

## 1. Title

### **Is 'end-of-life' care more valuable? Measuring societal views on health care resource allocation using the new Q2S method.**

## 2. Importance

Supplementary guidance issued by the National Institute for Health and Clinical Excellence (NICE) in 2009 for the appraisal of end of life (EoL) technologies (1) permits their committees to attribute extra weight to health gains for terminally ill patients compared with all other health gains. This move followed a recommendation in the Richards report to the Secretary of State for Health (2). Reports in the media and high profile campaigns by patient groups continually highlight cases where patients have been prevented from accessing cancer drugs that have been appraised and judged too costly in relation to their health benefits. These cases are often presented as the National Health Service (NHS) failing taxpayers at their moment of greatest need (3-7). Despite the creation of a Cancer Drug Fund by the UK government, the small size of this fund means that such issues cannot be avoided and the NHS occupies a difficult position in attempting simultaneously to act in the best interest of current patients and of the wider population. NICE has adopted an explicit, population-based perspective (8) emphasizing the opportunity cost of providing new treatments, most obviously where resource requirements are high and health benefits are uncertain or small.

Little is known about whether the new guidance reflects societal views regarding health care resource allocation and distributive justice and research is needed to inform policy. Yet public opinion plays a central role in NICE's decision-making framework. More specifically, its 'Fundamental Operating Principles', particularly its commitment to 'inclusiveness', 'transparency' and procedural justice require detailed information on public opinion to allow its guidelines to be accountable and justifiable (8). Conducting research to gain detailed information on the views of the public raises methodological questions about how best to elicit and describe the different moral positions that might exist in society and how to establish the level and extent of 'support' for such views in the population. The former requires qualitative approaches which can only be feasibly applied in smaller samples, whilst the latter requires quantitative methods applied in much larger samples. In this study, we develop a methodological approach that builds on an established method for investigating public opinions in-depth, Q methodology, and breaks new ground in the development of Q methods for use in survey research. This new methodological approach we call Qsort-to-survey, or Q2S. Although applied to views about the value of EoL therapies here, the method could be used to establish societal views and their distribution in other areas of controversy regularly faced by bodies such as NICE.

## Background

In resource constrained, publicly funded health care systems decisions about which health care technologies will be provided and, by implication, which technologies will not, are unavoidable. In many advanced economies this has led to the establishment of institutions and processes to evaluate the costs and benefits of new and existing technologies. In England, NICE have adopted a cost-utility based framework to evaluate health technologies. The Scottish Medicines Consortium (SMC) and the All Wales Medicines Strategy Group (AWMSG) have adopted similar evaluative frameworks. Typically, benefits are measured in terms of quality adjusted life years (QALYs) and ratios presented in terms of the incremental cost per QALY gained. However, recommendations about provision also require a judgement to be made regarding the *value* of benefits (i.e. the value of QALYs gained). NICE apply a 'soft' cost-effectiveness threshold such that technologies which cost £20,000-£30,000, or less, per QALY gained are usually recommended for provision by the NHS. Above £30,000 technologies are usually rejected unless a special case can be made for their recommendation (9). An equal weighting is currently applied to all QALYs regardless of the characteristics of the beneficiaries or the types of QALYs (e.g. improvements in quality of life versus extensions in life expectancy). However, the *relative* value of health gains for different groups of people has been a subject of debate since before the inception of bodies such as NICE (10) and remains a current research question (11, 12). There is provision within the procedures of NICE committees for deliberation and for deviation from the threshold implying that a higher social value may be attached to certain health benefits over others. In their guide to the methods of technology appraisal, NICE state explicitly that the Appraisal Committee will take into account "*Social Value Judgements*" (SVJs) (13) p9.

The SVJs NICE committees refer to are provided in a set of principles, issued by the NICE Board, that articulate the values and processes that must be adhered to for NICE to consider its guidance legitimate (8). The SVJ principles were developed by drawing on a range of sources including legislation, the opinions of NICE advisory bodies and the reports of meetings of the Citizens Council NICE set up in 2002 to ensure that public opinion was represented within its guidance. As such the SVJs are grounded in the views of the general public and NICE should be commended for investing in the Citizens' Council, although some commentators have criticised NICE's reliance on this relatively small group of individuals as a representation of societal views (14). Notwithstanding, the concept of procedural justice at the heart of NICE's commitment to SVJs provides the Institute with a practical way of making decisions when faced with conflicting interests and plural societal views. Importantly, for NICE to deliver on its commitment to inclusivity and transparency, stakeholders with an interest in decisions, such as the general public, must be able to see how their perspectives are taken into account. That is, if guidance on issues like the distribution of resources at the EoL is to be morally and procedurally justifiable to the public it must be clear to them how their views were assessed relative to other perspectives. To enable this process it is imperative to draw on a reliable account of public opinion. This project aims to provide a novel and sophisticated method for accessing the detailed, accurate information on societal views required to ensure policy is fair and transparent.

### **Supplementary guidance as a specific exception for NICE**

The new EoL guidance represents a specific departure for NICE whose committees are now permitted to recommend therapies which have cost per QALY ratios above their standard threshold, subject to specific conditions including: that patients have less than 2 years to live, that the drug is licensed for a relatively small patient group, and that treatments would result in a gain of at least 3 months of increased life expectancy (1). The introduction of such an exception implies that health gains of this type are considered to be of greater social value than other types of health gain, and as such a *weight* is applied to the QALY benefits. The SMC has taken similar steps and include a number of 'decision modifiers' in their Guidance to Manufacturers, which may be called into play when the cost per QALY is relatively high (15) and the AWMSG refers directly to NICE guidance on end of life (16). How high the cost per QALY threshold can be pushed is not stated in the NICE guidance but in an update report in July 2009, reviewing the first four months of implementation, Longson and Littlejohns calculate implicit QALY weights based on the decisions that had invoked the supplementary guidance. They show that the committees had accepted an implicit QALY weight of 1.7. In other words, the health gains in this case were considered by the committee to be 70% more valuable than QALY gains in other cases. Longson and Littlejohns requested that the Board support the case for further research:

"The supplementary advice highlights that *"the Institute intends to ensure that the supplementary advice is robust for the long-term and that it achieves its intended purpose"* (see paragraph 1.2) therefore the Board is asked to agree that further research is required to test the assumptions of the EoL advice and to advise on the nature of that research." (17) p5.

If there is general consensus in society that life extensions for those at the end of their life is accorded special value then NICE's supplementary guidance will lead to more efficient use of scarce resources. If, on the other hand, this is not supported then the supplementary guidance will lead to a misallocation of resources. It is likely, however, that the subject is more complex than simply establishing whether there is extra value attached to months of life at the end of life. Interrelated ethical arguments are also likely to relate to patients' age and to the *premature* end of life (consistent with, for instance, the 'fair innings' argument (18)). Based on the technologies that NICE have assessed with high ICERs and when they have invoked the new guidance, such decisions are also concentrated on cancer drugs. It is possible, if there is a social premium for end of life technologies, that this might relate to a dread of cancer. The Health and Safety Executive (HSE) apply a value of twice the Value of a Prevented Fatality (VPF) for cancer. This effectively double-weights the health benefits of programmes that reduce the risk of cancer death relative to those which reduce the risk of death by other causes. Whilst this would appear to reflect the existence of a societal 'cancer premium' there is little research evidence to support this policy. Since the nature of societal views is not known it is even possible, more radically, that the evaluation of end of life technologies entails an entirely different evaluative space (19, 20). In the same way that economic evaluation of palliative care presents challenges within existing evaluative frameworks it is possible that EoL technologies should be valued in quite different ways, requiring different techniques to measure outcomes. In short, research is needed to

further develop methods which can delineate and describe the views to which different members of society subscribe in order that health economic methods can be applied appropriately.

This research will use established Q methods to

- i. identify and describe societal perspectives on the (relative) value of end of life technologies by eliciting the views of both members of the public and experts in relevant fields; and *develop* methods to
- ii. investigate the distribution of those views, including their association with other characteristics in a nationally representative sample of the UK general public.

### **Methodological challenges**

Though often used together in research projects, the interpretive and analytic approaches used to address (even closely-linked) qualitative and quantitative questions, such as those set out in i) and ii) above, generally remain separate. It is the task of each multi-disciplinary research team to find means to combine qualitative and quantitative analyses or, at the least, to combine the results of separate analyses.

Further development of Q methodology will enable inter-connected qualitative-quantitative research questions such as those set out above to be addressed, within a single methodological framework. Well-established Q methods can be applied to (i) whereas methodological development is required for (ii). Because methods to extend Q studies for use in population surveys have not been extensively used by researchers (in part, perhaps, due to the paucity of texts offering methodological guidance) there is a need to establish appropriate methods for Q survey design and analysis. This research project will establish a methodological standard for the use of Q in the design and analysis of survey questions (Q2S).

Q methodology is not new; it was first devised by Stephenson 75 years ago (21) whose seminal work was published in 1953 (22). It has been applied in a range of research fields, notably psychology and political science and, more recently, in health (23-26). The use of Q in large survey samples, however, is rare, despite the fact that Stephenson devoted a chapter of his 1953 book to the subject and "Q block" methods for questionnaire research were described in a conference paper in 1963 (27). Consequently methodological work is needed which establishes methods for the design and analysis of Q-surveys. There are a number of approaches that have been applied (opportunistically) by the applicants but purposefully-designed, methodological research is needed in order to test different approaches. This project will involve a detailed investigation of a range of approaches, applying Q methodological and statistical skills within the team to identify the most appropriate methods, establishing practices for future studies of societal views.

Building on previous exploratory work and utilising pilot datasets which we have generated in the past, we will experiment with different analytic approaches. By piloting our analytic methods we will identify issues of survey design associated with different statistical approaches before selecting the most effective methods. These will then be operationalised in this study which (unlike previous smaller, exploratory studies by the applicants) is designed for specific methodological purposes. Once established, such methods could be generalised to any study concerned with the nature and distribution of societal views.

## **3. Scientific potential**

### **3.1. People and track record**

RB, JvE and HM are at the forefront of methodological work in the Q2S area (28, 29) and have a record of successful research collaborations (e.g., the European value of a QALY (EuroVaQ) study project (30, 31)). They are joint authors of a publication forthcoming in the Q methodology journal *Operant Subjectivity* (28) (available on request) in which they present an account of their experiences with Q2S methods and highlight outstanding methodological issues. This research team is the only one, internationally, with expertise in health economics *and* Q methodology and this combination sets them apart as methodologically innovative within both academic communities. RB has experience of managing large and complex research studies (11, 30). She has expertise in qualitative methods and preference elicitation techniques. JvE has expertise in quantitative methods, economic evaluation, Q methodology, led the Q methods workpackage of the EuroVaQ study (with RB, CD and HM), and is senior researcher in a 4-year project on broader social benefits of health care interventions in the Netherlands (32, 33). HM is an experienced Q researcher who has recently completed an ESRC funded post-doctoral research fellowship. Her

areas of expertise include methods in the valuation of statistical life and QALYs (34). CD is a senior health economist with an established international reputation. He was principal investigator of both the UK based Social Value of a QALY (SVQ) study and the EuroVaQ study, both of which incorporated Q methods into the study of public preferences and distributional justice (11). LW is a Research Fellow in Health Ethics and a Wellcome Research Fellowship "Health ethics in the age of autonomy: Public engagements with the social challenges of health policy". LW will provide an important ethical perspective to the design and interpretation of the research. JG is a senior statistician with extensive experience of statistical methods in health research. LW and JG will offer advice and guidance throughout, taking a more practical role where relevant. CH is a Consultant Nurse in Cancer Services and will offer insights into the clinical and 'real world' impact and applicability of the research design and findings. She will help to identify relevant stakeholders, expert groups and patient representatives to take part in the research and dissemination events. An advisory group includes experts from relevant fields.

## **Environment**

Applicants (with the exception of HM, CH and JvE), are based in the newly established (May 2010) Yunus Centre for Social Business and Health, and the recently established (February 2009) Research Institutes in Applied Health and Social Justice Research at Glasgow Caledonian University (<http://www.gcu.ac.uk/research/researchatglasgowcaledonianuniversity/researchinstitutes/>). The quality and relevance of research in the health field is demonstrated by achieving an outstanding performance in the 2008 Research Assessment Exercise, placing GCU first for rehabilitation science and in the top ten Universities for its' submission for Allied Health Professions. These two University-wide Institutes facilitate cross-disciplinary approaches to research by drawing together individuals and teams producing internationally excellent research, methodological rigour and innovative thinking to collaborate within focused thematic areas in health and social justice fields. We have a strong commitment to generating research of the highest international standard and reflecting GCU's strong social mission, we focus on addressing research questions of major policy and practice relevance to Scotland, the UK and beyond.

The Yunus Centre and Institutes are located together in new premises sharing newly created space, facilities, equipment and support staff. The University has recently invested in a number of new academic posts, predominantly at Professorial and Reader level, to ensure strong and effective research leadership across Institutes. Much of our funding is from highly competitive sources including UK research councils, the Wellcome Trust, Chief Scientist Office (Scotland), National Institute for Health Research, Canadian Institute for Health Research, the European Commission and leading charities (e.g. Arthritis Research Campaign).

GCU is a member of the Scottish Academic Health Sciences Collaboration (Glasgow node) the benefits of which include increased access to high quality imaging facilities, tissue banking, clinical research support and IT capacity, the Scottish School of Primary Care and AqMen, an ESRC and Scottish funding Council funded quantitative research methods network the purpose of which is to build capacity in the social sciences. We also have long standing research links with the Glasgow Centre for Population Health and Community Health Sciences at Glasgow University (including the MRC Social and Public Health Sciences Unit and Departments of Public Health and Health Policy and General Practice and Primary Care).

## **3.2. Research Plans**

### **Objectives**

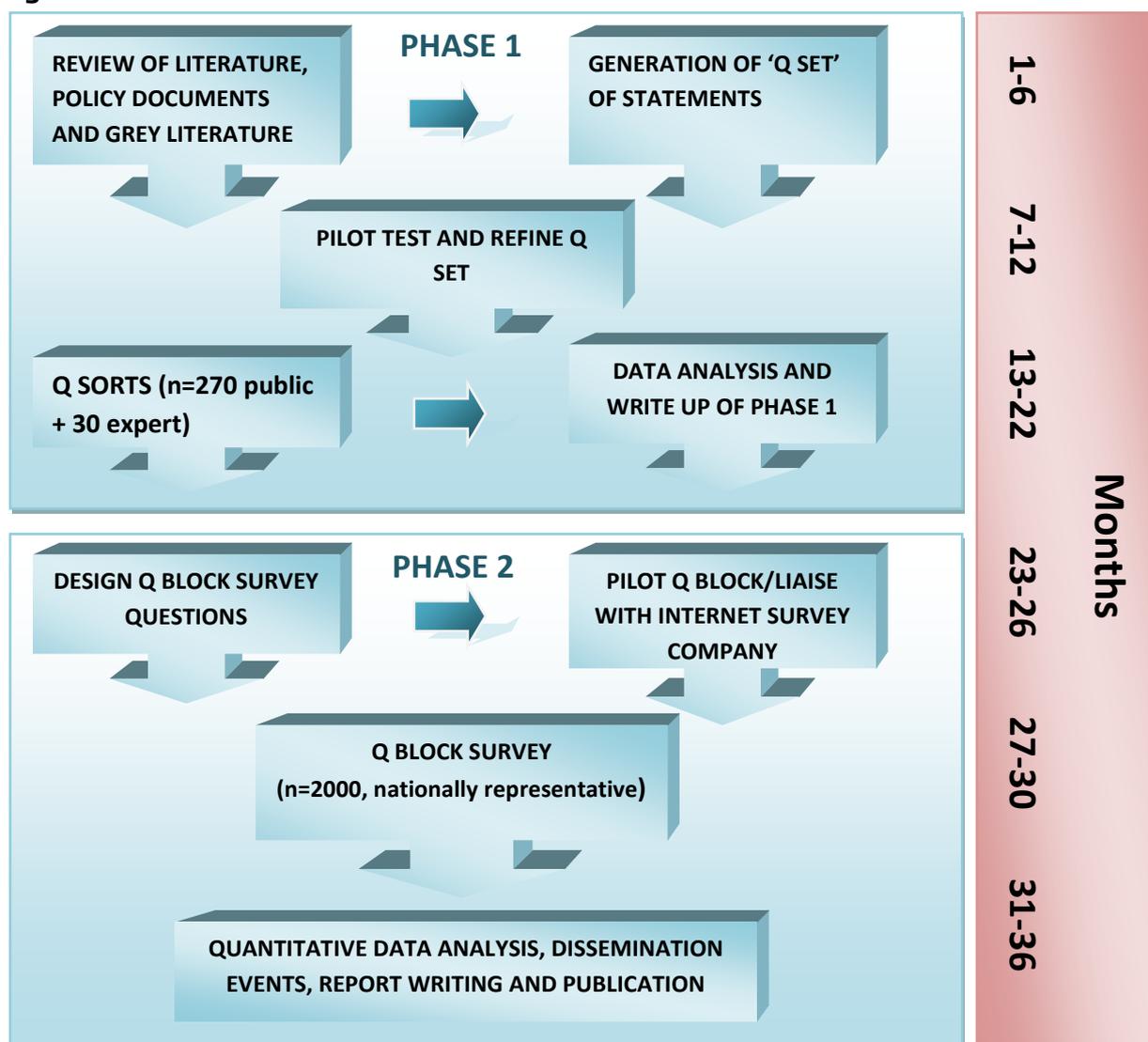
1. To develop an approach, based on techniques associated with Q methodology and quantitative survey methods (Q2S), for establishing the nature and pattern of societal values with respect to controversial health care resource allocation decisions and distributional justice.
2. In applying this methodology to end-of-life technologies, to elicit and describe the views of the UK general population regarding the NHS provision of end of life technologies when competing for public funding with treatments for all other conditions.

### **Methods**

The project is structured in two consecutive phases (see Figure 1). The first phase uses established methods to provide rich descriptions of public narratives about end-of-life technologies. In the second phase we develop methods to measure the extent and patterning of those views in a large survey population. We will apply Q2S methods in phase 2 that are novel

and have been only rarely applied, outside of the work of the applicants. We will establish a methodological standard for the application of Q methods in survey research which can be applied in any study of public opinion where establishing the views in a population is important.

**Figure 1**



**Phase 1 (Q sort study)**

Q methodology can be characterised by: the data collection method which involves the rank ordering of cards, printed with statements of opinion, onto a grid; and the analytic method which is an inverted form of factor analysis (by-person factor analysis). Phase 1 methods are outlined briefly here but are fairly typical of Q study methods which are detailed elsewhere (35-38).

Statements relating to the value of EoL technologies will be derived from academic, policy and media sources using systematic search methods. Search strategies will be devised and piloted for use in academic databases (e.g. Web of Science/ Medline) and separate search strategies for use in media databases (e.g. Factiva/ ProQuest). There will follow an exhaustive process, extracting relevant opinion statements from all sources and removing duplicates/opposites until a draft 'Q set' of statements is compiled. (It is common for Q sets to be based on interviews. Given the sensitivity of this topic, and the accessibility of source documents, interviews with patients/families are not necessarily justifiable. CH and hospice contacts will offer insights into patients' perspectives and, if possible, a small number of patients/ families will be interviewed subject to relevant ethical approval). The draft Q set will then be presented to expert interviewees (e.g. clinicians, NHS policy makers, the NICE Citizens' Council (if possible), hospice and charity representatives, academic experts) and revised based on their suggestions and added statements. A small pilot study (n=15) will be conducted before finalising the Q set. Examples of Q statements that could be adapted for use in this study are presented below. (These are readers' online responses to newspaper articles and are intended for illustration only.)

*"Individuals dying of cancer deserve our heartfelt sympathy and often have harrowing stories to tell but ultimately someone has to decide how the limited NHS budget should be spent and where it can do the greatest good to the largest number of people."*

*"People have paid NI contributions all of their working lives in the belief that it would insure them for such an eventuality."*

*"We are all going to die. It is just a matter of when. Surely if these drugs extend life by even a few weeks it is worth it, otherwise, why not end it all now?"*

Respondents will be guided through a ranking procedure leading to the arrangement of all statements onto a sorting grid labelled "most agree" to "most disagree". Since there are often as many as 50 statements in a Q set, the sorting process is guided by the researcher and conducted in stages, beginning by placing the cards into three piles, "agree", "disagree" and "neutral". (see (31) for a working, online Q sort). Once the cards have been placed onto the grid the position of each card is recorded. Respondent samples in Q studies are relatively small since, as in qualitative methods, additional respondents offer little additional information once views have been specified and described by a carefully selected, purposive sample. Nonetheless, a relatively large sample of 300 is proposed here: approximately 250 of whom will be drawn from the general public and 50 from patient and professional groups. The size of the sample reflects the need to include people with different socio-demographic characteristics from different regions of the UK.

By-person factor analysis will identify shared accounts (factors) based on similar patterns in respondents' Q sorts. Each factor represents a different societal viewpoint and is interpreted based on a 'composite' Q sort calculated for each factor and respondents' open ended comments. Statistically significant issues of consensus and distinction between views will be identified. A pooled analysis (including both public and 'expert' respondents) will be followed by a comparative analysis which will treat the datasets separately. The findings of Phase 1 will be written as an academic paper and submitted for publication at the end of year 2.

## **Phase 2 (developing Q2S methods)**

The results of Phase 1 will be used to design questionnaire items which will be administered, in Phase 2, to an online survey of 2000 respondents. This sample will be nationally representative, bearing in mind that the sample is selected from the 'online population'. (NB We have considered the costs and merits of internet versus the ideal which is face-to-face data collection methods. All approaches generate different sampling biases. We have shown in a previous study (30) that lower income and older respondents can be recruited online using questionnaire panels and some of the sampling issues are offset by the capacity to generate much larger online samples at much lower cost. However, the method we propose is not dependent on internet administration and Phase 2 could be conducted face-to-face, but this would have resource implications.)

There are a number of approaches to the design of Q2S items (27, 28, 39) but all approaches aim to link questionnaire respondents to the viewpoints originating from the Q study (in Phase 1). Three main approaches to Q2S have been devised (28): i) a subset of salient, distinguishing statements (identified in Phase 1) is presented individually, with Likert scales to indicate agreement, on the basis of which a standardized factor index score is calculated; ii) a subset of salient, distinguishing statements is presented in blocks, with each block containing one statement distinguishing each of the viewpoints, and respondents are instructed to rank order each block, on the basis of which an overall rank-order is computed and iii) short paragraphs describing the point of view described by each factor and ranking or rating procedures, or a combination of both, to establish respondents' adherence to each viewpoint.

There has been no systematic, methodological research relating to the appropriate treatment of Q2S data, but there is great potential in quantitative analysis of this type. Q factor analysis generates valuable, quantitative information about the importance of each statement within each point of view (in the form of normalised z-scores), and about the strength of respondents' association with different points of view (correlations known as *factor loadings*). Such information could be used in quantitative analyses. In our own work we have applied different scoring systems to survey data to assign *factor membership* to respondents and have a range of different datasets which will be used as pilot data for experimental, methodological work in this study. We will pilot different analytic approaches including discrete choice, random utility models and latent class analysis to existing data and inform the design and analysis of the data which will be collected for both methodological and empirical purposes in this study. Phase 2 will culminate in two publications in social science/ medical journals: i) setting out the methodological issues

and establishing a methodological standard for Q2S and ii) presenting the empirical findings describing societal views on EoL, the distribution of those views in the UK population; the similarity and distinction between the views of the general public and experts; and the association between points of view and socio-demographic characteristics of respondents.

This study will provide a significant contribution to methodological and empirical knowledge. The issues at stake are likely to be complex and contingent and research methods are needed which can account for complexity and highlight issues of consensus and disagreement. This will provide an evidence base for policy at regional and national levels as well as generating important information for the subsequent development of health economics methods such as willingness to pay (WTP) and other preference elicitation techniques.

**4. Ethics** Ethical approval will be obtained from appropriate committees before research begins.

**5. Data preservation for sharing** Datasets will be archived for sharing according to MRC policy. Data will be preserved as text and SPSS files and stored together with a 'data dictionary' defining variables and questionnaire items.

**6. Public engagement in science** This research aims to devise methods for incorporating the views of the public into health care policy. The results will be presented at dissemination events in different locations around the UK. Patient and lay representatives from hospices and charities will be invited together with policy makers to take part in interactive half-day events.

**7. Exploitation and dissemination** Results will be presented at academic conferences as well as at special dissemination events aimed at policy and public audiences. These events will be held towards the end of the project and will convene groups of key stakeholders in different locations across the UK, and explore our findings with experts and members of the public. Individuals will be invited from NICE, SMC, AWMMSG, Health Boards and Trusts/ Commissioning Consortia, patient organisations and charities, hospices and other public/ professional/ patient groups identified during the course of the project. As part of these events participants will complete their own Q sorts and the results will be analysed, compared with the views of the general population from Phase 1, and presented to participants for discussion. Dissemination through existing networks will include the UK Forum on Priority Setting in Health Care.

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