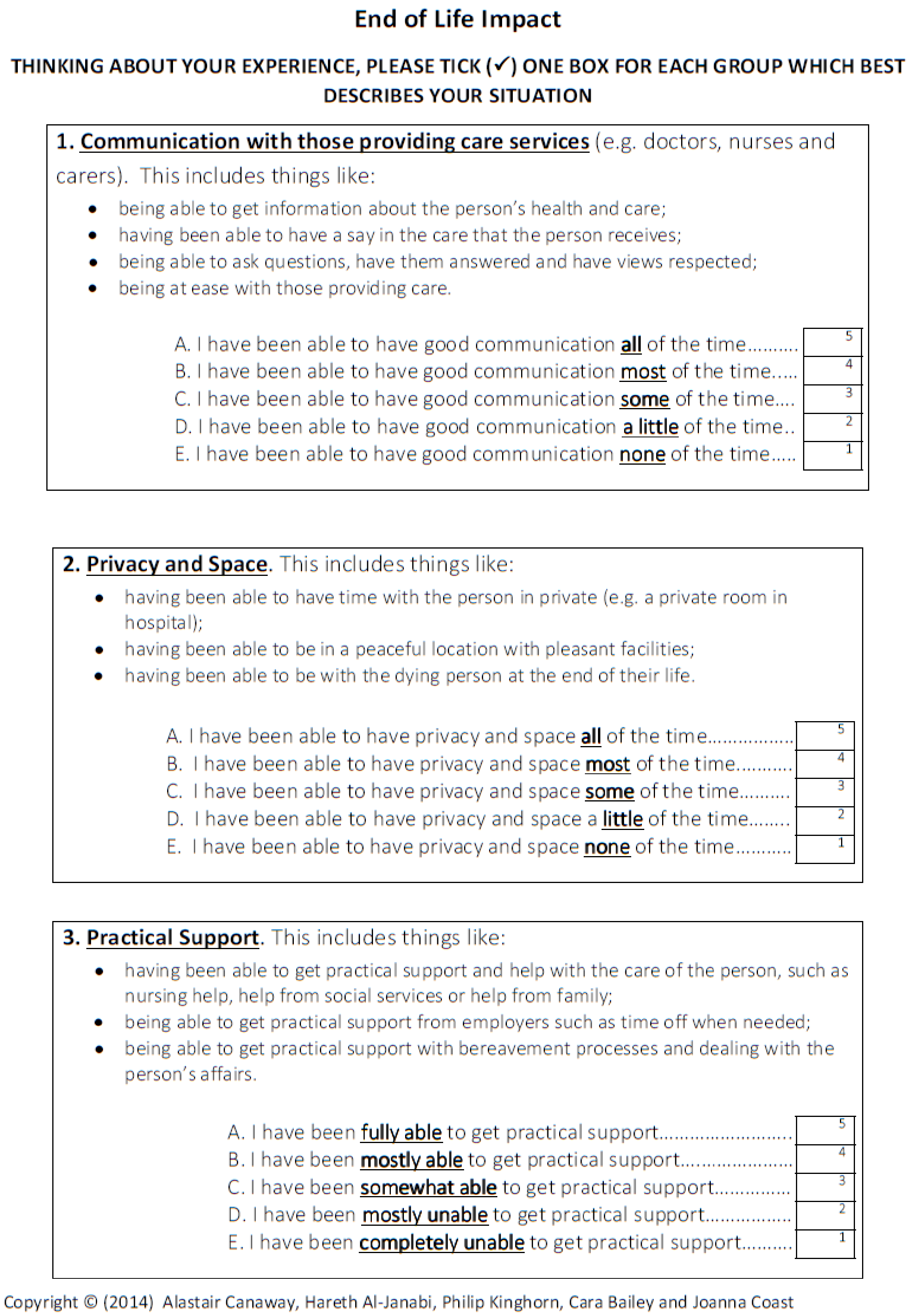
If you are willing to help us by talking to us again, please tell us when it would be most convenient to contact you.

The best time to contact me is: ....
....

Thank you again for your help. We are very grateful

If there is anything else you would like to comment on, please use the space below.

Appendix nine – the close-person measure



End of Life Impact

THINKING ABOUT YOUR EXPERIENCE, PLEASE TICK (✓) ONE BOX FOR EACH GROUP WHICH BEST DESCRIBES YOUR SITUATION

1. <u>Communication with those providing care services</u> (e.g. doctors, nurses and carers). This includes things like:

- being able to get information about the person's health and care;
- having been able to have a say in the care that the person receives;
- being able to ask questions, have them answered and have views respected;
- being at ease with those providing care.

A. I have been able to have good communication **all** of the time.......... ☐ 5
B. I have been able to have good communication **most** of the time..... ☐ 4
C. I have been able to have good communication **some** of the time.... ☐ 3
D. I have been able to have good communication **a little** of the time.. ☐ 2
E. I have been able to have good communication **none** of the time..... ☐ 1

2. <u>Privacy and Space</u>. This includes things like:

- having been able to have time with the person in private (e.g. a private room in hospital);
- having been able to be in a peaceful location with pleasant facilities;
- having been able to be with the dying person at the end of their life.

A. I have been able to have privacy and space **all** of the time................ ☐ 5
B. I have been able to have privacy and space **most** of the time........... ☐ 4
C. I have been able to have privacy and space **some** of the time.......... ☐ 3
D. I have been able to have privacy and space a **little** of the time........ ☐ 2
E. I have been able to have privacy and space **none** of the time........... ☐ 1

3. <u>Practical Support</u>. This includes things like:

- having been able to get practical support and help with the care of the person, such as nursing help, help from social services or help from family;
- being able to get practical support from employers such as time off when needed;
- being able to get practical support with bereavement processes and dealing with the person's affairs.

A. I have been **fully able** to get practical support.......................... ☐ 5
B. I have been **mostly able** to get practical support...................... ☐ 4
C. I have been **somewhat able** to get practical support.............. ☐ 3
D. I have been **mostly unable** to get practical support................. ☐ 2
E. I have been **completely unable** to get practical support.......... ☐ 1

4. Emotional Support. This includes things like:

- being able to get emotional support through family, friends or colleagues;
- being able to get emotional support through other services including charities and religion if applicable.

A. I have been **fully able** to get emotional support………………………	5
B. I have been **mostly able** to get emotional support…………………	4
C. I have been **somewhat able** to get emotional support…………	3
D. I have been **mostly unable** to get emotional support…………	2
E. I have been **completely unable** to get emotional support……	1

5. Preparing and Coping. This includes things like:

- being prepared for the person's death;
- having the person's post-bereavement affairs and funeral arrangements in order;
- being free from guilt and regrets.

A. I have been **fully able** to prepare for and cope with, the person's death………………	5
B. I have been **mostly able** to prepare for, and cope with, the person's death………	4
C. I have been **somewhat able** to prepare for, and cope with, the person's death…..	3
D. I have been **mostly unable** to prepare for, and cope with, the person's death……	2
E. I have been **completely unable** to prepare for, and cope with, the person's death	1

6. Emotional Distress to you, related to the condition of the person. This includes things like being free from emotional distress resulting from:

- seeing the person in pain and discomfort;
- seeing the loss of dignity, or a lack of respect given to the person;
- seeing a lack of care and attention given to the person.

A. I have been **fully able** to be free from emotional distress………………	5
B. I have been **mostly able** to be free from emotional distress……………	4
C. I have been **somewhat able** to be free from emotional distress…….	3
D. I have been **mostly unable** to be free from emotional distress………	2
E. I have been **completely unable** to be free from emotional distress…	1

Thank you for your help with this research

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