

## A deliberative approach to valuing capabilities

Kinghorn, Philip; Canaway, Alastair; Bailey, Cara; Al-Janabi, Hareth; Coast, Jo

DOI:

[10.1080/19452829.2021.2008885](https://doi.org/10.1080/19452829.2021.2008885)

License:

Creative Commons: Attribution-NonCommercial-NoDerivs (CC BY-NC-ND)

*Document Version*

Peer reviewed version

*Citation for published version (Harvard):*

Kinghorn, P, Canaway, A, Bailey, C, Al-Janabi, H & Coast, J 2021, 'A deliberative approach to valuing capabilities: assessing and valuing changes in the well-being of those close to patients receiving supportive end of life care', *Journal of Human Development and Capabilities*. <https://doi.org/10.1080/19452829.2021.2008885>

[Link to publication on Research at Birmingham portal](#)

### **Publisher Rights Statement:**

This is an Accepted Manuscript version of the following article, accepted for publication in *Journal of Human Development and Capabilities*. Philip Kinghorn, Alastair Canaway, Cara Bailey, Hareth Al-Janabi & Joanna Coast (2021) A Deliberative Approach to Valuing Capabilities: Assessing and Valuing Changes in the Well-Being of those Close to Patients Receiving Supportive End of Life Care, *Journal of Human Development and Capabilities*, DOI: 10.1080/19452829.2021.2008885. It is deposited under the terms of the Creative Commons Attribution-NonCommercial-NoDerivatives License (<http://creativecommons.org/licenses/by-nc-nd/4.0/>), which permits non-commercial re-use, distribution, and reproduction in any medium, provided the original work is properly cited, and is not altered, transformed, or built upon in any way.

### **General rights**

Unless a licence is specified above, all rights (including copyright and moral rights) in this document are retained by the authors and/or the copyright holders. The express permission of the copyright holder must be obtained for any use of this material other than for purposes permitted by law.

- Users may freely distribute the URL that is used to identify this publication.
- Users may download and/or print one copy of the publication from the University of Birmingham research portal for the purpose of private study or non-commercial research.
- User may use extracts from the document in line with the concept of 'fair dealing' under the Copyright, Designs and Patents Act 1988 (?)
- Users may not further distribute the material nor use it for the purposes of commercial gain.

Where a licence is displayed above, please note the terms and conditions of the licence govern your use of this document.

When citing, please reference the published version.

### **Take down policy**

While the University of Birmingham exercises care and attention in making items available there are rare occasions when an item has been uploaded in error or has been deemed to be commercially or otherwise sensitive.

If you believe that this is the case for this document, please contact [UBIRA@lists.bham.ac.uk](mailto:UBIRA@lists.bham.ac.uk) providing details and we will remove access to the work immediately and investigate.

**A Deliberative Approach to Valuing Capabilities: Assessing and Valuing changes in the Well-Being of those Close to Patients Receiving Supportive End of Life Care**

**Philip Kinghorn<sup>1</sup>, Alastair Canaway<sup>2\*</sup> Cara Bailey<sup>3</sup>, Hareth Al-Janabi<sup>1</sup> and Joanna Coast<sup>4</sup>**

<sup>1</sup> Health Economics Unit, Institute of Applied Health Research, University of Birmingham; <sup>2</sup> Warwick Clinical Trials Unit, Warwick Medical School, University of Warwick; <sup>3</sup> School of Nursing, Institute of Clinical Sciences, University of Birmingham; <sup>4</sup> Population Health Sciences, Bristol Medical School, University of Bristol.

\*Corresponding author

Philip Kinghorn ORCID ID: 0000-0002-9333-1962

Alastair Canaway ORCID ID: 0000-0002-4270-6808

Cara Bailey ORCID ID: 0000-0003-0865-9240

Hareth Al-Janabi ORCID ID: 0000-0002-3691-8310

Joanna Coast ORCID ID: 0000-0002-3537-5166

**Corresponding Author Contact Details:** [a.canaway@warwick.ac.uk](mailto:a.canaway@warwick.ac.uk)

**Funding Statement:** This work was supported by the European Research Council (Grant No. 261098 EconEndLife).

**Disclosure Statement:** All authors confirm that there are no relevant financial or non-financial competing interests to report.

**Data Availability Statement:** Anonymised quantitative data can be requested from [p.kinghorn@bham.ac.uk](mailto:p.kinghorn@bham.ac.uk)

## MAIN DOCUMENT

### **Abstract**

*Aim:* Explore the use deliberative valuation to elicit relative weights for a set of capabilities identified as being important and relevant to those close to patients receiving supportive care at the end of life.

*Methods:* Focus groups, involving the general UK population (n=38) and policy-makers (n=29) with experience of, and influence on, priorities for end of life care. Public participants completed two valuation tasks (budget pie and visual analogue scale (VAS)) individually, discussed their responses, and then recorded a final (individual) response. Policy-makers completed the VAS tasks in a separate series of focus groups. Quantitative and qualitative analysis of participants' responses are reported.

*Results:* Individual values were aggregated to form relative weights for the capabilities. Capabilities given greatest weighting were 'good communication between care providers and close persons' and 'practical support for close persons'. The quantitative impact of deliberation on weights overall was negligible, but qualitative findings indicated that disclosure of personal experiences did appear to prompt others to consider issues from new perspectives.

*Discussion:* Deliberative valuation was found to be a potentially feasible method for generating weights. However, further consideration needs to be given as to how to optimise recruitment whilst ensuring that participants actively engage with the task

**Keywords:** End of Life; Valuation; Deliberation; UK; ICECAP-CPM

## Introduction

Scarce healthcare resources necessitate difficult decisions regarding prioritisation. Economic evaluation can provide evidence to inform resource allocation decisions. Economic evaluation can be defined in broad terms as the systematic comparison of alternative courses of action in terms of their associated costs and outcomes (Drummond et al. 2005). The specific form of economic evaluation required in health and care contexts by decision-making organisations internationally, including the National Institute for Health and Care Excellence (NICE) in the UK, is cost-utility analysis (CUA) (NICE 2013). CUA rests on the premise that the objective of the healthcare system is to maximise health across the population (Coast 2009, Culyer 1989).

Increasing interest in the application of Sen's capability approach within health and care contexts has been noted previously (Kinghorn 2015). Two motivations for operationalising the capability approach in health and care contexts were identified from that previous debate (Kinghorn 2015, p600): "(i) as an alternative to utilitarian health maximization... and (ii) facilitating agreement on a core concept of health ... with which to drive policy reform."

With respect to the latter of these two motivations, Ruger seeks to specify an objective global standard for assessing health by setting out her Health Capability Paradigm, which focuses on the capability to avoid premature mortality and the capability to avoid premature morbidity (Ruger 2009b, p81). With respect to the former, the maximisation of health outcomes has since been argued to be particularly inappropriate within the context of supportive end of life care (Kinghorn and Coast 2019). Normand (2009) highlights the paradox of evidence, suggesting that people wish to give priority to palliative care interventions which would not be deemed cost-effective when evaluated using a QALY framework. The capability to experience a good death (Coast 2014) has been proposed as a more suitable conceptual approach.

One set of outcome measures noted as aligning to the first motivation (which can be thought of as expansionist because of the desire to broaden the evaluative space beyond health) are the ICECAP measures (Al-Janabi, Flynn, and Coast 2012, Grewal et al. 2006), which capture the impact of health conditions and public services on the self-reported well-being of those directly impacted. The ICECAP-Supportive Care Measure (ICECAP-SCM) is a measure of care-related well-being, developed for use in economic evaluations of supportive end of life care (Sutton and Coast 2014), which can be interpreted as assessing elements of the capability for a good death.

The negative impact of bereavement on close persons has been well evidenced (Stroebe, Schut, and Stroebe 2007), and was famously acknowledged by Dame Cicely Saunders (a pioneer of current models of hospice care): “How people die remains in the memory of those who live on” (Saunders 1989). In terms of national guidance, NICE lists sixteen ‘Quality Statements’ relating to adult end of life care in the UK, which includes the following explicit reference to families and carers (referred to in this paper as ‘close persons’) (NICE 2017):

*Families and carers of people approaching the end of life are offered comprehensive holistic assessments in response to their changing needs and preferences, and holistic support appropriate to their current needs and preferences.*

A measure has been developed (the ICECAP-CPM) to complement the use of ICECAP-SCM by capturing outcomes of importance to close persons (see (Canaway et al. 2016) for further details). The measure has six attributes:

- Communication with those providing care services
- Privacy and space (for example, the close person being able to spend time with the patient in a private, peaceful location)

- Practical support (for example, support to enable the close person to care for the patient)
- Emotional support
- Preparing and coping
- Emotional distress (to the close person, related to the condition of the decedent)

Each attribute has five levels, ranging from “fully able/[able to achieve the outcome] all of the time” to “completely unable/none of the time”. The ‘best’ level is coded as 5 (for the purposes of data entry), and the ‘worst’ level is coded as 1. 15,625 ( $5^6$ ) unique states are defined by the measure. The measure is available to view at [www.bham.ac.uk/icecap](http://www.bham.ac.uk/icecap).

It is important that the relative weighting of attributes within an economic measure reflect the underlying value judgements and priorities of society. Whilst any progress (in terms of enabling the capabilities on ICECAP-CPM) will be associated with positive benefit, in light of resource scarcity, innovation and/or investment enabling those capabilities most important to close persons should, *ceteris paribus*, be prioritised over those which enable less important capabilities. Some way of gauging and quantifying public priorities and values is therefore necessary, as this will be reflected in the relative weighting of attributes. A scoring system will combine information on the weighting of attributes and attribute levels, so as to be able to summarise any state of the world defined by the measure as a single numerical score, often ranging between a defined lower anchor and a defined upper anchor. Such a scoring system exists for ICECAP-SCM (Huynh et al. 2017), and was developed through the use of a Discrete Choice Experiment (DCE) and Best-Worst Scaling, administered through an online survey. This type of methodology readily facilitates a large sample size, from a representative sample of the population, and enables sophisticated analysis, in the case of ICECAP-SCM, for example, capturing interaction effects between the attributes.

The purpose of this study was to explore deliberative valuation methods as a means of eliciting relative weights for the states defined by ICECAP-CPM. Deliberation was deemed appropriate because of its conceptual alignment with the guidance of Amartya Sen, who advocates tackling some of the more practical steps in operationalising the capability approach (such as establishing the value of particular capabilities) via reasoned consensus, involving public discussion and democracy (Sen 1999). Public deliberation has been defined as “an approach designed to capture in-depth and informed public perspectives on complex topics” (Carman et al. 2015). Deliberation allows respondents time to reflect upon and discuss their values and to share the experiences which have influenced those values, as well as being exposed to the experiences of others. The deliberative process is intended to prompt respondents to articulate, reflect upon and possibly defend their values.

In contrast to traditional economic methods for the elicitation of individual preferences (which either prompt respondents to or assume that they will naturally adopt the perspective of individual welfare maximising consumers), deliberative methods often seek to elicit citizen perspectives or group verdicts (Jacobs 1997). For economists, deliberation facilitates the *formation* of numerical expressions of the relative importance of different options or attributes in contexts where respondents are unlikely to have clear pre-existing values (Jacobs 1997).

This work represents a significant methodological and normative shift away from the elicitation of individual values from a large online sample, towards the elicitation of considered, societal values from a smaller sample of participants actively engaged through a facilitated and interactive process of data collection.

Here we report the use of focus groups to facilitate the sharing of views and experiences relating to end of life care, to inform the reporting of numerical values by the public and professionals, indicating the relative importance of a set of pre-determined capabilities

(Canaway et al. 2016). Qualitative analysis was used to identify: participants' willingness to share experiences relating to a sensitive topic; acknowledgement of the views of others and any explicit acknowledgment of the influence of this on participants' own views; reaction to and reflections on the valuation tasks. We are able to compare and contrast numerical values and qualitative accounts from both members of the public and a separate sample of professionals with career experience relevant to end of life care.

## **Methods**

One series of focus groups was held with participants from the general population and a separate series of focus groups was held involving professionals/policy-makers with experience and influence relevant to supportive end of life care.

Ethical approval for the study was obtained from the Science, Technology, Engineering and Mathematics Ethical Review Committee at the University of Birmingham (ERN\_11-1296).

Public participants were recruited over Summer 2014 via the edited (open) electoral register, from purposefully selected electoral wards from across the West Midlands region (UK). Six electoral wards were chosen to achieve diversity with respect to: rural versus urban; high, mid and low deprivation; and provision of hospice services.

For public participants, names were selected at random from the electoral registers and those selected were sent an invitation letter and information leaflet by post, with a target of recruiting approximately six to 10 participants per focus group. Initially, 300 invitations were sent per electoral ward, but numbers were increased where response levels were low, meaning that, in total, 2,050 invitations were sent out across the six area. Those recipients who were interested in participating were asked to return an expression of interest form; they could also contact the research team by email or telephone if they had questions or concerns.



Individuals who had been bereaved within a six-month period were excluded for ethical reasons. The focus groups were held at accessible locations within the selected electoral wards. Participants were refunded for travel costs, but no incentive was offered for participation. Groups lasted for between 75 and 120 minutes. The Information Leaflet is presented as Appendix D.

Policy-makers and service managers (referred to in general terms as policy-makers from hereon in) were recruited to participate in one of four focus groups. Policy-maker focus groups either ‘piggybacked’ on planned meetings of existing local/regional networks (for example, Clinical Commissioning Groups and forums for healthcare leaders) or brought together individual national and regional policy-makers with experience and influence relating to end of life care identified and recruited directly by the research team.

Focus groups began with introductions from the research team and from participants. An open discussion was then invited and facilitated relating to end of life care generally. For both public and policy-makers, a budget pie task was used to explore the relative importance/value of the six attributes (see Appendix A). In addition, public participants completed visual analogue scales (VAS) to explore the relative value of the attribute levels. Policy-makers were not asked to complete the more time consuming VAS tasks as the focus groups were typically shorter in duration and policy-makers discussed some additional topics relevant to the wider research project, but falling outside of the scope of this paper.

The VAS tasks were completed first in the public focus groups. All respondents were presented with a VAS for each of the six attributes, printed within a workbook (see appendix A). The ‘best’ level (portraying the highest capability) was fixed at 100 on the VAS and represented the upper anchor; the ‘worst’ level (portraying the lowest level of capability) was fixed at zero, and represented the lower anchor. Respondents were asked where on the scale they felt that the remaining three attribute levels would fit, according to how good or bad they

perceived them as being, and relative to the two anchor points. Respondents completed the tasks individually and then shared their responses with the group as a stimulus for discussion. Following this discussion, respondents were asked to record a final response; there was no pressure for respondents to change their responses, but they had the ability to do so at this point.

For the budget pie method, respondents were presented with a circle, divided into six (approximately equal) segments (within the workbook). Each segment was labelled with one of the six attributes (Appendix A). Respondents were asked to divide 100 tokens between the six attributes (segments). Respondents were advised to allocate more tokens to attributes they considered to be of greater importance, to allocate all 100 tokens, and that, should they wish, it was acceptable to allocate zero tokens to one or more of the attributes. Budget pie was considered to be a relatively simple task, which could be completed with ‘paper and pen’, but which encompassed an element of scarcity and necessitated respondents to make trade-offs. Respondents completed the task individually but then shared their responses with the group as a prompt for comparison and discussion. Following this discussion, respondents were asked to record a final response.

All focus groups were digitally audio recorded; recordings were transcribed verbatim and pseudonymised. Qualitative analysis of the transcripts was conducted following a constant comparative approach (Strauss and Corbin 1990, Glaser and Strauss 1968) to provide a deeper understanding on how individuals weigh attributes, their openness to deliberation, and the impact of deliberation on their values. Following initial familiarisation with the transcripts, transcripts were divided into two batches: transcripts for focus groups where changes were recorded, following discussion, and focus groups where no changes were made. A coding framework was developed for transcripts within the same batch, before the development of analytical accounts. Finally, there was comparison of analytical accounts

between batches (Coast and Jackson 2017). Where quotations are used to illustrate qualitative themes, ‘G’ is used to identify members of the general public, and ‘P’ to identify policy-makers. Letters are also used after the initial prefix of ‘G’ or ‘P’ to indicate which focus group the participant contributed to (A to E for the public, and A to D for policy-makers). A number denotes the specific participant within that group, e.g. “GA1” for participant one, within public group A. The symbol “>” is used to indicate the continuation of a conversation or exchange (a quotation directly follows that above in conversation).

Descriptive statistics are presented for quantitative responses. VAS and budget pie responses were both rescaled from a zero to 100 scale onto a zero to one scale. A paired t-test was used to explore differences in attribute weightings between sample subgroups, defined by age and gender, and between the public and policy-maker samples.

Scores were calculated by multiplying weights for attribute levels by the relative weighting of the attribute. The scoring system (denoted in equation 1) is therefore additive: the overall score (V) is calculated by adding the weights reflecting the relative goodness of the level of capability (L), adjusted by the relative attribute weighting (A), across the six attributes. L is the value from the VAS task (it will be 1 for the best attribute level and 0 for the worst attribute level); A is the value from the budget pie task (it will also be a value between 0 and 1). Hence, a score of 1 reflects the highest possible level of capability (the best level on all six attributes, full capability) and 0 represents the worst possible state (the bottom level on all six attributes, no capability).

$$V = (L_{\text{Communication}} * A_{\text{Communication}}) + (L_{\text{Privacy}} * A_{\text{Privacy}}) + (L_{\text{Practical}} * A_{\text{Practical}}) + (L_{\text{Emotional}} * A_{\text{Emotional}}) + (L_{\text{Preparing}} * A_{\text{Preparing}}) + (L_{\text{Distress}} * A_{\text{Distress}})$$

[Equation 1]

The scoring system presented is based on public values only, because policy-makers did not complete the VAS task.

## **Results**

This section begins by providing details of those who participated in the research (public and policy-makers). Quantitative results from the public sample are presented, and then compared with quantitative results from policy-makers. We explore differences between participants' initial responses and their responses following discussion within the group, before presenting themes from the qualitative analysis (views relating to the attributes and justifications given for relative weightings, and the nature of the deliberative process).

### ***Recruitment and Participants:***

In response to 2,050 invitation letters, there were 72 initial expressions of interest (an initial response rate of 3.5%); initial response rates varied (by electoral ward) between 0.5% and 5.4%. Seven potential respondents were excluded at initial screening due to recent bereavement. Because of the extremely low response rate of 0.5% from one electoral ward, this focus group was cancelled. Across the remaining five electoral wards, 65 individuals were sent confirmation letters inviting them to attend; 38 did attend. Where response rates were high from a particular electoral ward, two focus groups were conducted.

One focus group was held in each of wards A (urban, mid-deprivation; n=3), B (urban, high deprivation; n=1) and C (urban, mid-deprivation; n=6). Two focus groups were held in wards D (n=6 for D1 and n=6 for D2) and E (n=9 for E1 and n=7 for E2). Wards D and E were rural, low deprivation areas. Because only one participant attended the ward B 'focus group', values from this participant are excluded from analysis.

Older people, those reporting their ethnicity as white British and females were over-represented in the sample (table 1). Approximately a third of participants had experienced bereavement between six months and two years prior to receiving the invitation letter.

[Insert table 1 here]

29 policy-makers participated across the four focus groups targeted at this sample group. Groups A (n=9) and B (n=7) involved existing teams; group C (n=3) an existing network. Groups A, B and C were local teams/networks of professionals with responsibility for the commissioning and provision of health and end of life care; Group D (n=10) brought together experts from across the UK in the field more generally, including those with expertise in terms of both local and national policy making.

### ***Quantitative results from the public workshops***

Table 2 reports the weighting of the attribute levels (values are rescaled from zero to one). Table 3 reports the relative weighting of the attributes, from the budget pie task (again, with values rescaled from zero to one). The attribute which received the greatest weight in the budget pie task was ‘good communication’ between close persons and those providing care services. The combined weighting for ‘communication’ and ‘practical support’ (0.549) is greater than the combined score for the remaining four attributes. ‘Emotional support’ (for the close person) received the lowest weighting.

[Insert tables 2 & 3 here]

When results are examined for subgroups, defined according to age (below 65 years (n=16) and above 65 years (n=22)), ‘communication’ remains as the attribute with the greatest weight (0.291 and 0.284 respectively). The biggest difference between the two sub-samples defined according to age, is observed for the ‘Emotional Distress’ attribute, given a weighting

of 0.179 by the younger sub-sample, but just 0.088 by the older sub-sample. The ‘Emotional Distress’ attribute was the only attribute for which there was a statistically significant difference (at the 5% level) in the weighting between the two age sub-samples. There were no statistically significant differences (at the 5% level) between the weighting of attributes between sub-samples defined according to either gender (male/female) or bereavement status (bereaved or not bereaved within the last two years).

[Insert Table 4 here]

A scoring system for the ICECAP-CPM is presented in table 4; as an example, the state 4,4,4,4,4,4 would have a score of:

$$0.2479 + 0.2245 + 0.0990 + 0.0788 + 0.0905 + 0.0965 = 0.8372$$

### ***Public Versus Policy-Maker Weighting:***

‘Privacy and space’ was the only attribute for which there was no statistically significant difference (at the 5% level) between the mean scores of the public and of policy-makers (table 4). Members of the public gave greater weight to ‘communication’ and ‘practical support’ than did policy-makers. There was greater variation/distinction in the weighting given across the attributes by the public (in terms of the difference between the attribute receiving the greatest weighting and the attribute receiving the lowest weighting) than by policy-makers, although the attributes at the two extremes are the same for both groups. Three of the policy-makers gave equal weight to all six attributes, but no members of the public gave equal weight in this way. Other policy-makers gave very similar weight across the six attributes.

Variation across participants was narrower in the case of responses from policy-makers, compared to the public, for every attribute. The range of values across public participants for the same attribute was equal to or exceeded 0.25 across all attributes (and was 0.4 or above for four of the six). The range across policymaker values for the same attribute was below 0.4 for all of the attributes, with a range of values across policy-maker participants of below 0.25 for three attributes.

***Impact of deliberation upon quantitative responses:***

For the attribute weighting task (budget pie), there were five public participants (13.5%) who made at least one change to their initial response following discussion (Appendix B). To change the weighting of one attribute and still have scores totalling 100, it was clearly necessary to also change the weighting of at least one other attribute. Three of the five participants who chose to change their response on the weighting task were in public group C. Two of the five participants made four changes each. Just over half of the 14 changes (n=8) brought the participant's weighting closer to the initial group mean value. In changing the weighting of one attribute so that it was closer to the initial mean/modal value for the group, some participants adjusted the weighting for another attribute such that it diverged further from the initial group mean/mode.

To give an indication of the limited scale of the impact of specific discussion of values on the final scoring system (as reported in table 5, using public values only), had participants' *initial* responses been used to calculate the scoring system (rather than the final responses), level 2 of the attribute 'emotional support' would have been 0.0745 rather than 0.0788; this was the largest difference at -0.0043.

Only one policy-maker changed their responses following discussion, reducing their weighting of privacy and space and allocating those ‘tokens’ instead to ‘practical support’.

### ***Discussion relating to the attributes***

There was generally more discussion relating to attributes that were given lower weights than there was for attributes given greater weight. Participants often gave little more justification for giving high weight to communication and practical support than to state that they were important, and the general consensus within the group meant that this view was unchallenged. Practical support was seen as important for protecting the physical and mental well-being of the close person, and for ensuring the safety of the patient.

*... if you don't have the support you need to help look after them then that's going to affect them quite adversely (GE68, aged 18-29)*

*... if you haven't got the practical help, how are you going to function? (GE7, Aged 30-44)*

Good communication was seen as important at a point in time that was referred to as being ‘scary’ for both the patient and close persons. Some participants discussed close persons taking on an advocacy role on behalf of the patient and helping the patient to absorb and process information at a challenging time for them. Good communication was also referred to as enabling close persons to have a sense of control and to act with more confidence in supporting the patient practically.

*you, as a carer, have to give trust to somebody else, but actually you want the communication as well, you want to know what's happening because that's the only bit of control that you might have (PA3)*

*If you don't know you can't act for yourself, let alone anyone else (GE4, Aged 65+)*



There was a common sense that if communication and practical support are done well then achievement on the remaining attributes will follow:

*I thought they all needed a score of some sort but I happened around good communications and practical support as the highest because lots of the others all depend on those two (GE61, Aged 65+)*

*I think that communication with family and friends relieves most of the other things ... so if healthcare professionals ... do that effectively and competently and honestly, then that reduces the distress that they're feeling (PD5).*

A variety of views were expressed in relation to emotional distress. One view was that emotional distress in response to the death of a loved one is a natural (even desirable) human response, a response which cannot be avoided. A contested view was that emotional distress would diminish over time; other participants countered this viewpoint based either upon their own personal experiences or those of their friends and family.

*I don't think you're going to avoid emotional distress (GD2, Aged 65+)*  
*for them, losing that person can't be resolved; it's just something you've got to deal with (PA1)*

*In my experience it doesn't go away (GA3, Aged 65+)*

There was a feeling by some participants that family members witnessing loss of dignity (which was referred to in the description of the emotional distress attribute) is totally unacceptable. The emotional distress attribute was seen as relating more directly to the care of the patient and hence those wishing to prioritise the patient tended to give it a relatively high weighting.

Many participants regarded emotional support as something that would be provided (exclusively) through family, social and religious networks, and questioned the need to fund

external support, although a minority of participants stressed the value of external/professional sources of support, such as counselling.

*I-mean it's important to get emotional support from family and friends but I don't see how that can be arranged from an outside agency? (GA3, Aged 65+)*

There was also a view that priority should be given to avoiding emotional distress, and that as a result, the need for emotional support would be alleviated. In response to the emotional support attribute, a minority of participants suggested that people should 'get over it' (GE2, Aged 65+); whereas one participant noted that their generation do not have the "stiff upper lip" mentality of older generations (GE7, Aged 30-44).

*For me it's, this is nice to have, at the risk of sounding a cold fish. (GE63, Aged 45-64)*

With respect to being prepared, some participants questioned whether you can ever be prepared for the death of a loved one, and some questioned whether it is possible to prepare for something that is uncertain.

*...nobody can [be prepared for the death of a loved one], it doesn't matter who you are; either that or you've got a block of stone inside (GC5, Aged 65+)*

Others considered the need for close persons to find some 'head space' to process and come to terms with events and hence begin to prepare, particularly if they were heavily burdened with practical care responsibilities. C1, a carer for a terminally ill son, expressed this view:

*say [if] you're a full time carer and you-know you were very busy and you couldn't prepare for it, so, to be given the opportunity to be able to prepare for it would be lovely, as in even being told what's going to happen (GC1, Aged 18-29).*

Whilst some participants highlighted the possible cost of providing privacy and space, as well as questioning the practical feasibility of doing so, one participant felt that if the close persons could be offered privacy and space then this would help to alleviate emotional distress.

Some policy-makers found it difficult to generalise across the diverse cases they had observed, in terms of identifying one capability that would be of significantly greater importance, and hence inclined towards giving equal (or near equal) weight amongst the capabilities.

*I'd look at one and think, 'Oh yes, that is really important; maybe more so than the others' and then you'd think about different families ... and you think, 'Well actually, no because that was more important to them' or 'that was more important to them' and it's, it's such a personal thing (PB2)*

### ***The nature of the deliberative contribution***

Public participants were observed to contribute in several ways. The first was through facilitating debate by demonstrating active listening, and/or by supporting and challenging the contributions of others. In the second, a small minority of participants revealed an 'agenda', in terms of either their *a priori* expectations and interpretations of the research topic and/or their particular enthusiasm for discussing a specific topic (potentially steering discussion back to this topic at separate time-points over the course of the discussion). The third type of contribution involved those who drew primarily upon their own personal or professional experience(s) in relation to the tasks and when engaging in the discussion. It would be false to claim that all (or even most) participants could be categorised as conforming exclusively to 'one type or another'; instead, they often contributed at different times in different ways.

(i) 'Active listening'

Active listening is defined here as explicitly acknowledging the views of others, often acknowledging differences of opinion, and in some cases either confirming agreement with or challenging the views of others. This “supporting and challenging” extended to the nature of the task and instruction and background information given by the research team.

*Can I touch on that, [be]cause that's quite relevant actually with what [C5] was saying... (GC2)*

Acknowledgement of other people's views did not necessarily indicate that a participant was prepared to change their own:

*I think I'll keep my original, but it's you-know it's very fluid isn't it? (GA3)*

*I think it's important but doubt whether it's attainable. I get your point... (GD4)*

'Challenge' was observed (and the term challenge is not used to imply hostility) to a limited degree in group D (in which individual policy-makers were brought together), but not in those groups involving existing teams. An example of challenge from within group D can be drawn from discussion of the emotional distress attribute (see below).

*I assessed it as the impact on the carer, these guys have assessed it as the patient... (PD9)*

*> No, I've assessed the fact that the patient is dying in pain or distress as having an impact on the carer (PD8)*

Across all policy-maker groups, participants acknowledged where there was similarity in the distribution of their weights.

(ii) Revealing an agenda

Three explicit examples of participants seemingly revealing an agenda were identified. GA1 drew upon his experience of having pancreatic cancer, and appeared to use his experience both as an illustration of (as a means of signalling) his own strength (both in challenging the initial prognosis and seeking alternative medical support, and in the way he has ‘stayed strong’ for his family) and in terms of promoting his view about the duty of family to provide care, a theme he returns to throughout the focus group. Participant E4 anticipated that the focus group would consider voluntary euthanasia and sought confirmation of this early in the opening discussion; GC2 also made reference to assisted suicide.

*... a person should be cared for preferably by the family. And the family should be encouraged to look after the person unless there's a professional reason not to do.*

*(GA1)*

*I'm a really strong man but my family isn't strong you-know, my children are not strong (GA1)*

*But I was going to ask the question whether this ties in with this new debate that's going on about you-know assisted suicide and stuff (GC2)*

No text from the policy-maker focus groups was coded as relating to this theme, although it should be acknowledged that discussion in these groups was typically briefer and that they were attending the focus group in a professional capacity.

### (iii) Drawing heavily on personal experiences

One participant (a younger adult) who brought a particularly unique perspective was the parent of a terminally ill child, another spoke about her experience relating to the sudden death of a sibling; a third (another younger adult) disclosed that her mother is terminally ill (GE6). Those sharing personal or professional experiences which introduced new and

distinct perspectives to the discussion (as in the cases illustrated above) appeared to influence the group by doing so.

*It's a good point. The point about the young man - we've all been thinking, I think, about older people dying or in the process of dying. We didn't think about the ones that have that sort of problem. (GD4)*

*...I was going on seventeen and my sister died at twelve, she had a car accident and she died a week later, the vent was taken off her and I wasn't told, my parents just came home distraught ... and I knew nothing about it, and even though -yes it's about forty five years ago- it still hurts (GC3)*

*Well I was just going to say about hospices, for instance my son is terminally ill and he's nine at the moment... (GC1)*

*> I think what [C1] said has set something off in me that I hadn't really considered, is that you assume the communication is coming one way and you're getting your questions answered, but like [C1] said for her son, she needs to communicate to them to enable them to care for her son because she knows him best (GC2)*

GC1 was the last participant to speak during the opening discussion in Group C. E6 said relatively little throughout focus group E. However, what both participants did say had an emotional impact. The fact that these participants disclosed emotionally impactful personal experiences without appearing to dominate or steer discussion distinguished them from those identified as revealing a personal agenda, where the agenda was typically acknowledged by

others in the group, but did not appear to influence discussion significantly. Participants in group C prompted GC1 at several points during the discussion, enquiring about her experiences. Participants in Group C made more changes to their initial responses than did participants in any other group. E8 only revealed during the final/closing discussion that her father had committed suicide when she was aged 26, perhaps after developing a level of trust with other group participants; tasks, by this point had been completed.

Some participants in the public focus groups drew upon professional experiences, using medical/specialist terminology and acronyms (albeit rarely); they also challenged comments from other participants which they regarded as inaccurate, for example, GC3 challenged GC4 when GC4 said that staff coming in and taking a pulse would be reassuring: “Why would they want to take your pulse?”.

Where groups/teams of policy-makers were interdisciplinary, some participants made reference to their specific specialism shaping their perspective, and policy-makers drew on their personal as well as their professional experiences. Participants in the policy groups also drew upon their professional experiences, to varying degrees.

## **Discussion**

This is the first paper to report values for the ICECAP-Close Person Measure (CPM). Values were elicited following deliberation amongst focus group participants; a methodology specifically selected because of the suggestion by Sen to tackle practical steps in operationalising the capability approach via public discussion and democracy (Sen 1999).

Enabling close persons to have good communication with those professionals caring for the dying patient and enabling close persons to access adequate practical support as they themselves provide care were attributes that were singled out by public participants as being

of particularly high value or importance; they also received the greatest weighting from policy-makers, although with less differentiation in the weights across the attributes from this latter group. The only generational difference of statistical significance within the public groups related to weighting of the emotional distress attribute. Conversely, the more explicit generational differences identified from the qualitative analysis related to the emotional support attribute, with some older participants suggesting either that this should exclusively be provided by family networks, or that those experiencing bereavement should 'get over it', but with younger participants seemingly having more awareness and acceptance of external sources of support, and rejecting a 'stiff-upper-lip' mentality. Because participants appeared to link emotional distress and emotional support, with similar attitudes being expressed by participants in response to both attributes, the generational differences more explicitly observed in discussion coded as relating to emotional support are likely to have applied equally to emotional distress.

Scores can be used within a cost-effectiveness analysis, whereby the results of an economic evaluation would be the cost per improvement in close person outcomes. There is also potential to combine outcomes for close persons with outcomes for patients, as per the suggestion of Coast et al. (2021).

Policy-makers came to the focus groups having already considered issues relating to end of life care and some focus groups 'piggybacked' on existing networks, where participants may already have had experience of working together to reach joint decisions. It could either be that policy-makers were more homogenous in terms of their views, or they could have been less inclined to disagree because of a reluctance to harm ongoing team dynamics and working relationships. This may explain why there was less variation in the values reported by policy-makers, why challenge was rarely identified in qualitative analysis of the policy-maker groups, and why only one policy-maker changed their values following discussion. Policy-



makers however, did –to some extent– draw upon personal as well as professional experiences and did not necessarily find the budget pie task any easier than did members of the public. Policy-makers were more inclined to give equal or similar weight across the attributes than were members of the public, possibly reflecting the difficulty of distilling the diversity of cases they have observed into a ‘one size fits all’ value.

Quantitatively, there was negligible difference in the values reported by the public following discussion, as compared to their initial values. There are relatively few cases of deliberation being used to elicit numerical values that we are aware of, but limited impact of deliberation on numerical values was also identified in previous research by Karimi *et al.*, who elicited time trade-off values before and after deliberation within focus groups (Karimi, Brazier, and Paisley 2019). There were significant differences between this research and that reported by Karimi *et al.*, in the sense that a relatively simple task was used here, with greater transparency within the focus groups with respect to the values, and in the sense that whereas changes were observed in the responses of 75% of participants in the study by Karimi *et al.* (which essentially ‘averaged out’ at an aggregate level, hence the overall impact being negligible), here only 13.5% of the public changed their responses on the budget pie task.

Hence, whilst it has been reported that participants are willing to publicly acquiesce or compromise to reach a group decision (Delli Carpini, Cook, and Jacobs 2004), few of them changed their private (numerical) values in this study, where there was no pressure to reach a group decision. As well as the lack of pressure to publicly acquiesce, the negligible quantitative impact of the specific discussion of differing values may reflect the fact that exposure to the views and experiences of others during the opening group discussion may already have begun to influence the views of participants before they were presented with the valuation tasks. It is even possible that the views and values of respondents were influenced through discussions with friends, family members and colleagues prior to attending the

group, given that the topic of the focus group was known to respondents in advance of attending. It should therefore be acknowledged that, whilst it is possible to quantify the difference between initial responses (respondents' first attempt at the task) and final responses (following discussion), this is an imperfect approximation of the impact of deliberation. Alternatively, it is possible that the minimal time available within the focus groups is inadequate for impactful deliberation.

Karimi *et al* partly attribute the lack of systematic change in aggregated values elicited during their focus groups to the fact that discussion in their focus groups did not result in new information being generated. Some participants in our study made significant personal disclosures, which did appear to resonate with other participants; it prompted them to consider the topics from alternative perspectives (most noticeably in Group C), and perhaps to some extent made the hypothetical tasks seem more real. These significant personal disclosures suggest a level of comfort and trust amongst participants.

Although participants shared their own values with the group, they were not presented with summary statistics, such as a mean (this aggregate level analysis was undertaken retrospectively), and this was a limitation in terms of participants having a clear metric with which to judge how their own values compared to those of others. One potential limitation of the simple way in which the tasks were presented was that attributes were presented in the same order for all participants and all groups, and that the budget pie task presented participants with approximately equal sized segments for each attribute. This may have introduced bias as either participants may have spent more time considering attributes presented first (perhaps even implying importance from their ordering on the task), or been more inclined to give equal weight across attributes when presented with equal segments in the budget pie. Indeed, both public and policy-maker participants gave most weight to communication and practical support attributes, which were considered first, although

qualitative analysis reveals considered reasons for this. The weighting assigned to different attributes in the budget pie task differed considerably for the public groups.

We do not recommend combining weights from the public with those from policy-makers as the latter sample only completed the budget pie task to weight the attributes, and because there were statistically significant differences between the means of the two samples.

Whilst it was possible to identify themes through the qualitative analysis, the themes only reflect views that participants chose to verbalise within the group and where there was similarity in the responses given by participants they often felt little need to justify their responses.

Recruitment proved to be challenging and the limited sample size and the over-representation of older and female participants, as well as those living in rural, low deprivation areas is a clear limitation of this research. Difficulty with recruitment may reflect the sensitive nature of the topic of end of life care, that recruitment followed a single route, involving only the mailing out of invitation letters, and that no financial incentive was offered to participants. A multi-pronged recruitment strategy involving online and media forums and/or an element of personal interaction could be explored in future. There is a trade-off between enabling sufficient time for meaningful discussion and requiring participants to give up significant amounts of their time. Generous financial or other incentives are likely to be necessary to achieve acceptable sample sizes that are representative of the wider population.

It was seen in this study that participants participated in a variety of ways. Achieving sample sizes that are sufficiently large will be important so as to include participants with diverse views and experiences but may also be important in terms of including diverse character traits. Some participants contributed to creating a 'safe space' by acknowledging the views

of others, as well as differences of opinion, by seeking clarity in relation to the tasks and in prompting others to contribute to the discussion.

Other ICECAP measures have been valued using Best-Worst Scaling or DCE. These methods are typically complex, trading off multiple attributes simultaneously. These are challenging methods to facilitate in terms of ‘paper and pen’ completion, and usually rely on individuals making choices that would impact upon their own welfare. The simpler VAS and budget pie tasks that we used here elicited individual values and separated the estimation of the weights given to the attributes from the weights given to the levels. There was, however, perhaps more scope for respondents’ responses to reflect societal considerations. Group discussion will have exposed respondents (to some extent) to the views and experiences of others, as well as potentially prompting them to consider attributes and the meaning of attributes more carefully than they would have if completing the tasks individually (for example, online). It is unclear whether there would be value in facilitating group discussion prior to respondents then completing a DCE or BWS task individually; given that it might be difficult for respondents to reflect societal considerations within individual pairwise choices, such face to face discussion may be an expensive way of prompting respondents to consider the topic of focus, as well as significantly restricting sample sizes. This type of deliberative valuation may also be most effective when valuation methods are used which do allow respondents to express a more societal viewpoint.

## **Conclusion**

A provisional scoring system has been developed for ICECAP-CPM, a measure designed to capture the ability of individuals to provide care for and to spend time with a dying loved one, in a safe and appropriate environment, with appropriate emotional and practical support

and without being subjected to experiences which they find distressing. Mean weights from both members of the public and policy-makers indicate that two of the six attributes, relating to communication and practical support are of particular importance. A range of personal and professional experiences were shared within the focus groups, and may have influenced participants' responses, although there is limited scope to capture this, with quantitative differences between pre and post-discussion responses on the valuation tasks being negligible.

For future work, researchers will need to consider the methods used for definitive value elicitation (and the extent to which these reflect societal considerations or individual welfare maximising decisions), the value of deliberation in relation to the chosen elicitation methodology and the impact on sample sizes of using deliberative valuation.

### ***Acknowledgements:***

We would like to thank all those who generously gave their time to participate in the focus groups. Pauline Mutimer provided valuable administrative support to the project.

## References:

- Al-Janabi, H., T Flynn, and J. Coast. 2012. "Development of a self-report measure of capability wellbeing for adults: the ICECAP-A." *QUALITY OF LIFE RESEARCH* 21 (1):167-76.
- Canaway, A.G., H. Al-Janabi, P. Kinghorn, C Bailey, and J. Coast. 2016. "Development of a measure (ICECAP-Close Person Measure) through qualitative methods to capture the benefits of end-of-life care to those close to the dying for use in economic evaluation." *Palliative Medicine* doi: 10.1177/0269216316650616.
- Carman, K, C Mallery, M Maurer, G Wang, S Garfinkel, M Yang, D Gilmore, and A Windham. 2015. "Effectiveness of public deliberation methods for gathering input on issues in health: Results from a randomized trial." *Soc Sci Med* 133:11-20.
- Coast, J. 2009. "Maximisation in extra-welfarism: A critique of the current position in health economics." *Social Science & Medicine* 69:786-792.
- Coast, J. 2014. "Strategies for the economic evaluation of end of life care: making a case for the capability approach." *Expert Review of Pharmacoeconomics & Outcomes Research* 4:473-482.
- Coast, J., C. Bailey, A. Canaway, and P. Kinghorn. 2021. "'It is not a scientific number it is just a feeling': Populating a multi-dimensional end-of-life decision framework using deliberative methods." *Health Economics* 30 (5):1033-1049.
- Coast, J., and L. Jackson. 2017. "Understanding Primary Data Analysis." In *Qualitative Methods for Health Economics*, edited by Coast J. London: Rowman & Littlefield International Ltd.
- Culyer, A. J. 1989. "The Normative Economics of Health Care Finance and Provision." *Oxford Review of Economic Policy* 5 (1):34-58.
- Delli Carpini, M, FL Cook, and LR Jacobs. 2004. "Public Deliberation, Discursive Participation, and Citizen Engagement: A review of the empirical literature." *Annual Review of Political Science* 7:315-44.
- Drummond, M, M Sculpher, G. W. Torrance, B O'Brien, and G Stoddart. 2005. *Methods for the Economic Evaluation of Health Care Programmes*. Third ed. New York: Oxford University Press.
- Glaser, B. G., and A. L. Strauss. 1968. *The discovery of grounded theory: Strategies for qualitative research*. London, UK: Weidenfeld and Nicolson.
- Grewal, I, J Lewis, T Flynn, J Brown, J Bond, and Joanna Coast. 2006. "Developing attributes for a generic quality of life measure for older people: Preferences or Capabilities?" *Social Science & Medicine* 62:1891-1901.
- Huynh, E., J. Coast, J. Rose, P. Kinghorn, and T. Flynn. 2017. "Values for the ICECAP-Supportive Care Measure (ICECAP-SCM) for use in economic evaluation at end of life." *Soc Sci Med* 189:114-128.
- Jacobs, M. 1997. "Environmental Valuation, Deliberative Democracy And Public Decision-Making Institutions." In *Valuing Nature: Economics, Ethics and Environment*, edited by J Foster. London: Routledge.
- Karimi, M., J. Brazier, and S. Paisley. 2019. "Effect of Reflection and Deliberation on Health State Values: A Mixed-Methods Study." *VALUE IN HEALTH* 22 (11):1311-1317.
- Kinghorn, P. 2015. "Exploring Different Interpretations of the Capability Approach in a Health Care Context: Where Next?" *Journal of Human Development and Capabilities* 16 (4):600-616.
- Kinghorn, P., and J. Coast. 2019. "Appropriate frameworks for economic evaluation of end of life care: A qualitative investigation with stakeholders." *Palliative Medicine* DOI: 10.1177/0269216319839635.
- NICE. 2013. "Guide to the Methods of Technology Appraisal 2013." *Process and Methods Guides* 04 April (<http://publications.nice.org.uk/pmg9>).
- NICE. 2017. "End of life care for adults." accessed 02 October. <https://www.nice.org.uk/guidance/qs13>.

- Normand, CE. 2009. "Measuring outcomes in palliative care: limitations of QALYs and the road to PaLYs." *Journal of Pain and Symptom Management* 38 (1):27-31.
- Saunders, C. 1989. "Pain and impending death." In *Textbook of Pain*, edited by P. Wall and R. Melzak. Churchill Livingstone.
- Sen, A. 1999. *Commodities and Capabilities*. New Delhi: Oxford University Press.
- Strauss, S., and J. Corbin. 1990. *Basics of qualitative research. Grounded theory procedures and techniques*. London: Sage.
- Stroebe, M., H. Schut, and W. Stroebe. 2007. "Health Outcomes of Bereavement." *Lancet* 370 (9603):1960-1973.
- Sutton, E., and J. Coast. 2014. "Development of a supportive care measure for economic evaluations of end-of-life care using qualitative methods." *Palliative Medicine* 28 (2):151-157.

**Table 1: Respondent Characteristics for Public Workshops**

<b>Characteristic</b>		<b>Number of Respondents (n=38)</b>
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



**Table 2: Weighting of the Levels across Attributes**

Attribute	Level 5 <sup>1</sup>	Level 4 <sup>2</sup>	Level 3 <sup>3</sup>	Level 2 <sup>4</sup>	Level 1 <sup>5</sup>
Communication	1	0.864 (0.821, 0.906)	0.508 (0.423, 0.584)	0.215 (0.143, 0.286)	0
Practical Support	1	0.857 (0.812, 0.900)	0.499 (0.438, 0.560)	0.133 (0.080, 0.186)	0
Privacy & Space)	1	0.820 (0.778, 0.869)	0.510 (0.449, 0.561)	0.190 (0.146, 0.244)	0
Emotional Support	1	0.817 (0.769, 0.865)	0.522 (0.460, 0.586)	0.128 (0.099, 0.156)	0
Preparing and Coping	1	0.838 (0.799, 0.876)	0.551 (0.490, 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

95% confidence interval presented within brackets. <sup>1</sup> Expressed on the measure either in terms of ability to experience the attribute “all of the time” or “fully able to” experience the attribute. <sup>2</sup> “all of the time” / “Fully able”. <sup>3</sup> “Some of the time” / “Somewhat able”. <sup>4</sup> “a little of the time” / “Mostly unable”. <sup>5</sup> “None of the time” / “completely unable”.

**Table 3: Attribute Weighting**

<b>Attribute</b>	<b>Public<sup>†</sup> Weighting (95% confidence interval)</b>	<b>Policy-Maker<sup>††</sup> Weighting (95% CI)</b>	<b>p-value (95% Sig. level)</b>
Communication	0.287 (0.243, 0.331)	0.225 (0.202, 0.249)	P=0.015 <sup>#</sup>
Practical Support	0.262 (0.217, 0.307)	0.188 (0.168, 0.208)	P=0.004 <sup>#</sup>
Privacy and Space	0.120 (0.098, 0.143)	0.133 (0.119, 0.147)	P=0.330 <sup>#</sup>
Emotional Support	0.096 (0.076, 0.117)	0.132 (0.117, 0.147)	P=0.007 <sup>#</sup>
Preparing and Coping	0.108 (0.088, 0.129)	0.144 (0.127, 0.162)	P=0.011
Emotional Distress	0.126 (0.094, 0.158)	0.178 (0.153, 0.202)	P=0.012 <sup>#</sup>

<sup>#</sup> Equal variances not assumed, <sup>†</sup> n=38, <sup>††</sup> n=29

**Table 4: ICECAP-CPM Scoring System**

<b>Attribute</b>	<b>Level 5<sup>†</sup></b>	<b>Level 4<sup>†</sup></b>	<b>Level 3<sup>†</sup></b>	<b>Level 2<sup>†</sup></b>	<b>Level 1<sup>†</sup></b>
Communication <sup>†</sup>	0.2871	0.2479	0.1458	0.0616	0.0000
Practical Support <sup>†</sup>	0.2621	0.2245	0.1309	0.0348	0.0000
Privacy & Space <sup>†</sup>	0.1202	0.0990	0.0607	0.0234	0.0000
Emotional Support <sup>†</sup>	0.0965	0.0788	0.0504	0.0123	0.0000
Preparing and Coping <sup>†</sup>	0.1081	0.0905	0.0595	0.0139	0.0000
Emotional Distress <sup>†</sup>	0.1260	0.0965	0.0604	0.0235	0.0000
Total	1	0.8372	0.5077	0.1695	0.0000

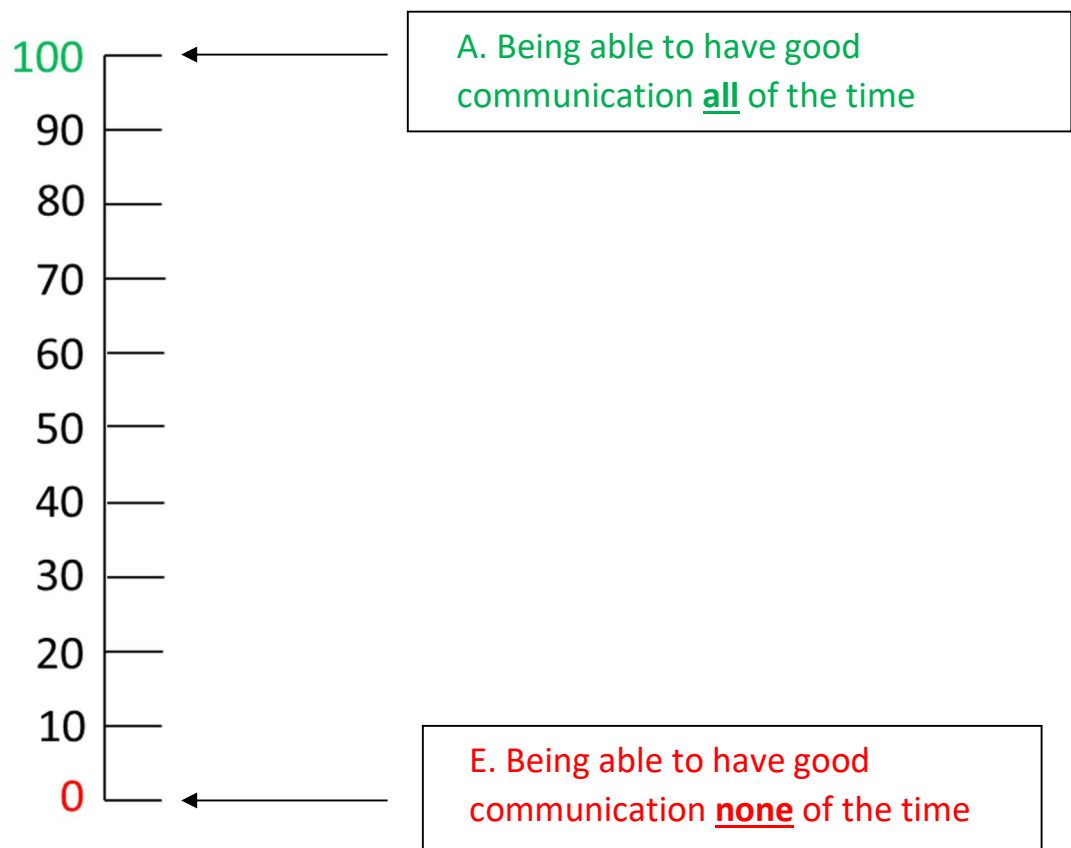
## APPENDICES

## Appendix A: Example of how the tasks were presented to participants:

### 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



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

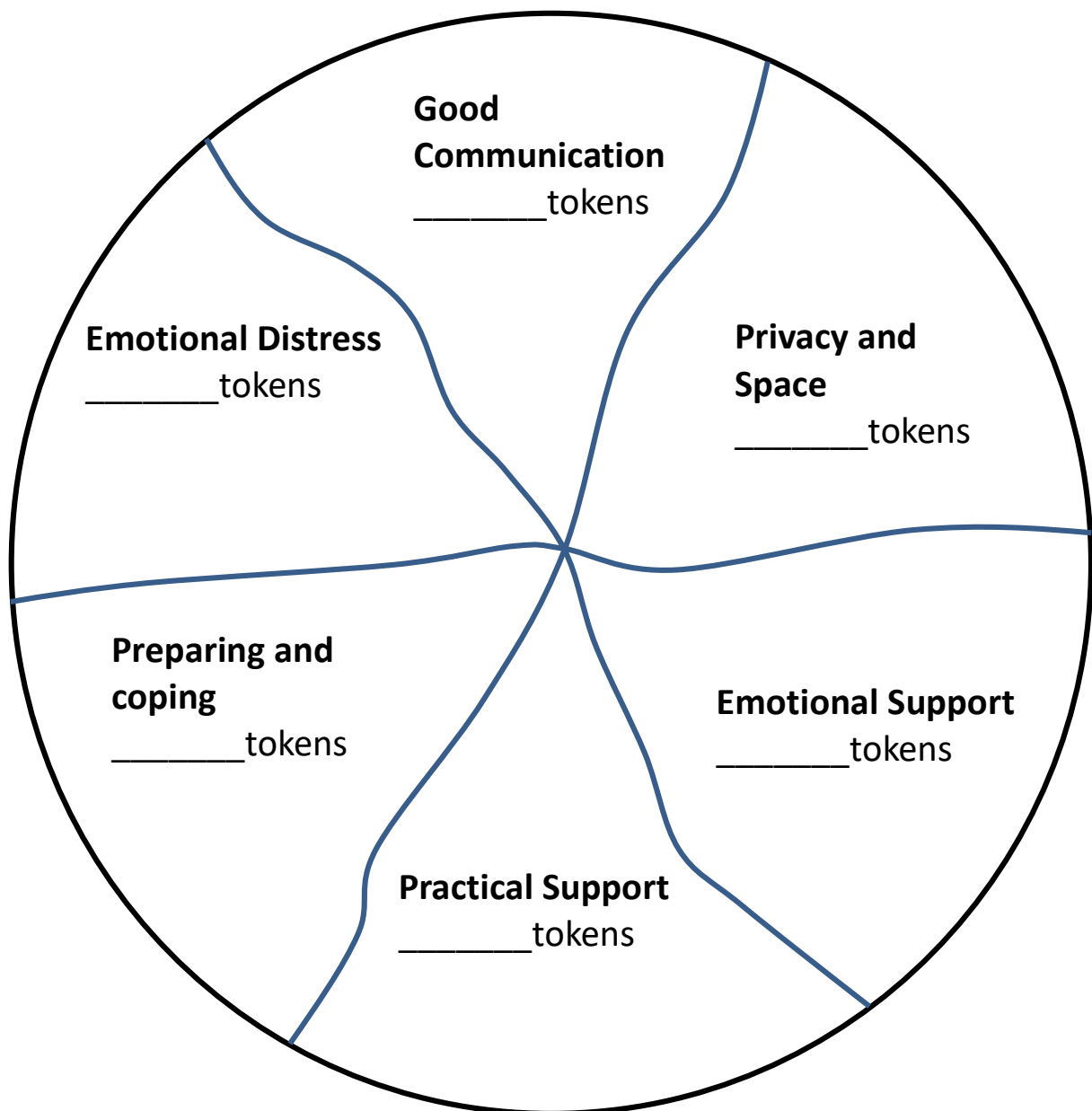
Change answer

please note your changes: B = .....; C = .....; D = .....

## Task 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.

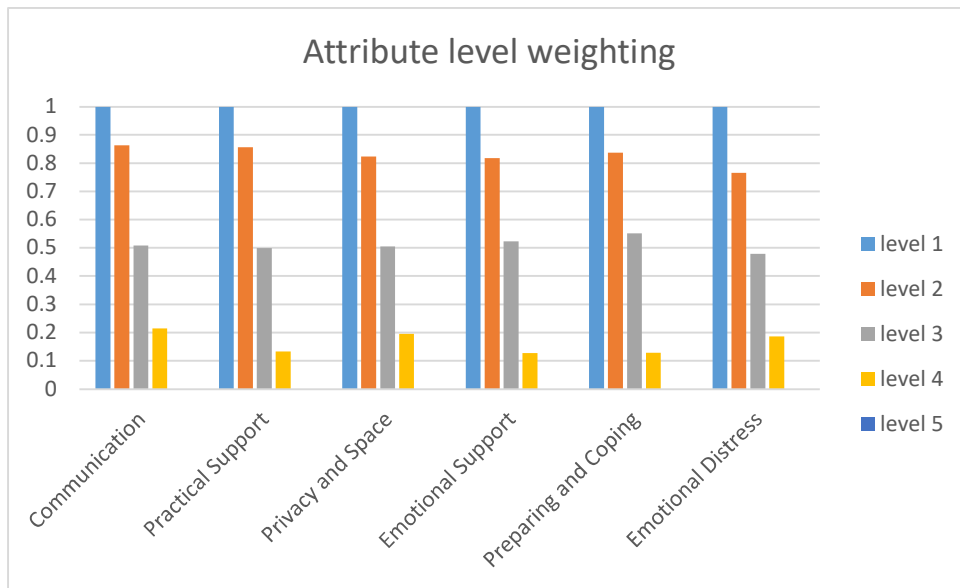
Remember to use all of your 100 tokens.



## Appendix B: Changes to the Weighting of Attributes

ID	Attribute	Original weighting relative to group average	Original weighting relative to group mode	Response/Change
C2	Privacy & Space	Below (-1.2)	Equal	Reduced weighting (-5)
C2	Emotional Support	Above (+3.8)	Above (+10)	Reduced weighting (-5)
C2	Preparing & Coping	Above (+5.7)	Above (+10)	Increased weighting (+5)
C2	Emotional Distress	Above (8.3)	Above (+20)	Increased weighting (+5)
C3	Emotional Support	Above (13.8)	Above (+20)	Reduced weighting (-10)
C3	Practical Support	Below (-21.7)	No mode	Increased weighting (+10)
C4	Emotional Distress	Below (-1.7)	Above (+10)	Increased weighting (+10)
C4	Practical Support	Above (+28.3)	No mode	Reduced weighting (-10)
E3	Communication	Below (-10)	Equal	Increased weighting (+5)
E3	Practical Support	Above (+38.3)	Above (+40)	Reduced weighting (-5)
2E8	Communication	Below (-6.9)	Equal	Increased weighting (+5)
2E8	Privacy & Space	Below (-5.4)	Below (-10)	Reduced weighting (-5)
2E8	Practical Support	Below (-1.9)	Equal	Increased weighting (+5)
2E8	Preparing & Coping	Above (+5.9)	Equal	Reduced weighting (-5)

### Appendix C: Attribute level weighting:





# Exploring Decision-Making relating to End of Life Care

## Participant information sheet

We would like to invite you to take part in our research study. Before you decide it is important to understand why the research is being done and what it would involve for you. We suggest that you take a couple of minutes to read through the information below and ask any questions about the research that you may have.

## Brief summary of research

The UK National Health Service has a set amount of money to spend on providing health services. Because of this it has to decide which services to provide and which services not to provide. End of life care is one of those services provided, in part, by the health service. This study is looking at whether current approaches to decision-making around end of life care are acceptable to the public and to policy-makers.

The research is being carried out by the [REDACTED] and is funded by the European Research Council. The study has been approved by the Science, Technology, Engineering and Mathematics Ethical Review Committee of the [REDACTED].

## Questions you may have

### **Why have I been invited to take part?**

In order to recruit a group of participants which reflects the diversity seen in the general population, we have randomly chosen names from the electoral register. Your name has been selected in this way. We are NOT seeking people who have any specific personal experiences or any special knowledge. We will introduce and explain topics before inviting discussion from the group.

### **Do I have to take part?**

No, you are under no obligation to take part. Participation is entirely voluntary; however, the success of this research is dependent on the goodwill and cooperation of those who are invited to take part. Participation in this



research does not mean you will be required or obliged to participate in any future research.

It is generally considered best practice not to include those who have been bereaved recently (within the last six months) in research focused on care at the end of life. In previous research those who were recently bereaved reported mixed experiences, mostly positive, but with a small number finding discussions upsetting.

### **What is the research about?**

We are asking you to take part in a focus group discussion covering three questions: (1) which priorities should decision-makers consider when choosing which types of care to fund? (2) What is the relative importance of different influences on the quality of life of the family and friends of a patient who is dying? (3) To what extent should resources be used to improve quality of life for those who will be/are bereaved, given that resources are limited? At the end of the focus group discussion we may ask you to take part in a follow-up interview to further explore these issues.

### **What will the information be used for?**

The results will be used to inform future research, and ultimately, they may inform policy decisions about how end of life care is evaluated and would therefore influence the funding decisions that are made.



### **What will happen if I take part?**

The group discussion would take about two hours (this will include a short break). During this time you will be asked to discuss your views about the economic evaluation of end of life care, covering the broad questions outlined above. There will be approximately 6-10 people in the group, all members of the public. Topics will be introduced and the group supported by researchers from the University of Birmingham. The group meeting will be tape-recorded.

### **Am I free to withdraw from the research?**

You are free to withdraw from the group discussion and the research, without the need to provide a reason. You can do this at any time up to two weeks after the group discussion by sending us an email [-----](mailto:-----), writing to us (at the address on the letter), telephoning [-----](tel:-----) or, at the meeting, speaking to one of us. If you withdraw from the research we will ask you if you want your contribution so far to be included. If you would like us to not

include your contribution we will destroy your written responses and we will not report anything you say when we write-up the research and when we publish the findings. There will be no consequences for you if you withdraw.

**Is the research confidential?**

Yes, the research is confidential and will follow ethical and legal best practice. Once the focus group (and any subsequent interview) has been recorded, a unique identity code will be allocated to the information you have provided. This allows us to keep your details and the recording separate. We will store the information you provide on a secured computer network. In any publications resulting from this research your name will not be used and all efforts will be made retain your anonymity.

**Where can I get more information?**

If you would like to ask any questions or would like more information about the study, please call [REDACTED].

**What is the complaints procedure?**

If you feel you need to complain or raise concerns about any aspect of this research please contact [REDACTED]

**What now?**

You are free to take your time to consider whether you would like to participate. If you are happy to participate please complete the attached form or contact [REDACTED]

## Appendix E: SRQR Checklist

### Standards for Reporting Qualitative Research (SRQR)

<http://www.equator-network.org/reporting-guidelines/srqr/>

Page/line no(s).

#### Title and abstract

<b>Title</b> - Concise description of the nature and topic of the study Identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended	Title
<b>Abstract</b> - Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions	Abstract

#### Introduction

<b>Problem formulation</b> - Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement	Page 5 para 3, Page 6 paras 1-3
<b>Purpose or research question</b> - Purpose of the study and specific objectives or questions	Page 5 para 2

#### Methods

<b>Qualitative approach and research paradigm</b> - Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., postpositivist, constructivist/ interpretivist) is also recommended; rationale	Page 5 paras 2-4. Page 8 paragraph 3.
<b>Researcher characteristics and reflexivity</b> - Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, and/or transferability	The research team varied but in all cases comprised academics (PhD) trained in qualitative methods.
<b>Context</b> - Setting/site and salient contextual factors; rationale**	Page 7 paragraph 1
<b>Sampling strategy</b> - How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale**	Page 6 paras 4 and 5, Page 7 paras 1 and 2
<b>Ethical issues pertaining to human subjects</b> - Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	Page 6 paragraph 3
<b>Data collection methods</b> - Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale	Page 6 paragraph 4 and 5, Page 7, paragraphs 1-4. Page 8 paragraph 1-3, page 9 paras 1-3.

<b>Data collection instruments and technologies</b> - Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study	Page 8 paragraph 3. Page 9 para 1
<b>Units of study</b> - Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	Page 10 paras 2-3, page 11 paras 1-3, Table 1.
<b>Data processing</b> - Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/de-identification of excerpts	Page 8 paragraph 3. Page 9 para 1.
<b>Data analysis</b> - Process by which inferences, themes, etc., were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale	Page 5 paras 2-4, Page 8 paragraph 3.
<b>Techniques to enhance trustworthiness</b> - Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale	Page 8 paragraph 3. Page 9 paragraph 1

### Results/findings

<b>Synthesis and interpretation</b> - Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	Throughout "Results" section beginning page 10
<b>Links to empirical data</b> - Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings	Throughout "Results" section beginning page 10

### Discussion

<b>Integration with prior work, implications, transferability, and contribution(s) to the field</b> - Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/generalizability; identification of unique contribution(s) to scholarship in a discipline or field	Page 22 - all, page 23 all, page 24 paras 1-2, page 25 paras 1-2. Page 26 para 2.
<b>Limitations</b> - Trustworthiness and limitations of findings	Page 24 para 3, page 25 para 1-3, page 26 para 1 and

### Other

<b>Conflicts of interest</b> - Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed	Title Page
<b>Funding</b> - Sources of funding and other support; role of funders in data collection, interpretation, and reporting	Title page

Reference: O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. **Standards for reporting qualitative research: a synthesis of recommendations.** *Academic Medicine*, Vol. 89, No. 9 / Sept 2014  
DOI: 10.1097/ACM.0000000000000388