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**Priority setting and clinical decision making
as viewed by Swedish physicians**

**Empirical study on physicians' experiences in clinical care and
attitudes towards the ethical platform and the national guidelines**

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To my family

“Is humanity as a reality and as an idea a point of departure or a point of arrival?

I do not claim to know what a human life is worth – the question cannot be answered by word but only by action, by the creation of a more human society.

All that I do know is that our present society wastes and, by the slow draining process of enforced hypocrisy, empties most of the lives which it does not destroy: and that, within its own terms, a doctor who has surpassed the stage of selling cures, either directly to the patient or through the agency of a state service, is unassessable.”

(John Berger, *A Fortunate Man, The Story of a Country Doctor*, 1967)

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Introduction

The challenge of rising health care costs

Health care is essential for all countries; promoting not only individual health and well-being but also employment, economic growth, social stability, health security, social cohesion, political stability, and economic diversification and innovation (UN 2019). However, health care systems are increasingly facing challenges regarding rising costs. Internationally, approximately 10% of the global gross domestic product (GDP) is now spent on health care; with health costs increasing faster than the total economy in most countries between 2000 and 2017 (WHO 2019). Rising health care costs are a consequence of several factors, including for example medical engineering progress, which is often expensive and leads to a greater disease detection; demographic change with a rising number of older multimorbid inhabitants; epidemiological transition of mortality with a rising proportion of chronic diseases as causes of death; as well as socio-cultural changes, which lead to a new consciousness of health and rising expectations of patients.

These challenges raise questions regarding the fair and effective allocation of health care resources. Overall, is it acceptable or just definable to put a price on health and thereby on life (Ubel 2000)? Does socio economic status change treatment (Buyx 2010)? What is solidarity (Prainsack and Buyx 2016, West-Oram and Buyx 2017)? In this thesis the deeper philosophical background will not be addressed in detail. However, in addition many more practical and more applied questions have to be solved. This is the broader background against which the topic of this thesis was the firmament. This thesis asks how a well-established approach to face these challenges namely the Swedish example of priority setting in medicine is experienced in clinical life. It does so by examining the views of Swedish physicians on clinical decision making and the Swedish system of priority setting in health care.

As the promotion of health care concerns every human being the challenges are internationally discussed. The United Nations campaign to “ensure healthy lives and promote well-being for all” points out the importance to “achieve universal health coverage,

including financial risk protection, access to quality essential health-care services and access to safe, effective, quality and affordable essential medicines” (UN 2015). In order to achieve universal health coverage not only a well-functioning health care system is needed but also a health workforce (WHO 2016, Kuhlmann, Batenburg et al. 2018). Three different levels of key actors in health care, all affected by the challenges of rising costs, are commonly described. The ‘macro level’ characterises the “national, regional and/or supranational policy-making”, the ‘meso level’ the “hospital governance” and the ‘micro level’ the “day-to-day operational management of staff and services inside the organization”, also called “hospital management” (WHO 2011). All levels have to deal with the challenges of rising costs, higher demands and possibilities and the questions of allocation of resources.

Within the ‘micro level’ each physician -in explicit manager position or not- experiences consequences in daily practice, as he/she needs to fulfil two roles. First of all physicians are the patients advocates and are expected to act medically right, do everything they can but at the same time they are more or less obliged to act cost-efficiently within the scope of their health care system and their respective hospital/practice management. In literature this phenomenon is described as ‘double agent’ (Blomqvist 1991, Shortell, Waters et al. 1998, Buyx 2007). There are different ways of handling the challenges. Each country reacts in its own way within its pre-existing framework of health care and politics. Knowing about the challenge of rising costs as well as the global aim of universal health coverage, the questions raise: how to ensure universal health, distribute the resources and deal with the conjunction of medicine and economy?

Approaches to address rising health care costs

Key approaches to address rising health care cost typically fall under one of three different concepts: rationalisation, rationing, and prioritisation. There exist no commonly agreed definitions of these. (Arvidsson 2013, Schmitz-Luhn 2015)

1. rationalisation, Latin ‘rationalis’ – of or belonging to reason, logic
2. rationing, Latin ‘ration’ – apportion in fixed amounts
3. prioritisation/ priority setting, Latin ‘prioritas’ – fact or condition of being superior

Rationalism aims to utilise health care resources more efficiently, either by using the same

resources more effectively so more profit is obtained or by using less resources to achieve the same profit. It is widely agreed that rationalism should be realised before rationing takes place. (Wohlgemuth 2009, Deutscher Ethikrat 2011, Schmitz-Luhn 2015).

Rationing limits access to health care. Different types of rationing are described. Hard rationing in health care results in all patients having the same medical options without exceptions, while soft rationing allows patients to pay on their own for additional options. Implicit or covert versus explicit or open rationing describes how decision makers are dealing with rationing, either transparent or not. Direct versus indirect rationing concerns the realisation of it. Direct implies the exclusion of defined patients or medicines whereas indirect money budgeting or staff shortage which due to scarcity leads to exclusion. In addition, seven strategies of rationing throughout all levels have been described by Klein: denial, selection, deflection, deterrence, delay, dilution and termination. (Klein 1996, Deutscher Ethikrat 2011, Arvidsson 2013)

Prioritisation/ priority setting in health care requires deciding on the relative importance of services. This can occur horizontally within one level (e.g. in one specialty), or vertically across two or more levels (e.g. in different specialties). Priority setting can be used in order to invest, reallocate or disinvest. However, in case of disinvestment, the distinction between the terms “rationing” and “priority setting” are not always clear and the terms are sometimes used synonymously in this context. Over time a shift of the meaning and the use of terms was even experienced, from rationing in the beginning over resource allocation to sustainability in future (Singer 2000). Priority setting can in case of disinvestment be done before rationing, as a basis for explicit and direct rationing. (Deutscher Ethikrat 2011, Arvidsson 2013)

The issue of priority setting was widely discussed internationally in the 1970s and 1980s due to, among others, economic recession. Initially, the focus was on solutions such as cost effectiveness analysis. At this time, priority setting was primarily understood to be evidence-based (Sackett, Rosenberg et al. 1996), and various methods were developed, including health technology assessment (HTA) (Jonsson and Banta 1999) and the method programme budgeting and marginal analysis (PBMA) (Mitton and Donaldson 2004). However, priority

setting subsequently became more complex, focusing also on normative aspects. Daniels' and Sabin's framework of accountability for reasonableness (A4R) for example, described four conditions that were required to achieve a fair process of priority setting: 1. publicity (public accessibility of decisions), 2. reasonableness (agreement on relevant rationales), 3. appeals (revising mechanisms), 4. enforcement (voluntary or public regulation) (Daniels 1999, Singer 2000). Although the framework was developed with the privately funded U.S. health system in mind, its relevance for publicly funded systems and other important elements of fairness in priority setting (like "leadership, internal transparency, understanding, opportunity to express views, agenda setting") have been highlighted (Martin, Giacomini et al. 2002). Besides normative aspects and cost effectiveness analysis also clinical effectiveness should be kept in mind (Buyx, Friedrich et al. 2011).

During the 1980s and 1990s, Norway, Sweden, Denmark, and the Netherlands, started to discuss and define concrete principles regarding priority setting. At the same time the U.S. state of Oregon, the UK, Israel, and New Zealand, started to discuss and implement measures to limit rising health care costs (Sabik and Lie 2008, Schmitz-Luhn 2015). Both, reaching consensus regarding the rationales and principles of priority setting as well as agreement concerning transparent processes of implementation were found to be difficult (Daniels 2000), (Holm 1998). In the course of gaining more experiences, early methods like PBMA were further developed, multi-criteria decision analysis (MCDA) became popular (Baltussen and Niessen 2006, Peacock, Mitton et al. 2009), an effort was made to increase the integration of ethics (Hofmann 2014), evidence-informed deliberative processes were described (Baltussen, Jansen et al. 2016), and middle and low developed countries and overall frameworks were focused on (Kapuriri and Chanda-Kapata 2018). In the project of this thesis the case of Sweden was examined in detail. In the following section its health care system and its experiences with priority setting are described.

Priority setting and clinical care in Sweden

Sweden's approach to priority setting in health care is recognised as one of the first and most meaningful approaches internationally, with elaborated methods of implementation for a fair and evidence-based resource allocation system (Raspe and Schulze 2013, Schmitz-Luhn 2015). Although Sweden's health care system is nationally led by the policies of the

national government, the system is highly decentralised, with the 21 county councils (in Swedish 'läns') and 290 municipalities (in Swedish 'kommuner') having directly elected political authorities with the responsibility to provide health care. Counties have the rights to decide on taxes (which fund the main part of health care) and on the organisation of health care packages. However, the national government is encouraging the counties to become more equal within their packages, and there is a trend to create larger regions, already starting with six health care regions providing highly specialised care. Overall, there are seven university hospitals, approximately 70 county hospitals and six private hospitals. (Glenngård, OECD 2019)

Health coverage is universal and automatic. About 10% of all Swedish employees have supplementary private health insurance, mostly covered by the employer (OECD 2019). Through the 1177 national telephone number and website, people can seek medical information, call medical staff 24 hours a day, manage their appointments and prescriptions, and view their medical records. Medical records are electronically shared among health professionals. The nationally guaranteed access to healthcare (in Swedish 'vårdgaranti') ensures access following the 0-7-90-90 rule: Patients should get instant contact seeking medical advice, an appointment with a general practitioner within seven days, an appointment with a specialist within 90 days and treatment after being diagnosed within 90 days. In case cancer is suspected, there are further rules of standardised care (in Swedish 'standardiserade vårdförlop'). In order to promote equality and high quality, there exist comparisons between counties regarding various aspects of care, including access, diagnostics, therapies, and patient satisfaction.

Priority setting in Sweden became official when in 1992 the Swedish government initiated a Parliamentary Priorities Commission consisting of politicians and professional experts. The Commission examined the issue by conducting questionnaire studies and organising discussions with many different stakeholders, including the public. In their final report 'Health Care's Difficult Choices' in 1995, they presented the 'ethical platform' as framework for priority setting, by defining three key principles for decision making which should be used on all levels in health care:

1. Principle of human dignity:

“All people have equal value and equal rights, regardless of personal characteristics and functions in society.”

2. Principle of need and solidarity:

“Resources should be committed to those fields (activities, individuals) where needs are greatest.”

3. Principle of cost-effectiveness:

“When choosing between different fields of activity or measures, one should aim for a reasonable relation between cost and effect, measured by improved health and enhanced quality of life.”

The Commission specified that these internationally established principles should be ranked hierarchically by their order. It was decided that other criteria that have been argued to be important in the literature (Norheim 2016) – like chronological age (Callahan 1990, Marckmann 2003), birth weight, lifestyle, self-responsibility (Buyx 2005, Buyx 2008) , and economic or social situation (Buyx 2010) – should not be taken into consideration. Furthermore, it was argued that priority setting should be performed transparently and medical assessment of people seeking care should be performed as soon as possible. In 1997, the proposals of the Commission were turned into legislation. (Socialdepartementet 1995, Socialdepartementet 1996/97)

In 2001, the National Centre on Priority Setting in Health Care was formed in Linköping in order to conduct research, develop new methods, spread experiences, maintain networks and provide education in priority setting. In 2002, the National Board of Health and Welfare, NBHW, started to develop national guidelines, in collaboration with experts and health care professionals, to support decision makers in health resource allocation. The guidelines include non-binding recommendations in the form of rankings of condition and treatment pairs, ranked from one to ten, one marking highest priority, as well as the category ‘FoU’ – ‘forskning och utveckling’, meaning ‘research and development’, and the category ‘Icke-göra’, meaning ‘should not be done’ (see the following figure 1). They combine the currently known evidence with the ethical principles outlined above.

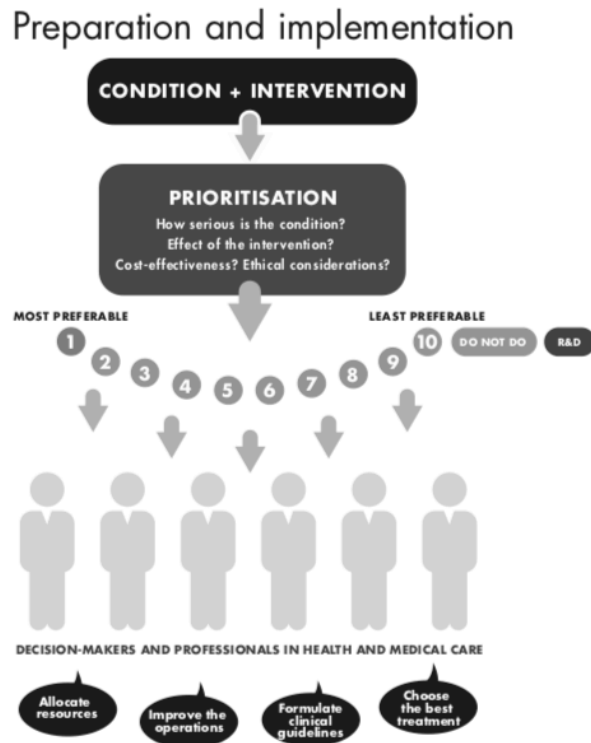


Figure 1 Preparation and implementation of national guidelines (Socialstyrelsen 2015)

In 2004, the first national guideline of cardiac care was published (an extract see figure 30 - 32 in the appendix). It was a broad advancement of the rather little national guideline of coronary artery diseases of 2001 consisting the very first advice on priority setting. By spring 2020, 18 national guidelines had been published, three guidelines were in revision, and another guidelines was being developed. The existing guidelines cover asthma/COPD, breast/prostate/colon and rectal cancer, dementia, depression/ anxiety, diabetes, cardiac care, prevention of unhealthy lifestyle habits, lung cancer, abuse and addiction, multiple sclerosis/Parkinson disease, palliative care, musculoskeletal system diseases, schizophrenia, stroke and dental care. The national guidelines are mainly thought as a support for decisions for patient groups on the meso and macro level, but are also known to be applied in individual cases on the micro level. As there exist other national guidelines in Sweden not only from the NBHW (in Swedish 'Socialstyrelsen'), but for example from the Swedish Agency for Health Technology Assessment and Assessment of Social Services (in Swedish abbreviated 'SBU'), we used the term 'Socialstyrelsens' national guidelines' within the questionnaire and within the thesis 'the national guidelines' meaning the ones from NBHW. The big difference between 'ordinary' guidelines and those of the NBHW, is the explicit

combination of evidence-based medical facts with the ethical principles including cost-effectiveness data.

In 2003, Östergötland was the first county to run a formal and explicit priority setting process, both horizontal as well as vertical. It resulted in a new allocation of resources and limitations characterised by a final list of disinvestments. As they were first to dare to disinvest and due to other reasons their approach received a lot of criticism, and the process was revised during the following years. In 2007, the first national model for transparent prioritisation as support for decision makers on meso and macro level was published, and was revised in 2011 and 2017 (Carlsson, Kärvinge et al. 2007, Broqvist, Branting Elgstrand et al. 2011, Prioriteringscentrum 2017) (see the following Figure 2 and Figures 33 - 34 in the appendices). Subsequently, many other regions, counties, municipalities and professional associations have followed and invested in transparent priority setting processes. Challenges remain but the experiences are encouraging.

Human Dignity Principle			
Needs and solidarity Principle		Cost-effectiveness Principle	
Severity level of a health condition	Patient benefit/effects of the intervention	Cost-effectiveness of intervention	E V I D E N C E
<ul style="list-style-type: none"> * Current health condition - suffering - functional impairment - quality of life <ul style="list-style-type: none"> * Risk for - premature death - disability/continued suffering - lower quality of life 	<ul style="list-style-type: none"> * Effects on current health condition - suffering - functional impairment - quality of life <ul style="list-style-type: none"> * Effects on risk - premature death - disability/continued suffering - lower quality of life <ul style="list-style-type: none"> * Risk for side effects and severe complications from intervention 	<ul style="list-style-type: none"> * Direct costs - health service interventions, - other measures, e.g. travel <ul style="list-style-type: none"> * Indirect costs <div style="border: 1px solid black; padding: 5px; margin-top: 10px;"> <p>... in relation to benefit of the intervention</p> </div>	

Figure 2 Three key components of priority setting as described in the National Model (Carlsson, Kärvinge et al. 2007)

Germany's perspective on priority setting and clinical care

In the following the German perspective on health care and priority setting should be shortly depicted in order to show the importance of the Swedish example for Germany. Actually, Germany has the longest history in the world concerning universal health care. In 1883, chancellor Otto of Bismarck launched the Sickness Insurance Law and thereby the first kind

of universal health care worldwide. To date health insurance is mandatory. But in contrast to Sweden it is split in a statutory health insurance and a substitutive private health insurance. About 86% of the population are in the statutory health insurance. The statutory health insurance is provided by 110 competing non-profit non-governmental health insurance funds (GKV-Spitzenverband). About 11% of Germans are in private health insurances, they are provided by 41 companies, of which 25 are for-profit (PKV-Verband 2018). They are to some degree regulated by the government, but set their risk related premiums and health packages on their own. Private health insurances account for about 9% of all health expenditures (DESTATIS 2016). The German government decides upon the ambulatory care capacity and the 16 state governments (in German 'Bundesländer') decide upon the hospital capacity. There are 1942 hospitals in total of which 560 are public, 662 charitable and 720 private (DESTATIS 2018). Overall, there are 33 university hospitals (VUD 2018).

There have been debates about the background of priority setting in Germany since a long time, however discussions about concrete strategies are missing (Deutscher Ethikrat 2011). Single scientific papers from the 1990s on the topic as well as the reports of the Central Ethics Committee in 2000 and 2007 attained little attention (Zentrale Ethikkommission 2000, Zentrale Ethikkommission 2007). Only when Prof. Dr. med. Jörg-Dietrich Hoppe, president of the German Medical Association at that time, introduced the Congress of German Physicians in 2009 by highlighting the implicit rationing and urgent need for priority setting, a broad public discussion started. While the main part of the German Medical Association supported Hoppe, among other Ursula Schmidt, Minister of Health, named priority setting "inhuman" (NRZ 2009) and others showed their dislike, too. One year later, 2010, Philipp Rösler, the following Minister of Health, continued to put priority setting under a political taboo stating that: "I also cannot reconcile such a hierarchy with my ethical ideas as a physician. (...) Prioritization would mean accepting that the solidarity system can no longer do everything. However, at least for the tasks that a solidarity system must indisputably perform, there must be no gradation, ranking or rationing." (Rieser and Stüwe 2010).

But in this system, partly regulated by the market, rationing already took place (Strech, Danis et al. 2009, Strech 2011). Two research groups continued to work on priority setting 'FOR655 – Priorisierung in der Medizin', financed by the DFG (German Research Foundation) from

2007 to 2013, and the 'AG für Priorisierung in der Medizin' launched by the German Medical Association from 2012 to 2015.

In Germany not only rationing in terms of under care but also over and inappropriate health care takes place (Sachverständigenrat 2018). Furthermore, there exist many different economic incentives for making profit with health care (Dohmen and Fiedler 2015, Marckmann and Marschmann 2017). Even while if politicians did not want to stress the discussion about rationalisation, rationing and priority setting, it became reality in the German health care system in a non transparent and unguided way (Schnoor, Braehler et al. 2017). In discussions about health resource allocation in Germany, physicians are expected to take a stand for fair mechanisms (Diederich and Schreier 2010, Strech 2014, Diederich, du Bois et al. 2015) and Sweden with its ethical principles and national guidelines is recommended to be seen as a model (Buyx 2007, Raspe and Schulze 2013). Questions are raised, how well this model function, whether it is known at the base and whether the physicians' decision making is thereby limited.

Physicians' views on clinical priority setting in Sweden

There has been limited research examining the micro level, the clinicians' views on priority setting and the national guidelines in Sweden. Ridderstolpe conducted a questionnaire among 208 cardiologists, cardiothoracic surgeons and anaesthesiologists, response rate 44% (Ridderstolpe, Collste et al. 2003). Ekerstad performed a questionnaire study among 255 cardiologists, response rate 69% as well as a questionnaire case study among 41 cardiologists, response rate 71% (Ekerstad, Lofmark et al. 2010, Ekerstad 2011, Ekerstad, Lofmark et al. 2011). Werntoft and Edberg led interviews with 18 physicians (Werntoft and Edberg 2011). More studies focused on the heads of departments or medical managers (Waldau 2007, Linander 2011, Vårdanalys 2015). Others concentrated on groups including other staff within general practices (Arvidsson 2013), politicians (Werntoft and Edberg 2009a, Werntoft and Edberg 2009b, Rosen, De Fine Licht et al. 2014, Kalkan, Sandberg et al. 2015) or different professions as other therapists, economists or ethicists (Waldau, Lindholm et al. 2010, Nedlund 2012, Eckard, Janzon et al. 2014, Waldau 2015).

Regarding knowledge and application, Ridderstolpe reported that 80% of the cardiologists,

cardiothoracic surgeons and anaesthesiologists were informed about the ethical principles but only 40 to 55% of the physicians knew the meaning of them (Ridderstolpe, Collste et al. 2003). 64% were informed about priority setting and 58% knew the national guideline for coronary artery diseases, a predecessor of the later and broader national guideline for cardiac care, but only 26% were educated and trained in prioritisation (Ridderstolpe, Collste et al. 2003). Ekerstad stated that 90% of the cardiologists were very familiar with the contents of the national guideline for cardiac care and 81% used it extensively (Ekerstad, Lofmark et al. 2010). Arvidsson experienced that only few personnel of general practices knew about the ethical principles and the national guidelines and that they were unsure about the contents (Arvidsson 2013). Regarding the heads of different hospital departments in Sweden, 76% answered to apply the national guidelines, 33% in their original form, 69% through local guidelines and 38% through lists of recommended drugs by the counties (Vårdanalys 2015). 68% applied the national guidelines to create local guidelines, 48% as support in patients' contacts and 42% as support to prioritise resources of the department (Vårdanalys 2015). Werntoft found a difference of application of priority setting measures between younger and older physicians, younger ones relied mostly on the advice of older colleagues whereas older colleagues were in favour of the ethical platform and asked for more practically applicable national guidelines (Werntoft and Edberg 2011).

72% of the questioned chiefs confirmed high and very high trust in the national guidelines, 60% perceived them as containing all relevant condition and treatment pairs, 65% as up-to-date (Vårdanalys 2015). In total the national guidelines were seen as relevant and important, 40% expected them to lead to less inequality (Vårdanalys 2015). Chiefs applying the national guidelines were more positive towards them (Vårdanalys 2015). Just as cardiologists who were concerned with writing the national guideline were more positive, besides some stated that the national guidelines too quickly become out of date (Ekerstad, Lofmark et al. 2010). Only 24% of the cardiologists, cardiothoracic surgeons and anaesthesiologists experienced the national guidelines for cardiac care as supportive (Ridderstolpe, Collste et al. 2003). A lack of accordance regarding the use of the national guidelines was expected to lead in unequal treatment (Ridderstolpe, Collste et al. 2003).

Furthermore, physicians expressed a lack of support structures (Werntoft and Edberg 2011)

and a lack of basic training and support of ethical principles (Ridderstolpe, Collste et al. 2003). They were in need for more open dialogues and discussions about priority setting and more practical and clearer national guidelines (Ridderstolpe, Collste et al. 2003, Werntoft and Edberg 2011), as well as more data and specific guidelines for the treatment of elderly multimorbid patients (Ekerstad 2011).

In sum previous studies about priority setting in Sweden mostly lightened its background, contents and development. Descriptions of ways of implementation mostly focused on the macro and the meso level. The NBHW conducts follow ups of the national guidelines a few years after their respective introduction, mostly concentrating on investigations of different numeric indicators. So far, only few studies examined the physicians' views, almost exclusively in the fields of cardiology and general practice.

Research gaps regarding physicians' views on clinical priority setting

The Swedish ethical platform and the national guidelines are frequently described as a successful model and template for a fair and evidence-based allocation of health care resources in terms of priority setting. But there is still a lack of knowledge regarding how Swedish clinicians of different specialties perceive the ethical platform and the national guidelines in their everyday clinical work. Are these national efforts known and appreciated at the 'bottom'? This lack was described in Swedish as well as German literature (Marckmann 2009, Arvidsson 2013, Waldau 2015). Furthermore, the question of possible limitations of the freedom of decision making of physicians in a process of priority setting is often raised in German discussions (Zentrale Ethikkommission 2007, Strech 2009, Schmitz-Luhn 2015). In order to understand the particular perception of physicians, it was essential to understand their situation of daily clinical life and their way of decision making. Besides all decisions on macro and meso levels, in the end the physicians are the ones who take the final decisions for their individual patients on the micro level. This is why we decided to look on Sweden and examine this case by questioning physicians.

Aim of this thesis

The primary aim of this project is to identify the Swedish physicians' point of view on clinical decision making and priority setting by conducting an online-questionnaire-based study among physicians. Thereby we want to stimulate the Swedish discussion on the implementation of priority setting as well as to enhance the discussions on how priority setting could be applied in other countries, like for example Germany. This will be achieved by examining the following research questions:

1. How do Swedish physicians experience their daily clinical conditions?
 - 1.1. What is their impression of today's patient care?
 - 1.2. Do they experience scarcity of resources?
 - 1.3. Do they feel limited in their clinical decision making?
 - 1.4. What is their clinical decision making based upon?
2. How are national priority setting efforts taken up by clinical physicians?
 - 2.1. What is their knowledge of and their attitude towards the ethical platform and the national guidelines?
 - 2.2. Do views differ between cardiologists and physicians from other specialties?

It is hypothesised that:

1. All patient care is optimal, physicians have all the resources they need, do not feel limited at all and their clinical decision making is reasonable.
2. All Swedish physicians, cardiologists slightly more than other physicians, do know about the national priority setting efforts in health care, apply and appreciate them.

The thesis is composed of five chapters. The first one establishes the background and the importance of our research questions, the second presents the methodology of our study, the third our findings, in the fourth chapter the limitations and implications of these are discussed and finally, in the fifth we draw a conclusion.

Methods

General project framework

This study was a collaborative project of the University of Kiel with the National Centre for Priority Setting in Health Care at the Department of Medical and Health Sciences, Division of Health Care Analysis, University of Linköping, Sweden. Alena Buyx and the author of this thesis presented the idea of the study to the centre's former chief Per Carlsson. His colleagues at the centre Barbro Krevers, senior lecturer and former occupational therapist, and Niklas Ekerstad, researcher and cardiologist, joined the project. Beside email correspondence, meetings were organised in Linköping and at conferences of priority setting to discuss the ongoing work of the author. For a deepened practical insight into the clinical conditions of priority setting and the possibility of data gathering on site the University hospital of Örebro in Sweden was chosen. The author completed a four months' internship from May to September 2016 there. First results of the project were presented in form of a poster at the international conference 'Priorities 2018' held by the international society on priorities in health in Linköping, Sweden, in September 2018 (see appendices).

Study design and implementation

The data in this study were collected with an electronic questionnaire of two different samples of Swedish physicians. Invitation letters including the link to the English questionnaire were sent by e-mail. Non-responders were reminded up to four times and asked to state the reason for not participating. The data collection for 'group 1' occurred between August and September 2016, and for 'group 2' between November 2016 and January 2017. The study did not require approval by a research ethics committee in Sweden or Germany (SFS 2003). Though, we have applied ethical research principles of the declaration of Helsinki (WMA 2013). The survey was conducted with the program EvaSys Automation Software Version 6 (Electric Paper Ltd. 2016). The invitation letter and the reminder were in Swedish in order to address more physicians. All documents as well as the explanations of non-responders are annexed.

During the first phase, invitations were sent to a list of 349 physicians working at the University hospital in Örebro. This 'group 1' consisted of physicians from twelve different departments: general medicine, cardiology, pulmonology, geriatrics, general surgery, cardiothoracic and vascular surgery, anaesthesia/intensive care, emergency department, urology, oncology, neurology, and psychiatry. These departments were chosen due to the existence of corresponding national guidelines. Heads of departments approved the study, informed physicians of the study and allowed short oral presentations by the author.

During the second phase, further invitations were sent to 'group 2' consisting of 1068 members of the Swedish society of cardiology. The society approved the study project and provided a list of email addresses of their members in August 2016. A member is defined in the society's statute as: "Member can be any Swedish cardiologist, Swedish physicians interested in cardiology as well as scientists, physicians-to-be and representatives of cardiology departments." (Svenska-Kardiologföreningen 27.09.2013). Consequently, the list also included non-cardiologists as well as retired cardiologists. This reduced the number of potential and willing physicians able and willing to take part in the survey. The exact numbers were not definable.

The invitation letter explained the aim of the study and shortly its background to ensure that participants understood what priority setting and the national guidelines meant. Furthermore, voluntariness and anonymity were assured and it was stated that the data will be kept on servers of the University of Kiel up to 10 years and then deleted. It was estimated that it would take approximately 15 minutes to complete the questionnaire. Each participant was asked to answer each question, as accurately as possible and to only choose the alternative 'can't say' in case of uncertainty or abstention. With a personal transaction code, it was possible to open a website with the questionnaire on computers as well as tablets or mobile phones. Participants were able to save their answers temporarily and to complete the survey later on. It was stated that the study results will bring new knowledge for the Swedish as well as the international discussion of priority setting and each participant will be informed when results are published. Physicians were asked to contact the author via email in case of any questions.

Questionnaire design and contents

The questionnaire was developed by the author of this thesis herself and was based on an extensive literature review and on established methods of questionnaire development (McColl, Jacoby et al. 2001, Edwards 2010). It was written in English to ensure a better analysis in cooperation with the German, English and Swedish speaking project partners as well as to allow a direct result presentation within national as well as international publications and avoid potential deviations due to translation. In Sweden, English is commonly used in academia and everyday life (Bolton and Kuteeva 2012). Terminology was discussed with several Swedish physicians to ensure comprehensibility. Furthermore, the contents of the questionnaire were frequently discussed with project partners including Alena Buyx, Barbro Krevers and Niklas Ekerstad. In addition Christoph Borzikowsky, scientist at the Institute of Medical Informatics and Statistics at the University of Kiel, supported the project as a statistician. Different specialists within clinical care (Stella Cizinsky and Jörg Carlsson), medical ethics (Heiner Raspe), economics (Per Carlsson) and psychology were contacted to increase the quality of the questionnaire. The questionnaire was pretested by members of the Institute of Experimental Medicine at the University of Kiel, including two English native speakers, and a small group of Swedish and German residents.

The response options were kept simple and similar throughout the whole questionnaire in order to provide a fluent completion of the questionnaire. The most common type of answering scale was an ordinal-scaled five-point Likert response, ranging from either 'never to very often' or 'not at all to very well'. Participants were asked twice to specify the frequency by choosing one option out of 'at least once per day, at least once per week, at least once per month, less than once per month, until now never'. Ten questions were multiple choice questions for which the author set whether it was possible to choose only one or multiple answers, depending on the question. Furthermore, there were also single open-ended questions for own ideas as well as single questions where the participants needed to fill in either a percentage between zero and one hundred or a number of years of age and working. In case of years of age and working there was an appropriate range of years set in EvaSys Automation Software in order to prevent non-evaluable answers. The answer possibility 'can't say' was provided for each question and each question needed to be answered in order to finish the survey. There were only two exceptions for this. Firstly, all

open-ended questions were optional and secondly in part two participants, who were not at all acquainted with the ethical platform or any of the national guidelines or could not express it, were automatically directed to a later question, which they were able to answer.

The questionnaire was divided into three parts. The first part consisted of general questions about patient care, resources in clinical work, and clinical decision making. The answering options regarding patient care were based on the ethical principles without naming them. Regarding resources, physicians were asked to describe the frequency of scarcity of resources, possible consequences and their way of handling. Regarding clinical decision making, the independence in decision making, limiting and influencing factors as well as sources of information were examined.

The second part continued with questions about the ethical platform and the national guidelines for priority setting. In addition to general questions about physicians' knowledge, application and assessment of the ethical platform and the national guidelines, more specific questions followed concerning the evaluation of the national guidelines. The first part was purposely placed in front of the part two, in order to gain an insight into the physicians' work as a whole. Physicians not knowing priority setting were thereby able to express their views, too, and then directed to the last part of part two, in which wishes and further comments were able to be stated.

The third part ended the questionnaire with demographic questions about age, clinical work duration, gender, employment, specialisation, kind of hospital, county/region working in and possible participation in writing guidelines. There were 46 questions in total, including six open-ended questions. Please have a look at the questionnaire in the appendix.

Data analysis

Due to the online questionnaire and the setting options of EvaSys Automation Software (Electric Paper Ltd. 2016) no missing values occurred. Data management and analysis of quantitative results were performed using IBM SPSS Statistics for Mac (IBM 2016).

Descriptive and inferential statistics were calculated (Field 2009, Bortz 2010). Responses were compared between 'group 1', physicians from the University hospital in Örebro, and

'group 2', cardiologist from all of Sweden. In case of categorical, nominal or ordinal-scaled questions the two-dimensional χ^2 -test was calculated including the p-values. The expected frequencies were greater five in each of the response categories and thereby the assumptions of the χ^2 -test were met. The significance level was $\alpha=.05$. P-values of χ^2 -tests were computed as asymptotic two-sided significances, as exact significances were not possible to compute with the SPSS version of the author. However, the significances should be unbiased as the sample sizes exceeded 30 participants in each of the two groups.

Several questions were multiple-choice questions. In these cases, responses to each single response category were coded as 0 = no (disagreement) or 1 = yes (agreement). It was calculated with the cumulative percentages of agreement. Box plots were used for the illustration of the gradation and weighting of responses among different questions. Participants stating no knowledge ('not at all') or insecurity ('can't say') in knowing the ethical platform as well as the national guidelines were excluded by the system for the more specific questions on the national guidelines (questions 6.2-3 and 7.2-9). Frequencies for these questions were calculated and named as valid without the ones excluded by the system. Means, standard deviations, minimums and maximums are given for questions with metric scaled response categories. In these cases, two-sample t-tests for independent samples were calculated for examining differences between 'group 1' and 'group 2'. Due to the large sample sizes in both groups ($n_1=162$ and $n_2=166$) t-tests were robust against non-fulfilling the assumption of normal distribution. Levene's test was used to check for the assumption of equal variances. Answers to open-ended questions as well as reasons of non-responders were evaluated in content by the author herself.

Results

Basic demographic information

Within 'group 1' invitation emails were sent to 349 email addresses, eight email addresses didn't exist any longer, eight persons were not working during the whole time of data gathering and two stated no ability to answer the questions. Of the remaining 331, we received 162 responses; a response rate of 48.9 %. Moreover, four non-responders stated technical problems and 38 were partly on holidays during data gathering. Physicians of 'group 1' who received the invitation email were male at a percentage of 60.1%. This proportional distribution is in line with the actual participants of 'group 1' which were male at a percentage of 61.1%. Further background data were not available.

The size of the twelve different departments from which participants were recruited varied between seven to 57 employed physicians and their respective responder frequency varied between 31.4% and 76.2%. The highest responder frequency occurred within the department of urology (76.2%, 16 of 21), followed by cardiology (66.7%, 16 of 24), geriatrics (57.1%, 8 of 14), emergency (57.1%, 4 of 7), cardiothoracic and vascular surgery (56.3%, 9 of 16), anaesthesia/intensive care (53.3%, 24 of 45), oncology (50.0%, 14 of 28), pulmonology (50.0%, 4 of 8), general surgery (43.6%, 24 of 55), neurology (42.9%, 9 of 21), internal medicine (40.4%, 23 of 57) and psychiatry (31.4%, 11 of 35).

Of 1068 email addresses of 'group 2' 99 email addresses didn't exist any longer and 46 persons were not working during the whole time of data gathering. Of the remaining 923 we received 166 responses and thus the response rate was 18.0 %. Like in 'group 1' four non-responders stated technical problems and five were partly on holidays. For 'group 2' no background data of the members existed by the Swedish society of cardiology itself. But the demographic composition of our sample is well representative of cardiologists in Sweden and can be compared with data of the society named in another study, where a mean age of 54 years and a percentage of 75% for male members is stated and standard deviation not stated (Braunschweig 2015). The mean age of participants of 'group 2' was 49.9 years, standard deviation 11.6, and the percentage of male participants 73.5%.

Results

An overview of demographic and work related characteristics for both groups is given in the following Table 1. Results of t-tests to compare the age and the years of clinical work in both groups are given in Table 2 and 3 in the appendices. There was a significant difference in age; 'group 1' M=44.0, SD=11.7 and 'group 2' M=11.6, SD=11.6; $t(326)=-4.56$, $p < .00$.

Likewise, there was a significant difference in the scores for years of clinical work; 'group 1' M=16.6, SD=11.8 and 'group 2' M=21.5, SD=10.9; $t(326)=-3.89$, $p < .00$. These results suggest that both groups are not similar regarding these two characteristics.

Demographic and work related characteristics	Group1	Group 2	In total	Test	p value
Participants in total	162	166	328		
Age in years					
- mean	44.0	49.9	47.0	t(326)=-4.56	< .00
- standard deviation	11.7	11.6	12.0		
- minimum	25	27	25		
- maximum	69	85	85		
Years of clinical work					
- mean	16.6	21.5	19.1	t(326)=-3.89	< .00
- standard deviation	11.8	10.9	11.6		
- minimum	1	2	1		
- maximum	45	52	52		
Gender (%)					
- female	38.9	26.5	32.6	$\chi^2(328)=5.72$.02
- male	61.1	73.5	67.4		
Employment (%)					
Not legitimised assistant doctor	8.0	0.6	4.3	$\chi^2(328)=24.48$	< .00
Legitimised assistant doctor	17.9	9.0	13.4		
Specialist	28.4	26.5	27.4		
Senior doctor	40.7	50.6	45.7		
Chief of department	3.7	7.8	5.8		
Other	1.2	3.6	2.4		
No employment	0	1.8	0.9		
Specialisation (%) - most common (over 5%) - multiple responses					
None - still under training	19.8	6.6	13.1	$\chi^2(328)=12.40$	< .00
Internal Medicine	16.0	71.7	44.2	$\chi^2(328)=102.90$	< .00
Anaesthesia and intensive care	12.3	0.0	6.1	$\chi^2(328)=21.83$	< .00
Surgery	11.1	0.0	5.5	$\chi^2(328)=19.52$	< .00
Oncology	8.6	0.0	4.3	$\chi^2(328)=14.99$	< .00
Cardiology	7.4	82.5	45.4	$\chi^2(328)=186.64$	< .00
Urology	7.4	0.0	3.7	$\chi^2(328)=12.76$	< .00
Hospital size (%)					
Small	0.0	16.3	8.2	$\chi^2(328)=110.28$	< .00
Mid-sized	0.6	25.9	13.4		
Large/academic	99.4	48.2	73.5		
Other	0.0	9.6	4.9		
Landsting/region (%) - most common (over 5%)					
Region Örebro län	96.9	0.0	49.4	$\chi^2(328)=293.77$	< .00
Stockholms läns landsting	0.0	19.3	9.8		
Västra Götalandsregionen	0.0	16.9	8.5		
Region Skåne	0.0	15.1	7.9		
Region Östergötland	0.0	7.8	4.0		
Landstinget i Uppsala län	0.0	5.4	2.7		

Participation in writing guidelines (%) - multiple responses					
Local guidelines	53.1	57.8	55.5	$\chi^2(328)=0.75$	0.39
National guidelines of NBHW	13.6	13.9	13.7	$\chi^2(328)=0.01$	0.94
Other national guidelines than the ones from NBHW	15.4	9.0	12.2	$\chi^2(328)=3.13$	0.08
National recommendations on internet based support resources	1.2	4.2	2.7	$\chi^2(328)=2.73$	0.10
None	39.5	36.1	37.8	$\chi^2(328)=0.39$	0.53

Table 1 Demographic and work related characteristics

Impression of patient care

The first set of questions aimed to illustrate the patient care as seen by the participating physicians by examining four aspects. The first three aspects described the three ethical principles without naming the origin, in order to get a first insight without asking for special knowledge of priority setting or presuming it. The fourth aspect was a summarizing statement; firstly 'All patients are equally treated', secondly 'All resources are distributed according to patients' need', thirdly 'All decisions are made in consideration of costs in relation to patients' need' and fourthly 'All patient care is optimal'. An overview of the responses by 'group 1' and 'group 2' is given in box plots in Figure 3 and 4. The exact results as well as the results of the χ^2 -test and p-value are shown in Figures 35 - 38 in the appendices. What stands out right away in both box plots is the same gradation of aspect one to three, one as highest and three as lowest. Aspect four is weighted in between aspect two and three.

The responses to each aspect compared between the two groups were only in case of aspect three related and no significant difference was found, χ^2 (df=5, N=328) = 4.234, p = .375. For all other aspects the p-value was < .05 and thereby the test was significant and the responses seem to be rather different between both groups. But both groups had the same median for each aspect. Most physicians had the impression that all patients were 'very often' treated equally ('group 1': 58.0%; 'group 2': 47.6%), that all resources were 'often' distributed according to patients' need ('group 1': 48.1%; 'group 2': 45.2%), that all decisions were 'somewhat' to 'often' made in consideration of costs in relation to patients' benefit ('group 1': 70.4%; 'group 2': 73.5%) and all patient care were 'often' optimal ('group 1': 55.6%; 'group 2': 42.2%).

Results

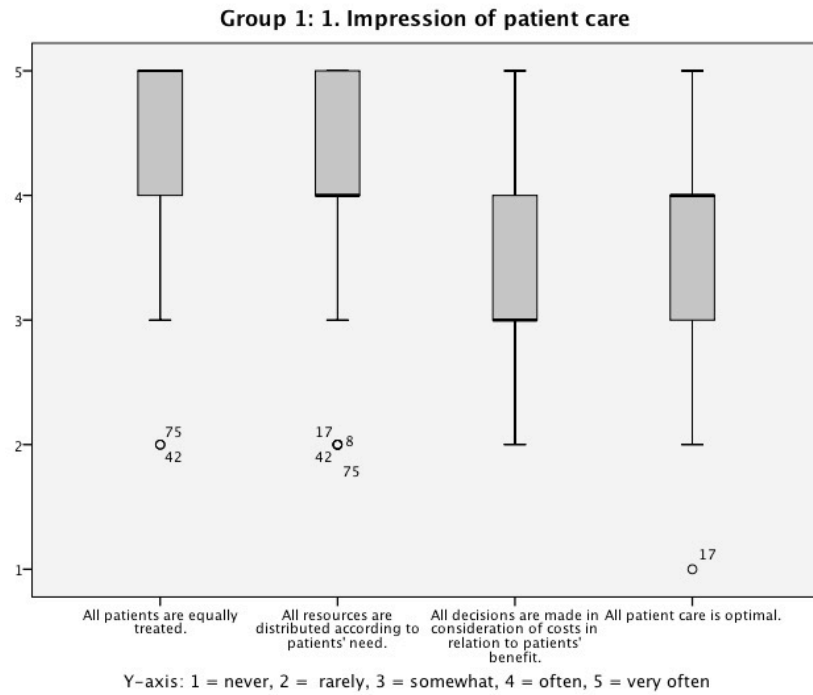


Figure 3 1. Impression of patient care box plots Questions 1-4 'group 1'

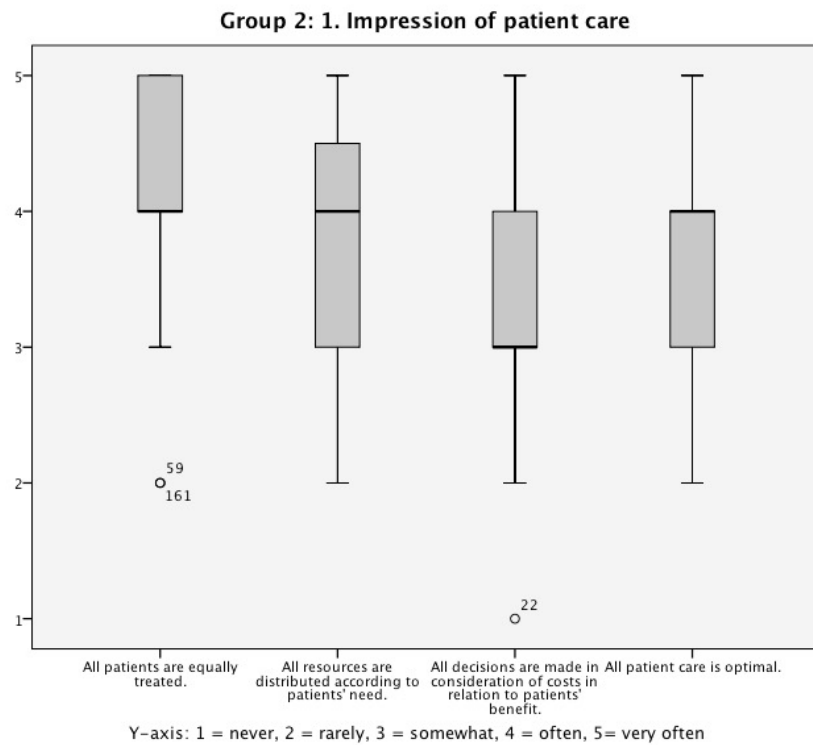


Figure 4 1. Impression of patient care box plots Questions 1-4 'group 2'

Resources in clinical work

The second group of questions examined the availability of clinical resources as well as the handling of scarcity of resources. Figure 5 shows the occurrence of scarcity of resources in physicians' clinical work during the last six months when answering the questionnaire. Response frequencies were widely spread from 'at least once per day' to 'until now never'. Most physicians faced scarcity of resources more often than 'at least once per month' ('group 1': 61.1%; 'group 2': 56.7%). In both groups no significant differences were found, χ^2 (df=5, N=328) = 8.707, $p = .069$.

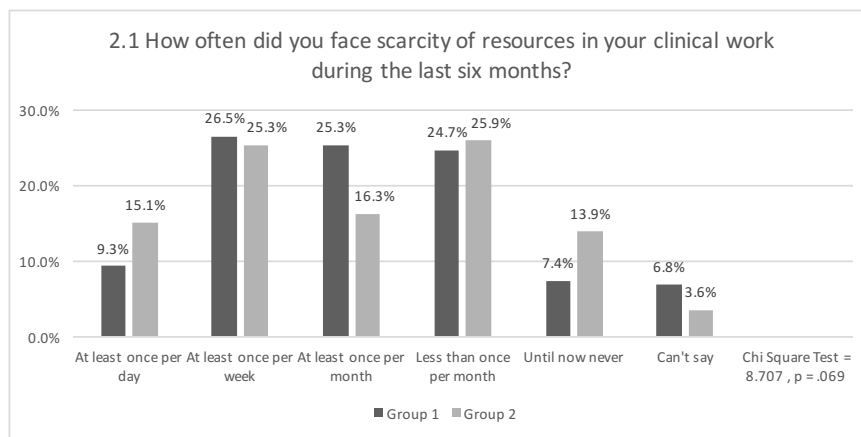


Figure 5 2. Resources in clinical work Question 1

As shown in figure 6, scarcity of resources rarely or never led to a non-prescription or non-performance of a diagnostic or therapeutic measure during the last six months before data gathering. There were no significant differences between the two groups: χ^2 (df=5, N=328) = 4.562, $p = .335$. Nearly half of all physicians had 'until now never' denied a clinical measure ('group 1': 45.1%; 'group 2': 41.0%) and about one third 'less than once per month' ('group 1': 29.6%; 'group 2': 37.3%).

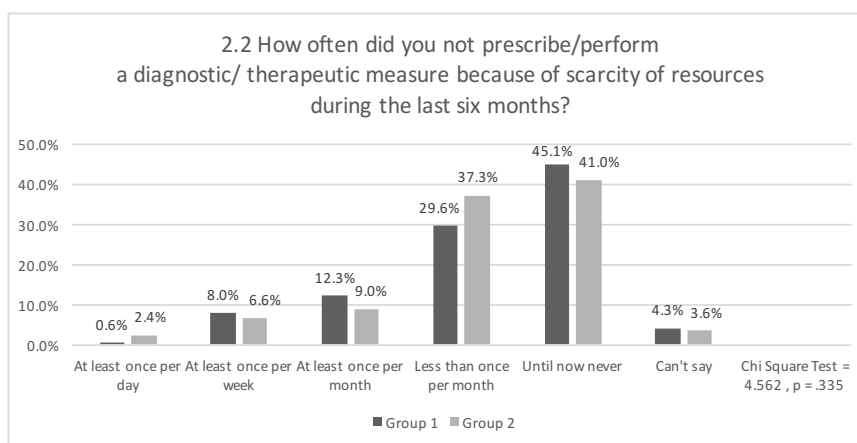


Figure 6 2. Resources in clinical work Question 2

Results

When it comes to handling strategies of scarcity of resources the four most important handling strategies were the same for both groups: discussing with colleagues ('group 1': 75.9%; 'group 2': 63.9%), discussing with superiors ('group 1': 56.8%; 'group 2': 47.0%), putting patients on a waiting list ('group 1': 35.8%; 'group 2': 31.3%), and talking to the patient about it ('group 1': 34.0%; 'group 2': 31.3%) (see following Figure 7, single χ^2 -test results and p-values in Table 4 in the appendices). Cardiologists, in contrast to the mixed group of physicians, referred significantly more often to the national guidelines ('group 1': 14.8%; 'group 2': 27.7%), χ^2 (df=1, N=328) = 8.123, p = .004, and the ethical platform ('group 1': 4.3%; 'group 2': 13.9%), χ^2 (df=1, N=328) = 8.969, p = .003. Recommendations to private health insurances played almost no role at all ('group 1': 0.6%; 'group 2': 3.0%).

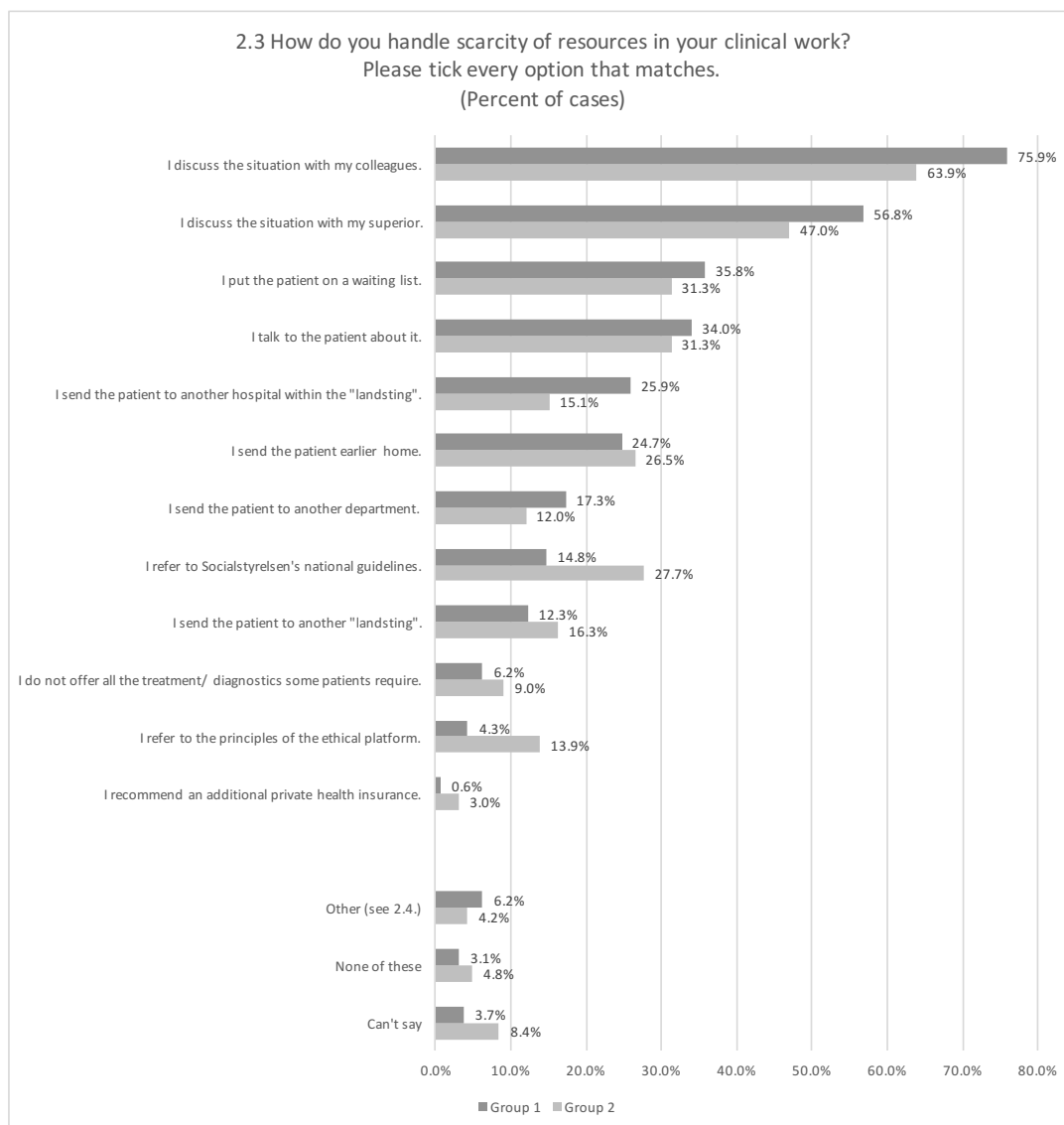


Figure 7 2. Resources in clinical work Question 3

Physicians also identified additional ways to handle scarcity of resources in free text responses. The statements were categorised into five sections: 'Other ways to handle scarcity of resources', 'Examples/experiences', 'Causes of scarcity of resources', 'Others' and 'Comments which correspond with a response option already chosen in 2.3'. They can be found in the appendices (3. Resources in clinical work). Further handling strategies included 'continuous improvements', 'work more efficient' and 'rule out obsolete treatment options'. As consequence physicians expressed 'frustration' and 'cynicism'. Physicians of 'group 1' described usage of computed tomography instead of magnetic resonance imaging and a 'grey-zone' of decision making. Physicians of 'group 2' raised the question of the 'definition of scarcity' as well as mentioned 'there will always be a wish for more resources'. Regarding causes of scarcity of resources, a lot of physicians stated 'lack of beds' or 'shortage of ward-places'. One physician wrote that he/she is doing often 'work that other members of the staff should have done'.

Physicians in both groups were neither rather well nor rather little personally prepared to handle scarcity of resources. Figure 8 presents the response distribution and shows that the median in both groups was 'somewhat'. Most physicians felt less than 'well' prepared to handle scarcity of resources ('group 1': 59.2%; 'group 2': 60.2%).

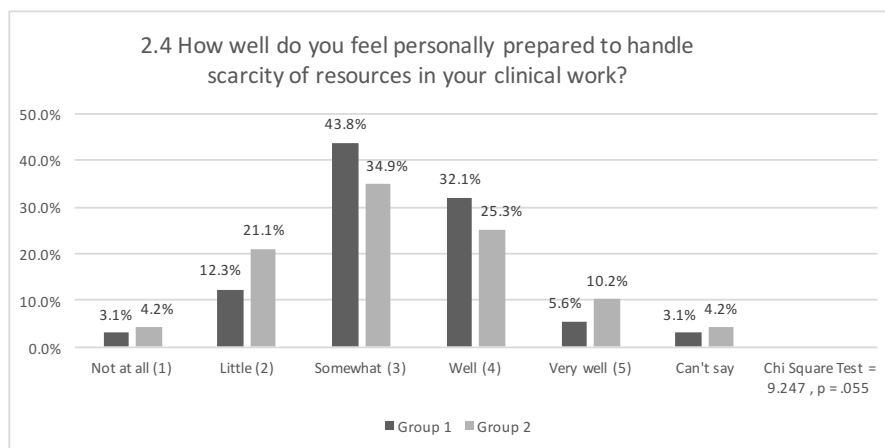


Figure 8 2. Resources in clinical work Question 4

Figure 9 provides similar frequency distributions for the question whether physicians thought that resources were wasted in their hospital, the median answer was 'somewhat' ('group 1': 48.1%; 'group 2': 33.7%) and almost half of them thought resources were being wasted 'often' or 'very often' ('group 1': 37.1%; 'group 2': 48.2%).

Results

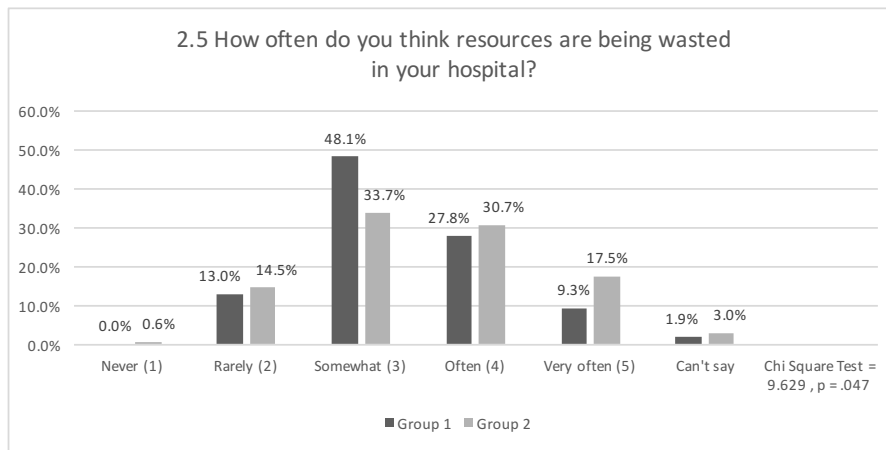


Figure 9 2. Resources in clinical work Question 5

Circumstances of clinical decision making

Regarding the frequency of making independent clinical decisions according to their own assessment without being limited, 88.9% of physicians from Örebro and 83.2% cardiologists from all of Sweden answered 'often' or 'very often'. Only single physicians chose 'rarely' and 'can't say' and nobody chose the alternative 'never'. No significant difference were found between the two samples: χ^2 (df=5, N=328) = 4.308, p = .230, see figure 10.

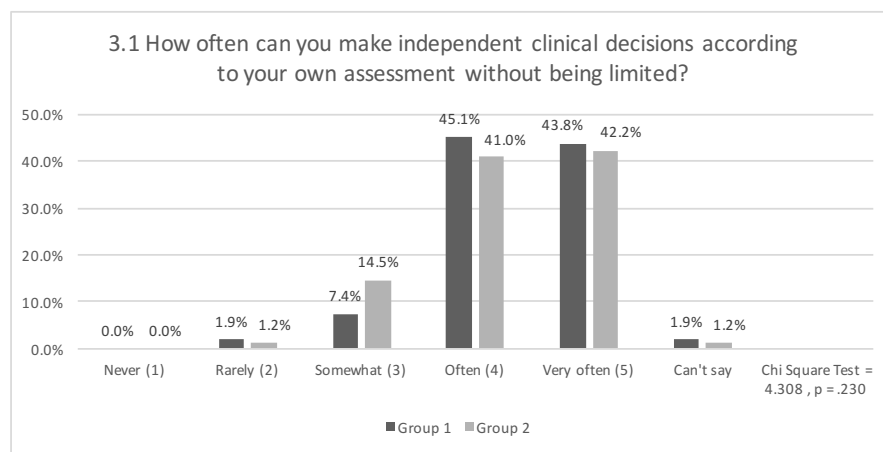


Figure 10 3. Circumstances of clinical decision making Question 1

From a list of thirteen different factors, which could limit the physicians' choices of diagnostic and therapeutic options in their clinical decision making, physicians from both groups agreed that the most important factor is a 'local lack of staff per patient' ('group 1': 52.5%; 'group 2': 38.6%). However, significantly more physicians in Örebro (52.5%) identified a 'lack of staff' as a limiting factor as cardiologists (38.6%): χ^2 (df=1, N=328) = 6.404, p = .011. Other frequently selected, over 15%, limiting factors included for both groups 'political

directives (for example 'guaranty of care' or 'standardisation of care processes'), 'local lack of diagnostic/therapeutic resources', 'administrative & bureaucratic tasks', 'local clinical guidelines', and 'Socialstyrelsen's national guidelines and their follow up'. As important as these ones was the factor 'regional medication and device recommendations' for 22.7% of cardiologists. The factors with the lowest influence on physicians' decisions were 'economic incentives to undertreat' ('group 1': 3.7%; 'group 2': 10.2%) and 'economic incentives to overtreat' ('group 1': 0.6%; 'group 2': 4.2%). Notable is that 'incentives to overtreat' were slightly less known than 'incentives to undertreat' and in comparison both were less known in Örebro than of cardiologists in Sweden, in case of undertreating χ^2 (df=1, N=328) = 5.374, $p = .020$, in case of overtreating χ^2 (df=1, N=328) = 4.464, $p=.035$. (See following Figure 11 and Table 5 in the appendices)

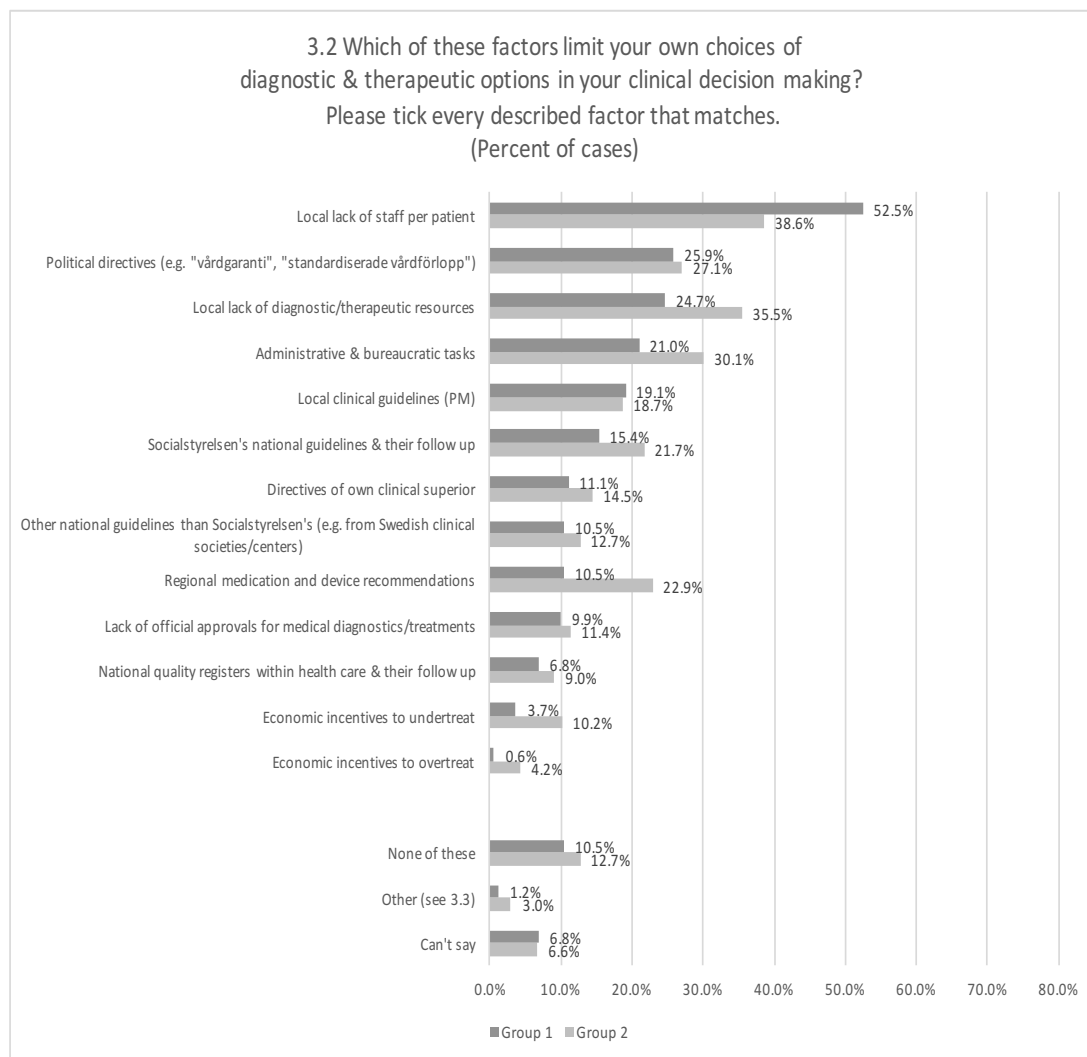


Figure 11 3. Circumstances of clinical decision making Question 2

Physicians identified additional limiting factors in free text responses, question 3.3, including 'lack of beds', 'clinical judgement', 'different opinions between doctors', 'insufficient reimbursement systems' and 'people without Swedish personal number'. Furthermore, several physicians stated that they rather feel supported and not limited by the factors named in question 3.2. – 'many of the above not limiting but rather giving strength to make medical correct decisions', 'I do not think the guidelines limit my choices, rather help me to use resources in an evidence-based way' or 'I do not feel limited by all guidelines. I use them if I want as a resource'. Two other limiting factors were named, an inadequate functioning 'operation planning program' as well as 'political decisions, which are not to the advantage of our health care'. All comments can be found in the appendices (see section 4. Circumstances of clinical decision making)

Importance of different factors in clinical decision making

In relation to importance of different factors in clinical decision making, the three most commonly identified factors were 'your own medical assessment' (very much & much - 'group 1': 93.2%; 'group 2': 94.6%), 'guidelines in general' (very much & much - 'group 1': 86.4%; 'group 2': 89.2 %), and 'a colleague's medical assessment' (very much & much - 'group 1': 59.3%; 'group 2': 54.3%). For 'group 1' followed on rank four 'a superior's medical assessment', on rank five 'a patient's preference/wish' and on rank six 'costs in relation to patients' benefit (cost-effectiveness-ratios)'. For 'group 2' these three factors were also on rank four to six but in another order, rank four was 'a patient's preference/wish', rank five 'costs in relation to patients' benefit (cost-effectiveness-ratios)' and rank six 'a superior's medical assessment'. Rank seven to nine were again the same for both groups, 'your sympathy for a patient' followed by 'costs for the hospital' and 'costs for the patients'.

Besides the once more occurring concordance of both groups, it stands out that the participating physicians assessed, after their 'own medical assessment', 'guidelines in general' to have the second most influence on their decision making and that costs have only little influence on them. See the following Figure 12 and 13 and in the appendices Table 6 and 7. The median and a calculated rank as well as exact frequencies of both groups can be found. Besides the median the rank considered also the mean, even if one should not use the mean directly because of the categorical response scale.

Results

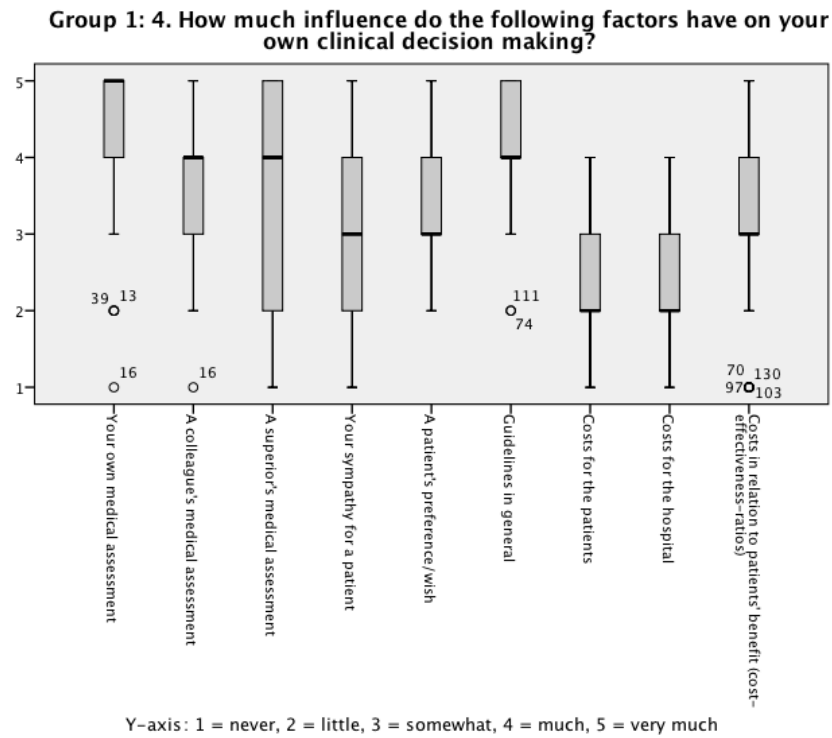


Figure 12 4. Importance of different factors in clinical decision making box plots Questions 1-9 'group 1'

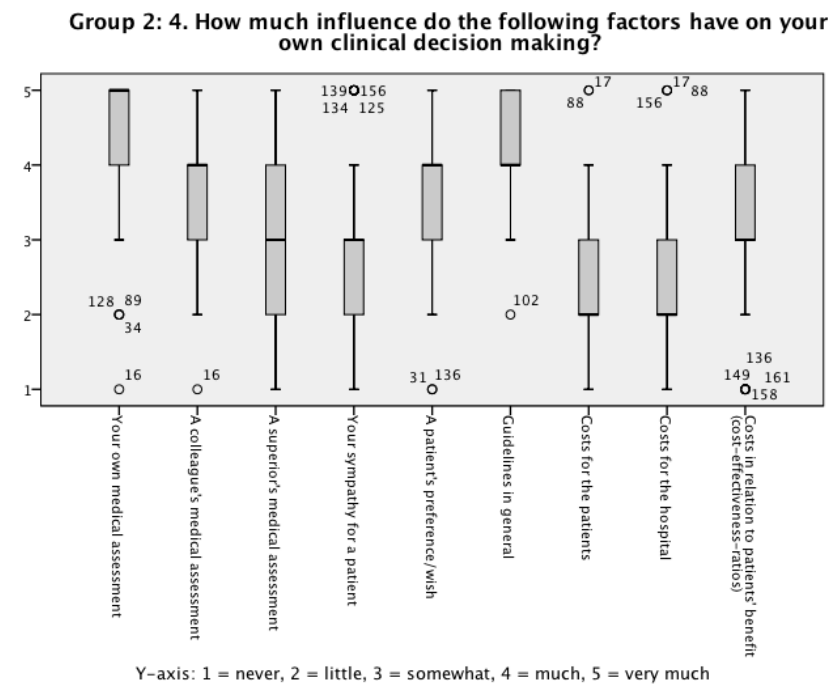


Figure 13 4. Importance of different factors in clinical decision making box plots Question 1-9 'group 2'

Importance of different sources of information in clinical decision making

Regarding the importance of different sources of information in clinical decision making, the results of both groups varied. For physicians from Örebro the most important source of information was 'local clinical guidelines' (very much & much - 'group 1': 77.8%), followed by 'other national clinical guidelines/recommendations than Socialstyrelsen's' (very much & much - 'group 1': 69.1%), and 'Socialstyrelsen's national guidelines' (very much & much - 'group 1': 66.7%). Less important for them were from rank four to seven: 'European clinical guidelines' (very much & much - 'group 1': 43.2%), 'national internet based support resources' (very much & much - 'group 1': 36.4%), 'American clinical guidelines' (very much & much - 'group 1': 22.9%) and 'international internet base support resources' (very much & much - 'group 1': 26.6%).

Whereas for cardiologists, the most important sources of information were firstly 'European clinical guidelines' (very much & much - 'group 2': 84.9%), secondly 'Socialstyrelsen's national guidelines' (very much & much - 'group 2': 68.7%), thirdly 'local clinical guidelines' (very much & much - 'group 2': 68.7%), fourthly 'other national clinical guidelines/recommendations than Socialstyrelsen's' (very much & much - 'group 2': 64.5%), fifthly 'American clinical guidelines' (very much & much - 'group 2': 29.5%), and sixthly 'national internet based support resources' (very much & much - 'group 2': 34.4%). Only the seventh rank was the same in both groups, 'international internet base support resources' (very much & much - 'group 2': 26.6%). (Figure 39 and 40, Table 8 and 9 in the appendices)

Ethical platform of Swedish priority setting

With regards to physicians' knowledge and assessment of the ethical platform containing the three ethical principles, no significant differences between the groups were found, χ^2 (df=5, N=328) varied between 0.718 and 3.135 with p between .426 and .949. Exact numbers are shown in Figure 14 to 16. The knowledge of the ethical platform varied from 'not at all' to 'very much' (figure 14). The median was 'somewhat', in both groups about one third chose this category ('group 1': 30.1%; 'group 2': 33.3%).

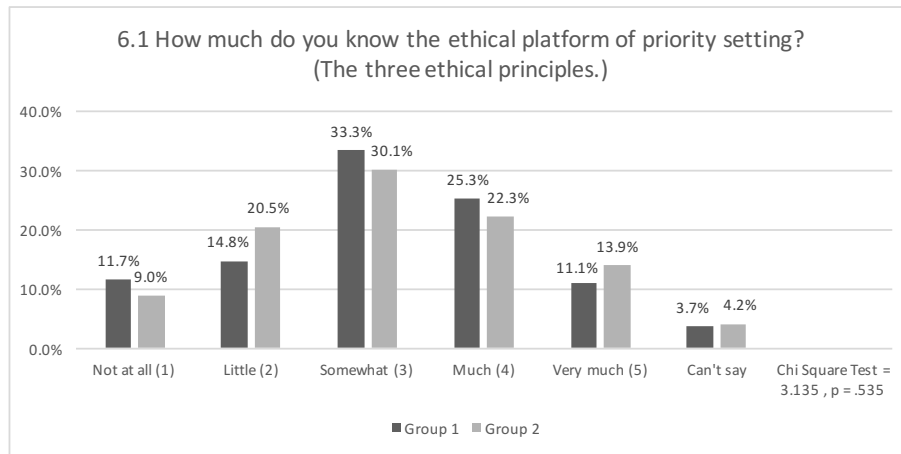


Figure 14 6. Ethical platform of Swedish priority setting Question 1

When comparing the results regarding the physicians' assessments of the helpfulness of the ethical platform regarding their own clinical work as well as the Swedish health care, Figure 15 and 16, the median is 'somewhat' in case of their own clinical work and 'much' in case of the Swedish health care. In both cases the median is characterised by both groups by a frequency of 36 to 41%. The starting point and endpoint 'not at all' and 'very much' were chosen by about 5% in cases of their own clinical work. Regarding Swedish health care only single physicians, about 1 to 3%, chose 'not at all'. For both questions no significant difference between both groups could be found, χ^2 (df=5, N=328) = 0.718, p = .949 and χ^2 (df=5, N=328) = 3.854, p = .426.

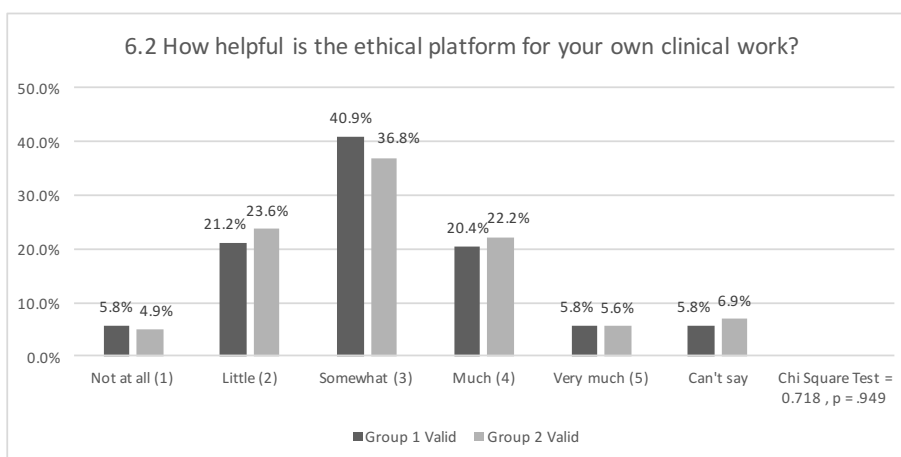


Figure 15 6. Ethical platform of Swedish priority setting Question 2

Results

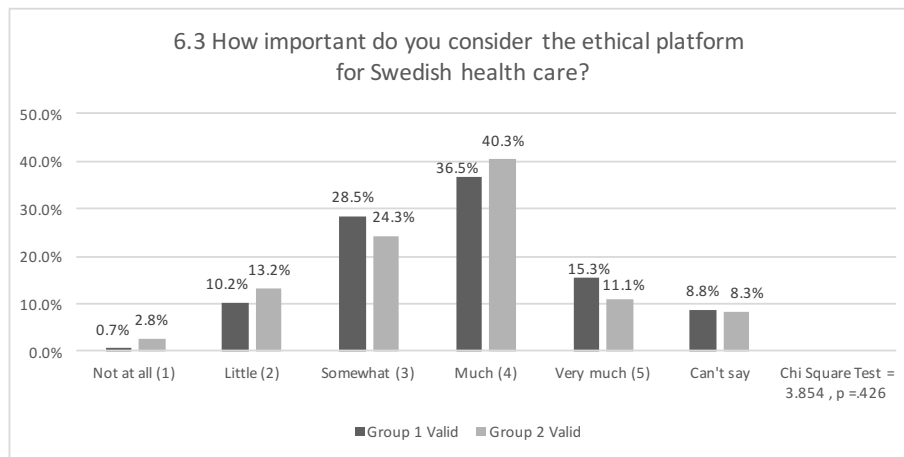


Figure 16 6. Ethical platform of Swedish priority setting Question 3

Socialstyrelsen's national guidelines

Regarding knowledge of national guidelines, more physicians in 'group 2' – the cardiologists- knew more about national guidelines than in 'group 1' – the mixed group of Örebro. 75.3% of 'group 2' towards only 40.6% of 'group 1' knew 'much' or 'very much' of the national guidelines. 11.1% of 'group 1' chose the option 'can't say'. Frequencies varied between both groups and a significant difference was shown, χ^2 (df=5, N=328) = 33.096, $p < .000$. Further frequency distributions are shown in the following Figure 17.

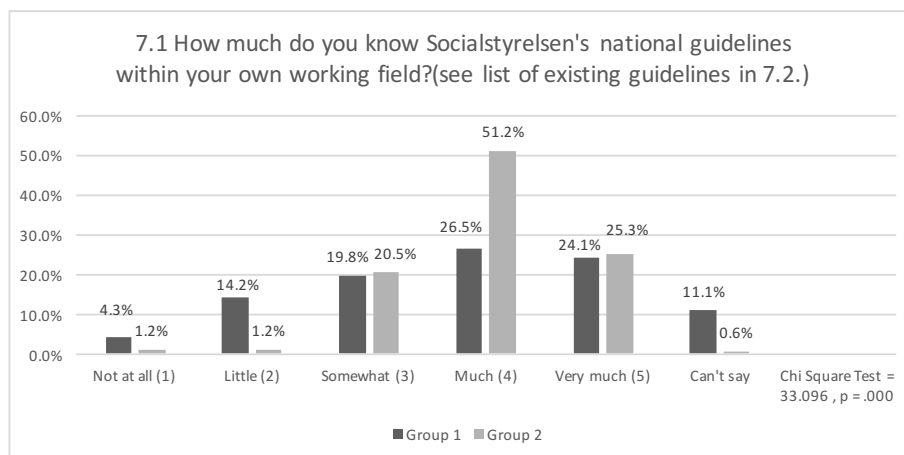


Figure 17 7. Socialstyrelsen's national guidelines Question 1

The clinical work of physicians of 'group 1' were mostly concerned by the national guideline for breast-, prostate- & colorectal cancer, followed by cardiac care, palliative care, depression and anxiety, stroke, lung cancer, asthma/COPD and abuse and addiction. The clinical work of 'group 2' was mostly concerned by the national guideline of cardiac care, followed by diabetes, stroke, methods of preventing diseases, asthma/COPD and palliative

care. These distributions are in accord with the proportion of the departments of the participating physicians. All named national guidelines showed frequencies above 12%, more details can be found in Table 10 and 11 as well as a Figure 41 in the appendices.

Being asked for the helpfulness for their clinical work as well as the importance for the Swedish health care of national guidelines physicians of both groups seem to be align, similar to these questions concerning the ethical platform, no significant difference between both groups could be found, χ^2 (df=5, N=328) = 6.664, p = .155 and χ^2 (df=5, N=328) = 2.927, p = .570. Most of the physicians assessed national guidelines as 'somewhat' as well as 'much' important (in total 'group 1': 66.4%; 'group 2': 78%) for their own clinical work, whereas for the Swedish health care they mostly assessed them as 'much' important ('group 1': 43.8%; 'group 2': 52.1%). Further frequencies can be found in the following figures 18 and 19.

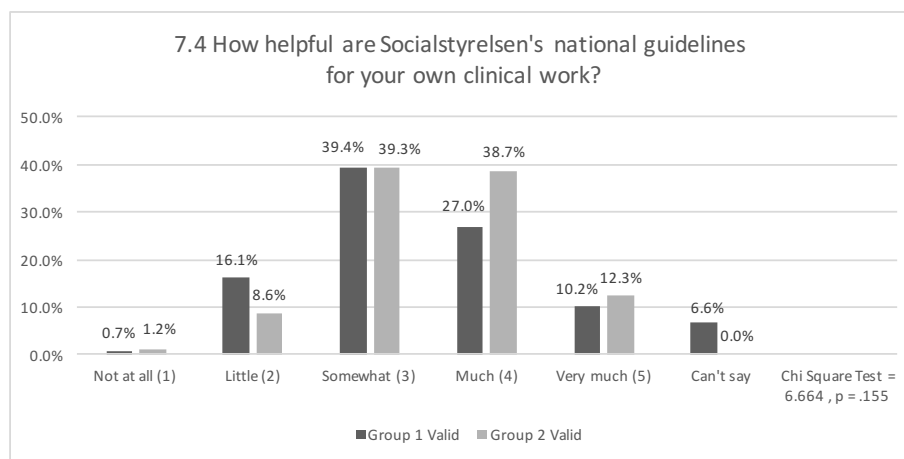


Figure 18 7. Socialstyrelsen's national guidelines Question 4

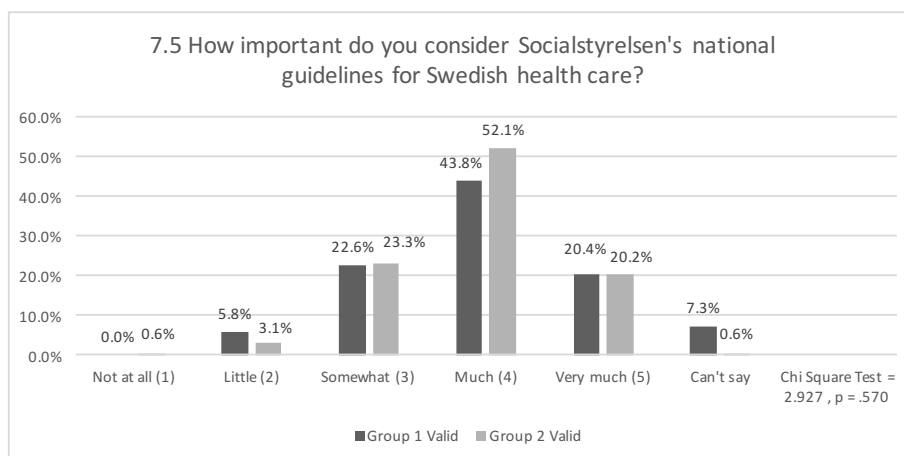


Figure 19 7. Socialstyrelsen's national guidelines Question 5

The remaining four questions of question group seven concerning national guidelines were more specific. The response frequency for the option 'can't say' was notably higher in 'group 1' for these questions than for other questions before and also compared to 'group 2'. This goes along with the result that physicians in 'group 1' knew the guidelines less well than physicians in 'group 2'. Up-to-dateness was perceived mostly as 'somewhat' and 'much' ('group 1': 59.1%; 'group 2': 84.2%), trustfulness as 'much' ('group 1': 51.1%; 'group 2': 47.9%), influence by economic interests as 'little' and 'somewhat' ('group 1': 62.8%; 'group 2': 61.3%). More numbers as well as the results of the Chi Square tests can be found in the Figure 20 - 22.

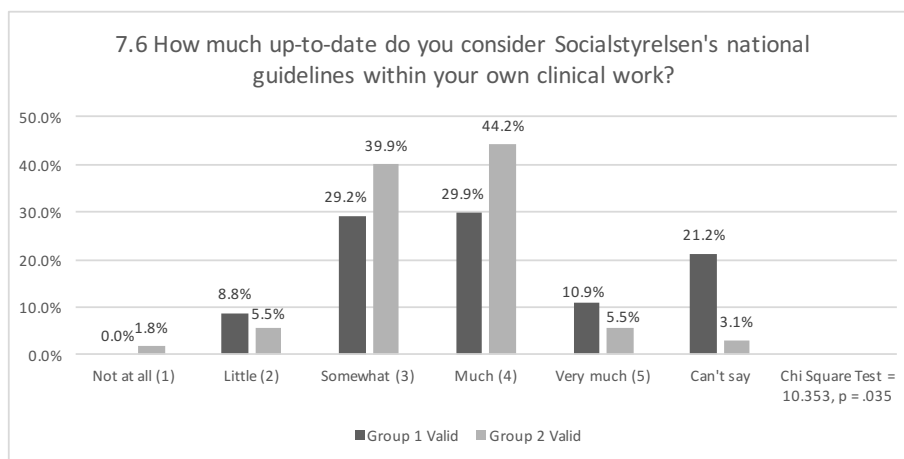


Figure 20 7. Socialstyrelsen's national guidelines Question 6

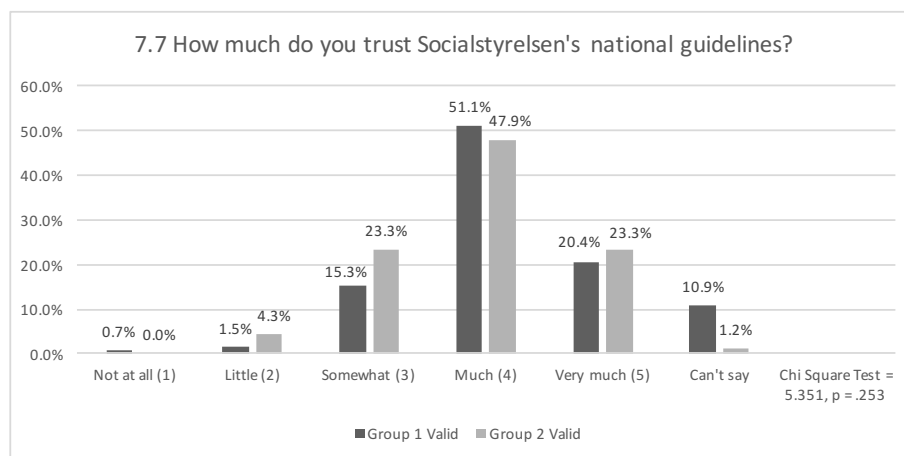


Figure 21 7. Socialstyrelsen's national guidelines Question 7

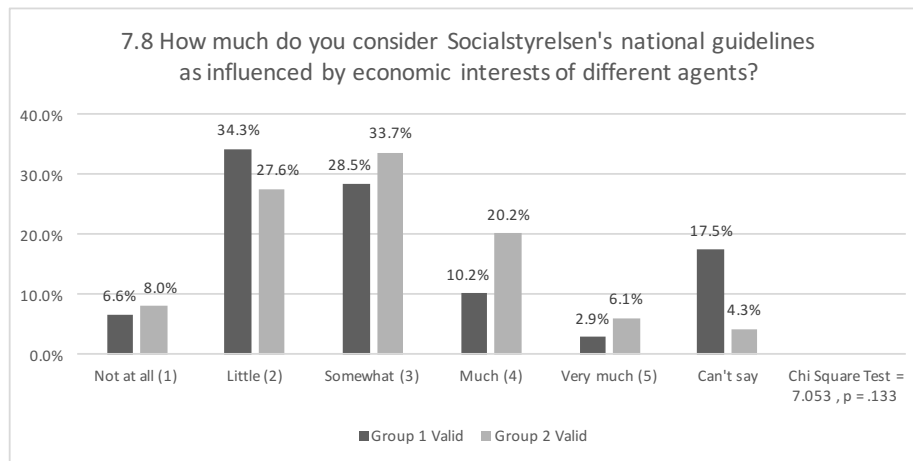


Figure 22 7. Socialstyrelsen's national guidelines Question 8

The last question of this section asked for the aspects in which physicians considered the national guidelines to be helpful. Both groups seem to be in accord with all the proposed aspects except for the aspect 'priority setting of clinical measures in times of scarcity of resources', χ^2 (df=5, N=328) = 7.116, p = .008. 'group 2' experienced the national guidelines for this aspect as more important ('group 1': 38.0%; 'group 2': 53.4%). For 'group 1' the most important aspect was 'improvement of equity of patients in health care' (54.0%), followed by 'improvement of quality of patient care' (50.4%) and 'writing local guidelines' (46.7%). For 'group 2' the most important aspect was 'priority setting of clinical measures in times of scarcity of resources' (53.4%), followed by 'improvement of quality of patient care' (52.8%) and 'improvement of equity of patients in health care' (49.7%). Frequencies for all named aspects are listed in the following figure 23. The aspects, which stand for the three principles of the ethical platform, are ranked according to their ranking within the ethical platform. Aspects as 'health care politics' ('group 1': 31.4%; 'group 2': 33.7%) and 'hospital management' ('group 1': 24.1%; 'group 2': 23.9%) are ranked low. About one third assessed the national guidelines as helpful in 'every clinical decision for which there is information in them' ('group 1': 27.7%; 'group 2': 29.4%). All information is shown in Figure 23 and in the appendix Table 12.

Results

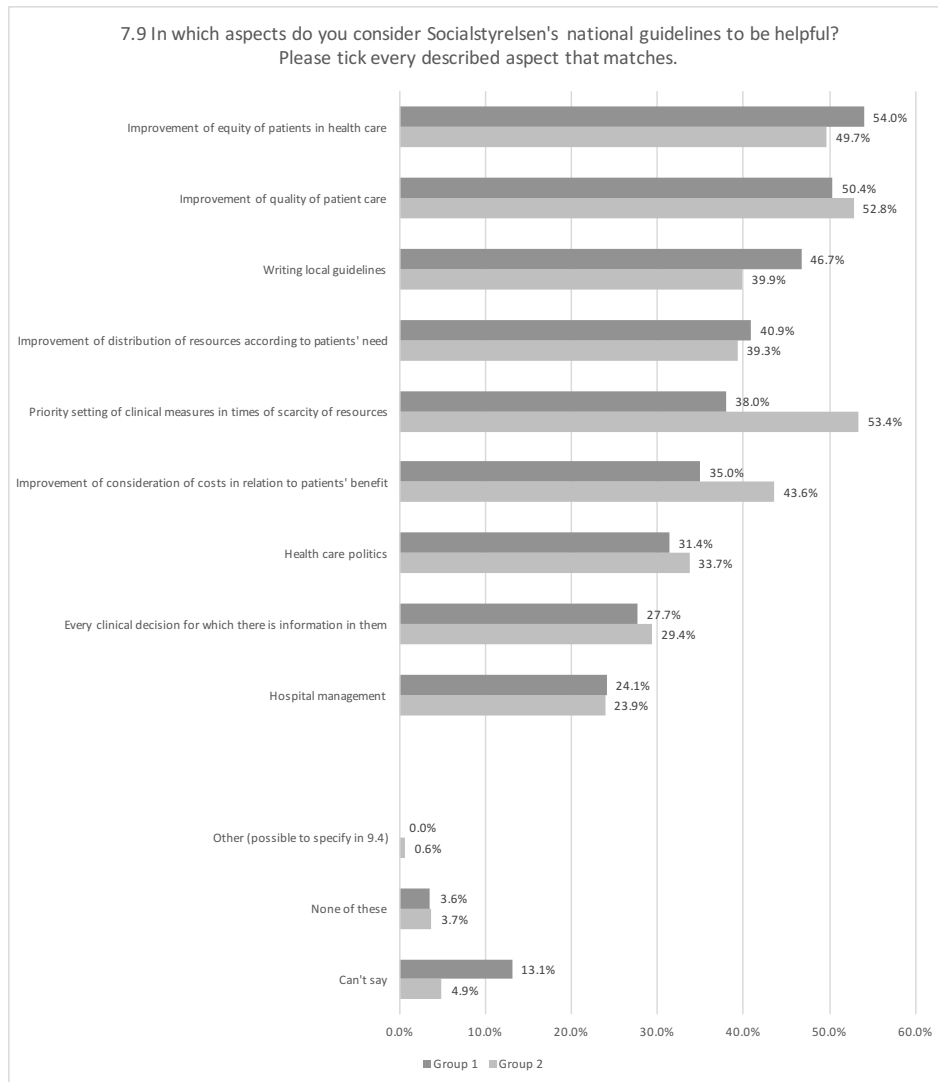


Figure 23 7. Socialstyrelsen's national guidelines Question 9

Application of Socialstyrelsen's national guidelines

Concerning the application of the national guidelines, the questions were even more specific than the previous ones. The frequencies for 'can't say' reached from 37.2% to 50% for 'group one'. Answers of 'group one' are thereby rather not representative. At first physicians were asked for an assessment of the approximate number of their patients that were covered by recommendations in the national guidelines.

For 'group 1' the mean was 61.47, standard deviation 28.178 and for 'group 2' the mean was 69.56, standard deviation 19.453. An independent samples t-test was conducted to compare the number of covered patients in both groups. There was a significant difference; $t(153.254) = -2.41$, $p = .017$ (Table 13 to 16 in the appendices). The number of covered patients

for 'group 2' seems to be significantly higher. The next question asked for an approximate estimation of the number of patients, which needed to be excluded from application of the recommendations due to criteria like severe frailty or multi morbidity. For 'group 1' the mean was 21.68, standard deviation 18.451. For 'group 2' the mean was 24.11, standard deviation 18.704. The independent samples t-test was not significant and implies that there seems to be no difference between both groups, $t(214)=-0.93$, $p=.353$.

When asked how much they agreed with the priority setting rankings (1-10, "icke-göra", "FOU") for the guidelines within their working field most physicians answered 'much' ('group 1': 38.7%; 'group 2': 47.9%). Within 'group 2' the other half was divided between 'somewhat' (22.7%) and 'very much' (20.9%). (See Figure 24)

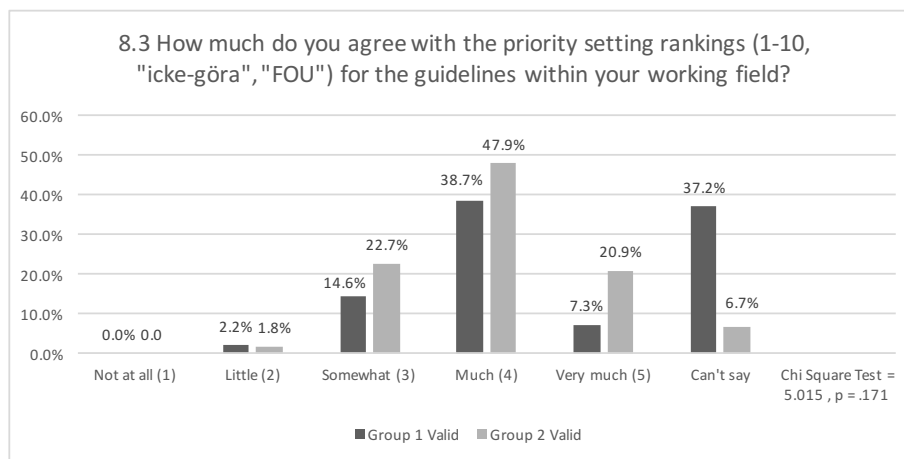


Figure 24 8. Application of Socialstyrelsen's national guidelines Question 3

Regarding the possible consequence of a lower quality of care for single patients due to a total prohibition of measures within "icke-göra" and "FOU" physicians estimated the frequency mostly as 'rarely' ('group 1': 24.8%; 'group 2': 41.7%) and 'somewhat' ('group 1': 27.0%; 'group 2': 25.8%). (See figure 25)

Results

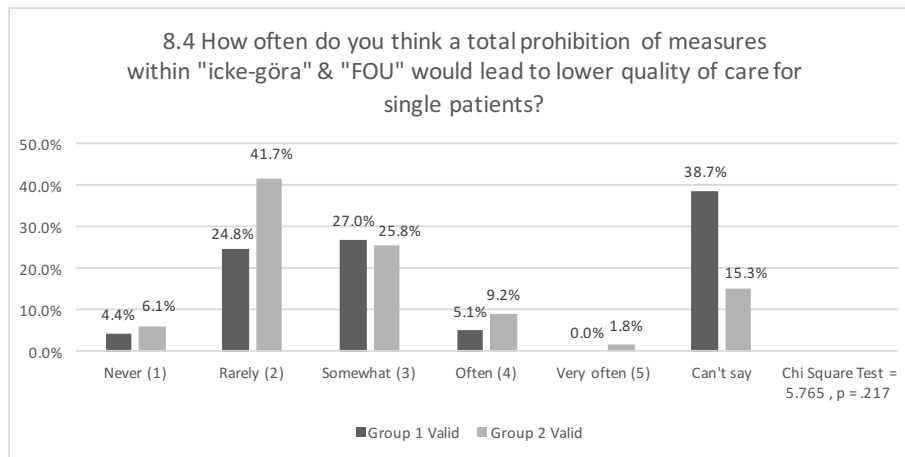


Figure 25 8. Application of Socialstyrelsen's national guidelines Question 4

The questioned physicians mostly stated that they could prescribe measures of lower priority grades (about eight to ten) to their patients without obstacles ('group 1': 49.6%; 'group 2': 55.2%), only a smaller part denied it ('group 1': 8.0%; 'group 2': 19.6%). By contrast in case of measure of 'icke-göra' and 'FOU' a larger proportion, especially within 'group 2' said no, they could not prescribe measures of these categories without obstacles ('group 1': 16.8%; 'group 2': 42.9%). About a third of the physicians stated that they could prescribe them ('group 1': 38.0%; 'group 2': 36.2%). (See Figure 26 and 27)

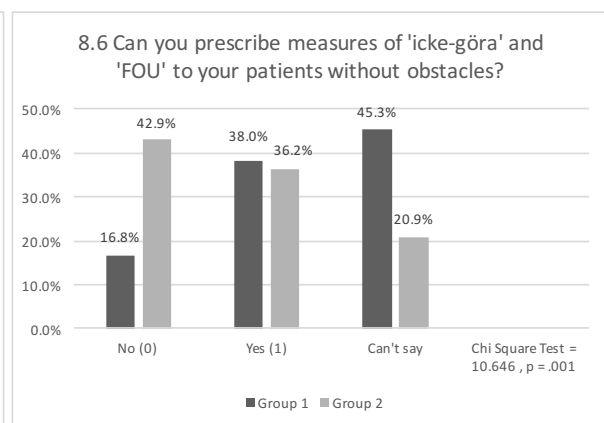
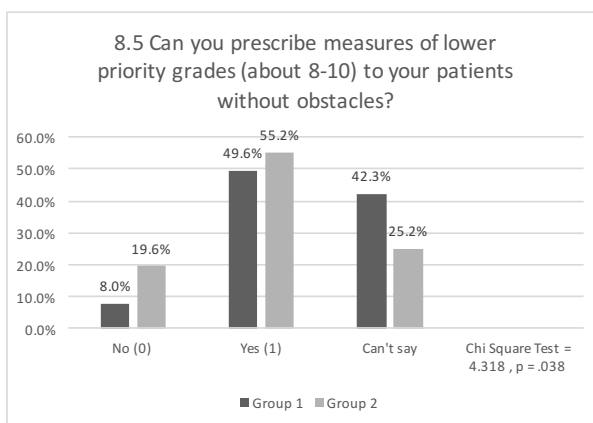


Figure 26 8. Application of S.'s national guidelines Question 5 Figure 27 8. Application of S.'s national guidelines Question 6

Potential wishes and comments

The very last two questions of the questionnaire aimed to take a look into the future. The physicians were asked whether they would like to obtain further training in the ethical platform and the application of the national guidelines. More than half of all participants reported that they would like to have further knowledge and training regarding the ethical

platform ('group 1': 56.8%; 'group 2': 56.6%) as well as further support for the application of the national guidelines ('group 1': 50.6%; 'group 2': 51.8%). Slightly more physicians wished training in case of the ethical platform. There were no significant difference between the two samples: χ^2 (df=3, N=328) = 0.203, p = .652 and χ^2 (df=3, N=328) = 0.015, p = .902. (See Figure 28 and 29)

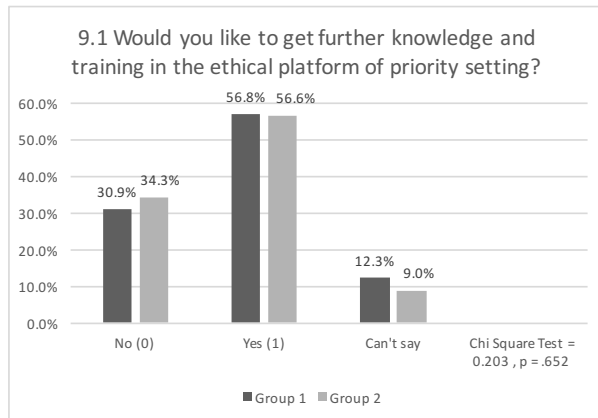


Figure 28 9. Final potential wishes and comments Question 1

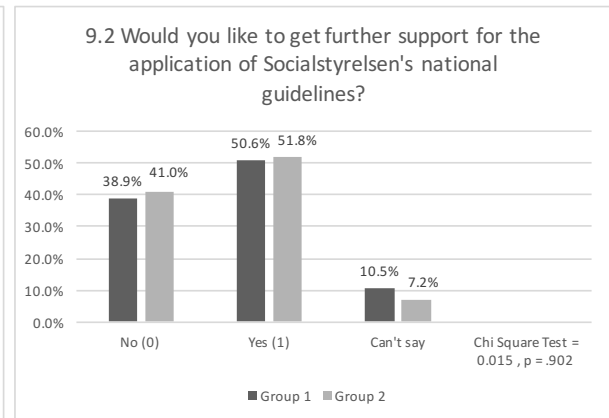


Figure 29 9. Final potential wishes and comments Question 2

Finally, all physicians had the possibility to write comments regarding the Swedish priority setting activities as well as the national guidelines. Comments for both questions were divided into three sections 'advantages' 'problems' and 'wishes/advices'. By several physicians the Swedish priority setting was seen positively, they describe it as 'worthwhile' and 'very good and especially as it follows the laws'. Many physicians stated problems regarding the up-to-dateness, 'always outdated'. Besides, few physicians described the challenge of horizontal prioritisation as 'difficult – impossible', 'very low prioritised are geriatrics care, dementia care, psychiatry and primary care. Other problems were the lack in some fields, 'not very developed for psychiatry', higher importance of other guidelines, 'from regional cancer centre', balance between different guidelines, the presentation, 'more on paper than in reality', the role of economy, 'economy plays a big role, and slow in adjusting to new studies' and the role of politicians, 'Priority setting should be made by the decision making politicians. However, they (...) fail to do this (...). If they had left it without restrictions/instructions to the medical profession it would have been fine. (...) However, there are number of restrictions (...). The politicians become the "de facto" decision makers without paying the blame for controversial issues'. An overall problem is the reduced actuality, 'the debate among doctors, health bureaucrats, media and politicians and thus level of knowledge and influence was higher some years ago'.

Wishes were to gain a 'deeper knowledge', to focus on 'user-friendly digital sources' and to introduce new methods in controlled clinical studies. Advices highlighted the importance of the topic, 'priority is very important and soon in the future impossible to avoid', 'early updates' as well as to 'broaden the expert committee. Not with GPs but with clinical expertise.' One physician specified 'We still have a long way to go before health care is delivered equal'.

Regarding the national guidelines in particular, advantages of them were described as 'support with which I can explain the situation to the patient, when the patient asks for something that is proven to be ineffective or wrong', 'useful for discontinuing practise', 'very wise that they take the economics into regard. The European and American guidelines are very cost rising (...)'. Named problems to this open-end question were alike to the problems named to the question above, they focus on the covered fields and the lacking up-to-dateness, 'important areas are not focused' and 'problems with continuous updates'. Moreover, the presentation is taken up again several times, like 'marketing is poor' and 'too much text'. Few physicians reminded of the controversial situation of population based recommendations versus individual based decisions. Advices and wishes took up the problems, 'needs to be updated more frequently', 'Socialstyrelsen should focus on fewer but important and high priced treatments', 'marketing to patients and relatives ought to be done' and 'new guidelines need to be sold on a wider basis, like 'obligatory' webinars or web based knowledge tests (...)'. All comments can be found in the appendices (10. Potential wishes and comments).

Discussion

The main objectives of this thesis are to enlighten the clinical physicians' perception of the national efforts on priority setting in Sweden, to understand their working situation in order to see the complexity and to draw conclusions for the future. The two main research questions are:

1. How do Swedish physicians experience their daily clinical conditions?
2. How are national priority setting efforts taken up by clinical physicians?

Therefore, two groups of physicians were questioned. 'Group one' consisted of 162 physicians of different departments within one university hospital. The response rate of 48.9% was good and similar to or better than in previous studies (Ridderstolpe, Collste et al. 2003, Ekerstad, Lofmark et al. 2010, Vårdanalys 2015). Within 'group two', 166 cardiologists in Sweden, the response rate was low with 18.0%. We can point out that the demographic composition was alike to the one of the society of Swedish cardiologists (Braunschweig 2015). In the following sections main findings to both research questions are highlighted, discussed and compared to other published findings. In addition, Germany's situation regarding clinical resource allocation and implications of our results as well as the limitations of the study are depicted.

Clinical care – patient care and resources

Concerning physicians' impression of patient care and their experiences of scarcity of resources, clinical care was 'often' or 'very often' perceived 'optimal' by the physicians ('group 1': 64.9%, 'group 2': 53.6%). Surprisingly their impression of patient care was according to the hierarchal gradation of the three principles of the ethical platform. Without assuming their knowledge of the principles or stating the origin of the statements, both groups perceived the treatment of patients rather as 'very often' equally, resource distribution as rather 'often' according to patients' need and consideration of costs in relation to patients' benefit in decision as rather 'somewhat' to 'often'. These results are encouraging and show that the relevance of the ethical principles have become apparent even in their gradation in clinical care. Still, the assessments of clinical care could be

expected to be even more positive. About one third in both groups experienced patient care only as 'somewhat' optimal.

Regarding resources in clinical work speaking about scarcity of resources is complicated as there will be on the one hand side always a need for more and on the other hand side the tendency to deny and neglect scarcity (Alexander, Werner et al. 2004, Strech, Synofzik et al. 2008). Open comments of participants like "Definition of Scarcity? There will always be a wish for more resources regardless of economic reality." or "Everything can't be done at once." (see appendices) showed how difficult a common understanding of scarcity was. The biggest issue of scarcity named in open comments was the lack of hospital beds, respective the closing of beds due to lack of staff. Actual rationing, described as not prescribing or performing a diagnostic or therapeutic measure during the last six months, occurred approximately for about 9% of Swedish physicians once a day or once a week ('group 1'= 8.6%, 'group 2'= 9%) and for about 44% once a month or even less ('group 1'= 41.9, 'group 2'= 46.3%). In comparison, 13% of German physicians within intensive care units and cardiology rationed once a day or once a week and 64% once a month or even less (Strech, Danis et al. 2009). Physicians from Great Britain, Italy, Norway and Switzerland being asked the same questions rationed at a percentage of 15% once a day or once a week and 41.3% once a month or even less (Hurst, Slowther et al. 2006). These numbers suggest that Swedish physicians ration slightly less often than colleagues in Europe. Do they ration less because they have the national guidelines or despite having them? The Swedish efforts of priority setting could be seen as support in "muddling through elegantly", doing it "elegantly", neither being dictated explicit rationing nor being left alone with decisions in order to ration implicit (Hunter 1995).

Many handling strategies identified by physicians focused on communication, with discussions with colleagues and superiors being identified as most important for about by half to three quarter of the physicians. While about a third of physicians reported talking to the patients about it, about a quarter reported sending patients home earlier, and a minority reported 'not offer all the treatment/diagnostic some patients required'. This supported physicians' view regarding the rarity of rationing. Only 14% of physicians thought that resources were wasted in their hospital 'never' or 'rarely', which indicates a potential for

rationalism. Overall, the physicians wanted more assistance regarding such decisions, 60% of participants stating that they felt less than 'well' ('not at all', 'little' or 'somewhat') prepared to handle scarcity of resources.

Regarding the discussion of scarcity in health care, unpleasant consequences of some political directives and consequences of scarcity need to be kept in mind; naming for example the queue billion in 2005, favouring some patient groups while blinding out others as well as the expansion of administrative and economical structures while minimising professional ethics (Jansson, Nitz et al. 2013, Makdessi and Halmin 2013, Hansson 2014). As waiting times for patients exceeded up to eight to 16 hours, extra money for county councils was promoted reducing waiting time of first contacts. As a consequence, waiting times for return visits got extended and wrong patients were prioritised. Public debates raised and many physicians stressed the intolerant situations in the hospital. The Swedish Medical Association, the Swedish Teachers' Union and the Swedish Police Union published an article where they claimed: "Reliance on professional responsibility has been replaced by a control system that risks leaving professional ethics aside and threatens the basic human qualities of the work to be done." (Jansson, Nitz et al. 2013). Further physicians published a second appeal stating: "Production-centred healthcare puts our professional ethics at risk. According to medical ethics the principles of need and human value should always have priority. Today's system is ruled by the principle of cost-efficiency. (...) Where politicians relish shortened queues to healthcare we see how chronically ill patients are displaced by patients with minor ailments. Where politicians require shorter completion times in emergency departments we see how patient safety is threatened. Where politicians see efficiency improvements, we see lack of hospital beds (...). Where politicians see shortened hospital stays as efficiency gains we are worried by increased number of readmissions and complications. (...) We want a healthcare governed by the patient's needs (...) where we can act according to our professional competence." (Makdessi and Halmin 2013).

These perceptions of time-taking administrative control burdens, political incentives, focus on economy, loss of professional responsibility and quality of care may be explanations for the potential gap of improving the situation as identified by the participants in this study. In contrast to the second appeal, participants in our study did not seem to agree that actual

decisions in health care were primarily made due to cost-efficiency reasons, but rather of patients' need and their equality. The following group of questions examined the described loss of professional responsibility and medical ethics.

Clinical decision making

Independence in decision making seemed to exist to a great extent. In contrast to the expression of the feeling of limitation in the two appeals named in the section above (Jansson, Nitz et al. 2013, Makdessi and Halmin 2013), in our study a vast majority of physicians of both groups reported that they were 'often' or 'very often' able to make independent decisions according to their own assessment without limitations ('group 1'= 88.9% , 'group 2'= 83.2%). Only about 20% of Swedish physicians identified guidelines as limiting ('local clinical guidelines' - 'group 1': 19.1%, 'group 2': 18.7%; and 'Socialstyrelsen's national guidelines and their follow up' - 'group 1': 15.4%, 'group 2': 21.7%). Physicians expressed conflicting opinions regarding these issues in the open comments: 'I do not think the guidelines limit my choices rather help me' or 'I do not feel limited by all guidelines. I use them if I want as a resource' (see appendices).

These two results, that Swedish physicians mostly did feel independent in decision making and guidelines were perceived mostly not as limiting, close preliminary gaps in literature. Even though, these aspects should be further discussed in relation to Swedish socio-cultural aspects and compared to further studies. From a German perspective, it is a very relevant point as one of the major concerns is whether physicians feel limited by guidelines for priority setting or not. In Germany, 44% of physicians assessed (hypothetical) guidelines that would include information about costs as a limitation of their freedom in clinical decision making (Marckmann and Strech 2009).

Swedish physicians identified a number of limitations of the current system. For example, participants reported that they experienced 'local lack of staff per patient' ('group 1': 52.5%, 'group 2': 38.6%), followed by 'political directives' ('group 1': 25.9%, 'group 2': 27.1%), 'local lack of diagnostic/therapeutic resources' ('group 1': 24.7%, 'group 2': 35.5%) and 'administrative & bureaucratic tasks' ('group 1': 21.0%, 'group 2': 30.1%). These factors support the two appeals of Swedish physicians (Jansson, Nitz et al. 2013, Makdessi and

Halmin 2013). The political directives in Swedish health care (like guarantee of care, standardised care course or the queue billion), aimed for more standardisation and thereby validation and efficiency. Practically something which is craved both by politicians in order to reduce the risk of blame and provide equality, and by physicians, in accord with their wish for an equal evidence-based medicine (Hood 2011). But as shown in the two physicians' appeals, it can collide with the self-governance of the profession, its role and responsibility (Timmermans and Berg 2003).

In our sample, economic incentives were perceived to have little influence on clinical decision making in relation to undertreatment ('group 1': 3.7%, 'group 2': 10.2%), and even less so regarding overtreatment ('group 1': 0.6%, 'group 2': 4.2%). This may indicate that there was little economic pressure on clinical decisions of the questioned physicians in 2016, in contradiction to the claim of the two appeals in 2013. However, it may also suggest that physicians did not perceive economic pressure because it occurs in a more implicit manner. The lack of staff and the burden of administrative tasks, which were highly rated, can be seen as consequences of economic pressure. The controversial political incentive of the queue billion was rescinded after five years in 2015. In the beginning the waiting time had been reduced, but during the last years it was slightly more than doubled (Sveriges Kommuner och Landsting 2018). A new professional as well as a patient billion were introduced, promoting more education of professionals and shortening of queues.

It should be highlighted that undertreatment was more often experienced than overtreatment, suggesting that rationing was performed due to economic reasons rather than resources were wasted due to economic reasons. In Germany, both incentives to undertreat and overtreat are commonly known. Reifferscheid's study among German chiefs of departments implied that economic incentives were experienced to a high degree, leading slightly more to undertreatment than to overtreatment. In the study, 46% of participants reported that they have refused useful measures due to economic reasons, and 39% had the impression that economic reasons have led to an excessive number of cases, especially in orthopaedics and cardiology (Reifferscheid, Pomorin et al. 2015). Furthermore, 70% stated to have felt limited in their medical profession by the economic framework (Reifferscheid, Pomorin et al. 2015).

The biggest influence, 'much' and 'very much', on physicians' decision making in our study was their 'own medical assessment' ('group 1': 93.2%; 'group 2': 94.6%) directly followed by 'guidelines in general' ('group 1': 86.4%; 'group 2': 89.2%). In another study, physicians own clinical experience was the most important one as well, followed by the patients' view (Ekerstad, Lofmark et al. 2010). In another study, 93% physicians assessed discussions with their colleagues as most important knowledge support, 72% internet based resources, and 65% local guidelines (SOU 2017). Discussions were identified as most important handling strategies in times of scarce resources in our study. Meanwhile internet-based resources had the least importance.

When asked to differentiate the guidelines, 'group 1' assessed local guidelines, followed by the national guidelines of NBHW and to a similar extent other national guidelines or recommendations from Swedish centres or societies as most important guidelines. For 'group 2' European guidelines were the most important ones, followed by the ones from NBHW and local guidelines, other national ones were less important. This may be explained by the national guideline of cardiac care being the first guideline, well known and in its development and revision supported by the cardiologists. It is commonly known that in other departments the national guidelines are less popular and often cover fewer areas. There is some confusion between the many different national guidelines and recommendations. In consequence, it is difficult for the physicians to keep track of important information (Simon 1971, Vårdanalys 2015). Worldwide seen, an example of outlining the existing research is the Cochrane library, a collection of medical databases and provider of systematic reviews and meta-analyses.

In Sweden, the development of and the concentration on single and concise clinical national guidelines by one authority including the medical facts with the ethical principles and cost effectiveness data would be of help. Guidelines have much impact on physicians and are rather seen as supporting help than as limiting rules. In 2017, the State planned to revise and clean the national guidelines, make them applicable especially for the persons in management positions and support the clinical professionals by uniting many different local and national guidelines in one place as guiding but not binding knowledge support including

the priority setting information as stated in a state public report (SOU 2017). It is aimed to put trust and confidence in the work of professionals and to let them decide due to scientific evidence and their own clinical experience (SOU 2017). A very welcome initiative. In sum, at least based on our findings, Swedish physicians did not perceive Swedish national guidelines as limiting but as supporting. They do influence their decision making a lot. Physicians wish for more clarity in the many different national guidelines and economic pressure is perceived as little.

The ethical platform and the national guidelines

Some insights concerning the ethical platform and the national guidelines have been gained and discussed already within questions of the first part of the study concerning clinical care and decision making. In the following sections the physicians' specific knowledge of and attitudes towards them will be underlined and discussed. In addition, it will be shown whether the views between cardiologists and physicians from other specialties differed.

Knowledge and attitudes

The ethical platform was less known than the national guidelines themselves. About one third of the physicians knew 'much' or 'very much' about the ethical platform ('group 1': 36.4%; 'group 2': 36.2%). About half of 'group 1' (50.6%) and three quarters of 'group 2' (76.5%) knew 'much' or 'very much' about the national guidelines in their department. Regarding the ethical platform both groups were alike, regarding the national guidelines 'group 2', the cardiologists, knew the national guidelines to a higher degree. As explained earlier this may be due to the outstanding role of the national guideline of cardiac care to be the first national guideline ever.

A previous study among cardiologists, cardiothoracic surgeons and anaesthesiologists in 2001/2002 showed a higher knowledge of about 48% on average of the meaning of each of three ethical principles and a low appreciation of being supportive of the national guideline of coronary artery diseases of 24%, a predecessor of the extensive national guideline of cardiac care (Ridderstolpe, Collste et al. 2003). A study among cardiologists in 2007/2008 showed that 90% were very familiar with the national guideline of cardiac care and 94% considered it mainly positively (Ekerstad, Lofmark et al. 2010).

These differences can be explained, probably among others, by the development in the course of time. When the ethical platform was inaugurated in 1997 and the extensive national guideline for cardiac care in 2004, they were more popular and discussed in the media than it later could be observed. Little knowledge and insecurity about the contents were experienced in the ambulant sector and on management level as well (Arvidsson 2013, Kalkan, Sandberg et al. 2015). In comparison to the results of other studies a decline of knowledge in the course of time is found.

The ethical principles were assessed relatively alike by both groups, concerning the importance for their own work rather 'little' and 'somewhat' helpful ('group 1': 62.1%, 'group 2': 60.4%) and for the Swedish health care rather 'much' and 'very much' important ('group 1': 51.8%, 'group 2': 51.4%). Answers are limitedly evaluable as most, about two thirds, did not know them well. The national guidelines were assessed as more helpful for their own clinical work than the principles, 'much' and 'very much', ('group 1': 37.2%, 'group 2': 51.6%) as well as more important for Swedish health care, 'much' and 'very much' ('group 1': 64.2%, 'group 2': 72.3%). By 'group 2' these two aspects of the national guidelines were assessed higher than by 'group 1', showing the higher importance for those knowing them better.

The trust in the national guidelines was high, ('group 1': 71.5%, 'group 2': 71.2%), and similar to the result of the study among department chiefs which stated a high or very high trust at a percentage of 72% (Vårdanalys 2015). National guidelines were rather 'somewhat' to 'much' assessed to be up-to-date and 'little' to 'somewhat' influenced by economic interests of different agents in any meaningful way. The confusion between the different national guidelines not only developed by NBHW was found again: 22.6% of 'group 1' marked 'others' and were thereby not able to distinguish between the guidelines. Although a description was given in the invitation email and a notice before the question asked them only to answer if they knew national guidelines of NBHW. Answers of 'group 1' concerning the national guidelines therefore need to be evaluated with caution, remembering the uncertainty among participants. However, given the high proportions of participants from 'group 1' that answered 'can't say', the limitation is already minimized by the uncertain participants

themselves. In total, we found a high acceptance and a high trust in the system, most probably because priority setting measure were developed with the support of the physicians themselves. For other countries, one should learn that bottom up organisation proved to be helpful.

Ways of application

The national guidelines were considered as helpful especially for improving quality of patient care, achieving the aims of the ethical principles and priority setting. About half of the physicians ('group 1': 54%, 'group 2': 49.7%) expected them to improve equity of patient care. A few years before, chiefs of departments had expected the same at a percentage of 40% (Vårdanalys 2015). The clinical relevance was high. The national guidelines were considered as helpful for 'writing local guidelines' ('group 1': 46.7%, 'group 2': 39.9%). Remembering that guidelines in general had the second most important influence on decision making and that local guidelines were among the most important sources of information for physicians in our study, an implicit application of information of the national guidelines can be assumed. Furthermore, the national guidelines were seen as helpful for 'every clinical decision for which there is information in them' ('group 1': 27.7%, 'group 2': 29.4%). These results are in contrast to the objection of some people that the national guidelines are not meant for clinicians. Surprisingly, slightly less physicians considered them helpful for hospital management ('group 1': 24.1%, 'group 2': 23.9%), and only little more of them for health care politics ('group 1': 31.4%, 'group 2': 33.7%). These results are in accord with the finding that the national guidelines are difficult to understand for politicians and rather applied by the medical profession (Kalkan, Sandberg et al. 2015).

Ekerstad found a high rate of application among cardiologists, 81% stated extensive use (rather frequent or very frequent) of the national guideline of cardiac care (Ekerstad, Lofmark et al. 2010). Participants in our study were not asked for their rate of use but rather their perception and assessment as presented above and furthermore by specific questions concerning the concrete application. In 'group 1' partly up to 50% stated inability to answer these specific questions. This showed the complexity of the questions, which were only answerable with knowledge of the national guidelines. Thus, we focused on the answers of 'group 2'. 68.8% cardiologists agreed with the rankings in the national guidelines 'much' and

‘very much’. They assessed that 69.6% of their patients were covered by the national guideline and 21.7% needed to be excluded due to criteria like severe frailty or multi morbidity. These results were better than the result that 60% of chiefs of different departments perceived the national guidelines as containing all relevant condition and treatment pairs (Vårdanalys 2015). Not only a high agreement by the cardiologists can be seen in the results but also an explanation for the gap of patients not being covered, the complexity of decisions concerning multimorbid patients, which was shown earlier, too (Ekerstad 2011).

Physicians knowing the priority setting measures better, ‘group 2’, applied them as handling strategy in times of scarcity of resources two to three times more often than ‘group 1’, they were about a third more limited by the national guidelines and at the same time considered the national guidelines about a third more helpful. This raise in positive perception was in line with the grade of knowledge that was shown among chiefs of departments, too (Ekerstad, Lofmark et al. 2010, Vårdanalys 2015). It is described that people in order to apply guidelines need to fulfil three requirements: 1. they need to understand the intention and task, 2. they need to be able to act in accordance to the guidelines, having the resources, and 3. they need to want to act accordingly to the guidelines given their trust (Lundquist 1984, Winblad Spångberg 2003, Vengberg 2012, Vårdanalys 2015). Summarising, it should be highlighted that due to implicit application via local guidelines the actual application of priority setting contents can be assumed much higher. Even though priority setting measures are mostly expected to be helpful on the meso level, physicians rated them as helpful for writing local guidelines and clinical life, too. This knowledge could be relevant and instructive for other countries, too.

Wishes and implications for the future

The participants’ wishes for the future are in line with the described requirements for applying national guidelines. In order to understand the intention of the national guidelines the origins based on the ethical platform as well as their content should be known. About half of both groups would like to obtain further knowledge and training for the ethical platform (‘group 1’: 56.8%, ‘group 2’: 56.6%) as well as the national guidelines (‘group 1’: 50.6%, ‘group 2’: 51.8%). Physicians were slightly more interested in the ethical platform.

This is important as ethical principles themselves cannot be the base on their own but need to be lived by people understanding them in order to frame morality (Limentani 1999, Griffiths and Dunlop 2002). By a better understanding of the ethical platform physicians would be able to understand and live the further measures of priority setting as for example the national guidelines. Uncertainty in understanding and handling of the national guidelines were described in other studies, too, and more communication and dialogue was claimed (Kalkan, Sandberg et al. 2015). Our study supports this claim of more communication between the levels as discussions were considered as the most important handling strategy in times of scarcity of resources. Resources themselves were claimed indirectly as the lack of staff and beds were described as a very limiting factor in their professional decision making. Resources will always be scarce but are needed for example in order to allow discussions, teaching and training, as stated in other studies as well (Ridderstolpe, Collste et al. 2003, Waldau 2007, Kalkan, Sandberg et al. 2015). The national guidelines also need to be better promoted. Trust was already shown as high. Together with willingness, both will be even higher on condition of understanding, application, co-creation and transparency. It is appreciated that they combine medical evidence-based knowledge with cost information. These are all important aspects, which need to be kept in mind when introducing new steering measures in health care.

At present, there are many encouraging efforts being implemented in Sweden around these issues. In several counties local level coalitions, networks of different professions, exist working on the implementation of the national guidelines (Kalkan, Sandberg et al. 2015). Some specialty societies do work on their own on guidelines including priority setting measures. Municipalities, like Motala, work on explicit and transparent priority setting. Ethical groups are formed at hospitals, like the ethical council and ethical forum at Sahlgrenska University hospital in Gothenburg. In 2015, Swedish professions working in primary care together with the Swedish Association of local authorities and regions (SALAR, in Swedish Sveriges Kommuner och Landsting, SKL) started working on a quality improvement system, being probably the first in the world. They have created about 100 evidence-based multi-professional indicators, which are automatically taken of already existing data in order to, for example, find patients, avoid losing them and control the continuity of care. The overall aim is to improve quality and equity of primary health care. In

2018, SALAR initiated as a further project, a common system for knowledge guidance, which should lead to a more equal and efficient overall health care in Sweden. They have formed new groups in order to improve the communication between the micro, meso and macro levels. Furthermore, they want to summarize the many different national quality registers and unit many different national as well as local and regional guidelines. Therefore, they created the new Internet platform 'nationelltklinisktkunskapsstod.se'. Regarding efforts in priority setting the biannual national Swedish conference on priority setting organised by the national centre for priority setting in health care as well as the biannual international priority setting conferences organised by the international society on priorities in Health should be noted and highlighted.

Priority setting regarding Germany

Even if at the moment German politicians do not take a stand for priority setting and research about priority setting is rare and not well supported, the needs get more and more visible in terms of dissatisfaction of health care staff and the over-and under treatment of patients (Sachverständigenrat 2018). Once, a value based framework assumed, implicit rationing performed by physicians was accepted as the best option to perform a patient oriented rationing (Mechanic 1995). But over time implicit rationing was not only attended with non-transparency and thereby the danger of inequality but also a shift of standards (Huster, Strech et al. 2007). Physicians are expected to guard patient rights and to decide upon the allocation of resources (Diederich and Schreier 2010). Encouragingly, different initiatives by physicians emerged in recent years. At the beginning of the German priority setting discourse the proposal of guidelines including cost information was not popular (Marckmann and Strech 2009). But a few years later, in 2012, the initiative 'Choosing wisely' from the United States, aiming to promote less overmedication and more physician patient communication got very popular internationally. They published for example 'not-to-do-lists' of expensive but not very beneficial measures. Many countries followed their example.

The German Society for Internal Medicine (Deutsche Gesellschaft für Innere Medizin, DGIM) launched the German project 'Choosing Wisely' in 2014 and the Association of the Scientific Medical Societies (Arbeitsgemeinschaft der Wissenschaftlichen Medizinischen Fachgesellschaften e.V., AWMF) installed a commission 'Choose Wisely Together' in 2015.

Both are working on recommendations including positive ‘to-do-lists’ as well as negative ‘not-to-do-lists’ in order to enlighten over care as well as under care. These are not legally fixed but initiatives created by medical staff itself, from the bottom upwards. It was the first time something like this happened in Germany. Furthermore, in order to prevent a shift of standards and the perception that patients are customers, physicians are tradesmen and hospitals are commercial enterprises; the German Society of Internal Medicine in 2017 launched the clinical codex ‘Medicine before Economy’. The aim was to support a reflection on the professional ethics, patient welfare and the consequences of economisation in medicine (Schumm-Draeger, Mann et al. 2016). The German Medical Association in 2018 decided to support the project. Patient welfare as an ethical criterion was claimed as well by the German Ethics Council and operationalized by patients’ autonomy, good quality of care and a fair allocation of resources regarding equity in use and equality in access (Deutscher Ethikrat 2016). In order to intensify these efforts Swedish priority setting can be seen in many aspects as a role model. Special attention should be paid to the commonly agreed ethical principles as a base of clinical work and common efforts should be carried out to reach national equity with help of different projects overarching several levels. Fear of limitation and of insufficient trust in priority setting measures was not shown by our study.

Limitations

Regarding our study several limitations can be named. Overall, one could wish for a study in not only one country but also several at the same time in order to compare physicians’ decision making and their situation of priority setting. Therefore a much bigger scale of operation would have been needed. We decided to investigate only one country but with two groups, one local and one national one. In ‘group 1’ the proportion of the single departments ranged from seven to 57 participants. Comparisons between departments would have been only limitedly feasible. Considering the amount of data due to the length of the questionnaire these comparisons were renounced.

The response rate of ‘group 2’ was low and therefore results must be interpreted with caution. For example, the sample of 166 cardiologists could have a bias towards those who have engaged in the past or have a particular interest in priority setting. It is assumed that of the 923 email addresses of the Swedish society of cardiology further addresses were not up

to date anymore, invitations were marked as spam and a proportion of members was not able to take part, as members were not by necessity only clinically working cardiologists. Therefore, the response rate might have been higher, but this is speculation. Differences between less and more experienced physicians and between the single departments remain open as we decided not to analyse these at this step.

The questionnaire was in English and not in the native Swedish to allow for international collaboration between Sweden and Germany. However, English language speaking ability is quite high in Sweden (Bolton and Kuteeva 2012). The questionnaire itself was relatively long and some physicians probably quit during answering. In further questionnaire studies we would prefer a shorter questionnaire. Regarding the content we pointed out that we investigate the case of the national guidelines by NBHW and no other ones, explaining the circumstances in the invitation letter as well as the questionnaire. Nevertheless, there might have been confusion as physicians were not always able to distinguish between the several existing national guidelines, not all existing indicators of priority setting. Our results can be mostly interpreted for Swedish health care but are indirectly very instructive for other countries as well.

Conclusion

Scarcity of resources in health care due to rising costs and demands are facing the wish for encompassing universal health coverage. Debates about their feasibility and limits are inevitable. Priority setting is a handling strategy for resource allocation focusing on the relative importance of things in order to decide upon investment, reallocation and disinvestment. In case of disinvestment, it can help to conduct explicit instead of implicit rationing. Sweden, as one of the first countries in the world, developed legally fixed ethical principles and national guidelines including cost-effectiveness data to perform priority setting in health care. This thesis aimed to examine the Swedish example in order to gain a better understanding of the process and prospective implications for Sweden itself as well as other countries. Results were gained by a questionnaire study among two different groups of Swedish physicians. The focus was laid on the physicians' perception, as little was known about their actual awareness of priority setting measures. In order to understand their point of view, their clinical conditions and decision making were portrayed, too.

The physicians in our sample rather often perceived clinical care as optimal. The gradation of the three ethical principles was displayed: patients' equality in treatment as most frequent, followed by distribution to patients' need and decision making in consideration of cost-effectiveness. Most physicians faced scarcity of resources more often than 'at least once per month'. They rationed less often than their colleagues in Europe. Most physicians felt less than 'well' prepared to handle scarcity of resources, indicating a need for support. The most important ways of handling were discussions with colleagues and superiors. Independence in clinical decisions according to their own assessment was perceived as high, which contradicts the common fear of limitation when debating priority setting. About a fifth of the physicians assessed guidelines to be limiting. Even though, guidelines had the second most influence on physicians' decision making after their own medical assessment and were rather seen as supporting. Economic incentives or costs of measures almost did not matter.

The knowledge of priority setting measures has declined during recent years compared to other studies. Only about one third of the physicians knew 'much' or 'very much' about the ethical platform. Whereas about two thirds knew 'much' or 'very much' about the national

guidelines in their department. The national guidelines were considered as helpful especially for improving health care corresponding with the ethical principles as well as for writing local guidelines. As guidelines had a huge impact on physicians' decisions the embodiment of priority setting ideas in guidelines are promising, but often confusing for clinicians as for example there exist guidelines of different national sources not all including priority setting. Views of both groups were mostly in accord, but physicians who knew the priority setting measures better, the cardiologists, applied them as handling strategy in times of scarcity of resources more often and considered them as more helpful. About half of both groups would like to obtain further knowledge and training regarding the ethical platform as well as the national guidelines.

In summary, within Sweden as well as internationally it is worth paying more attention to the many efforts of Swedish priority setting as they are appreciated and applied. In future, more efforts should be made to demonstrate them in a clearer way to the professionals and the public. The original intention, basing on the ethical principles should be highlighted more again and existing interest should be taken up. Continuous communication, guidance and support between and within all levels are essential and should be enabled. A trend towards this direction is already seen in recent projects. Germany should learn from the very instructive model of Sweden. Fear of limitations should not be an obstacle. Priority setting should be seen as empowerment to fair and transparent decision making. The focus should be on on-going development as challenges cannot be solved "by word but only by action, by the creation of a more human society" (Berger 1976).

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Appendices

Invitation letter



Ämne: Frågor om läkares kliniska beslutsfattande och attityder till prioriteringar

Bästa kollega,

Varje dag fattar läkare ett stort antal kliniska beslut och prioriteringar måste göras eftersom hälso- och sjukvårdens resurser är begränsade. Men det är inte alltid tydligt hur det går till eller på vilka grunder. Med en webbaserade enkät vill vi undersöka läkares förutsättningar då de fattar sina kliniska beslut samt hur deras kännedom är om Socialstyrelsens nationella riktlinjer.

Sverige är ett av få länder i världen som har nationellt beslutade etiska principer för hälso- och sjukvård samt nationella riktlinjer som inkluderar bland annat tillstånds-åtgärds-listor med prioriteringsgrad 1 till 10 som rekommendationer för prioriteringar. Det är dock oklart om och hur etablerade dessa är bland läkarkåren och vilka faktorer som påverkar läkares kliniska beslut. Därför är vi mycket intresserade att ta del av din erfarenhet och åsikt som läkare!

I denna studie riktar vi oss till kardiologer/läkare inom hela Sverige. Vi har tidigare genomfört en lokal studie med läkare inom olika medicinska specialiteter vid ett enstaka universitetssjukhus. Din e-mailadress fick vi från Svenska Kardiologföreningen.

Enkäten är på engelska, ditt deltagande är frivilligt och du kan avbryta den om du vill. Dina svar samlas in helt anonymt och all presentation av resultat sker på gruppnivå. Ingen obehörig har tillgång till samlad data. Data finns på en server på universitet i Kiel, Tyskland och arkiveras i 10 år för att därefter raderas. Att besvara enkäten tar ungefär 15 minuter. Vi ber dig besvara varje fråga och välja det svar som du anser passa bäst. Om du är osäker på svaret eller inte vill svara så välj alternativ "can't say".

Du kan öppna enkäten online genom att gå in på nedanstående länk med din kod (transaction number "TAN"). Du kan göra detta via dator, laptop, surfplatta eller mobil. Du behöver inte besvara hela enkäten på en gång utan du kan logga in igen och fortsätta samt även ändra dina svar så länge du inte har skickat in den. Glöm dock inte att skicka in den när du är klar.

Länk: [SERVER]
TAN: [TAC]

Studien kommer att ge oss ny kunskap som kommer att bidra till svensk och internationell diskussion om utvecklingen av hälso- och sjukvård och systematiska prioriteringar. Resultaten kommer bland annat att spridas lokalt samt via vetenskapliga tidskrifter och föredrag. Vi kommer att meddela alla via e-mail när resultaten blir publicerade.

Om du har frågor tveka inte att kontakta Catharina Drees: c.drees@iem.uni-kiel.de

Bästa hälsningar,
Doktorand Catharina Drees
(Kiel universitet, Tyskland; läkarpraktikant på Örebro universitetssjukhus, Sverige)

Doc. Barbro Krevers & Med. Dr. Niklas Ekerstad : barbro.krevers@liu.se; niklas.ekerstad@liu.se
(Prioriteringscentrum Linköping universitet, Sverige)

Prof. Med. Dr. Alena M. Buyx, M.A. fil., FRSA : medizinethik@iem.uni-kiel.de
(Medicinsk etik, Kiel universitet, Tyskland)

Hänvisning: E-målet skickas automatiskt. Koden kan inte spåras till dig. Dina svar är helt anonyma.

Questionnaire

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Mark as shown: ☐ ☒ ☐ ☐ Please use a ball-point pen or a thin felt tip. This form will be processed automatically.

Correction: ☐ ☒ ☐ ☐ Please follow the examples shown on the left hand side to help optimize the reading results.

1. Impression of patient care

How often do the following statements match the hospital patient care that you are familiar with?

	Never (1)	Rarely (2)	Somewhat (3)	Often (4)	Very often (5)	Can't say (101)
1.1 All patients are equally treated.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
1.2 All resources are distributed according to patients' need.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
1.3 All decisions are made in consideration of costs in relation to patients' benefit.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
1.4 All patient care is optimal.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

2. Resources in clinical work

	(1)	(2)	(3)	(4)	(5)	(101)
2.1 How often did you face scarcity of resources in your clinical work during the last six months?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2.2 How often did you <u>not</u> prescribe/perform a diagnostic/therapeutic measure because of scarcity of resources during the last six months?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2.3 How do you handle scarcity of resources in your clinical work? Please tick every option that matches.						
<input type="checkbox"/> I discuss the situation with my superior.	<input type="checkbox"/> I discuss the situation with my colleagues.	<input type="checkbox"/> I talk to the patient about it.				
<input type="checkbox"/> I put the patient on a waiting list.	<input type="checkbox"/> I send the patient to another department.	<input type="checkbox"/> I send the patient to another hospital within the "landsting".				
<input type="checkbox"/> I send the patient to another "landsting".	<input type="checkbox"/> I send the patient earlier home.	<input type="checkbox"/> I do not offer all the treatment/diagnostics some patients require.				
<input type="checkbox"/> I refer to the principles of the ethical platform.	<input type="checkbox"/> I refer to Socialstyrelsen's national guidelines.	<input type="checkbox"/> I recommend an additional private health insurance.				
<input type="checkbox"/> Other (see 2.4)	<input type="checkbox"/> None of these	<input type="checkbox"/> Can't say				

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2. Resources in clinical work [Continue]

2.4 Other ways you handle scarcity of resources or further comments:

2.5 How well do you feel personally prepared to handle scarcity of resources in your clinical work?

☐ Not at all (1)
 ☐ Somewhat (2)
 ☐ Very well (3)
 ☐ Well (4)
 ☐ Very well (5)
 ☐ Can't say (101)

2.6 How often do you think resources are being wasted in your hospital?

☐ Never (1)
 ☐ Rarely (2)
 ☐ Somewhat (3)
 ☐ Often (4)
 ☐ Very often (5)
 ☐ Can't say (101)

3. Circumstances of clinical decision making

3.1 How often can you make independent clinical decisions according to your own assessment without being limited?

☐ Never (1)
 ☐ Rarely (2)
 ☐ Somewhat (3)
 ☐ Often (4)
 ☐ Very often (5)
 ☐ Can't say (101)

3.2 Which of these factors limit your own choices of diagnostic & therapeutic options in your clinical decision making? Please tick every described factor that matches.

- | | | |
|--|--|---|
| <input type="checkbox"/> Local lack of diagnostic/therapeutic resources | <input type="checkbox"/> Local lack of staff per patient | <input type="checkbox"/> Directives of own clinical superior |
| <input type="checkbox"/> Local clinical guidelines (PM) | <input type="checkbox"/> Regional medication and device recommendations | <input type="checkbox"/> Socialstyrelsen's national guidelines & their follow up |
| <input type="checkbox"/> Other national guidelines than Socialstyrelsen's (e.g. from Swedish clinical societies/centers) | <input type="checkbox"/> National quality registers within health care & their follow up | <input type="checkbox"/> Political directives (e.g. "vårdgaranti", "standardiserade vårdförlopp") |
| <input type="checkbox"/> Lack of official approvals for medical diagnostics/treatments | <input type="checkbox"/> Economic incentives to undertreat | <input type="checkbox"/> Economic incentives to overtreat |
| <input type="checkbox"/> Administrative & bureaucratic tasks | <input type="checkbox"/> Other (see 3.3) | <input type="checkbox"/> None of these |
| <input type="checkbox"/> Can't say | | |

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3. Circumstances of clinical decision making

[Continue]

3.3 Other factors which limit your clinical decision making or further comments:

4. Importance of different factors in clinical decision making

How much influence do the following factors have on your own clinical decision making?

	None (1)	Somewhat Little (2)	Very much Much (3)	(4)	(5)	Can't say (101)
4.1 Your own medical assessment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4.2 A colleague's medical assessment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4.3 A superior's medical assessment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4.4 Your sympathy for a patient	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4.5 A patient's preference/wish	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4.6 Guidelines in general	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4.7 Costs for the patients	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4.8 Costs for the hospital	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4.9 Costs in relation to patients' benefit (cost-effectiveness-ratios)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

5. Importance of different sources of information in clinical decision making

How much influence do the following sources of information have on your own clinical decision making?

	None (1)	Somewhat Little (2)	Very much Much (3)	(4)	(5)	Can't say (101)
5.1 Local clinical guidelines (PM)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5.2 Socialstyrelsen's national guidelines	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5.3 Other national clinical guidelines/ recommendations than Socialstyrelsen's (e.g. from Swedish clinical societies/centers)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5.4 National internet based support resources (e.g. internetmedicin.se)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5.5 European clinical guidelines	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5.6 American clinical guidelines	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5.7 International internet based support resources (e.g. uptodate.com)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

6. Ethical platform of Swedish priority setting

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6. Ethical platform of Swedish priority setting [Continue]

	Not at all (1)	Little (2)	Somewhat (3)	Much (4)	Very much (5)	Can't say (101)
6.1 How much do you know the ethical platform of priority setting? (The three ethical principles.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6.2 How helpful is the ethical platform for your <u>own</u> clinical work?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6.3 How important do you consider the ethical platform for Swedish health care?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>


7. Socialstyrelsen's national guidelines

	Not at all (1)	Little (2)	Somewhat (3)	Much (4)	Very much (5)	Can't say (101)
7.1 How much do you know Socialstyrelsen's national guidelines within your <u>own</u> working field? (see list of existing guidelines in 7.2)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<i>If you are not at all acquainted with any of Socialstyrelsen's national guidelines or cannot say it, mark that answer and then go directly to the questions of part 9.</i>						
7.2 Which of Socialstyrelsen's existing national guidelines concern your <u>own</u> clinical work?						
<input type="checkbox"/> Abuse and addiction	<input type="checkbox"/> Asthma/COPD	<input type="checkbox"/> Breast-, prostate- & colorectal cancer				
<input type="checkbox"/> Cardiac care	<input type="checkbox"/> Dementia	<input type="checkbox"/> Depression and anxiety				
<input type="checkbox"/> Diabetes	<input type="checkbox"/> Lung cancer	<input type="checkbox"/> Methods of preventing disease				
<input type="checkbox"/> Multiple sclerosis & parkinson's disease	<input type="checkbox"/> Musculoskeletal diseases	<input type="checkbox"/> Palliative care				
<input type="checkbox"/> Schizophrenia	<input type="checkbox"/> Stroke	<input type="checkbox"/> Other (please specify in 7.3)				
<input type="checkbox"/> None of these	<input type="checkbox"/> Can't say					
7.3 Specification of the answer option "other" in 7.2:						

	Not at all (1)	Little (2)	Somewhat (3)	Much (4)	Very much (5)	Can't say (101)
7.4 How helpful are Socialstyrelsen's national guidelines for your <u>own</u> clinical work?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7.5 How important do you consider Socialstyrelsen's national guidelines for Swedish health care?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7.6 How much up-to-date do you consider Socialstyrelsen's national guidelines within your <u>own</u> clinical work?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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7. Socialstyrelsen's national guidelines [Continue]

- 7.7 How much do you trust Socialstyrelsen's national guidelines? ☐ ☐ ☐ ☐ ☐ ☐
- 7.8 How much do you consider Socialstyrelsen's national guidelines as influenced by economic interests of different agents? ☐ ☐ ☐ ☐ ☐ ☐
- 7.9 In which aspects do you consider Socialstyrelsen's national guidelines to be helpful? Please tick every described aspect that matches.
- | | | |
|---|--|---|
| <input type="checkbox"/> Every clinical decision for which there is information in them | <input type="checkbox"/> Priority setting of clinical measures in times of scarcity of resources | <input type="checkbox"/> Improvement of equity of patients in health care |
| <input type="checkbox"/> Improvement of distribution of resources according to patients' need | <input type="checkbox"/> Improvement of consideration of costs in relation to patients' benefit | <input type="checkbox"/> Improvement of quality of patient care |
| <input type="checkbox"/> Writing local guidelines | <input type="checkbox"/> Hospital management | <input type="checkbox"/> Health care politics |
| <input type="checkbox"/> Other (possible to specify in 9.4) | <input type="checkbox"/> None of these | <input type="checkbox"/> Can't say |

8. Application of Socialstyrelsen's national guidelines

- 8.1 Approximately how many of your patients are covered by recommendations in Socialstyrelsen's national guidelines? (Please state a number between "0" and "100" (%) & for "can't say" state "101".)

- 8.2 Approximately how many of your patients do you need to exclude from application of the recommendations because of criteria like severe frailty or multi morbidity? (Please state a number between "0" and "100" (%) & for "can't say" state "101".)

- 8.3 How much do you agree with the priority setting rankings (1-10, "icke-göra", "FOU") for the guidelines within your working field?

Not at all (1) Somewhat (3) Very much (5) Can't say (101)

Little (2) Much (4)

☐ ☐ ☐ ☐ ☐ ☐

- 8.4 How often do you think a total prohibition of measures within "icke-göra" & "FOU" would lead to lower quality of care for single patients?

Never (1) Somewhat (3) Very often (5) Can't say (101)


Rarely (2) Often (4)

☐ ☐ ☐ ☐ ☐ ☐

No (0) Yes (1) Can't say (101)

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EvaSys	<u>Clinical decision making & priority setting by Swedish doctors</u>	
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8. Application of Socialstyrelsen's national guidelines [Continue]

- | | | | |
|--|--------------------------|--------------------------|--------------------------|
| 8.5 Can you prescribe measures of lower priority grades (about 8-10) to your patients without obstacles? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 8.6 Can you prescribe measures of "icke-göra" and "FOU" to your patients without obstacles? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

9. Final potential wishes and comments

- | | | | |
|---|--------------------------|--------------------------|--------------------------|
| | No (0) | Yes (1) | Can't say (101) |
| 9.1 Would you like to get further knowledge and training in the ethical platform of priority setting? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 9.2 Would you like to get further support for the application of Socialstyrelsen's national guidelines? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 9.3 Do you have any further comments or remarks on Swedish priority setting activities? | | | |

- 9.4 Do you have any further comments or remarks on Socialstyrelsen's national guidelines (e.g. their exact meaning for yourself or problems with them)?

10. Demographic questions


- 10.1 How old are you? (Please state your age in years, XX.)

- 10.2 How many years have you been working as clinical doctor? (Please state the number of years, X- XX. For less than 1 year state also 1.)

- 10.3 Please identify your gender: ☐ Female ☐ Male ☐ Other

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EvaSys	<u>Clinical decision making & priority setting by Swedish doctors</u>	
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10. Demographic questions [Continue]

- 10.4 What is your employment?
- | | | |
|---|--|--|
| <input type="checkbox"/> "Icke-legitimerad Underläkare" | <input type="checkbox"/> "Legitimerad Underläkare" | <input type="checkbox"/> "Specialist läkare" |
| <input type="checkbox"/> "Överläkare" | <input type="checkbox"/> "Verksamhets-/ Områdeschef" | <input type="checkbox"/> Other |
| <input type="checkbox"/> No employment | | |

10.5 What are you specialist in?

- | | | |
|--|--|--|
| <input type="checkbox"/> None - still under training | <input type="checkbox"/> Internal Medicine | <input type="checkbox"/> Cardiology |
| <input type="checkbox"/> Pulmonology | <input type="checkbox"/> Endocrinology | <input type="checkbox"/> Geriatrics |
| <input type="checkbox"/> Urology | <input type="checkbox"/> Oncology | <input type="checkbox"/> Neurology |
| <input type="checkbox"/> Psychiatry | <input type="checkbox"/> Anesthesia and intensive care | <input type="checkbox"/> Palliative care |
| <input type="checkbox"/> Surgery | <input type="checkbox"/> Abdominal surgery | <input type="checkbox"/> Breast surgery |
| <input type="checkbox"/> Thoracic surgery | <input type="checkbox"/> Vascular surgery | <input type="checkbox"/> Neuro surgery |
| <input type="checkbox"/> Other | | |

10.6 Other specialty than named in 11.5 that you are specialist in:

- 10.7 In which kind of hospital do you work?
- | | | |
|---|---|--|
| <input type="checkbox"/> "Länsdelssjukhus" / "Lasarett" | <input type="checkbox"/> "Länssjukhus" / "Centralsjukhus" | <input type="checkbox"/> "Universitetssjukhus" |
| <input type="checkbox"/> Other | | |

10.8 In which "landsting/region" do you work?

- | | | |
|---|---|---|
| <input type="checkbox"/> Landstinget Blekinge | <input type="checkbox"/> Landstinget Dalarna | <input type="checkbox"/> Region Gotland |
| <input type="checkbox"/> Region Gävleborg | <input type="checkbox"/> Region Halland | <input type="checkbox"/> Region Jämtland Härjedalen |
| <input type="checkbox"/> Region Jönköpings län | <input type="checkbox"/> Landstinget i Kalmar län | <input type="checkbox"/> Region Kronoberg |
| <input type="checkbox"/> Norrbottens läns landsting | <input type="checkbox"/> Region Skåne | <input type="checkbox"/> Stockholms läns landsting |
| <input type="checkbox"/> Landstinget Sörmland | <input type="checkbox"/> Landstinget i Uppsala län | <input type="checkbox"/> Landstinget i Värmland |
| <input type="checkbox"/> Västerbottens läns landsting | <input type="checkbox"/> Landstinget Västernorrland | <input type="checkbox"/> Landstinget Västmanland |
| <input type="checkbox"/> Västra Götalandsregionen | <input type="checkbox"/> Region Örebro län | <input type="checkbox"/> Region Östergötland |
| <input type="checkbox"/> Can't say | | |

10.9 Have you participated in writing any of the following guidelines or recommendations?

- | | | |
|--|---|--|
| <input type="checkbox"/> Yes, for local guidelines (PM) | <input type="checkbox"/> Yes, for Socialstyrelsen's national guidelines | <input type="checkbox"/> Yes, for other national guidelines than the ones from Socialstyrelsen |
| <input type="checkbox"/> Yes, for national recommendations on internet based support resources like internetmedicin.se | <input type="checkbox"/> Other than named here | <input type="checkbox"/> None |
| <input type="checkbox"/> Can't say | | |

Dear participant, you now finished the survey.
After pressing "submit" your data will be saved electronically.

Thank you very much for your participation!
Once again, we are extremely grateful for the contribution of your valuable time and your honest information.

As soon as all the information is evaluated and a paper published we will inform all participants by email.

DRAFT

Reminder



Ämne: Påminnelse – Frågor om läkares kliniska beslutsfattande och attityder till prioriteringar

Bästa kollega,

För ett tag sedan fick du inbjudan att framhäva läkares åsikter om kliniska beslutsfattande och attityder till prioriteringar. Vi är väl medvetna om att de flesta läkare har en stressig vardag men vore mycket tacksamma, om du ville ägna några minuter åt den webbaserade enkäten.

Ditt svar vore mycket värdefullt. Det kan hjälpa oss att komma fram till en bättre beskrivning av påverkande faktorer av kliniska beslutsfattande som bland annat resurstillgång i vardagen och etablering av systemet av prioriteringar hos läkare.

Det är naturligtvis frivilligt att delta och anonymt. Om du väljer att inte besvara enkäten, får du gärna skriva ett email till Catharina varför.

Du kan öppna websidan med länken och TAN ("transaction number") nedannämnd på datorn, laptop, surfplattan eller mobilen. Du kan ändra dina svar så länge du inte har skickat i väg enkäten och det går även att logga ut & sedan in igen om man inte svarar på hela enkäten på en gång. Glöm dock inte att skicka in den när du är klar.

Länk: XX

TAN: XXX

Vi kommer att meddela alla via e-mail när resultatet blir publicerat. Om du har frågor tveka inte att kontakta Catharina Drees: c.drees@iem.uni-kiel.de

Bästa hälsningar,

Doktorand Catharina Drees
(Kiel universitet, Tyskland;
läkarpraktikant på Örebro universitetssjukhus, Sverige)

Dr. med. Barbro Krevers & Dr. med. Niklas Ekerstad : barbro.krevers@liu.se; niklas.ekerstad@liu.se
(Prioriteringscentrum vid Linköping universitet, Sverige)

Prof. Dr. med. Alena M. Buyx, M.A. phil., FRSA : medizinethik@iem.uni-kiel.de
(Medicinsk etik vid Kiel universitet, Tyskland)

Hänvisning: E-målet skickas automatiskt. Koden i e-målet kan inte spåras till dig. Dina svar är helt anonyma.

Further Tables and Figures

a. Introduction

Kranskärslssjukdom

Vid akut kranskärslssjukdom har oftast en åderförfettningssplack brustit och lett till en blodproppsbildning. Blodproppen kan helt eller delvis täppa till kärlet och åstadkomma akut syrebrist i hjärtmuskeln. Om syrebristen varar i mer än 10–15 minuter uppkommer en permanent skada av hjärtmuskeln, en akut hjärtinfarkt. Om syrebristen snabbt går över skadas inte hjärtmuskeln permanent, men den kan leda till instabil kärlkramp (instabil angina pectoris) som innebär återkommande bröstsmärtor vid liten eller ingen ansträngning. Graden av besvär kan variera mycket mellan olika patienter.

Knappt 31 000 personer fick diagnosen akut hjärtinfarkt i Sverige 2012 [6]. Till detta kommer ett okänt antal hjärtinfarkter som inträffat utan att patienten sökt vård. Akut hjärtinfarkt är ett tillstånd som obehandlat har en mycket hög dödlighet. Såväl förändringar av riskfaktorer i befolkningen (färre rökare, bättre blodtrycksbehandling och lägre kolesterolnivåer) som allt effektivare akut och sekundärpreventiv behandling har dock lett till mer än en halvering av den förtida dödligheten under de senaste 20 åren. Trots detta är kranskärslssjukdom, till exempel hjärtinfarkt, fortfarande den dominerande dödsorsaken i Sverige. Antalet patienter som lider av kärlkramp i Sverige är dåligt känt.

Vid symtom på kärlkramp är det viktigt att få en uppfattning om hur utbredd kranskärslssjukdomen är och hur stora delar av hjärtmuskeln som är drabbad av syrebrist vid belastning. För dessa ändamål kan kranskärslsröntgen och olika former av stresstester användas.

Den akuta behandlingen vid hjärtinfarkt är främst inriktad på att ta bort blodproppen i kranskärlet eller förhindra att den utvecklas eller kommer tillbaka. En blodpropp som helt stoppar blodflödet åtgärdas genom så kallad reperfusionsbehandling. Den består vanligen av ballongvidgning och insättning

Figure 30 Kranskärslssjukdom Nationella Riktlinje Hjärtsjukvård sida 20 (Socialstyrelsen 2018)

av ett metallnät (stent), så kallad PCI, men också av blodproppslösande läkemedel (så kallad trombolyt). Trombolyt används främst i delar av landet där det är långa transporter till ett sjukhus med tillgång till PCI.

Vid både akut och kronisk kranskärlssjukdom finns vanligen en eller flera förträngningar av kranskärl på grund av åderförfettning. Förträngningarna försvårar blodflödet i kranskärlen. Det kan leda till syrebrist i hjärtmuskeln, vilket ofta ger symptom i form av bröstsmärtor. Dessa förträngningar kan åtgärdas genom så kallad revaskularisering. Revaskularisering kan göras med PCI eller med öppen kranskärlsoperation, så kallad CABG (från engelskans "coronary artery bypass graft"). Vid mer komplicerade fall av förträngning används främst öppen kranskärlsoperation. Valet av revaskulariseringsmetod i de mer komplicerade fallen skiljer dock stort mellan olika delar av landet.

Om hjärtinfarkten åstadkommit nedsatt pumpförmåga hos hjärtat ges också läkemedel för hjärtsvikt, såsom betablockerare, angiotensin convertering enzyme (ACE)-hämmare och mineralokortikoidreceptorantagonister (MRA). I övrigt inriktas behandlingen mot att minska risken för återinsjuknande genom blodproppshämmande och blodfettshämmande läkemedel samt åtgärder för att förändra ohälsosamma levnadsvanor (till exempel rökstopp, fysisk träning och stresshantering).

Stöd att sluta röka

(Rad i tillstånds- och åtgärdslistan: A03.03)

Tobaksrökning är en viktig orsak till sjuklighet och förtida död. Rökning hör även till en av de större riskfaktorerna för att drabbas av hjärt-kärlsjukdomar, såsom hjärtinfarkt och kärlkramp. Enligt Socialstyrelsens rapport [17] uppskattas att rökning står för drygt en femtedel (knappt 7 000) av fallen som insjuknar i akut hjärtinfarkt. Registeruppgifter från kvalitetsregistret SWEDEHEART-SEPHIA [18] visar att det är stora skillnader mellan olika sjukhus i landet gällande hur stor andel av personer som slutar röka efter en hjärtinfarkt.

Nationella riktlinjer för prevention och behandling vid ohälsosamma levnadsvanor [1] innehåller rekommendationer om olika metoder för stöd att sluta röka, och är därför ett viktigt komplement till riktlinjerna för hjärtsjukvård.

Motivering till rekommendation

Enligt Socialstyrelsens rekommendation bör hälso- och sjukvården erbjuda stöd att sluta röka till personer med kranskärlssjukdom som röker. Avgörande för rekommendationen är att rökstopp minskar risken för dödlighet och återinsjuknande i hjärtinfarkt.

Rekommendation

Hälso- och sjukvården bör

- erbjuda stöd att sluta röka till personer med kranskärlssjukdom som röker (prioritet I).

Figure 31 Kranskärlssjukdom Nationella Riktlinje Hjärtsjukvård sida 21 (Socialstyrelsen 2018)

Bilaga 1. Tillstånds- och åtgärdslista

Tillstånds- och åtgärdslistan innehåller cirka 170 rekommendationer för hjärtsjukvård.

En mer detaljerad tillstånds- och åtgärdslista finns att ladda ner från Socialstyrelsens webbplats, www.socialstyrelsen.se/nationella_riktlinjer. Där är det också möjligt att söka efter enskilda rekommendationer i sökdatabasen *Sök i riktlinjerna* (där vetenskapligt underlag för varje tillstånds- och åtgärdspar presenteras) eller läsa samlad information om samtliga rekommendationer i bilagan *Vetenskapligt underlag*.

Rad	Hälsotillstånd och åtgärd	Motivering till rekommendation	Rekommendation
A01.01	Symtomfri person utan känd kranskärtsjukdom <i>Kalciumscoring av kranskärten</i>	Personerna är friska och åtgärden har ingen effekt.	Icke-göra
A02.01	Bröstsmärta och intermediär sannolikhet för kranskärtsjukdom <i>Datortomografi av kranskärten</i>	Åtgärden har prognostisk betydelse för framtida död samt betydelse för beslut om behandling. Evidens saknas för betydelse för förändrat utfall vid behandling. Åtgärden medför strålningsbelastning.	6
A02.02	Bröstsmärta och intermediär sannolikhet för kranskärtsjukdom <i>Kranskärtsröntgen</i>	Åtgärden är invasiv och medför strålningsbelastning.	7
A02.03	Bröstsmärta och intermediär sannolikhet för kranskärtsjukdom <i>Myokardscintigrati</i>	Evidens finns för att åtgärden har betydelse för beslut om behandling samt för förändrat utfall. Åtgärden medför strålningsbelastning.	4
A02.04	Bröstsmärta och intermediär sannolikhet för kranskärtsjukdom <i>Stressekardlograti</i>	Åtgärden ger ingen strålning men är operatörsberoende i större utsträckning än alternativa åtgärder.	5
A03.01	Kranskärtsjukdom <i>Stress- och livsstilsintervention</i>	Tillståndet har en måttlig till stor svårighetsgrad. Åtgärden har begränsad effekt på viktiga effektmått.	6
A03.02	Kranskärtsjukdom <i>Fysisk träning inom hjärtrehabilitering</i>	Åtgärden har god effekt och en låg till måttlig kostnad per kvalitetsjusterat levnadsår jämfört med standardbehandling.	2
A03.03	Kranskärtsjukdom <i>Stöd att sluta röka</i>	Rökstopp har en mycket god effekt på både kranskärtsjukdom och andra sjukdomar. Åtgärden påverkar livslängden.	1
A04.01	Efter hjärtinfarkt, PCI eller kranskärtskirurgi <i>Identifiering av hjärtpatienter med nydebuterad depression</i>	Tillståndet har en måttlig till stor svårighetsgrad. Det råder såväl underdiagnostisering som underbehandling. Med tillgängliga test får man dock en betydande andel falskt positiva eller falskt negativa resultat.	5

Figure 32 Bilaga 1, Nationella Riktlinje Hjärtsjukvård sida 74 (Socialstyrelsen 2018)

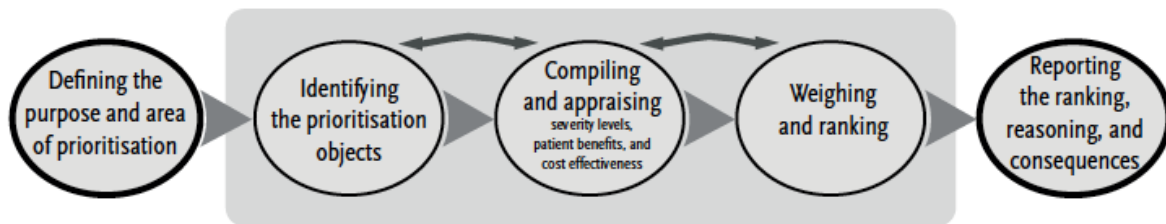


Figure 33 Illustration of the National Model for Transparent Prioritisation (Broqvist, Branting Elgstrand et al. 2011)

Condition	Intervention	Condition's severity level	Patient benefits	Quality of knowledge base	Costs/ effects	Quality of knowledge base	Ranking	Comments/ consequences

Figure 34 Worksheet of the National Model for Transparent Prioritisation (Broqvist, Branting Elgstrand et al. 2011)

b. Basic demographic information

Levene's Test for Equality of Variances	F	Sig.
Question 10.1 - Age	0.181	0.671
Question 10.2 - Years of clinical work	1.19	0.276

Table 2 10.1+2 Age + Years of clinical work, Levene's Test

t-test for Equality of Means	t	df	Sig. (2-tailed)
Question 10.1 - Age	-4.557	326	0.000
Question 10.2 Years of clinical work	-3.885	326	0.000

Table 3 10.1+2 Age + Years of clinical work, t-test

c. Impression of patient care

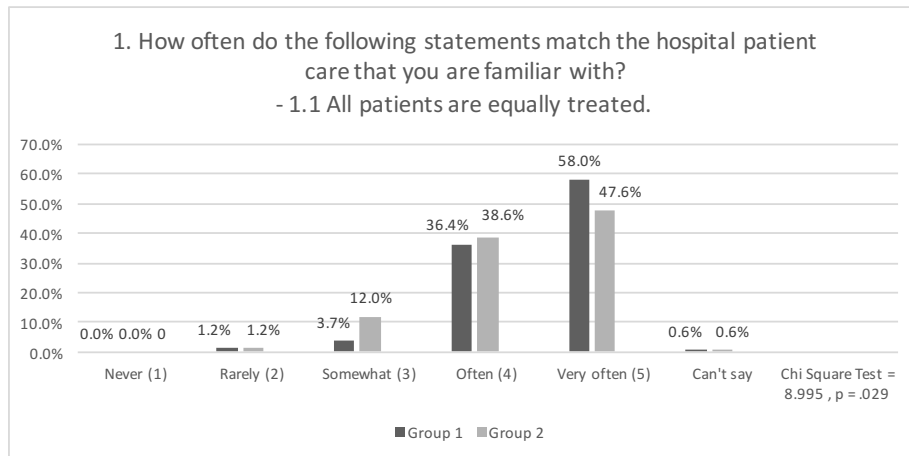


Figure 35 1. Impression of patient care Question 1

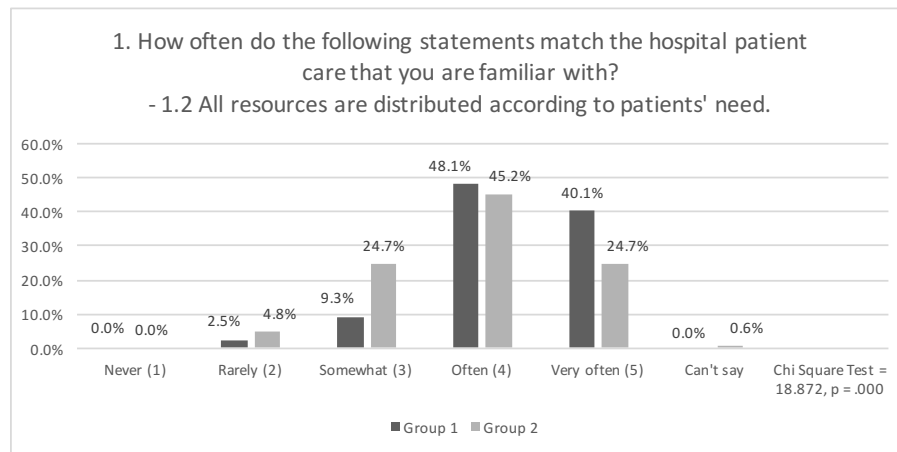


Figure 36 1. Impression of patient care Question 2

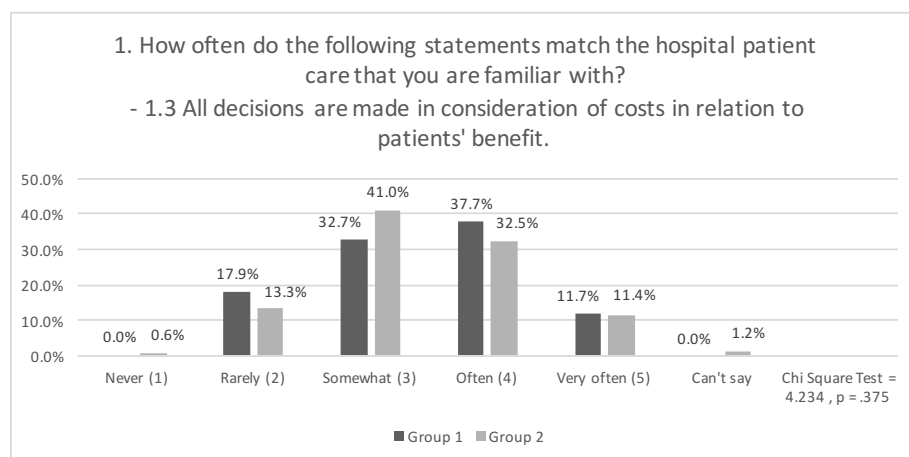


Figure 37 1. Impression of patient care Question 3

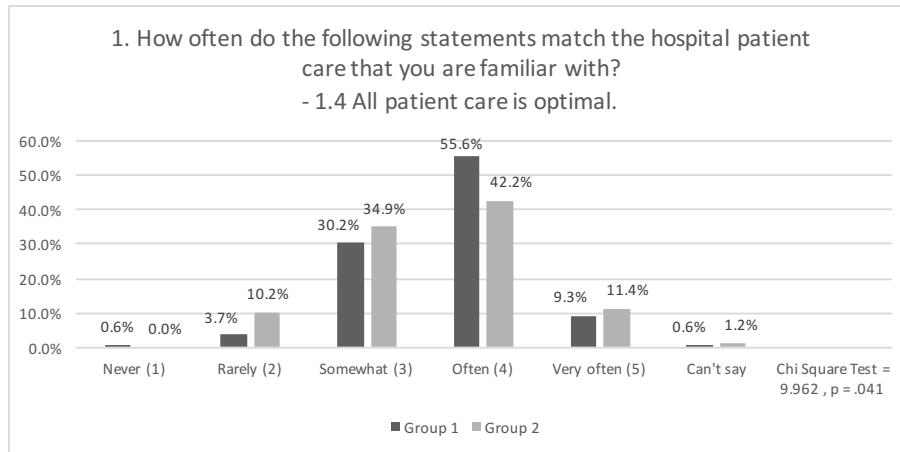


Figure 38 1. Impression of patient care Question 4

d. Resources in clinical work

2.3 How do you handle scarcity of resources in your clinical work? Please tick every option that matches. (Percent of cases)	Group 1	Group 2	Chi Square Test	p value
Can't say	3.7%	8.4%	3.204	0.073
None of these	3.1%	4.8%	0.647	0.421
Other (see 2.4.)	6.2%	4.2%	0.638	0.424
I recommend an additional private health insurance.	0.6%	3.0%	2.618	0.106
I refer to the principles of the ethical platform.	4.3%	13.9%	8.969	0.003
I do not offer all the treatment/ diagnostics some patients require.	6.2%	9.0%	0.955	0.329
I send the patient to another "landsting".	12.3%	16.3%	1.026	0.311
I refer to Socialstyrelsen's national guidelines.	14.8%	27.7%	8.123	0.004
I send the patient to another department.	17.3%	12.0%	1.799	0.180
I send the patient earlier home.	24.7%	26.5%	0.142	0.707
I send the patient to another hospital within the "landsting".	25.9%	15.1%	5.955	0.015
I talk to the patient about it.	34.0%	31.3%	0.257	0.612
I put the patient on a waiting list.	35.8%	31.3%	0.737	0.391
I discuss the situation with my superior.	56.8%	47.0%	3.155	0.076
I discuss the situation with my colleagues.	75.9%	63.9%	5.669	0.017

Table 4 2. Resources in clinical work Question 3

Question 2.4: Other ways you handle scarcity of resources or further comments

'group 1':

'Other ways to handle scarcity of resources':

- Clinical skills
- Frustration.
- Recommend private psychotherapy.
- Try to improve routines to make work more efficient, that can sometimes improve (i.e. waiting time) for the patients

'Clinical examples/experiences':

- I am mainly thinking about MRI-Scans for brain disorders. There are other options, and the patients do not suffer a worse outcome because of this. But there are an increasing number of situations where an MRI-scan is state of the art (rather than CT-scan).
- If the reason for diagnostic investigation is strong I always perform it. But there are also a weaker "grey-zone" and in these cases it can happen that I don't perform the investigation.
- Another issue is using the CT imaging, which is sometimes too much for various reasons.
- In psychiatry there are mostly scarcity of Resources in investigation of psychologist and therapy. And often the patients either do not get the treatment/investigation Or get to stay on a long waiting list.

'Causes of scarcity of resources':

- In my opinion biggest problem in Swedish Medical system is shortage of ward-places, sometimes I was forced to make priorities and put, what in the beginning seems more stable patient in a ward with less Resources.
- Scarcity in our hospital is most frequently too few beds.
- Scarcity regards primarily hospital beds, not diagnostic/therapeutic measures of other kind.
- The most often occurring resource lack is lack of hospital beds resulting/solved by sending pat. home too early, trying to take care of them in the outpatient clinic although not quite satisfying, putting responsibility on relatives/family of pat. Etc
- The most usual scarcity is the amount of inpatient places. Usually this is managed, but sometimes it's rather difficult
- The only scarcity I have faced is "lack of beds" in the hospital.
- The only scarcity of resources I have encountered is lack of hospital beds. I have never personally sent a patient home early or denied a bed in the hospital when I feel it is needed but sometimes I have to send patients to other hospitals in the region.
- The scarcity I face very often is lack of beds in the ward due to too few nurses
- The scarcity of Resources is due to lack of nurses which is a problem for the whole country which demands political measures.

'Others':

- I find most scarcities relative än therefore a matter of discussion.
- åb istället inläggning

‘Comments which correspond with a response option already chosen in 2.3’:

- As an anaesthesiologist we have to transfer patients to another ICU either at another hospital or thorax-ICU or to an intermediary ward.
- If by scarcity you mean that a certain procedure can not be done at this hospital we usually discuss among colleagues and if it is a medially "sound" request send the patient (or question) to Another hospital or landsting (e.g. 2nd opinion)
- Oftast kan man efter en viss väntan få fram de resurser som krävs i det enskilda fallet. Det blir således mer en fråga om när den nödvändiga åtgärden kan göras än att den inte utförs alls.
- Often discuss with a superior and accept the situation, maybe refer to "primärvården".
- Omprioritering, Flyttar eventuellt en patient som kan vänta utan att riskera försämring av sjukdomen.
- Since I work in ICU we don't send patients home, although we sometimes send them to the ward earlier than we otherwise would if we are short of beds.
- We send patients to nearby hospitals with our region (former landsting) instead of treating them at our hospital which we always did before the present lack of hospital beds at the surgical ward (which started 2014).

‘group 2’:

‘Other ways to handle scarcity of resources’:

- At my hospital continuous improvement is a natural part of every Days work in order to improve flow efficiency and quality (Capio S:t Gorans Hospital). The problem is not enough resources but the way they are used. For example, radiology.
- If I can't do the optimal I at least do what is necessary.
- We try to rule out obsolete treatment options.
- Cynicism

‘Clinical examples/experiences’:

- Definition of Scarcity? There will always be a wish for more resources regardless of economic reality.
- Everything can't be done at once. If that is called scarcity of resources, then, yes we have it. For me a waiting list is not a problem.
- In SUS I have never encountered the problem of having to deny or change treatment to a patient due to scarcity of resources.
- There is always scarcity of resources, by definition. The questions are not adequate. It's about prioritization.

‘Causes of scarcity of resources’:

- I do a lot of moments in work that other members of the staff should have done. That "steals" time from my patients.
- Scarcity of hospital beds is on the other hand a relevant problem.
- For us scarcity of resources is all about not having enough vårdplatser and not

enough nurses working at the clinic.

- I refer to lack of suitable hospital beds. Patients are then admitted to a suboptimal ward or admitted to an extra bed
- However, occasionally we indirectly have to postpone a treatment, i.e. surgery, for a couple of days or so because of personal shortness, especially nurses. This shortness of nurses has led to fewer beds in especially the surgery departments, with some higher waiting time for treatment as follows. This effect primarily the non-acute surgery.
- Scarcity of Resources at my hospital is always about too few hospital beds, especially in the ICU
- Scarcity of resources is mostly not monetary but more often lack of Manpower and Time is the most needed resource
- The lack of hospital beds is the main problem
- The most important part of it is loss of beds in Hospital.
- The scarcity of resources I experience are scarcity of staff and rooms at the departments.
- The scarcity of resources is mainly due to lack of beds in the hospital wards. Those that get a bed gets all the diagnostic/therapeutic measurements needed.

‘Others’:

- I correctly work in research and don't see patients.
- Work mainly in out-patient clinic where these alternatives don't apply

‘Comments which correspond with a response option already chosen in 2.3’:

- /

e. Circumstances of clinical decision making

3.2 Which of these factors limit your own choices of diagnostic & therapeutic options in your clinical decision making? Please tick every described factor that matches. (Percent of cases)	Group 1	Group 2	Chi Square Test	p value
Can't say	6.8%	6.6%	0.004	0.953
Other (see 3.3)	1.2%	3.0%	1.24	0.265
None of these	10.5%	12.7%	0.372	0.542
Economic incentives to overtreat	0.6%	4.2%	4.464	0.035
Economic incentives to undertreat	3.7%	10.2%	5.374	0.020
National quality registers within health care & their follow up	6.8%	9.0%	0.567	0.452
Lack of official approvals for medical diagnostics/treatments	9.9%	11.4%	0.212	0.645
Regional medication and device recommendations	10.5%	22.9%	9.029	0.003
Other national guidelines than Socialstyrelsen's (e.g. from Swedish clinical societies/centers)	10.5%	12.7%	0.372	0.542
Directives of own clinical superior	11.1%	14.5%	0.822	0.364
Socialstyrelsen's national guidelines & their follow up	15.4%	21.7%	2.119	0.146
Local clinical guidelines (PM)	19.1%	18.7%	0.011	0.915
Administrative & bureaucratic tasks	21.0%	30.1%	3.59	0.058
Local lack of diagnostic/therapeutic resources	24.7%	35.5%	4.581	0.032
Political directives (e.g. "vårdgaranti", "standardiserade vårdförlopp")	25.9%	27.1%	0.059	0.808
Local lack of staff per patient	52.5%	38.6%	6.404	0.011

Table 5 3. Circumstances of clinical decision making Question 2

Question 3.3: Other factors which limit your clinical decision making or further comments

'group 1':

"Other limiting factors":

- Clinical judgement
- Different opinions between doctors.
- Lack of beds for patient in the hospital or I admit patient to a less suitable department
- lack of hospital beds.
- Lack of competent staff
- Lack of my own Clinical experience.
- people without Swedish personal number

"Further comments":

- I do not think the guidelines limit my choices rather help me to use Resources in a evidence-based way

- Many of above not limiting but rather giving strength to make Medical correct decisions (e.g. quality registers, national and local guidelines)
- Our region (former landsting) is very much hampered by political decisions which are not to the advantage of our Health care.
- Resources are frequently wasted because the operation planning program does not care for reality, just slots in a time planner. If needed personal exists or not are up to some pore nurse at a planning desk to keep track of without the help of any computers or central planning.
- Förtydligande 2.6: Felanvändning av resurser när bl.a personer med hög kompetens tvingas göra arbete de är överkvalificerade för, ex administrativt arbete som adm kan göra alt när läkare gör undersköterske /sköterske uppgifter eller när överläkare gör underläkarjobb.

‘group 2’:

“Limiting factors”:

- Brist på vårdplatser och sjuksköterskor
- For certain diagnostics/treatment we depend on other hospitals
- Lack of "hospital beds" in my department, hospital and "landsting".
- Lack of beds
- Lack of beds is a big problem sometimes forcing us to send the patient home to early.
- lack of staff and beds in the hospital
- Insufficient reimbursement systems

“Further comments”:

- #.2. you mean "limit" or "impact"
- I do not feel limited by all guidelines. I use them if I want as a resource.
- I have an "etablering" and don't have these problems. My decisions are governed by what the pat need and is reasonable.
- Only the first one is seen as negative

f. Importance of different factors in clinical decision making

4. How much influence do the following factors have on your own clinical decision making?									
GROUP 1	None (1)	Little (2)	Somewhat (3)	Much (4)	Very much (5)	Can't say	Median	(Mean)	Rank
1. Your own medical assessment	0.6%	1.9%	3.7%	22.2%	71.0%	0.6%	5	4.62	1
2. A colleague's medical assessment	0.6%	9.3%	30.9%	41.4%	17.9%	0.0%	4	3.67	3
3. A superior's medical assessment	2.5%	24.1%	18.5%	27.8%	24.7%	2.5%	4	3.49	4
4. Your sympathy for a patient	9.3%	25.9%	34.6%	21.0%	4.3%	4.9%	3	2.84	7
5. A patient's preference/wish	0.0%	9.9%	48.1%	34.6%	7.4%	0.0%	3	3.40	5
6. Guidelines in general	0.0%	1.2%	12.3%	49.4%	37%	0.0%	4	4.23	2
7. Costs for the patients	22.8%	42.0%	23.5%	9.3%	0.0%	2.5%	2	2.20	9
8. Costs for the hospital	14.2%	48.8%	32.1%	4.9%	0.0%	0.0%	2	2.28	8
9. Costs in relation to patients' benefit (cost-effectiveness-ratios)	5.6%	13.0%	36.4%	36.4%	6.2%	2.5%	3	3.25	6

Table 6 4. Importance of different factors in clinical decision making ‘group 1’

4. How much influence do the following factors have on your own clinical decision making?									
	None (1)	Little (2)	Somewhat (3)	Much (4)	Very much (5)	Can't say	Median	(Mean)	Rank
GROUP 2									
1. Your own medical assessment	0.6%	1.8%	2.4%	27.1%	67.5%	1.0%	5	4.60	1
2. A colleague's medical assessment	0.6%	9.6%	34.9%	41.6%	12.7%	0.6%	4	3.56	3
3. A superior's medical assessment	8.4%	25.3%	24.1%	21.1%	16.9%	4.2%	3	3.13	6
4. Your sympathy for a patient	8.4%	30.1%	35.5%	15.1%	8.4%	2.4%	3	2.85	7
5. A patient's preference/wish	1.2%	12.7%	31.3%	39.8%	14.5%	0.6%	4	3.54	4
6. Guidelines in general	0.0%	0.6%	9.6%	45.8%	43.4%	0.6%	4	4.33	2
7. Costs for the patients	19.9%	36.1%	33.7%	6.6%	1.2%	2.4%	2	2.31	9
8. Costs for the hospital	11.4%	41.6%	36.1%	7.2%	1.8%	1.8%	2	2.45	8
9. Costs in relation to patients' benefit (cost-effectiveness-ratios)	3.6%	12.0%	33.7%	34.9%	13.9%	1.8%	3	3.44	5

Table 7 4. Importance of different factors in clinical decision making 'group 2'

g. Importance of different sources of information in clinical decision making

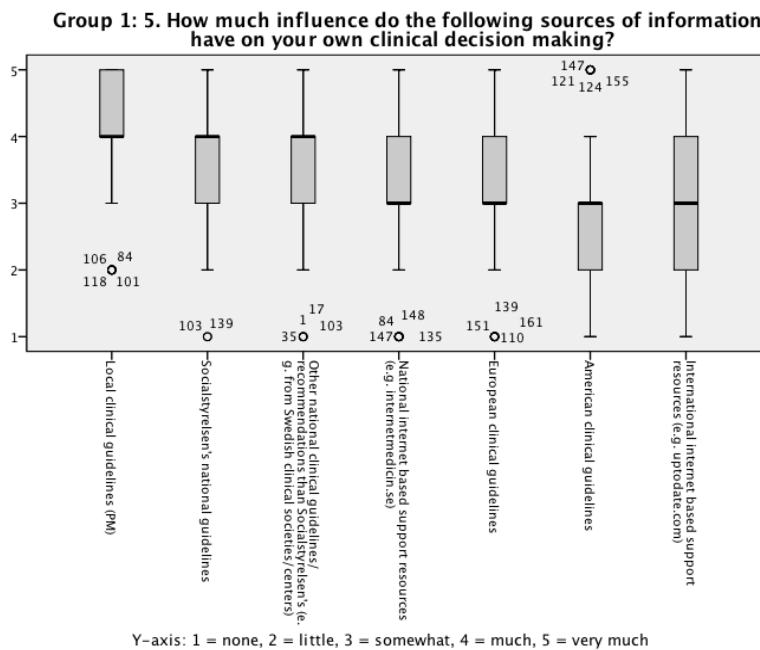


Figure 39 5. Importance of different sources of information in clinical decision making box plots Questions 1-7 'group 1'

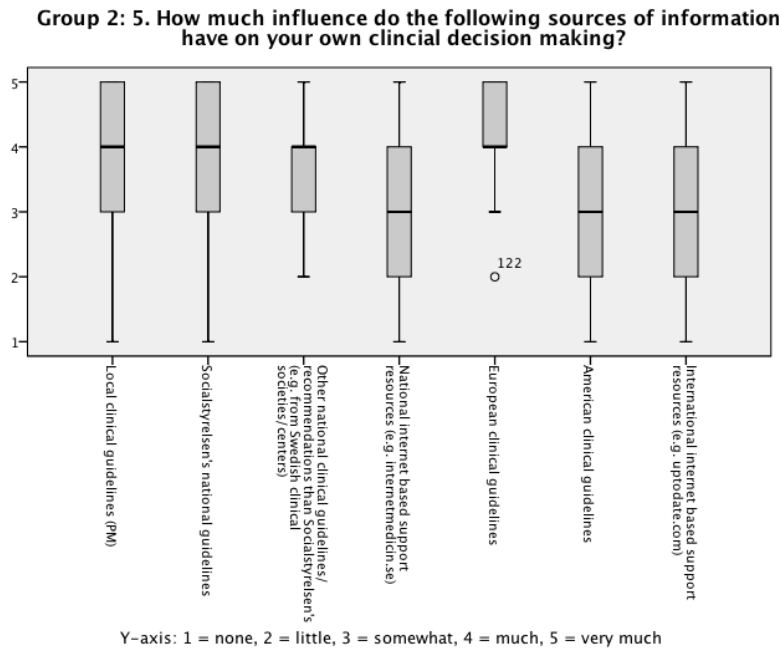


Figure 40 5. Importance of different sources of information in clinical decision making box plots Questions 1-7 'group 2'

5. How much influence do the following sources of information have on your own clinical decision making?									
	None (1)	Little (2)	Somewhat (3)	Much (4)	Very much (5)	Can't say	Median	(Mean)	Rank
GROUP 1									
1. Local clinical guidelines (PM)	0.0%	4.3%	17.9%	43.8%	34.0%	0.0%	4	4.07	1
2. Socialstyrelsen's national guidelines	1.2%	4.9%	24.7%	46.3%	20.4%	2.5%	4	3.82	3
3. Other national clinical guidelines/ recommendations than Socialstyrelsen's (e.g. from Swedish clinical societies/centers)	2.5%	5.6%	20.4%	46.9%	22.2%	0.0%	4	3.83	2
4. National internet based support resources (e.g. internetmedicin.se)	5.6%	17.3%	40.1%	29.0%	7.4%	0.6%	3	3.16	5
5. European clinical guidelines	6.8%	16.7%	32.1%	28.4%	14.8%	1.2%	3	3.28	4
6. American clinical guidelines	12.3%	32.1%	30.9%	16.7%	6.2%	1.9%	3	2.72	6
7. International internet based support resources (e.g. uptodate.com)	14.8%	29.0%	27.8%	24.1%	2.5%	1.9%	3	2.70	7

Table 8 5. Importance of different sources of information in clinical decision making 'group 1'

5. How much influence do the following sources of information have on your own clinical decision making?									
	None (1)	Little (2)	Somewhat (3)	Much (4)	Very much (5)	Can't say	Median	(Mean)	Rank
GROUP 2									
1. Local clinical guidelines (PM)	1.2%	5.4%	23.5%	41.6%	27.1%	1.2%	4	3.89	3
2. Socialstyrelsen's national guidelines	6.0%	4.8%	24.7%	42.2%	26.5%	1.2%	4	3.9	2
3. Other national clinical guidelines/ recommendations than Socialstyrelsen's (e.g. from Swedish clinical societies/centers)	0.0%	10.2%	23.5%	47.0%	17.5%	1.8%	4	3.73	4
4. National internet based support resources (e.g. internetmedicin.se)	7.8%	22.9%	33.1%	27.7%	6.7%	1.8%	3	3.02	6
5. European clinical guidelines	0.0%	6.0%	13.3%	47.6%	37.3%	1.2%	4	4.23	1
6. American clinical guidelines	3.6%	21.7%	44.0%	21.1%	8.4%	1.2%	3	3.09	5
7. International internet based support resources (e.g. uptodate.com)	9.0%	28.9%	33.7%	21.1%	5.5%	1.8%	3	2.85	7

Table 9 5. Importance of different sources of information in clinical decision making 'group 2'

h. Socialstyrelsen's national guidelines

7.2 Which of Socialstyrelsen's existing national guidelines concern your own clinical work?	Group 1	Group 2	Chi Square Test	p value
Can't say	5.8%	0.0%	9.779	0.002
None of these	2.9%	0.6%	2.416	0.120
Other ((see 7.3))	22.6%	1.8%	32.008	0.000
Musculoskeletal diseases	4.4%	0.6%	4.633	0.031
Methods of preventing disease	8.0%	18.4%	6.792	0.009
Multiple sclerosis & parkinson's disease	8.8%	0.0%	14.872	0.000
Schizophrenia	9.5%	0.0%	16.168	0.000
Diabetes	10.2%	30.7%	18.506	0.000
Dementia	11.7%	8.0%	1.169	0.280
Abuse and addiction	12.4%	3.1%	9.558	0.002
Asthma/COPD	12.4%	17.8%	1.661	0.197
Lung cancer	13.1%	4.3%	7.622	0.006
Stroke	13.9%	27.6%	8.372	0.004
Depression and anxiety	15.3%	4.3%	10.709	0.001
Palliative care	27.0%	12.9%	9.521	0.002
Cardiac care	27.7%	98.2%	164.507	0.000
Breast-, prostate- & colorectal cancer	32.1%	0.0%	61.348	0.000

Table 10 7. Socialstyrelsen's national guidelines Question 2

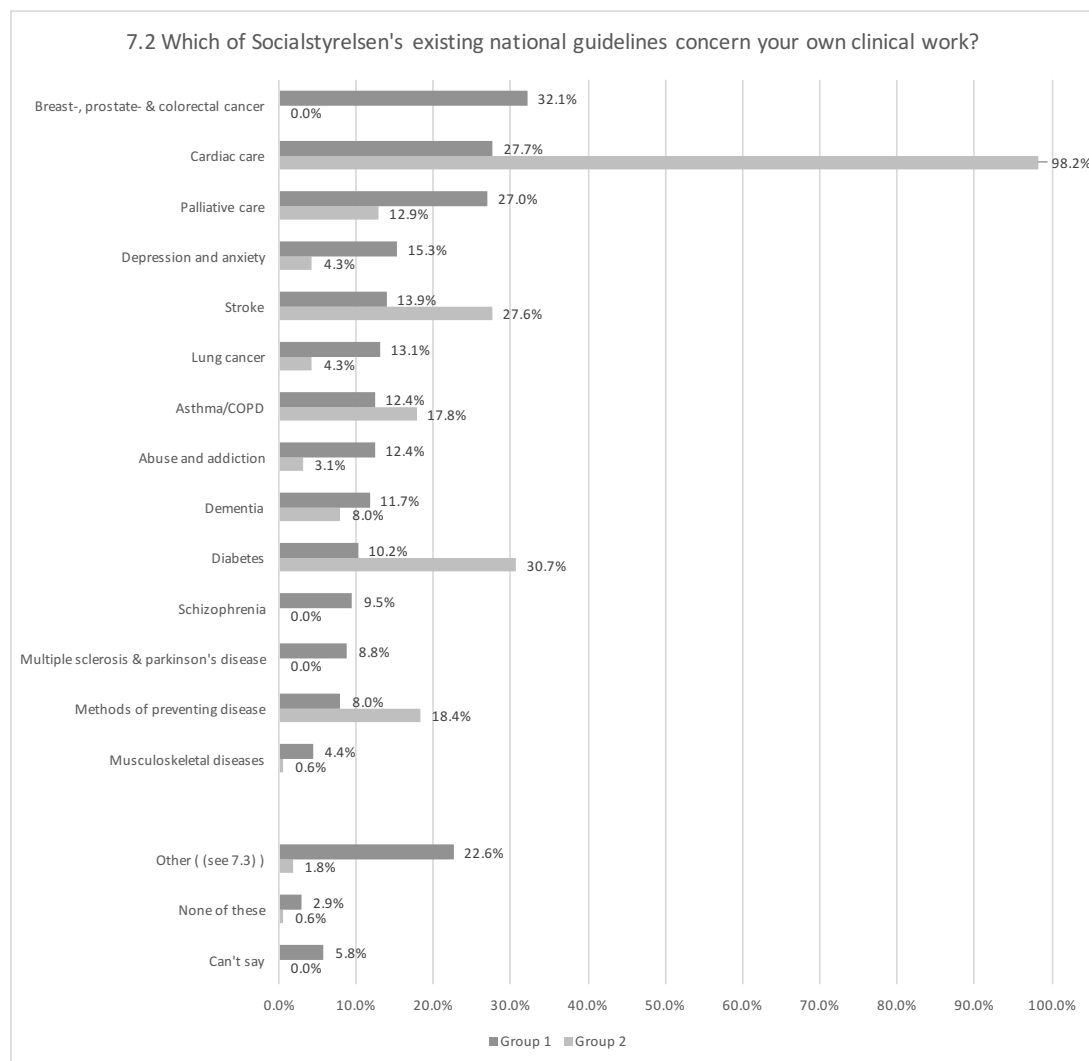


Figure 41 7. Socialstyrelsen's national guidelines Question 2

7.3 Specification of the answer option “other” in 7.2
- Cardiology
- Hematological diseases
- Paediatric Cardiology
- Sällsynta sjukdomar
- social styrelsens rekommendationer för hjärt vård

Table 11 7. Socialstyrelsen's national guidelines Question 3

7.9 In which aspects do you consider Socialstyrelsen's national guidelines to be helpful?			Chi Square	
Please tick every described aspect that matches.	Group 1	Group 2	Test	p value
Can't say	13.1%	4.9%	6.371	0.012
None of these	3.6%	3.7%	0.000	0.989
Other (possible to specify in 9.4)	0.0%	0.6%	0.843	0.358
Hospital management	24.1%	23.9%	0.001	0.974
Every clinical decision for which there is information in them	27.7%	29.4%	0.107	0.744
Health care politics	31.4%	33.7%	0.188	0.665
Improvement of consideration of costs in relation to patients' benefit	35.0%	43.6%	2.259	0.133
Priority setting of clinical measures in times of scarcity of resources	38.0%	53.4%	7.116	0.008
Improvement of distribution of resources according to patients' need	40.9%	39.3%	0.081	0.776
Writing local guidelines	46.7%	39.9%	1.420	0.233
Improvement of quality of patient care	50.4%	52.8%	0.171	0.679
Improvement of equity of patients in health care	54.0%	49.7%	0.557	0.456

Table 12 7. Socialstyrelsen's national guidelines Question 9

i. Application of Socialstyrelsen's national guidelines

8.1 Approximately how many of your patients are covered by recommendations in Socialstyrelsen's national guidelines? (Please state a number between "0" and "100" (%) & for "can't say" state "101".)		
.	Group 1	Group 2
N valid	94	135
N missing	68	31
Mean	61.47	69.56
Std. Deviation	28.178	19.453
Variance	793.972	378.413
Minimum	0	10
Maximum	100	100
Percentile 25	50	56
Percentile 50	70	75
Percentile 75	81.25	80

Table 13 8. Application of Socialstyrelsen's national guidelines Question 1

8.2 Approximately how many of your patients do you need to exclude from application of the recommendations because of criteria like severe frailty or multi morbidity? (Please state a number between "0" and "100" (%) & for "can't say" state "101".)		
.	Group 1	Group 2
N valid	81	135
N missing	81	31
Mean	21.68	24.11
Std. Deviation	18.451	18.704
Variance	340.446	349.831
Minimum	0	0
Maximum	85	95
Percentile 25	10	10
Percentile 50	20	20
Percentile 75	30	30

Table 14 8. Application of Socialstyrelsen's national guidelines Question 2

Levene's Test for Equality of Variances	F	Sig.
Question 8.1	24.316	0.000
Question 8.2	0.056	0.814

Table 15 8. Application of Socialstyrelsen's national guidelines Question 1-2 Levene's Test

t-test for Equality of Means	.	t	df	Sig. (2-tailed)
Question 8.1	Equal variances assumed	-2.57	227	0.011
	Equal variances not assumed	-2.411	153.254	0.017
Question 8.2	Equal variances assumed	-0.93	214	0.353
	Equal variances not assumed	-0.933	170.389	0.352

Table 16 8. Application of Socialstyrelsen's national guidelines Question 1-2 t-test

j. Potential wishes and comments

Question 9.3: Do you have any further comments or remarks on Swedish priority setting activities?

'group 1':

"Advantages":

- /

"Problems":

- The debate among doctors, health bureaucrats, media and politicians and thus level of knowledge and influence was higher some years ago
- National guidelines from Regional cancer centre are much more important within my field.
- Those are not very developed for psychiatry.
- Den tidigare föreslagna prioriteringen (läs: "prioriteringsutredningen") mellan olika patientgrupper fungerar inte idag när man t ex satser så mycket på att korta köer och att

med sannolikt mycket begränsad effekt korta led-tiderna för cancersjukdomar. Områden som, relativt sett, blivit kraftigt nedprioriterade är åldringsvård, demensvård, psykiatri och primärvård. Detta trots att dessa områden har det mest bekymmersamt i svensk sjukvård.

“Wishes/Advices”:

- Because the continuous increase of cost in health care the discussion of priority is very important and soon in the future impossible to avoid. Have the politicians understood that...
- I think many physicians would like to acquire a deeper knowledge regarding priority issues but do not feel they have the time nor energy to penetrate this field as much as preferred.
- We still have a long way to go Before Health care is delivered equal (with regards to socio economic status, where in the country you live etc.)
- the importance of user-friendly digital sources cannot be overestimated
- Åtgärder under FoU sker genom att inkludera patienter i kliniska studier. Viktigt så många patienter som möjligt inkluderas i studier där sådana finns. Ny metoder ska introduceras kontrollerat. Inte ad hoc.

‘group 2’:

“Advantages”:

- Very good and especially as it follows the laws (prioriteringslagen and Hälso och sjukvårdslagen)
- They are very worthwhile especially in directing resources.
- Provides current knowledge and evidence-based medicine
- I really like that the guidelines are up-to-date for example using Sotalol is now closest to not do as it should be

“Problems”:

- Always outdated
- By updating them once in a 5 years time period is in my opinion not sufficient in real life. Cardiology has a fast development vid new therapy strategies, so if Social styrelsen want to influence daily practice, they have to up date their guidelines more often.
- Economy plays a big role, and slow in adjusting to new studies
- More on paper than in reality for many doctors (not me, I think)
- Ibland undrar jag huruvida alla de timmar som läkare avsätter på arbetet med dessa gigantiska riktlinjer betalar tillbaka sig i form av lättare arbete för dem som dagligen står på golvet och inte fått möjlighet att sitta och läsa istället för att träffa patienter och delta i de många möten som måste ha föregått de. Nu vet jag visserligen att mycket arbete sker på ideell basis så ingen skugga över de som deltagit.
- It is difficult to balance between Socialstyrelsen's national guidelines and clinical Scientific guidelines because of different aims.
- Priority setting should be made by the decision-making politicians. However, they are cowards - mainly interested to maintain their political position - and fail to do this as soon as it becomes controversial. If they had left it without restrictions/ instructions to the medical profession it would have been fine. However, there are a number of restrictions, "you are not allowed to do that"...and with such a system the politicians become the "de facto" decision-makers without paying the blame for controversial issues.
- The time guaranty force me to examine rather healthy new patients instead of helping very sick patients who already are "in the system"
- Priority settings among your own speciality is mostly simple. Priority between different specialities are more problematic.
- Vertikala prioriteringar ibland svåra, medan horisontella är svåra - omöjliga. Hälsoekonomi ett viktigt hjälpmedel men inte ssk exakt!

- Yes. It is too focused on individual disease management and too little on prevention and health over the whole lifetime. It also rarely give advice on HOW certain measures should be applied, on resources required to apply these and similar big issues.

“Wishes/Advices”:

- Broaden the expert committee. Not with GPs but with clinical expertise.
- Early updates

Question 9.4: Do you have any further comments or remarks on Socialstyrelsen's national guidelines (e.g. their exact meaning for yourself or problems with them)?

‘group 1’:

“Advantages”:

- When the patient asks for something that is proven to be ineffective or wrong the guidelines provide a good support with which I can explain the situation to the patient.
- More useful for making local policy decisions and deciding what treatments etc. are available in the local/regional setting. Exception, useful for discontinuing practise that is "icke-göra"

“Problems”:

- Important areas not covered.
- (Applicable om gastrointestinal surgery limited!)
- Ej alltid praktiskt användbara när det blir som en lärobok, exempelvis bröstcancerprogrammet, för mycket text.
- They are generally not applicable within my field of expertise.

“Wishes/Advices”:

- Acceptable if they are revised every 5 years.
- You must apply the recommendations and use them as a basic ground for your decision making. But you must of course take in the patients’ whole situation in your decision making and apply them individually. The recommendations are based on population but your patient is an individual.

“Others”:

- As an anaesthetist we are quite far from make the important clinical decisions. It's the patient care clinicians who made the important decision from an resource utilising point of view.
- I use guidelines from the Swedish national society of haematology but not Socialstyrelsen's.
- I'm not sure about "Socialstyrelsen's national guidelines".
- We follow guidelines in most routine cases but they are national (via "RCC"), regional (most often via "RCC") or local.
- They usually don't apply directly to my field but is applied through the different guidelines (e.g. in SvF guidelines and national guidelines)

‘group 2’:

“Advantages”:

- It is very wise that they take the economics into regard. The European and American

guidelines are very cost rising and they tend to vary more over time according to lobbying from new medications and devices.

- They have been very helpful. Easy to apply on a group much much more difficult in front of your patient you are going to make decision about at the moment.

“Problems”:

- A number between 1-10 for what you should do or not do gives a false sense of security that may replace good clinical judgment. In the individual patient you always have access to information that is too special or complex to be taken into account when issuing general guidelines.
- During my 12 years as an active practitioner, I cannot recall having ever read their guidelines (for my particular field) in full. Socialstyrelsen does not seem to have any ambition to communicate them to the medical community in general.
- I don't feel that they are working fully bedside.
- I think they take too much time before they adapt international guidelines into the national ones. Therefore, I tend to follow the ESC guidelines, and am not that familiar with the national ones. I was trained elsewhere in the EU and only came to Sweden a year ago, so I am not very acquainted with all the national guidelines as a Swedish trained colleague would be.
- Marketing is poor and very many colleges do not read them.
- Medical development is very rapid and not seldom guidelines are irrelevant when published (as it takes a year or two of meetings, committees, writing... etc. to get them ready)
- The problem with continuous updates
- They are poorly known.
- They are not aimed for clinicians but for policymakers and administration.

“Wishes/Advices”:

- Marketing to patients and relatives ought to be done.
- Need update more often
- Needs to be updated more frequently/continuously
- När nya riktlinjer kommer måste de säljas in på en bredare bas. "Obligatoriska" webinarer och även nätbaserad kunskapskontroll borde avkrävas specialister inom de områden som berörs av riktlinjerna.
- SoS borde fokusera på ett mindre antal viktiga och kostnadsdrivande åtgärder. De nuvarande riktlinjerna är alltför omfattande och till stora delar faktiskt helt ointressanta! Det externa inflytandet känns lite stötande ibland. Exempelvis har NOAK och tikagrelor fått lite av gräddfil. Intravenöst järn enligt ESC: s guidelines ges prio 6 vilket innebär att beslutet lämnas över till den enskilda kliniken. Är det rimligt?

“Others”:

- I am a pensioner 85 years old. You should have had an age limit
- I don't use the SS national guidelines, but the ESC and ACC/AHA guidelines, which are held up to date.

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In the first place I would like to thank Alena Buyx, former director of the Institute of Experimental Medicine at the Christian-Albrechts-University Kiel. I remember our first talk as it was yesterday, it was after she reported on priority setting and the example of Sweden within her very first lectures in Kiel. I was a bit nervous as I knew that she already had chosen her doctoral students for the first term. But I felt that this would be the one and only topic I would love to do research on. She was open and interested in my thoughts about this thesis project and fortunately accepted me as additional doctoral student. I cannot conceal that she had high demands from the beginning. I really would like to thank her for this demanding but always sincerely supportive manner. She was a very encouraging 'doctor mother', as we like to call our thesis adviser in German. She pushed me to get the best out of myself and without her most probably I would never have written a thesis at all.

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Original Article



Clinical Priority Setting and Decision-Making in Sweden: A Cross-sectional Survey Among Physicians

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Abstract

Background: Priority setting in healthcare that aims to achieve a fair and efficient allocation of limited resources is a worldwide challenge. Sweden has developed a sophisticated approach. Still, there is a need for a more detailed insight on how measures permeate clinical life. This study aimed to assess physicians' views regarding (1) impact of scarce resources on patient care, (2) clinical decision-making, and (3) the ethical platform and national guidelines for healthcare by the National Board of Health and Welfare (NBHW).

Methods: An online cross-sectional questionnaire was sent to two groups in Sweden, 2016 and 2017. Group 1 represented 331 physicians from different departments at one University hospital and group 2 consisted of 923 members of the Society of Cardiology.

Results: Overall, a 26% (328/1254) response rate was achieved, 49% in group 1 (162/331), 18% in group 2 (166/923). Scarcity of resources was perceived by 59% more often than 'at least once per month,' whilst 60% felt less than 'well-prepared' to address this issue. Guidelines in general had a lot of influence and 19% perceived them as limiting decision-making. 86% professed to be mostly independent in decision-making. 36% knew the ethical platform 'well' and 'very well' and 64% NBHW's national guidelines. 57% expressed a wish for further knowledge and training regarding the ethical platform and 51% for support in applying NBHW's national guidelines.

Conclusion: There was a need for more support to deal with scarcity of resources and for increased knowledge about the ethical platform and NBHW's national guidelines. Independence in clinical decision-making was perceived as high and guidelines in general as important. Priority setting as one potential pathway to fair and transparent decision-making should be highlighted more in Swedish clinical settings, with special emphasis on the ethical platform.

Keywords: Priority Setting, Sweden, National Guidelines, Physician, Fair Allocation, Decision-Making

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Key Messages

Implications for policy makers

- In the pursuit of fair allocation of scarce healthcare resources the Swedish approach to priority setting is an instructive example. Physicians in Sweden overall do not feel restricted in their independent clinical decision-making by national priority-setting guidelines.
- Firm and well-reasoned guidelines are important for clinical decision-making and appreciated by clinicians.
- Continuous communication on priority setting guidance at all levels of experience, as well as training and support, are needed and should be further developed and established.
- The implementation of ethical priority setting can be seen as one pathway towards higher equity and quality in healthcare by enabling transparent decision-making.

Implications for the public

Resources in healthcare will never be unlimited. Rising demands and rising diagnostic and treatment possibilities are continuously increasing costs. This has long been recognized as a challenge both for health policy-makers as well as for physicians. Decision-making about scarce resources includes difficult questions about fairness, need, equity, solidarity etc. Priority setting is one option to address this challenge. It combines ethical principles and transparent discussions to enable fair and evidence-based guidance on resource allocation. Sweden's approach to priority setting has been widely recognized as an early and successful approach. This study investigated how Swedish physicians view their country's priority setting approach and its impact on their clinical decision-making. It thus provides important findings on how a well-established priority setting approach translates into the clinic, and affects those who have to implement it, thereby offering an instructive example for other countries struggling with questions of fairness and equity in healthcare allocation.

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Background

Healthcare is essential in all countries; promoting not only individual health and well-being but also employment, economic growth, social stability, health security, social cohesion, political stability, and economic diversification and innovation.^{1,2} However, healthcare systems around the world are increasingly facing challenges with regard to rising costs; with health costs increasing faster than the total economy in most countries.³ Priority setting, in addition to rationing and rationalisation, is one of the key approaches in addressing these challenges. This involves deciding on the relative importance of services.⁴ The process of resource allocation within healthcare involves many different stakeholders. While the macro level, consisting of national, regional and/or supranational policy-making, sets the framework, and the meso level involves the institutional level of hospitals, it is individual physicians (or other healthcare professionals) on the micro level who ultimately make the final clinical priority decisions on a daily basis.⁵ Physicians need to treat patients based on the evidence and offer what is medically indicated, as well as cost effective. This phenomenon has been described as the 'double agent' phenomenon.⁶⁻⁸ Against a background of scarcity, priority setting guidance at the clinical level can serve to solve potential conflicts between cost-effectiveness and medical indication, and enable transparent discussions about allocation of resources.

Sweden's approach to priority setting in healthcare is recognised as one of the early and most meaningful approaches internationally, with elaborated methods of implementation for a fair resource allocation system.⁹⁻¹⁰ Although Sweden's healthcare system is led by national government policies, the system is highly decentralised. The coverage is universal, automatic and tax-funded by regions and municipalities. Fully privately funded care is rare, but in addition to publicly funded healthcare, about 10% of all Swedish employees have supplementary private health insurances.^{11,12} Priority setting in Sweden became recognised in 1992 when the Swedish government initiated a Parliamentary Priorities Commission consisting of politicians and professional experts. A parliamentary decision in 1997 ratified the Commission's proposal and the Health and Medical Services Act was amended accordingly.¹³ The primary outcome of this decision was the ethical platform consisting of three key ethical principles in descending order: (1) Principle of human dignity: ensuring equal human values and rights, (2) Principle of need and solidarity: ensuring distribution according to the greatest needs, (3) Principle of cost-effectiveness: ensuring reasonability between costs and effects.¹⁴

The Swedish National Board of Health and Welfare (NBHW) has developed national guidelines in collaboration with experts and healthcare professionals, to function as support in priority setting for decision-makers in healthcare. They combine the currently best available evidence – including, if available, cost-effectiveness data – with the recommendation of priority setting based on the ethical principles. They can be regarded as a type of knowledge governance in the pursuit of equal and effective healthcare. They include non-binding recommendations in the form of rankings of condition and

treatment pairs, ranked from one to ten, with one marking the highest and ten the lowest priority. In 2004, the first national guideline by NBHW was published in the field of cardiac care. By 2021, 18 different NBHW national guidelines for specific disease groups had been published. The combination of ethical aspects, best medical evidence and cost-effectiveness data sets the NBHW's national guidelines apart from most other clinical guidelines, be they international, national, or local ones. The ethical platform has remained unchanged to the present day and serves as the core foundation of all future measures of priority setting.

To date, there have only been a few studies examining physicians' perception of clinical priority setting in Sweden. Most of them were published shortly after the ethical platform for priority setting was introduced and the focus was on cardiology, as the first NBHW's national guideline concerned cardiology. In 2003, it was reported that 64% of clinicians were informed about priority setting, 40% to 55% knew the meaning of each ethical principle and 58% knew the national guideline for coronary artery diseases, a predecessor of the later and broader national guideline for cardiac care.¹⁵ In 2010, 90% of clinicians were reported to be very familiar with the contents of the national guideline on cardiac care and 81% used it extensively.¹⁶ However, in 2013, it was reported that only a small amount of personnel in general practices knew about the ethical principles and the NBHW's national guidelines and that they were unsure about the contents.¹⁷ In 2015, it was reported that 76% of the heads of different hospital departments applied the NBHW's national guidelines, 33% in their original form, 69% through local guidelines.¹⁸ Further studies have reported that physicians expressed a lack of support structures¹⁹ and a lack of basic training and support of ethical principles.¹⁵ There was a need for more open dialogues and discussions about priority setting, more practical and clearer national guidelines,^{15,19} as well as more evidence for the treatment of elderly multimorbid patients.²⁰

Although Sweden has developed a sophisticated approach to priority setting in healthcare, there is thus still a need for a more detailed insight on how it permeates the micro level of decision-making. Most of the former research focused on specific aspects of the available guidance, but a wider perspective is needed to evaluate the existing priority setting measures. To date, studies focussing on how the national priority setting approach is perceived by physicians in clinical decision-making are lacking. Such research requires an understanding of the situation of physicians, including their background of patient care and decision-making. This study therefore included such information; it aimed to examine physicians' views regarding (1) the impact of scarce resources on patient care, (2) priority setting and clinical decision-making, and (3) the ethical platform and the NBHW's national guidelines for healthcare including recommendations for priority setting. These were investigated in a local sample in one large healthcare institution across different departments (group 1) and in a national sample of physicians in the field of Cardiology, where priority setting guidance exist longest (group 2). This was done to achieve local depth across various specialties, as well as spread across the country.

Methods

The study did not require approval by a research ethics committee in Sweden, according to the Swedish legislation.²¹ However, the ethical principles of the declaration of Helsinki were observed throughout.²²

Survey Implementation and Population

The online survey was conducted between August 2016 and January 2017. Two samples were generated (N in total = 1254). The first sample consisted of 331 physicians from twelve different departments at the Örebro University hospital including general internal medicine, cardiology, pulmonology, geriatrics, general surgery, cardiothoracic and vascular surgery, anaesthesia/intensive care, emergency department, urology, oncology, neurology, and psychiatry. Departments were chosen based on the existence of corresponding national guidelines. The second sample consisted of 923 members of the Swedish Society of Cardiology (predominantly clinical cardiologists). Swedish invitation emails were sent, including information about the aim of the study and Swedish priority setting as well as a personal transaction link to the English online questionnaire, created with the EvaSys automation software.²³ Reminders were sent up to four times over several weeks and reasons were asked in the event of non-participation. Due to the setting options of the EvaSys automation software²³ no missing values occurred.

Survey Contents

The survey was based on a questionnaire in English language, created by the researchers. It was based on an extensive literature review, established methods of questionnaire development,^{24,25} comparisons to similar questionnaire studies^{15,20,26,27} and discussions with many different Swedish and German medical specialists as well as experts at the Swedish National Centre for Priorities in Health Care. The questionnaire consisted of 46 questions in total and was pilot tested in Germany as well as in Sweden, taking approximately 15 to 30 minutes to complete. It was divided into three parts; the selection of questions and response options was again based on literature research and aforementioned studies as presented in the introduction section.

The first part of the survey consisted of general questions about patient care, resources in clinical work, and clinical decision-making. The second part continued with questions about physicians' awareness and application of the ethical platform and the NBHW's national guidelines. The third part included demographic questions. To clarify which guidelines were meant, the ones including priority setting measures created by NBHW were described as 'Socialstyrelsen's national guidelines' in the questionnaire, in order to distinguish these from other national and international guidelines not including priority setting measures. The specificity of the NBHW's national guidelines regarding priority setting was stressed twice, once in the invitation letter and once in the questionnaire, to prevent false responses. The questionnaire strove for simple, descriptive language, therefore no supplement with further explanations was added.

The most common type of answering scale was an ordinal-

scaled five-point Likert scale with responses ranging from either 1 = 'never' to 5 = 'very often'; 1 = 'not at all' to 5 = 'very well' or 1 = 'at least once per day'; 2 = 'at least once per week'; 3 = 'at least once per month'; 4 = 'less than once per month' to 5 = 'until now never'. Another common question type were multiple choice questions with either one answer or multiple answers possible. The possibility of answering 'can't say' was provided for each question. Each question needed to be answered in order to finish the survey, with the exception of open-ended questions and participants who reported no knowledge of the ethical platform or of any of the NBHW's national guidelines. These participants were automatically directed to the next question they were able to answer.

Data Analysis

The data management and analysis of the quantitative results were performed using the IBM SPSS Statistics for Mac version 24.²⁸ Descriptive and inferential statistics were calculated.^{29,30} In order to analyse whether a difference existed between the two sample groups, the two-dimensional chi-square-test was used for categorical nominal or ordinal-scaled data including *P* values. The expected frequencies were greater five in each of the response categories and thereby the assumptions of the chi-square test were met. The significance level was $\alpha = 0.05$. A gender analysis was conducted and *P* values were calculated with Fisher exact test. In cases of metric scaled response categories medians, means and standard deviations as well as the two-sample *t* tests for independent samples were calculated for examining differences. Due to the large sample sizes in both groups *t* tests were robust against non-fulfilling the assumption of normal distribution. Levene test was used to check for the assumption of equal variances. Some questions were multiple-choice questions. In these cases, responses to each single response category were coded as 0 = no (disagreement) or 1 = yes (agreement). It was calculated with the cumulative percentages of agreement.

Results

The presented results are mainly based on the total sample, including groups 1 and 2. Results that concern group 1 (participants from one University hospital) and group 2 (participants from the national cardiology register) are only stated in case of relevant and significant differences between the two groups. The physicians are called 'the participants' or 'group 1' or 'group 2' from here on in order to avoid misunderstandings. All results can be found in Supplementary file 1.

Characteristics of Respondents

Overall, a total of 328 completed questionnaires were returned (26% response rate). In group 1, 49% of participants completed the survey (162/331). Participants of group 1 who received the invitation email were 60% male. This proportional distribution is in line with the actual participants of group 1, who were 61% male. In group 2, 18% of the members of the Swedish Society of Cardiology completed the survey (166/923). The members were not only clinical physicians. The mean age of participants of group 2 was 49.9 years, and

the percentage of male participants was 73.5%. Based on a comparison with demographic data of the society published in another study, where the mean age was 54 years, and 75% male,³¹ the demographic composition of our sample is well representative of cardiologists in Sweden. Gender effects were rarely observed, meaning that overall presented findings are not seriously influenced by participants' gender. Significant findings are stated. Further demographic data can be seen in Table.

Clinical Patient Care

Regarding patient care, 53% of the participants had the impression that all patients were 'very often' treated equally. 47% stated that all resources were 'often' distributed according to patients' healthcare need. Seventy-two percent thought that all decisions were 'somewhat' (37%) to 'often' made considering costs in relation to patients' benefit and 49% reported that all patient care was 'often' optimal. The majority of participants, 59%, faced scarcity of resources more often than 'at least once

Table. Demographic and Work-Related Characteristics

Demographic and Work Related Characteristics	Group 1	Group 2	Total	Test	P Value
Participants in total	162	166	328		
Average age in years (SD)	44.0 (11.7)	49.9 (11.6)	47.0 (12.0)	$t(326) = -4.56$	<.00
Average years of clinical work (SD)	16.6 (11.8)	21.5 (10.9)	19.1 (11.6)	$t(326) = -3.89$	<.00
Gender (%)					
Female	38.9	26.5	32.6	$\chi^2(328) = 5.72$.02
Male	61.1	73.5	67.4		
Employment (%)					
Not legitimised assistant doctor	8.0	0.6	4.3	$\chi^2(328) = 24.48$	<.00
Legitimised assistant doctor	17.9	9.0	13.4		
Specialist	28.4	26.5	27.4		
Senior doctor	40.7	50.6	45.7		
Chief of department	3.7	7.8	5.8		
Other	1.2	3.6	2.4		
No employment	0.0	1.8	0.9		
Specialisation (%) – most common (over 5%) – multiple responses					
None – still under training	19.8	6.6	13.1	$\chi^2(328) = 12.40$	<.00
Internal medicine	16.0	71.7	44.2	$\chi^2(328) = 102.90$	<.00
Anaesthesia and intensive care	12.3	0.0	6.1	$\chi^2(328) = 21.83$	<.00
Surgery	11.1	0.0	5.5	$\chi^2(328) = 19.52$	<.00
Oncology	8.6	0.0	4.3	$\chi^2(328) = 14.99$	<.00
Cardiology	7.4	82.5	45.4	$\chi^2(328) = 186.64$	<.00
Urology	7.4	0.0	3.7	$\chi^2(328) = 12.76$	<.00
Hospital size (%)					
Small	0.0	16.3	8.2	$\chi^2(328) = 110.28$	<.00
Mid-sized	0.6	25.9	13.4		
Large/academic	99.4	48.2	73.5		
Other	0.0	9.6	4.9		
Region/landsting (former official name of regional councils) (%) – most common (over 5%)					
Region Örebro län	96.9	0.0	49.4	$\chi^2(328) = 293.77$	<.00
Stockholms läns landsting	0.0	19.3	9.8		
Västra Götalandsregionen	0.0	16.9	8.5		
Region Skåne	0.0	15.1	7.9		
Region Östergötland	0.0	7.8	4.0		
Landstinget i Uppsala län	0.0	5.4	2.7		
Participation in writing guidelines (%) – multiple responses					
Local guidelines	53.1	57.8	55.5	$\chi^2(328) = 0.75$.39
National guidelines of NBHW	13.6	13.9	13.7	$\chi^2(328) = 0.01$.94
Other national guidelines than the ones from NBHW	15.4	9.0	12.2	$\chi^2(328) = 3.13$.08
National recommendations on internet-based support resources	1.2	4.2	2.7	$\chi^2(328) = 2.73$.10
None	39.5	36.1	37.8	$\chi^2(328) = 0.39$.53

Abbreviations: SD, standard deviation; NBHW, National Board of Health and Welfare.

per month.' For 43% scarcity led 'never' and for 34% 'less than once per month' to a non-prescription or non-performance of a therapeutic or diagnostic measure during the last 6 months before data gathering. About a tenth of the participants, 11%, did not prescribe or perform a medical measure 'at least once per month,' as well as, 9%, 'at least once per week' during the last six months before the survey. Most participants, 60%, felt less than 'well' prepared to handle scarcity of resources.

The four most important strategies of dealing with perceived scarcity of resources were: (1) discussing with colleagues – 70%, (2) discussing with superiors – 52%, (3) putting patients on a waiting list – 34%, (4) talking to the patient about it – 33%. Rationing – 'not offering all the treatment/diagnostic some patients required' – occurred in 8% of all participants. There was a significant difference in how often participants referred to the NBHW's national guidelines and the ethical platform, with group 2 referring to these more often than group 1 (national guidelines: group 1: 15%; group 2: 28%; group 1+2: 21%, $\chi^2 (328) = 8.12$ with $P < .00$; the ethical platform: group 1: 4%; group 2: 14%, group 1+2: 9%), $\chi^2 (328) = 8.97$ with $P < .00$). Recommendations to private health insurances played almost no role whatsoever (2%) (see Figure 1).

Clinical Decision-Making

A large majority of the participants, 86%, were 'often' and 'very often' able to make independent clinical decisions according to their own assessment without being limited (see Figure 2, due to rounding percentages do not sum up to

100%). Significantly more male participants stated they made independent decisions very often ($P = .03$).

Asked to state which of a list of factors limited the participants' own choice of diagnostic and therapeutic measures in clinical decision-making, the most limiting factor for 45% was 'local lack of staff per patient.' Evidence based guidelines, local ones as well as the NBHW's national guidelines, were each experienced as limiting by 19%. The factors with the lowest influence on participants' decisions were 'economic incentives to undertreat,' 7%, and 'economic incentives to overtreat,' 2%.

The biggest influence ('very much' and 'much') on participants' decision-making was for 94% their 'own medical assessment,' for 88% 'guidelines in general' and for 57% 'a colleague's medical assessment.' Only 7%, assessed 'costs for the hospital' as influential ('very much' and 'much'). The most important guidelines ('very much' and 'much') for group 1 were local guidelines (group 1: 78%), followed by 'other national clinical guidelines/recommendations than Socialstyrelsen's' (group 1: 69%), and 'Socialstyrelsen's national guidelines' (group 1: 67%). For group 2, the most important sources of information ('very much' and 'much') were firstly 'European clinical guidelines' (group 2: 85%), secondly 'Socialstyrelsen's national guidelines' (group 2: 69%), and thirdly 'local clinical guidelines' (group 2: 69%).

Clinical Priority Setting

About one third, 36%, of the participants stated that they

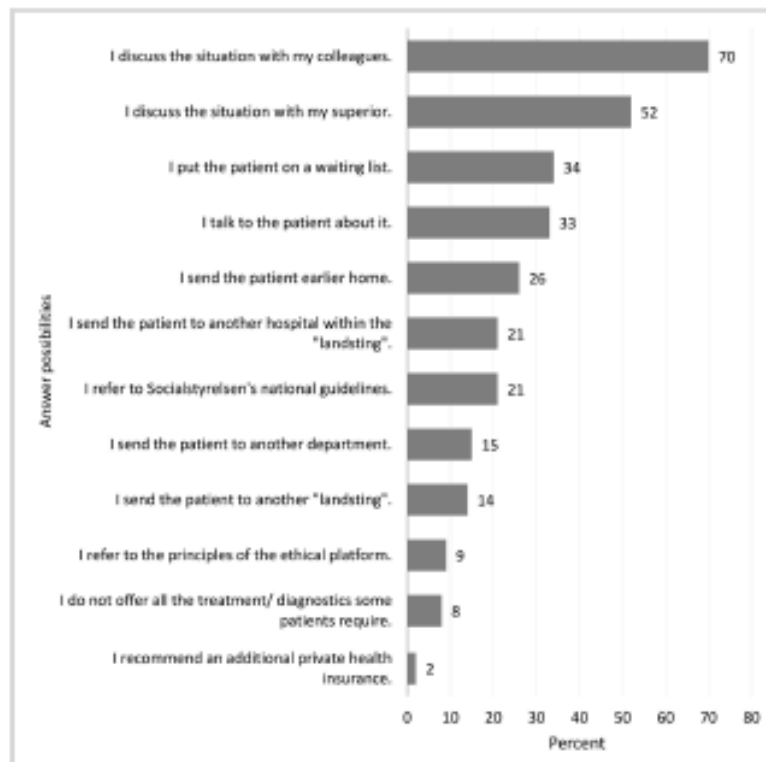


Figure 1. How the Participants Handle Scarcity of Resources in Their Clinical Work (Group 1+2).

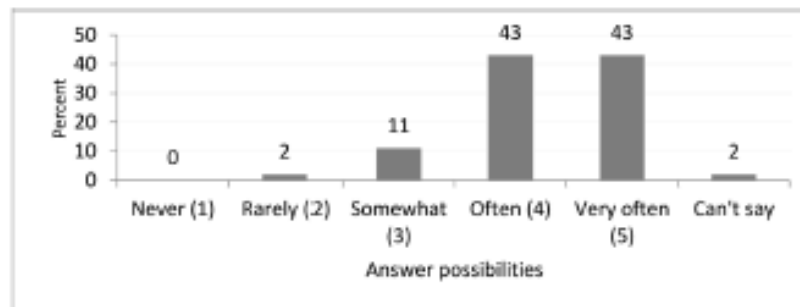


Figure 2. How Often the Participants Make Independent Clinical Decisions According to Their Own Assessment Without Being Limited (Group 1+2).

knew 'much' or 'very much' about the ethical platform. About two thirds, 64%, indicated to know 'much' or 'very much' about the NBHW's national guidelines in their area, (group 1: 50.6%, group 2: 76.5%). Regarding knowledge of the NBHW's national guidelines, participants of group 2 were more aware of them than group 1. 11 % of group 1 chose the option 'can't say'. Frequencies varied between both groups and a significant difference was shown, $\chi^2 (328) = 33.10$ with $P < .00$. The NBHW's national guidelines were considered as helpful especially for 'improvement of equity in healthcare' and 'improvement of quality of patient care' each by 52%, for 'priority setting of clinical measures in times of scarcity of resources' by 46% and for 'writing local guidelines' by 43% (see Figure 3). Group 2 assessed the NBHW's national guidelines as more helpful even for 'priority setting of clinical measure in times of scarcity of resources,' than group 1 (group 1: 38%, group 2: 53%, group 1+2: 46%, $\chi^2 (328) = 7.12$, $P = .01$). Over half of all participants, 57%, reported that they would like to have further knowledge and training regarding the ethical platform. Slightly fewer participants, 51%, expressed a wish for more support in the application of the NBHW's national guidelines. Significantly more female participants asked for more support both regarding the ethical platform ($P = .03$) and the NBHW's national guidelines ($P = .01$).

Discussion

As far as we are aware, this is the first study analysing whether and how clinical decision-making of physicians is influenced by the Swedish measures of priority setting. While the Swedish model is generally viewed in a favourable light, one of the concerns that was expressed in an international context was that explicit priority setting schemes might severely limit physicians in their ability to make decisions based on their own clinical experience and judgement.^{18,32,33} We wanted to examine Swedish physicians' perception of scarcity of resources and freedom in decision-making in healthcare as well as their awareness of priority setting guidance. Our findings could be instructive for other countries considering implementing priority setting schemes in their healthcare systems.

Clinical Patient Care

Rationing, described as not prescribing or performing a diagnostic or therapeutic measure during the last 6 months

and not including rationing by time (waiting lists), were indicated by only 9% of the participating Swedish physicians once a day or once a week and for 44% once a month or less. By comparison, 13% of German physicians in intensive care units and cardiology stated that they ration once per day or once per week and 64% once per month or less.²⁷ Physicians from Great Britain, Italy, Norway, and Switzerland rationed at a percentage of 15% once a day or once a week and 41% once a month or less.³⁴ These numbers might suggest that Swedish physicians ration slightly less often than colleagues in Europe, or at least not more frequently. However, research on rationing is hampered by the fact there is usually a wish for more resources on the part of physicians, and that a tendency exists to deny and neglect scarcity.^{35,36} These factors could be at play in explaining lower frequencies. Nevertheless, only a minority, less than a tenth of all participants in our sample, reported that they restricted needed diagnostic or therapeutic measures due to scarcity of resources. This was in line with the finding on rationing.

Coping strategies focused on communication and peer support, with discussions with colleagues and superiors identified as most important for more than half to three quarters of participants in the two groups. Approximately a third of participants reported talking to the patients about addressing scarcity. Simultaneously, more than half of all participants felt less than well-prepared to deal with scarcity in the clinical setting. These findings are in line with previous studies done when the ethical platform and the NBHW's national guidelines were first introduced and highlight that readiness in dealing with perceived scarce resources has not improved.³⁵

Clinical Decision-Making

Previous political directives in Swedish healthcare aimed to provide more standardised validation by evidence-based medicine, efficiency and equity.³⁷ There have however been some concerns regarding the risk that these would collide with the self-governance of the profession, its role and responsibility.³⁸ Worries that ability and freedom in decision-making would be curtailed by New Public Management-associated bureaucratic actions including administrative as well as economical structures was expressed in two physicians' appeals in Sweden.³⁹⁻⁴¹ In addition, fears that priority setting would be limiting freedom in clinical decision-making has

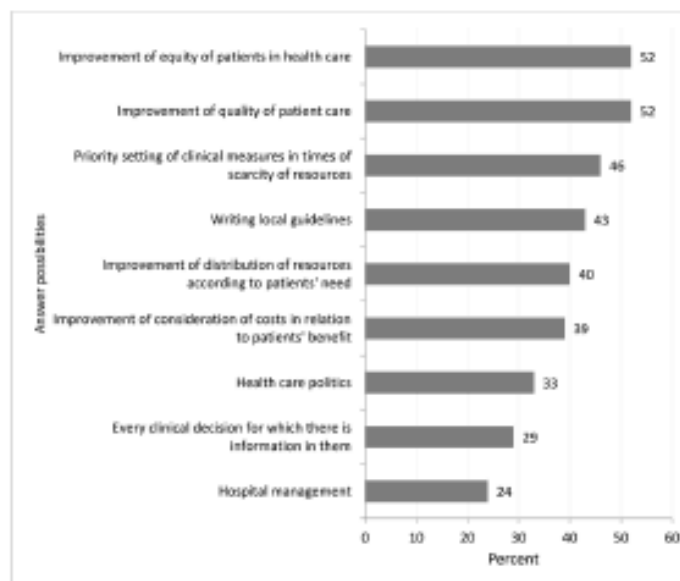


Figure 3. In Which Aspects Participants Consider NBHW's National Guidelines to Be Helpful (Group 1+2). Abbreviation: NBHW, National Board of Health and Welfare.

been expressed in other countries, too.²⁶ In our study though, a large majority, 86%, of participants reported that they were 'often' or 'very often' able to make independent decisions according to their own assessment without any limitations, with male doctors stressing independence even more than female physicians. This is a relevant finding closing a gap in the literature. It is of course possible that results are due to Swedish socio-cultural aspects not transferable to other settings, but even after two decades of a priority-setting platform in place, local guidelines as well as the NBHW's national guidelines were experienced as limiting each by only 19%. In comparison, 44% of German physicians assessed (hypothetical) guidelines that would include information about costs as a limitation of their freedom in clinical decision-making.²⁶

These findings are particularly striking in view of the fact that 'guidelines in general' were the second biggest influence on clinical decision-making in our sample, following 'own medical assessment'. Guidelines as support for evidence based medicine is highly appreciated.⁴² While the importance of guidelines is in line with other studies,^{16,43} it is nonetheless interesting to observe that even in the context of scarce resource allocation, a large majority of physicians in our sample felt largely unrestricted. In clinical life there still exist confusion about the multitude of national guidelines and recommendations,^{18,44} however, Swedish authorities plan to reduce confusion by uniting many different local and national guidelines in one place.⁴⁵

Clinical Priority Setting

The ethical platform as the foundation of Swedish priority setting was lesser known (36%) than the NBHW's national guidelines themselves (64%). This might be seen as unexpected, since these guidelines in fact are based on best available evidence, expert views and an operationalization of

the ethical platform. There was also a significant difference in knowledge, with higher knowledge in participants in cardiac care (group 2) as compared to other participants (group 1). This likely reflects that the national guideline of cardiac care was the first one ever published by NBHW and received significant attention. A previous study in the field of cardiology showed higher knowledge, about 48%, regarding the meaning of each ethical principle of the platform.¹⁵ A later study indicated that 90% of cardiologists/internists were very familiar with the contents and 94% positively considering the national guideline of cardiac care.¹⁶

The NBHW's national guidelines were considered in our sample as helpful especially for improving quality and equity of patient care, achieving the aims of the ethical principles and priority setting. A similar result was found among chiefs of departments,¹⁸ however, until now this was not replicated in a sample with a wider range of experience and decision-making scope. Clinical relevance of the NBHW's national guidelines was high as they were considered as helpful for 'writing local guidelines.'

Unsurprisingly, cardiologists (group 2) with their better awareness of the NBHW's national guidelines applied them two to three times more often in situations of scarcity than the other participants (group 1) and considered the NBHW's national guidelines about a third more helpful. This positive perception in line with the grade of knowledge was shown in previous studies, too.¹⁸

These positive assessments could be explained by the fact that NBHW's national guidelines for priority setting might be seen as a successful operationalization of the ethical platform. Further, and more broadly speaking, the principles underlying the ethical platform and the NBHW's guidelines are in line with those implicitly expressed in Swedish healthcare legislation, which might lend them some democratic legitimacy. And finally, in addition, the healthcare professions in Sweden,

particularly physicians, are now closely and continuously involved in developing guidelines and integrating best available evidence with ethical principles, with a large number of guidelines available in different healthcare specialities. As a part of this process, some successful method development has been carried out, eg, via collaboration between the National Centre for Priority Setting in Health Care and the NBHW.⁴⁵⁻⁴⁷

In view of the wish for more knowledge, support and training about the ethical platform, expressed particularly by female physicians, it can be expected that the positive perception of the guidelines will rise further in future. Interestingly, regarding training, participants were more interested in the ethical platform than in the NBHW's national guidelines, despite the latter being far more concrete and including an operationalization of the ethical platform. While the need for training has been found in other studies as well,^{15,48,49} more focus on the ethical principles, in response to our finding, could increase physician buy-in.

Limitations

The findings must be interpreted with caution as the response rates differed between 49% in group 1 to 18% in group 2, although these are common rates for this type of research.^{51,52} The real response rate of group 2 was likely higher, as the invitation to the study probably did not reach all due to out-of-date email addresses and not all members of the Society of Cardiology were clinical physicians. However, demographic characteristics of our respondents even in group 2 corresponded with the demographic of the overall population of physicians engaged in cardiac care.⁵¹ Even though data gathering occurred in 2016 and 2017, results are expected to still be valid since no changes in general priority setting measures were implemented and NBHW's national guidelines are now longstanding. The questionnaire was in English and not in the native Swedish to allow for international collaboration. The ability to communicate in English is quite high in Sweden,⁵³ particularly in well-educated populations and thus we can assume that there was no significant language barrier. It cannot be fully excluded that the phrasing of questions might have led to subjective interpretations, however, pre-testing showed high consistency in the understanding and interpretation of questions. Finally, the questionnaire was quite long, which most likely had a negative impact on the response rate.

Conclusion

Our study has shown that the participating physicians had a fairly good awareness of the national guidelines by the NBHW including recommendations for priority setting, which are based on the Swedish ethical platform for priorities in healthcare. Compared to earlier studies, overall knowledge has declined. The NBHW's national guidelines were especially considered to be helpful for improving equity and quality in healthcare as well as writing local guidelines. As non-binding evidence-based guidelines were assessed as very important in clinical decision-making, an implicit application of information of the NBHW's national guidelines can be assumed. Participants who knew the NBHW's national

guidelines better, applied them more often and considered them as more helpful. The ethical principles expressed in the ethical platform as the foundation of all other priority setting measures, were lesser known and participants wished for further training.

Even though unpreparedness of handling scarcity of resources was often reported, rationing was not reported to be more frequent than evidenced in studies from other European countries. Our findings should also assuage the worries that explicit priority setting overly restricts of physicians' ability to make independent clinical decisions. Independence in decision-making based on own clinical assessment was perceived as high and limitations by guidelines as rare. NBHW's national guidelines are non-binding and do offer however guidance on which interventions should be offered and which ones should not. The Swedish model can be seen as being somewhere between mandatory and voluntary.

There are several ongoing challenges connected to the Swedish priority setting activities. First, as shown here and in previous studies, there is still a shortage of knowledge and awareness of the ethical platform among relevant decision-makers, including clinicians.⁴⁵ There is also a lack of coordination of priority setting measures among different levels and stakeholders in the healthcare system. Furthermore, as in many other countries, in today's Sweden different, parallel incentive structures and systems are at play, which sometimes are not fully compatible with the ethical principles expressed in the Swedish priority setting legislation. Alternative investments, concepts and logics, eg, value based medicine as well as new public management-inspired market solutions, might lead to growing health inequalities in the Swedish healthcare system and hinder the achievement of consequent, coherent and transparent priority setting.^{45,50}

That said, our study results show that it is well worth paying more attention to the many efforts of Swedish priority setting, both in Sweden as well as internationally. Priority setting guided by ethical principles can be regarded as one pathway to fair and transparent decision-making. In Sweden, the original intention based on the ethical principles should be highlighted with renewed emphasis and continuous communication within all professional levels, as well as additional training and support, should be enabled. More focus should be laid on clearer ways to present the priority setting efforts and their importance to clinicians. In addition, there are a number of open research questions. For the future we suggest investigating different stakeholders' views on clinical priority setting, for example on fair priority setting processes, or on the reallocation and disinvestment of healthcare resources.

Ethical Issues

Ethical approval was not applicable/not necessary for this type of study, neither in Germany (document from the ethics committee at Kiel university attached) nor in Sweden (Swedish law on ethics approval in research concerning humans, 2003:460, <https://www.riksdagen.se/sv/dokument-lagan/dokument/svensk-forfattningssamling/lag-2003460-om-etikprovering-av-forskning-som-sts-2003-460>). Participation of this study was voluntary and anonymous. All participants were informed by writing.

Competing Interests

Authors declare that they have no competing interests.

Authors' contributions

AMB developed the idea of the study with CD. CD and AMB developed the study with help from BK, NE, CB, AR. CD conducted the study. CD and SM analysed the data and wrote the manuscript with help from AMB, BK, NE, CB, AR. All authors read and approved the manuscript.

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Supplementary files

Supplementary file 1 contains Table S1.

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