

# **It takes a giraffe to see the big picture - Citizens' view on decision makers in health care rationing**

Mari Broqvist and Peter Garpenby

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## **Cover page**

### **It takes a giraffe to see the big picture – citizens' view on decision makers in health care rationing**

Mari Broqvist and Peter Garpenby

Department of Medical and Health Sciences, The National Centre for Priority Setting in Health Care, Linköping University, Linköping, Sweden

Correspondence: Mari Broqvist, The National Centre for Priority Setting in Health Care, Linköping University, SE- 581 83 Linköping, Sweden. [mari.broqvist@liu.se](mailto:mari.broqvist@liu.se)

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## **Abstract**

Previous studies show that citizens usually prefer physicians as decision makers for rationing in health care, while politicians are downgraded. The findings are far from clear-cut due to methodological differences, and as the results are context sensitive they cannot easily be transferred between countries. Drawing on methodological experiences from previous research, this paper aims to identify and describe different ways Swedish citizens understand and experience decision makers for rationing in health care, exclusively on the programme level. We intend to address several challenges that arise when studying citizens' views on rationing by (a) using a method that allows for reflection, (b) using the respondents' nomination of decision makers, and (c) clearly identifying the rationing level. We used phenomenography, a qualitative method for studying variations and changes in perceiving phenomena. Open-ended interviews were conducted with 14 Swedish citizens selected by standard criteria (e.g. age) and by their attitude towards rationing.

The main finding was that respondents viewed politicians as more legitimate decision makers in contrast to the results in most other studies. Interestingly, physicians, politicians, and citizens were all associated with some kind of risk related to self-interest in relation to rationing. A collaborative solution for decision making was preferred where the views of different actors were considered important. The fact that politicians were seen as appropriate decision makers could be explained by several factors: the respondents' new insights about necessary trade-offs at the programme level, awareness of the importance of an overview of different health care needs, awareness about self-interest among different categories of decision-makers, including physicians, and the national context of long-term political accountability for health care in Sweden. This study points to the importance of being aware of contextual and methodological issues in relation to research on how citizens experience arrangements for rationing in health care.

Key words:

Sweden; health care; rationing; programme level; decision maker, citizens' view; interview; phenomenography.

## **Introduction**

To impose restrictions on health services is agonizing for everyone involved – decision makers as well as those affected by the decisions. When available resources fail to meet public expectations, efforts to regulate the consumption of health services turn into political drama, which challenges health care as a right. Setting limits in health care tends to evoke strong feelings of injustice among citizens. Since justice plays a major role in all social relations, it is commonly alleged to be essential that people perceive the process (Daniels & Sabin 1997) or the outcome (Beauchamp & Childress 1994) related to limit setting as fair. Yet another crucial component – apart from process and outcome – in the concept of democratic legitimacy is public confidence in those who decide; a single decision maker or those included in a decision-making arrangement (Peter 2009). Having said this, it is not surprising that scholars' interest in citizens' perceptions of rationing in health care has increased, not least concerning the issue of who the decision maker should be. This paper reports selected findings from a study on Swedish citizens' views about justice in resource allocation and issues related to rationing. Perceptions on what brings about acceptance for standing aside in public health care have been reported elsewhere (Anonymous 2014). In this paper we focus on the complicated issue of who should decide on the rationing of health services.

The dominant picture in previous research on this topic seems to be that citizens prefer physicians as decision makers for rationing in health care (Richardson et al 1992, Myllykangas et al 1996, Bowling 1996, Kneeshaw 1997, Busse 1999, Litva et al 2002,

Wiseman et al 2003). Some studies indicate that citizens themselves believe they could have a role in rationing decisions (Bowling et al 1993, McIver 1998), while politicians are seldom mentioned as important actors (Bowling et al 1993, Wiseman et al 2003). Few studies have reported Swedish citizens' views on appropriate decision makers, but they show results similar to those mentioned above (Mossialos & King 1999, Rosén 2006, Werntoft et al 2007).

Although the results are seemingly consistent, the findings are far from clear-cut. Hence, this should be treated as a complicated area of research. Other researchers have identified at least four problems with interpreting the results. First, that rationing is carried out on multiple levels, which complicates the issue. Litva et al (2002), distinguishing between three different levels, explained that citizens' views might vary according to the level being addressed. Making decisions at the systems level refers to different welfare systems, e.g. education, culture, health care, and infrastructure. At the programme level, the choices are between groups of patients or population groups with different needs. Furthermore, at the patient level the choices are between individuals and their treatments. Most studies reporting on citizens' views of decision makers do not differentiate between those levels – as is the case in all studies reporting from the Swedish context. Questions like “*With whom should the responsibility of health care rationing rest?*” provide little clue to respondents regarding what rationing is all about (Wiseman et al 2003). Litva et al (2002) focus on public involvement in rationing and highlight the importance of specifying the decision level. Mitton et al (2009) point to the programme level as under-researched with regard to studies of citizens and priority setting. Accordingly, the focus of this paper is exclusively on rationing at the programme level.

Secondly, *rationing* and *priority setting* are elastic concepts, often used interchangeably. In

surveys, failing to clearly distinguish between situations of priority setting in general and rationing in particular make it difficult to depict public judgements (Busse 1999). We use *priority setting* to denote a process of scoring or ranking that could be used for disinvestments as well as investments, while rationing is entirely about limiting the possibilities to optimally satisfy health care needs. In this study we address issues related to rationing.

Thirdly, scholars have drawn attention to the differences in questions about citizens' willingness to participate in rationing processes (Bowling 1996, Mossialos & King 1999, Litva et al 2002, Lee et al 2002, Wiseman et al 2003). In the 1960s Arnstein pointed to the importance of clarifying the degree of participation, ranging from manipulation to real control (Arnstein 1969). Without this information, the results related to citizen participation in rationing would be difficult to interpret and compare. In this study, however, we take a broader view on the choice of appropriate decision makers – beyond just the degree of public involvement.

Fourthly, studies of appropriate decision makers often present citizens with hypothetical rationing situations (Heginbotham 1993, Busse 1999, Mossialos & King 1999, Litva et al 2003, Wiseman 2005). Traditionally, such studies (including those reporting from the Swedish context) have used closed questions where respondents were asked to choose between alternatives, e.g. physicians, politicians, patients, relatives, health service managers, health insurers, and the public (Bowling 1996, Busse 1999, King et al 1999, Dolan et al 1999, Mossialos & King 1999, Wiseman et al 2003, Rosén 2006, Werntoft et al 2007). Arguments for a more open-ended approach allowing for the exploration of alternative decision makers in rationing situations have been put forward (Coast 2001). Moreover, some scholars claim

that surveys that fail to give respondents the opportunity for reflection are of doubtful value (Dicker & Armstrong 1995, Dolan et al 1999, Busse 1999, Litva et al 2002, Wiseman et al 2003). It is worth noting that most studies in this research area are surveys using quantitative data, aiming to generalize the result to the population level. In line with Coast (2001) we argue that quantitative and qualitative studies should be looked upon as complementary. The latter are particularly useful for understanding the reasoning behind complex phenomena like rationing, not least regarding decision making and decision makers.

We found four studies that in one way or another address the methodological issues highlighted above, which in turn is reflected in their design. In contrast to our study, however, three of them focus particularly on citizens' preferences for public involvement in rationing situations (Litva et al 2002, Bruni 2010, Coast 2001). The remaining study by McKie et al (2008) used focus group interviews to compare the views of citizens with those of health professionals and administrators at three different decision levels. Here the study participants favoured a solution that involved a range of parties collaborating, viewing this as the best approach towards making decisions for rationing. However, this study reports results from a health care context that differs from the Swedish; namely that in Australia. Wiseman (2003) noted that public preferences on limit setting in health care are not necessarily the same worldwide. Hence, the results from one country cannot easily be generalized to another national context (Busse 1999, Coast 2001). Following Mossialos and King (1999), we argue that perceptions on rationing should be interpreted within a political, cultural, and time context. Our findings should be considered within the Swedish context, which is characterized by universal health care funded mainly by taxes, where responsibility for providing health services rests with 21 directly elected regional bodies (county councils). Political responsibility for health service delivery has a long tradition in Sweden (Ham 1992,

Magnussen et al 2009). Hence, regional politicians are formally accountable to the public for distribution between different service areas at the programme level. Resource allocation decisions at the regional level are supported by national guidelines for clinical standards and ethical principles for priority setting decided by the Parliament (Socialdepartementet 1996/97). It is worth noting that in Sweden, as in many other countries, the public is only marginally involved in health policy making (Coulter & Docteur 2012, Sabik & Lie 2008). In summary, previous studies point to the importance of clarifying the decision level, clearly distinguishing between rationing and other phenomena related to limit setting, allowing for participants to reflect freely on appropriate decision makers, and being aware of contextual influences. Drawing on these experiences, this paper aims to identify and describe different ways Swedish citizens understand and experience decision makers when it comes to rationing in health care at the programme level.

## **Material and methods**

To examine how citizens understand and experience decision makers, we analysed qualitative interview data using phenomenography. Instead of focusing on finding the most representative views, this inductive method aims at capturing *variations* in how people experience a phenomenon. In contrast to what is the case in some other qualitative methods (e.g. phenomenology), *experience* could encompass conceptual thoughts about the phenomenon being studied, not just “lived” experience. The method is built on the epistemological assumption that there are a limited number of qualitatively different ways to understand and experience a phenomenon, and that those thoughts could change, due to new insights. In phenomenography, the objective is to disclose variations (and changes) as collective experience, regardless of whether these appear within or between individuals. The results are presented as a few core descriptive categories of variations, each built by similar



perceptions or conceptions and the so-called outcome space descriptive of how these categories relate to each other. This method does not strive to tell anything about the prevalence of different understandings; it strives to show variations of experience that *could* exist among people with the same characteristics and in the same context as in the current study (Marton & Booth 1997, Barnard et al 1999). Although this approach is unusual in health care research, some scholars argue that it has the potential to demonstrate how people understand and experience health care and health care systems (Barnard et al 1999, Brammer 2005).

### *Respondents' selection*

The sampling process in phenomenographic studies focuses on finding variations. In the present study these variations concern attitudes related to rationing in health care. Mossialos and King (1999), when studying the link between attitudes towards rationing and standard variables such as age, gender, employment status, political ideology, and health status, found that associations between some variables were confirmed (e.g. education level) in some countries – but not in all cases and settings. In the absence of solid evidence for correlations between attitudes and standard variables we decided to use a two-step sampling technique. First we used non-proportional quota sampling when respondents answered a questionnaire. The questionnaire addressed nine quota groups mirroring different groups in society; two work sites requiring university education (high technology and culture) and three requiring upper secondary education (trade, agriculture, and mechanical engineering), a pensioners' club, a project for young unemployed arranged by the Swedish Public Employment Service, a university, and an immigrant organization. We distributed 124 questionnaires to these groups along with written information about the study. The questionnaire (which was used only for the sampling process) included four questions focusing on the broader aim of the project

(justice in health care, resource allocation, and rationing). We received 72 questionnaires in return, resulting in 9 different combinations of answers (of 24 possible). Regarding the question related to decision makers, health care staff was the most frequent respondent type (Table 1).

**Table 1** Respondent types represented among those interviewed.

Respondent type	Who should decide about rationing?	Is transparency important in priority setting?	Could we gain general, accepted allocation?	Is health care equal today?	Number interviewed
Type 1	Politicians	Yes	Yes	Yes	2
Type 2	Politicians	Yes	Yes	No	2
Type 3	Health care staff	No	Yes	Yes	1
Type 4	Health care staff	Yes	No	Yes	1
Type 5	Health care staff	Yes	Yes	No	3
Type 6	Health care staff	Yes	No	No	2
Type 7	Health care staff	No	No	Yes	1
Type 8	Health care staff	Yes	Yes	Yes	2
Type 9	Citizens	Yes	Yes	No	1

In the second step we conducted a purposeful sampling, drawing on the nine types answering the questionnaire. Some of the nine respondent types were represented by one person only, who was automatically included in the study. No exclusion criteria were used. For the types represented by more than one person, we chose step-by-step randomly, by lottery, respondents from stratified groups to secure variations in gender, age, and employment. In total, 15 respondents were chosen for interviews. In phenomenographic research a sample size of 15 to 20 has shown to be sufficiently large to reveal most of the possible viewpoints of the phenomena to be studied and makes the data manageable in the analysis phase (Trigwell 2000). Some scholars even regard a minimum of six participants as appropriate in phenomenographic studies (Uljens 1989).

#### *Data collection*

Data were collected through face-to-face, open-ended, single interviews conducted in 2006 by one of the authors (Anonymous). The questions were designed to capture how respondents

understand and experience the following topics:

- meaning of “fairness”
- acceptance of delay, dilution, and denial of health care
- appropriate decision makers in times of rationing
- appropriate decision-making process
- public involvement in decision making.

Three pilot interviews were conducted, resulting in minor adjustments before the main study commenced. Two questions about decision makers were posed to the participants, starting with an open one: “*Who should decide on rationing in health care?*” While the interest of this study focused on the programme level, and no participants spontaneously mentioned that level, the interviewer continued by asking all participants the same following question: “*In rationing situations, who should decide about resource allocations between different services, e.g. resources for paediatric and geriatric care or between mental and cancer care?*” These are service areas that could be assumed to be well-known in Sweden, and other studies have used similar questions in linking to the programme level (Coast 2001, Litva et al 2002). Follow-up questions dealt only with deepening the understanding of a given answer and stimulating further reflections, such as; “*Tell me more about this, give me an example*”. In addition to the follow-up questions, we used projective questions to ask respondents how they thought citizens in general reasoned about decision making for rationing. Here our intention was to capture opinions that were not directly stated. Apart from the questions, no information was given, and expressions of agreement or disagreement from the interviewer were avoided. The interviews lasted 30 to 70 minutes and were conducted at sites chosen by the respondents.

### *Data analysis*

All interviews were digitally recorded and fully transcribed verbatim. Following what is customary in phenomenography, all of the transcripts were treated as a single unit, constituting the empirical material for the data analysis. As a first step of analysis we familiarized ourselves with the material by repeatedly re-reading the transcript. Although not all questions directly addressed the decision-maker theme, all material was read while considering the entire context as essential in phenomenography. Secondly, we compiled significant citations concerning decision makers by marking these citations in the text and sorting them into preliminary categories of similar answers. These categories were compared with each other to find qualitative differences in the understanding of decision makers. Up until this step the authors separately analysed the material, but to establish the categories we jointly discussed the analysis. After having established the relationships between the categories we finally named them (Dahlgren & Fallsberg 1991).

Verbatim quotes were used to support the relevance of the categories chosen. We also used member checking when the 14 respondents were invited to comment. Of these, seven responded to invitations (sent by letter) to read and confirm that the analysis represented their perceptions. One comment was given, but not associated to decision makers.

### *Ethics*

In compliance with Swedish legislation on ethics in research, and when recruiting respondents outside of a health care setting (Socialdepartementet 2003), all respondents were assured of anonymity and confidentiality and were requested to give their informed consent

before answering the questionnaire and being interviewed. Only the research team had access to the raw data, which were protected as confidential.

## Results

### *Respondents*

Fourteen persons (5 men and 9 women) were interviewed after one woman had cancelled the interview. As the last to be interviewed she was not replaced since we already had two persons representing her type of answers to the questionnaire. Table 2 presents the characteristics of the respondents.

**Table 2** Characteristics of interviewed respondents.

Occupational group	Total	Men	Women	Age 18- 29	30- 39	40- 49	50- 59	60- 69	70- 79	>80
Non-manual employment	4	2	2	0	2	1	1	0	0	0
Manual employment	3	1	2	0	0	3	0	0	0	0
Student	1	0	1	1	0	0	0	0	0	0
Retired	3	2	1	0	0	0	0	2	1	0
Unemployed	3*	0	3	3	0	0	0	0	0	0

\* Including 2 respondents from an immigrant organization

### *Main findings*

Our material identifies four categories describing variations in how decision makers for rationing on the programme level are experienced and understood:

- Decision makers as a necessity for control of rationing
- Decision makers as an unreflected institution
- Decision makers as a risk for unfairness
- Decision makers as a collaborative arrangement

In phenomenography, perceptions can relate to each other as either equal or hierarchical. Hierarchical perceptions are increasingly inclusive, as is the case in this study. This means that categories further up in the hierarchy include perceptions from lower categories (Marton & Booth 1997, Barnard et al 1999). Here they are presented from the least to the most complex category. The result also includes descriptions of changes, expressed by the respondents and associated with the choice of decision makers. As is customary in phenomenographic studies, the results will not be reported in quantitative terms. Hence, the perceptions reported here could emanate from one person or from all of the respondents.

### ***Decision makers as a necessity for control of rationing***

This basic category is made up of understandings that limitations in health care exist and that decision makers are a necessity for handling rationing. Perceptions of health care needs as endless were present, and increasing expectations for a long and healthy life of high quality were felt to escalate the demands for health care. This category includes serious doubts on whether resources would ever be enough to cover needs, and rationing was viewed as inevitable.

*“...they can't do everything for everyone because all must be financed by the public system.”(R13)*

*“...there are not enough resources. You must accept that. You can't expect magic.”(R12)*

Acknowledgement of limited resources leads to a call for decisions to be made, and under those circumstances decision makers for rationing were perceived as a necessity in handling resources.

*“We can't offer health care to everyone that has a health care need, so we must establish some system for making decisions.”(R2)*

*“ There must be people who decide how resources should be allocated.”(R1)*

### ***Decision makers as an unreflected institution***

Despite awareness of the necessity for control of rationing, the core of this category suggests that rationing at the programme level is unknown and thereby perceived as an unreflected institution when it comes to decision makers. The options for dealing with resource limitations on a group level were virtually unknown and came as a surprise. Faced with the question of who should decide about rationing between geriatric and paediatric care or between mental and cancer care respondents could express confusion.

*"I don't know how this [decision making] is worked out today."(R1)*

*"It has never occurred to me that someone has to decide how much money should be spent on treating cancer versus geriatric care...strange really."(R3)*

In contrast, the material acknowledged rationing both on the system and patient levels. At the system level, rationing health care could be described as necessary to enable other needs in society, e.g. culture or education. Rationing at the system level was also reflected upon in terms of not spending money on items perceived as unnecessary, in contrast to health care. Politicians were said to play a self-evident role in such decisions.

*"There would be many more resources for health care if we did not spend them on motorways or on applications to arrange the Olympic Games."(R2)*

*"Politicians must provide resources to the public health care sector [in the competition with other welfare sectors]".(R14)*

Furthermore, rationing on the patient level was spontaneously mentioned as an example of limitations that can occur in health care. While politicians were preferred on the system level, physicians were nominated at the patient level.

*"When I was going to have plastic surgery I was fully aware that I would have to wait for this, no problem. I understand if someone hurt himself badly in the face or something, he should of course have higher priority."(R5)*

*"Closer to the patient, the physicians must decide what to do or not to do, what you could ration or not."(R11)*

### *Decision makers as a risk for unfairness*

This category describes the risk for unfairness associated with decision makers on the programme level, and encompasses awareness of the need for decision makers for rationing at this level. Each aspect of risk could be associated with different kinds of unfairness and various decision makers (Table 3).

**Table 3.** Illustration of category: Decision makers as a risk for unfairness.

<b>Unfairness associated with decision making on rationing</b>	<b>Risk for unfairness</b>	<b>Aspects of risk</b>	<b>Decision maker associated with the risk</b>
Not resources according to needs Not the same amount of health care No majority acceptance for the result	Lack of competence	Lack of medical knowledge	Politicians Citizens
		Lack of experience-based knowledge	Politicians
		Lack of overview over health care needs	Physicians
	Self-interest	Self-interest in own health care	Citizens Politicians
		Self-interest in being re-elected	Politicians
		Self-interest in own working domain	Physicians
	Lack of courage	Avoiding not being re-elected	Politicians

Although fairness was perceived as something highly individual and not really possible to define uniformly, there were also perceptions of fairness as a collective feeling, formed by norms and political values in society.

*"We are living in a society where justice is connected with democracy. In Sweden, a long period with Social Democrats in government has shaped the publics' perception of justice and expectations on the welfare system. Views on justice reflect the society you live in." (R11)*



The different views on potential unfairness related to decision making in rationing were: if the majority does not accept how resources are used, if people do not receive resources according to their needs, or if everyone does not receive an equal share of health care.

Unfairness could become a reality if the decision maker;

- lacks the necessary competence
- is driven by self-interest
- lacks the courage to act.

**Lack of competence** includes a lack of medical knowledge, lack of experience-based knowledge, and the absence of a good overview of health care needs. Lack of *medical knowledge* was related to limited knowledge about the severity of diseases and appropriate treatments. This risk was associated with both politicians and citizens. Concern was expressed about political will without medical knowledge.

*“Politicians don’t know anything about treatments, or medical things like that.*

*How could they decide about rationing, I don’t understand.”(R1)*

*“Politicians are elected as councillors in the county councils without*

*knowing anything. The only thing they have is their labels.”(R8)*

Respondents considered it all too easy for citizens to have an opinion about health care without having the necessary medical knowledge. Hence, much of the public’s opinion on health care was perceived to be pure speculation.

*“It’s easy to form opinions about health care without knowing the facts.*

*It’s very easy.”(R8)*

*“An opinion could be expressed without having solid grounds because*

*you are an amateur.”(R2)*

The lack of necessary competence referred not only to a lack of theoretical medical knowledge, but also limited *experience-based knowledge*. This risk was mentioned in relation to politicians who were felt to lack real experience in the functioning of the health service.

*“How many politicians know what the routines are in a nursing home?  
How many know how a casualty department is functioning? At the hospital,  
what is a day like for the patient? [How could they know] if they hadn't been  
sick themselves?”(R8)*

The lack of an *overview of health care needs* at the programme level was yet another concern for decision making in this category. It refers to the risk of losing perspective and approaching rationing with a too limited scope, failing to consider all relevant alternatives between patient groups according to their different needs. The material reveals that perceptions about this risk were linked entirely to physicians.

*“I don't think they [physicians] know about the needs within other specialities, they don't have the necessary overview.”(R1)*

Yet another risk associated with decision makers at the programme level was *self-interest*, viewed as an obstacle against fair rationing. This risk was associated with all types of decision makers, but in different ways, e.g. self-interest related to one's own health care problems, to not being re-elected, and to one's own working domain. Self-interest *in one's own health care problems* was related both to citizens and politicians.

*“I would not be able to answer what's best to ration...I don't want to ration health care that I need for myself. I'm selfish, like all of us.”(R12)*  
*“That they [decisions about rationing] are not the best for the politician's daughter or the politician's mother, but best for as many people as possible.”(R2)*

Moreover, politicians could be regarded as driven by self-interest when trying *to be re-elected* by making “popular” rather than “hard” decisions.

*It's (only) about getting their name in the newspaper; “This I have decided, this is my thing....no it isn't, it's my idea” ... you know how politicians are.”(R7)*

The material revealed descriptions of physicians as wanting to acquire a maximum of resources for their *own working domain*, sometimes at the expense of other patient groups. In the interviews this was described as a new insight emanating from awareness about choices

that had to be made between resources for different patient groups. This reasoning led to a reconsideration of the appropriate decision maker at the programme level and a move away from physicians towards politicians.

*"The same goes for physicians and health care staff. That won't do, it's too biased in some way because physicians and health care staff all want all resources on their own table. If you are working at the emergency [department] you want all money for this sector." (R11)*

*"Thinking about how to allocate resources I start to wonder if physicians are so appropriate as I thought from the start.....How do you mean?[interviewer]....Well, each speciality in health care considers their clinics to be the most important...they don't ration themselves." (R1)*

The last risk mentioned regarding decision makers was the ***lack of courage*** to act. Politicians were perceived as lacking the courage to stand up for rationing decisions, despite the possibility to please the public as a whole.

*Citizens held such different views ...you can't expect everyone to Accept it [rationing]. (R5)*

### ***Decision makers as a collaborative arrangement***

The most complex category, which includes both awareness of resource limitations and needs for rationing on the programme level, describes the understanding of decision makers as a collaborative arrangement, i.e. as a strategy for controlling the risk for unfairness. Owing to the different risks associated with decision makers at the programme level, difficulties arose in identifying one single decision maker for rationing on this level that could be assumed to be fair.

*"Who should that person be? One who has qualifications both as a politician and a health professional... a skilled physician with a political mind? No, I don't think that single person exists." (R12)*

*"It takes a giraffe, one who has a high neck enabling him*

*to see the big picture, has an overview and at the same time the biggest heart.”(R10)*

In light of those risks, and with the aim to achieve a fair rationing process, reflections on various strategies and desirable characteristics of decision makers commenced. Given a lack of competence and, in particular, an inadequate overview of health care needs, decision makers with a broad *overview of health care needs* were sought. The result was another shift in nominating an appropriate decision maker – from physician to politician.

*“It must be hard for them [the doctors] to know about all [services] ...I think I’ll change my answer, politicians are better than physicians...they could distribute money to all kinds of patients.”(R9)*

*“There has to be little more overall so it [rationing] will be more equal, and then you must end up higher somewhere in the county council organization ..... some kind of political director maybe.”(R12)*

It was not deemed necessary to have a strong grasp of medical facts, but more important to have a general awareness about health care and how it functions in practice. Although politicians could be perceived by the participants to have limited theoretical and experience-based knowledge, they could nonetheless collaborate with physicians and other health care staff, thereby securing an adequate foundation for their decisions. All professions in the health service, as well as ordinary citizens with their life experiences, were perceived as able to make important contributions to the health care puzzle.

*“But they [politicians] must consult medical staff, because they are not medically educated.”(R13)*

*“Not just physicians, there are more staff, nurses, and everyone else working in health care that could supplement physicians’ views about patients’ needs. Take advantage of their competence.”(R8)*

*“Anyone who has life experiences.”(R1)*

Acquiring the necessary overview to make rationing decisions was viewed as impossible when involving only one category of decision maker. In the absence of an ultimate decision

maker, a diverse group of *collaborating* decision makers was felt to improve legitimacy. It was considered inappropriate to concentrate power to one category of decision maker (health care staff, citizens, or politicians). In fact, collaboration was seen as extremely important and a means to counteract any tendency towards self-interest. It was also assumed to encourage more *altruism*, which in this context could be interpreted as more concern for the welfare of others.

*"I refer back to my standpoint about the group, because*

*I think that it's dangerous if one person has too much power."*(R2)

*"I think it needs to be a small group, a consultation group...*

*extremely difficult task to consider everything and be impartial...*

*no, you must have cooperation between politicians, staff, and patients...us."*(R10)

*"If the persons who have the power could think altruistic instead of selfish, then*

*we may have fairness [in health care]."*(R2)

Within this category, collaboration could range from an arrangement where a few parties considered proposals in a sort of referral procedure to a situation where all parties played an active role in decision making, but with politicians having the final say; provided that the consultative process also engaged health care staff and citizens. Standing up for unpopular rationing decisions was perceived to be an important characteristic for politicians, being the ones to take the final decisions;

*"It's of course politicians that have the power over money, but I*

*think that you ought to ensure the staff's acceptance for this*

*[rationing] decision."*(R6)

*"I think that one [citizens] should have the right to voice [opinions], but maybe not*

*the final decision or so."*(R4)

*"Actually I think it's rather difficult if you make decisions about*

*rationing which are difficult to accept for the public; you just have*

*to stand up for that decision."*(R5)

Interestingly, the importance of collaboration between different political parties was

highlighted; perceived as unusual today.

*“There is collaboration again. It’s not so important what political party you support, you must put that aside and just work together. No sandbox mentality, but a real, sensible decision.”(R7)*

## **Discussion**

This study addresses the important issue of citizens’ views regarding appropriate decision makers for rationing in health care. As this is – to our knowledge – the first study of its type to focus exclusively on the programme level, its intended contribution is to expand and deepen knowledge regarding how citizens could reflect about appropriate decision makers on this level of rationing. Our main finding was that politicians were viewed as more legitimate decision makers, in contrast to the results from most other studies where physicians are usually favoured (Richardson et al 1992, Myllykangas et al 1996, Bowling 1996, Kneeshaw 1997, Busse 1999, Litva et al 2002, Wiseman et al 2003).

New insight among the respondents about the rationing level, provides an important clue regarding why politicians appear to be appropriate decision makers. The tendency in other studies not to clearly define the decision making level could be one reason why politicians are often disregarded. However, in the study by Litva et al (2002) the participants – after having become aware of the different rationing levels – still preferred professionals to control decision making on the programme level (in this study politicians were hardly mentioned at all). One explanation could be that politicians in Sweden enjoy more public confidence than in some other countries. There are indications of differences between e.g. Sweden and Britain in this respect (SCB 2011, British Social Attitudes 2013). However, the fact that directly elected regional bodies in Sweden have, for many years, been responsible for providing health care is an even more plausible explanation to why the participants viewed politicians

as suitable to manage rationing (see above in Introduction). In England, a country with few locally elected health care politicians, citizens would consequently be less likely to identify politicians as suitable for decision making on the programme level. It is worth noting that McKie et al (2008) in their study from Australia – a country where state governments are responsible for health care – found some support for politicians as decision makers on the programme level. However, in their study the contribution by politicians was motivated mainly by democratic arguments (decisions should reflect public opinions and the public's wishes) while our respondents used other arguments. Although the long-term political accountability for health care in Sweden could be an important factor why politicians were identified at all, the fact remains that they usually rank lower than physicians in surveys on the public's trust in this national context (Holmberg & Weibull 2013).

Hence, to understand the upgrading of politicians, additional aspects linked to the respondents' insights regarding the decision level have to be considered. It is notable that the respondents identified self-interest as a risk for unfairness and should be counteracted. Interestingly, physicians, politicians, and citizens were all associated with some kind of risk related to self-interest. In relation to rationing, politicians are the group usually associated with a risk of acting in self-interest (Williams et al 2012). Respondents in the study by McKie et al (2008) associated self-interest with politicians, and they were also concerned about "strong lobby groups". It is, however, unclear whether the latter group included physicians. Bias in favor of some particular interest is often mentioned as a major obstacle against involving the public in rationing activities (Coast 2001, Litva et al 2002). Strikingly, this argument is seldom used when it comes to physicians and health care staff, and research or public debate seldom touch upon self-interest in this group in relation to limit setting in health care. This could explain why our respondents were surprised by their insight that

physicians could be driven by self-interest. Awareness of self-interest is also an important clue to why a collaborative solution was preferred, where politicians were given a prominent role. In relation to the collaborative solution, however, more puzzle pieces remain to be considered.

Our respondents clearly understood that health care is a knowledge-intensive undertaking (Wickramasinghe et al 2005). To increase fairness in rationing they found it important to underpin decisions with relevant knowledge. Evidence based medicine (EBM) has been intensively discussed and at times criticized on the grounds that the concept does not sufficiently incorporate experience-based knowledge (Dobrow et al 2004). It is noteworthy that citizens participating in our study saw a need to supplement scientific evidence with professional experiences and patients' experiences of their illnesses. Hence, they preferred a multi-professional perspective on rationing; something that is not always present in priority setting and rationing activities in Sweden today (Linander 2011). Respondents also emphasized the need for decision makers to command an overview of different health care needs. This could explain why they ended up favoring a collaborative solution where they felt the views of different participants were important. The importance of a more inclusive, pluralistic, and context-adapted process in relation to rationing in health care has also been discussed by others (Dobrow et al 2004, Williams et al 2012).

As indicated above, we have attempted to address several challenges that arise when studying citizens' views on rationing. We approached this challenge by: (a) using a method that allows for reflection, (b) using the respondents' own nomination of decision makers, and (c) clearly identifying the rationing level. Previous research shows that deliberation, in combination with information (Rosén 2006) or without information (Dolan et al 1999, McKie 2008) on topics



related to priority setting/rationing, could bring about changes in attitudes among the participants. It could be assumed that the result is dependent both on how the deliberation sessions are arranged and on the amount of information given to participants. One important lesson from our study is that individual interviews providing the opportunity for reflection on a topic that is normally not well thought out could make respondents reconsider their views; the most striking example being the shift away from the view of the physician being the most appropriate decision maker at the programme level.

To avoid social desirability bias during the interviews, we refrained from giving any information. However, we could not know if the respondents answered “from the heart” or if they were trying to give “politically correct” answers. We sought to achieve variations in perceptions among respondents by using a particular sampling process, although greater comprehensiveness would have required the inclusion of further participants in the quota-groups. Even so, this might not have yielded greater variation, as most previous research indicates that in surveys citizens place physicians as their first choice.

This study has pointed to the importance of being aware of contextual and methodological issues in relation to research on how citizens experience arrangements for rationing in health care. If we should take the request for consultative arrangements and a more pluralistic process in limit setting seriously, it will be important to further refine the design of research aimed at underpinning such schemes.

## **References**

Arnstein, S. R. (1969). A Ladder of Citizen Participation. *The Journal of the American Institute of Planners* 35 (4): 216-224.

- Barnard, A., McCosker, H., & Gerber, R. (1999). Phenomenography: A Qualitative Research Approach for Exploring Understand in Health Care. *Qualitative Health Research* 9:212-226.
- Beauchamp, T.L., & Childress, J.F. (1994). *Principles of Biomedical Ethics Fourth Edition*, Oxford University Press, New York.
- Bowling, A., Jacobson, B., & Southgate, L. (1993). Health service priorities: Explorations in consultation of the public and health professionals on priority setting in an inner London health district. *Social Science & Medicine* 37: 857-857.
- Bowling, A. (1996). Health care rationing: The public's debate. *British Medical Journal* 312: 670-674.
- Brammer, J. (2005). A phenomenographic study of registered nurses' understanding of their role in student learning—An Australian perspective. *International Journal of Nursing Studies*, 43: 963-973.
- British Social Attitudes (2013). *Trust, politics and institutions*.<http://bsa-30.natcen.ac.uk/read-the-report/key-findings/trust,-politics-and-institutions.aspx>
- Anonymous (2014). Details omitted for double-blind reviewing.
- Busse, R. (1999). Priority-setting and rationing in German health care. *Health Policy*, 50: 71-90.
- Coast, J. (2001). Priority Setting and the Public. *Health Expectations* 4: 75-76.
- Coulter, A., & Docteur, E. (2012). *Patient-Centeredness in Sweden's Health System*. Vårdanalys Rapport 2012:7.
- Dahlgren, L.O., & Fallsberg, M. (1991). Phenomenography as a qualitative approach in social pharmacy research. *Journal of Social and Administration Pharmacy* 8: 150-156
- Daniels, N., & Sabin, J.E. (1997). Limits to health care: fair procedures, democratic

- deliberation and the legitimacy problem of insurers. *Philosophy and Public Affairs* 26: 303-350.
- Dicker, A., & Armstrong, D. (1995). Patients' views of priority setting in health care: An interview survey in one practice. *British Medical Journal* 311: 1137-1139.
- Dobrow, M.J., Goel, V., & Upshur, R.E. (2004). Evidence-based health policy: context and utilisation. *Social Science & Medicine*. 58(1): 207-17.
- Dolan, P., Cookson, R., & Ferguson, B. (1999). Effect of discussion and deliberation on the public's views of priority setting in health care: Focus group study. *British Medical Journal* 318: 916-919.
- Ham, C. (1992). Reforming the Swedish health services: The international context. *Health Policy* 21: 129-141.
- Ham, C., & Coulter, A. (2001). Explicit and Implicit Rationing: Taking Responsibility and Avoiding Blame for Health Care Choices. *Journal of Health Services Research and Policy* 6: 163-169.
- Heginbotham, C. (1993). *Health care priority setting: A survey of physicians, managers and the general public*. In R. Smith (ed.), *Rationing in Action*. London: BMJ.
- Holmberg, S., & Weibull, L. (2013). *Förtroendet för samhällets institutioner. Utvecklingen i Sverige 1986-2012*. SOM-institutets temaserie. 2013:1.[In Swedish]
- Kneeshaw, J. (1997). *What does the public think about rationing? A review of the evidence*. In B. New (Ed.), *Rationing: Talk and action* (pp. 58-76). London: King's Fund.
- Lee, K., Buse, K., & Fustukian, S. (2002). *An introduction to global health policy* in Lee, K., Buse, K., & Fustukian, S. (eds.) *Health Policy in a Globalising World*. Cambridge University Press, Cambridge, pp. 3-17.
- Linander, A. (2011). *Explicit Health Care Priority Setting in Practice - Clinical managers views of performing vertical prioritization in Västerbotten County Council*. Umeå

universitet.

- Litva, A., Coast, J., Donovan, J., Eyles, J., Shepherd, M., Tacchif, J., Abelson, J., & Morgane, K. (2002). 'The public is too subjective': public involvement at different levels of health-care decision making. *Social Science & Medicine* 54:1825-1837.
- Magnussen J., Vrangbaek K., Saltman R.B., & Martinussen P.E. (2009). Introduction: The Nordic model of health care. In: Magnussen J, Vrangbæk K, Saltman R.B. *Nordic Health Care Systems. Recent Reforms and Current Policy Challenges*. Berkshire: Open University Press.
- Marton, F., & Booth, S. (1997). *Learning and Awareness*. Mahwah, NJ: Erlbaum Associates.
- McIver, S. (1998). *Healthy debate? An independent evaluation of citizens' juries in health settings*. London: King's Fund Publishing.
- McKie, J., Shrimpton, B., Hurworth, R., Bell, C., & Richardson, J. (2008). Who should be involved in health care decision making? A qualitative study. *Health Care Analyses* 16: 114-126.
- Mitton, C., Smith, A., Peacock, S., Evoyd, B., & Abelson, J. (2009). Public participation in health care priority setting: A scoping review. *Health Policy* 91:219-228.
- Mossialos, E., & King, D. (1999). Citizens and rationing: analysis of a European survey *Health Policy* 49 (1):75-135.
- Myllykangas, M., Ryyanen, O., Kinnunen, J., & Takala, J. (1996). Comparison of physicians', nurses', politicians' and public attitudes to health care priorities. *Journal of Health Services Research and Policy* 1: 212-215.
- Peter, F. (2009). *Democratic legitimacy*. New York: Routledge.
- Richardson, A., Charny, M., & Hanmer-Lloyd, S. (1992). Public opinion and purchasing. *British Medical Journal* 304: 680-684.
- Rosén, P. (2006). Public dialogue on healthcare prioritization. *Health Policy* 79: 107-116.

- Sabik, L.M. & Lie R.K. (2008). Priority setting in health care: Lessons from the experiences of eight countries. *International Journal for Equity in Health* 7 (4).
- SCB (2011). *Åttapartivalet 2010. Allmänna valen. Valundersökningen*. Stockholm: Statistiska Centralbyrån. [In Swedish].
- Socialdepartementet. (1996/97). *Regeringens proposition Prioriteringar inom hälso- och sjukvården*. Prop 1996/97:60. [In Swedish].
- Socialdepartementet. (2003). *Regeringens proposition. Lag om etikprövning av forskning som rör människor*. Prop 2003:46. [In Swedish].
- Trigwell, K. (2000). A phenomenographic interview on phenomenography. In Bowden, J.A., & Walsh, E. (Eds), *Phenomenography*. Melbourne: RMIT. 62-82.
- Werntoft, E., Hallberg, I., & Edberg, A-K.(2007). Prioritization and resource allocation in health care. The views of older people receiving continuous Public care and service. *Health expectations* 10; 117-28.
- Williams, I., Robinson, S., & Dickinson, H. (2012). Involving the general public in priority setting: experiences from Australia. *Social Science & Medicine* 56 (5): 1001-1012.
- Wickramasinghe, N., Gupta, J., & Sharma, S. (2005). *Creating knowledge-based healthcare organizations*. Publisher: Idea Group Publishing, Hershey, PA, USA.
- Wiseman, V., Mooney, G., Berry, G., & Tang, K.C. (2003). Involving the general public in priority setting: experiences from Australia. *Social Science & Medicine* 56 (5): 1001-1012.
- Wiseman, V. (2005). Comparing the preferences of health professionals and members of the public for setting health care priorities: experiences from Australia. *Applied Health Economics and Health Policy* 4: 129-137.