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From Representing Views to Representativeness of Views: illustrating a new (Q2S) approach in the context of health care priority setting in nine European Countries

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Abstract

Governments across Europe are required to make decisions about how best to allocate scarce health care resources. There are legitimate arguments for eliciting societal values in relation to health care resource allocation given the roles of the general public as payers and potential patients. However, relatively little is known about the views of the general public on general principles which could guide these decisions. In this paper we present five societal viewpoints on principles for health care resources allocation and develop a new approach, Q2S, designed to investigate the extent to which these views are held across a range of European countries.

An online survey was developed, based on a previously completed study Q methodology, and delivered between November 2009 and February 2010 across nine countries to 33,515 respondents. The largest proportion of our respondents (44%), were found to most associate themselves with an egalitarian perspective. Differences in views were more strongly associated with countries than with socio-demographic characteristics. These results provide information which could be useful for decision makers in understanding the pluralistic context in which they are making health care resource allocation decisions and how different groups in society may respond to such decisions.

Keywords: Europe; Health Care; Decision Making; Societal Views; Q methodology; Q survey

Introduction

It is well established that health care resources are limited and thus, insufficient to meet all demands for care in society. Therefore, difficult decisions have to be made how best to allocate these scarce resources. Decisions about which services and technologies to provide (and consequently those to not provide) are controversial as they raise questions about the basic principles and values of the health care system (Buxton and Chambers, 2011).

One way many countries have sought to inform decisions about which services and technologies to provide is through an assessment of the costs and benefits of an intervention (Oortwijn et al., 2013, O'Donnell et al., 2009). Economic evaluation techniques such as cost utility analysis (Drummond et al., 2015) are established as a key input into health care resource allocation decisions. In cost utility analysis the costs and health outcomes of an intervention are compared with those of a comparator, with outcomes measured in terms of quality adjusted life years (QALYs). QALYs are a generic outcome measure comprising length and quality of life, which allows for the comparison of interventions across different disease and patient groups.

The standard cost per QALY analysis approach assumes that all QALYs are equally valued (Weinstein et al., 2009). However, there is a growing body of quantitative research focusing on 'weighting QALYS' (Bobinac et al., 2012, Dolan et al., 2005, Schwappach, 2002, Shah et al., 2013, Whitty et al., 2014, Lancsar et al., 2011, Baker et al., 2010a), which seeks to determine if members of the public do attach equal value to QALY gains or weight some QALY gains more heavily than others. In the latter case, some QALY gain maybe traded off for other goals, such as an equitable distribution of health care. This line of research has included eliciting public preferences for health gains benefiting different groups of patients; for example, whether higher weight is given to QALYs gained by patients who are more severely ill versus patients in less severe health states, for younger versus older

people, based on the lifestyle of the patient or the characteristics of the health benefit itself (Whitty et al., 2014, Baker et al., 2010a).

Understanding respondents' priorities when faced with single issues such as severity or age is only one element that decision makers may need to consider when making resource allocation decisions. In combination with these specific attributes, it is also useful for decision makers to be aware of the broader principles and values members of the public hold on what should underpin resource allocation decisions. However, there is very little evidence available on these wider views (Buxton and Chambers, 2011). Given this lack of evidence in many countries, research is needed to first determine what the views of the public are regarding health care prioritisation. Once these views have been identified and described, it is also useful for decision makers to know the extent to which these views are supported within the population and if there are any differences between people who are associated with different viewpoints (Baker et al., 2014)..

This paper presents the results of a study designed to determine the distribution of previously identified views on health care prioritisation in a number of European countries. The design builds on the results of a Q methodology study which identified and described in-depth five viewpoints on the broader principles which should underlie health care resource allocation (van Exel et al., 2015). Q methodology combines qualitative and quantitative techniques for in-depth study of subjective views on any given topic (Watts and Stenner, 2012) (Brown, 1980). The methods and results of the initial Q methodology study are described in detail elsewhere (van Exel et al., 2015). The Q methodology study included 294 members of the public across the 10 countries participating in the EuroVaQ project (Denmark, France, Hungary, Netherlands, Norway, Poland, Spain, Sweden, Palestine and the UK). Each respondent ranked a set of 34 statements expressing views and values in relation to health care priority setting including: characteristics of patients, illnesses, treatments and health and non-health effects of treatment. Analysis of these data revealed five viewpoints on resource

allocation in health care identified from the public, each comprising a different combination of principles and values. These viewpoints were titled (I) “Egalitarianism, entitlement and equality of access”; (II) “Severity and the magnitude of health gains”; (III) “Fair innings, young people and maximising health benefits”; (IV) “The intrinsic value of life and healthy living”; and (V) “Quality of life is more important than simply staying alive”. Short summaries of the five viewpoints are provided in Table 1 and full accounts provided in van Exel (2015).

The description of these perspectives represented new information on the views of the public. However, the analysis conducted as part of the initial Q study did not provide information on the representativeness of these five viewpoints within each country. Having information on the level of support for, and the distribution of, views may be important (and useful) for policy makers if they wish to be responsive to societal preferences when making health care resource allocation decisions. Information can provide evidence to support the processes that are used in health care resource allocation so that the decisions that are made are in line with the views of the public. This may be especially important in publicly funded health care systems, when decisions not to fund particular interventions can be contentious and potentially challenged by stakeholders. Having information on societal views on the same topic across a number of countries also allows individual countries to understand not only the views that exist within their own country but also how they compare to others in Europe. This can make the exchange of experiences or process for priority setting between countries or settings easier if it is known which countries are similar in terms of societal views and why these processes may not be as readily adopted if the underlying views are different (Littlejohns et al., 2012).

To examine the distribution of views requires a survey which can be delivered to a large respondent sample. In this paper we report the results of a large, online survey to examine the distribution of our five public perspectives about health care resource allocation, across nine countries in Europe.

Method

Q methodology is used when addressing questions of views, opinions or beliefs and produces in-depth descriptions of the shared viewpoints that exist around a topic (Baker et al., 2014, Watts and Stenner, 2012). Q studies are designed to be in-depth and exploratory, with the aim of identifying and describing in some detail the viewpoints that exist, not to determine how many people hold those viewpoints (Brown, 1980). Conducting Q sorts with large groups of respondents is not practical as data collection is intensive and time consuming and exploring the distribution of viewpoints in large respondent samples requires survey methods that can be administered more efficiently (and, increasingly, using online survey tools). Essentially, the aim of Q-based survey design (which we have named Q2S), is to extract, from the initial Q study, the defining features of each viewpoint and to summarise those key elements in a way that can be presented in short questions in a survey. There are several ways of going about survey design based on that basic aim. This can include the development of short summary descriptions representing the viewpoints from the original Q study (van Exel et al., 2006) or the presentation of selected statements which most characterise each viewpoint that respondents are asked to rank order or rate on a Likert scale (Baker et al., 2014). A discussion of the range of different methods that have been used in Q-based survey design is outlined by Baker et al (2010b).

Design

The Q2S survey method used in this study is based on short summary descriptions of the most characterising and distinguishing features of each of the five viewpoints referred to above. Three researchers developed the short descriptions, working from more detailed accounts of the perspectives (van Exel et al., 2015) and distilling the key points from each one. There are two important considerations in summarising the perspectives: salience and distinction. The salient features in each description are those that respondents in the initial Q study who were highly

associated with that point of view care strongly about (most agree or most disagree). Distinguishing features are those that set each perspective apart from the other perspectives. The final summary descriptions presented to respondents are presented in Table 1.

The survey was delivered as the last section of an online questionnaire following a series of questions designed to elicit the monetary value of a QALY as part of the EuroVaQ project (Donaldson, 2010, Pennington et al., 2015, Robinson et al., 2013)

To introduce the survey section of the questionnaire, respondents were given the information presented in Supplementary Materials Annex 1 [INSERT LINK TO ONLINE SUPPLEMENTARY MATERIALS ANNEX 1]. This outlined the context of there being limited resources for health care and the necessity to make choices about which treatments and services to provide. Next, the five descriptions were presented individually in random order. A seven point Likert scale accompanied each description and respondents were asked to indicate their agreement with each viewpoint on a scale labelled 'very unlike my point of view' (1 on the Likert Scale) to 'very much like my point of view' (7 on the Likert Scale). Responses to these questions were used to indicate respondents' relative strength of agreement with all five viewpoints. Respondents who gave the same highest score to more than one viewpoint were presented with their top-rated descriptions again, after all five viewpoints had been rated, and asked to choose which one would best reflect their view (See Supplementary Materials Annex 2 [INSERT LINK TO ONLINE SUPPLEMENTARY MATERIALS ANNEX 2] for example of how the question and follow up tie break were presented on screen).

Data Collection

The online survey was programmed and administered by Survey Sampling International (www.surveysampling.com) between November 2009 and February 2010. Respondents were sampled from the online survey panel with targets set for age, gender and socioeconomic status

based on population statistics from local census agencies in each country (a full list of the agencies is provided in the Supplementary Materials Annex 3 [INSERT LINK TO ONLINE SUPPLEMENTARY MATERIALS ANNEX 3]). One of the original EuroVaQ countries (Palestine) was unable to collect a nationally representative sample as online coverage is lower; as a result, the data from Palestine has been excluded from this analysis. Table 2 presents the main characteristics of respondents in each of the nine remaining countries.

Analysis

The Likert Scale scores for each viewpoint were analysed in two different ways. Firstly, to examine the distribution of viewpoints the Likert Scale scores were treated as ‘votes’, assigning each respondent to a single viewpoint based on the viewpoint they most agreed with according to their Likert scale score. For respondents who gave equal highest score to more than one viewpoint, the result of the tie break question described above was used to associate them with a single, most preferred viewpoint. This information was used to examine the distribution of viewpoints across countries. Secondly, logistic regression analysis was used to explore the associations of the assignment to each of the viewpoints with socio demographic characteristics of the respondents and country dummy variables. Regarding the latter, the country with the lowest proportion respondents assigned to that particular viewpoint was selected as the reference country in the regression.

Ethics

At the time of the study (2007-2010) the Principal Investigator was based at Newcastle University in England and the project met the requirements of that University’s Faculty of Medicine Ethics committee.

Results

Sample size and exclusion criteria

A total of 39,560 respondents completed the online survey questions as part of the EuroVaQ Questionnaire. Of these, 1,849 respondents (4.7%) were removed because of missing data on at least one of the viewpoints. A further 4,196 (10.6%) were removed because they gave the same score to all of the viewpoints. It is possible (although perhaps unlikely, given the low correlations between each viewpoint) that such respondents have precisely the same level of agreement with all factor summaries, but it is also plausible that many of those respondents 'clicked through' the survey quickly and without sufficient consideration of the questions. Because it is not possible to distinguish respondents giving genuine answers from those who failed to give careful consideration to the questions in the exercise, all these respondents were excluded from the analysis. A final sample of 33,515 was used for the analysis; the characteristics of these respondents are presented in Table 2. This final sample was compared against the targets set for recruitment based on interlocking age and gender groupings and socioeconomic groups (presented in Supplementary Material Annex 4 [INSERT LINK TO ONLINE SUPPLEMENTARY MATERIALS ANNEX 4]). There is variation in achievement in the targets across the countries and categories. In particular there are low numbers of older respondents compared with the targets in France, Hungary, Poland and Spain.

Summary statistics

For each viewpoint all possible scores from 1 to 7 were given, with the mean score ranging from 4.0 for Viewpoint III "fair innings, young people and maximising health benefits" up to 5.7 for Viewpoint I "Egalitarianism, entitlement and equality of access" (see Table 3). Paired sample tests showed that all means were statistically significantly different ($p < .001$). The correlations between scores on all five viewpoints were low. Figure 1 shows how the distribution of Likert scale scores varied across the viewpoints. For all viewpoints the distribution was left skewed, but this pattern was more

pronounced for Viewpoint I where more than 43% of the scores on this viewpoint were scored at 7 ('very much like my point of view').

Of 33,515 respondents, 20,491 (61.2%) gave at least one (but not all) viewpoints a score of 7 and 8,454 (25.2%) gave a maximum score of 6 to at least one viewpoint. This would indicate that the majority of respondents found something like their point of view in at least one of the five viewpoints identified in the original Q study. 938 (2.4%) respondents gave a score of 4 or lower to all viewpoints, indicating that they could not find their views represented in the five we identified in the first study.

Distribution of Viewpoints

Respondents were assigned to one of the five viewpoints based on their highest Likert scale score, where possible. A total of 13,867 respondents (41.4%) were 'pure types' (i.e. gave their highest score to a single viewpoint), while 19,648 respondents (58.6%) tied their highest score across two or more viewpoints and were presented with the follow-up question.

The largest number of respondents were assigned to Viewpoint I with 14,737 (43%) scoring the description "Egalitarianism, entitlement and equality of access" as most like their point of view. 5,567 (16.6%) respondents were assigned to Viewpoint II "Severity and the magnitude of health gains". Viewpoint III "Fair innings, young people and maximising health benefits" was chosen by the fewest number of respondents, with only 1,423 (4.2%) as most like their point of view. 5,242 (15.6%) respondents chose Viewpoint IV "The intrinsic value of life and healthy living", and 5,608 (16.7%) respondents agreed most with Viewpoint V "Quality of life is more important than simply staying alive". 938 (2.4%) respondents were not assigned to any viewpoint (reported as 'none' in Table 4), having scored all viewpoints at less than 4 on the Likert Scale. Table 4 presents a breakdown of these results according to 'pure types' and those for whom at least one tie had to be broken.

Table 4 also shows the distribution of the five viewpoints in each country (see Supplementary Materials Annex 5 [INSERT LINK TO ONLINE SUPPLEMENTARY MATERIALS ANNEX 5], Tables B and C for additional breakdown of country results). All five viewpoints were observed in each country. Viewpoint I “Egalitarianism, entitlement and equality of access” was the predominant viewpoint in all nine countries and Viewpoint III meets with least agreement in all countries. Although the largest proportion of respondents agreed most with Viewpoint I in all countries, the size of that proportion differed across the countries; from 35.4% in Hungary to 51.5% in Sweden. Viewpoint II “Severity and the magnitude of health gains” was rated as most like their point of view by 20.5% of the Dutch sample but only 12% of the French sample. Viewpoint IV “The intrinsic value of life and healthy living” was selected by 20% of the UK sample as most like their point of view but was lower in France with only 11% rating this most highly.

Examining the relationship between viewpoints and other characteristics

Logistic regression analysis was used to examine the relationship between assignment to each of the five viewpoints and the socio demographic characteristics and country of origin of the respondents. The results of the analysis are shown in Table 5.

This analysis indicates that the assignment of respondents to the viewpoint they agreed with most was varyingly associated ($p < .05$) with their socio demographic characteristics. Viewpoint I – “Egalitarianism, entitlement and equality of access” - was associated with higher age, being female, lower education level, not being employed, and lower health. Viewpoint II - “Severity and the magnitude of health gains” – was related lower age and being male. Viewpoint III - “Fair innings, young people and maximising health benefits” - was also related lower age and being male, and to lower education and not being employed. Viewpoint IV - “The intrinsic value of life and healthy living” – was related to all socio-demographic characteristics and, except for age and sex, mostly in

the opposite direction as the other viewpoints. Viewpoint V - “Quality of life is more important than simply staying alive” – was related to higher age, not having children, being employed and in lower health. Associations with country of origin were mostly statistically significant and most of the odds ratios were considerably larger than for the socio-demographic characteristics of respondents. In addition, the country coefficients were all larger than one and therefore consistent with the results presented in Table 3.

Discussion

When making health care resource allocation decisions there are many trade-offs that need to be made to determine what to fund, and what not to fund. Societal views on the distribution of health care resources are increasingly important in decision making processes (Chalkidou, 2012).

Understanding the plurality of views that exist and the extent to which they are supported in the wider population may be useful to decision makers. It may help provide reasons why people may respond to new policy in different ways and why certain decisions are not well received (at least by some, while others may embrace the same decision). This also implies that quantitative approaches, often relying on averaging individual responses, which may reflect fundamentally divergent views, may not provide the best guidance for optimal societal decision making. Having more information on the plural views on the principles that should guide allocation of health care resources may help to highlight areas of consensus and of differences within public views, allowing decision makers to be more responsive to societal preferences when making resource allocation decisions.

Five societal views were elicited in a Q methodological study (van Exel et al., 2015), briefly summarised in Table 1. The distribution of these five viewpoints across the population was estimated using survey methods and administered online to 33,515 people in nine countries. The large majority of respondents agreed with at least one of the factors, suggesting that they see their

point of view on prioritisation of health care represented in the results of the primary Q study.

Across the five viewpoints, the largest proportion of respondents were associated with Viewpoint I 'Egalitarianism, entitlement and equity of access'. Overall 44% of respondents were assigned to this viewpoint. With 50% of respondents who were allocated without the need for a tie break selecting it. This suggests that, for those respondents who were most sure about which view they most agreed with, Viewpoint I best expressed the principles they would like to see underlie health care priority setting within their country. This pattern is also true in the data of all nine countries individually.

The core of Viewpoint I is that access to health care should be based on health need rather than any other personal characteristics of the patient, and financial contribution to the health care system should not play a role in prioritisation of patients. The predominance of this viewpoint may be a reflection of, or, put otherwise, *reflected in*, the health care systems and means of financing and delivery of health care in the nine countries we studied. These are generally publicly-financed systems where health need is a key driver in prioritisation decisions.

While Viewpoint I was the most commonly selected viewpoint in each country, the proportion of respondents associating themselves with each viewpoint still varied across the nine countries.

Qualitative data on the reasons why respondents scored each viewpoint as they did was not collected as part of the online survey. Therefore, it is not possible to give explanations based on this but one may reflect on these distributions in relation to the political ideology, income levels and health care systems of each country. The highest proportion of respondents agreeing most with Viewpoint I was found in the Scandinavian Countries. These countries may be viewed as fairly egalitarian with tax-based health care systems attempting to ensure equal access. A feature of Viewpoint II is that there is nothing wrong with people paying for treatment in the private sector as long as it does not affect the treatment of others. Higher proportions of respondents in Poland and Hungary associated with this view, which may be related to the fact that these countries have the highest proportion of out of pocket payment for health care of all nine countries (OECD, 2014),

making payment for treatment more common and accepted. Viewpoint III (which focuses on age) met least agreement across all countries and this is consistent with principles and legislation prohibiting age discrimination. The UK had a higher proportion of respondents associated with Viewpoint IV in which health services should be about saving lives and preventing illness. It is interesting to note that the focus on extending lives is also reflected in supplementary guidance given by the National Institute for Health and Care Excellence in the UK on appraising life-extending, end-of-life treatments for technology appraisals. This guidance allows higher weight to be given to life extending treatments provided to people with terminal illness within the evaluation process (National Institute for Health and Care Excellence, 2009). Viewpoint V is focused on quality of life, whereby health care is not just about prolonging life if treatment cannot restore quality of life to an acceptable level. The Netherlands had the highest proportion of respondents in agreement with this viewpoint. Here, one could speculatively draw a parallel between our findings and the (discussion on) legislation in The Netherlands, which, under strict conditions, offers the possibility of euthanasia for patients with a terminal illness who are judged to have an unbearable quality of life, without prospect of improvement.

The regression analysis indicated that there were many significant relationships between scores on viewpoint and socio demographic variables, but that the coefficients were all very low. This result was not surprising as ex-ante there were no clear hypotheses as to the relationships of key demographics such as age, gender, or health status related to each of the viewpoints identified. We observed stronger associations with country variables, indicating that differences in views between countries may be more strongly related to shared values (and health care systems that are a reflection of them) within countries.

The results of this study provide useful information for the individual countries, but, given the range of countries involved, also gives the opportunity to make comparisons over a range of different

health care systems. The EuroVaQ study countries were selected on the basis of their ability to contribute to the main aim of the overall project which was to elicit the monetary value of a QALY. The countries were selected to cover a range of health care systems including, at the inception of the project, newer EU countries such as Hungary and Poland, and for the different approaches to Health Technology Assessment and the importance of the monetary value of a QALY within this. Although the viewpoints and the proportions of respondents associated with each one are specific to the countries in which the study was conducted, there are general messages from the results which could be useful to other countries. As is indicated by the results of the initial Q study, there was a plurality of viewpoints and it can be expected that this will be the case in all countries. Therefore decision makers may wish to be aware of what these are when making and developing new policy.

There are two key strengths of this study: (i) the large sample size across multiple countries and (ii) the design of a Q2S survey based on an initial, in-depth analysis of the nature of perspectives. Regarding (i), the large sample size and breadth of countries involved in the study have allowed for a greater examination of views on health care prioritisation within each country and for comparison across countries (as called for by Buxton and Chalmers (2011)). This is the most ambitious, in-depth, investigation of public perspectives internationally. Regarding (ii), the design of the survey was based on an initial, in-depth analysis of the nature of public views which was analysed before an attempt to measure the distribution of those views. This is only possible in a two-phase study and an important feature that offers validity to the survey design. Q methodology involved a combination of qualitative and quantitative techniques and so is well suited to feed into survey design. The study adds to the literature on surveying social attitudes offering a new method (Q2S) for understanding societal views.

A number of methodological limitations and challenges need to be mentioned. The design and wording of the short summaries of the five viewpoints is of key importance. These summaries are

based on rich, in-depth accounts produced from the Q methodology study. The aim of the summary is to distil the key features of these longer accounts. However, by reducing the viewpoint in this way there is the potential for some meaning to be lost and for respondents preferences towards them to be different then they would have been if they had seen the fuller description. In this study 2.4% of respondents scored all viewpoints lower than 4, and were not assigned to a viewpoint. Although this is a small number, it does indicate that the views of these respondents may not have been captured in our first Q study. The proportion of respondents not assigned to a view also differs by country, with 1.4% not matched in the UK with 4.3% not matched in the Netherlands. This could indicate that there may be country-specific views that were not identified in our Q methodology study, which was based on a pooled across country data set.

The decision was made to remove respondents who gave the same score to all 5 viewpoints, which resulted in almost 10% of our sample being removed. This decision was made on the assumption that, given there are substantial differences between the viewpoints, as indicated by the low correlations between them, it is unlikely that respondents could agree equally with all of them. We cannot be entirely sure that there was not a genuine reason why respondents gave all viewpoints the same score, but, to avoid potentially biasing the results with those respondents who used this pattern to 'click through' the survey quickly, they were removed. Whilst 'speedsters' are routinely excluded in online surveys and respondent were excluded from this survey if their overall completion time was faster than would be feasible for respondents to read all the text presented, , we do not have a completion time for the Q2S section of the survey alone, which might have helped to determine those who may have rushed through this section in particular (Pennington et al., 2015, Robinson et al., 2013). This survey followed a set of willingness to pay (WTP) questions which may have had some influence on the responses participants gave to this part of the overall questionnaire. We had no *a priori* hypothesis of how these questions may influence the results especially as the WTP take an individualistic perspective and in the Q2S survey questions respondents are asked to

consider a more societal perspective. As such, we do not speculate on which (if any) direction this may bias the results but note that this should be considered while reading the results.

A further, potential limitation of the study is that data collection was conducted through an online panel. Quota sampling methods were used to set targets for respondent characteristics (age, gender, socio economic group) that reflect the population within each country but this is necessarily restricted to those people who are registered with online panels and, despite the penetration of internet coverage in all countries and across demographics, in some countries there was difficulty in recruiting some groups, in particular older women. The socio demographic characteristics included in our analysis are not exhaustive and we recommend future research that might also take account of intra country differences with respect to trends in unemployment, immigration and changes in health policy, for example, which were beyond the scope of this work.

Online administration also meant that there was limited scope for qualitative information, which might have been useful in better understanding why views might be supported differently in different countries.

This paper has presented one of the first studies to both identify societal views on principles which should guide health care prioritisation and investigate the extent to which these views are held across a range of European countries. Studies that look, in depth, at public preferences in relation to high-level principles for health care resource allocation are rare and international studies examining the same even more so. The World Health Study conducted by the World Health Organisation (World Health Organisation, 2004, King NB et al., 2013), elicited the views of the public for general health care goals (such as 'Minimising Health Inequalities' and 'Fairness in Financial Contribution'). These goals contain elements similar to the viewpoints we identified but are not grounded in previous in-depth study to identify the perspectives before measurement. A Q study that formed part of the Social Value of a QALY (SVQ) project examined societal perspectives in the UK (Baker et al., 2010a, Baker et al., 2014). The SVQ study was a precursor to the EuroVaQ study and the authors

identified three viewpoints which are similar to those identified in this study; including an egalitarian-based viewpoint, a viewpoint on maximising health benefits and a viewpoint which focused on preventive health, saving lives and caring for vulnerable people. In the EuroVaQ work we have been able to improve on the study delivered in the UK, refining the statements that were presented to participants, and developed a new way to create a survey which could be delivered to large participant samples.

Conclusion

This paper reports the largest study so far to investigate societal views on health care prioritisation. The results highlight that there are multiple viewpoints which exist and we have identified that, while Viewpoint I “Egalitarianism, entitlement and equality of access” had the most support, this is not a majority viewpoint within any of the nine countries involved. This is important new knowledge as it has implications for how people respond to rationing decisions. It can provide reasoning why some sections of a population are in favour (or not) of the decisions that are made. Going further, as engaging with society is increasingly important, these results indicate it may be more important for decision makers to include people who hold these different viewpoints in groups who offer advice and guidance within health care decision making processes, such as the Citizen Council operated by NICE in England and similar committees elsewhere in the world. Representation based on the viewpoints is arguably a more appropriate means of including different voices and views in policy deliberations, rather than representing different sociodemographic characteristics (presumably) in the expectation that different views are representative.

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Table 1. Summary Descriptions of the Five General Public View

<p><i>Viewpoint I: “Egalitarianism, entitlement and equality of access”</i></p> <p>I think access to health care is a basic right for all citizens. It should not be related to individual, social, family circumstances or lifestyle, it is more important that everyone in need of care is equally entitled to treatment. All life has the same value regardless of quality of life before and after treatment, past use of health services, financial contributions to the health services in the past, or ability to pay for private treatment.</p>
<p><i>Viewpoint II: “Severity and the magnitude of health gains”</i></p> <p>I think everyone is equally worthy of treatment, but it is important to consider need and how much patients will benefit. People with worsening health or who would otherwise die should take priority over others. However, the characteristics of patients, such as their age, gender or income should not be used to prioritise between them. There’s nothing wrong with people paying for treatment in the private sector as long as it doesn’t affect the treatment of others.</p>
<p><i>Viewpoint III: “Fair innings, young people and maximising health benefits”</i></p> <p>I think that the health budget should be spent on treatments that generate the most health. Younger people should be given priority because they haven’t had their fair share of life yet and they are likely to benefit more from treatment than older people. Access to health care should not be based on where people live, their lifestyle, their financial contribution to the health services in the past, or their ability to pay for private treatment.</p>
<p><i>Viewpoint IV: “The intrinsic value of life and healthy living”</i></p> <p>I think life itself is valuable. Health services should be about saving lives and preventing illness. It is also individuals’ own responsibility to lead a healthy lifestyle. This would create a more healthy society and prevent costs to the health care system. Parents with dependent children should be given priority. People should be allowed to pay privately for treatments as long as it doesn’t affect the treatment of others.</p>
<p><i>Viewpoint V: “Quality of life above all else”</i></p> <p>I think that health care should be about the quality of life of patients. There’s no use prolonging lives if treatment won’t restore quality of life to an acceptable level. In general people should have equal access to treatment but priority should be given to prevention and treatments that generate the most health. Individual characteristics of patients, such as their age, gender or income and financial contributions to the health care system in the past should not be used to prioritise between them.</p>

Table 2 Sample description (total and by country)

Variable		Total (n=33,515)	Denmark (n=4,368)	France (n=3,271)	Hungary (n=3,779)	Netherlands (n=4,207)	Norway (n=3,297)	Poland (n=3,599)	Spain (n=4,071)	Sweden (n=4,103)	UK (n=2,820)
Age in years mean(s.d)		44.3 (15.3)	48 (15.7)	44.2 (14.8)	41.4 (13.7)	47.8 (15.1)	44 (15.4)	38.1(13.5)	40.9 (13.8)	46.7 (15.8)	47 (16.1)
Sex	Male	15,797 (47.9%)	2,106 (48.2%)	1,505 (46%)	1,630 (43.1%)	2,000 (47.5%)	1,739 (52.7%)	1,726 (48%)	2,005 (49.3%)	1,784 (43.5%)	1,302 (46.2%)
	Female	17,718 (52.1%)	2,262 (52.2%)	1,766 (54%)	2,149 (56.9%)	2,207 (52.5%)	1,558 (47.3%)	1,873 (52%)	2,066 (50.7%)	2,319 (56.5%)	1,518 (53.8%)
Marital status ^a	Living alone	11,979 (35.7%)	1,568 (36.5%)	1,178 (36.4%)	1,190 (32.3%)	1,470 (35.8%)	1,095 (34%)	1,175 (33.2%)	1,622 (40.2%)	1,591 (39.9%)	1,090 (39.1%)
	Living with a partner	20,848 (62.2%)	2,723(63.5%)	2,058 (63.6%)	2,495 (67.7%)	2,639 (64.2%)	2,127 (66%)	2,366 (66.8%)	2,350 (59.2%)	2,392 (60.1%)	1,698 (60.9%)
Children ^{b,c}	No	22,754 (68.0%)	3,151 (72.2%)	2,103 (64.3%)	2,438 (64.7%)	3,139 (74.7%)	2,185 (66.3%)	2,161 (60.1%)	2,623 (64.5%)	2,912 (71%)	2,042 (72.4%)
	Yes	10,739 (32.0%)	1,215 (27.8%)	1,167 (35.7%)	1,333 (35.3%)	1,065 (25.3%)	1,110 (33.7%)	1,436 (39.9%)	1,446 (35.5%)	1,189 (29%)	778 (27.6%)
Education level ^d	Low	4,207 (12.6%)	669 (15.3%)	351 (10.7%)	930 (45.3%)	506 (12%)	240 (7.3%)	32 (1.6%)	810 (19.9%)	389 (9.5%)	280 (9.9%)
	Middle	13,164 (39.3%)	1,713 (39.2%)	1,474 (45.1%)	752 (19.9%)	1,727 (41.1%)	1,257 (38.1%)	820 (42%)	1,762 (43.3%)	1,877 (45.8%)	1,782 (63.3%)
	High	12,752 (38.0%)	1,983 (45.4%)	1,443 (44.2%)	371 (18.1%)	1,972 (46.9%)	1,798 (54.6%)	1,099 (56.3%)	1,496 (36.8%)	1,833 (44.7%)	757 (26.9%)
Employment status ^e	Employed full-time	15,255 (45.5%)	1,872 (42.9%)	1,351 (41.3%)	2,157 (57.2%)	1,489 (35.4%)	1,727 (52.4%)	2,074 (57.7%)	1,849 (45.5%)	1,716 (41.9%)	1,020 (36.2%)
	Employed part-time	3,344 (10.0%)	369 (8.5%)	302 (9.2%)	220 (5.8%)	749 (17.8%)	357 (10.8%)	251 (7%)	332 (8.2%)	374 (9.1%)	390 (13.8%)
	Working in the home	3,215 (9.6%)	54(1.2%)	280 (8.6%)	195 (5.2%)	438 (10.4%)	69 (2.1%)	151 (4.2%)	271 (6.7%)	71 (1.7%)	257 (9.1%)
	Not working	1,786 (5.3%)	370 (8.5%)	434 (13.3%)	341 (9%)	255 (6.1%)	115 (3.5%)	236 (6.6%)	787 (19.3%)	425 (10.4%)	252 (8.9%)
	Retired/unable to work/ disabled	7,184 (21.4%)	1,295(29.7%)	746 (22.8%)	629 (16.7%)	1,011 (24%)	696 (21.1%)	413 (11.5%)	487 (12%)	1,110 (27.1%)	797 (28.3%)
	Student	2,705(8.1%)	405 (9.3%)	157 (4.8%)	229 (6.1%)	263 (6.3%)	331 (10%)	471 (13/1%)	342 (8.4%)	403 (9.8%)	104 (3.7%)
Health	Low	9,924 (29.6%)	1,096 (25.1%)	980 (30.0%)	1,584 (42.0%)	1,172 (27.9%)	868 (26.3%)	1,236 (34.4%)	880 (21.6%)	1,149 (28.0%)	959 (34.0%)
	Middle	8,186 (24.4%)	1,001 (22.9%)	910 (27.8%)	771 (20.4%)	1,001 (23.8%)	837 (25.4%)	915 (25.4%)	1,048 (25.8%)	1,101 (26.8%)	602 (21.3%)
	High	15,383 (45.9%)	2,269 (52.0%)	1,380 (42.2%)	1,416 (37.5%)	2,032 (48.3%)	1,590 (48.3%)	1,445 (40.2%)	2,141 (52.6%)	1,851 (45.1%)	1,259 (44.6%)

Notes: ^a 688 (2.1%) missing values. ^b 22 (0.1%) missing values. ^c mean (for those with children) = 1.7 (range 1-15). ^d 3,392 (10.1%) missing values. ^e 26 (0.1%) missing values. ^f two sub-samples received different health questions, either EQ-5D 3L (n=19,440) or EQ-VAS (n=14,053); a health score ranging between 0 (lowest) and 10 (highest) was computed as follows: [10 - sum EQ-5D dimension scores] or [VAS score divided by 10].

Table 3 Descriptive statistics and correlations between scores on viewpoints

	Descriptive statistics						Correlations			
	Range	Mean	SD	Med	Skewness	Kurtosis	II	III	IV	V
Viewpoint I: "Egalitarianism, entitlement and equality of access"	1 - 7	5.7	1.50	6	-1.261	0.66	.31	.03	.14	.18
Viewpoint II: "Severity and the magnitude of health gains"	1 - 7	5.3	1.51	5	-0.87	0.30		.12	.34	.25
Viewpoint III: "Fair innings, young people and maximising health benefits"	1 - 7	4.0	1.74	4	-0.10	-0.88			.23	.22
Viewpoint IV: "The intrinsic value of life and healthy living"	1 - 7	4.9	1.62	5	-0.66	-0.22				.18
Viewpoint V: "Quality of life is more important than simply staying alive"	1 - 7	5.0	1.65	5	-0.72	-0.21				

Table 4 Results of matching respondents to viewpoints based on highest (untied) score and follow up question

		Matched to Viewpoint						Total
		I	II	III	IV	V	None	
Viewpoint I: “Egalitarianism, entitlement and equality of access” (<i>highest score</i>)		6,894	0	0	0	0	0	6,894
Viewpoint II: “Severity and the magnitude of health gains” (<i>highest score</i>)		0	1,988	0	0	0	0	1,988
Viewpoint III: “Fair innings, young people and maximising health benefits” (<i>highest score</i>)		0	0	722	0	0	0	722
Viewpoint IV: “The intrinsic value of life and healthy living” (<i>highest score</i>)		0	0	0	2,024	0	0	2,024
Viewpoint V: “Quality of life is more important than simply staying alive” (<i>highest score</i>)		0	0	0	0	2,239	0	2,239
Matched without need for tiebreak (N)		6,894	1,988	722	2,024	2,239		13,867
Matched without need for tiebreak (%)		50	14	5	15	16		100
Matched using follow-up question (N)		7,843	3,579	701	3,218	3,369	938	19,648
Matched using follow-up question (%)		40	18	4	16	17	5	100
Total (N)		14,737	5,567	1,423	5,242	5,608	938	33,515
Total (%)		44.0	16.6	4.2	15.6	16.7	2.8	100
% by country *	Denmark	47.7	14.0	4.3	15.2	17.2	1.6	-
	France	47.6	12.0	4.7	10.8	21.8	3.1	-
	Hungary	35.4	20.0	4.2	19.8	17.1	3.4	-
	Norway	46.1	16.2	5.6	16.4	14.1	1.6	-
	Poland	47.7	19.1	4.2	19.1	6.5	3.5	-
	Spain	41.8	16.7	5.1	15.1	18.1	3.1	-
	Sweden	51.5	14.4	3.5	15.0	12.9	2.7	-
	The Netherlands	36.6	20.5	2.6	11.0	25.0	4.3	-
	UK	41.3	16.1	4.5	19.7	17.0	1.4	-

Note: Respondents are named *pure type* in case they gave their highest score to only one viewpoint and, accordingly, could be matched to a viewpoint directly. Remaining respondents were matched to the viewpoint that was most like theirs using a follow-up question (see Supplementary Materials Annex 1). * Minimum and maximum scores per viewpoint across countries are printed in bold.

Table 5 Results of logistic regressions examining relationship between assignment to viewpoint and sociodemographic characteristics and country of origin

Characteristic	Viewpoint									
	I		II		III		IV		V	
	O.R.	P	O.R.	P	O.R.	P	O.R.	P	O.R.	P
Age (years)	1.004	<0.001	.991	<0.001	.983	<0.001	.996	<0.001	1.010	<0.001
Sex (female)	1.280	<0.001	.936	.038	.638	<0.001	.747	<0.001	1.051	.117
Partner (yes)	.981	.461	1.031	.382	.965	.577	1.112	.004	.944	.089
Children (yes)	.971	.289	1.029	.431	1.084	.222	1.125	.002	.911	.013
Education (middle)	.973	.466	.999	.987	.997	.976	1.170	.005	.982	.718
Education (high)	.891	.003	.974	.615	.809	.027	1.382	<0.001	1.098	.061
Employed (yes)	.915	<0.001	1.052	.126	.898	.080	1.081	.025	1.075	.030
Health (middle)	.940	.060	1.007	.882	.937	.421	1.285	<0.001	.982	.670
Health (high)	.891	<0.001	.961	.302	.912	.196	1.529	<0.001	.913	.016
Country ^a										
Denmark	1.657	<0.001	1.264	.001	1.670	<0.001	1.506	<0.001	3.081	<0.001
France	1.667	<0.001	-	-	1.811	<0.001	-	-	4.294	<0.001
Hungary	-	-	1.923	<0.001	1.355	.055	2.206	<0.001	-	-
Norway	1.638	<0.001	1.419	<0.001	2.116	<0.001	1.526	<0.001	3.083	<0.001
Poland	1.878	<0.001	1.690	<0.001	1.305	.091	1.733	<0.001	2.513	<0.001
Spain	1.351	<0.001	1.441	<0.001	1.776	<0.001	1.460	<0.001	3.559	<0.001
Sweden	1.924	<0.001	1.285	<0.001	1.373	.017	1.497	<0.001	2.182	<0.001
The Netherlands	1.051	.399	1.988	<0.001	-	-	1.027	.727	4.907	<0.001
UK	1.246	<0.001	1.461	<0.001	1.682	<0.001	2.207	<0.001	3.086	<0.001
Constant	.481	<0.001	.202	<0.001	.088	<0.001	.088	<0.001	.042	<0.001

Dependent variables: assigned to viewpoint (binary yes, no).

^a in each regression, the reference country is the one with the lowest proportion respondents assigned to that viewpoint

(see Table 4): Hungary for viewpoint I & V; France for viewpoints II & IV and The Netherlands for viewpoint III.

Figure 1 Scores on the five viewpoints (n=33,515)

Viewpoint II: "Severity and the magnitude of health gains"

Viewpoint III: "Fair innings, young people and maximising health benefits"

Viewpoint IV: "The intrinsic value of life and healthy living"

Viewpoint V: "Quality of life is more important than simply staying alive"