Asking the public

Citizens' views on priority setting and resource allocation
in democratically governed healthcare

Mari Broqvist

Department of Medical and Health Sciences
Linköping University, Sweden
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It takes a giraffe to see
the big picture

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ABSTRACT

Resource allocation in publicly funded healthcare systems is inevitably linked with priority setting between different patient groups and between different service areas, so-called meso level priorities. Behind every priority-setting decision (investments, reallocating or rationing), are values affecting both the content of the decisions and how the decisions are made. The importance for priority-setting to reflect social values, has been emphasised for the legitimacy of the healthcare systems and the decision makers. Also important, if supposed to provide enough guidance in practice, is that content values, expressed in ethical principles and criteria, are further operationalised. Few studies exist where Swedish citizens have been asked about priority setting and rationing at meso level, and findings from other countries cannot automatically be transferred to the Swedish context.

The overall aim of this thesis is to extend and deepen the knowledge of the Swedish citizens' views on acceptance of rationing in healthcare, on appropriate decision makers for rationing, and on the severity criterion for priority setting. Two qualitative and one mix-method study were conducted, where citizens were interviewed. Citizens' views on severity were also compared, both with a Severity Framework, derived from parliamentary-decided ethical principles and used for resource allocation, and with health professionals' and politicians' ranking of different aspects of severity in a quantitative, survey study.

Study I shows that citizen participants perceived that acceptance of rationing at meso level is built on the awareness of priority-setting dilemmas between patient groups. No such spontaneous awareness was found. Depending on reactions of self-interest or solidarity, acceptance was also perceived to be built on acceptable principles for rationing and/or access to alternatives to public care. Study II shows that awareness of the meso level forms the basis for awareness of different risks of unfairness, linked with potential decision makers (even health professionals). Collaborative arrangements were promoted in order to control for such risks, especially the risk of self-interest. Politicians, in contrast to previous studies, were favoured as final decision makers for rationing healthcare. In study III, citizen participants identified the same severity aspects as health professionals and experts had done in the Severity Framework. They contributed with some possible refinements, but also promoted aspects not in line with established ethical criteria for priority setting in Sweden. Study IV shows that citizen respondents differ to a larger proportion compared to politicians' ranking of severity aspects, than with that of health professionals'. The greatest number of significant differences was found between politicians and health professionals.

This thesis has several implications. Politicians ought to strive for greater public awareness of the priority-setting dilemma at the meso level in healthcare, both according to the process and the content values behind the decisions. Social values not in accordance to the parliamentary decision indicate a need to facilitate an ongoing dialogue, reason-giving activities and promotion of content values of solidarity. To capture social values on priority setting and rationing, ambitious public deliberation is not the only way. Methodologically stringent research, with a variety of study designs, could contribute in many important ways.

SVENSK SAMMANFATTNING

Resursfördelning i offentligt finansierad hälso- och sjukvård är oundvikligen förknippad med att prioriteringar måste göras mellan patientgrupper och mellan olika specialiteter, d.v.s. prioriteringar på så kallad mesonivå. Bakom varje prioriteringsbeslut, oavsett om det handlar om investeringar, omfördelning eller ransonering av resurser, finns värderingar som påverkar såväl prioriteringarnas innehåll, som det sätt på vilka besluten fattas. Att såväl processer som principer och kriterier för prioritering återspeglar sociala värden bland medborgare har ansetts viktigt för legitimiteten för sjukvårdssystem och dess beslutsfattare. Det har också ansetts viktigt att sådana prioriteringsprinciper operationaliseras för att de ska kunna ge tillräcklig vägledning och implementeras i praktiken. Det finns dock få studier där svenska medborgare har tillfrågats om prioritering och ransoneringar som görs på mesonivå i vården, och forskningsresultat från andra länder med andra sjukvårdssystem kan inte självklart överföras till den svenska kontexten.

Det övergripande syftet med denna avhandling är att fördjupa kunskapen om svenska medborgares syn på vad som skapar acceptans för ransoneringar i vården, hur medborgare ser på lämpliga beslutsfattare för ransonering samt på svårighetsgrad som ett kriterium för prioriteringar i samband med resursfördelning. I detta syfte genomfördes två kvalitativa och en mixed-metod studie, med intervjuer med medborgare. Deltagarnas uppfattningar om vilka aspekter som är relevanta att beakta för att värdera vad som är ett svårare hälsotillstånd än ett annat, jämfördes också med en Svårighetsgradsmatris. Matrisen är härledd från riksdagens riktlinjer för prioriteringar för att användas i resursfördelningssituationer i Sverige. I en enkätstudie jämfördes sedan medborgares rangordning av olika aspekter av svårighetsgrad med hur hälso- och sjukvårdspersonal och landstings/regionpolitiker rangordnade dessa aspekter.

Studie I visar att de deltagande medborgarna uppfattade att acceptans för ransoneringar på meso-nivå bygger på medvetenhet om de prioriterings dilemma som uppstår i valen mellan patientgrupper. Deltagarna uttryckte att denna prioriteringsnivå var okänd för dem. Beroende på om medvetenhet om prioriteringar på mesonivå leder till reaktioner av egenintresse eller av solidaritet, uppfattades acceptans för ransoneringar även bygga på acceptans för de principer besluten grundas på och/eller tillgång till olika alternativ till offentlig vård. Studie II visar att medvetenheten om prioriteringar på mesonivån dessutom utgör

basen för medvetenhet om olika risker för orättvisa, kopplade till potentiella beslutsfattare (även hälso- och sjukvårdspersonal). Samarbetsarrangemang förordades som beslutsform för att kunna kontrollera sådana risker, särskilt risken för egenintresse hos beslutsfattare. I motsats till tidigare studier, förordades politiker som slutgiltiga beslutsfattare för ransoneringar av vård. Medborgare som deltog i studie III identifierade samma aspekter av svårighetsgrad som hälso- och sjukvårdspersonal och experter gjort då de tolkade riksdagens riktlinjer för prioriteringar och konstruerade Svårighetsgradsmatrisen. En del av de nya aspekter som deltagarna dessutom såg som relevanta, kan ses som förtydliganden av matrisens aspekter. Andra överensstämde inte med de av riksdagens beslutade principerna och kriterierna för prioritering i Sverige. Studie IV visade att medborgarnas val av viktiga svårighetsgradsaspekter till större del skilde sig från politikernas val än jämfört med hälso- och sjukvårdspersonalens val. Det största antalet signifikanta skillnader fanns dock mellan politiker och vårdpersonal.

Denna avhandling har flera implikationer för politikers agerande. Resultaten talar för att politiker borde sträva efter att öka allmänhetens medvetenhet om prioriteringsdilemma som uppstår på mesonivå inom vården. Sociala värden bland medborgare som inte överensstämmer med riksdagens beslut om prioriteringar, indikerar att dialogen om grunderna för prioriteringar behöver hållas levande, politiker behöver förklara på vilka grunder prioriteringar görs i resursfördelningssituationer samt sträva efter att stärka den medborgliga viljan till solidariskt handlande när det kommer till hur hälso- och sjukvårdens resurser ska fördelas. För att ta del av medborgarnas syn på prioriteringar är det inte självklart att det behövs ambitiösa, deliberativa aktiviteter. Metodiskt stringent forskning, där både kvantitativa och kvalitativa metoder används, kan bidra med viktig kunskap till beslutsfattare.

LIST OF PAPERS

- I. Mari Broqvist, Peter Grapenby. To accept, or not to accept, that is the question: citizen reactions to rationing. *Health Expectations*, 2014, Vol.17:82–92.
- II. Mari Broqvist, Peter Garpenby. It takes a giraffe to see the big picture. Citizens' view on decision makers in health care rationing. *Social Science & Medicine*, 2015, Vol. 128:301-308.
- III. Mari Broqvist, Lars Sandman, Peter Garpenby, Barbro Krevers. The meaning of severity – do citizens' views correspond to a severity framework based on ethical principles for priority setting? *Health Policy*. Submitted.
- IV. Mari Broqvist, Lars Sandman, Peter Garpenby, Barbro Krevers. Different aspects of an important priority setting criteria in health care- comparisons of citizens', health professionals' and politicians' views on severity of ill health. Manuscript.

INTRODUCTION

My name is Sara and am 94 years old. You are asking about a very important issue, priority setting in healthcare. Now I am too old to answer your questionnaire, but I wish that someone had asked me before.

Letter that came in connection with the survey study

This thesis is about priority setting and resource allocation in healthcare. It is also about values. Behind every priority setting decision, regardless of whether it concerns adding resources into healthcare, reallocate them within the system or cutting back on resources, there are values affecting both the content of the decisions and how the decisions are made (Clark & Weale, 2012; Hoedemackers & Dekkers, 2003). Not paying attention to values has during the last decades, given a false impression that there exists a neutral, 'technical', approach to informing such decision-making (Harrison, 1998; Hoedemackers & Dekkers, 2003; Williams, Robinson & Dickson, 2012). If instead a more pluralistic perspective is acknowledged, with openness to incorporating different kind of values into the priority setting process (Williams et al., 2012) then the question arises: who should inform such an undertaking? While politicians, health professionals, and other experts are surely relevant candidates, to ask the citizens, as desired by Sara 94 years old, has not been quite as self-evident (Mitton, Smith, Peacock, Evoy & Abelson, 2009). However, not paying attention to public views, does not seem to be a realistic option for those responsible for the use of society's healthcare resources. Constraints on healthcare induce strong reactions among citizens, especially in countries with a publicly funded healthcare system (Daniels & Sabin, 2008). This is surely easy to understand. Healthcare is about life and death, facts and values, political governance and professional autonomy, hierarchy and power, and at the end of the day, about you and me. Citizens' reactions manifest themselves in many different ways. For example, in 2017, (mainly) women marched through Swedish cities, protesting against perceived rationing in childbirth care and even occupied the maternity ward in Sollefteå (Ek, 2017, Jan 29; Torvinen & Lundberg, 2017, Aug 20). Another example of citizens engagements concerned whether or not restoration of failed beauty operations should be within the public commitment. The media debate reflected the diversity in public preference, some advocating self-responsibility, others consider it reasonable to fund such operations with tax (Kjöllér, 2017, Sept 26; Pouron, 2017). Since every democracy is described to be based on trust, signs of dissatisfaction like these must be taken seriously by the politicians in charge (Lenard, 2008).

How to best achieve (sufficient) understanding that priority setting inevitably have to be done in healthcare, continues to challenge politicians. Actions for increased transparency, and increased public participation (or at least ambitions for increased involvement) are solutions suggested and somewhat initiated in Sweden (Anell, Glenngård & Merkur, 2012; Sveriges kommuner och landsting, 2018). Establishment of parliamentary-decided ethical principles on which priorities should be based, is another action taken at national level (Prop. 1996/97:60). But how do Swedish citizens themselves reason concerning what could create acceptance for rationing in healthcare and who should make such difficult decisions? These two questions started the exploratory research process that constitutes my thesis. At the time for my first study, there were a lot of theoretically-based assumptions from a wide range of disciplines on how to create legitimacy for healthcare priorities among citizens, but little empirical investigation on how citizens themselves perceive priority setting and rationing issues (Abelson, Forest, Eyles, Smith, Martin & Gauvin, 2003; Daniels, 2000; Mooney, 1998).

Based on the results from my first two studies, new research questions regarding citizens' views emerged. To answer these questions, I accepted the challenge of Ham & Coulter (2000), not to focus on either process or content in priority setting, but to study them both, as they both seem to be of importance to the citizens. Furthermore, I will do so on the type of priority setting that are explored to a lesser extent (Mitton et al., 2009): when it concerns choices between groups of patient or different service areas, the so-called meso level.

The research area of the thesis

The contribution made by this thesis is in the empirical field, as I have turned to citizens themselves to obtain answers. There are two main types of empirical studies of citizens' views on priority setting. One draws on 'real-life' activities, where regional health authorities or governmental agencies initiate public consultations. The other type of study is researched initiated (Mitton et al., 2009), as in this thesis. The difference is important, not necessarily for the findings but for the participants in the studies – knowing for what purpose they are asked tricky questions about priority setting and rationing and what impact their contributions are supposed to have. In a democracy of the Swedish type, where the healthcare is publicly funded, priority setting is a complex interplay between the processing of facts, social values in civil society, political goals and the capacity of institutions. So, even if acknowledge the importance of taken social values into account, there is no guarantee that decision makers will take findings of citizens' views, explored by research, into account in policy making or priority decisions (which in fact is also the risk with 'real' consultations). Furthermore, this is a very context-sensitive research area (and for that matter also design-

sensitive). Findings of public views on priority setting could not automatically be generalised from one country to another, or from studies with one research design to another (Busse, 1999; Coast, 2001; Hunter, Kieslich, Littlejohns, Staniszweska, Tumilty, Weale & Williams, 2016). In this thesis I will concentrate on the Swedish healthcare system and its political, ethical and organisational context. As I see it, it places this thesis within the interdisciplinary field.

Preconception

Understanding something about the position, perspective, beliefs and values of the researcher is an issue in all research, but particularly in qualitative research where the researcher is often constructed as the 'human research instrument'. (Cohen & Crabtree, 2006)

Even though I have used different research design in this thesis, the qualitative approach dominates. In such research (as in fact in all research) the reflexivity, i.e. the awareness of the influences of the researcher, is an important part of the process (Barry, Britten, Barber, Bradley & Stevenson, 1999; Malterud, 2001). Reflexivity begins with identifying the preconception of the researcher. Previous personal and professional experience, prestudy beliefs about what is to be investigated, motivation, qualifications – all affects what to study, how to study it, and the communication of findings and conclusions. As Malterud (2001, p. 484) stated: *"Preconceptions are not the same as bias, unless the researcher fails to mention them"*.

Priority setting in healthcare has been a co-traveller throughout my whole working life, beginning in the 1980's as an occupational therapist facing the bedside priorities, as a teacher preparing healthcare students for their professional roles, and as a tutor for local politicians in their meetings with patients and relatives when Region Östergötland¹ established so-called disease-oriented policy programmes. Since 2001 I am working at the National Centre for Priority Setting in Health Care at Linköping University in Sweden. The Centre is a national resource to support development and transfer of new knowledge on priority setting in healthcare. This means, for example that I have been engaged in the development of a priority-setting model and framework, which I explore in this thesis. I see this experience of mine as both a strength and a limitation, and something that will be further reflected upon at the end of this thesis.

¹ Before 2015 Region Östergötland was named Östergötland County Council .

AIM

The overall aim of this thesis is to extend and deepen the knowledge of the citizens' views in Sweden on acceptance of rationing in healthcare, on appropriate decision makers for rationing and on the parliamentary-decided severity criterion for priority setting when used in resource allocation situations. Another objective in this thesis, is to discuss the implications of the findings for the decision-making process and the content values behind resource allocation. In accordance with this aim, a number of research questions have been explored:

- What do Swedish citizens themselves perceive influences their acceptance of having to stand aside for others in a public health service? (Study I)
- In what ways do Swedish citizens understand and experience decision makers for rationing at meso level in healthcare? (Study II)
- What aspects do Swedish citizens consider relevant when evaluating the severity level of ill health in resource allocation situations? (Study III)
- How do Swedish citizens' views correspond with how the Swedish severity criterion have been operationalised into a Severity Framework, as used in resource allocation situations? (Study III)
- How do Swedish citizens rank different aspects of a severity criterion of ill health when used in priority-setting principle for resource allocation in health care, compared to health professionals' and politicians' ranking? (Study IV)

BACKGROUND

The Background chapter starts with describing arguments for asking citizens about priority setting, before introducing the concepts social values, content values and process values. Then definitions and methodological consideration that are considered important when studying social values on priority setting will be presented. Further, the context for this study is described: the parliamentary-decided principles and criteria for priority setting, the formal structure for setting priorities in Sweden, plus follow-ups and implementation actions. The final section presents research (mainly from Sweden) regarding perspective of citizens on priority setting and rationing, and highlights where there are still gaps to be researched.

Arguments for asking citizens

Priority setting is only successful when it reflects the civic ideals and norms of the broader society. (Williams et al.,2012, p. 14)

The quote from Williams et al. (2012) mirrors the importance that has been given to the citizens' views on priority setting and how resources should be allocated in healthcare. Ever since the debate started in the United States in the 1970s, and reached Australia and Europe in the 1980s and 1990s, the interest in priority setting has been inevitably connected with public emotions (Daniels & Sabin, 2008; Landwehr, 2013). There are several reasons for this interest. In most countries, as in Sweden, healthcare, being a 'life-course risk policy'², has a long tradition of being regarded as one of the most important social institutions by the public (Oscarsson & Bergström, 2017³; Vis, 2016). It is probable that all citizens could easily identify themselves as potential users of the healthcare system with an interest in access to healthcare. They are also financiers, at least in publicly funded healthcare systems and, as such, have an interest in their tax money being used in a way that they consider reasonable and fair (Garpenby, 2001). As citizens living in a democracy their position is that of being indirect decision makers through their political representatives. Based on these reasons, politicians have every motive to be interested in what citizens' views on priority setting can contribute when it comes to resource allocation in healthcare.

² In her article about blame avoidance Barbara Vis (2016) distinguished policies addressing life-course risks (e.g. health) from policies addressing labour-market risks (e.g. unemployment).

³ Based on a survey made by SOM Institute, an independent survey research organisation at the University of Gothenburg in Sweden, that since 1986 has conducted investigations on the attitudes of Swedes.

In addition to these general motives for why citizens have an interest in how resources are allocated in healthcare, three kinds of argument for asking citizens about priority setting and rationing are commonly put forward in the priority-setting literature. One is the *democratic* argument. It applies to politicians and governmental agencies having an interest in fostering active citizenship by engaging the public in deliberative activities, and allowing the public a voice as a self-evident right in a well-functioning democracy (Frankish, Kwam, Ratner, Higgins & Larsen, 2002; Litva et al., 2002; Williams et al., 2012). Even if used somewhat inconsistently in theories of democracy, most definitions of 'deliberation', irrespective of what subject it concern, require arenas for meetings and discussion between different stakeholders. Often mutual understanding is described as the goal of deliberative activities (Dalton, 2014; Gilljam & Hermansson, 2003; Williams et al., 2012). However, the thought of consensus as the ultimate goal of such activity has been questioned, as the very point of a democracy is to deal with different views and conflicts (Gilljam & Hermansson, 2003). However, to study what effects such activities could have on citizens is beyond the scope of this thesis.

Another common argument for asking citizens, is *educational*, and about raising the publics' awareness of priority setting (Frankish et al., 2002; Hunter et al., 2016; Williams et al., 2012). The intention is then not just to capture social values, the intention is also to inform the public in order to promote acceptance for rationing in healthcare (Williams et al., 2012). In fact, sometimes 'education' in this context could be solely about one-way communication, from the decision makers to the public (Rowe & Frewer, 2004). However, no educational argument for asking the citizens applies to my thesis. Instead I am interested in and have studied citizens' own points of view on what creates acceptance, especially for rationing of healthcare.

The two arguments mentioned above are usually linked to 'real-life' public consultations, initiated by decision makers. The argument that directly applies to this thesis is instead *the instrumental argument*. It is built on the assumption that asking citizens can improve the quality of decision-making, by providing broad and relevant information on essential aspects of priority setting (Frankish et al., 2002; Mitton et al., 2011; Williams et al., 2012). Whether or not such activity is research-initiated or part of a deliberative public consultation, information about citizens' views is meant to be an important in-put for decision makers alongside results from evidence-based medicine, health technology assessments, political goals, and laws and regulations that affect priority decisions.

The idea behind adding knowledge about the citizens' perspective to other kinds of support for resource allocation decisions, is unambiguously linked to the assumption that such undertakings would increase the legitimacy of priority setting (Hunter et al., 2016; Clark & Weale, 2012). In literature on public justification of priority setting, 'legitimacy', 'confidence', 'trust' and 'acceptance' are frequently used concepts, connected, but also somewhat different (Nedlund, 2012; Nedlund & Baerøe, 2014). Each of them exists, respectively, on a continuum, rather than being 'all or nothing'. Trust, or rather distrust, for example, could be characterised by more or less distrust (Lenard, 2008). I will not go deeper into this conceptual discussion⁴ but instead in the following refer to legitimacy in accordance with Dryzek's definition (2010): something, "*an institution, a value, a policy, a decision*", is legitimate if accepted as proper by those to whom it is supposed to apply. Additionally, Dryzek mean, legitimacy requires some notion of public approval of decision makers to make decisions (in my case on priority setting and rationing).

Content and process values in priority setting

When asking the citizens, two kinds of values associated with priority setting are of interest: content values and process values. *Content values* apply to values on *what* priorities should be made, and foremost on what basis these decisions should be grounded. *Process values* instead apply to values on *how* priority setting should be done (Clark & Weale, 2012). The importance of content and process values, for the legitimacy of priority setting are grounded in decades of research (Gilson, 2003; Daniels & Sabin, 2008; MacCoun, 2005; Dolan, Edlin, Tsuchiya & Wailoo, 2007).

Content and process values, could have different origins. They could be ethical values, emanating from ethical theories that normatively prescribe which actions are right or wrong. Social values, on the other hand, are empirically based and shaped by the prevailing social, cultural, religious and institutional features in each society at a particular time⁵ (Biron, Rumbold & Faden, 2012; Clark & Weale, 2012). However, the distinction between social values and normative ethical values is not straightforward. Social values may correspond with ethical values but could just as well differ (Biron et al., 2012). In the other direction, the influence of prevailing social values most certainly has an influence on theoretic-

⁴ Legitimacy could be seen as a presumption for trust in priority setting, while legitimacy of decision makers and the healthcare system can remain even if there is not trust in all kinds of decisions and actions taken by the decision makers - which is hardly likely to ever happen (Nedlund, 2012).

⁵ Social values, is a concept with a wide range of definitions, depending on discipline. In philosophy it could refer to moral values used to strengthen the relations of an individual with the society (Baeva, 2014). In psychology, social values could relate to the constructions of an individuals' identity (Menard, 2015), while in administrative science or marketing, it is about what contributions an activity could give to the society (Brown, 2017).

cal assumptions, made in certain countries in a certain era. A broad understanding of social values could mean values held by anyone in the society, irrespective of whether these values are held by e.g. health professionals, politicians or citizens. However, in this thesis I will use the concept in a more restricted way, referring to social values as values that exist among the public, healthcare professionals and politicians excluded⁶ (see definition of 'public' on p. 20). In contrast to public opinion, social values do not need to mean values held by a majority or numerous individuals, or alternatively by the most vocal group of people (Hoewe, 2016). Instead, a social value could be a value held by only one person, it is still a social value in the way I will use the term. Likewise public opinion often refers to an attitude, positive or negative, to a phenomenon while social values are broader than that, including also perceptions, understanding and experiences of a phenomenon without a valuation.

In the next section a brief overview of common normative ethical values, both content and process values, in academic literature dealing with priority setting, will be presented, as they are important for the Swedish context.

Content values in priority setting

The importance of content values, can be traced all the way back to ancient Greece when discussing distributive justice. Decision makers must be able to balance a plurality of such values when making decisions about priorities and resource allocation (Biron et al., 2012; Cookson & Dolan, 2000). Different theories give different directives in how to look at fairness in resource allocation. While *utilitarians* advocate allocation that results in maximisation of population well-being, *prioritarians* pay attention to the worse off (Parfit, 1991). *Egalitarian* on the other hand focus on equality between peoples (Rawls, 1971). *Sufficientarianism* instead states that it is morally important for all people to have enough, but beyond that point relative inequality has no moral importance (Frankfurt, 1984).

Each of the distributive theories can be interpreted in terms of mid-level ethical principles, i.e. principles that are more related to a certain context or a certain situation, such as healthcare (Beauchamp & Childress, 2009). For example *equity* is an important mid-level principle meaning, in the context of healthcare, "*that like cases should be treated as like and unlike as unlike*" and that distinctions irrelevant to health conditions⁷ should be left aside (Clark & Weale, 2012, p. 306). *Solidarity* is another example of a mid-level principle. It forms the basis

⁶ Leaning on this definition, I will in the following use the terms social values, public views and citizens' views interchangeably.

⁷ However, distinctions between what is relevant and irrelevant for priority setting is not always clear-cut, and age, life-style etc. have been widely debated (Clark & Weale, 2012).

for the financing of a healthcare system in order to provide for the disadvantaged. The principle of solidarity could also mean that attention should be given to those who “*cannot care for themselves*”, i.e. those who themselves cannot draw attention to their health care needs (Hoedmacker & Dekker, 2003, p. 330).

Still another mid-level ethical principle is the principle of *need* (Gustavsson, 2017), related to e.g. prioritarism and the focus on the worse off. In turn, a principle such as ‘need’ must further be defined in order to give enough guidance in practice – what constitutes a healthcare need? Therefore, also mid-level ethical principles can be further distinguished in terms of different criteria. Criteria (partly) defining the principle of need are *the severity criterion* (which in turn can be divided into different *aspects*, described further in connection with the description of the severity criterion in Swedish context). The assumption behind the severity approach is that the need of healthcare is dependent on the level of severity of ill health. The criteria have also been described as defining the size of health improvement as “*greater the greater the severity of the patient’s initial condition*” (Nord, 2005, p. 258). The criterion says that it is morally justified to give higher priority to those with a more severe condition than those with a less severe one (Williams et al., 2012).

Many countries, such as Norway, Sweden, Denmark, Finland, the Netherlands and New Zealand have formulated similar national ethical principles and criteria. Even if not formally decided, Great Britain and Canada act on comparable principles (Melin, 2008). Similarities are especially found in relation to the principle of need and in that the severity of the ill health plays a central role for resource allocation. Cost-effectiveness are another principle that appears in all the above mentioned countries, as well as there being similarities between the countries on valuing what should *not* constitute a basis for prioritisation, e.g. chronological age and social responsibility. The principles and criteria in Sweden will be described in more detail later in this thesis.

Process values in priority setting

Over time, doubt arose as to whether any principle, could gain enough public acceptance to justify the grounds on which priority setting and rationing ought to be set in healthcare (Daniels & Sabin, 2008). Instead scholars interest shifted to what could be considered as fair processes. Processes are considered important for several reasons. One assumption is that when a process is perceived as fair, the outcome of a priority setting could likewise be considered fair. Another assumption is that a process considered as fair, could increase legitimacy for decision makers (Dolan et al., 2007).

Among theories of procedural justice Daniels and Sabin (2008) accountability for reasonableness, A4R, has become the leading model. Four conditions are set up for what should constitute a fair priority-setting process. The *publicity* condition refers to the transparency of the resource allocation decisions and their rationales and disqualifies implicit priority setting from being fair. The *relevance* condition holds that decisions should be influenced by evidence, principles and criteria that 'fair-minded'⁸ people would consider to be relevant. The *revision and appeals* condition means that there must exist a guarantee for new decisions to be made in the light of new evidence or arguments. The last condition, *enforcement*, means that effective mechanisms are required in order to implement the other three conditions (Daniels & Sabin, 2008). Although endorsed by many countries the A4R have also been criticised for, as an example, the vagueness in what could be considered as a relevance condition (Sabik & Lie, 2008; Williams et al., 2012). Whether content, or process values, take precedence over the other in importance for legitimacy, has also been disputed. In this thesis I will join the standpoint of Biron et al. (2012, p. 319) that these values should be seen as an 'interconnected whole' when it comes to priority setting.

Besides the A4R there are further process values that through the years have been highlighted in academic literature on priority setting. In their review of procedural literature Dolan et al. (2007) listed e.g. *neutrality* (i.e. decision makers without preconceptions and self-interest), *consistency* (i.e. stability between different decisions and over time), *voice* (i.e. the possibility for those potentially affected to contribute in the decision making) and *transparency*. Transparency (similar to the publicity condition in A4R), is a process value put forward in many healthcare systems (Clark & Weale, 2012; Daniels & Sabin, 2008). The assumption behind transparency is that what is not known cannot be scrutinised by the public, and those responsible for the decision could not be held *accountable* (for either the content of the decision or the way the decision has been made). Transparency, is a rather elastic concept, and could also mean opportunities for citizens to participate in a decision-making process, in so-called pluralistic bargaining (Nedlund, 2012). Such a definition interrelates transparency to another process value, *participation*, which means involving different actors, such as patients, the public, health professionals etc. in the decision-making process (Clark & Weale, 2012).

⁸ By fair-minded, Daniels and Sabin (2008) mean people who want to cooperate in ways that they could justify to each other – as rules accepted in fair games.

To study social values in priority setting

Different research methods could be used to study social values, according to the aim of the studies. In this section I will briefly present different types of such studies and describe some methodological deficiencies that researchers have previously identified in this research area.

Different types of studies

Studies of social values in priority setting could be categorised into three different types.

The first type incorporates deliberation, i.e. discussion between different stakeholders. When it comes to priority setting and rationing in health care, studies of deliberative activities where citizens and e.g. health professionals and health service providers are engaged, are sparse (Abelson, Eyles, McLeod, Collins, McMullan & Forest, 2003; Boivin, Lehoux, Burgers & Grol, 2014; Ralston, 2008).

A second type of study (and the most common of the three different types), focuses exclusively on citizens' views on priority setting and rationing, without interaction or dialogue with other stakeholders (Mitton et al., 2009). These studies could either concentrate on individual views (by individual interviews, surveys etc.) or on the interactions and discussions between citizens, e.g. in focus groups (Coast, 2001; Coast, Donovan, Litva, Eyles, Morgan, Shepherd & Tacchi, 2002; de Fine Licht, 2011; Diederich, Winkelhage & Wirsik, 2011; Fredriksson, Eriksson & Tritter, 2018; Litva et al., 2002; Richardson, Charry & Hammer-Lloyd, 1992; Rogge & Kittel, 2016; Werntoft, Edberg, Rooke, Hermeren, Elmstahl & Hallberg, 2005; Winkelhage & Diederich, 2012; Wiseman, Mooney, Berry & Tang, 2003).

The third type of study is the one which compares citizens' views on priority setting and rationing issues with those of other stakeholders' (without any deliberative activity). The few comparative studies that exist between citizens, health professionals and politicians in this area, concern weighing different distributive principles against each other (Bowling, Jacobson, & Southgate, 1993; McKie, Shrimpton, Hurworth, Bell & Richardson, 2008; Myllykangas, Ryyänen, Kinnunen & Takala, 1996; Rosen & Karlberg, 2002; Ryyänen, Myllykangas, Kinnunen & Takala, 1999; Wiseman et al., 2003).

Each one of these three types of studies could comprise different designs. Roughly, at one end there are exploratory studies with an open-ended approach. At the other end, which is more usual, there are preference studies dealing with hypothetical priority setting or rationing situations, where citizens

are asked to choose between different given alternatives (e.g. different candidates for decision makers), and/or weigh the importance between different priority principles and criteria (Busse, 1999; Roberts, Bryan, Heginbotham & McCallum, 1999; Litva et al., 2002; Mossialos & King, 1999; Wiseman, 2005).

Definitions of public, citizens and patients

It has been stated that all too often the meaning of 'public' in academic literature, relating to studies of citizens' views on priority setting, is unclear, blurring the findings (Williams et al., 2012). 'Public' could stand for a) individuals speaking on their own behalf b) organised interest groups supposedly speaking on behalf of their members, or c) patients or users of services if they could be relied upon to provide in-put from a broader societal perspective rather than an exclusive patient perspective (Mitton et al., 2009; Whitty, Lancsar, Rixon, Golenko & Ratcliffe, 2014). Because of the risk of ambiguity, it may be appropriate to define how the concepts public, citizens and patients will be used in this thesis. As the difference in rights and obligations between judicial citizens and the public⁹ are not relevant for this thesis, 'citizens' and 'public' are used interchangeably. On the other hand I will make a distinction between the 'general public' and the 'public', the former including all people, also health professionals and politicians who are not included in my definition of 'public'. In addition, I differentiate between 'patient' and 'citizen'/'public'. The Swedish government agency, the National Board of Health and Welfare, define patient as a citizen who has some form of ongoing ill health, or a proven risk of future ill health, and who receives or is registered to receive healthcare (Socialstyrelsen, 2018a). The clue in the definition is that it refers to an ongoing process, in contrast to having had previous experience of being ill and having received healthcare, as applies to almost every citizen (Versteegh & Brouwer, 2016). The reasons for this distinction is often not explained. Fredriksson and Tritter (2017) argue that patients are expected to contribute with their own specific, experience-based knowledge on quality in results of healthcare interventions, and performance of the health professionals. In-put from patients, they mean, focuses on enhancing internal legitimacy, i.e. legitimacy between actors within the healthcare system as e.g. between health professionals and the patients. The public, on the other hand, contributes with what Fredriksson and Tritter (2017) call the 'collective perspectives', generated from (greater) diversity and focusing instead on external legitimacy, i.e. legitimacy between the health service and the public (Fredriksson & Tritter, 2017; Whitty et al., 2014). Even if the public are the primary target population for recruitment to the studies in this thesis, and the partici-

⁹ Turning to English dictionaries *citizen* (svenskans medborgare) could be defined as a native or naturalised person that by legislation has both obligations to, and is entitled to protection from the state, whereas a member of the *public* (svenskans allmänheten) is anyone, which could include visitors, foreigners etc. (Cambridge English Dictionary, 2018; Oxford Dictionaries, 2018).

pants is expected to speak on their own behalf, being a patient or being organised in an interest group is not an exclusion criterion.

Definitions of priority setting and rationing

Apart from the public, priority setting and rationing are the core of this thesis. They are also examples of concepts often taken for granted in studies of public views⁷ on resource allocation in healthcare. ‘Rationing’ and ‘priority setting’ are not often distinguished, which contributes to the difficulties interpreting the findings, and also in making syntheses of the results from different studies (Busse, 1999; William et al., 2012). When the term *priority setting* is used in this thesis it refers to ranking. Ranking implies that different options (e.g. conditions/interventions) are given different levels of importance in relation to some set of values (e.g. ethical principles and criteria). Priority setting applies to different kinds of resource¹⁰ allocation situations in healthcare. In all such situations there are choices to be made: when resources are added into the healthcare system (i.e. investments), reallocated within the system, or when resources are reduced (i.e. disinvestments). For priority-setting activities specifically aimed at limiting the possibilities to optimally¹¹ satisfy healthcare needs, the term *rationing* will be used.

Studies on different priority-setting situations

Linked to the vagueness of the concept of priority setting, is the vagueness of what priority-setting situation questions, posed to the citizens, refer to. For example “*Who is the appropriate decision maker for rationing in healthcare?*” is an interesting but rather difficult question to answer, as priority setting and rationing concern different types of priority-setting situations, and consequently different types of choices. The priority-setting situation to which the public is supposed to give voice is not always clarified, and makes findings hard to interpret and compare. Three different situations, often called ‘levels’, have been distinguished in former articles and, described in slightly different ways (Ham & Coulter, 2000; Klein, 1993; Litva et al., 2002; Wiseman et al., 2003). The following distinctions will be used in this thesis: Making priorities at *macro level* (sometimes called system level) means deciding on funding to be allocated to the health services in competition with resources to other welfare sectors such as education, culture, infrastructure etc. Priority setting at *meso* (or programme)

¹⁰ Resources refer to anything that affects the possibility to perform healthcare interventions. It could be money invested in infrastructure (e.g. new hospitals), medical equipment such as pharmaceutical products, medical devices (e.g. x-ray equipment, robotic-assisted technologies), and assistive devices (e.g. wheelchairs, hearing aids). Resources also refer to access to human resources, including health professionals’ competence and the use of their time (Broqvist, Branting, Carlsson, Eklund & Jakobsson, 2011).

¹¹ A healthcare need is optimally served if the intervention results in the greatest possible satisfaction of need, given the scientific prerequisites at the time (Liss, 2004).

level, means choices between groups of patients (or population groups) with different healthcare needs or between different health services (e.g. between obstetric and primary care). Priorities at the *micro* (or patient) *level* are about choices between individuals and their treatments. These three different kinds of priority-settings situations could be decided on at several different *decision levels*, depending on what healthcare system are referred to. In Sweden four different levels could be identified: at the national level, at the county council (or regional/local) level, at the clinical, management level and at the clinical individual (professional) level (Garpenby & Carlsson, 2007). The Swedish health care system will be further described on p. 23.

Related to the importance of clarifying the priority setting or rationing situation, is the importance of clarifying what kind of impact is asked for, when asking citizens about appropriate decision makers. For example, on an unspecified question such as “*Are you willing to participate in priority setting in healthcare?*”, the public’s answers could refer to support (or non-support) for anything from being informed to actually deciding on priority setting and resource allocation (Arnstein, 1969; Bowling, 1996; Lee, Fustukian & Buse, 2002; Litva et al., 2002; Mossialos & King, 1999; Wiseman et al., 2003; Tritter & McCallum, 2006).

Contextual studies

Analyses of how different countries deal with priority setting have traditionally focused on ‘technical’ judgements, i.e. on what methods are used for health technology assessments or how decision processes are organised. Studying values behind the methods and processes is seen as a more recent approach. Such studies have disclosed that the diversity of principles and criteria for priority setting in different countries may be greater than expected. Even if there are similarities between countries, doubts have been raised as to whether there exist any universal values that could support priority setting, when it comes to process or content values (Biron et al., 2012; Clark & Weale, 2012; Kieslich, 2012; Littlejohns, Sharma & Jeong, 2012; Nedlund & Garpenby, 2008). In light of the importance given to ethical principles and criteria to be in line with social values for the legitimacy of priority setting, more studies ought to include values held by the public (Clark & Weale, 2012; Frankish et al., 2002; Rogge & Kittel, 2016; Sabik & Lie, 2008). As social values, as the concept is used in this thesis, are values held by the public in each society at a particular time, country specific studies are important (Biron et al., 2012; Clark & Weale, 2012). Findings from studies of social values could not automatically be generalised from one country with certain social, cultural, religious, political and institutional contexts to another national setting (Busse, 1999; Coast, 2001). Therefore, the need of more country-contextual studies has been highlighted (Abelson & Gauvin, 2006; Chalkidou, Ryans, Culyer, Glassman, Hofman & Teerawattananon, 2017).

Priority setting in Sweden

The context for this thesis is the Swedish healthcare system. This section presents a description of the formal structure for setting priorities in the Swedish healthcare system, and the role different actors play. But first, the parliamentary-decided ethical principles and criteria that apply to priority-setting situations in healthcare in Sweden, are presented.

Parliamentary-decided content values in Sweden

In 1992 a Parliamentary Priorities Commission in Sweden was asked with suggesting what basic ethical principles should guide necessary prioritisation of healthcare resources. Although the Commission was considered to have the expertise required to be able to form normative, ethical principles, it was deemed important that these principles could be broadly perceived as fair by the Swedish public (SOU 1995:5). Even if allowed to be inspired by priority discussions in other countries, the importance of the Swedish contextual assignment was clearly stated to the Commission. The principles should be to guide priority setting regardless of the role and responsibility of the decision makers in healthcare, which include both politicians and different providers, as well as the health professionals. The Commission worked in two phases. First members of the Commission and an expert group discussed principles, conducted surveys and studied foreign priority investigations. The surveys included authorities, patient organisations, pensioners' organisations and health professionals. In a second step a proposal for principles was issued on a broad referral. In addition, the Commission organised five regional conferences to inform about their work and obtain comments from the public, the employees in the healthcare and representatives of health authorities in county councils and municipalities respectively (SOU 1995:5).

The Government bill on priorities in health care contained some changes to what the Commission had suggested but followed, on the whole, the proposal of the Commission (Prop. 1996/97:60). This bill did form the basis for the parliamentary decision, taken by the Swedish parliament in 1997, on ethical principles and how to undertake priority setting in Sweden (Riksdagen, 1997). When in doubt about how to guide priority setting, actors in Sweden may consult the original bill. The so-called ethical platform for priorities in the decision, is constituted in its main features in the Health and Medical Service Act (SFS 1982:763; SFS 2017:30; Prop. 1996/97:60). The principles could be described as the following:

The human dignity principle: all humans have equal value and equal rights, irrespective of their personal characteristics and function in society. It is the overriding ethical principle of the platform, and also addresses personal characteris-

tics and functions in society that should *not* determine the priorities for care, e.g. talent, social position, social responsibility, income, chronological age or gender. Likewise, the Swedish Commission dismisses self-inflicted injuries as a criterion for prioritisation, because of difficulties to determining the extent to which some forms of ill health result from a particular lifestyle or from genetic factors.

The needs-solidarity principle: more of healthcare's resources should be given to those in greatest need, which implies those with the most severe ill health, and those with the lowest [health-related] quality of life. Even if major consideration is given to the severity level of disease, substantial importance is also given to patient benefit;

... one needs only that from which one can derive benefit, or conversely, one does not need that from which one derives no benefit. (Prop. 1996/97:60, p.18)

Solidarity does mean that healthcare outcomes should be as fair as possible (i.e. best possible health and health-related quality of life for all), but also implies a special responsibility to pay attention to the needs of people who cannot themselves address their healthcare needs.¹²

The cost-effectiveness principle: in selecting between different interventions or areas of activity, one should aim for a reasonable relationship between cost and effect, as measured by improved health and [health-related] quality of life.

There is an order between the principles that implies that one should take into account the principle of human dignity before the principle of need-solidarity, and that the same relation should apply between the principle of need-solidarity and the principle of cost-effectiveness.¹³ Regarding the balance between the need-solidarity principle and the cost-effectiveness principle, the guideline can be interpreted so that patients with more severe conditions can be treated with interventions that are less cost-effective (Prop. 1996/97:60).

Parliamentary-decided process values in Sweden

In the Government bill that formed the basis for the parliamentary decision on how to undertake priority setting in Sweden, process values are also highlighted, even if not explicitly labelled as principles or criteria in the bill (Prop. 1996/97:60). One of them is *transparency*, said to be especially important when

¹² In other words, the assessment of their healthcare needs should have a high priority. Then there is the level of need that governs the continued priority, not the reduced autonomy itself (Broqvist et al., 2011).

¹³ This hierarchy between principles is not pronounced in other countries (Melin, 2008).

it comes to the grounds on which priorities are set, in order to maintain trust in the publicly funded healthcare system:

For the population to have a high level of trust in health services, the grounds for prioritisation must be openly discussed (p. 47)...To promote public understanding about priorities, people working in healthcare have a duty to inform about the discussions on prioritisation. (Prop. 1996/97:60, p. 14)

In addition to transparency, the importance of observing a *relevance* criterion of priority setting was stated in the bill, meaning that values behind decisions (referring to the ethical platform presented above), must be perceived as fair and reasonable:

...the values that guide both access to care and prioritisation decisions must be shared by most of the population and perceived to be reasonable and fair.
(Prop. 1996/97:60, p. 47)

By amending several parts of the ethical principles in the Health and Medical Services Act (SFS 1982:763; SFS 2017:30), the government wanted to ensure a mechanism for *enforcement*. They also assigned the government authority, the National Board of Health and Welfare, to provide the local health providers with evidence-based guidelines for the care of patients with serious chronic illness, which include recommendations to the local level for decisions on priority setting (Anell et al., 2012; Socialstyrelsen, 2018b).

The importance of a *revision and appeals condition* with an on-going discussion about priority setting was also stated:

Experience from other countries shows that a transparent discussion about priority setting is necessary but difficult and therefore must be seen as a long-term activity, but also that the perspectives on established principles and priorities are shifted as experiences are gained in real-life priorities. Thus, one approach could never be once and for all given. Priority setting in healthcare is a never-ceasing process, with constant preparation to reconsider.
(Prop. 1996/97:60, p. 22)

The government also stated that the public should be given opportunities to influence priority setting by a 'democratic dialogue' where the public is allowed a voice, in order to create acceptance of necessary priorities (Prop. 1996/97:60).

The priority-setting process in Sweden

Most healthcare in Sweden operates within a politically governed system, funded mainly through taxes. A distinguishing feature for the Swedish healthcare

system is that a large part of the responsibility for resource allocations is placed in a regionalised system, with twenty-one regional bodies (county councils or regions) with taxation rights. Responsibility for healthcare is also to some extent with the municipalities. The regional bodies are each governed by an assembly of directly elected regional or local politicians (Anell et al., 2012; Fredriksson et al., 2018). However, it has recently been suggested that the traditional consensus-based governance, where the Swedish state negotiate with representatives of the local government rather than imposing binding regulations, has gradually changed. The development of open comparison, legislated choice in primary care etc. are signs of ambitions to steer towards national equity in Swedish healthcare (Fredriksson, 2012). Basic policies and frameworks affecting priority setting are made by the state and, through the Ministry of Health and Social Affairs, expressed in laws and regulations (Fredriksson et al. 2017; Lillrank, Torkki, Venesmaa & Malmström, 2011). Independent government agencies¹⁴ assist the government in the implementation of their decisions. For example, The National Board of Health and Welfare are guiding meso level priorities with their national guidelines. The Dental and Pharmaceutical Benefits Agency¹⁵, decide on subsidisation of pharmaceutical products, medical devices or dental care procedures, decisions that also affect local priorities (Anell et al., 2012; Socialstyrelsen, 2018b; Tandvårds- och läkemedelsförmånsverket, 2018). Sometimes national politicians also provide resources directed at targeted groups e.g. at young people at risk of mental ill health, or cancer patients (which in reality are also meso level priorities as some other patient groups get less or nothing).

Despite the national policy instruments, at the county council/regional level the local politicians are still responsible for the resource allocation between different kinds of health service. Meso level priorities are also undertaken at the clinical level within clinical centres, i.e. centres that include many different health services (for example resource allocation between cardiology, renal medicine and infectious diseases). Here responsibility for resource allocation lies with the clinical manager in charge. At the patient level (micro level) the choices are made by each individual health professional (Anell et al., 2012).

The description above is the formal account for the priority-setting process in Sweden. In practice there is a complex interaction between the different decision levels, and with many stakeholders involved with different degrees of power. Physicians have historically a strong position on the priority-setting scene in Sweden (Qvarsell, 2007), as in most other countries (Blank & Burau, 2004). Their position in healthcare in Sweden grew in line with the development of medical

¹⁴ Even if autonomous the authorities are monitored and evaluated by the government (Anell et al., 2012).

¹⁵ Tandvårds- och läkemedelsförmånsverket (TLV).

science. What should be considered as ill health is largely defined by doctors, based on conditions that can be addressed through medical interventions. However, the power balance in healthcare has slowly changed. Professions other than that of physician were assigned professional skills, teamwork was introduced, and administrators and economists attained the legal right to become managers of healthcare (Qvarsell, 2007). Although physicians' managerial positions have decreased, they are still well represented in management groups and in a national level priority-setting context in Sweden, e.g. working with national guidelines at the National Board of Health and Welfare.

Besides those already referred to, other stakeholders (e.g. pharmaceutical industry, media, administrators) that have influence on priority setting, could have been mentioned here. The patients is surely one of these potentially important actors. As the patients' role as passive receivers of healthcare diminished, they started to be seen as decision makers in their own healthcare. They were also assigned, being citizens (organised in interest groups or not), to potentially have opinion as to how resources should be allocated in healthcare (Qvarsell, 2007). Also the increased access to information about healthcare has strengthened the position of the citizens as healthcare users (Arnetz, Zhdanova & Arnetz, 2016; Wennberg, Hörnsten & Hamberg, 2015). News about innovative health technology travels fast and is often accessible by a search on the internet. In 2015, a new law was introduced in Sweden, Patient Act, in order to further strengthen and clarify the patient's position and to promote patient integrity, self-determination and participation (SFS 2014:821).

Implementation of priority-setting principles and criteria in Sweden

In the previous section the parliamentary-decided principles and criteria for priority setting in Sweden, both according to content values in explicit ethical principles and the more implicitly described process values in the bill were presented (Prop. 1996/97:60). But how is compliance with these decisions when it comes to real-life priority setting? In 1997 a parliament working party, *Prioriteringsdelegationen*, was assigned to follow up the implementation of the decisions (SOU 2001:8). In 2005, the Swedish Government assigned the National Board of Health and Welfare¹⁶ to conduct a new follow-up in order to identify whether problems existed in applying the parliamentary decisions for priority setting in healthcare and, if so, consider whether the principles and criteria ought to be revised. In total 155 interviews were carried out with politicians, administrators (e.g. county council directors) and healthcare executives at (e.g.

¹⁶ The authority commissioned the National Centre for Priority Setting in Health Care to support them in this follow-up with interviews etc.

directors of hospitals and health services). In addition a literature review of studies of health professionals' views on priority setting was done (Broqvist, 2004; Höglund, 2003; Lämås, Jacobsson, Lindholm & Engström, 2004; Prioriteringscentrum, 2008). Below, the findings from these follow-ups are presented, as well as some actions taken to deal with the implementation in Sweden. In addition, some findings from international studies are presented.

Follow-up on decided content values

At the time of the first follow-up, Prioriteringsdelegationen found that healthcare executives and health professionals were rather unaware of the priority-settings principles, but nevertheless noted some activities in the county councils (SOU 2001:8). The second follow-up showed that although the parliamentary-decided ethical principles for priority setting were perceived as relevant (although not still broadly known), some problems had arisen with the implementation. One reason put forward was that resource allocation at meso level between patient groups was perceived to be influenced by many other factors that could obviously conflict with the principles. Distributions built on a previous budget without any revised analysis of healthcare needs, the strong influence of technological innovations and new breakthroughs in medical research, and the strength of public or professional demands, are some of the competing influences (Broqvist, 2004; Höglund, 2003; Lämås et al., 2004; Prioriteringscentrum, 2008).

Another obstacle for implementation was that the ethical principles were perceived as vague and to some extent contradictory, not giving enough guidance in real-life priority setting (Prioriteringscentrum, 2008). The same criticism was made in an international comparison of six different countries, where Sweden was included. Kenny and Joffres (2008) meant that the vagueness of decided principles had jeopardised the realisation of the intentions in principles decided on in these countries. It is considered a risk that different priority-setting tools aimed at supporting priority decisions are constructed with intentions other than to operationalise country-specific ethical principles. Other (often implicit) values, will then be used and thereby undermine compliance to the decided ethical principles. There are studies indicating that such lack of compliance may be a reality not only in Sweden (Fredriksson & Tritter, 2017; Riksrevisionen, 2004), but in a number of countries (Chalkidou et al., 2017; Clark & Weale, 2012; Giacomini, Kenny & DeJean, 2009; Kenny & Joffres, 2008). To use the same generic priority-setting tools world-wide has of course numerous advantages if they are validated, but might not be warranted if they are not in compliance with each country's own priority-setting principles.

Actions for operationalisation of Swedish ethical principles and criteria for priority setting

As stated above, vague ethical principles often run the risk of being only symbolic, sometimes described as ‘political decoration’, with deficient guiding function and non implementation in real resource allocation situations. If supposed to provide enough guidance in practice, they need to be operationalised, both in policy documents and in priority setting tools and frameworks, because depending on what content values inform priority decisions, the result of priority setting will be quite different (Giacomini et al., 2009; Kenny & DeJea, 2009; Kenny & Joffres, 2008).

However, Sweden is an example of a country that has made substantial efforts to operationalise parliamentary-decided ethical principles in order to give more guidance. Already by the late 1990s, one of Sweden’s county councils (Region Östergötland) started to transform the ethical principles into a guiding framework that has latterly been developed into a national model, The National Model for Transparent Prioritisation in Swedish Health Care (Figure 1).

Condition	Intervention	Compared intervention	Condition's severity level	Intervention's patient benefits	Costs in relation to patient benefits	Quality of knowledge base	Ranking	Comments/
			Very high-low	Very high-low	Very high-low		1 (highest) 10 (lowest)	

Figure 1. The National Model for Transparent Prioritisation in Swedish Health Care

Today, the model is used by government authorities, e.g. by the National Board of Health and Welfare, in their work with recommendations on priority setting (Socialstyrelsen, 2018b), and by different regional decision makers in the allocation of resources between different patient groups with different interventions (Andrén et al., 2011; Bucht, Hall, Johansson, Erlandsson, Tinnert, Fränkel & Broqvist, 2013; Edin, Gunnarsdotter, Tegnevik & Broqvist, 2011; Engström, 2009; Garpenby, Bäckman, Broqvist & Nedlund, 2010; Waldau, 2009; Östling, Weitz, Bäckman & Garpenby 2010). The evaluation of condition’s severity level is one component in the model, along with evaluation of patient benefit, cost-effectiveness and quality of knowledge-base (evidence), and these components are all qualitatively weighed together into a ranking order. The human dignity principle is an overriding principle not explicitly incorporated into the model (Prioriteringscentrum, 2017).

As more healthcare resources should be allocated to those with the most severe ill health, severity holds an important position in the model. Over time request emerged to make the evaluation of severity more consistent with the criteria stated in the Government bill for Swedish priority setting (Prioriteringscentrum, 2017; Prop 1996/97:60).

The need of more consistency and transparency in what was to be incorporated into the evaluation of severity level was first acknowledge in a local priority-setting project within rehabilitation in the Kalmar County Council (Ahlström, Blomé, Broqvist, Göransson, Nilsson & Pettersson, 2008). No existing severity assessment tool (e.g. life-quality assessment tool) was considered to fully cover the different severity aspects stated in the Government bill. Therefore, a first draft of a framework, a Severity Framework, was developed by multi-professional and interdisciplinary groups familiar with priority-setting policies, both at local and national level. They tried to interpret what was stated regarding severity in the bill. The Severity Framework has since then been further developed in corporation between the National Board of Health and Welfare and the National Centre for Priority Setting in Health Care. The framework is aimed at providing a structured approach for qualitatively evaluating severity level at meso level, in accordance with statements on severity in the bill (Prioriteringscentrum, 2017).

From the Government bill it was possible to deduce that both [health-related] *quality of life* and *the risk of premature death* play a role for the severity of a condition, as well as the *duration* of the condition and *the risk for future ill health*. No aspect is explicitly deemed more important than others for deciding the severity level. The bill also declares that health should be defined in accordance with the World Health Organization (WHO) model of health, i.e. with a holistic view on health (Prop. 1996/97:60). Since the principles and criteria for priorities were decided in the late 1990s, the WHO model has been conceptually developed and incorporates impairments of bodily function (including physical and psychological impairments), as well as activity limitations (practical consequences of ill health), and participation restrictions (social consequences of ill health) (Figure 2). Also, environmental factors (e.g. personal relationships), and personal factors (e.g. gender, age and life-style) are considered to have an effect on health. According to the Swedish Government bill, caution should be exercised in giving environmental or personal factors any importance for priorities if no connection can be made between those aspects and certain needs of healthcare interventions.

Figure 2. The World Health Organization Model of Health (WHO, 2014)

In the Severity Framework (Figure 3) the quality-of-life impact is covered by: impairment of bodily functions, activity limitations, participation restrictions¹⁷, and the occurrence and duration of these problems, plus the risk of future ill health. The future ill health includes both the risk of new symptoms and the risk of deterioration in already diagnosed ill health. The impact on life-length comprises both the level of risk of premature death (i.e. regardless of how far in advance death occur) and time to death (i.e. expected time to death). *Occurrence*, is also included in the framework despite not being explicitly pronounced in the bill. It stands for how often (constantly, monthly etc.) the patient group is usually aware of their health problem (Prioriteringscentrum, 2017). As the framework is aimed for use at the meso level (not for evaluation of individuals) the aspects are evaluated by how they normally/most often appear in the patient group.

Impact on health-related quality-of-life							Impact on life-length		Cumulated evaluation
Current ill health					Future ill health				
	Impairment of bodily functions	Activity limitations	Participation restrictions	Occurrence	Duration	Risk of future ill health	Risk of pre-mature death	Time to death	
Very high									
High									
Moderate									
Low									
None									

Figure 3. The Severity Framework¹⁸

¹⁷ These terminology is based on WHO's International Classification of Functioning, Disability and Health (ICF), used for measuring health and disability at individual and population levels (WHO, 2014).

¹⁸ Since Study III was conducted the Severity Framework has been slightly changed, the head-lines of 'Impact on health-related quality of life' and 'Impact on life-length' deleted.

The framework is intended for use for all kinds of ill health conditions, from minor ailments to multi-morbidity conditions. The cumulated evaluation has a qualitative scale from very high to low severity. Due to the priority-setting situation, different instruments (e.g. life-quality instruments or visual analogue scales) could be used to support the considerations in the framework, by providing measurements. The framework has been evaluated among professionals working with national guidelines at the National Board of Health and Welfare¹⁹ (Broqvist & Sandman, 2015). It was found to have face validity, i.e. to be subjectively viewed as supportive to enabling compliance to the bill, when deciding on severity level.

When establishing the ethical principles in Sweden, the Parliamentary Priorities Commission consulted the public in a survey and found substantial support for giving higher priority to those with the most severe ill health (without further defining what was meant by the most severe). This was an important finding as the importance of ethical principles being in line with social values has been emphasised for the legitimacy of priority setting (Clark & Weale, 2012; Frankish et al., 2002; Rogge & Kittel, 2016; Sabik & Lie, 2008). However, agreement generally tends to decrease when vague principles are more precisely defined (Liss, 2008), and neither patient groups, nor representatives of the public have been involved in the process of operationalising the severity criterion into the Severity Framework in Sweden. However, the framework is still open for discussion and reappraisal.

Follow-ups on decided process values

In the follow-up conducted in 2006, the *transparency* concerning priorities and priority setting processes *within* the healthcare system was perceived to have increased due to the parliamentary decision (Prioriteringscentrum, 2008). At that time some of the Swedish county councils had engaged in more transparent ways of setting priorities (Garpenby & Bäckman, 2016). Still transparency, directed not just at patients but at the public in a broader sense, was considered to be of limited extent (Prioriteringscentrum, 2008). However, the national guidelines for severe diseases issued by the National Board of Health and Welfare is one example of explicit priorities, accessible to the public e.g. by the authority's website (Socialstyrelsen, 2018b).

Another process value of importance, was the possibility for the public to take part in the dialogue of priority setting. Since the follow up by Prioriteringsdele-

¹⁹ At the time of the evaluation, the Severity Framework had been tested in three national guidelines: heart diseases, diabetes and COPD/Asthma. The framework was evaluated by questionnaires and based on the result, complemented with interviews with those most positive and most negative to the use of the framework.

gationen, some participatory forms of public involvement that could relate to resource allocation (but not evidently to priority setting and rationing) have emerged in Sweden (Fredriksson et al. 2018; Rosén, 2006). Different forms of so-called 'citizen dialogue' have been tested, in some counties occasionally, in others on a more regular basis (Garpenby & Bäckman, 2016; Fredriksson et al., 2018; Rosen, 2006). Still, in comparison with for example England, public involvement is described as mainly leaning on democratically elected representatives in the county council/healthcare regions, rather than on more between-election activities involving the public (Fredriksson et al., 2018). This despite the fact that deliberative ideas have dominated the general democratic debate in recent years in many countries, with increased transparency and public participation as the centre of attention (Dalton, 2014). Even during the last decade governmental inquiries in Sweden have suggested that the current representative democracy in Sweden should be complemented with activities that encourage increased public participation (SOU 2001:1). The thought of increased public involvement as a way of maintaining legitimacy has also gained support when it comes to confidence in resource allocation in healthcare in many countries (Williams et al., 2012). Democratic participation take many forms and, as stated by Dalton (2014), people tend to focus on the activity they prefer. In Sweden signing petitions, contacting local politicians and engaging in interest organizations are examples of such engagement (Gilljam & Hermansson, 2003). To what degree such public activities apply to healthcare and priority setting is not known.

No new national follow-up on the parliamentary decisions for priority setting in its entirety has been carried out since 2006.

Former research

What is known about citizens' views on priority setting and rationing at meso level and what is still to be uncovered in this research area? Below, empirical studies where citizens have been asked about their views will be included, while studies restricted to patients, health professionals' or other actors' views are not commented on, nor are studies published before 1995.

An overview

In 2009 Mitton et al. (2009) published a scoping review of articles about public involvement in priority setting. Since then the reporting on public views on priority setting has increased and a few more reviews in this field have been published. An essential part of the literature deals with citizens' views on prioritisation between patient groups with specific diagnoses, or specific interventions (e.g. between prevention vs treatment), and are linked to cost-utility analysis

and QALY²⁰ as an outcome measure (Gu, Lancsar, Ghijben, Butler & Donaldson, 2015; Mitton et al., 2009; Whitty et al., 2014). In other reviews on priority setting, the bulk of articles were found to involve preference studies with trade-offs between different kinds of priority settings criteria, e.g. between severity and health gain (Shah, 2009; Whitty et al., 2014). Krevers et al. (2015) find that among 155 articles the following questions areas have been put to citizens (in descending order): preferred priority-setting criteria, preferred methods for public involvement, specific priority setting cases, acceptance of priority setting and rationing, appropriate decision makers, appropriate priority setting process and attitudes towards transparency. Commonly, each study spans a wide range of questions (Krevers, Bäckman & Broqvist, 2015). At the time of the first studies in this thesis there was a demand for more qualitative studies in general when it came to studies about citizens' views on priority setting (Busse, 1999; Coast, 2001; Dicker & Armstrong, 1995; Dolan et al., 1999; Litva et al., 2002; Wiseman et al., 2003).

Attempts have also been made to establish the relationship between attitudes towards priority setting and sociodemographic variables such as age, gender, education etc. Some associations have been confirmed (e.g. between higher education level and higher acceptance of rationing) but not in all cases and settings (Green, 2009; Mossialos & King, 1999; Nord, 1995; Oddsson, 2003; Ryyänänen et al., 1999; Winkelhage & Diederich, 2012). Conflicting findings across countries, e.g. about the association between views on priority setting and age and gender, reflect the fact that each healthcare system works within a unique context and creates its own nature of associations (Mossialis & King, 1999).

Until 2006, European studies only represented a small amount (8%) of articles about citizens' views on priority setting, published in English-language articles (Mitton et al., 2009). In Sweden there are just a handful of studies that address citizens' view on priority setting and/or rationing in resource allocation situations at the meso level (de Fine Licht, 2011, 2014a; Fredriksson et al, 2018; Mossialos & King, 1999; Rosén & Karlberg, 2002; Werntoft, Hallberg & Edberg, 2007; Werntoft, Hallberg, Elmståhl & Edberg, 2006; Werntoft, Hallberg, Elmståhl & Edberg, 2005; Wiss, Levin, Andersson & Tinghög, 2017). Three of these studies focused on patient level, but with one or two questions about priority setting at meso level. In the following I will concentrate on what is known about citizens' views linked to my own research questions. It means focusing on citizens' acceptance of rationing, including citizens' views on appropriate decision mak-

²⁰ Quality-Adjusted Life Year (QALY) is a generic measure of disease burden that takes into account the impact of an medical intervention both on the health-related quality of life and on quantity, i.e. life expectancy.

ers, and on operationalisation of the severity criterion. Also studies comparing citizens' views on priority setting issues with other stakeholders will be described.

Studies of citizens' acceptance of priority setting and rationing

There are many indications that citizens in welfare communities have not just high, but sometimes unrealistic expectations of access to healthcare, but there are very few studies that explicitly explore citizens' awareness and acceptance of rationing of healthcare, especially at meso level. Coast et al. (2002) found that citizens were more reluctant to accept rationing than health professionals, as citizens thought politicians could easily provide more funding to the health services (Coast, Donovan, Litva, Eyles, Morgan, Shepherd & Tacchi, 2002). The Eurobarometer Survey from 1998, conducted in seven European countries, showed that 76,9% of Swedes were unwilling to set limit in healthcare, even for those less severely ill (Mossialos & King, 1998). A survey study done by Rosén and Karlberg (2002), which included two questions where Swedish citizens' views on desired access to healthcare were compared with politicians', administrators' and physicians' views, gave the same result. The findings showed that the public have high expectations of access to healthcare even for 'trivial troubles', compared to the other groups (Rosen & Karlberg, 2002). This could indicate a rather low awareness of the limitation of healthcare resources.

de Fine Licht (2011) conducted experimental interview studies in Sweden on how transparency, expressed in different framings of priority decisions, affected the legitimacy of priorities in specific cases. Her study indicates that transparency might have the power to increase public acceptance of rationing, especially when citizens were provided with justifications for the decisions presented to them. However the results were far from clear-cut. Another Swedish researcher, Elisabet Werntoft focused on older people's views on prioritisation (Werntoft et al., 2007). A structured interview study was conducted with 446 people (of which one third were in receipt of healthcare and services). At the same time as the participants accepted priority setting as a necessity at the meso level between patient groups, they were (somewhat contradictory) reluctant to anyone taking precedence over other at the individual, patient level (i.e. giving lower or higher priority to one cancer patient compared to another cancer patient) (Werntoft et al., 2007). In two different surveys Werntoft et al. (2007) included some closed-questions about the acceptance for different priority-setting criteria. The older people did not emphasise age as a criterion for priority (with the exception of children), and less support was given to taking into account patients' financial situation or self-inflicted ill health, while on the other hand the severity of ill health was accepted as criterion (Werntoft, et al., 2005b; Werntoft et al., 2006). In another study, a population survey was conducted with the aim

of investigating general preferences toward rarity as an acceptable criterion priority setting associated to orphan drugs. No support for such preferences was found (Wiss et al., 2017).

Studies of appropriate decision makers

Internationally, different actors have been the target of studies of citizens' views on legitimate decision maker for priority setting (some studies explicitly for rationing decisions): politicians, health professionals (foremost physicians), patients, the public and sometimes experts and administrators. The framing of the questions, however, is a bit different in the surveys, hence it is unclear to what priority-setting situations (macro, meso or micro level) the questions refer. Closed questions with restricted alternatives about appropriate decision makers could also be problematic, as they could leave other possible options out of question (Busse, 1999; Coast, 2001; Dicker & Armstrong, 1995; Dolan, Cookson & Fergusan, 1999; Litva et al., 2002; McTaggart-Cowan, Tsuchiya, O'Cathain & Brazier, 2011; Wiseman et al., 2003). Even if sparsely explored there is some indication that the choice of different method will give different results when it comes to citizens' view on decision makers for priority setting in healthcare (Litva et al., 2002). In a review published as late as in 2015 there was still a dominance of quantitative studies of citizens' views on appropriate decision makers (Krevers et al., 2015).

In international research that more directly addressed the question of appropriate decision makers for priority setting and rationing, politicians are seldom mentioned as important actors (Bowling et al., 1993; Wiseman et al., 2003). Instead, several studies show that citizens prefer physicians to make such decisions (Bowling, 1996; Busse, 1999; Kneeshaw, 1997; Litva et al., 2002; Myllykangas et al., 1996; Richardson et al., 1992; Wiseman et al., 2003). This choice has partly been explained as a knowledge-based confidence, people do think that health professionals are highly skilled, also when it comes to prioritising (although it is uncertain whether this applies to meso level). Additionally, people place high belief in that physicians are their agents and will secure resources for their healthcare, rather than impose limits (Mechanic, 1998). Some studies indicate that citizens themselves believe they could have a role in priority setting and rationing decisions (Bowling et al., 1993; Bruni, Laupacis, Levinson & Martin, 2010; Litva et al., 2002; McIver, 1998; Richardson et al., 1992; Wiseman, 2005). However, there are conflicting findings indicating that citizens' involvement is not self-evident in the eyes of citizens themselves (Litva et al., 2002; McKie et al., 2008).

One way of looking at legitimacy is to relate the concept to three different levels: the level of ideas, the institutional level and the level of actors (Bretzer

2015, 2017; Norris 2011). Theoretically there could be high confidence in one of these levels, but low in another. In many countries there seems to be support for democratic ideas and for democratic government, but dissatisfaction with political institutions (Dalton, 2014; European Values Survey, 2008). Swedish studies that directly address the question of what citizens think about appropriate decision makers for priority setting, are sparse. General studies on confidence and legitimacy of the Swedish healthcare system may give some indications. In the European Values Survey (2008) 95% of Swedes answered that democracy as an idea is better than other forms of government, but only 42% supported how democracy is practiced by politicians. In 2016, 63% stated that they had rather low or very low confidence in Swedish politicians in general. Regional and local politicians, those who are closest to the citizens and responsible for healthcare, inspired the lowest confidence (Andersson, Ohlsson, Oscarsson & Oskarson, 2017). In contrast, a Swedish national survey from 2016 showed high confidence on the actors' level, with references to health professionals. Actually, they came top among 15 common professions in Sweden (Oscarsson & Bergström, 2017).²¹ In summary this indicates that, in Sweden as in many other countries (Dalton, 2014), we may have a situation of high confidence in democratic ideas and in health professionals, but a public that is rather dissatisfied with the political leadership in healthcare, which probably could have a bearing of citizens views on who should decide on resource allocation.

One study has reported Swedish citizens' views on appropriate decision makers at meso level. When posing with the question *"If limits must be set, who should decide which types of treatment is given a higher priority?"*, there was a clear preference for doctors (81%) above the general public, national politicians, nurses and managers (Mossialos & King, 1999). Another cross-country survey explored the provision of local healthcare services in England and Sweden. The findings showed that the Swedish public were more interested in being involved in local decisions about provision of services (55%) than the public in England (33%). The regionalised healthcare system was put forward as a possible explanation for this difference (Fredriksson et al., 2018). However, the meaning of 'involvement' was not defined and the concept of priority setting or rationing not used in their study.

Studies of citizens' views in accordance with operationalising country specific priority-setting criteria

Most international studies that have explored citizens' views on severity as a priority setting criterion have reported it to be an important, and often the most

²¹ Such confidence can in turn improve the legitimacy for the healthcare system (Abelson, 2009; Misztal, 1996).

important, criterion (Franken, Stolk, Scharringhausen, de Boer & Koopmanschap, 2015; Green, 2009; Nord & Johansen, 2014; Ryyvönen et al., 1999; Shah, 2009). How the characteristics of the most severely ill should be understood and assessed has long been under discussion among scholars and health professionals internationally as well as in Sweden. Reviews on priority setting show that there is considerable heterogeneity in the definitions of severity in the literature (Gu et al., 2015; Nord & Johansen, 2014; Shah, 2009).

Citizens' contributions in studies of severity are concentrated into preference studies. In such studies citizens are supposed to rank pre-determined, alternative choice options, i.e. weighing of severity between different diseases (e.g. cancer vs psychosis), weighing different severity aspects (e.g. life-quality vs premature death) or the severity criterion against other priority-setting criteria in importance (Richardson, McKie, Peacock & Iezzi, 2011; Shah, 2009; Schmueli, 2000; Whitty et al, 2014). There is a lack of studies of citizens' views on how to operationalise the severity criterion by freely nominating aspects that are important from the citizens' perspective. However, this is not unique for the severity criterion. There is a general lack of studies which illuminate what citizens could contribute to in operationalisation and designing of priority-setting tools and frameworks (Mitton et al., 2009).

A few comparative studies (Myllykangas et al., 1999; Ryyvönen et al., 1996), one of them Swedish (Rosén, 2002), exist that explore differences between citizens, politicians and health professionals when it comes to priority setting and severity as a priority setting criterion. No article is published about comparison regarding citizens', health professionals' and politicians' ranking of different aspects of a severity when used as a criterion for priority setting and rationing at meso level.

To sum up: What is already known? What remains to be studied?

Based on what has been presented in the background, the rationale for this thesis could be summed up as follows:

- Knowledge of social values (both about process and content values) in a priority-setting and rationing context is considered to have instrumental benefits, adding quality to resource allocation decisions. Such knowledge is relevant for politicians in a democratically governed, publicly funded healthcare system, and has been claimed to have the potential to sustain legitimacy for priority setting in resource allocation.
- Studies about citizens' views on priority setting have been found to be very context-sensitive with results not easily transferred from one country to another. Few studies exist where Swedish citizens (and not only patients or health professionals) have been asked about priority setting and rationing in healthcare.
- Research about citizens' views on priority setting and rationing in healthcare has mainly been concentrated on trade-offs between different specific diseases, different interventions, or different priority setting principles and/or criteria. Most of these studies have been referring to patient level, based on case descriptions. There are also studies focusing on macro priorities at national level (e.g. funding solutions for limited resources). However, there is a lack of knowledge about citizens' views on meso level priorities, i.e. priority setting between different patient groups or different health services at the county council (or regional/local) level and at the clinical management level.
- Methodological deficiencies in studies of citizens' views have been identified in previous research, which make findings hard to interpret and compare. Especially there is a need of qualitative studies with a more open-ended approach, where citizens are allowed to express their thoughts and understanding about priority setting more freely, both according to content and process values.
- There is a lack of studies where citizens have been involved in operationalising parliamentary-decided ethical principles and criteria, in this case the severity criterion, and have had their views compared with actors such as health professionals and politicians.

METHOD

This thesis comprises different types of research questions and consequently requires the use of different types of designs and methods. An overview of the methodological approaches in the four studies introduces the chapter (Table 1). Each study is then described according to choice of method, settings, sampling process, data collection and data analysis. Ethical considerations end the chapter.

Table 1. Overview of methodological approaches in the thesis

Study	Aim & Focus	Design	Participants	Method & Analysis
I	To identify and describe Swedish citizens' perceptions of what influences their acceptance of having to stand aside for others in a public health services. Focus: Process and content values	Qualitative, exploratory.	Citizens (n=14). Purposeful sampling based on different sociodemographic characteristics and attitudes towards priority setting.	Individual interviews. Phenomenography.
II	To identify and describe different ways Swedish citizens' understand and experience decision makers for rationing at meso level in healthcare. Focus: Process values	Qualitative, exploratory.	Same as study I.	Individual interviews. Phenomenography.
III	To examine what Swedish citizen's consider relevant when evaluating severity level of ill health in resource allocation situations, and how their views correspond with how the Swedish severity criterion have been operationalised into a Severity Framework, as used in such situations. Focus: Content values	Mixed method, descriptive.	Citizens (n=15). Purposeful sampling based on different sociodemographic characteristics, ill health experience and attitudes towards severity as a priority criterion.	Individual interviews. Embedded mixed method: directed content analysis.
IV	To compare citizens', health professionals' and politicians' ranking of different aspects of a severity criterion when used in a priority setting principle for resource allocation in healthcare. Focus: Content values	Quantitative, descriptive. Cross-sectional comparative.	Citizens (n=123), health professionals (n=185) and politicians (n=129). Randomised sampling.	Survey study. Descriptive statistics. Pearson's Chi-square test for between-group differences in proportions.

Studies I-II

Studies I and II were based on the same data collection, using a phenomenographic approach. Phenomenography is a qualitatively oriented empirical research method. It was first developed by the Department of Education and Special Education at the University of Gothenburg in the 1970s, as a method for studying learning processes from the perspective of the learner (Dahlgren, 1975). In 1981 Ference Marton developed the thoughts behind the method and introduced the term phenomenography (Marton, 1981). Since the introduction of phenomenography a large bulk of research within the field of pedagogy has emerged. The method has also been proven to have potential to demonstrate how people understand and experience phenomena related to healthcare (Barnard, McCosker & Gerber, 1999; Brammer, 2005; Röing, Holmström & Larsson, 2018).

The choice of phenomenography

When limited knowledge exists about a phenomenon (as in the case with Swedish citizens' views on priority setting and rationing at meso level in healthcare), an important first step is to identify the variety of *"different ways in which people experience, interpret, understand, apprehend, perceive or conceptualize"* the phenomenon under study (Marton, 1981, p. 178). The epistemological assumption behind phenomenography is that people, through different interactions with the world, have different experiences with the phenomena they encounter. People then make different analyses and act or react on how they perceive these phenomena (Marton & Booth, 1997). The method rests on a non-dualistic ontology, i.e. that reality is not entirely about facts but dependent on the experiences of the facts (Marton, 1995). Within phenomenography the scholars are interested in how different phenomena are understood and perceived by the people themselves (the so-called second order perspective), regardless of whether it is 'true' or not (Marton & Booth, 1997).

'Experience' within phenomenography does not have to be lived experience, it could just as well be the conceptual thoughts of the phenomenon in study (Marton & Booth, 1997). In studies I and II it means that people do not need to have faced rationing in healthcare themselves to have thoughts about how to understand this phenomenon. All variations of experiences are of interest, regardless what the experience comes from (in contrast to phenomenology where the interest is in lived experience).

Different ways of understanding a phenomenon are not seen as individual qualities, but as categories of description. It means that the categories are stable, while individuals can move between the categories depending on the context

(Marton, 1981). In fact, the same person could have several, sometimes contradictory, understandings of a phenomenon. It means that within phenomenography, no attention is given to frequency in the material (Marton & Booth, 1997). Another assumption behind the method is that the understanding can be changed as new insights and new experiences are gained (Hasselgren & Marton, 1982). The categories in phenomenography are related to each other in different ways. They could exist independently of each other or they could be hierarchically ordered, which means that they depend on each other, and gradually describe more inclusive or complex ways of understanding the phenomenon under study (Marton & Booth, 1997).

Study setting

There is reason to believe that public views on priority setting in healthcare are affected by one’s own (or others’) experiences of access to healthcare (Delhey & Newton, 2002). In addition, research has shown that information received through media strongly influences views on resource allocation in healthcare (Garattini & Bertelè, 2000; Iyengar & Kinder, 1987; McCombs, 2014), especially when upsetting the public when individuals are denied service (Edgar, 2000). It means that in the regionalised healthcare system in Sweden, the inhabitants in each county council or region could have different experiences of healthcare. In order to increase the possibility of finding variations in citizens’ ways of perceiving acceptance of rationing, and decision makers for rationing, we recruited citizens from two different counties, Region Östergötland and Kalmar County Council. At the time of the study, 2006, there had been a high level of media coverage of ongoing rationing activities in Östergötland (Bäckman, Nedlund, Carlsson & Garpenby, 2008). It was probably the first county council in Sweden to arrange a formal, explicit rationing process with the aim of limiting the supply of healthcare interventions due to economic restraints (Garpenby & Bäckman, 2016). In the Kalmar County Council there was no such similar explicit activity at this time. Additionally, citizens in the two counties differed in confidence in their healthcare (lower in total in Kalmar), and in how they perceived access to healthcare (lower in Östergötland²²) (Anna Kjellström, Enhet Regional vårdanalys, Västra Götalandsregionen, personal communication, May 15, 2006).

22

	Kalmar	Östergötland
Experience of having very high/high access to healthcare	83%	72%
Very high/high confidence in primary health care	65%	72%
Very high/high confidence in hospital care	77%	76%

Sampling

In the absence of solid evidence for association between attitudes to priority setting and sociodemographic characteristics, a two-step sampling process was used in studies I and II, taking into account *both* sociodemographic characteristics *and* attitudes.²³

The first step in the sampling process

Questionnaires were distributed in the two county councils to different groups with the intention of capturing a diversity in age, gender, education and ethnicity: to different workplaces, two requiring university education (non-manual employment in high technology and culture) and three requiring upper secondary education (manual employment in trade, agriculture and mechanical engineering); a pensioners club; a project for young unemployed; a university and an immigrant organisation. Contacts at these sites were approached by letter or in person and asked for their willingness to distribute the questionnaires to their groups.

In the questionnaire information was given about the background and aim of the study. Besides noting age and gender the respondents were asked to answer four questions, one each about their attitudes to appropriate decision makers for resource allocation in healthcare, desirability of transparency in priority setting, the possibility to achieve fairness in resource allocation, and the actual state of equity in healthcare (Appendix A).

The second step in the sampling process

Of 124 people who were approached with the questionnaire, 72 returned the questionnaire. It resulted in nine typologies of answers, based on the four questions about attitudes to priority setting (Table 2). From one of each typology a purposeful sampling was made. For the typologies represented by more than one person, we stratified each type according to gender, age and occupational group and step-by-step randomly, by lottery, chose participants in a way that secured differences in these sociodemographic characteristics. Fourteen people were interviewed (Table 2).

²³ Analysing associations between characteristics and the findings of the studies is beyond the scope of this thesis.

Table 2. Sociodemographic characteristics and attitudes to priority setting among the participants in studies I-II

ATTITUDES TO PRIORITY SETTING					SOCIODEMOGRAPHIC CHARACTERISTICS															
					Occupational group					Gender		Age								
Typologies	Who should decide about rationing?	Is transparency important in priority setting?	Could we gain general accepted allocation?	Is healthcare equal today?	Non-manual employment	Manual employment	Student	Retired	Unemployed	Female	Male	18-29 years	30-39 years	40-49 years	50-59 years	60-69 years	70-79 years			
					X					X										
					X															
P=4,H=9,C=1					4	3	1	3	3	9	5	4	2	4	1	2	1			
Y=11,N=3					Y=10,N=4					Y=7,N=7										

Interviews

Data was collected by semi-structured, individual interviews.

Interview guide

As is customary in phenomenographic studies a semi-structured interview guide was used with open-ended questions (Appendix B). The interview technique rest on the idea that when answering a question, the interviewees respond based on how they interpret the question and not necessarily on what the interviewer was referring to with the question. Therefore, seeking to understand the meaning of phenomenon in the interviewee's life-world, the so-called 'what-aspect' is addressed first in phenomenographic interviews (Alexandersson, 1994; Marton, 1981). The interview guide started with questions about the meaning of 'fairness', especially in relation to resource allocation in healthcare. The interview guide then covered the following topics:

- acceptance of different forms of rationing: delay (through waiting lists), dilution (limiting the quality in healthcare e.g. by not offering the best treatment in praxis) and denial (excluding certain services or patient groups from the public menu)
- appropriate decision makers for rationing decisions
- public involvement in decision making for rationing
- appropriate decision-making process for rationing

In order to capture thoughts that were not directly stated, as suggested by Given (2008), some projective questions were used regarding participants' thoughts on other citizens' understanding concerning the acceptance of rationing in healthcare. Three pilot interviews of the interview guide were conducted, resulting in minor adjustments, thus the pilots were not included in the results.

Data collection

The data was collected in 2006, all interviews were conducted by one of the authors (M.B). Follow-up questions took place in an interpersonal interaction and were, as recommended, adapted according to each participant's reasoning e.g. *"Tell me more about this, give me an example"* (Marton & Booth, 1997). As it turned out that no participants spontaneously associated the question of appropriate decision makers for rationing to the meso level, all participants were addressed with the same follow-up question: *"Who should decide about resource allocations between different services, e.g. resources for paediatric and geriatric care or between mental and cancer care?"* Apart from this question no diagnosis were mentioned in the interview questions. The interviews lasted 30-70 minutes and were conducted at sites chosen by the participants. Apart from the questions, no information was given in the interviews. They were digitally

recorded, transcribed by a professional transcriber. Conformity with the recordings was then checked by one of the authors (M.B).

Analysis

All transcripts of interviews were analysed together as one unit of analysis and followed the steps described by Dahlgren and Fallsberg (1991). The analysis started with *familiarisation* with the material, by repeatedly re-reading all the transcripts. In study I all sentences were marked that related to what the participants perceived influences the acceptance for having to stand aside for others, both according to content and process values. In study II, statements related to decision makers for rationing in healthcare were marked. Significant statements were *condensed* into their central meaning, *compared* with each other and *grouped* into qualitative different preliminary categories. By revisiting the whole material and *articulating* the categorisation made so far, the categories were *labelled*. By *contrasting* the categories against each other the relationship between them was established in the so-called outcome space, which is the final result in a phenomenographic study (Dahlgren & Fallsberg, 1991). The analysis process is exemplified in Figure 4 by an example from study II.

Familiarisation (marked citation):

"The same goes for physicians and healthcare staff. That would not do, it is too biased in some way because physicians and healthcare staff all want all resources on their own table. If you are working in the emergency [department] you want all the money for this sector."

Condensation:

Would not do – biased - physicians and healthcare staff want all resources.

Comparison:

What is in focus?: *The risk of bias.* **Why** is this important to the participant?: *Rationing in healthcare risks an unfair result (content).*

Grouping with other similar statements

Preliminary category: *Risk of self-interest.*

Articulation:

Reconsidering grouping and preliminary categorisation placed the *Risk of self-interest* as one of several subcategories under the preliminary category *Risks of unfairness.*

Labelling:

As the phenomenon under study is decision makers for rationing the category was finally labelled *Decision makers as a risk of unfairness*, with several sub-categories.

Contrasting

The category *Decision makers as a risk of unfairness* was viewed as hierarchically related to the other categories, built on awareness of limitation in healthcare at meso level.

Figure 4. Example of the phenomenographic analysis process in study II

Study III

Study III has a mixed method approach using directed content analysis. There is no single definition of what a mixed method is. However, a prerequisite is that qualitative and quantitative data must be integrated at some stage of the research process. In study III a so-called embedded design of mixed method has been used, meaning that all data were collected at the same time, in this case with a qualitative research technique, but with a quantitative analyze added to the qualitative one (Creswell & Plano Clark, 2014).

Directed content analysis

Originally content analysis was used for quantitative description of the manifest content of communication (Berelson, 1952). Over the years a more interpretivist version of the method appeared, placing the focusing instead on subjective interpretation of the content of text data through systematic coding and identification of themes or patterns. Directed content analysis is one of these approaches. The method is used to find descriptive support or nonsupport for a particular framework. It means that it is deductive in character, using already established key concepts as initial coding categories. However, working with content analysis means relying on the thought that there are multiple interpretations of reality among people. Therefore, besides the predetermined categories, directed content analysis allows for new categories and sub-categories to be found. Such categories could offer a contradictory view of the framework, be totally in line with it or might further refine, extend, and enrich the framework conceptually. Used in combination with the qualitative approach, the quantitative dimension in directed content analysis does not aim for statistical tests of differences, but to descriptively show the extent of support (and non-support) for the framework under study (Hsieh & Shannon, 2005).

Study setting

Participants were recruited from regions/county councils that, at the time of the recruitment in 2014, reflected differences in public experience of accessibility to, and confidence in, healthcare: Region Gävleborg, Region Uppsala, Region Östergötland, Stockholm County Council and County Council Dalarna (Sveriges Kommuner och Landsting, 2015)²⁴.

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	Gävleborg	Uppsala	Östergötland	Stockholm	Dalarna
Experience of having very high/high access to healthcare	75%	81%	81%	82%	71%
Very high/high confidence in primary healthcare	63%	68%	64%	64%	57%
Very high/high confidence in hospital care	55%	73%	77%	73%	71%

Sampling

Educational level (Löve, Hensing, Holmgren & Torén, 2013), gender (Bekkera, Rutteb & Van Rijswijkc, 2009), age (Alemayehu & Warner, 2004), urban/rural residence (Wallin & Carlberg, 2000) and illness adaptation (McTaggart-Cowan et al., 2011), are all characteristics that are known to correlate with the search pattern of healthcare and sick leave, which potentially could have some bearing on citizens' views on severity. To handle the uncertainty regarding the characteristics, a two-step purposeful sampling process was used, taking into account *both* sociodemographic characteristics *and* attitudes toward severity as priority criterion.

The first step in the sampling process

A questionnaire was used to generate a participant pool. To find diversity in sociodemographic characteristics we approached, via contacts, different work sites, three requiring university education (high school, judiciary and culture), and three requiring upper secondary (preschool, administration and marketing). Furthermore, we included a sports club with elite athletes who use their bodies as their professional tools and a sport club for amateurs. Questionnaires were also distributed in a retirement home among people who were expected to have experienced ill health in their life. The same assumption was made when contacting patient associations, one representing people with mainly psychological health problems and one representing mainly physical (neurological) problems.²⁵ With the expectation of finding people with less experience of personal ill health and healthcare, we approached young people at a student dorm.

Besides information about the background and aim of the study, the questionnaire consisted of questions about the respondents age, gender, health in the last year, earlier experience of personal or relatives' severe ill health, and one attitude question: whether they perceived that the most severely ill gained the highest priority in healthcare today (Appendix C). The contact information, given by the respondents, gave information about their rural or urban residence.

The second step in the sampling process

Sixty-seven respondents returned the questionnaires (of 120 people approached). Ten typologies of answers, based on ill health experience and attitude to the severity criterion, were categorised (Table 3). For the final sample, data saturation principles according to Francis et al. (2010) were practiced. The method is developed for interview studies where theory-driven approaches of

²⁵ They were informed that they were asked to join the study as individuals speaking on their own behalf.

content analysis, as directed content analysis, are used. It means starting with an a priori decision of an initial analysis sample, where the analysis of the interviews begins. As recommended we set this sample size to 10 interviews. These 10 participants were chosen by purposeful sampling from each of the 10 present typologies. The sampling method include deciding a priori a stopping criterion, i.e. the amount of further interviews to be done where no new themes should emerge (Francis, Johnston, Robertson, Glidewell, Entwistle, Eccles & Grishaw, 2010). In our case we chose five interviews as the stopping point (three being recommended). One by one we successively incorporated and analysed each added interview until this point was reached. This analysis process resulted in 15 people being interviewed (Table 3). Exclusion criteria were having ongoing employment in the healthcare service or a political mandate.

Table 3. Sociodemographic characteristics, ill health experiences and attitudes to the severity criterion among participants in study III

ILL HEALTH EXPERIENCES AND ATTITUDES TO THE SEVERITY CRITERION				SOCIODEMOGRAPHIC CHARACTERISTICS							
Typologies	Your health in the last year	Experience own/ relatives' severe ill health	The most severely ill gain highest priority today	Education level			Gender		Age	Living settings	
				University	Upper secondary	Elementary school	Female	Male		Urban	Rural
1	Good (G)	Yes (Y)	Yes (Y)	X			X		66		X
2	Good	Yes	Yes	X	X			X	71		X
	Good	Yes	No (N)				X		43		X
3	Good	Yes	No		X		X		83		X
4	Good	Yes	Do not know (Dk)	X		X	X		67		
	Good	No (N)	Yes				X		60		X
5	Good	No	Yes	X				X	20		X
	Good	No	No		X				23		
6	Moderate (M)	Yes	Yes	X			X		42		X
7	Moderate	Yes	No	X	X		X		57	X	
	Moderate	Yes	No						50	X	
8	Moderate	No	Yes	X		X	X		88		X
	Moderate	No	Yes			X	X		51		X
9	Moderate	No	Do not know	X				X	37	X	
10	Bad (B)	Yes	Yes		X		X		45	X	
G=8, M=6, B=1				7	5	3	11	4	Median=51	10	5
Y=9, N=6				Y=8, N=5, Dk=2							

Interviews

Data was collected by semi-structured, individual interviews.²⁶ One week in advance of the interviews the participants were approached by e-mail or letter informing them about the interview situation. In this information they were asked to imagine a fictive situation, where their county politicians want to consult them as citizens, on what aspects they thought should be considered when evaluating severity level of ill health in resource allocation situations. The participants were also informed that the reason for the interest in severity is the decision of the Swedish parliament that more of healthcare's resources should be given to those in greatest need and with the most severe ill health.

Interview guide

The interview guide used in study III consisted of two parts: a) open-ended questions where the participants could freely reflect on aspects relevant for evaluating severity level, and b) targeted questions about the relevance of aspects of severity incorporated in the Severity Framework: impairment of bodily functions (physical and psychological symptoms), activity limitations, participation restrictions, duration, occurrence, risk of future ill health, risk of premature death and time to death. No diagnoses were mentioned in the questions (Appendix D). One pilot group interview with four people was conducted to test the interview guide, resulting in a reduced number of questions, why the pilots were not included in the results.

Data collection

The interviews were conducted in 2014 and 2015, lasted 25 to 60 minutes (on average 40 minutes), were digitally recorded and conducted at sites chosen by the participants. In order to reduce the risk of so-called social desirability bias (Dahlgren & Hansen, 2015), the participants were not at any time in the study informed about the existence of the Severity Framework, or given any other kind of information besides the questions. New aspects of severity that were brought up by the participants during an interview were not presented to the other participants in later interviews. The interviews were transcribed by professional transcribers and the conformity with the recordings checked by one of the authors (M.B).

²⁶ The participants were given the opportunity to choose whether they would like to participate in a group or an individual interview. Everyone chose individual interview.

Analysis

In the analysis each interview was considered as a unit of analysis, recommended as large enough to be considered as a whole and still small enough to be manageable in content analysis (Graneheim & Lundman, 2004).

Coding process

The first step in the analysis in directed content analysis, is to create a coding scheme, which is a multistage process (Hsieh & Shannon, 2005). As we were interested in comparing the participants' views on severity with the Severity Framework, the framework was chosen as the initial coding scheme. The next step is to define explicit coding rules with operational definition for the key concept in the coding scheme (Hsieh & Shannon, 2005). The coding was following the ICF linking rules, chosen because the terminology in the Severity Framework is partly based on the ICF terminology. The ICF linking rules have been developed in order to make it possible to analyse and compare the content of frameworks, used within healthcare e.g. different health-state measurements (Cieza, 2005). In each interview all meaning units, consisting of one to three sentences that concerned severity, were highlighted and coded in accordance with these rules. For meaning units that did not fit into any category in the Severity Framework inductive category development was performed, as recommended by Mayring (2014). This process gave an extended coding scheme to be used in the final analysis (for coding rules see Appendix E). The coding rules were tested independently by the research team on interview material samples, and compared in order to ensure a common understanding of the coding rules.

Dichotomous classification

Notifying the dichotomous presence (yes/no) of each category in the participants' reasoning and creating a ranking based on that, is an example of descriptive quantification that has been recommended in directed content analysis (Onwuegbuzie, 2003). Therefore, for each severity aspect in the coding scheme and for each participant, we marked whether the aspect was considered relevant or not by the participant for evaluating severity level of ill health, either in the open ended questions and, if not in that section, in the targeted questions. Ranking order was used to illustrate how frequently each aspect was considered relevant by the group.

Study IV

Study IV is deductive in character and based on a survey. As we were interested in how pre-defined aspects of severity of ill health were distributed between citizens, health professionals and politicians, a quantitative study allowed us to statistically test if there were any differences between these actors.

Study setting

Study IV was undertaken in Kalmar County Council, Västerbotten County Council, Västra Götaland Regional Council, and Region Västmanland. These counties were chosen for several reasons. One was the differences in how the citizens in each county council/region perceived the accessibility to healthcare and their confidence in healthcare (Sveriges Kommuner och Landsting, 2016a, 2016b, 2016c, 2016d).²⁷ As for politicians, we were interested in reaching both those engaged in county councils where their political mandate is more focused on healthcare issues, and those in regions with increased responsibility for regional development and where healthcare is one of many types of societal issues.

Sampling

From each of the four county councils/regions, we ordered a random selection of 100 citizens (400 in total) and 100 professionals (400 in total), aged 18 years and older, from different national registers (the Swedish Population Register²⁸ and the Register of licensed health professionals²⁹). The citizens were stratified according to gender and the health professionals according to profession: physicians, nurses, occupational therapists, physiotherapists, dietitians and speech therapists. These professions were chosen as they might represent different paradigms according to their view on ill health. The restricted number of politicians in these four counties allowed us to include them all, 680 in total (both regular members and alternates).

Survey

To perform the comparison between citizens, health professionals and politicians a questionnaire was used.

²⁷

	Västra Götaland	Kalmar	Västmanland	Västerbotten
Experience of having very high/high access to healthcare	81%	89%	85%	86%
Very high/high confidence in primary healthcare	56%	69%	59%	63%
Very high/high confidence in hospital care	65%	77%	70%	73%

²⁸ Statens Personadressregister, Skatteverket.

²⁹ Registret över legitimerade hälso- och sjukvårdspersonal, Socialstyrelsen.

Questionnaire

The Severity Framework was used as the framework for constructing the questions in the questionnaire. Additionally, we included questions about aspects deemed to be of importance for evaluating severity of ill health, that were brought up by Swedish citizens in the interview study III.³⁰ The questions were organised into three parts:

- a) sociodemographic questions³¹
- b) choice of which one of two different severity aspects characterised the most severe health problem (Figure 5)

	Alternative 1	vs	Alternative 2
1	Long duration of ill health giving rise to severe symptoms now and then.	vs	Short duration of ill health with constantly severe symptoms.
2	Minor ill health problem with negative impact on relatives.	vs	Major ill health problem without negative impact on relatives.
3	No practical consequences of ill health (e.g. difficulties with personal care, house-holding) but major social consequences (e.g. with relations, work, leisure etc.).	vs	No social consequences of ill health but major practical consequences.
4	Minor ill health problem giving rise to major changes in lifestyle.	vs	Major ill health problem giving rise to minor changes in lifestyle.
5	Minor ill health problem with emotional difficulties in coping with the ill health.	vs	Major ill health problem with no emotional difficulties in coping with the ill health.
6	Major impairment in health-related quality of life but no premature death.	vs	Minor impairment in health-related quality of life but premature death.
7	Minor ill health problem today.	vs	Healthy with a high risk of major future ill health.
8	Minor ill health problem today.	vs	Healthy with a low risk of major future ill health.

Figure 5. The pairs of choices on which severity aspects characterise the most severe health problem

- c) choice of the five most and the five least important aspects (of 12 possibilities) for determining the severity level respectively: physical symptoms; psychological symptoms; activity limitations; participation restrictions; occurrence; duration; risk of future ill health; premature death; prevalence; negative impact on relatives; difficulties coping with ill health and multi-morbidity.

³⁰ We excluded the aspects *societal costs* and *possibility to affect the impact of ill health* from study III, as we regarded these to be more related to other criteria in the Swedish ethical platform.

³¹ This was the only part in the questionnaire that different questions were asked to citizens, politicians and health professionals.

The questionnaire also included questions on familiarity with discussing severity of ill health, and the participants' thoughts about what influenced their answers in the questionnaire (Appendix F). No diagnoses were mentioned. Similar questions had been tested in interview study III. The questionnaire was also piloted with three people, representing one politician, one health professional and one citizen (with no employment in healthcare service or a political mandate). The pilots were not included in the results, as some questions were reformulated.

Data collection

The survey was conducted from November 2016 to January 2017 including two reminders. The questionnaires were distributed as postal surveys to the citizens and the professionals, and by e-mail to the politicians, based on available contact information. The sample population was informed that the reason for the interest in severity was the decision of the Swedish parliament, that more of healthcare's resources should be given to those in greatest need and with the most severe ill health, and that we were interested in their view on what distinguishes the most severe ill health problems from the less severe ones. They were invited to respond in their respective roles as citizens, politicians or health professionals. Responses could be made by post or on-line in a web-based survey tool, the Sunet: Survey and Report, Linköping University, 2016.

Analysis

Data from the questionnaires was registered into an excel database. Descriptive statistics were used to analyse frequencies and distributions in the material. Pearson's Chi-square tests, with expected counts greater than 5, were performed to analyse potential differences between citizens', professionals' and politicians' ranking of severity aspects. The statistics software package SPSS version 24.0 was used for the statistical tests.³² As multiple comparisons were made, familywise error was controlled with Bonferroni correction. The adjusted significance level was set to $p < .05$.

Ethical consideration for the studies

Under the Swedish Act on Ethical Review of Research Involving Humans (SFS 2003:460), the approval of a board for ethics review is a mandatory legal requirement for certain types of research. This is notably the case for research involving physical interventions, psychological manipulations, use of human biological material and research on certain sensitive personal data (health, racial origin, political or religious opinions, sexual life, and criminal convictions). Stud-

³² IBM Corp. Released 2016. IBM SPSS Statistics for Windows, version 24.0. A monk, NY: IBM Corp.

ies I and II in this thesis did not address these kinds of questions. In concordance with this legislation, and when recruiting respondents outside of a healthcare setting, no ethical approval was required for these studies. Ethical approval was obtained for study III and IV from the Regional Ethical Review Board, Linköping University (No 2015/118-31).

All participants in the studies were informed of the aim of the study, and assured of their confidentiality in the research process and in any publication or presentation. Anonymisation was done by encoding the data. All traffic to and from the survey service was encrypted and could only be accessed by the research group. Code numbers and names were registered and stored according to the Personal Data Act (SFS 1998:204), and the Archive Act (SFS 1990:782). The participants gave their informed consent when joining the studies (by sending in their answered questionnaires or giving written consent in connection with the interview) and were informed of their right to withdraw from the study without having to state any reasons.

RESULTS

In this chapter the main findings from the studies are presented in abbreviated form. Detailed results from each study are to be found in the separate papers (Paper I-IV). The chapter is introduced with a short summary of the main findings (Table 4).

Table 4. Summary of main findings

	Aim	Main findings in summary
Study I	To identify and describe Swedish citizens' perceptions of what influences their acceptance of having to stand aside for others in a public health services.	Categories describing what were perceived to influence citizens' acceptance of rationing in healthcare at meso level: a) <i>Awareness of limitations in healthcare</i> b) <i>Reactions of self-interest or solidarity</i> c) <i>Awareness and acceptance of principles applied to rationing</i> d) <i>Alternatives to publicly funded healthcare</i>
Study II	To identify and describe different ways Swedish citizens' understand and experience decision makers for rationing at meso level in healthcare.	Categories describing how citizen participants experienced decision makers for rationing at meso level: a) <i>A necessity due to limited resources</i> b) <i>An unreflected institution</i> c) <i>Linked with different risk of unfair rationing</i> d) <i>Preferred as a collaborative arrangement</i> Politicians were viewed as more legitimate than in earlier findings.
Study III	To examine what Swedish citizens consider relevant when evaluating severity level of ill health in resource allocation situations, and how their views correspond with how the Swedish severity criterion have been operationalised into a Severity Framework, as used in such situations.	Participants perceived 15 aspects relevant when evaluating severity level in resource allocation situations: 1) impairments of bodily functions 2) activity limitations 3) participation restrictions 4) general negative perception of ill health 5) dependency on other people 6) occurrence 7) duration 8) risk of future ill health 9) risk of premature death 10) time to death 11) prevalence 12) possibility to affect the impact of ill health 13) multi-morbidity 14) societal costs 15) personal factors. The ten first aspects are in line with the Severity Framework, enabling some potential refinements. Some of the other are ethically disputed aspects or aspects covered by other ethical principles.
Study IV	To compare citizens', health professionals' and politicians' ranking of different aspects of a severity criterion when used in a priority setting principle for resource allocation in healthcare.	A larger number of significant differences were found between the citizen and the politician respondents' ranking of severity aspects, than between citizens' and health professionals'. Most significant differences were found between the politician and the health professional respondents. In total differences concerned: negative impact on relatives, changes in life-style, emotional difficulties in coping, risk of future ill health, premature death, social consequences and psychological symptoms.

Citizens' views on what influences citizens' acceptance of standing aside in public health (study I)

The analysis of what Swedish citizen participants perceived influence citizens' acceptance of rationing at meso level in public healthcare resulted in four categories.³³ This section starts with a presentation of how these categories relate to each other. The categories are then further defined (in *Italics*), followed by descriptions of the participants' reasoning about each of them.

The relation between the categories

The categories in study I are hierarchically ordered, meaning that they depend on each other, and gradually become more and more comprehensive (Marton & Booth, 1997). Awareness of limitations in healthcare and the options facing decision makers when rationing at meso level, form the basic prerequisite for reaching acceptance for standing aside. Reactions of self-interest or solidarity could be built on such awareness. Somewhat different strategies are linked to each of these reactions. Closely connected with reactions of self-interest is the thought that no principles applied to rationing could lead to acceptance of rationing, while availability to alternatives (private healthcare or self-care), could have that effect. In contrast, reactions of solidarity could lead to acceptance of rationing both by reason-giving of principles behind rationing and availability to alternatives. The hierarchy of the categories is illustrated in Figure 6.

Figure 6. The relation between categories of influences of citizens' acceptance of rationing in health care

³³ Findings applying to the participants' views on decision makers for rationing are presented in study II.

Category a) Awareness of limitations in healthcare

Awareness of limitations in healthcare applies both to awareness of resource limitations, and to the options facing decision makers when having to impose rationing in healthcare at meso level.

Data revealed awareness among the participants of resource limitations affecting both the patient (micro) level and the macro level, while the necessity to set priorities between different groups of patients or between different healthcare services was an unknown phenomenon:

It has never occurred to me that someone has to decide how much money should go towards treating cancer versus geriatric care...strange really. (Citation from study I)

One explanation for the limitations of resources in Swedish health services exists in the material, namely that the expectations among citizens of what the health service can and should deliver have increased over the years. Whether the demands were related to the state of health of the population, or if it was just a change in attitude towards the use of the public system, was called into question.

Category b) Reactions of self-interest or solidarity

Reactions of self-interest to rationing in healthcare at meso level mean to always preferring the best treatment for oneself, or for one's next of kin, or at least not accepting further rationing than applies to other groups.

Reactions of solidarity to rationing in healthcare mean a) to be prepared to stand aside for the benefit of others b) to be prepared to try to live a healthy life and not unnecessarily burden the healthcare system and c) to expect solidarity from other citizens to do the same thing in return.

Concerns about current social norms were expressed among the citizen participants, as the norm today promote a more individualistic perspective on healthcare ("What's in it for me?"). Solidarity in healthcare was perceived as more of an ideal than a reality in Sweden, but nevertheless an important factor if striving for more acceptance of priority setting and rationing. Self-interest was described as a natural human reaction, but also as a problem, decreasing the acceptance of rationing. Reactions of self-interest were presumed to be especially pronounced when comparing one's own access to healthcare with those not contributing to the healthcare system by paying taxes, or with patient groups with some sort of self-inflicted ill health.

Category c) Awareness and acceptance of principles applied to rationing

Awareness and acceptance of principles and criteria applied to rationing concerns knowledge about the reasons behind the rationing decisions, including reason-giving as to why other groups are getting higher priority, and acceptance of these reasons.

Acceptance of rationing was considered compromised when insufficient knowledge existed concerning the reason for rationing decisions. A lack of reason-giving was perceived to generate general misunderstanding (such as ageism) and dissatisfaction with how resources are allocated in healthcare. Different principles and criteria were given different support as presumptions for acceptance. Severity of ill health was described to be the most important criterion to consider in rationing decisions. Otherwise, what comprise a fair principle varied depending on the method of rationing (Table 5). Most principles/criteria considered to be fair were associated with denial (exclusion). Dilution (not offering the best treatment in praxis), on the other hand, could not be fully justified by any principles or criteria (except possibly if dilution meant that more people could be treated).

Table 5. Linkage between rationing methods and fair principles and criteria for rationing

Rationing method	Denial	Delay	Dilution
Principles/criteria	Minor needs Non-medical ill health Self-inflicted ill health Private care options Knowledge of self-care	Minor needs Age Function in society	(Number of sick treated)

Category d) Alternatives to publicly funded healthcare

Alternatives to publicly funded healthcare when facing rationing, apply as access to private market options and/or the possibility to undertake self-care, including knowledge that such alternatives exist.

Among the citizen participants opposed positions existed on whether private alternatives were acceptable or not. Diminishing knowledge on self-care in society was perceived to decrease the acceptance of standing aside for others.

Citizens' views on appropriate decision makers for rationing at meso level (study II)

The main finding in study II is the citizens participants' gradually more inclusive way of perceiving the appropriate decision maker, considering politicians as more legitimate decision makers than previously shown, where physicians had normally been preferred. The findings are schematically described in Figure 7 (in a slightly different way than in Paper II).

Figure 7. Categories of citizens' views on decision makers for rationing at meso level

Awareness of rationing at meso level

The primary categories in study II are that decision makers are *a necessity for control of rationing* because of the limited resources in healthcare, but at the same time decision makers are *an unreflected institution* at meso level. Awareness of rationing at the meso level form the basis for the other categories.

Faced with the question of who should decide on rationing between geriatric and paediatric care or between mental and cancer care, unawareness was expressed of how decision making is carried out at this meso level. In contrast, politicians were identified as self-evident decision makers of resource allocation at macro level, expected to secure resources for healthcare in competition with resources for other welfare sectors. Physicians were nominated as decision makers at micro (patient) level.

Awareness of the risk of unfairness linked to different decision makers

The awareness of *decision makers as a risk for unfairness* in rationing at meso level, depends on awareness of the existence of priority setting and rationing at meso level.

Three different understandings of unfairness in rationing exist in the material. It is unfair: a) if patient groups are not getting enough resources according to their healthcare needs, b) if patient groups are not getting the same amount of healthcare, irrespective of their needs, and c) if there is no public majority acceptance for the results of the rationing, irrespective of how resources are allocated between patient groups. These situations (one or all of them) were per-

ceived to be occurring if the decision makers lack competence, are driven by self-interest and/or lack the courage to act and make the rationing decisions. The link between different aspects of these risks and different decision makers is presented in Table 6.

Table 6. Linkage between risks of unfair rationing, aspects of these risks and decision makers

Risks for unfairness	Aspects of risk	Decision makers related to the risk
Lack of competence	Lack of medical knowledge	Politicians Citizens
	Lack of experience-based knowledge	Politicians
	Lack of overview over healthcare needs	Physicians
Self-interest	Self-interest in own healthcare	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

Politicians, citizens and physicians were all related to the risk of self-interest and lack of competence, but in somewhat different ways. What was described as a new insight, emanating from the awareness of choices that had to be made between different patient groups, was the self-interest that was connected to physicians as decision makers. They were perceived to be a risk of unfair rationing as they were expected to strive to get the maximum resources for their own working domain:

Thinking about how to allocate resources I start to wonder if physicians are as appropriate as I thought from the start ... How do you mean?[interviewer]
Well, each specialty in healthcare considers their clinics to be the most important ... they don't ration themselves. (Citation from study II)

Strategies for controlling risks with decision makers - the collaborative arrangement

The most developed category in the material, decision makers *as a collaborative arrangement*, is a strategy built on awareness of the existence of priority setting and rationing at meso level, and of the different risks of unfairness in rationing, linked to different presumptive decision makers.

The views on the collaborative arrangement as appropriate for decision making include different strategies to control for the risk of unfair rationing. Politicians were said to be able to grasp the important overview of healthcare needs in a county council. In contrast, physicians were expected to be at risk of having too a limited focus, failing to embrace all relevant alternatives of patient groups with different healthcare needs. On the other hand, physicians were considered important in order to contribute with medical knowledge, as with other professionals in healthcare. A multi-professional participation in decision making was advocated, to allow for different perspectives of ill health and healthcare needs. But not merely theoretical knowledge was highlighted. Experience-based knowledge of ill health and of the performance of health professionals were expressed as important in-put in the decision making. Here it seemed insufficient to lean entirely on politicians. In order to secure an adequate foundation for rationing decisions a pluralistic, inclusive process was advocated where citizens with their life experiences could make important contributions. Not least collaborative arrangement was desired for controlling the risk of a rationing process driven by self-interest.

It was perceived as possible to arrange collaboration in several ways, ranging from the possibility for different actors to be consulted from the beginning, to be part of a referral procedure, or to have a more active role in decision making, provided that politicians had the final say. Standing up for unpopular rationing decisions was perceived to be an important characteristic for politicians, as they had to make the final decisions.

Citizens' views on an important priority-setting criterion (study III)

Study III explored both citizen participants' free reflection on aspects relevant for evaluating severity level in resource allocation situations, and their views when faced with targeted questions about the aspects in the Severity Framework.

Aspects considered relevant when evaluating severity of ill health in resource allocation situations

The results from the **open-ended questions**, showed that severity was perceived as a *multi-factorial concept*, and that as many as 14 different aspects of severity were spontaneously considered relevant (Table 7).

Table 7. Aspects considered relevant for evaluating severity of ill health in resource allocation situations

	Aspects more frequently considered as relevant				Aspects medium frequently considered as relevant				Aspects less frequently considered as relevant					
	Impairments of bodily functions	Participation restrictions	Possibility to affect the impact of ill health	Personal factors	General negative perception of ill health	Duration	Risk of future ill health	Risk of premature death	Activity limitations	Dependency on other people	Prevalence	Multi-morbidity	Occurrence	Societal costs
Frequency of aspects mentioned in open-ended section	15	14	13	12	11	11	8	8	7	6	6	6	4	2
Ranking order due to frequency	1	2	3	4	5	5	7	7	9	10	10	10	13	14

Among the aspects mentioned by most of the participants were *participation restrictions*, which relate to social consequences of ill health. Consequences were described as disturbances in the ability to engage in conversations, sports, culture, social activities, or civic life. Consequences were also described as having negative impact on relatives and major life areas, e.g. education and work. Several of the other aspects of severity were mentioned by the participants as related to these kinds of social consequences, making the ill health more severe:

Pain is of course problematic if you are having so much pain that you can't do so much...and socialising. (Citation from study III)

The aspect, *personal factors* was also mentioned by most of the participants and included age (related to what could be considered as 'normal' health in accordance to a certain age), ability to emotionally handle ill health (coping strategies) and differences in life styles that could lead to differences in the consequences of ill health. Among the aspects medium frequently considered relevant, were *risk of future ill health* and *risk of premature death* (regardless of how far in advance future ill health or death occurs). *Duration* got a higher ranking order due to frequency than *occurrence* (i.e. how often the patient group is aware of their health problem).

When the citizen participants were asked **targeted questions** about whether they considered specified aspects to be relevant for evaluating severity, 15 aspects were deemed relevant. Besides the 14 aspects already mentioned in the open-ended section, *time to death* was now also considered relevant for evaluating severity, especially when giving the chance to live a long life. This was the least frequently considered aspect of severity, and when mentioned always weighted against the importance of evaluating the quality-of-life impact in a prolonged life. In general, frequency ranking of the aspects from the open-ended section remained more or less the same when adding the targeted questions (for details of results from the targeted section see Table 2 in Paper III).

Participants' views compared with the Severity Framework

The result showed high similarities between the participants' views on what aspects are relevant for evaluating severity and the aspects in the Severity Framework. Of 15 aspects that participants considered as relevant, we considered 10 to be in line with the framework (Table 8). In reality the framework only consists of eight aspects used for evaluating severity level. However, at the time the study was conducted, health-related quality-of-life was an overarching aspect in the framework and we considered one aspect mentioned by the participants, *the general negative perception of ill health* to be in line with that aspect. *Dependency on others* is also not an individual aspect in the framework, but strongly connected to activity limitations and/or participation restrictions in the citizen participants' reasoning, and therefore considered to also correspond with the framework.

Table 8. Comparison between citizen participants' views and the Severity Framework (% in brackets)

	Aspects of severity of ill health in line with the Severity Framework		Aspects of severity of ill health not covered by the Severity Framework	
	Frequency of aspects mentioned in the open section	Frequency when targeted questions also included	Number of <u>new</u> aspects / all aspects mentioned by the participants	Number of <u>in line with the framework</u> / all aspects mentioned by the participants
			Personal factors	0
			Societal costs	6
			Multi-morbidity	11
			Possibility to affect the impact of ill health	15
			Prevalence	9
			Time to death	6
			Risk of premature death	11
			Risk of future ill health	14
			Duration	12
			Occurrence	12
			General negative perception of ill health	15
			Dependency on other people	14
			Participation restrictions	15
			Activity limitations	11
			Impairment of bodily functions	15

In total 68% (69% including the targeted questions) of all aspects that the participants (as a group) mentioned as relevant for evaluating severity level were in line with the framework, and 32% (31%) were not. The 32% consist of five aspects, not incorporated in the Severity Framework. Two of them, personal factors (e.g. age, social responsibilities) and prevalence, do not correspond with the Swedish ethical principles of human dignity. One other, societal cost, is instead incorporated in the cost-effectiveness principle in Sweden. Remains the aspects 'possibility to affect the impact of ill health' (at least part of the aspect, when it comes to the possibility to affect ill health by own action of avoiding ill health) and multi-morbidity.

Comparing citizens' views on a priority-setting criterion with professionals' and politicians' (study IV)

The response rate in the survey in study IV for citizens was 31%, (n=123), health professionals 48% (n=185) and politicians 19% (n=129), $\pm$ 3% for each respondent group in each county council/region. In total 36 people contacted us for refusal, evenly distribute among the three groups. The health professionals had on average 15 working years, the range was 1-44 years. The proportion of the different professions varied between 13% and 14%, except for speech therapist (18%) and dietitians (22%). The characteristics of the respondents, compared to the population of Swedish citizens, health professionals and county council politicians (SCB, 2016; Sveriges Kommuner och Landsting, 2016a, 2016b, 2016c, 2016d; Socialstyrelsen, 2016) are presented in Table 9.

When comparing the views of citizens with those of health professionals' and politicians' on the severity criterion, the main findings were that citizens differ to a larger proportion when compared to the ranking of politicians, than when compared to the ranking of health professionals (when taking all the questions about severity in the survey into account). On the other hand, few (but still some) significant differences, were found between the views of citizens and those of health professionals. The largest number of significant differences were found between politician and health professional respondents. For the full result see Paper IV.

Table 9. Characteristics of the respondents in Study IV (% in brackets)

	Education level				Gender		Age	Additional roles		Familiarity with discussing the severity aspects				Perceived influences of own answer				
	University	Upper secondary	Elementary school	Other	Female	Male	Year (mean)	Employed in healthcare	Healthcare politician	Discussed all aspects	Discussed many aspects	Discussed some aspects	Never discussed	Experience of own ill health	Experience of others' ill health	Media	Health professionals' views	Available re-health care
Citizens	39 (32)	43 (35)	34 (28)	7 (6)	73 (59)	50 (41)	56.2	13 (11)	2 (2)	5 (4)	22 (18)	52 (42)	44 (36)	17 (20)	32 (38)	6 (7)	8 (10)	21 (25)
Swedish population	(37)	(46)	(17)	(2)	(50)	(50)	50	(6)	(1)									
Health professionals	(100)	0	0	0	156 (84)	29 (16)	42.2		3 (2)	15 (8)	51 (28)	74 (40)	43 (24)	24 (13)	84 (45)	23 (12)	22 (12)	34 (18)
Population of health professionals*	(100)	0	0	0	(85)	(15)	43.7	-	-									
Politicians	84 (65)	29 (22)	10 (8)	6 (5)	58 (45)	71 (55)	55.3	23 (18)		4 (3)	44 (35)	47 (38)	17 (14)	12 (11)	35 (32)	3 (3)	34 (31)	25 (23)
Population of county council politicians**	(52)	(39)	(9)	0	(48)	(52)	-	(21)	-									

* Based on statistics for physicians, physiotherapists and nurses (Socialstyrelsen, 2016).

** Based on statistics for Kalmar County Council, Västerbotten County Council, Västra Götaland Regional Council, and Region Västmanland (Sveriges Kommuner och Landsting 2016a-d)

Pairwise choices

In the eight pairwise choices regarding what characterises the most severe condition, four significant differences were found between politician and citizen respondents, concerning (Figure 8):

- negative impact on relatives (deemed important for the severity level by a larger proportion of citizens than politicians)
- major changes in life-style (deemed important by a larger proportion of citizens than politicians)
- emotional difficulties in coping (deemed important by a larger proportion of citizens than politicians)
- future low risk of high severity (deemed important by a smaller proportion of citizens than politicians)

Figure 8. Significant differences between citizen and politician respondents in the pairwise choices regarding what characterise the most severe condition

The same differences as between citizen and politician respondents were found between politicians and health professionals. An additional difference concerned social consequences of ill health. A smaller proportion of politicians saw this as a sign of a more severe condition than health professionals did (Figure 9).

Figure 9. Significant differences between politician and health professional respondents in pairwise choices of what characterises the most severe condition

No significant differences were found between citizen and health professional respondents in these pairwise choices.

The most important aspects

When choosing the five most important aspects for evaluating severity level citizen respondents significantly differed from the other groups on a few aspects. A larger proportion on citizen respondents considered negative impact of relatives to be more important than did either health professionals or politician respondents (Figure 10). On the contrary a smaller proportion of citizens considered social consequences and psychological symptoms to be more important than did health professionals (Figure 10).

Figure 10. Significant differences between citizen, health professional and/or politician respondents when choosing the most important aspects for evaluating severity level

Three significant differences were found between politician and health professional respondents in this respect. Premature death, as well as risk of future high severity of ill health, were considered as important for evaluating severity level by a larger proportion of politician respondents than health professional respondents. On the contrary, a larger proportion of health professionals valued emotional difficulties in coping with ill health to be important (Figure 11).

Figure 11. Significant differences between politician and health professional respondents when choosing the most important aspects for evaluating severity level

Ranking order of severity aspects

When choosing the five most important aspects for deciding severity, all 12 aspects in the questionnaire were chosen, but with different frequency. As in study III we produced a ranking based on frequency of choice. The ranking of the citizen respondents' choice placed social and practical consequences of ill health at the top, while future risk, occurrence of symptoms and prevalence, landed at the bottom. Negative impact of relatives ranked in the middle, while for politicians this aspect came (almost) last (rank 11). However, for all actors social consequences were ranked number one (Table 10).

Table 10. Ranking order of the most important aspects for evaluating severity level

Aspects of severity	Ranking order based on valid %		
	Citizens	Health professionals	Politicians
Social consequences	1	1	1
Practical consequences	2	3	6
Multi-morbidity	3	3	2
Physical symptoms	4	7	7
The duration of the ill health	5	6	4
Negative impact on relatives	6	9	11
Psychological symptoms	7	2	3
Premature death and impact of life-length	8	9	5
Emotionally difficulties in coping with ill health	9	5	9
Risk of future high severity of ill health	10	11	8
Occurrence of symptoms during ill health	11	8	9
Prevalence of the ill health in the population	12	12	12

DISCUSSION

Sara, 94 years of age, unfortunately felt too old to voice her thoughts about priority setting in health care. But other citizens said yes, and thereby contributed to extending and deepening the knowledge of citizens' views in Sweden on important priority-setting and rationing issues. Another objective in this thesis, was to discuss the implications of the findings for the decision-making process and the content values behind resource allocation. I will (mainly) concentrate the discussion on the Swedish context, and relate the findings to the processes, principles and criteria that apply to our country. The research process has also added knowledge to the methodological field of how to study citizens' views on such a complex matter, discussed further in a somewhat extended Methodological considerations.

Creating awareness of resource allocation and rationing at meso level

On the 27th of July 2017, the Swedish Minister of Health, Gabriel Wikström, resigned for personal reasons. In a final interview, on the question of which mistakes he thought he had made and which his successor ought to avoid, he responded:

What I always wrestled with during my time as a minister... sometimes succeeding, but many times not, is to hit the nerve. Or communication. Or whatever makes this complex system [the healthcare system], and the transition we face, understandable even for those who are not involved in healthcare policy. Given the importance of this issue to the citizens there ought to be more people who understand the complexity [of healthcare] and the issue should be debated a lot more today and perhaps in more depth... My tip to her [the successor] is to put a lot of energy into this... to help citizens understand... (Jens Krey, 2017, July 28)

What the former minister hinted at in his interview is in line with the findings in studies I-II in this thesis. There was no spontaneously recognised awareness among the citizen participants that healthcare resources have to be allocated between different patient groups or different healthcare services. The resource allocation was simply a phenomenon, going on in the county councils and at the clinical, management level, that was unreflected. However, the reluctance, not seldom expressed in public debate, to set different health care needs 'against' each other, was gradually recognised as a necessity in the eyes of the participants.

How then could the findings in this thesis of unawareness of meso level be understood, since at the same time we found awareness of rationing both at macro level (choices between welfare sectors) and micro level (between individuals), and also awareness of the fact that resources in healthcare are not endless? Could trust in those responsible for how resources are allocated make citizens feel that they do not have to think about how resources are allocated between different health care needs in their county council/region? If that is the case, such reactions could potentially be a sign of support for the representative democracy idea, citizens leaning on politicians in confidence? In fact, in a Swedish public survey representative democracy received a majority over between-election democracy as the ultimate government (Gilljam & Hermansson, 2003). Between-election-democracy is a summary term that is used for all kinds of interactions between representatives and the represented, between the elections (Esaïasson & Narud, 2013). However, when the question of citizens' willingness to engage were specified to sectors of society, of which many people are supposed to have experience (as healthcare surely is) the majority shifted standpoint, and favoured more public involvement than just as voters. They become more positive towards contributing, and less willing to leave the decision process totally in the hands of politicians (Gilljam & Hermansson, 2003). Even those standing behind the idea of 'stealth democracy', i.e. the thought that people do not want to intervene in public policy but leave politics in the hands of 'selfless' politicians and experts, mean that this only applies if it concerns issues that the public do not care about or when things not are perceived to be 'going wrong' (Hibbing & Theiss-Morse, 2002; Ruostetsaari, 2017). Healthcare does not fit in to this description. Instead, healthcare has both been proven to be valued as one of the most important social institutions by the public, yet often the target of upset public feelings regarding perceived erroneous political priorities (such as the decision made by politicians on closing Sollefteå maternity ward). Together with findings from public surveys that showed reduced confidence, especially in local politicians (Andersson et al., 2017), trust in politicians is probably not the most logical explanation of the unawareness expressed by the participants in studies I and II. A more plausible explanation is that the democratic institutions in charge of public healthcare in Sweden have failed (or avoided?) to describe the dilemmas associated with limited resources and the need to set priorities and rationing at a meso level.

Should politicians then strive to raise awareness regarding the dilemma that arises when setting priorities between patient groups? We know that the Swedish government, as well as many other governments, have pointed to the importance of transparency in priority setting processes as well as in content and grounds for priority decisions, in order to gain public trust and legitimacy for political decision (Curtin & Meijer 2006; Grimmeliikhuijsen 2012; Heald 2006; Worthy 2010). The likelihood of being able to achieve such an effect have how-

ever been questioned. Way back at 1997, Mechanic, instead advocated a cautious line in which the majority of difficult priority-setting decisions should be made implicit, without public awareness and debate, by 'muddling through elegantly'. Some empirical studies, of which one experimental study was performed in Sweden, have shown that increased transparency may actually make people (at least to a point) less trusting than if less or no transparency exists (de Fine Licht, 2011). Hypothetically, it could mean that being aware of the necessity to pit the need for healthcare of some groups against the need for healthcare of other groups (based on severity level or other kinds of criteria), could make the public even more hesitant to accept politicians as decision makers. However, the findings in study II point in another direction. Reflections on the risks with different decision makers, that awareness of choices at meso level could start, seem to be potentially important presumptions for viewing regional and local healthcare politicians as more legitimate. A cautious mind, not a distrust but a mistrust, towards decision makers must not be seen as a threat to democracy. Instead it is an incentive for the public to demand transparency and reason-giving for decisions taken. Being in a state of mistrust, people are actually sensible to information and reason-giving, which motivates actions from decision makers (such as politicians), for raising awareness (Lenard, 2008). To evaluate the effect of transparency on legitimacy more longitudinal studies are required.

If the objective is to raise awareness of priority-setting dilemmas at the meso level, which way to try? Considering what constitute public views on the healthcare system, there are at least two alternatives. Information received through media is one of them (Edgar, 2000; Garattini & Bertelè, 2000; Iyengar & Kinder, 1987; McCombs, 2014). This could be seen a bit contradictory, as the media branch itself is describing a failing public trust in media reporting, where media is attaching labels such as 'mainstream media' or 'fake news' (Andersson & Weibull, 2017). Failing trust could potentially be the reason why the largest proportion of citizen, health professionals and politician respondents in study IV, reported that media had the least impact on their answers concerning the priority setting-criteria under study. However, what could be signs of mistrust of the media, have not been confirmed in national surveys about Swedes' attitudes to media (Oscarsson & Bergström, 2017). In particular news-reporting on healthcare attained the highest confidence of all social reporting in Sweden. Among the Swedish public 53% stated that they have very or fairly high confidence in media reporting in health care (Andersson & Weibull, 2017).³⁴ However, for the decision makers such public confidence could be troublesome. That is, because media reporting to the majority consists of contrasting, negative ex-

³⁴ The question in the survey was "How much confidence do you have in reporting Swedish news media on the following topics?: Healthcare" (Andersson & Weibull, 2017).

periences from individuals affected by restrictions and limitations in healthcare, without any problematisation of priority-setting dilemma (Coast et al., 2002). In addition, de Fine Licht describes the Swedish medias' acting with regard to priority setting as *"taking their pride in presenting a critical views of the ones in power"* (de Fine Licht, 2014b, p. 40). Her research, as well as study I in this thesis, point to the importance for regional health authorities and local politicians to strengthen their communication strategies, especially for a more active (maybe even pro-active) reason-giving for priority and rationing decisions.

The second potential way of creating awareness among the public about priority setting and rationing dilemmas, is in meetings, as individuals, with health professionals (Assarson, 1995; Nedlund & Baerøe, 2014; Sabin, 1998).

Every clinical appointment, whether with a general practitioner, a specialist, or a district nurse, is an opportunity for patients to learn about priorities and rationing and for clinicians to learn about what these policies mean in their patients' lives. When we clinicians support policies about priorities and rationing we can be educators and salespeople. But when we oppose the policies we can undermine them and foment resistance. We may not always be wise in our judgments, but no national approach to priorities and rationing will work without our strong support. (Sabin, 1998, p. 1002)

However, instead of contributing to awareness of the necessity of priority setting, it has been claimed that professionals contribute to the 'do-everything', maximalist expectations in the public (Blank & Burau, 2004). Patients seem to prefer to see physicians as a giving patient advocacy, not as withholding gatekeepers. Saying 'no' could be a stressful undertaking (Carlsen & Norheim, 2005; Sabin 1998). Although such a task is not perceived as easy to perform, Swedish physicians are in fact expected, by a professional code of ethics, to be able to handle both taking care of the individual's needs and taking account of how common resource are used (Svenska läkarförbundet, 2018). Maybe preparation during health professionals' education period and later collegial discussions could strengthen the way in which this kind of 'hard stuff' could be delivered. Sabin (1998) has given an example of how he, as a physician, dealt with such a situation:

We did not explain the priority system by presenting cost effectiveness analyses or complex ethical arguments. We used simple, commonsense terms that made fundamental human sense. (Sabin, 1998, p. 1002)

Besides collegial support political support could be of importance, instead of blame-shifting where politicians delegate responsibility for unpopular decisions to other, preferably to administrative agencies, or even more commonly to health professionals (Garpenby & Nedlund, 2016; Kang & Reich, 2014). As pow-

erful opinion leaders it seems unwise not to try to reach an agreement (or at least an understanding) between politicians and health professionals about important rationing decisions (Garpenby & Nedlund, 2016). Which leads us over to the suggestion from citizen participants, reported in study II concerning the collaborative arrangement.

Collaborative arrangement and inclusive processes

Another interesting finding in this thesis, is the process where citizens changed their choice of appropriate decision makers for rationing. The preferred arrangement for rationing decisions involved some form of collaborative arrangement, with citizens and health professionals (i.e. multi-professional) as consults, and politicians as final decision makers. In comparison with international studies (with reservations regarding how the questions were formulated in each of these studies), where physicians are considered to be self-evident in the eyes of the citizens, (Bowling, 1996; Busse, 1999; Kneeshaw, 1997; Litva et al., 2002; Myllykangas et al., 1996; Richardson et al., 1992; Wiseman et al., 2003) politicians were up-graded as decision makers in our study.

One study from a different healthcare system, the Australian, has shown similar results, i.e. preferring politicians as decision makers for priority setting. The motives leant on democratic arguments about politicians being the representatives for the public voice. Another argument was that *“the power of special interest groups (such as clinicians) should be kept in check”* (McKie et al., 2008, p. 114). This was also the main reason in study II for promoting the collaborative arrangement: the insight that risks of self-interest, and thereby risk for unfairness in priority setting, could be linked to *all* kinds of actors, and needs to be controlled for. Again, this insight emanates from a new awareness of the meso level's priority-setting and rationing options. In relation to rationing, politicians are the group usually believed to be at risk of acting in self-interest (McKie et al., 2008; Williams et al., 2012), as well as citizens themselves (Coast, 2001; Litva et al., 2002).

The corner-stone in the concept self-interest, is that personal interest or advantage drives one's action, at the expense of others (Fowler & Kam, 2007). The fear of self-interest is a commonly used argument for excluding citizen (or patient) participants from priority setting processes, unless they could be expected to provide in-put from a broader societal perspective (Mitton et al., 2009; Whitty et al., 2014). It is interesting to reflect on why this argument is more seldom used for physicians and healthcare staff when it comes to rationing in healthcare, even if criticism against self-interest among professionals occasionally occurs (Carlsen & Norheim, 2005). A possible explanation is that physicians, as well as health professionals in general, are associated with evidence-based

knowledge and science (Qvarsell, 2007), knowledge that could possibly be viewed as value-free. Respect for professional knowledge can in turn, create the impression that the people practicing the knowledge, are acting value-free in every sense.

Another explanation, could be related to what was stated in the Background about the power balance within healthcare between different professions, and their opportunities to influence priority setting in resource allocation. The fact that there is, what has been described as, an ongoing struggle between different healthcare professions, concerning who is entitled to carry out certain healthcare interventions (and thereby get access to resources), may remain unknown to the public (Anell, 2007; Sebrant, 2014). The very basic idea in professionalising, is to strive for autonomy to perform within their profession and to demarcate their commitment. Also the internal competition between different specialities within medicine, constitutes the very basis for the healthcare organisation today, where some diseases, and associated to these, some specialities (such as cardiology and neurosurgery), are accorded a high status, and others (e.g. general practice, psychiatry and geriatrics), a low status (Anell, 2007; Album & Westing, 2008; Album, Johannessen & Rasmussen, 2017). Of course, what could be viewed as self-interest from each speciality or profession may be the result of seeing ones main task as being the patient's advocate, defending resources for heart diseases over mental ill health for instance.

The question is: if we want to test whether the findings in study II, that citizen participants' insight in professionals' self-interest increased their acceptance of politicians as appropriate decision makers, could be generalised to the public – is this desirable from a political perspective? Would a reduced confidence in health professionals, not the knowledge-based confidence, but the confidence in their influences on a fair allocation of resources, damage the legitimacy for the public healthcare system? Given their strong position in healthcare, to problematise the health professionals' role could be important, but would certainly be delicate (Mechanic, 1998). To organise collaborative arrangements in some way, as proposed by the participants in study II, is another alternative. It might be better to control for self-interest by including different stakeholders' perspectives in priority-setting processes, than to argue for exclusion of some actors' views for the same reason.

Public in-put in the operationalisation of a priority criterion

Studies III and IV are both, in different ways examples, where citizen participants' views are added to politicians and health professionals' perspectives. In this thesis the severity criterion has been used as a case. In study III citizens'

views were compared to politicians' decisions (on the Swedish ethical platform for priority setting which included the severity criterion) and to health professionals' and other experts' attempts to operationalise the severity criterion. In study IV the perspective of citizens' is directly compared to that of health professionals' and politicians'.

One could see that citizen participants in study III were able to reason about and identify nearly the same aspects of severity deemed to be important for resource allocation, as the health professionals and experts did when creating the Severity Framework. The multi-professional and inter-disciplinary arrangement behind the design of that framework could be one explanation, as such an arrangement has been advocated in order to define the concept of the worst off (Franken et al., 2015). From study III we could also learn what differences could exist between citizens, health professionals and politicians in their views on what to incorporate when evaluating severity level in resource allocation situations. The comparison in study IV showed few differences between citizen and health professional participants. This is an important finding because, in contrast to Fredriksson and Tritter (2017), I mean that the effect of asking the public could strengthen, not only the external legitimacy, but also the internal legitimacy. Knowledge about citizens holding similar views on what matters when deciding severity level, could justify and encourage the use of priority setting tools and frameworks as the Severity Framework. In this respect, the findings of differences between health professional and politician participants, have implications for the implementation process of politically decided values not held by the professions. However, I will now concentrate on how differences between citizen and politician participants could be understood, and in the next section discuss alternative strategies for politicians to handle such differences.

One difference between citizen and politician respondents found in study IV, concerns the importance of social consequences (i.e. the participation restrictions) in terms of *negative impact on relatives*, for determining the severity level of ill health. It is interesting to note that a larger proportion of citizen respondents valued this to be important, than did the politician respondents. Theoretically, one possible explanation could be, that politicians in general are supported with medical facts to a higher degree than citizens, and more influenced by medical evidence in their considerations of important severity aspects. In study IV a larger proportion of politicians stated, that professional knowledge had influenced their views on severity, than citizen respondents did. Evidence-based medicine (EBM) has a long history of being the predominant means for priority setting, sometimes described as 'politically appealing policy' for neutralising priority setting and blaming priority setting on experts (Frith, 1999; Harrison, 1998; Mitton & Donaldson, 2004; Saarni & Gylling, 2004). In contrast, in previous research when citizens have been asked about the value of evidence as

a prioritisation criterion, the public have expressed some, but not self-evident, support (Diederich & Salzmann, 2015). However, in study IV the citizen respondents' views seems to be more in line with evidence on how impact on relatives affects the severity of ill health than the politicians'. In research it is well-known that the burden on relatives, not only burdens the relatives themselves but also affect the people with the health problem, e.g. with shared anxiety and even increased risk of mortality (Hendriksen, Williams, Sporn, Greer, DeGrange & Koopman, 2015; Nissen, Madsen & Zwisler, 2008; Paprocki & Baucom, 2017). In study IV citizen respondents to a larger extent than politicians stated that their views on severity were based on experience of others ill health, which could mean that they themselves have experienced their relatives to have such shared burden.

An alternative explanation for differences in standpoints on relatives and severity level, could be awareness of the national legislated ethical principles for priority setting in Sweden. The human dignity principle is one such example (Prop. 1996/97:60). To assume that politicians as decision makers are more aware of legislated law for priority setting than citizens are supposed to be, seems reasonable. This awareness could well be the most plausible explanation for why a larger proportion of politician participants in study IV are hesitant to incorporate relatives' well-being in the evaluation of severity level. This could presumably also explain why they as a group less often considered e.g. changes in lifestyle to be a sign of a more severe health condition. On the other hand, the difference in the respondents views on social consequences could as likely depend on different standpoints on the reasonableness of the human dignity principle. In contrast to countries that lack a welfare-system, social responsibility in terms of obligations to care for others, has been rejected as a priority criterion in Sweden as well as in many other countries (Norheim, 2016). The Government bill in Sweden establishes that social functions such as responsibilities, and social position shall not be grounds for prioritisation (Prop. 1996/97:60). Even if not clearly stated, the intention is probably to prevent patients without next of kin to be discriminated against, i.e. to be subject to lower priority on what are perceived to be unfair grounds. This form of reasoning does not take into account what is claimed by participants in Study III (and also stated in WHO:s health model), that environmental factors, such as personal relationships, are part of what constitutes health (and ill health).

A further difference in study IV, between politician and citizen respondents concerned how to regard severity and risk of future ill health, where the citizens considered this to be less important than the politicians. When asking instead about the magnitude of prevention, previous studies have shown support from both citizens and professionals (Kaplan & Baron-Epel, 2013). Actually, there is some evidence that the public hold prevention above all other types of health

care (Ubel, Spranca, Dekay, Hershey & Asch, 1998). Hypothetically there could be a difference between asking about the importance of different interventions rather than of asking about aspects that determine the severity level. Hope of avoiding future ill health, has been used as an explanation of preferences for prevention even when there is vague evidence for success (Ubel et al, 1998). When focusing on severity in study IV, future risks ranked low due to the frequency of citizen respondents' choice, while they were ranked higher by the politicians group. Prevention is often at the forefront of political discussion and several reforms are directed at supporting this in order to ensure social justice and a wish for lower health-care costs. However, in situations of scarcity, prevention is often rationed, which indicates an ambivalent attitude among decision makers on how to view at the importance of future risks (Cohen, Neumann & Weinstein, 2008; Luyten, Kessels, Goos & Beutels, 2015).

Many studies also point to citizens prioritising life-saving interventions, even if there are other studies where increasing life-quality is more important than life-prolongation (Diederich & Salzmann, 2015; Exel, Baker, Mason, Donaldson, Brouwer & EuroVaQ Team, 2015; Wijmen, Pasman, Widdershoven & Onwuteaka-Philipsen, 2015). When moving from the 'intervention- and effect-perspective', and instead focus on the severity level, in the pairwise comparisons a larger proportion of all our categories of respondents (citizens, health professionals and politicians) chose long-term impaired life quality over premature death as a sign of a more severe condition. However, when valuing the most important aspects for severity, a larger proportion of politician respondents consider premature death as important, than did either citizens or health professionals. Survival has a strong position as regarded as maybe the most important treatment goal and study endpoint, and as such, a heavy argument in resource allocation discussions, not easy for politicians to question.

Discussed above are some of the differences in views on severity found in studies III and IV. How ethical principles and criteria finally are operationalised, needs to be taken seriously, because as stated by Mitton et al. (2009) when it comes to priority setting:

What gets measured is what gets done. (Mitton et al., 2009, p. 226)

Political strategies for handling results when asking the public

This thesis provides knowledge about citizen's views on different aspects of priority setting and rationing in healthcare, both according to process and content values. It gives information about what citizens perceive could create acceptance of rationing, who could be perceived as appropriate decision makers,

and how they think about what should constitute the important 'more severely' ill when informing priority decisions. How could this knowledge be used by politicians in charge, especially where there are deviating views between citizens, health professionals and politicians? Throughout the studies in this thesis, there are elements of citizen participants' views that conflict with priority-setting principles and criteria stated by democratically elected assemblies in Sweden (e.g. the view upon self-inflicted ill health as a fair criterion for rationing in study II). Here I will take differences in the views on severity as an example when discussing strategies for handling the differences found in studies III and IV.

One strategy for politicians could relate to the educational argument, linked to reason-giving: politicians should inform the public on what grounds priority setting should rest in Swedish healthcare, and the rationale behind these principles and criteria (Williams et al., 2012). This strategy rests on the assumption that politicians should act not only on social values, but consider other values as well, e.g. normative ethical values, to be in the best interest of the society (Oswald, 2015; Williams, Philips, Nicholson & Shearer, 2014). In addition, politicians need to give convincing accounts for their standpoints and, in particular, for their actions (Esaïasson & Narud, 2013). Strategies related to blame avoidance, e.g. not talking about priority setting because of the risk of electoral punishment, is not necessarily the 'right' way to go. There is actually some evidence of risk being merely a *perception* of risk, rather than a reality (Vis, 2016). Responsiveness actions from politicians that signal willingness to listen and to explain, has even in some contexts been found to be more effective for decision acceptance than following majority opinion (Esaïasson & Wlezien, 2017).

An opposite strategy, could be to give citizens real power and ensure that public views are recognisable in resource allocation decisions in health care, even in a situation where politicians do not agree with the public (Giacomini et al., 2009; Williams et al., 2014). Responsiveness to social values is often used for evaluating the success of a politically governed system, even if not promoting direct democracy (Dalton, 2014). Drawing on one example from studies III and IV, the strategy of giving social values more impact would mean that e.g. patient groups with major social consequences of their ill health should have more healthcare resources, compared to similar patient groups without such consequences.

A third strategy for politicians, could of course be to simply dismiss social values disclosed in research, or 'cherry-pick' results that suit them (Williams et al., 2012). By arguing that research concerns issues that citizens 'care less about', politicians could justify actions of disagreement discounting (Harrison, 1998; Butler & Dynes, 2015). As stated already, what speaks against this argument is

the fact that several studies point toward citizens valuing healthcare issues as highly important (Oscarsson & Bergström, 2017). In addition, citizens have stated, like the participants in study II, that they could contribute with social values and experiences in the provision of healthcare and priority-setting processes (Bowling et al., 1993, McIver, 1998; Fredriksson et al., 2018). Another justification to dismiss citizens' views that has been put forward is that the public understand less about priority setting and rationing (Harrison, 1998; Butler & Dynes, 2015). Working with methodological support concerning priority setting for 14 years, I still have not met the politician or the health professional who claims that they perceive priority setting as being easy. One could claim that handling this complexity is about having the 'right' knowledge. The logical question is then; what could be considered the right knowledge? It has been claimed that democratic elitists have placed too high an expectation on citizens to be fully informed, in order to make rational contributions in decision-making processes – expectations that will never be fulfilled (Dalton, 2014). In the eyes of the participants in study II, no category of actors will fulfil that requirement – if they are not giraffes: *"It takes a giraffe to see the big picture"*! Instead they promote medical knowledge, experience-based knowledge and maybe above all, an overview of all healthcare needs that have to be met in a county council. To take the advice given by the citizens who have participated in my studies, to promote a pluralistic perspective, and more collaborative arrangements in policy making may be challenging, but nevertheless worth trying.

METHODOLOGICAL CONSIDERATIONS

In this thesis both quantitative and qualitative methods have been used. The two of them are deemed to be based on different ontological and epistemological assumptions: the one that is described as searching for the unbiased way to view the one and only reality that is perceived to exist, and the other viewing reality as a complex and multidimensional phenomenon with multiple versions of answers (Denzin & Lincoln, 2005). Drawing up that kind of strict line between the two may, however, be an overly simplified approach in my opinion, when it comes to a research area such as priority setting in healthcare. To assume that scholars who perform quantitative research are not aware of the multifacety of priority setting, is not credible. The division of the epithelium objective and subjective that is sometimes described to characterise quantitative and qualitative research has also been questioned (Gelman & Hennig, 2015). When science is thought of as objective, the subjectivity that the researchers must apply in their collecting and choice of data, in the analysis and in their presentation of data, is not acknowledged.

When evaluating rigor in qualitative research, the use of applied labels has been debated, in order to find what could actually mirror the essence of each paradigm. To distance qualitative research from the positivistic paradigm many naturalistic scholars have preferred to use a different terminology (Shenton, 2004). Lincoln and Guba (1985) established four criteria that are common use for judging so-called trustworthiness: credibility (in preference to validity); transferability (in preference to external validity/generalisability); dependability (in preference to reliability), and conformability (in preference to objectivity). Irrespective of the paradigm (which in fact differs also between different qualitative methods), and of what labels are used, the essence of all good research is to strive for exclusion of error (Meyrick, 2006; Patton, 2002; Sin, 2010). In this chapter firstly methodological considerations of the interview studies (studies I-III) will be made, before reflecting on the quantitative survey (study IV).

Methodological reflections on the interview studies (studies I-III)

Here the sampling process, the data collection of the interviews and the methods used for analysing the data will be scrutinised for the studies using the phenomenographic method (studies I-II) as well as for the study using directed content analysis (study III).

The capturing of variations in the sampling processes

One of the most common question in research is the extent to which the findings can be generalised or, as more relevant in qualitative research, how the transferability of the findings is to other groups or settings beyond the study (Lincoln & Guba, 1985). In studies I-III we were interested in finding *variations* in citizens' views on different priority-setting and rationing issues, not in finding the most common views. The most obvious pitfall, especially in phenomenography, would be to select a sample that is not diverse enough to catch variations in experiences of the phenomenon being studied (Collier-Reed, Ingerman & Berglund, 2009; Marton & Booth, 1997; Sin, 2010). The relevant question then becomes: Could there be further variations in the Swedish population that were not captured in studies I-III, or could the findings be expected to cover variations that exist in other groups too?

Central to answering this question, is to look at the choice of the participants in studies I-III (and also of course the dependability in the analysis which I will comment on further ahead). Several actions were taken to secure the variation. One was in the sampling process. As long as there is a lack of evidence on which sociodemographic characteristics constitute attitudes towards priority setting, I consider it wise to use a multi-stage sampling technique, taking into account both sociodemographic characteristics and attitudes towards priority setting and rationing. In terms of attitudes, the selections of participants in studies I-III is balanced with regard to those having a positive, and those having a negative attitude in some respect to priorities in Sweden. When looking at the sociodemographic of the participants, the oldest (i.e. people over 79 years of age) were not represented in the participant pool in the phenomenographic studies (studies I-II). As this group are clearly the ones most in contact with healthcare, this must be regarded as a limitation, and could have been retrieved by turning to a retirement home for example (as in study III). Another observation is that there is a dominance of female participants, due to the fact that many of the sample typologies were only represented by women. Sampling surveys in workplaces that have exclusively male employees could have been a solution. There are of course also other characteristics that could have been relevant, e.g. different ethnic and religious backgrounds in the study of citizens' views on severity. As Sweden has become more multi-cultural, such studies would be an inter-

esting continuation of my studies. Having said this, again it is difficult to value the importance of any deviation of characteristics, while we do not know more about the association between them and attitudes towards priority setting and rationing in healthcare.

In capturing variations in attitudes, the usefulness of the attitude questions in the sampling process must also be reflected upon. It is of course a balancing act to find relevant questions that could reveal differences in attitudes and at the same time avoid leading the participants in any certain direction as early as in the sampling process, by too many or too specified questions. We chose rather broad questions (e.g. *“Could we gain generally accepted allocation?”* and *“Do the most severely ill gain the highest priority in healthcare today?”*), which turned out to capture 9 and 10 different attitudes, respectively in the qualitative studies. Distribution of further questionnaires (and maybe to other kinds of groups) could have resulted in further combinations of attitudes towards priority setting, and in turn could have resulted in further variations in the findings. On the other hand, such action might not have yielded fully the variation in studies I-II, as most previous research indicates that citizens answered as they did in the recruitment surveys in our studies: they place physicians as their first choice of appropriate decision makers. The likelihood of finding participants that have chosen politicians as decision makers may be limited (but perhaps not impossible) (Bowling, 1996; Busse, 1999; Kneeshaw, 1997; Litva et al., 2002; Myllykangas et al., 1996; Richardson et al., 1992; Wiseman et al., 2003).

Both within phenomenographic studies and studies using different approaches of content analysis, there are several recommendations available for suitable sample size, with quite a wide range. However, rationales behind such recommendations are seldom presented (Guest, Bunce & Johnson, 2006). The argument that qualitative research should have a manageable amount of material so as not to risk the analysis being too superficial, is in itself an important argument. Still, this is not a good enough reason for not trying to find as many variations as possible. I have gradually learned that an additional way (besides a rigor recruitment process) to make sure that a variety is captured, is to use data saturation. In articles describing qualitative health science research, saturation is frequently said to have been used (Byrne, 2001; Fossey, Harvey, McDermott & Davidson, 2002; Francis et al. 2010; Sandberg, 2000). But the strategy has also been criticised, not for being an inappropriate method but for almost constantly being poorly described (Guest et al., 2006). Using strict principles for data saturation, specified by Francis et al. (2010), in study III made it possible to demonstrate how we have handled saturation. We even strengthen their recommendation, taking five (instead of three) additional interviews without finding any new aspects before stopping the inclusion of participants. The fact that 87% of the data was already covered after four interviews, has in other studies been

found to be an indication that the likelihood of finding more variations if extending the sample, is low (Guest et al., 2006; Francis et al., 2010). It is an important ethical question not to use either research resources or citizens' time by striving for a larger sample, if not needed for the credibility of the result (Francis et al., 2010).

The capturing of citizen participants' views in data collection

Besides the relevance of the participants in the qualitative studies, another adequate question for trustworthiness concerns the credibility of the study. How well have the questions managed to capture the data the study is aiming at? Here the quality of the interviews is crucial (Lincoln & Guba, 1985). The formulation of the questions used is one part of the quality, the interviewer's position and skill in putting the questions is another. Hence, an analysis of the trustworthiness in data collection also needs to be the subject of a reflexive analysis of myself as a data collection instrument (Barry et al., 1999; Malterud, 2001).

One crucial point in studies I and II is whether it was clear enough from the questions, that the studies concern rationing at meso level. As noted in the Introduction, 'rationing' is often not distinguished from the more overall concept of 'priority setting', nor are the different priority setting situations (i.e. macro, meso or micro level) clarified (Busse, 1999; Litva et al. 2002; Ham & Coulter, 2000). To tackle these challenges, the participants in studies I and II were addressed with questions about concrete forms of rationing (delay, dilution and denial). Study III concerned resource allocation situations between patient groups, irrespective whether they related to investment or disinvestment. We noticed that the participants' reasoning about severity referred to both of these situations, which indicates that they have understood the context. The interview for studies I and II took its starting point on the micro level, referring to personal (empirical) experience of rationing, before moving to questions on rationing between patient groups in resource allocation situations. As the meso level showed to be an unknown decision level, this order proved to be a wise strategy to allow the participants to gradually become more familiar with discussing a rather complicated phenomenon.

Interviews with predominant open-ended questions have been noted to be rather uncommon when studying citizens' views on priority setting and rationing in healthcare (Coast, 2001; Litva et al., 2002; Wiseman et al., 2003). It still, in 2018, seems to be the case. In Sweden, to the best of my knowledge, no such study regarding meso level has been published. Our findings have strengthened the belief that, given the opportunity to reflect and to freely nominate e.g. decision makers or severity aspects, citizens could come up with new alternatives, not captured in surveys with given alternatives (Coast, 2001). As mentioned be-

fore in this thesis, some scholars even claim that surveys, based on these arguments, are of doubtful value when studying citizens' views on priority setting (Busse, 1999; Dicker & Armstrong, 1995; Dolan et al., 1999; Litva et al., 2002; Wiseman et al., 2003). In my opinion, instead of disqualifying quantitative methods, researchers in this field should strive for a better balance between qualitative and quantitative methods, to enhance the understanding of citizens' reasoning behind complex, still under-researched phenomena such as priority setting and rationing. To use open-ended questions was also important for me because I am part of the system that I was investigating. For example, being involved in the construction of the Severity Framework could of course mean a risk of bias, me wanting answers from the participants which was consistent with the aspects in the framework. The follow-ups were therefore strictly based on the participants' own answers (e.g. *"Could you explain more?"* or just repeating their answers) and I tried to be aware of my body language so as not to indicate the 'right' answer. At the same time, being familiar with a subject is double-edged, and can increase credibility (Lincoln & Gruba, 1985), and made me prepared to follow different lines of reasoning.

Further, it has been intensively debated whether or not citizens' ought to be given information about the priority setting issue that they are supposed to answer questions about (Rosen & Karlberg, 2002; Dolan et al., 1999; McKie et al., 2008). The answer must depend on the aim of the study. However, when conducting phenomenographic studies the answer is in one way self-evident, as the interest lies in the second order perspective, i.e. in peoples' own experiences and thoughts regardless of whether it is true to the 'reality' of priority setting or not (Marton & Booth, 1997). Likewise, I considered it wise not to inform about the existence of the Severity Framework in study III in order to avoid social desirability bias (Dahlgren & Hansen, 2015). Despite this strategy, and the attempts to avoid leading questions, there could exist what are perceived as 'politically correct' answers. Would it, for example, be likely to claim that being a man is a sign of a higher severity of ill health – especially as I am a female? Or could voices advocating decision makers for rationing of certain ethnicity be possible? And even if one can assume that The National Centre for Priority Setting in Health Care, is not publicly known, I as the interviewer could have been perceived as a representative of authorities with a definite opinion as to what would be the 'right' answer. To somewhat compensate for this, projective questions were used in the phenomenographic studies. This interviewing technique is mainly intended to allow participants to project their own understanding and thoughts onto someone else, and thereby reveal their own understanding of a phenomenon (Fisher, 1993). There is some evidence for the validity of such a technique, especially in topics that could be assumed to be governed by strong norms (Fisher, 1993; Steele, 1964). Actually, in the interviews there were some cases where the participants declared that other people probably think differ-

ently. However, a reasonable conclusion is that assumptions about others' perceptions describe ways of understanding phenomena that likely exist in the society.³⁵ In the future, I consider data on social media platforms to be an interesting, complementing source for studying public attitudes towards priority setting. The potential of such sources has gained more and more attention in healthcare research, but accompanied with an adequate demand for more guiding ethical regulation (Azer, 2017).

Although we made every effort in all studies to clarify the context of the study for the participants, I could not guarantee that the interviews were not perceived as real situations of economic restraint in their own county. For example it was noted that the participants had more difficulties (at least in the beginnings of the interviews), to reason about what they considered constituted minor severity level, than major severity. One interpretation may be that there is a resistance to describe something that might be used as an argument for giving some kinds of ill health a lower priority in resource allocation situations. On the other hand, the participants clearly expressed the relevance of making distinctions between higher and lower severity. Ultimately, even if not initiated by politicians or officials, research of social values is expected, by both citizens and scholars, to be taken into account – why else should citizens bother to participate?

Truth value in data analysis

In order to meet the demand of confirmability, several steps have been taken in this thesis. Rigor and explicit descriptions of the sampling processes, the avoidance of leading questions and information that could bias the results, are all actions taken to achieve a high degree of conformability (i.e. objectivity). Despite rigor in the data collection, no analysis method is without drawbacks. The researcher's individual attributes and perspectives can have an important influence on the analysis process. Reflexivity of my own pre-understanding and underlying motives and reflection on the confirmability and dependability of the study is always important (Denzin & Lincoln, 2005; Elo, Kääriäinen, Kanste, Pölkki, Utriainen & Kyngäs, 2014). The researcher's voice in reporting the findings is also inevitable (Marton, 1981).

For the time of studies I and II, the importance of the participants' ability to identify themselves in the result was still promoted (Kvale, 1989; Marton & Both, 1997). The appropriateness of this so-called internal communicative credibility in phenomenographic studies was later found to be problematic. The aim

³⁵ In studies I and II all categories derived from answers on projected questions were also expressed as answers to the open-ended questions (even if not by the same participants).

in phenomenography is to describe the phenomenon in categories. The individual participant does not need to recognise him/herself in all of these categories for the analysis to still be trustworthy. This is especially true as another phenomenographic assumption is that an individual's experience of a phenomenon is 'context sensitive' and can change during the course of an interview or until the time when they are supposed to make their check on the final categories (Collier-Reed et al., 2009).

In order to achieve conformability and dependability all analyses in studies I-III have involved some kind of researcher triangulation even if one of the authors (M.B) has done the majority of interpretation. However, in phenomenography, the question has been put as to whether it is possible, or even desirable to strive for replicability: *"The original finding of the categories of description is a form of discovery and discoveries do not have to be replicable"* (Marton, 1988, p.148). However, the categories must be able to be communicated and understood by other researcher (Marton, 1997; Sjöström & Dahlgren, 2002). Collaboration within our research team, have pursued clarity in the findings, illustrated by using quotations.

In studies III data analysis triangulation was used. Over the years the proponents of content analysis have shifted focus back and forth between qualitative and quantitative approaches, between positivism and interpretivist epistemological paradigms, at times in a rather dissociating manner (Dieronitou, 2014; Morgan, 1993). In contrast, other researchers within this field claim that the best versions of the method are neither entirely qualitative nor quantitative, but a combination of those perspectives (Berelson, 1952; Crabtree & Miller, 1992; Gbrich, 2007; Guest et al., 2006; Humble, 2009; Miles & Huberman, 1994; Morgan, 1993; Morgan & Zhao, 1993; Onwuegbuzie, 2003; Sandelowski, 2000; Schreier, 2012; Silverman, 2006; Tesch, 1990; Vaismoradi, Turunen & Bondas, 2013). In research labelled as qualitative, it is not uncommon that quantitative terms such as 'most of', 'a few', 'some' etc. are used, without any specification (Onwuegbuzie, 2003). Learning from this mistake in paper I, I wanted to be more explicit in study III. Word-frequency count has been used in former research with directed content analysis approach to indicate importance of the aspects under study, but has also been criticised because of the risk of bias. How often a word (or theme) is mentioned by each interviewed person could just reflect different ways of expressing oneself (Vaismoradi et al., 2013). By using dichotomous counting we eliminated that risk. Using strict, explicit coding rules in the analysis also strengthens the confirmability of study III.

Methodological reflections on the survey (study IV)

There ought to be some reflection on the survey study, both in regard to possible errors of non-observation and errors of observation, and their importance in what conclusion could be made from the findings (Groves & Lyberg, 2010).

Assessing potential non-response bias

There is a trend of decreasing response rates to surveys in many countries (Cook, Dickinson & Eccles, 2009; Hellevik, 2016; Kohut, Keeter, Doherty, Dimock & Christian, 2012; Mindell, et al., 2015). Some claim that it has never been harder than it is today to get a high response rate (Brick & Williams, 2013; Wenemark, 2010). This is confirmed in study IV where the most evident limitation is the low response rate, especially for politicians (19%) but also for citizens (31%). The question is whether there are differences between respondents and non-respondents that could bias the findings and make it hard to generalise to the Swedish population.

Starting with the citizens, given a randomised sample, a comparison with total population statistics (SCB, 2016), estimates that the nonrespondents correspond reasonably well with survey respondents in sociodemographic characteristics (Table 9). There are slightly more females among the respondents as well as older people, which is the same pattern shown in most other survey studies, both in Sweden and in other countries (Markstedt, 2014). Normally people with lower education are underrepresented in relation to the population (Markstedt, 2014), which was not the case in study IV. What these deviations will mean for the results is hard to interpret for several reasons. The possibility to test for bias, by comparing with Swedish population distributions on views of the severity aspects explored in the survey, is limited. For example, the national survey conducted by The Public Health Agency of Sweden showed that female and younger people score themselves with a higher degree of mental ill health, as well as those people with a lower educational level (Folkhälsomyndigheten, 2016). If more younger people had responded in our survey on severity, would psychological symptoms have more frequently been ranked high in importance for evaluating severity level or, if less females had answered, ranked lower? As no comparison between different aspects of severity is made in The Public Health Agency's survey we cannot compare these two studies in a meaningful way. Surveys with higher response rates from other countries, concerning citizens' (and not only patients') weighing of severity aspects in the context of priority setting in resource allocation, are sparse and do not cover the aspects explored in study IV.

When it comes to politicians, the respondents corresponded well with the Swedish population of county council politicians according to age and gender, while

the respondents had higher education in general (Sveriges Kommuner och Landsting, 2016a, 2016b, 2016c, 2016d). No possibility of comparison with Swedish politician population's distribution on severity aspects exists, nor with international surveys as no such study has been found. For health professionals there is available statistics for a comparison with three of the six occupations included in the study, which makes the comparison more unsure (Socialstyrelsen, 2016). For these occupational groups (physicians, physiotherapists and nurses), gender and age corresponded well. In spite of the similarities of the sociodemographics described above, caution should be applied in generalising the results from study IV. Instead, the findings should be considered as a first step toward identifying differences that could exist between key actors, in their views of what is important when evaluating severity in resource allocation situations at meso level.

Motives for non-respons

Based on the comments made by the citizens who contacted us for refusal, non-respondents can be assumed to be depending on different kinds of so-called respondent burdens (Biemer & Lyberg, 2003; Wenemark, Frisman, Svensson & Kristenson, 2010). *Cognitive burden*, thinking that there is a 'right' answer requiring professional knowledge, was one explanation given. An additional possible respondent burden can be linked to *distress* (Wenemark et al., 2010). Even if the information letter that accompanied the questionnaire (including the reminders), did not contain words such as 'limitations' or 'restrictions', the description of severity as a criterion for resource allocation could have made the approached citizens aware of health care resources not being unlimited and the ethical dilemmas associated with such limitations. "*I will not contribute to someone getting nothing*" is one example of a comment. On the other hand, there are comments among the responders expressing respondent satisfaction, priority setting regarded as an important society issue (Wenemark et al., 2010). A follow-up interview study on a sample of non-responders could have given us more information about the motives for not wanting to participate in the study (Wenemark, 2017).

Another respondent burden declared in the comments, is related to *unnecessary work*, referring to the question in the questionnaire where the least important aspects should be listed. The respondents declared that they had already answered that question, when ranking the most important aspects of severity. To use such a control question could be positive, but also risks being perceived as *distrust* from the researcher, and thereby have a negative effect on the willingness to complete the survey (Wenemark et al., 2010).

An analysis of the politician non-respondents in study IV is equally important. If citizens could be supposed not to be familiar with issues related to resource allocation in health care, then in contrast, politicians could be assumed to be more familiar with the issues, which was also confirmed in the comments (Table 9). It is, also part of their political mandate and something they could be expected to be interested in. However, comments, both from politician respondents and non-respondents who have contacted us, have expressed the same cognitive burden as citizens, when it comes to answering about severity. Another explanation, that has been put forward in other contexts (Cleemput, Christiansens, Kohn, Daue & Denis, 2015), is the blame avoidance, expressed in the survey study in comments as *“This [to define what characterises the most severely ill] is for physicians to do”*.

In order to increase the response rate we rejected adding further reminders, as this has been shown to have a marginal effect related to the costs (Wenemark, 2017). Study IV really confirms the need for revaluating the use of surveys for studying public views on priority setting issues. Instead, mixed methods with both quantitative and qualitative methods have been advocated as a future way of capturing a multifaceted phenomenon such as priority setting (Helfer, 2016; Shah, 2009).

Reflection on the statistical analysis

Finally, with regard to the statistical analysis, we have chosen to report the original p-value as well as the adjusted p-value for multiple comparisons. At the same time as familywise error could be a problem, the risk of increasing the number of false negative significances, by making adjustments, could be troublesome in areas where little research has been done, as in our case (McDonald, 2014). All findings could thus be worth notifying and further examining. By presenting both applications, we hope to provide a good base for any future research in the field.

CONCLUSIONS AND IMPLICATIONS

This thesis brings two types of knowledge into the interdisciplinary field where empirical studies of citizens' views on priority setting and rationing belong. One is the knowledge about citizens' views, on processes as well as on the basis for priority and rationing decisions, and the implications of those values for decision makers. However, with respect to contextual dependency, to transfer conclusions from this thesis to other countries requires sensitivity for each country's political, cultural, religious uniqueness and certainly for their healthcare systems. The other type of knowledge concerns methodological experiences that could bring in even more stringency when studying public views.

Based on the studies included in this theses I will draw the following main conclusions:

- Awareness of limited resources and priority-setting dilemmas that arise when allocating resources between different patient groups and service areas, forms the basis (but is not a guarantee!) for acceptance of rationing in health care. The findings in study I indicate that priority-setting dilemmas at the meso level, may not have reached the public.
- The collaborative arrangement, including health professionals, citizens and politicians, as appropriate for making rationing decisions is a strategy promoted in study II, in order to control for each actors' risk of unfair rationing:
 - a) risk of lack of medical competence as well as experience-based knowledge and overview of health care needs
 - b) risk of self-interest (associated with citizens, politicians and, as was described as a new insight, also with physicians)
 - and c) possible lack of political courage.
- Awareness of priority setting at the meso level, and different risks of unfairness, linked to a decision maker, could have implications for a change in citizens' views on the role of politicians. This finding is in contrast to previous studies where physicians have been favoured as decision makers for rationing healthcare.

- According to citizen participants in study I, what constitutes a fair distributive principle could vary depending on what method is used for rationing (dilution, denial etc.). The findings could give rise to hypotheses, such as: More criteria related to fairness must be fulfilled before acceptance could be reached for exclusion, as compared to rationing by delay.
- Citizen participants in study III were able to identify the same aspects as health professionals and experts have done when operationalising an important severity criterion into a priority-setting framework. Findings of similarities could have the potential to strengthen the internal legitimacy among health professionals, in the use of such frameworks, and in addition enable politicians to communicate the justifiability of how severity is decided in resource allocation in health care.
- Study III showed that citizens could also contribute added values that could further refine a priority-setting framework in use. However, several of the studies in this thesis reviled social values not in line with established ethical principles and criteria for priority setting in Sweden, which indicates a need to facilitate an ongoing dialogue and debate related to priority setting.
- Finally, when comparing the views on what aspects of severity should be considered when separating major ill health from minor, citizen respondents differ to a larger proportion compared to politicians' ranking, than when compared to health professionals'. Few significant differences were found between the views of citizens and health professionals. The greatest number of aspects differed between politicians and health professionals, which could affect both internal and external legitimacy for priority setting in healthcare.

The other contribution of this thesis lies in highlighting the importance of methodological stringency when studying citizens' views on priority setting and rationing, which have been hinted at in prior research. The priority-setting situation must be defined: to what kind of choices (between individuals, patient groups or welfare sectors), are the public supposed to give voice about? Concepts must be sorted out: are we asking for views on priority setting as in new investments, or are we asking for views on restrictions – or other kinds of consequences of priority setting? This thesis has also shown that deliberation (people discussing together), is not the only way to enable people to reconsider previous positions on priority setting. Also individual interviews as (mainly) used in this thesis (and with no additional information given), give opportunities for reflection and changes in views on priorities. I will also join those who are advocating the use of mixed method to build up a more and more comprehensive picture of this complicated, but challenging research field.

Finally, what are the implications of this thesis for the politicians, those who, among many involved actors, are ultimately held accountable for the priority setting and resource allocation in Sweden? Condensed into three, somewhat simplified points, these implications are:

- Politicians ought to strive for greater public awareness about priority-setting dilemmas at the meso level in healthcare, both in accordance with the process and the content, in order to create potential for increased acceptance of politically governed resource allocation.
- The citizen participants' message that solidarity is an important content value in favour of creating acceptance for standing back for others in healthcare, but threatened today by a sense of growing individualism, is a complicating, but nevertheless, a challenging and inevitable political issue to tackle.
- Public deliberation initiated by regional health authorities or governmental agencies, is not the only way to capture social values on priority setting and rationing. Methodologically stringent public research, captured with a variety of study designs, could contribute in many important ways to inform resource allocation decisions, or even more importantly, inform policy making that concerns priority setting and rationing at meso level.

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APPENDICES

Appendix A: Questionnaire for sampling, studies I-II

Appendix B: Interview guide, studies I-II

Appendix C: Questionnaire for sampling study III

Appendix D: Interview guide, study III

Appendix E: Coding rules study III

Appendix F: Questionnaire citizens, study IV

APPENDIX A URVALSENKÄT STUDIE I-II

Medborgarnas uppfattning om rättvisa i hälso- och sjukvård

*Ett forskningsprojekt vid
Institutionen för hälsa och samhälle (IHS)
Linköpings universitet*

Peter Garpenby
Docent/projektledare
Telefon: 013-22 49 91
peter.garpenby@ihs.liu.se

Mari Broqvist
Intervjuare
Telefon: 0705- 28 05 85
m.broqvist@telia.com

Information till dig som deltar i studien

Syfte?

Detta är ett forskningsprojekt om rättvisa vid prioritering av hälso- och sjukvård. Bakgrunden är de senaste årens diskussioner om hur gapet mellan förväntningar och tillgängliga resurser i vården ska hanteras.

Hur?

Vi vill be dig besvara dessa fyra frågor samt fylla i dina personuppgifter. Då det är din egen uppfattning vi är intresserade av ber vi dig besvara frågorna individuellt.

Vad händer sedan?

Beroende på utfallet av enkäten kommer vi eventuellt att kontakta dig för en intervju (fyll i namn och telefonnummer). Efter att intervjupersonerna valts ut förstörs enkäterna. Intervjun tar cirka 1–1,5 timme och genomförs på tid och plats som passar dig bäst. Frågorna kommer att handla om din uppfattning om rättvisa i vården. Intervjun bandas. Svaren i resultatet kommer inte att kunna knytas till person utan du är garanterad anonymitet. Din medverkan är förstås helt frivillig och du kan när som helst avbryta deltagandet utan att ange orsak.

1. Vem anser du bör ha störst inflytande över hur sjukvårdens resurser fördelas idag?

☐	☐	☐	Politiker
☐	☐	☐	Läkare och annan vårdpersonal
☐	☐	☐	Allmänheten

2. Är det viktigt att allmänheten känner till vilka som har företräde till vårdens resurser?

☐	☐	Ja
☐	☐	Nej

3. Kan man hitta en fördelning av hälso- och sjukvårdens resurser som de flesta i samhället tycker är rättvis?

☐	☐	Ja
☐	☐	Nej

4. Anser du att patienter på det stora hela får vård på lika villkor idag?

☐	☐	Ja
☐	☐	Nej

☐	☐	Kvinna
☐	☐	Man

☐	18-29 år
☐	30-39 år
☐	40-49 år
☐	50-59 år
☐	60-69 år
☐	70-79 år
☐	80 eller äldre

Namn;

Tele.nr som jag kan kontaktas på;

.....

☐	Dagtid	☐	Kvällstid
--------------------------	--------	--------------------------	-----------

Lämnna enkäten till
Senast

Tack för din medverkan!

APPENDIX B INTERVJUGUIDE STUDIE I OCH II

Ingångsfrågor med fet stil, eventuella följdfrågor beroende på respondentens svar står med normal stil.

Uppfattningar om begreppet rättvisa

1. Om jag säger rättvisa vad tänker du på då?

- Kan du ge något exempel, vad som helst som du anser rättvist/orättvist?
- Finns rättvisa/ kan man uppnå rättvisa?

2. Vad är viktigt för att uppnå rättvisa (i allmänhet)?

- Utifrån det exempel respondenten gett på orättvisa; Hur kan man göra för att det ska bli mer rättvist i det fallet?

3. Om jag säger rättvisa i vården vad tänker du på då?

- Tycker du att vi har en rättvis fördelning av vårdresurser i Sverige idag? Varför? Varför inte?

Uppfattningar av rättvisa i vården i samband med ransonering

Har du själv erfarenhet av eller känner någon som fått vänta på vård?

4. Finns det något som skulle få dig att acceptera att vi har väntetider på vård om det finns andra som du måste dela resurserna med? (tidsransonering)

- Kan personalen göra något i en sådan situation för att du ska acceptera att vänta?
- Kan personalen/politikerna göra något för att du ska acceptera att det finns väntetider i vården?

5. Vad skulle få dig att acceptera att inte få den allra bästa vården, om det finns andra som du måste dela resurserna med? (ransonering genom lägre kvalitet)

- Om det finns andra som behöver insatser som är avancerande och dyra vad skulle få dig att själv acceptera en insats som kanske inte fullt hjälper dig lika mycket?
- Kan personalen göra något i en sådan situation för att du ska finna dig i att inte få det allra bästa?
- Kan personalen/politikerna göra något för att du ska acceptera att inte alla får den mest avancerade vården?
- Om några får den allra bästa vården när de söker sjukvård och det innebär att det finns andra som inte får den allra bästa vården – hur ser du på det?

Har du hört talas om fall där man inte får hjälp i vården idag? Vad har det handlat om? Vad var orsaken tror du?

6. Vad skulle få dig att acceptera att man tog bort någon insats/någon behandling från den vård som landstinget står för? (bortval)

- Vad skulle vara ett dåligt sätt/ sämsta tänkbara sätt att ta ett sådant beslut på?
- Hur skulle personalen/politikerna uppträda och göra i en sådan situation för att du lättare ska finna dig i en sådan situation?

Uppfattningar av rättvisa i beslutsfattandet

7. Tror du att man kan hitta en fördelning av resurser i hälso- och sjukvården som de flesta i samhället kan tycka är rättvist? (substansrättvisa)

- Hur kan man gå tillväga för att komma dit?
- Om inte alla kan bli nöjda, hur man kan göra för att minska missnöjet?

8. Om man måste dela upp hälso- och sjukvårdens resurser mellan olika sjukdomar, vad skulle få dig att tycka att ett sådant beslut har tagits på ett rättvist sätt? (procedurrättvisa)

- Om du blev ombedd att tycka något om ett sådant beslut vad skulle du då vilja veta för att kunna bilda dig en uppfattning?

Uppfattningar om medverkan av medborgare

9. Hur ser du på din egen roll för att nå en som du tycker rättvis fördelning av vårdresurser?

- Tror du allmänheten kan bidra på något sätt?
- Hur skulle det kunna gå till rent praktiskt?

Uppfattningar av rättvisa beslutsfattare i vården i samband med ransonering

10. Vem ska avgöra vems behov som är störst i hälso- och sjukvården?

- Vem ska bestämma hur mycket resurser som till exempel ska gå till barnsjukvård och hur mycket som ska gå till äldreomsorg eller mellan psykiatrisk vård och cancervård?

11. Om man måste begränsa någon vård som vi har tillgång till idag, vem ska ta ett sådant beslut?

12. Är det något övrigt du vill tillägga när det gäller hur rättvisa kan skapas vid olika begränsningar i vården?

APPENDIX C URVALSENKÄT STUDIE I-II

Intresserad av att delta i en intervju som handlar om prioriteringar i vård?

*Ett forskningsprojekt vid
Institutionen för medicin och hälsa
Linköpings universitet*

Varför?

Vid Linköpings universitet genomför vi nu ett forskningsprojekt där vi vill veta hur medborgare ser på olika svårighetsgrader av hälsoproblem. I media diskuteras ju ofta hur jämlikhet och rättvisa ska kunna skapas i vården. I Sverige har riksdagen beslutat att mer resurser ska gå till de med de största vårdbehoven och de största hälsoproblemen. Men hur kan man egentligen beskriva vad som är svårast att drabbas av? Vi är intresserade av att ta reda på hur du som medborgare resonerar om detta.

Vilka?

För att hitta olika sätt att se på detta vänder oss till olika grupper i samhället och till personer med olika erfarenhet av sjukdom och ohälsa. Genom att besvara frågorna i denna enkät hjälper du oss med urvalet.

Vad händer sedan?

Beroende på dina svar kommer vi eventuellt att kontakta dig för en intervju. Intervjun tar cirka 1 timme och genomförs på tid och plats som passar dig bäst, individuellt eller i grupp om du så önskar. Frågorna kommer att skickas till dig en vecka innan intervjun. Som brukligt är vid denna typ av forskning bandas intervjun för att sedan skrivas ut. Allt material kommer att förvaras vid Linköpings universitet på sådant sätt att inte obehöriga kan ta del av det. Förvaring sker under 10 år. Ditt deltagande är självklart helt frivilligt och du kan när som helst under datainsamlingen avbryta din medverkan utan att ange orsak.

Genom att lämna in denna blankett samtycker du till att bli kontaktad för att delta i en intervju.

Frågor?

Kontakta oss gärna!

Mari Broqvist
Doktorand vid Linköpings universitet
Telefon: 0705-280585
mari.broqvist@liu.se

Barbro Krevers
Filosofie doktor/Projektleddare
Telefon: 070-0850830
barbro.krevers@liu.se

1. Hur skulle du säga att din hälsa varit i allmänhet det sista året?

☐	☐	☐
	Bra	
	Någorlunda	
	Dålig	

2. Har du själv eller någon närstående någon gång haft stora hälso-
problem?

☐ Ja ☐ Nej

3. Tycker du att det verkar som att de med de största hälsoproble-
men prioriteras högst i vården idag?

☐ Ja ☐ Nej

Ange kön

Ange ålder

☐	☐	☐	☐	☐	☐	☐
18-29 år	30-39 år	40-49 år	50-59 år	60-69 år	70-79 år	80 eller äldre

Namn

Tele.nr som jag kan kontaktas på:.....

Dagtid
Kvällstid

Hellre kontakt via mailadress.....

Lämna enkäten i bifogat kuvert till
senast

Tack för din medverkan!

APPENDIX D INTERVJUGUIDE STUDIE III

I samband med intervjuerna besvaras först frågor angående demografiska uppgifter (kön, ålder, lantligt eller stadsboende, född i Norden/EU-land, högsta utbildningsnivå).

Huvudfrågor med fet stil, eventuella följdfrågor beroende på respondentens svar står med kursiv stil.

Öppna frågor

Hur skulle du vilja beskriva ett hälsoproblem som har mycket stor svårighetsgrad?

- *Kan du ge något exempel på ett hälsoproblem med mycket stor svårighetsgrad?*
- *Vad är det som gör att du tycker att detta hälsoproblem har en mycket stor svårighetsgrad?*
- Om den intervjuade uppger flera aspekter ställs fråga:
 - *Vad av detta tycker du är avgörande för att du uppfattar att hälsoproblemet har mycket stor svårighetsgrad?*

Vilka av de aspekter du varit inne på nu tycker du är viktiga att ta hänsyn till då man ska avgöra vad som är ett mer eller mindre svårt hälsoproblem när beslutsfattare ska fördela resurser mellan patientgrupper?

Samma frågor ställs för stor/måttlig och liten svårighetsgrad.

Riktade frågor

Vilken betydelse anser du att *fysiska symtom* har för att bestämma ett hälsoproblems svårighetsgrad?

Därefter följer likadana frågor om följande aspekter: *psykiska symtom, praktiska konsekvenser av ohälsa, sociala konsekvenser av ohälsa, hur ofta man känner av symtomen (frekvensen av symtom), varaktighet av ohälsan, risken för framtida ohälsa, risken för förtida död och tid till död.*

Om den intervjuade frågar efter betydelsen av dessa aspekter eller om det är oklart vad den intervjuade menar med olika begrepp ställs följdfrågor av typen:

- *Vad tänker du själv att det kan betyda?*
- *Vad menar du med? Kan du berätta vad du tänker på när du hör ordet*

APPENDIX E KODNINGSREGLER STUDIE III

Aspect in the data-material	ICF coding rules used	Additional information
Impairment of bodily functions	ICF b1-b8 Nd -ph Nd-mh	Definition of Body function in the ICF category Concepts referring to physical health (ph) Concepts referring to mental health (mh)
Activity limitations	ICF d1, d2, d4, d5, d6	Definition of Activity in the ICF category
Participation restrictions	ICF d3, d7, d8, d9, d4604, d177, e4 Nc -effect on others Nd-qol	Definition of Activity in the ICF category Definition of Environmental factors: Attitudes in the ICF category Concepts referring to effect on others Concepts referring to health related quality of life in general
General negative perception of ill health		
Dependency on other people	Nc- Dependency on other people	Concepts referring to dependency on other people because of ill health
Occurrence	Nc-occurrence	Concepts referring to occurrence of impairments, limitations and restrictions
Duration	Nc-duration	Concepts referring to duration of impairments, limitations and restrictions
Risk of future ill health	Nc-risk of future ill health	Concepts referring to risk of future ill health
Risk of premature death	Nc-risk of premature death	Concepts referring to risk of premature death
Impact of life-length	Nc-impact of life-length	Concepts referring to time to death or impact on life-length
Prevalence	Nc-prevalence	Concepts referring to prevalence of ill health
Possibility to affect the impact of ill health	Nc-possibility to affect ICF d570 Nc-urgency	Concepts referring to possibility to affect the impact of ill health Definition of d570 in the ICF category (self-care aspects) Concepts referring to how urgency can affect the severity level
Multi-morbidity	Nc-multi-morbidity	Concepts referring to fragility and multi-morbidity
Societal costs	Nc-societal costs	Concepts referring to societal costs for ill health
Personal factors	Pf	Concepts referring to particular features that, according to the definition in ICF, are not part of a health condition or health state

* = not definable i.e. the concept has not enough information for linking it to a precise ICF category

** = not covered i.e. the concept is not contained in the ICF category and is not a personal factor

APPENDIX F ENKÄT MEDBORGARE STUDIE IV

Vänligen se information om studien i din postenkät.

Allra först ber vi dig fylla i lite bakgrundsuppgifter.

1. Du som fyller i denna enkät på webben vänligen skriv in din **3-siffriga personkod** nedan. Du hittar den angiven på motsvarande ställe i din postenkät. Uppgiften behövs för att du ska slippa få påminnelser om du redan besvarat enkäten. Så fort vi får ditt svar avidentifieras din enkät.

2. Ange din ålder (år fyllda).

3. Ange kön.

4. Ange din högsta utbildningsnivå.

- ☐ Jag har som högst folkskole/ grundskoleutbildning
- ☐ Jag har som högst gymnasieutbildning
- ☐ Jag har som högst högskole-/ universitetsutbildning
- ☐ Annan

Kommentar

5. Är du för närvarande anställd som hälso- och sjukvårdspersonal?

- ☐ Ja
- ☐ Nej

6. Har du för närvarande ett förtroendeuppdrag som politiker i landstinget/regionen?

- ☐ Ja
- ☐ Nej

Nu följer några frågor som handlar om att jämföra två olika hälsoproblem.

I samband med frågorna finns alltid möjlighet för dig att kommentera ditt svar om du så önskar.

7. Vilken av dessa två patientgrupper anser du har det svåraste hälsoproblemet? Markera det alternativ som bäst överensstämmer med din uppfattning.

- ☐ En patientgrupp med långvarig ohälsa som ger stora besvär då och då.
- ☐ En patientgrupp med kortvarig ohälsa som ger konstant stora besvär.

Kommentar

8. Vilken av dessa två patientgrupper anser du har det svåraste hälsoproblemet? Markera det alternativ som bäst överensstämmer med din uppfattning.

- ☐ En patientgrupp med liten ohälsa som medför negativa konsekvenser för närstående.
- ☐ En patientgrupp med stor ohälsa som inte medför några negativa konsekvenser för närstående.

Kommentar

9. Vilken av dessa två patientgrupper anser du har det svåraste hälsoproblemet? Markera det alternativ som bäst överensstämmer med din uppfattning.

- ☐ En patientgrupp med ohälsa som inte medför några praktiska konsekvenser (t ex svårigheter med personlig vård, hushåll) men som medför stora sociala konsekvenser (t ex svårigheter med relationer, arbete, fritid, samhällsgemenskap).
- ☐ En patientgrupp med ohälsa som medför stora praktiska konsekvenser men som inte medför några sociala konsekvenser.

Kommentar

10. Vilken av dessa två patientgrupper anser du har det svåraste hälsoproblemet? Markera det alternativ som bäst överensstämmer med din uppfattning.

- ☐ En patientgrupp med liten ohälsa som medför stora förändringar av deras livsstil.
- ☐ En patientgrupp med stor ohälsa som medför små förändringar av deras livsstil.

Kommentar

11. Vilken av dessa två patientgrupper anser du har det svåraste hälsoproblemet? Markera det alternativ som bäst överensstämmer med din uppfattning.

- ☐ En patientgrupp med liten ohälsa och som har svårt att känslomässigt hantera sin ohälsa.
- ☐ En patientgrupp med stor ohälsa och som inte har svårt att känslomässigt hantera sin ohälsa.

Kommentar

12. Vilken av dessa två patientgrupper anser du har det svåraste hälsoproblemet? Markera det alternativ som bäst överensstämmer med din uppfattning.

- ☐ En patientgrupp med ohälsa som medför stor nedsättning av livskvaliteten men som inte dör i förtid.
- ☐ En patientgrupp med ohälsa som inte medför någon nedsättning av livskvaliteten men som dör i avsevärd förtid.

Kommentar

13. Vilken av dessa två patientgrupper anser du har det svåraste hälsoproblemet? Markera det alternativ som bäst överensstämmer med din uppfattning.

- ☐ En patientgrupp som nu har liten ohälsa.
- ☐ En grupp friska personer där risken är stor att de drabbas av stor ohälsa i framtiden.

Kommentar

14. Vilken av dessa två patientgrupper anser du har det svåraste hälsoproblemet? Markera det alternativ som bäst överensstämmer med din uppfattning.

- ☐ En patientgrupp som nu har liten ohälsa.
- ☐ En grupp friska personer där risken är liten att de drabbas av stor ohälsa i framtiden.

Kommentar

Följande två frågor handlar om vad som kan vara mer eller mindre viktigt för att bedöma hur svårt ett hälsoproblem är.

15. Sätt kryss för vad du anser är de **fem viktigaste aspekterna** att ta hänsyn till för att avgöra hur svårt ett hälsoproblem är för en patientgrupp.

- ☐ Hur långvarig patientgruppens ohälsa är.
- ☐ Hur stora psykiska symptom som patientgruppen har.
- ☐ Hur vanligt förekommande den ohälsa är som drabbar en patientgrupp.
- ☐ Hur stora praktiska konsekvenser (t ex svårigheter med personlig vård, hushåll) ohälsan har för patientgruppen.
- ☐ Hur stora fysiska symptom som patientgruppen har.
- ☐ Hur ofta patientgruppen känner av sina besvär.
- ☐ Hur stor risk patientgruppen har för att drabbas av stor ohälsa i framtiden.
- ☐ Hur stora sociala konsekvenser (t ex svårigheter med relationer, arbete, fritid, samhällsgemenskap) ohälsan har för patientgruppen.
- ☐ Hur mycket närstående påverkas av patientgruppens ohälsa.
- ☐ Hur svårt patientgruppen har att känslomässigt hantera sin ohälsa.
- ☐ Hur många olika typer av ohälsa en patientgrupp har samtidigt, dvs hur multisjuk patientgruppen är.
- ☐ .Hur mycket kortare liv patientgruppen får p g a sin ohälsa

Kommentar

16. Sätt kryss för vad du anser är de **fem minst viktiga aspekterna** att ta hänsyn till för att avgöra hur svårt ett hälsoproblem är för en patientgrupp.

- ☐ Hur långvarig patientgruppens ohälsa är.
- ☐ Hur stora psykiska symptom som patientgruppen har.
- ☐ Hur vanligt förekommande den ohälsa är som drabbar en patientgrupp.
- ☐ Hur stora praktiska konsekvenser (t ex svårigheter med personlig vård, hushåll) ohälsan har för patientgruppen.
- ☐ Hur stora fysiska symptom som patientgruppen har.
- ☐ Hur ofta patientgruppen känner av sina besvär.
- ☐ Hur stor risk patientgruppen har för att drabbas av stor ohälsa i framtiden.
- ☐ Hur stora sociala konsekvenser (t ex svårigheter med relationer, arbete, fritid, samhällsgemenskap) ohälsan har för patientgruppen.
- ☐ Hur mycket närstående påverkas av patientgruppens ohälsa.
- ☐ Hur svårt patientgruppen har att känslomässigt hantera sin ohälsa.
- ☐ Hur många olika typer av ohälsa en patientgrupp har samtidigt, dvs hur multisjuk patientgruppen är.
- ☐ .Hur mycket kortare liv patientgruppen får p g a sin ohälsa

Kommentar

Slutligen ber vi dig fundera lite över bakgrunden till hur du besvarat frågorna.

17. Har du någon gång diskuterat liknande frågor som dem du just har besvarat i denna enkät, i samtal om hur hälso- och sjukvården borde fördela sina resurser för att åtgärda olika hälsoproblem?

- ☐ Ja jag har diskuterat alla de ovan nämnda aspekterna av hur svårt ett hälsoproblem är.
- ☐ Ja jag har diskuterat de flesta av de ovan nämnda aspekterna av hur svårt ett hälsoproblem är.
- ☐ Ja jag har diskuterat några/något av de ovan nämnda aspekterna av hur svårt ett hälsoproblem är.
- ☐ Nej jag har inte diskuterat någon av de ovan nämnda aspekterna av hur svårt ett hälsoproblem är.

Kommentar

18. Vad upplever du har betydelse för hur du ser på vad som är ett svårt hälsoproblem? Markera i vad grad du tycker att nedanstående alternativ påverkat din syn på detta.

	I mycket stor grad	I stor grad	I liten grad	I mycket liten grad
Min erfarenhet av egen ohälsa.	☐	☐	☐	☐
Min erfarenhet av andra personers ohälsa.	☐	☐	☐	☐
Den bild media ger om ohälsa.	☐	☐	☐	☐
Min bild av vad vården bedömer vara svåra hälsoproblem.	☐	☐	☐	☐
Min bild av vilka resurser som finns tillgängliga till hälso- och sjukvård.	☐	☐	☐	☐

Kommentar

Stort tack för din medverkan!

Papers

The papers associated with this thesis have been removed for copyright reasons. For more details about these see:

<http://urn.kb.se/resolve?urn=urn:nbn:se:liu:diva-146217>