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Priority Setting and Rationing in Primary Health Care

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Om man försöker förenkla det komplexa är man ute i ogjort väder. Åverkan mot det komplexa i syfte att förenkla kränker dess kärna och upphäver dess existens.

[If we try to simplify the complex we will achieve nothing. Distorting the complex with the intent to simplify violates its essence and suspends its existence.]

Bodil Jönsson

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ABSTRACT

Background
Studies on priority setting in primary health care are rare. Priority setting and rationing in primary health care is important because outcomes from primary health care have significant implications for health care costs and outcomes in the health system as a whole.

Aims
The general aim of this thesis has been to study and analyse the prerequisites for priority setting in primary health care in Sweden. This was done by exploring strategies to handle scarce resources in Swedish routine primary health care (Paper I); analysing patients' attitudes towards priority setting and rationing and patients' satisfaction with the outcome of their contact with primary health care (Paper II); describing and analysing how general practitioners, nurses, and patients prioritised individual patients in routine primary health care, studying the association between three key priority setting criteria (severity of the health condition, patient benefit, and cost-effectiveness of the medical intervention) and the overall priority assigned by the general practitioners and nurses to individual patients (Paper III); and analysing how the staff, in their clinical practise, perceived the application of the three key priority setting criteria (Paper IV).

Methods
Both qualitative (Paper I and IV) and quantitative (Paper II and III) methods were used. Paper I was an interview study with medical staff at 17 primary health care centres. The data for Paper II and Paper III were collected through questionnaires to patients and staff at four purposely selected health care centres during a 2-week period. Paper IV was a focus group study conducted with staff members who practiced priority setting in day-to-day care.

Results
The process of coping with scarce resources was categorised as efforts aimed to avoid rationing, ad hoc rationing, or planned rationing.

Patients had little understanding of the need for priority setting. Most of them did not experience any kind of rationing and most of those who did were satisfied with the outcome of their contact with primary health care.

Patients, compared to medical staff, gave relatively higher priority to acute/minor conditions than to preventive check-ups for chronic conditions when prioritising individual patients in day-to-day primary health care.

When applying the three priority setting criteria in day-to-day primary health care, the criteria largely influenced the overall prioritisation of each patient. General practitioners were most influenced by the expected cost-effectiveness of the intervention and nurses were most influenced by the severity of the condition. Staff perceived the criteria as relevant, but not sufficient. Three additional aspects to consider in priority setting in primary health care were identified, namely viewpoint (medical or patient's), timeframe (now or later) and evidence level (group or individual).

Conclusion

There appears to be a need for, and the potential to, introduce more consistent priority setting in primary health care. The characteristics of primary health care, such as the vast array of health problems, the large number of patients with vague symptoms, early stages of diseases, and combinations of diseases, induce both special possibilities and challenges.

LIST OF PAPERS

I. Arvidsson E, Andre M, Borgquist L, Mårtensson J, Carlsson P. Day-to-day Rationing of Limited Resources in Swedish routine Primary Care – an interview study (submitted).

II. Arvidsson E, Andre M, Borgquist L, Lindström K, Carlsson P. Primary care patients' attitudes to priority setting in Sweden. Scand J Prim Health Care. 2009;27:123-8.

III. Arvidsson E, Andre M, Borgquist L, Andersson D, Carlsson P. Setting priorities in primary health care – on whose conditions? BMC Fam Pract. 2012; 13:114.

IV. Arvidsson E, Andre M, Borgquist L, Carlsson P. Priority setting in primary health care – dilemmas and opportunities: a focus group study. BMC Fam Pract. 2010;11:71.

ABBREVIATIONS

A4R	Accountability for reasonableness
CBT	Cognitive behavioral therapy
CCU	Coronary care unit
EBM	Evidence based medicine
GP	General practitioner
MRI	Magnetic resonance imaging
NHS	National Health Service
NICE	National Institute of Health and Clinical Excellence
OECD	Organisation for Economic Co-operation and Development
PCI	Percutaneous coronary intervention
PHC	Primary health care
PHCC	Primary health care centre
QALY	Quality-adjusted life year
SfamQ	Rådet för kvalitet och patientsäkerhet inom Svensk Förening för Allmänmedicin [Committee on Quality and Patient Safety in the Swedish Association of General Practice]
UK	United Kingdom
WHO	World Health Organization
WONCA	World Organization of Family Doctors (World Organization of National Colleges, Academies and Academic Associations of General Practitioners/Family Physicians)

BACKGROUND

Introduction

My interest in priority setting derives from experiences of a real need to handle a lack of resources in day-to-day primary health care (PHC). In the early 2000s I was part of the management group for health care in Kalmar County Council, one of 21 health care regions in Sweden. We faced long waiting lists for care in combination with budget deficits, and we were trying to find savings everywhere. My main medical responsibility was PHC. In addition to scarce financial resources, we were also short of staff, particularly general practitioners (GPs). From all of the primary health care centres (PHCCs), including the PHCC where I worked as a GP, the question was clear: "How can we make ends meet? We do not seem able to do everything expected of us. What should we stop doing, or do less of?" At this time the Swedish guidelines for priority setting were new, and my colleagues asked me to help find a way to apply them in our primary care setting. Thus, I started to search for answers. What are the prerequisites for setting priorities in PHC as a basis for decisions on rationing and resource allocation?

Now, several years later, the questions remain relevant. We still face a shortage of GPs, which contributes to making priority setting a day-to-day problem. Moreover, a recent report showed that only one-fifth of Swedish PHCC-managers thought that current funding principles support prioritisation of patients with high care needs, and two-thirds thought that funding principles can cause important patients groups to be forced aside (1).

From the perspective of health care staff, daily practice consists of meetings with individual patients. As some GPs have expressed it: "We don't treat populations, we treat individual patients". If resources are insufficient, prioritising and rationing care for individual patients will be a problem that staff has to deal with (either they consider it as their responsibility or not). This makes priority setting and rationing of individual patients an important issue.

From an international perspective, strengthening PHC is high on the agenda (2). An efficient and well-functioning primary health care system is essential,

now more than ever, in a situation of economic crisis (3, 4). Therefore I would argue that studies of the prerequisites for priority setting in PHC are urgent.

Priority setting and rationing – why and what it is

The problems PHC faces are not unique. During the past 50 years the percentage of gross domestic product spent on health care has increased from 3.7% to 9.4% in the OEDC countries. Growth in health spending has exceeded economic growth in almost all OECD countries over the past 15 years (5, 6). However, despite increasing spending on health care, resources are insufficient. Several reasons for the gap between patients' needs for health care and available resources have been suggested. New medical technology and safer treatments are continuously being developed and introduced (6). An aging population, higher expectations from patients, and decreasing acceptance of illness contribute to the gap (7, 8). This means that care has to be rationed, i.e. all health care needs cannot be optimally satisfied.

The situation with scarce resources in health care can be handled in different ways. Several studies show that rationing is often implicit (9-12). Physicians and other health care staff, may even be unaware of this kind of rationing; even if they know that resources are limited, they might not view the implications of their decisions as rationing (13). Patients might be even less aware of such rationing.

Implicit rationing is at risk of resulting in unequal treatment of patients (concerning geography, gender, age, etc.) and lower cost-effectiveness in health care at both the local and national levels (2, 6, 14-20). Non recognised rationing is also impossible for people to question and debate (21).

However, people's trust in the health care system is of crucial importance to maintain acceptance of solidarity-based funding (22, 23). Hence, rationing must be addressed in a way that is acceptable to everyone. It has therefore been suggested that decisions on rationing and resource allocation should be guided by priority setting, i.e. a ranking of different interventions or services based on agreed criteria. In addition, decisions and decision-making criteria and processes should be open to the general public (21).

In connection with the economic recession in the late 1970s and early 1980s, and the resource constraints that followed, a discussion about setting limits in public commitments started in Sweden. In the late 1980s, the debate became more focused on priority setting, and in 1992 a National Priority Setting Commission was launched as a political initiative with the intent to make priority decisions more open. The assignment to the Priority Setting Commission was to define the role of health services in the welfare society and to clarify what ethical principles should guide priority setting in health care. The initiative was partly stimulated by the report from the Norwegian National Priority Commission that was launched 1985 (24, 25).

Around the same time, priority setting discussions started in several other countries. Committees were set up in the Netherlands and Denmark to discuss methods, principles, and criteria for setting priorities. In New Zealand, the UK, and the state of Oregon in the USA, politicians tried to make concrete decisions on resource allocation openly, e.g. aiming to define a bundle of publicly financed services, or to develop clinical guidelines instead of principles (26). In the state of Oregon one of the first open processes for setting priorities took place in the late 1980s (27-30). However, the goals were hard to achieve, and neither in New Zealand nor UK was a definition of basic health care reached.

In Sweden, the National Priority Setting Commission suggested guidelines for priority setting including an ethical platform (consisting of three ethical principles) on which to base all priority settings. The Commission also declared that priority setting should be open (31). Thereafter, substantial work has been carried out to implement priority setting according to these guidelines in Swedish health care.

This thesis focuses on the primary health care aspects of Swedish priority setting and also addresses prioritising and rationing at the individual patient level. Using the included studies I explore priority setting and rationing in Swedish PHC.

Aspects of priority setting and rationing

In the literature and in everyday discourse, concepts like *rationing* and *priority setting* are not always used consistently (32-34). Hence, I introduce some definitions and discuss different aspects of some of the concepts that I will return to in the discussion section. Within the context of this thesis I intend to use the terms according to the descriptions given below.

Priority setting means to decide about resource allocation between different patient groups or different elements of care (35). To make these decisions, the competing interventions or services are placed in a rank order (36, 37). The ranking is based on decided criteria that may differ between countries and contexts (26, 38, 39). The rank listings must involve at least two options, and the ranked alternatives must be relevant.

The purpose of priority setting is to use the results for further decision-making. The rank listings can form the base for decisions on budget protection or in allocating additional resources to the highest ranked services. The listings can also be used to make budget cuts resulting in rationing of the lowest ranked services (38, 40). Rank listings can also form a valuable base for decisions to introduce and finance new services.

Many studies use rationing and priority setting synonymously (32, 33, 41). However, rationing can be defined as not optimally satisfying health (or social) care needs due to scarce resources (35, 42). Rationing concerning an individual patient is often referred to as *bedside rationing* (11, 12, 43). Examples from PHC could include not scheduling a patient for an appointment (even though it would probably be beneficial) because the GP is fully booked, or not referring a patient for further diagnostic tests (even though it would probably be beneficial) because the waiting list is too long.

Rationing has been classified in different ways (6, 44-46), but I have chosen to use Klein's classification, mainly because it appears to be the most frequently used in the literature (9, 44, 47-49). It consists of seven strategies for rationing: by denial, selection, deflection, deterrence, delay, dilution, and termination (35, 50)(Table 1). Each strategy may occur alone, but more commonly in different combinations. Some are the result of decisions at the system or programme levels, while others preferentially occur at the patient level, i.e. in bedside rationing (35).

Table 1. Different forms of rationing according to Klein (35).

Denial: Would-be beneficiaries of services or programmes are turned away on grounds that they are not suitable or that their needs are not urgent enough. By changing the threshold of eligibility, supply and demand can be matched.
Selection: The converse of denial, but can have the same outcome. Service providers select the would-be beneficiaries who are most likely to benefit from the intervention.
Deflection: Would-be beneficiaries are directed towards another programme or service. In effect the agencies safeguard their own resources by dumping the problem in the lap of someone else. A social problem becomes redefined as a medical problem and so on.
Deterrence: Making it difficult for patients to access services, e.g. by fees, short opening hours, incomprehensible forms to fill in and so on, to discourage them from coming.
Delay: Discouraging demand by giving patients appointments months away or putting them on waiting lists.
Dilution: Services and interventions are offered to as many as possible, but the content is reduced so everyone gets less, e.g. less time with the doctor, fewer tests, or cheaper and less effective treatment, i.e. lower quality.
Termination: To end a treatment or intervention (when it still would be beneficial to the patient or client), i.e. by discharging patents or declaring a case closed.

The base for rationing (and resource allocation) can be priority setting (rank listings), but rationing is often done without previous priority setting. In practice, most rationing is done implicitly and at the patient level. The staff might not be aware that their decisions are rationing decisions (13), and at times it is not possible to tell if failure to offer a certain service is rationing or not. To define it as rationing we need to know that the service was not offered because of *resource limitations* rather than other reasons. We also need to know that the intervention is *likely to be beneficial*, which is often difficult to know, especially in PHC (43, 51). In several situations withholding a treatment is *not* rationing. For example, treatment could be terminated because the patient is healthy, because it does not have the expected effect, because it has too many side effects, or because it is replaced with another treatment with the same or better effect.

Priority setting at different levels

Priority setting and rationing decisions take place at various levels in the health care system. It is useful to clarify which level is being addressed because this makes a difference concerning explicitness, responsibility, and methods for priority setting. However, the nomenclature and definitions for the different organisational levels of health care systems are not uniform. They are often called macro-, meso-, and micro-level which can refer to a hierarchical structure, such as national, regional, and local levels, but also to different type of decisions. In the latter case the three levels can refer to the health system level (resource allocation between local hospitals and/or PHC), the programme level (between different disease groups or patient groups), and the patient or individual level, at times called the clinical level (between individual patients) (42, 52, 53). Coast identifies four distinct levels: across whole services, within services but across treatments, within treatments (for one disease), and between individual patients (54). Decisions at different levels are related. System level decisions regarding funding for health care affect decisions at the programme and patient levels (42). In this thesis I focus on priority setting and rationing at the individual level, comparing it with the system or programme levels.

Vertical and horizontal priority setting

Another way to categorise priority setting decisions is as *vertical* or *horizontal*. Vertical priority setting involves ranking different interventions (prevention, diagnostic procedures, treatment, and rehabilitation) *within* one type of service, e.g. a medical specialty or concerning one health condition or disease (29, 55, 56). Traditionally, this is a task for health professional representatives. Horizontal priority setting involves ranking *between* different services, medical specialties, or between different conditions. At times, this is referred to as a task for politicians, but also for health care managers.

Vertical and horizontal priority setting are not distinctly separate concepts. Within one specialty, such as General Practice, many different types of conditions are common. Hence, to set priorities it is necessary to compare interventions concerning many different types of conditions.

Explicit and implicit priority setting

Open priority setting and rationing can be defined as when the decisions about resource allocation, the grounds for these decisions, and the expected consequences are available to anyone who wants to study them. *Explicit* priority setting or rationing is often used synonymously with open priority setting, both in the literature and in this thesis. *Implicit* rationing is the opposite; care is rationed, but neither the decisions nor the grounds for the decisions are clearly expressed (37, 45, 54).

Opinions differ on which is *preferable*, explicit or implicit priority setting and rationing. The arguments depend on the level in the health care system that is addressed; whether the issue explicitly concerns the whole process of priority setting (i.e. the grounds for decisions, the discussions preceding the decisions, the results, and the consequences of the decisions) or simply the decisions *per se*, and if it concerns internal explicitness *within* a health care organisation or "total" explicitness to the general public. Preferable or not, some argue that, total explicitness in rationing is not *possible* at the system and programme levels. Priority setting involves a process that is too complex to be explained by rational models (57). Explicit rationing would require rigid rules and excessive regulations. Furthermore, disaffected people would not accept rationing (once they learn about it), but would continue to complain and "confront government and the political process with unrelenting agitation for budget increases", which in the end would force policy makers to change their decisions (13). Increased explicitness about the results of decisions may reduce explicitness in how the decisions were made (58).

Nevertheless, policy makers in many countries, including Sweden, have tried to introduce policies to set priorities more openly (22, 26). With an open process it is possible for people to become aware of, and discuss, priority setting decisions and their basis, which is an important part of the priority setting process (59-61). Here, the underlying idea is that for people to perceive decisions as fair, both the actual result of decisions and the way the decisions were made, i.e. the process, is important.

The first aspect concerns *distributive justice* (outcome fairness), and the second *procedural justice* (fairness of the processes by which outcomes are allocated) (62). In health care, where public trust is essential, procedural justice is important (63). In studies about distributive justice (concerning decisions by the American Congress about general and specific funding) people appeared

to care as much, or more, about procedural justice as they did about the decision outcome (62). This is especially true when resources are limited and outcomes are uncertain, as is often the case in health care decision-making (64).

The idea of deliberative democracy is also an important argument for explicitness. The public discussions and reasoning where different aspects of an issue can be addressed before decisions are taken will yield better, more developed and considered decisions (21).

A third argument for explicitness is that with insight into how decisions are made, policy makers are forced to think through their decision-making (21).

Central components in priority setting

A main purpose of priority setting in health care is to distribute resources fairly. Some major components in priority setting could be categorised as *facts* (scientific or clinical facts about the services to be prioritised), *values* (ethical principles and criteria on which to base the decisions), and *process* (framework for the process). All are crucial components in priority setting, but their relative importance varies in different countries and contexts (26, 36).

Facts

In the 1980s and early 1990s a widespread opinion was that prioritisation could be based mainly on science, evidence, and clinical facts (65). Centres for health technology assessment were formed (66), and methods to systematically assess effects and cost-effectiveness were developed. Here, I will comment only on evidence based medicine (EBM).

Evidence based medicine

Sackett described EBM as "the conscientious, explicit, and judicious use of current best evidence in making decisions about the care of individual patients". In clinical work the practice of evidence based medicine means

"integration of the best available research evidence with clinical expertise and patient values" (67, 68). The scientific base for medical guidelines and priority setting decisions on a group level (regarding the benefits, risks, and cost-effectiveness of different interventions) is also referred to as EBM (60, 69). The purpose is to give lower priority to ineffective, inappropriate treatments or less cost-effective interventions so as to maximise the use of resources (36). EBM has become increasingly important in medicine even if the concept is not unquestioned, especially among GPs (70-72). To many clinicians it is difficult to combine EMB with traditional professional values such as independent and individual decision-making (73). EBM has met resistance from some GPs on the grounds that excessive focus on practising EBM interferes with patient-centred consultation. Hence, EBM and the patient-centred method seem to have become polarised instead of integrated (74). Moreover, lack of relevant and clear evidence in many areas of medicine creates difficulties in using evidence based methods as a primary basis for priority setting (75). This is especially problematic in PHC, where patients often have unclear and early symptoms, co-morbidities are common (76), and where there is a lack of research with a specific focus on PHC (77).

Values

In the 1990s, many argued that scientific knowledge or "facts" were not sufficient for setting priorities. In addition to facts, values grounded in moral views must form a basis for fair distribution of scarce resources (50, 78, 79). To make priority decisions openly, it is necessary to specify the values and ethical principles that are used (80). Different ethical principles originating from several ethical theories on distributive justice have been proposed for priority setting (42):

According to **utilitarianism** one should seek to maximise overall benefits at the societal level, i.e. recommend acts and policies that maximise aggregated welfare (81). This means that those with the highest capacity to benefit would receive highest priority. Benefit could be quantified as, e.g. sum of saved lives, or gained life years, or quality adjusted life years (QALYs) (78, 79). Critics of utilitarianism point out that since it addresses only the total quantity of welfare, not distribution, no attention is given to equality, to the worst off, or to the number of people who benefit (79, 82).

The basis of **egalitarianism** is that equality *per se* is valuable (82). All individuals should be treated equally and have equal opportunity to attain the basic goods in life, or equal chances to receive a scarce intervention (79, 81). This means that patients who are worst off would receive highest priority. However, this principle is insensitive to patients' likelihood to benefit from treatment (42).

In **prioritarianism** the concept of justice is that it is more important to improve health for worse-off than for better-off patients, but also (to a varying extent) involve the patients' capacity to benefit. This way of resource allocation applies even when only minor gains at high cost can be achieved, and thus a criticism is that prioritarianism ignores costs (79).

These principles have advantages and disadvantages. The goals of public health care systems are not unambiguous. They include maximising health, treating diseases, meeting health care needs, ensuring equality, and maintaining a sense of security in the population. Hence, political and social values are also important in priority setting (83, 84). Usually, priority setting frameworks use a combination of principles and criteria originating from different theories (42, 85).

Process

In the late 1990s, focus was placed on processes for fair priority setting. It was argued that people differ too much in background characteristics, e.g. ethnicity, gender, and income, to make it possible to reach consensus about what constitutes a fair allocation of resources to meet competing health care needs (23, 86, 87). Holm argued that even in countries where a national committee articulated principles that should govern priority setting, these principles could not form "a complete and non-contradictory set of rational decision rules", that "tell the decision-maker precisely how a given service should be prioritised in relation to other services" (85). In the absence of consensus on moral or ethical principles and criteria that could guide priority setting, procedural justice, i.e. a fair priority setting process, was emphasised (21, 62, 88).

The most well-known framework for a fair process of priority setting is Daniels' and Sabin's **accountability for reasonableness** (A4R). They have described four conditions important for a fair process of priority setting; relevance (rationales for priority setting decisions must rest on reasons that stakeholders can agree are relevant), publicity (priority setting decisions and their rationales must be publicly accessible to ensure that they are consistent), appeals/revisable decisions (a mechanism for revising decisions in light of new evidence and arguments), and enforcement (voluntary or public regulation of the processes) (21, 23, 59). Daniels' and Sabin's framework has had a major influence on priority setting work and research in many countries (49, 89, 90).

Daniels'' and Sabin's ideas originate from an American health care system different from the European systems (91). Private for-profit institutions, including managed care organisations and other insurers, oversee the provision of covered services to determine what is necessary and appropriate. This limits access to some beneficial medical services and forces patients to either forgo care or pay for it themselves (21, 92). However, decisions on limits regarding which care is offered, and the underlying reasons, are viewed as "trade secrets". Daniels and Sabin describe how this creates a "climate of suspicion and mutual cynicism" characterising the relationship between patients and health care providers. In this context Daniels and Sabin argue that in a just system, with mixed public and private institutions, even the private institutions must be publicly accountable and provide the rationale for decisions that affect the distribution of health care. This could include private, for-profit institutions in a large public discussion and deliberation process about priority setting in health care, "a major, unsolved public policy problem" (21).

Participants

When priority setting has been implemented and further evaluated, complementing aspects have been added to the frameworks. One important aspect is the participants, i.e. the people who make the priority setting decisions (88, 93, 94). A multidisciplinary decision-making group helps ensure that all relevant reasons are considered (36). Who should be included in the group depends on the decision level and context; international studies and reports usually suggest administrators and clinicians, but also members of the public and patients (both since they sometimes hade diverging opinions) (95, 96). Regarding the latter, emphasis has been placed on the importance of

empowerment (to optimise effective opportunities for participation in priority setting and to minimise power differences in the hierarchical health system) (36).

Synthesis

Neither facts, values, nor processes on their own, are considered to provide a sufficient base for priority decisions (36, 79, 97). Instead, a set of principles or criteria that are considered reasonable (representing facts, values, and process) are used to balance the different aspects in priority setting.

The three components (facts, values, and process) are balanced differently in different countries. Some countries, such as Norway, the Netherlands, Sweden, Denmark, and New Zealand, have nationally agreed on principles or criteria to guide prioritisation (26, 78, 98). Other countries, such as Canada and the UK have no nationally defined priority setting criteria (36, 86). In England and Wales, for example, the National Institute of Health and Clinical Excellence (NICE) uses cost-effectiveness as an important criteria for national decisions on introducing new technologies (60, 99), while UK's National Health Service (NHS) points out the importance of balancing all aspects, including values such as equity and need (100, 101). Concurrently, local health care providers define criteria reflecting their most relevant decision factors (or "reasons") as part of the prioritisation process (38). This might result in both varied and conflicting criteria (50, 80). For example, local criteria might give preference to local needs, e.g. where PHC trusts give highest priority to services in some sort of crisis, or where non-funding would lead to serious consequences such as service closure (38), or other important local issues like the choice of "strategic fit" and "academic commitments" as prioritisation criteria in Canadian health care (36).

Priority setting in Sweden

Ethical platform

The Swedish National Priority Setting Commission presented its proposal in 1995 (31). The Parliament made minor changes in the Commission's proposal and ratified it in 1997 (22). One stipulation was that priority setting in Swedish health care should be open. It should also be guided, at all levels, by three basic ethical principles very much influenced by the idea of prioritarianism, the so-called *ethical platform* (22).

The human dignity principle implies that everyone has equal value and equal rights. Personal characteristics and functions in society should not determine who should receive care, or the quality of care. Age and lifestyle, i.e. prioritising the "youngest first" with the intent to give everyone a chance for a long life, and giving lower priority to patients with disease caused by their choice of lifestyle, are debated (78, 102). According to the Swedish guidelines, biological age and future lifestyle could be considered since it might influence both the effects and the risk for side effects of different interventions.

The needs and solidarity principle states that resources should be directed to those in greatest need. According to the Government bill, solidarity means both equal opportunity of care and an effort to equalise the outcome of care, i.e. equal chances for life and health. Solidarity also means taking into account the needs of groups who are not aware of their human value, or are less able than others to make their voices heard and exercise their rights, e.g. children, the mentally ill, and elderly people with dementia.

The cost-effectiveness principle implies that when choosing between different interventions or patient groups one should strive for a reasonable relationship between cost and effect in terms of improved health and quality of life. According to the Commission, the cost-effectiveness principle should be applied only when comparing methods of treatment for the same disease since the effects cannot otherwise be compared in an equitable way. However, the Government bill states: "…it is essential to differentiate between the cost-effectiveness of a treatment for a particular individual and that for health care at large. A cost-effectiveness principle that concerns choices between different interventions for the individual patient must be applied as proposed by the inquiry, and is subordinated to the principles of human dignity and needs and

solidarity. Nevertheless, it is essential for health services to strive for high cost-effectiveness as regards health care services in general" (22). Here, the Government indicates different ranking of cost-effectiveness in priority setting between the individual level and the group (system or programme) level.

The ethical principles were placed in rank order, with the human dignity principle ahead of the need and solidarity principle, followed by the cost-effectiveness principle. A general interpretation of the ranking of the principles in the ethical platform implies that society is willing to pay more per health gain for patients with more severe conditions.

In 1997 the Swedish Parliament ratified the guidelines and integrated them into the Health and Medical Services Act (22). Also added was an amendment stating that every patient who contacts health care shall, as quickly as possible, be given a medical assessment of his or her state of health, if this is not obviously unnecessary. However, the law does not state that the assessment must be done in person. A telephone contact with a nurse can be sufficient.

According to the Government bill, the Swedish guidelines for priority setting were intended to support priority setting at all levels in health care, including the individual level (22). The government described a political/administrative level where priority setting decisions are population-based, concern resource allocation, and are based on "political values, epidemiological knowledge, and health economic evaluations". At the individual level, clinical-level priority setting was described as the responsibility of the health care staff. It was also stated that "each case is unique and must be assessed by the unique circumstances of the situation, but with the guidance of considered ethical principles" (22). Currently, however, little is known about how the priority-setting principles are actually being applied on the individual level.

Priority setting groups

On their own the ethical principles did not provide enough guidance to support priority setting in practice. The Swedish Government, in its bill, tried to give concrete examples about the application of the principles through some general guidelines for priority setting in health care (22). These general guidelines included four priority setting groups based on the type of disease or treatment in question. The groups were based on the ethical platform and

aimed to exemplify the guidelines. Highest ranked in these groups were care for acute, life-threatening disorders, care for disorders that would lead to permanent disability or premature death if left untreated, care for severe chronic diseases, palliative care, terminal care, and care of people with limited autonomy. Second ranked were prevention, habilitation, and rehabilitation, and third ranked was care for less-severe acute and chronic disorders. Care for reasons other than disease or injury were the lowest ranked. Self-care was emphasised in the guidelines: "In all priority setting groups, every opportunity should be taken to provide encouragement, instruction, and support for self-care." The Government bill clarified that the priority setting groups were only examples, and that the need for care in each case must be judged on the conditions of that particular case. It also noted that both acute and chronic diseases can vary in severity from time to time in the same patient. Hence, care of the same disease, even in the same patient, could at different stages fall into different priority setting groups.

The first medical assessment (making a diagnosis) was placed outside of the priority setting groups because the first medical assessment provides the basis for further management, i.e. the basis for priority setting. The Government bill stated: "Without a good initial medical assessment, it may therefore be difficult to apply the ethical principles for priority setting." In this context the role of PHC was emphasised. The Government bill also emphasised the importance of the diagnosis, and the need for highly skilled PHC for the first medical assessments to ensure good quality and cost-effectiveness of health care, since "more experienced personnel can both refrain from unnecessary testing and, at an earlier stage, decide if costly investigations are needed or not".

The national model for priority setting

Later the priority setting groups were criticised for being difficult to use for priority setting in practice. Care for the same disease could fall under different priority setting groups at different times. Moreover, the groups did not consider the patient benefit or cost-effectiveness of different interventions (45). Instead, the ethical principles and guidelines for priority setting were operationalised for practical use on the initiative of the National Board of Health and Welfare and the National Centre for Priority Setting in Health

Care, together with several professional organisations and county councils (98, 103).

The needs and solidarity principle and the cost-effectiveness principle were transformed into three key criteria: severity of the health condition, expected benefit of the intervention, and cost-effectiveness of the medical intervention (98, 104). According to the national model for practical priority setting, the human dignity principle is applicable in all types of prioritisation situations (since it tells us what aspects we are not allowed to consider). Table 2 schematically describes the relationship between the ethical principles and the criteria, as well as the variables that should be considered in appraising each criterion. The model was based on the practical experiences from priority setting in Sweden and was also inspired by the Norwegian priority setting guidelines (24). Severity, patient benefit, and cost-effectiveness are criteria often included both in nationally and locally decided frameworks for priority setting (26, 38, 39, 101).

Table 2. Three key criteria to be considered in priority setting (98).

<table>
<tr><td colspan="4">Human Dignity Principle</td></tr>
<tr><td colspan="2">Needs and Solidarity Principle</td><td colspan="2">Cost-effectiveness Principle</td></tr>
<tr><td>Severity level of a health condition</td><td>Patient benefit/effects of the intervention</td><td>Cost-effectiveness of intervention</td><td rowspan="2">E V I D E N C E</td></tr>
<tr><td>Current health condition
- suffering
- functional impairment
- quality of life

Risk for
- premature death
-disability/continued suffering
- lower quality of life</td><td>Effects on current health condition
- suffering
- functional impairment
- quality of life

Effects on risk
- premature death
- disability/continued suffering
- lower quality of life

Risk for side effects and severe complications from intervention</td><td>Direct costs
- health service interventions,
- other measures, e.g. travel

Indirect costs

→ … in relation to benefit of the intervention</td></tr>
<tr><td colspan="4">Prevention → Diagnostics → Treatment → Rehabilitation</td></tr>
</table>

The model implies that priority setting or rationing always consider pairs of conditions and interventions (the priority setting objects). The pairs are ranked on the basis of three key criteria (severity, patient benefit, and cost-effectiveness) (98, 104). "Facts" are also considered in the model. The quality of the knowledge base (concerning patient benefit and cost-effectiveness for an intervention) should also affect the final prioritisation. Thus, the Swedish national model is an example of how the aspects of priority setting (facts, values, and process) can be balanced.

The national model is used on a systems level by the National Board of Health and Welfare for producing national guidelines for priority setting. To date, guidelines concerning eleven different diseases or disease groups have been produced, e.g. depression and anxiety, cardiac care and stroke (55, 56). Studies show that some of the guidelines have been implemented at a programme level, especially in secondary care (105). Data show that the guidelines on heart disease are also used in priority setting of individual patients (106). The National Board of Health and Welfare has scrutinised and prioritised some methods commonly used in PHC concerning prevention of health problems and risk.

The national model has also been used for policy decisions (e.g. for priority setting as a base for rationing and for reallocation of resources to new services) in some county councils, e.g. Västmanland, Kronoberg, and Västerbotten (107-109). In these activities, PHC participated on a programme level.

Despite the integration of the ethical platform for priority setting in the Swedish Act on Health and Medical Care many national decisions concerning resource allocation in PHC are not in line with the platform. Examples include different targeted grants, e.g special compensation for CBT treatment for patients of working age and registration of patients in the dementia register (110, 111) and the prioritisation of care staff for immunisation during the swine influenza pandemic in 2009 (A(H1N1)pdm09, according to WHO nomenclature (112)).

Primary health care and priority setting

Primary health care and general practice are two different concepts (20, 113, 114). **Primary health care** is a sector of health services where GPs, nurses, physiotherapists, and other professionals commonly work together at health centres. Primary health care can be described as "first-contact, continuous, comprehensive, and coordinated care provided to populations undifferentiated by gender, disease, or organ system" (16). **General practice** (or **family medicine**), on the other hand, is a medical specialty, "an academic and scientific discipline with its own educational content, research, evidence base, and clinical activity, and a clinical specialty orientated to PHC" (113). A GP is a specialist in family medicine/general practice.

Becoming a specialist in family medicine and working as a GP in Sweden requires 5 years of specialist training. About 20% of all specialists are GPs (115). Three consultations with a physician per inhabitant and year is average; slightly more than half of these are with a GP (116). In Swedish PHC, teamwork dominates. GPs work in close collaboration with district nurses and other health care personnel. Most appointments with a GP are preceded by a telephone call to a nurse that decides whether to schedule the patient to see a GP, or whether advice by telephone will suffice. Prioritising takes place at an individual level where staff decide who will be given an appointment and who will have to wait, and also when decisions concerning the choice of interventions and treatments for individual patients are made during the consultations.

Much of the priority setting in practice, and many of the studies on priority setting, reflect conditions in secondary care rather than primary health care. In Norway, the results from the world's first National Priority Commission were launched. The Norwegian guidelines for priority setting did not cover PHC, but only hospital care. Some approaches for priority setting in PHC have been proposed (69, 89, 117). However, few examples of models and ideas for improvement are based on experiences from PHC, but rather secondary care (41, 49, 90). An explanation for the focus on secondary care in priority setting (both in practice and in the literature) might be that secondary care has some striking examples of the need for rationing, e.g. transplantations, limited number of beds in emergency departments, and some very expensive treatments (e.g. certain cancer treatments).

Presented below are some special characteristics of PHC that distinguish it from secondary care. They not only make priority setting important, but also may affect the prerequisites for priority setting in PHC.

High accessibility and early symptoms: As PHC is where most patients make their first contact with health care, it must be accessible when needed. Since PHC is the first line of care, many patients present with illness at an early stage. In more than half of a GP's consultations during a routine work week, the reason for the visit was attributed to new symptoms that the patient wanted to have evaluated (118). This makes the patients an important source of knowledge (119) and thus, patient-centred work is considered a core competence in PHC (120, 121). However, after the consultations the reason for the symptoms was still unclear for over 10% of the patients, i.e. no diagnosis was given (122).

Diversity of health problems: General practice provides preventive, curative, and rehabilitative services regarding common problems in the population. A high proportion of patients present with a vast variety of health problems. Acute and chronic health conditions are managed simultaneously. Many patients have no disease, but do not feel well anyway, a few have rare and serious diseases, many patients present several health problems at the same time and multimorbidity is common. According to recent studies more than one-fourth of the patients in PHC have two or more chronic diseases (123, 124).

Long-term relationship: PHC focuses on the long-term health of a person rather than on the short-term duration of a disease. Close and trusting relationships with GPs and nurses who know their patients is an essential quality to achieve better health outcomes in PHC (2). Continuity of care facilitates early detection and prevention of problems, which contributes both to better quality of care and better outcomes (19).

Primary health care population: PHC has a specific decision-making process determined by the prevalence and incidence of illness in the community (113).

Funding: Sweden has a predominantly public health care system. It is decentralised with 21 independent regions (county councils) governed by elected politicians. They are responsible for both funding (mainly by local taxation) and delivery of health care. The central government still attempts to

control the general direction of the health care system through targeted grants, regulation, subsidies, evaluations, and guidelines. Almost all staff, including GPs and other PHC staff, are salaried (73, 125, 126).

Expansion of the private and semiprivate sectors accelerated after the general election in 2006 when a new and pro-private coalition government was elected. However, most private health services are just privately *owned and produced* but still publicly financed (by taxation). Private care has to follow the same regulations as public care. This means that patients have access to more or less the same range of care, whether public or private. Consequently, the possibility to purchase care (out-of-pocket or by private insurance) that is not offered by the tax-financed system, which is a reality in many other countries, is almost non-existent in Sweden (21, 50, 92, 126).

Particularly in PHC, privately produced care has expanded the last years (127). Private actors are encouraged to provide health services with public financing. By a parliamentary decision, a new PHC system with freedom of establishment for accredited private providers who fulfilled requirements determined by the local county council has been mandatory in all county councils from 2010. In this system, patients choose their PHC provider and are free to make a new choice when they want (73, 128). In nearly all county councils each PHCC is funded by capitation fees based on the number (and often also the burden of disease and socioeconomic status) of listed patients. Several county councils also allocate a small percent for target payments (payment according to the degree of success, for example if certain quality goals are reached). In some county councils this is complemented with a small fee-for-service, i.e. the number of visits determines a small portion of the budget. Hence, in most regions each PHCC receives a limited, almost fixed, budget per month to serve its patients.

Contribution to health economics and outcomes

Patient-centred practice makes the patent perceive that common ground is achieved with the physician. It also improves health status and increases the efficiency of care by reducing diagnostic tests and referrals (121). A health system with a high PHC orientation is more likely to produce better population health outcomes with greater user satisfaction and at lower cost (16-18, 20, 34, 129). For the same type of patients, the same outcome can be attained using less expensive technology (130, 131). Countries with a higher

proportion of PHC physicians have, on average, 20% lower health care costs without lowering medical quality (132, 133). Availability to GPs correlates positively with health outcomes, e.g. age-adjusted and standardised overall mortality, mortality associated with cancer, stroke, respiratory, and cardiovascular diseases, neonatal mortality, and life expectancy (134, 135). Well-developed PHC has also been shown to reduce the consequences for public health that can be related to socio-economic inequalities in society (19, 136, 137). Moreover, well-developed PHC is associated with less need for hospitalisation of elderly, multiple-diseased patients and lower costs for their care (138-140).

Thus, the complexity of PHC is essential for its results. However, the same unique characteristics that cause the complexity can make priority setting difficult.

Experiences from priority setting in primary health care

During the early 2000s, priority setting according to the national guidelines became a topic of interest in PHC (141). Priority setting groups were considered a relatively easy concept, and the idea of placing the first medical assessment outside of the priority setting groups made sense to staff in PHC (because the first assessment forms the basis for priority setting). Also the Government's emphasis on conducting the first assessment in PHC was appealing. At several PHCCs the staff started to scrutinise their services from a prioritisation perspective, using the priority setting groups as a basis. The entire team participated, i.e. doctors, nurses, physiotherapists, occupational therapists, and others, in constructing rank listings and changing routines and schedules. The work entailed allocating resources to elderly, to patients with chronic diseases, and to rehabilitation at the expense of care for mild acute and semi-acute conditions (142). The Swedish Association of General Practice wrote a "study letter", a tool for continuing medical education (143) and the Committee on Quality and Patient Safety (SfamQ) constructed a priority setting indicator (a comparison between the number of visits for certain chronic and acute conditions where the target was more chronic than acute) that is still in use (144). The priority setting groups were also used as a basis for regional guidelines for priority setting in PHC in some county councils, for

national reports, and for inspections in PHC by the Swedish Board of Health and Welfare (103, 145, 146).

Some PHCCs still use the priority setting groups for day-to-day priority setting (147). However, after the initial attempts to use the priority setting groups as basis for priority setting, even Sweden is largely lacking broad initiatives to set priorities in PHC at both the programme and individual levels. The Swedish national model for priority setting seems to not have inspired PHC to take new initiatives on priority setting.

I have found only a few studies about how priority setting and rationing in routine PHC are *actually carried out*. One study analysed new ways for priority setting in PHC, i.e. how to establish a Priorities Forum Panel, find criteria and rank new funding proposals in primary health care trusts (38), and a recent UK report described different approaches to priority setting in PCTs (100). Also the prevalence of bedside rationing and the frequency of disagreements concerning rationing between patients and GPs have been studied (10, 148).

Hence, to find a direction for the future and perhaps also facilitate decisions on how priority setting could be further developed in PHC, more knowledge about the prerequisites would be beneficial. This includes knowledge about how staff in PHC deal with lack of resources in their day-to-day work, how staff and patients perceive this day-to-day rationing, their opinion on how priority setting and rationing should be carried out, and also knowledge about the practical applicability of the Swedish model with its priority setting criteria in PHC.

So, what are the prerequisites for the implementation of priority setting in PHC as a basis for decisions on rationing and resource allocation?

AIMS

The general aim of this thesis is to study and analyse the prerequisites for priority setting in PHC in Sweden.

Specific aims of the studies:
- to explore strategies to handle scarce resources in Swedish routine PHC (Paper I).

- to analyse: patients' attitudes towards priority setting and rationing, and patient satisfaction with the outcome of their contact with Swedish PHC (Paper II).

- to describe and analyse: 1) how GPs, nurses, and patients set priorities in routine PHC, and 2) the association between three key priority setting criteria and the overall priority assigned by the GPs and nurses to individual patients (Paper III).

- to analyse how GPs and nurses perceive the application, in their clinical practise, of the three key priority setting criteria: severity of the health condition, patient benefit, and cost-effectiveness of the medical intervention (Paper IV).

MATERIAL AND METHODS

Table 3 presents an overview of the characteristics of the four studies on which this thesis is based.

Table 3. Characteristics of Papers I-IV.

	Paper I	Paper II	Paper III	Paper IV
Study population	GPs, nurses/ district nurses, physiotherapists, PHCC managers	Patients in PHC	Patients in PHC GPs, Nurses/ district nurses	GPs, Nurses/ district nurses
Setting	17 randomly selected PHCCs	4 PHCCs purposely selected for being located in areas with different populations as regards age and social factors		
Material	62 interviews	2517 questionnaires	- 3679 staff questionnaires - 1851 matched pairs of questionnaires (i.e. 1 questionnaire from a patient and 1 from the staff)	8 focus groups with 16 GPs and 15 nurses
		38% visits at PHCC, 62% telephone contacts		
		33% contact with a GP, 53% with a nurse, 14% with rehabilitation staff	39% contact with a GP, 61% with a nurse	
Data collection	Interviews	Questionnaires	Questionnaires	Focus groups
Analysis	Qualitative	Quantitative	Quantitative	Qualitative

Study population and material

Paper I

To investigate the different ways of managing scarce resources in day-to-day PHC, an invitation to participate in the study was sent to the managers of 45 randomly selected PHCCs in south and mid Sweden (a large geographic area corresponding to 88% of Sweden's population and 823 PHCCs). Seventeen PHCCs accepted the invitation to participate. The main reason for not accepting was lack of time. To gain a broad perspective of opinions (sample saturation) we wanted to interview staff representing different professions,

including the PHCC manager, at each PHCC. We conducted 62 interviews; 28 with GPs (12 of whom were also managers), 23 with nurses or district nurses (11 managers), and 11 with physiotherapists. The average years of experience in PHC was 25 (range 6-42). Two-thirds of the respondents were women.

The interviews followed an interview guide constructed by the research team. Table 4 presents the interview themes and questions. The interviews also included questions that are reported elsewhere (149).

Table 4. Contents of interview guide.

Interview themes	Questions
Rationing and prioritising	Are there situations with a lack of resources at your PHCC? Examples? How do you handle such situations? Who do you think should be responsible for the different types of priority setting? Can you give examples of opting out or rationing at your PHCC? Were the rationing decisions preceded by conscious prioritisation?
Swedish guidelines for priority setting	Are the principles for prioritising in the Swedish guidelines (the so-called ethical platform established by a parliamentary decision in 1997) known to you? If so, how would you summarise them?
Need and demand	How do you perceive the general public's expectations of PHC? Do you think there are unrealistic expectations? Do you perceive that individual patients or patient groups are excluded due to patients with less important health care needs? Examples? Do you think that important patient groups being forced aside is a problem?
Open priority setting	Is there any kind of "open priority setting" at your PHCC? Examples? Do you think more open priority setting is desirable? How should the politicians be involved in priority setting?

Central concepts (rationing, prioritising, and open priority setting) were explained to the respondents during the interviews (Table 5).

Table 5. Definitions given during the interviews.

Rationing and prioritising: In a situation of a lack of resources it may be necessary to either opt out of something or to limit access to care (rationing). Rationing can be done by lowering quality, e.g. less time or less expensive drugs, but with a poor effect. Such decisions should ideally be preceded by a conscious ranking of different options. To prioritise means to put ahead of, i.e. that something is selected in favour of something else.
Open priority setting: Priorities can be more or less open. The degree of openness depends on the extent to which the decisions, the grounds, and the arguments (including consequences) are available to others.

Papers II, III, and IV

To learn about patients' opinions on priority setting (Paper II) and to try to use explicit priority setting criteria in day-to-day PHC (Papers III and IV), we collected data for all three studies at four PHCCs in three different county councils in southern Sweden. The PHCCs were chosen through purposive sampling; they were located in areas with different populations as regards age and social factors. Around 25 000 patients were served by the four PHCCs. Data were collected for studies II and III by using questionnaires to patients and staff during a 2-week period in 2004 (Table 3). For Paper IV, focus groups were conducted in 2005 with staff who participated in the questionnaire studies (Table 3).

For **Paper II** we distributed questionnaires about patients' opinions on priority setting and their experience of rationing (Appendix A) to all patients who had contact with the four PHCCs concerning health problems during the 2-week study period. The questionnaire included five statements. The first three concerned attitudes towards the fact that priorities are set (statements 1-3 in Table 8). These statements were used and validated in an earlier Swedish study regarding general public attitudes towards priority setting (150). The other two statements were constructed for the present study and dealt with whether politicians or health care staff should set priorities in cases of limited resources (statements 4 & 5 in Table 8). The patients could respond "fully agree", "partly agree", "don't agree", or "don't know" to each of the statements. Two questions concerning whether the patient "felt excluded due to lack of resources" and patient satisfaction "with the outcome of their contact" were added to the questionnaire (questions 6 & 7 in Table 8). To these questions the patients could respond "yes" or "no". Parents were asked to help fill in the questionnaires when children were involved. Patients who telephoned received the questionnaires by mail. During the study period, 3821 patient contacts were registered. In 3509 contacts, questionnaires were handed out to the patients, and 2517 (72%) were returned.

Data for **Paper III** were collected concurrently by an additional question in the patient questionnaire used in Paper II and by distributing paired questionnaires to the GPs or nurses with whom each patient had contact (Appendixes A and B). The questionnaires were pretested at two of the participating health centres, and minor adjustments were made before the study. Before the study the staff received oral and written information about the study and three key criteria. First, staff registered the health problem or

condition that was the main reason for the patient's contact and the related intervention or measure (e.g. further investigation, medical treatment, or health advice) either from a list of common conditions and interventions, or in free text (see examples in Table 6). Second, a 3-point rating scale (high, moderate, or low) was used to estimate the severity of the health condition, the expected patient benefit of the planned intervention, and the cost-effectiveness of the planned intervention. Finally, using a 10-point scale they assigned an overall priority to the patient by answering the question: How would you prioritise the patient on a scale of 1 to 10 where 1 is the highest? The patients used a similar 10-point rating scale to answer the question: "How important do you think your health care needs are compared to other patients?" During the two weeks, 3821 patient contacts were registered. Staff filled in 3679 questionnaires (96% of the contacts), and patients filled in 2150 questionnaires (56% of the contacts). From the 2150 patient questionnaires we identified 1851 matched pairs (i.e. 1 from patient + 1 from staff regarding the same contact). The 299 non-matched patient questionnaires were largely due to errors made by the staff in coding of the questionnaires that made matching impossible. In some cases the reason was attributed to missing questionnaires from staff.

To compare priority setting concerning different patient groups, two subgroups were created from the registered pairs of health conditions and interventions ("acute/minor" and "chronic stable"). Two of the authors (EA and MA, both senior GPs) independently sorted out the subgroups. Disagreements were resolved through consensus. The acute/minor group consisted of acute conditions and minor and time-limited health problems involving minor signs and symptoms, e.g. mild infections and minor injuries with little or no medical impact from the related medical interventions. The chronic stable group included check-ups for chronic stable conditions that were at risk for future complications, e.g. heart failure, diabetes, COPD, and atrial fibrillation. These two groups, or similar groups, are well-known in PHC (151, 152). Health conditions and interventions that we excluded were acute conditions *requiring* further diagnostic procedures or treatment, e.g. infections such as pneumonia or upper urinary tract infection. Also exacerbation of chronic conditions and long-lasting conditions with no or little risk for future complications were excluded (Table 6).

Table 6. Examples of health problems and related interventions included in the acute/minor category, the chronic stable category, and not included in any of the categories for analysis.

Acute/minor (n=343)	**Chronic stable (n=223)**	**Not included (n=1285)**
Conjunctivitis *Advice and possible medical treatment*	Hypothyreosis without present symptoms *Check up of medical treatment*	Pneumonia or suspected pneumonia *Examination and treatment with antibiotics*
Sore throat, fever below 38.5 *Advice by telephone*	COPD, patient smokes *Check up, advice on smoking cessation*	Suspected ischemic heart disease, not acute *Examination, and possible further investigation and medical treatment*
Mild abdominal pain *Advice by telephone*	Type 2 diabetes mellitus with complications *Check-up, intensified treatment, possible treatment of complications*	Eczema *Examination and treatment*
Myalgia or tendinitis, short duration *Examination and possible medical treatment or referral to physiotherapist*	Atrial fibrillation, risk factors for thrombosis *Anticoagulant therapy*	Osteoarthritis (hip or knee) *Training instructions, medical treatment*

In **Paper IV** we wanted to find out the staff's experience when using the Swedish key priority-setting criteria. Focus groups were chosen for data collection because this method is effective in exploring how people think and reason in certain situations and why they think the way they do (153). The interaction between participants enforces exploration and clarification of their views (154). Thus, we needed to compose a group not only with knowledge about the criteria, but also with experience in using them in day-to-day practice. Hence, participants for focus groups were recruited by inviting all GPs and nurses who participated in study III (in total 24 GPs and 54 nurses from the four PHC centres) to participate. Written information was sent to each of them. The focus group sessions were held at the PHCCs, one group with GPs and one with nurses at each PHCC. All GPs and nurses on duty the day of the focus groups (16 GPs and 15 nurses) took part. The focus groups met 5 months after the staff had participated in study III.

Qualitative analyses

For Paper I the interviews were audio-recorded verbatim and transcribed unedited for subsequent analysis. Initially, the transcripts were read several times to obtain an overview of the material. Subsequently, meaning units in the text were identified. A combination of different methods is common in qualitative research (155), and in the next steps the analyses continued using two methods:
1. Template analysis: Guided by our previous knowledge expressed in the interview schedules, the statements were manually sorted into themes (156-158).
2. Editing analysis style: Searching for new categories within the themes by identifying and coding different aspects of the themes. In the next step, categories were formed by analysing and combining coded units (156-159). Within the theme "handling lack of resources" three different categories were identified.

In connection with all focus group sessions (Paper IV), notes about the discussions, the group interactions, and the researchers' initial reflections were made (160). The focus group discussions were audio-recorded verbatim and transcribed unedited for subsequent analysis. The further analysis followed the key stages: familiarisation, identifying a thematic framework, indexing, charting, mapping, and interpretation as described by Rabiee (155). Initially the transcripts and research notes were read several times to obtain an overview of the material. Subsequently, meaning units in the text were identified and ideas and concepts were initially coded. In the next step, quotes were sorted out and subsequently (manually) rearranged into the themes developed from the first coding and concurrently also according to the topics from the main questions in the focus groups (i.e. the three key priority-setting criteria). The "long-table" approach was used (153). In this way themes developed both from the research questions and from the participants' narratives (155). In the last step, categories were formed by analysing and combining coded units (155-159).

During several meetings the research group discussed themes and categories for Papers I and IV. Disagreements were resolved through consensus.

Statistics

According to the patients' answers to statements 1-3 and 4-5 (Table 8) in Paper II, new categories were created based on the patients' opinions on priority setting (priority oriented/not priority oriented/no definite opinion) and preferred priority setter (politicians/medical staff/no definite opinion) (Table 9).

Bivariate correlations between all the variables were performed, and variables with significant correlations were then analysed, in both a univariate and a multiple logistic regression. Priority-oriented and patient satisfaction outcomes (yes/no) were used as dependent variables in the logistic regression analyses. Statistical analyses were performed using Statistica 6.0 (StatSoft). A p-value <0.05 was considered statistically significant.

In Paper III we used paired Student's t-test to determine the relation between patients' and staff's priority setting. Multiple regression analysis was used to study the relationship between the 10-point scale on overall prioritisation (dependent variable) and the 3-point scale for priority setting criteria (independent variables).

To examine if the type of consultation, i.e. acute/minor or chronic stable, affected the impact of each of the three different priority setting criteria on overall priority setting, the regression models included interactions between the predictors and types of consultation. All other two-way interactions were also examined. Estimations were made using robust standard errors. All independent variables were tested for multicollinearity by examining their Variance Inflation Factor (VIF). VIF values ≥ 2.5 were considered to indicate multicollinearity.

Ethics

The Research Ethics Committee of Linköping University approved the studies.

All eligible participants were informed about the studies, that participation was voluntary, and that they could decline to participate without giving any reason. All received written information about the studies, and consent was obtained according to the Swedish Act (2003:460) on Ethics Review of Research.

RESULTS

Paper I

Expectations from PHC and experience of a lack of resources

Most of the staff perceived that patients had high confidence in PHC as well as high and often unrealistic expectations concerning accessibility, referrals to all types of treatments and diagnostic procedures, and the staff's knowledge. The respondents described a constant lack of resources rather than single situations of scarcity. Shortage of staff, GPs in particular, was a major problem. Consequently, patients could not be given appointments with a doctor to the extent the staff thought they needed. Explanations for the situation were expressed as an imbalance between the task and the available resources; funding did not fully cover patients' needs and expectations. This situation was exacerbated by political promises to patients. Another reason given for the lack of resources was that tasks previously performed at hospitals had been shifted to PHCs without allocating extra resources.

Handling a lack of resources

Different ways to deal with the lack of resources were identified; on one hand, trying to avoid rationing and, on the other hand, ad hoc or planned rationing (Table 7).

Trying to avoid rationing could be done by prioritising patients with chronic disease to reduce later demand for care, trying to work more efficiently by finding new ways to address the work load, (e.g. by using group treatment, planning the staffing schedules to be more efficient, managing waiting lists differently, and having patients see residents or nurses instead of GPs but with back up from experienced GPs). Reducing tasks not directly connected to patient care was also a way to avoid rationing (e.g. time spent for administration, quality improvement, continuing medical education, and other forms of further training for staff). A different way to cope with the heavy workload and avoid rationing was simply that staff tried to work harder, e.g. stretching themselves thin, skipping lunch, and overbooking patients (Table 7).

Ad hoc rationing was defined as rationing decisions made to solve problems for the moment. This rationing was described as if it "just happened" without planning. Examples of ad hoc rationing included delaying appointments, placing patients on waiting lists, telling them to call back later, or directing them elsewhere. Staff at many health centres mentioned that this type of rationing resulted in undesired consequences, e.g. no time for preventive measures, lack of continuity for patients, difficulties to plan care for patients, and that certain patients were forced aside, especially the chronically ill and elderly, and mainly those who were silent and did not assert themselves (Table 7).

A few health centres **planned rationing** by ranking patient groups, e.g. prioritising patients with inadequately controlled diabetes over patients who wanted an allergy test or removal of a nevus and letting the lowest prioritised wait. However, most of the PHCCs that planned rationing did not rank their patient groups but tried to reduce the number of visits, e.g. by denying general health check-ups or annual check-ups for patients with non-severe conditions (e.g. hypertension with no other risk factors) and by reducing the number of return visits (e.g. avoid planning check-ups of patients after infections such as pneumonia). Instead, these patients were advised to contact the PHCC if they did not recover. Substituting visits at the PHCC with phone calls was also common. Periodically excluding certain tasks (e.g. treating cosmetic problems and issuing certain types of medical certificates, e.g. for driving licenses, employment, and sports) was also common. Physiotherapists reduced treatment time for each patient to see as many patients as possible instead. Redirecting certain patient groups and prescribing cheaper drugs were other common ways of planned rationing. Even if the consequences of rationing were considered, the staff expressed some doubt in their decisions. They worried about the possible consequences of the rationing, e.g. what could happen to the patients who got a cheaper drug, self-care instead of seeing a GP, or physiotherapy for only a short period (Table 7).

The examples of rationing we found corresponded to the forms of rationing identified by Klein (35) (Table 7).

Table 7. Different ways of handling a lack of resources.

Category	Actions	Type of rationing[1] (intended or unintended)
"Trying to avoid rationing"	Planning care by prioritising patients with chronic disease to prevent a later demand for care	No rationing
	Work more efficiently (use group treatment, manage waiting lists differently)	No rationing
	Having patients see residents or nurses instead of GPs	Dilution
	Reduce time for: administration, quality improvement, continuing medical education and other forms of further training for staff	Dilution, Deterrence
	Work harder, overbook patients	Dilution
"Ad hoc rationing"	Delay appointments Put patients on waiting lists	Delay
	Tell patients to call back later	Deterrence
	Forgo preventive actions	Denial
	Direct patients (in general) somewhere else	Deflection
"Planned rationing"	No check-ups for certain patients groups (general health check-ups, yearly check-ups of non-severe chronic conditions, check-ups after infections) Not issue medical certificates Not treat cosmetic problems	Denial
	Longer between check-ups Recommend self-care Substitute visit with phone call Reduce number of treatments/treatment time Prescribe cheaper drugs Self-care	Dilution
	Redirect patient groups	Deflection
	Rank patient groups before rationing (e.g. prioritise patients with inadequately controlled diabetes before patients who wanted an allergy test or a nevus to be removed)	Delay

[1] Type of rationing according to Klein (35)

Potential to improve the procedures for rationing

The staff expressed lack of guidelines for rationing and of support from politicians for their rationing decisions. A few respondents, mostly the managers of PHCCs, were aware of the Swedish ethical principles and criteria

for priority setting but uncertain of the content. Nearly all respondents expressed that they wanted more open priority setting in PHC. They believed that if the results from prioritisation decisions were open to public and patients, and patients knew what to expect from PHC, the communication between the patients and staff would be facilitated. A few thought that more open priority setting processes would force them to follow complicated guidelines and make them feel uneasy from having to say no to patients. Some also feared that "mandatory" guidelines would entail insecurity for patients.

Most of the respondents wanted politicians to be responsible for the overall allocation of resources, including setting the limits for the responsibilities of public medical services. They also wanted politicians to conduct a dialogue with the general public concerning the limited PHC resources available, and there was a clear opinion that politicians had not done this. Some pointed out that priority setting was a joint task between politicians and medical staff; they were prepared to contribute their medical knowledge. A few respondents thought that politicians lack competence in priority setting and should not take part at all.

Paper II

Most of the patients did not accept any resource limitations in health care. Less than 10% of them disagreed with the statements "best possible care should always be offered, regardless of cost", and "all health care needs should be met, even minor problems". However, 49% of the patients fully or partly agreed that some services must be excluded from tax-financed health care (Table 8).

According to their answers to statements 1 to 3 (Table 8), 6% of the patients were classified as priority-oriented, (i.e. they had a positive attitude towards prioritising) and 72% as non-priority-oriented (Table 9). Some 22% of the patients did not adopt a definite position on prioritising. Younger patients (<65 years old) were more priority-oriented than older patients, as were men compared to women.

A majority (73%) of the patients preferred medical staff to have the main responsibility for priority setting; some 5% were in favour of politicians setting priorities, and in this group patients had a more positive attitude towards priority setting; 22% did not adopt a definite position (Table 9).

Table 8. Results of the patient questionnaire.

Statements and questions	**Answers in percent, n=2517**			
Priority-oriented questions	**Fully agree**	**Partly agree**	**Don't agree**	**Don't know**
1. Public health services should always offer the best possible care, irrespective of cost	66	28	3	3
2. Everyone has the right to have their health care needs met, even minor problems	52	38	7	3
3. Tax-financed health care cannot afford all treatments and some things must be excluded	9	40	40	11
Preference-oriented questions	**Fully agree**	**Partly agree**	**Don't agree**	**Don't know**
4. Politicians in collaboration with medical staff should decide which diseases/ conditions should not be treated	9	22	55	14
5. Health care staff should decide what should not be treated	68	20	6	7
Question about feeling of being excluded due to lack of resources	**Yes**	**No**		
6. Did you get the impression that staff at the PHCC could not fully comply with your requirements and that you were excluded due to a lack of resources?	9	91		
Question about satisfaction with the result of the consultation	**Satisfied**	**Not satisfied**		
7. Are you satisfied with the result of today's contact?	91	9		

In total, 9% felt they were excluded due to a lack of resources (Table 8), and 91% were satisfied with the outcome of their recent contact (Table 8). Among patients who felt that they were excluded due to a lack of resources, 62% were satisfied. Younger patients were less satisfied than older. Gender and type of contact were not related to dissatisfaction with the consultation.

Table 9. Number and percentage of patients in different categories based on their opinions about priority setting (upper part of table) and who should be responsible for priority setting (lower part of table).

Categories	n	%
Opinion about priority setting.		
Based on answers in "priority-oriented questions" in Table 8 (1-3)		
Priority-oriented[1]	140	6
Not priority-oriented[2]	1656	72
No definite opinion[3]	506	22
Preferred priority-setter		
Based on answers in "questions about decision makers" in Table 8 (4-5).		
Politicians[4]	117	5
Medical staff[5]	1681	73
No definite opinion[6]	509	22

[1] This category includes patients who responded "Don't agree" to statements 1 and 2 and "Fully agree" to statement 3 as well as those who responded the same way in two of the statements, but "Partly agree" or "Don't know" to one of the other statement(s).

[2] This category includes patients who responded, "Fully agree", to statements 1 and 2, and "Don't agree" to statement 3 as well as those who responded the same way to one of the statements, but "Partly agree" or "Don't know" to the other statement(s).

[3] Patients with other combinations of responses to statements 1-3.

[4] This category includes patients who responded "Fully agree" or "Partly agree" to statement 4 and "Don't agree" to statement 5 and also those who responded "Fully agree" to statement 4, but "Partly agree" or "Don't know" to statement 5.

[5] This category includes patients who responded "Don't agree" to statement 4 and "Fully agree" or "Partly agree" to statement 5 and also those who responded "Partly agree" or "Don't know" to statement 4, and "Fully agree" to statement 5.

[6] Patients with other combinations of responses to statements 4-5.

Paper III

When comparing the patient's overall priority of the health condition and intended intervention, with the GP's or nurse's priority of the same clinical situation, we found that patients in general assigned a higher priority than staff did, especially for acute/minor conditions (Table 10). The acute/minor conditions comprised 21% of all contacts, and check-ups for chronic stable comprised 12%. The greatest difference was found between GPs and patients with acute/minor conditions, where the mean difference was 1.33. The most frequently registered acute/minor condition and intervention was *upper respiratory tract infection* and *medical examination and advice*. The mean overall rating of these patients on the 10-point scale (with 1 being the highest priority and 10 the lowest) was 8.1 by GPs and 5.6 by patients. One of the most frequently registered chronic conditions and interventions was the *yearly check-up for ischemic heart disease* where the mean ratings were 4.1 by GPs and 4.6 by patients.

Table 10. Overall prioritisation of common health conditions by patients and staff (paired t-test, means).

		n	Staff	Patients	Difference (95% CI)	P
All health problems	All staff	1851	5.53	4.75	0.79 (0.65−0.92)	p=<.0001
	GPs	718	5.69	4.63	1.05 (0.84−1.26)	p=<.0001
	Nurses	1133	5.43	4.82	0.62 (0.44−0.79)	p=<.0001
Acute/minor health conditions	GPs	169	6.02	4.69	1.33 (0.91−1.76)	p=<.0001
	Nurses	174	6.02	4.83	1.19 (0.74−1.64)	p=<.0001
Chronic stable health conditions	GPs	84	4.76	4.82	-0.06 (-0.63−0.51)	p=0.835
	Nurses	139	5.67	5.01	0.65 (0.19−1.12)	p=0.006

The three key criteria largely influenced the overall prioritisation of each patient for both GPs and the nurses. In the multiple regression analysis, severity of the health condition was the strongest predictor of the staff's overall prioritisation when analysing GPs and nurses together, followed by cost-effectiveness and patient benefit (Table 11). When analysing GPs and nurses separately, we found that GPs were most influenced by cost-effectiveness and nurses by the severity of the health condition.

An interaction analysis showed an interaction between the severity of the condition and the cost-effectiveness of the intervention for GPs. If both were scored low, then the prioritisation was not as low as it would have been without the interaction effect.

Interactions were tested to determine if the three key criteria were weighted differently depending on whether the condition was acute/minor or chronic stable. Only one interaction was found. For nurses, patient benefit was more important if the patient had a chronic stable condition rather than an acute/minor one.

Table 11. Multiple regression analyses on prioritisation for all staff, GPs, and nurses. P<0.0001 for all explanatory variables.

	All staff β (95% CI)	**GPs β (95% CI)**	**Nurses β (95% CI)**
Severity of the health condition	1.18 (1.09-1.28)	1.03 (0.88 - 1.19)	1.25 (1.14 - 1.36)
Patient benefit	0.70 (0.59-0.80)	0.68 (0.50 - 0.86)	0.68 (0.54 - 0.82)
Cost-effectiveness	0.74 (0.64-0.84)	1.12 (0.94 - 1.30)	0.54 (0.42 - 0.66)
n	3679	1489	2190
R^2	0.45	0.54	0.40

Paper IV

The GPs and nurses found the key priority setting criteria to be useful. They reported that the criteria stimulated them to think in a new way when prioritising, e.g. by more carefully considering the actual value of their planned measures (e.g. a diagnostic procedure or treatment) as a part of the basis for prioritising. The staff were more detailed (e.g. concerning what aspects should be concerned and giving examples of different cases) in discussions concerning the severity of the health condition and patient benefit than they were about cost-effectiveness of the intervention. Most of the staff reported difficulty in applying the cost-effectiveness concept in their priority setting, and some nurses explained that costs of care were not really their

responsibility to consider. In spite of this, cost-effectiveness was considered to be an important criterion in priority setting.

Three other categories describing additional aspects to consider in priority setting were identified: viewpoint (medical or patient's), timeframe (now or later), and evidence level (group or individual).

Viewpoint – medical or patient's

Throughout the focus group discussions, two aspects facing the GPs and nurses were apparent: 1) the need to treat the disease and 2) the need to understand the individual patients and their worries. These two aspects were often described as the medical viewpoint and the patient's viewpoint. The GPs referred to these two viewpoints with regard to both severity of the condition and patient benefit. The medical viewpoint was based on the use of medical knowledge to estimate the seriousness of the condition and the expected benefits and risks of different interventions. The patients' viewpoint was based on the GPs' or nurses' estimation of how patients experienced their symptoms, how worried the patients felt, and how satisfied the patients would be with the interventions. Some GPs considered the medical viewpoint more important, or even the only viewpoint that should be considered, especially when estimating patient benefit. However, most of the GPs found it important to take both viewpoints into account and balance them in estimating the severity of the condition and expected patient benefit.

Most nurses considered patient satisfaction to be an important aspect of patient benefit, but many GPs asserted that patient satisfaction is not directly related to the actual benefit of the treatment given. GPs and nurses also considered the two viewpoints when estimating cost-effectiveness, albeit more indirectly.

Timeframe – now or later

In most cases when the GPs and nurses estimated the severity of the patient's condition they focused on the patient's well-being at the time of the consultation and less on considering future risks. They found it relatively easy to estimate the severity of a condition in patients with obvious symptoms of a well-defined, usually acute, disease. These types of conditions were often considered more severe than asymptomatic chronic conditions. At times, the severity of a condition was equated with how soon the patient needed an

appointment, i.e. minor acute diseases could be considered more severe than chronic diseases that needed check-ups but could wait another day. Likewise, estimating patient benefit and the cost-effectiveness of an intervention was found to be easier when the intervention was uncomplicated and yielded a quick result that could be easily perceived or measured. It was more difficult to evaluate patient benefit in asymptomatic patients with chronic conditions and who are at risk for future complications, e.g. diabetes or hypertension. GPs expressed difficulties in knowing what benefit a patient would realise in the future from a particular intervention given today. Moreover, some GPs questioned the value of treating certain chronic conditions, e.g. hypertension. They considered such treatments to be overrated, which made the estimation of patient benefit even more difficult.

Evidence level – individual or group

In patients presenting with common symptoms, the staff found it easy to estimate severity, patient benefit, and cost-effectiveness. However, estimating severity, patient benefit, and cost-effectiveness for a non-symptomatic patient with a chronic disease was considered more difficult. The GPs had to first estimate the patient's risk for complications and the likely benefit of interventions, based on knowledge from population-based studies, and then also consider the individual patient's compliance with lifestyle recommendations that would also affect the health outcome. Hence, estimates of benefit and cost-effectiveness depended not only on the evidence-base for the intervention, but also on the expected characteristics of the individual patient.

GENERAL DISCUSSION

Central findings were that the staff perceived a constant lack of resources in PHC, particularly a shortage of GP capacity. In routine PHC, most of the rationing was done unawares or ad hoc, and no explicit criteria were used. The patients had little understanding of the need for priority setting. Although few patients had experienced any kind of rationing, most of them were satisfied with the outcome of their contact with PHC.

Patients, compared to medical staff, gave higher priority to acute/minor conditions than to preventive check-ups for chronic conditions. When applied in day-to-day PHC, the three key priority setting criteria (derived from the Swedish national guidelines for priority setting) largely influenced the overall prioritisation of each patient by both GPs and nurses. GPs were most influenced by the expected cost-effectiveness of the intervention and nurses by the severity of the condition. Both nurses and GPs perceived the criteria to be relevant and useful, but not sufficient. Three additional aspects to consider in priority setting and rationing in PHC, especially when it concerns prioritising individual patients, were viewpoint (medical or patient's), timeframe (now or later) and evidence level (group or individual).

Below I discuss some aspects of priority setting and rationing in PHC in relation to these findings: first, staff's and patients' opinions on priority setting and their perceptions of rationing in day-to day care; second, the use of Sweden's priority setting criteria; third, some reflections on open priority setting and rationing; and finally I will comment on the construction of priority setting objects and guidelines and on shared responsibility in priority setting.

Priority setting and rationing in day-to day care

The staff's perception of a lack of resources, including the shortage of GP capacity to meet the demand from patients (Paper I) is largely supported by

quantitative studies showing that rationing is a common phenomenon in PHC, but not exclusively in Sweden (10, 12, 148, 161).

We found that the three different categories of handling scarce resources were efforts to avoid rationing, ad hoc rationing, and planned rationing (Paper I).

At PHCCs where the main strategy was to **try to avoid rationing** some of the actions taken to avoid rationing (like working more efficiently and seeing patients early to reduce later demand for care) seemed to have resulted in the desired effects.

However, other actions (including diminishing quality improvement and continuing medical education for staff) might in fact have resulted in rationing implicit for both staff and patients; mainly by reducing quality, which is a strategy of rationing, i.e. rationing by dilution. In day-to-day practice as "If there is too much to do, I ration, mostly by dilution – I spread myself a little thinner, giving a little less to everyone but probably in much the same proportions" (47).

Hence, rationing by dilution seems to be a result of trying to avoid rationing. Rationing by dilution is said to be the most pervasive form of rationing and at the same time the least visible (47, 50, 162). GPs in a UK study opposed dilution as a means of rationing (9). Moreover, some of the measures rationed in our study were ranked high by patients in a large European study concerning their expectations and priorities regarding general practice, e.g. being offered preventive services and that GPs attend courses regularly to learn about recent medical developments (163).

The examples we found of **ad hoc rationing** were largely rationing by delay, deterrence, and deflection, i.e. the patents had to wait, were told to call back later, or to seek care somewhere else. This unplanned rationing resulted in consequences that were undesired for the staff and not in line with the Swedish priority setting guidelines, e.g. difficulties to plan care for patients, and pushing aside chronically ill and older patients (45).

At PHCCs where **rationing was planned**, a common form of rationing was rationing by denial, e.g. not offering check-ups for certain patients groups (general health check-ups, yearly check-ups of non-severe chronic conditions,

check-ups after infections), not issuing medical certificates, or not treating cosmetic problems.

The respondents also gave examples of working more efficiently to reduce the need for rationing, e.g. by using group treatment, planning the staffing schedules to be more efficient, and managing waiting lists differently. This is in line with other studies (29, 92, 164). Improving efficiency means to meet a need at less cost, or meet more need at no extra cost (60, 165), which are ways to reduce the need for rationing (92, 164). However, there is no sharp boundary between increasing efficiency and rationing. In some cases, for example, group treatment (instead of individual treatment for a certain condition) may be defined as rationing by dilution; in other situations, as a more efficient treatment regime. The difficulty of knowing when efficiency measures should be defined as rationing by dilution is described as "both a conceptual and a methodological puzzle" (50), and it is enhanced in situations where evidence concerning optimal treatment is lacking (29), which is often the situation in PHC.

Most of the staff did not know about, or were uncertain of, the content of the Swedish ethical principles and criteria for priority setting. Also at PHCCs where the staff described rationing as a planned process, no explicit ethical principles or criteria were reported as tools for priority setting and rationing. However, much of the planned rationing concerned measures in the lowest ranked priority setting groups in the Government bill (groups 3 and 4: "less-severe acute and chronic disorders" and "care for reasons other than disease or injury"). It is possible the staff at the PHCCs where rationing was planned had some knowledge about the priority setting groups even if they were not familiar with the ethical principles. Another possible explanation behind the lack of explicit criteria for rationing is the lack of GP capacity, i.e. the stressful situation itself that caused the need for rationing. In a UK study, GPs had an implicit understanding of substantive ethical principles, but they were not used in practice. According to the authors, "limited availability of GP time played an important role in this theory/practice gap" (166).

In conclusion, it appears to be important to monitor the quality of care to identify signs of unintended rationing (e.g. by dilution) that may have undesirable consequences. An open dialog – both among the staff at each PHCC and at the programme and system level concerning how rationing decisions are (and could be) made and the criteria on which they are (and

could be) based – seems important for achieving consistency in priority setting and rationing decisions in PHC.

Patients' demands and (un)acceptance of priority setting

The results in Paper II showed that most patients in PHC expected to have all their health care needs met, including "minor medical problems", and to always be offered "the best possible care, irrespective of cost". These findings correspond to the results from Paper I where the staff experienced high, and sometimes even unrealistic, expectations from patients in PHC. Corresponding results were also found by others (2, 150). However, we also found some acceptance of limitations among the patients; nearly half agreed that since health care resources are limited "some services must be excluded" (Paper II). This is confirmed in another study from PHC (167) and also from mixed or hospital settings (168, 169).

Thus, there is some inconsistency in the results. An explanation could be that people's acceptance of rationing depends on the level involved; the individual (personal) level or the group (system or programme) level. Patients might find rationing on the individual level easier to accept than priority setting and rationing on the system level. A study from an emergency department in the UK supports this tentative conclusion; patients in the study accepted and even expected rationing by delay if they received information on the reason for waiting. They also accepted rationing by selection and deflection in connection with their hospital visit. But they did *not* accept explicit rationing on a system level, e.g. reallocation of resources between different services (such as the emergency department and other services), but instead wanted more money to be directed into the health care system as a whole (44).

The opinion that better use of resources would make rationing unnecessary was one reason why people in a UK study were critical of priority setting and rationing in general (8). Another reason might be that the thought of limited resources in health care threatens the symbolic value of making people feel they live in a safe and secure society (170). It is possible that people would *accept* standing aside for others at an individual level for similar reasons; in a good society people care about each other.

Despite the rationing described by staff in Paper I, only a minor share of the patients in Paper II felt they were subjected to rationing. Moreover, most of the patients who felt they were subjected to rationing were still satisfied with their contact with PHC. An explanation might be found in what is mentioned above; when it comes to the individual level and concerns *real* health problems as in our study (as opposed to priority setting at a system level), patients not only accept standing aside, but are even comfortable in doing so. A recent interview study indicates that Swedish citizens would accept standing aside for others if they understood the limitations in health care (171). It is possible that the patents in our study who were involved in "real" rationing themselves had this particular understanding. With a qualitative research approach it would be possible to learn more about the factors behind this.

My interpretation of the results is that a majority of patients were critical towards priority setting and rationing in general terms, but they might be ready to stand aside at the individual level in a clinical situation, particularly if the reasons are explained.

Using the Swedish priority setting criteria

In Paper I we found that no explicit ethical principles or criteria were used as tools for priority setting and rationing, and that knowledge about the Swedish ethical principles for priority setting was limited. This is supported by other authors and might be viewed not only as a need for better knowledge about the existence of the criteria, but also for practical applicability of the criteria (45, 172).

When the PHC staff were asked to use the three key criteria for priority setting, the criteria largely influenced the overall prioritisation of the individual patients (Paper III). In the subsequent focus group sessions the GPs and nurses expressed that they found the criteria useful for day-to-day priority setting and rationing (Paper IV), which confirms the results from Paper III. However, they were more comfortable with using severity and patient benefit than with using cost-effectiveness.

Severity is a familiar concept in routine PHC work. It is important to the general public and is used as an established criterion for priority setting in several other countries (26, 38, 39, 101). For the GPs, estimated severity had a slightly smaller effect on overall priority than cost-effectiveness did. For the nurses, severity influenced overall priority much more than the other two criteria (Paper III).

Patient benefit is also a well known concept in day-to-day PHC. However, it had the least influence on the GPs' overall priority (Paper III). This was somewhat surprising, and it contrasts with a Canadian study concerning prioritisation of new technology where the general public, patients, health professionals, and administrators participated. In this study, patient benefit was the most important factor for decisions (93).

The third criterion, **cost-effectiveness**, was considered difficult to use by GPs and nurses (Paper IV). It was our intention to examine the use of the three criteria at the individual patient level. However, cost-effectiveness is particularly difficult to apply at the individual level. According to the Swedish Priorities Commission, cost-effectiveness at the individual level should only be considered when comparing methods of treatment for the same disease (31). One reason why the staff found cost-effectiveness difficult might be the dilemma of how to evaluate benefit for the individual patient compared to benefit for a group of patients or society at large. Several authors discuss this ethical issue (12, 71, 76, 86, 166, 173, 174).

Even at the group level, when cost-effectiveness is well accepted as basis for decision-making, practical application can be difficult (175). Moreover, formal health economic evaluations are seldom available for health conditions and interventions in PHC.

However, despite difficulties in applying cost-effectiveness as a criterion on the individual level, and the lack of formal analysis, it seems possible to take cost-effectiveness as a principle into consideration along with other aspects. In our study, the GPs and nurses made a rough estimation of anticipated benefits and cost-effectiveness for the individual patient by thinking of costs and effects for treatment in a group of similar patients. This way of thinking is in line with a Canadian study where priority setting committee members described how they tried to make a similar rough estimate of cost-effectiveness to use as a basis for their priority setting (93).

The use of the three criteria, especially cost-effectiveness, differed between GPs and nurses in their overall prioritisation. For the GPs it was the criterion that had the greatest influence on overall priority (Paper III). This seems to contrast with the above-described difficulties with using cost-effectiveness as a prioritisation criterion. However, the GPs also pointed out that cost-effectiveness is an important priority setting criterion in PHC (Paper IV). A possible explanation for this might be that GPs have an increased awareness of, and interest in, health care costs due to the new Swedish funding system for PHC where PHCCs have local responsibility for a limited budget that must cover everything, including drugs, for their patients (86, 128, 176).

Another explanation could be that many interventions common in PHC would receive high priority if cost-effectiveness were emphasised rather than severity of the health condition, e.g. treatment of hypertension and smoking cessation support. This is reflected in, e.g. the Swedish guidelines for priority setting of cardiac care where *"smoking without previously known cardiovascular disease"* + the intervention *"brief counselling incl. nicotine displacement"* have the same high priority as *"acute ST-elevation myocardial infarction + CCU bed with specialist care and thrombolysis or acute PCI"* (55).

The staff also pointed out that seeing patients with minor diseases in PHC to prevent them from going to an emergency department is cost-effective, which is supported by other authors (15, 20, 132, 133)

Hence, cost-effectiveness seems to be useful as a criterion in day-to-day PHC work, even at the individual level. The extent to which cost-effectiveness influences day-to-day priority setting in different settings is interesting since there might be a difference between actual practice and the use the Commission originally intended.

Additional aspects of the priority setting criteria

We found the following additional aspects that related to the priority setting criteria: viewpoint (medical or patient's), timeframe (now or later), and evidence level (group or individual) (Paper IV).

Viewpoint (medical or patient's)

When evaluating the severity of the condition and the expected patient benefit of the intervention, GPs emphasised the medical viewpoint (based on their scientific knowledge and experience). However, they also recognised the patient's viewpoint and took it into account (i.e. *their* understanding of the *patient's* anxiety, worries, and ideas about expected outcome). Daniels discusses subjective and objective criteria of well-being (177), where the objective aspect is something that a person *really* needs (even if he does not realise it) and not simply desires. However, both the medical and patient's perspectives can concern a real need for the patient. The perspectives resemble the concepts of "disease" and "illness" (178). A disease has some kind of distinct pathology, aetiology, and prognosis and can exist with or without the patient's knowledge. An illness is defined as the ill health a person identifies him- or herself with (179, 180). In our study, the patient's perspective includes worry, e.g. about transient symptoms (which might not be classified as a disease). Also, worry itself can cause (or add to) a real need.

Studies on cardiac care have also shown that patient factors other than biomedical criteria (e.g. psychosocial criteria) are used in priority setting (181, 182). General practice has long emphasised the need to consider both the medical view and the patient's view in decision-making (119, 183). The patients' perspective is particularly important in priority setting in PHC because of the role of general practice as first-line health care (19, 113), where patients often consult medical staff because of their anxiety about symptoms rather than about a well-defined disease (120).

In Paper IV we found disagreements about whether patient satisfaction (i.e. patients' perceived health service quality (184)) should also be considered as a dimension of patient benefit. The nurses emphasised patient satisfaction. However, many GPs argued that there is no link between patient satisfaction and what is "medically beneficial", and patient satisfaction should not be considered when estimating patient benefit, e.g. a patient could be satisfied even if he got the wrong treatment, like penicillin for a viral infection, or be unsatisfied even with a correct measure like being advised to quit smoking and reduce drinking instead of being prescribed a drug. Although the national model for priority setting does not explicitly include patient satisfaction, it is emphasised on a national level for PHC in Sweden through publicly published regular national surveys (185).

My conclusion is that the patients' perspective is important in PHC not only at the individual level, but also at the programme and system level. In the national model for priority setting, it can be considered as included in the dimensions of "suffering" and "quality of life" (Table 2), i.e. it should be integrated when severity and patient benefit are estimated at all levels. The different perspectives, as well as the opposing views, highlight the importance of open discussions on how to use and understand the priority setting criteria and how to balance different interests against each other.

Evidence level (group or individual)

The conflict between the individual and group in Paper IV could be interpreted both as a source of difficulty in practising evidence based medicine (EBM) and as a sense of doubt about the value of EBM in PHC (186).

The problem with practising EBM concerns how to apply knowledge about severity, benefit, or cost-effectiveness concerning a group or population in order to estimate the severity or benefit for an individual. This is not unique for PHC. The benefit from a particular intervention for an individual patient may not at all be represented by knowledge about the effect for a group (187, 188). The individual has personal characteristics and habits, a part of his or her own context, making him or her unique and different from the group. This is described as "the uncertainty inherent in the nature of medical evidence" (188). For example, smoking is a risk factor for several diseases, but population based studies cannot tell us which individuals will be affected (188). This makes it difficult to apply guidelines and knowledge from population based studies on the individual level (50, 75, 175). Moreover, each patient has his or her own lifestyle and compliance (with different interventions), which somehow should be integrated in the decision.

The second problem with EBM concerns doubt about its value in a PHC context. GPs do not have a general distrust in EBM (189), but in line with another study from PHC, the GPs considered the evidence regarding effectiveness to be insufficient and conclusions uncertain for many common treatments provided in PHC (175). Furthermore, many studies on prevention of complications for patients with diseases such as hypertension or diabetes are from populations other than "ordinary PHC patients" (190). This questioning of the accuracy of scientific results when applied to PHC caused difficulties in estimating benefit for individual patients with chronic diseases

where the main purpose of care is to prevent complications. This dilemma is reflected in the debate questioning how much of the agenda in day-to-day PHC should be based on future risks instead of the patient's present concerns (71). The doubt about the patient benefit of secondary prevention for chronic conditions might lead to underestimating the needs and effects of interventions for these patients.

In contrast to cases involving chronic disorders, EBM was neither a concern nor even discussed regarding management of acute conditions (Paper IV). Instead, effectiveness and patient benefit were often unquestioned, which could result in overestimating the benefits in these cases.

Timeframe (now or later)

The GPs and nurses in our study mainly based their estimates of severity and patient benefit on the patient's well-being at the present time rather than according to future risks (Paper IV). Secondary prevention can always wait another day while present problems are easy to perceive as more urgent. However, in general practice, many patients with acute conditions will eventually recover (without any intervention), while many patients with chronic conditions experience a continuing, often gradual, decline in well-being. Neglecting to integrate future risks and benefits in the assessment during the process of priority setting might result in underestimating the severity of the condition and the effectiveness of an intervention in patients with chronic conditions. The Swedish national model for priority setting asserts that both the current condition and future risks should be considered when estimating severity and benefit (98, 104), but the timeframe perspective must be emphasised at both the individual and group levels (programme as well as system levels).

In conclusion, awareness of how scientific evidence is perceived in priority setting and ensuring that the timeframe perspective is considered might help to balance how acute and chronic conditions are prioritised. The results also reflect the need for more research and scientific knowledge concerning common conditions in PHC.

Use of the criteria at the individual level

In Sweden, the three priority setting criteria are used only to a very limited extent for priority setting at the individual level. At the individual level, each patient's worries, capacity of coping with the situation, previous health condition, etc affects the severity of the health condition, the benefit of different interventions, and the cost-effectiveness. "Each case is unique" as stated in the Swedish Government bill (22). This is described as a "tension between population-based and individual-orientated criteria" (162). This is reflected in comments that some of the staff made in connection with their overall prioritising of their patients. They noted factors that influenced their prioritising of the individual patient, e.g. patient's worry, patient called several times before or patient having multiple diseases aside from the complaint for which they were seeking care (at times one being very serious, e.g. cancer or deep depression).

To further develop methods for priority setting at the individual patient level seems important. Without a useful method for prioritising at the individual patient level, there is a risk that decisions on the individual level would be made on grounds other than the nationally accepted ethical principles and key criteria (172, 191). Data from our studies point out the need for patient-related aspects to be added in the priority setting process at the individual level. Considering the three additional aspects concerning the priority setting criteria might facilitate priority setting of individual patients.

Priority setting and rationing at the programme and system levels could give support to priority setting at the individual level.

Patients' and medical staff's priority setting

Although the PHC staff tried to take the patient's viewpoint into account (Paper IV), it is something else to listen to the patient's own opinion. The findings from Paper III indicate that patients, GPs, and nurses hold different opinions on what type of health conditions and interventions should receive highest priority. In our study, patients gave the highest priority to acute/minor health problems. The results need to be confirmed by other studies, but the findings are of no surprise. Patients expect to receive health care even for trivial problems (Paper II), and they do not always have the same opinion as

their GPs on what is most important (192, 193). For present acute/minor health problems, the experience of need can be urgent (194, 195). The need for secondary prevention (to avoid possible future complications) for chronic stable conditions is less urgent. Furthermore, patients may have limited knowledge about the effect of preventive interventions.

The GPs generally gave higher priority to patients with chronic stable conditions, where the focus was on trying to prevent future complications. These findings contrast somewhat to the results just presented from Paper IV, i.e. that staff also focus on the present situation rather than future risk in their priority setting, and that GPs doubt the evidence on patient benefits from preventive check-ups for chronic conditions. Thus, it is possible that if the GPs were less influenced by the present situation, the differences in priority setting between GPs and patients would be even higher, as it would if more robust evidence concerning effects of secondary prevention for chronic conditions was available.

Implications at the system level

If there are differences between patients and staff in prioritising acute/minor and chronic stable conditions, as our study indicates, these differences need to be addressed in future priority setting in PHC. This concerns how to take the patients perceived needs and demands, according to their own agenda, into account and how to balance small present problems against larger future ones, which is the implication of the "viewpoint" and "timeframe" aspects.

The 2008 World Health Organization (WHO) report on PHC stresses the need for PHC to adapt to rising expectations of citizens (2). One step in this direction is the increasing focus on accessibility in health care by the government and the county councils (128). National figures are presented regularly on the number of days patients must wait for an appointment in PHC, and trends in health care statistics indicate that the number of visits in PHC are increasing and waiting times are decreasing (116, 186, 196). In recent years the policy paradigm in Swedish health care has shifted with the introduction of market-based reforms, e.g. a new funding system for PHC in which patients are encouraged to direct and redirect funds by choosing a different PHCC. The opposing views of patient satisfaction (between GPs and nurses) may reflect similar trends, i.e. health care regulations shifting from a

previous focus on patients' needs, to health care based on the legal claims underlying patients' rights with greater emphasis on patient satisfaction and good accessibility (174, 197).

However, if staff respond too much to demands rather than patients' needs, it might result in an unbalanced effort by PHC to treat patients with acute or minor self-limiting conditions, and thus influence consumption and allocation of health care in an unfair and inefficient way (2, 50, 198).

On the other hand, there is also some support for seeing patients early and on their own conditions. Episodes of care that begin with visits to a patient's PHC clinician, as opposed to other sources of care, are associated with significantly lower costs (15, 20, 132, 133). Moreover, patient satisfaction, which the GPs questioned as an aspect in priority setting, is a complex concept. It includes dimensions of the provider-patient relationship, and it is a predictor of health-related outcomes (64). Another aspect of consultations with expected "non-medical benefit" is the symbolic value for the citizens, i.e. that there is utility gained both for the individual and for the general public simply from the knowledge that an attempt has been made to help (85, 170). Thus, it is possible that even single consultations for minor problems that were ranked low by staff in Paper III might yield high patient benefit and cost-effectiveness in the long term and perhaps should be acknowledged more by GPs and nurses.

Moreover, the policy paradigm has not shifted completely towards market economy in PHC. The situation now is rather an incoherent policy paradigm (199, 200), which adds to the conflict for PHC. Market ideas have to be combined with retained goals for PHC; e.g. the Health and Medical Services Act states that care should be prioritised according to needs. Hence, it is a challenge for PHC providers to balance all expectations and demands with the patients' medical needs in a situation with restricted resources. The different opinions between patients and staff, and the lack of "a true answer" on what is a correct balance between different needs, highlights the need for an open dialogue about priority setting in PHC.

It is also important to systematically integrate future risks and benefits connected to chronic conditions in priority setting in PHC. Priority setting might be facilitated by integrating the aspects of viewpoint, timeframe, and evidence level into the process.

Open priority setting and rationing

Group level

Most staff were positive towards open priority setting (Paper I), which is consistent with other studies (9, 150, 168, 201). The interview questions did not clearly specify the priority setting level, but the staff referred to the programme or system level. They thought that open decisions on priority setting in PHC (from politicians) would help patients become better informed about what to expect from PHC and thus facilitate communication.

What would be preferable to the patients concerning explicitness still remains unclear. We did not ask the patients specifically about their opinion on *explicit* priority setting and rationing. Our findings indicate that patients were critical towards priority setting and rationing in general terms (Paper II), but this does not mean they are negative to explicitness. Explicitness at a programme and system level could give people an opportunity to influence priority setting and rationing decisions, as stated by the Swedish Government: "When all health needs cannot be met, an open discussion about the basis for priority setting decisions is necessary. The values that guide both access to health care and the prioritising must be shared by most of the population. Necessary priorities must be perceived as fair and just. This democratic support is important, not least in order to maintain confidence in healthcare" (22). Acceptance to stand aside for someone else in a clinical situation also requires some kind of explicitness both at the individual level and at the programme and system level.

Individual level

Less than one-tenth of the patients felt that they were subjected to rationing, although rationing in PHC is probably more frequent (Paper I) (10, 12). Hence, explicit priority setting and rationing at an individual level might result in more patients knowing that their care is rationed. However, there seems to be no easy answer as to whether this would be beneficial for the patients. Several authors consider it preferable, for doctors and patients alike, not to inform patients that their care is rationed (10, 12, 13, 54, 174, 202). Explicitness is even considered as a "disutility", i.e. unbeneficial both to patients and staff (54). Patients will feel better if they believe that they received the best care

available. Knowing about rationing might be even worse if patients find out that others "in greater need" got what they were denied (80). Even the staff in our study asserted that explicitness at an individual patient level was not desirable. In accordance with other studies, staff indicated that they would feel uneasy having to say no to patients (80, 174). Studies have shown that doctors tend to avoid telling their patients about rationed alternatives (10, 12, 43, 54, 148, 174, 202). Rationing "is carried out by doctors who are aware of the resources available and who ration by telling patients that they cannot help them, rather than explicitly stating that resources are not available" (54).

On the other hand, a reason for explicitness is that patients in general want to know about rationing. They expect to receive all relevant information about treatment options from their clinical professionals so they have a chance to consider paying for care themselves if necessary (171, 202, 203). Some authors argue that if patients are not informed and later discover the truth, they would feel betrayed. This could harm the doctor-patient relationship and patients' trust in health care (48, 80, 204, 205). Also, staff find it distressing to withhold the truth, especially if patients question them (80). The relationship in PHC between the GP and the patient (and sometimes the whole family) is often close and may span many years. How this affects explicit rationing we do not know. The Swedish funding system, where patents are encouraged by politicians to "vote with their feet" if they are dissatisfied with care, might also affect GPs' explicitness at the individual level.

Thus, when priority setting is being discussed it seems important to specify the level under consideration; the value of explicitness depends on the level in the health care system and on the type of information concerned. Also who is supposed to decide and inform, and who is judging, may affect the value of explicitness.

According to our studies, explicitness towards patients and the general public about the results of priority decisions on a programme and system level might be preferable, but explicitness towards individual patients about rationing is more complicated.

Priority setting objects and guidelines

A few additional aspects concerning the priority setting objects and guidelines for priority setting in PHC have emerged from the studies.

The Swedish national model for priority setting defines the item being rationed or prioritised (the priority setting object) as "a combination of a health condition and an intervention" (98, 104). The reason is that only if we prioritise a condition *and* an intervention can we apply all three priority setting criteria.

However, at the PHCCs where rationing was planned (Paper I), a few priority setting objects were described in concordance with this, e.g. certain medical certificates or check-ups *in combination with* a certain patient group. However, most of the rationing was not defined with both a health condition and an intervention, which is consistent with other studies (10, 11). In these studies, rationing is described in terms of either a health condition (e.g. "severely ill" or "not so ill" patients), or an intervention (e.g. time, MRI, routine x-ray, lab tests, drugs, or surgery), but not a combination of the two. It is possible that the combination of a health condition and an intervention works in a "top-down perspective", e.g. to produce guidelines and make rationing decisions in theory, but is difficult to use in describing "day-to-day practice".

Paper III registered over 1800 pairs of conditions and interventions, and although we formed only two very comprehensive groups (acute/minor and chronic stable conditions) only one-third of the pairs could be included. The remaining two-thirds were diverse pairs and could not be merged into larger groups. This illustrates one of the special challenges in priority setting induced by the characteristics of PHC, namely the vast number of different situations met, from minor health problems to serious diseases, combinations of diseases, elderly multiple-diseased patients, and palliative care (113, 206, 207). This complexity is also reflected the staff's comments in connection with their overall prioritising of the patients, e.g. co-morbidities. All health conditions require "their" interventions or combinations of interventions. Furthermore, many of the patients do not have a diagnosis describing their problem. In fact, much of PHC practice deals with health problems that are not, and may never be, resolved by diagnoses (16, 122, 208). This illustrates why the National Board of Health and Welfare's national guidelines for priority setting can be difficult to use to aid decisions in priority setting in PHC; only a few of the

pairs of health conditions and interventions common in PHC are covered by the guidelines.

Moreover, each guideline addresses a single disease or disease category, and it is not possible to compare one guideline's ranking of a health condition and its intervention to another guideline's ranking of a different health condition and its intervention. The challenge of comparing costs and benefits of interventions for different types of conditions in horizontal priority setting is described as an "absence of a common currency" (29). Although there are methods (e.g. QALYs (209)) to quantify the value of different medical interventions, it is difficult to compare completely different diseases with each other.

Nevertheless, in Paper I, staff asked for support and guidelines for rationing. If all "first assessments" would fall outside of priority setting guidelines (as they did in the priority setting groups) because they cannot be classified, the guidelines would not be very useful since they would not include much of the PHC work.

On the other hand, including all different health problems and interventions would not work either. The respondents in our study feared that guidelines for priority setting in PHC would be too complicated to be useful. This is in line with Mechanic's idea that general guidelines for priority setting "are likely to fall short relative to the complexity of circumstances surrounding serious illness and comorbidities or to be so complex and detailed that they are impracticable" (13).

One suggested solution to reduce complexity in guidelines for priority setting is to focus only on high-cost areas (13). For secondary care this might be helpful, but for PHC it might not help since most of the care is inexpensive. What generates costs in PHC is not a few very expensive cases as in secondary care (210).

Instead, a possible solution might be to look at how the staff described their rationing in our study. They used "general labels" e.g. "check-ups for patients with serious chronic disease" or "minor cosmetic problems". I believe that in PHC it might be more fruitful to use this type of broader priority setting object (i.e. bundles of conditions and interventions) rather than single health conditions and interventions, both to describe daily rationing and to construct useful guidelines for day-to-day practice. How these bundles should be

constructed to best fit the priority setting criteria, however, remains to be determined.

Shared responsibility in priority setting

The staff in Paper I, in line with other studies, requested support with priority setting decisions from the politicians (150, 211). They wanted politicians to set the limits for the responsibilities of public PHC services. This would make it easier for them to execute rationing at the individual level; they expressed that they would feel "let off" if they could use the argument, when speaking to individual patients, that a third party had decided what is and is not available. Other studies on rationing at the individual level reported similar results (164, 212, 213). This seems to be a way to reduce the "patient versus population dilemma" discussed by several authors (8, 12, 76, 86, 166, 174, 214). Even if it is argued that GPs both can, and are expected to, consider the needs of the individual patient while concurrently taking account of common resources (174), Weinstein et al. write: "It is ethically untenable to expect doctors to face this trade-off during each patient encounter; the physician cannot be expected to compromise the wellbeing of the patient in the office in favour of anonymous patients elsewhere" (173).

However, at the programme and system level the GPs in our study wanted to contribute their medical knowledge and participate in the priority setting and rationing decisions made by politicians. Such co-operation between PHC staff and the politicians might also make explicit rationing at the individual level more acceptable among staff.

The patients, on the other hand, expressed a different opinion (Paper II). In line with other studies involving patients and the general public, the patients in Paper II wanted doctors and other health care staff to take responsibility for priority setting (48, 52, 150, 168). The patients did not want politicians to be responsible, not even in collaboration with medical staff. A reason for this could be that the patients were thinking of priority setting and rationing at the individual level, where health care staff are probably the natural decision-makers for priority setting and rationing. The patients' negative attitude towards the role of politicians may simply reflect their negative attitude

towards priority setting and rationing at the programme and system level (Paper II).

During the interviews for Paper I, the participants were asked about their opinion on the general public's participation in priority setting (149). The staff did not trust *patients and the general public* to take part in priority setting and rationing decisions because they thought that patients lack insight into the problem of setting priorities since the issue is so complicated, or that they would be too selfish. However, several studies show the opposite; that patients give priority to what they perceive to be the needs of others rather than themselves, e.g. higher clinical acuity (167, 169). We do not know from our studies if the patients or the general public actually want to participate. Robertson et al. found that both doctors and patients thought that public consultation in decisions about funding for new treatments would be beneficial (215), but in other studies neither patients nor the general public were convinced that they should participate in the prioritisation of health care – certainly not at the individual level, but perhaps at the system and programme level and only for consultation without responsibility for decisions (52, 167).

In line with other studies we found that younger patients were less satisfied than older patients with the outcome of their PHC contact (216, 217). Dissatisfaction among younger patients is mentioned in the Swedish Government bill: "One of the conclusions [...] must be that younger people are placing higher demands on health care as a service organisation than elderly. [...] As the young grow older and therefore more in need of care there is a clear risk that the anchoring of the jointly funded health care in the population falters. Confidence can be further tempted if resources are scarce. Such a trend can be reversed if patients are given greater opportunities to gain insight into and influence health care." In this context our finding that younger patients had a more positive attitude towards priority setting and rationing is interesting. Perhaps this can be viewed as an opportunity to invite patients and citizens to discuss priority setting in PHC.

The dialogue itself can be important. Patients in our study had a negative attitude towards priority setting in general, but people change opinions and tend to accept priority setting even more after they have had an opportunity to discuss and learn more (102, 218).

Methodological considerations

New research areas gain from a combination of quantitative and qualitative methods since studies supplement each other (219) and strengthen criterion validity (the consistency with results from studies by others, or by other methods). For example, the staff's perception of high patient expectations from PHC as reported in Paper I (qualitative) corresponds with patients' expectations to always be offered "the best possible care, irrespective of cost" in Paper II (quantitative). Likewise, the influence that priority setting criteria had on overall priorities, as reported in Paper III (quantitative), is consistent with the finding in Paper IV (qualitative) that staff viewed the criteria as being useful.

I have chosen to study day-to-day PHC. However, given its complexity, it is difficult to study. When divided into small, defined parts to be scrutinised, we lose an important characteristic of PHC, i.e. the whole and its complexity. For example, important characteristics of effective and efficient PHC are continuity and long-term relationships. This dimension was lost when studying individual contacts at a single point in time.

The studies focus on priority setting and rationing of individual patients in PHC. Both "individual patients" and "PHC" present their own challenges and difficulties concerning priority setting and rationing. Additional studies on priority setting in PHC, on a programme level, as well as on prioritising individual patients in other settings, could give valuable additional knowledge.

The qualitative studies (Papers I and IV)

Validity and reliability are defined differently in qualitative and qualitative studies. Credibility, conformability, and transferability correspond to different aspects of validity in qualitative research (namely, internal validity, objectivity, and generalisability). Dependability corresponds to reliability in quantitative research (156, 158).

Credibility concerns study design, e.g. operational definitions, and whether the results are believable from the participants' perspective. To improve credibility in Paper I, we conducted four pilot interviews and discussed the

results within the research group and with other researchers familiar with the subject. The definitions of central concepts in Paper I (rationing, prioritising, and open priority setting) given to the participants (Table 2b) were not identical with the definitions given in this thesis. They might reflect a time (2004) when the concepts were less considered. However, the definitions in Paper I were written to be easily understandable for participants.

In most focus group sessions (Paper IV) the initial discussions about the key criteria reflected the instructions for their use given prior to the study, but soon participants' experiences, including new aspects of using the key criteria in PHC, became apparent. One example regards the medical and patient view, where discussions started about medical benefit from single interventions regarding one disease, then broadened to include the patient's feeling of satisfaction, and deepened into multi aspects even when participants continued to disagree on which of these aspects should be taken into account. These interactions – when participant's confirm and question each other's statements – promote clarification, which is also conducive to credibility (153, 220).

Respondent validation is a common way to check on the credibility of a qualitative research project (156). It has also been suggested for use as part of an error reduction process (which could generate further data) (221). Even if the interviews for Paper I were semi-structured and the questions were part of a dialogue, it is possible that some of the questions in the interview guide were leading. For example, it might have been easier to answer "yes" than "no" to: "Do you think there are unrealistic expectations?" or "Do you think that important patients groups being forced aside is a problem?" For both studies, however, credibility was strengthened by reporting and discussing the findings with the staff at some of the participating health centres and also in conferences and meetings for PHC personnel (221).

Confirmability in qualitative research concerns the degree to which the results could be confirmed or corroborated by others. Some of my research concerns new areas, and therefore the results are not confirmed by others. However, many of the findings are confirmed by similar studies, albeit sometimes in other settings.

To enhance confirmability, it is important to be clear about the methods of data collection and analysis, and to identify and describe the systematic

process (156, 158, 221, 222). A combination of two methods was chosen for paper I (155); template analysis style and editing analysis style (156-158). Analysis of focus group discussions followed the key stages of familiarisation, identifying a thematic framework, indexing, charting, mapping, and interpretation as described by Rabiee (155). This is described in more detail in the methods section.

The results from a study are to be shared and applied beyond the study setting. This is often referred to as transferability in qualitative research. It can be compared with external validity or generalisability in quantitative research. To strengthen transferability it is important that the sample is adequate and sufficiently varied (156, 158). As regards Paper I, the random sample, the diversity of health centres concerning size and location, the different professions and experiences of the respondents, and the large number of interviews strengthens the transferability of the results to similar settings (223). As regards Paper IV, the variation in the sample needed for reasonable transferability was achieved by the purposely selected PHCCs (located in areas with different populations in terms of age and social factors).

Dependability (or consistency) in qualitative research closely corresponds to reliability in quantitative research. It is about consistency between the theory and the data collected (221). It is possible that dependability could have been enhanced by independent analyses by other researchers. However, during the analytical processes the results were discussed in the research group during several meetings. Some of the results were also confirmed by other methods, i.e. quantitative studies (224).

Participation

For both studies the qualitative research makes it inappropriate to draw firm conclusions about the difference in opinions between GPs and nurses or to quantify results. What can be presented are trends that can help us generate hypotheses that can be further tested in quantitative research. However, in Paper I the relatively high number of interviews allowed us to make some statements like “most of the staff...” or “few of the participants...”.

Different techniques were used to ensure adequate sample size (to ensure variety) in qualitative research. Crabtree recommends 12 to 20 data sources when trying to achieve maximum variation (156). To ensure sample saturation

(i.e. different perspectives from informants with regard to gender, profession, PHCCs geographic location, etc.) in Paper I, our intent was to interview four persons, each representing a different profession, and to include the centre's manager at each PHCC. The PHCCs were randomly selected (45 of 823 in the area), which is a recommended method when there is no compelling *a priori* reason for a purposive approach (223). Seventeen PHCCs accepted the invitation to participate. At each PHCC, interviews were conducted with staff representing different professions, including the PHCC managers. The reason for not including all different professions from each PHCC was the difficulty in making appointments for the interviews, due to their lack of time. It is possible that additional interviews would have generated further information, but a total of 62 interviews was considered adequate since the last interviews yielded no new data.

For paper IV, all staff members who took part in the earlier study were invited to participate in the focus groups. Those present at work on the days the focus group sessions were held took part, i.e. two-thirds of the GPs and one-fourth of the nurses. Statements supporting all of the identified categories, were given in nearly all focus groups, but it is possible that additional sessions with the remaining staff would have generated further information, certainly from the nurses, since relatively fewer of them took part in the focus groups.

The participants in each focus group worked at the same PHCC. The advantage of using pre-existing groups is debated (155). However, Kitzinger suggests it is an advantage since the group members can comment on incidents in their shared day-to-day lives (154), which they frequently did in our study.

In all groups the climate was friendly and light-hearted. Participants in focus groups influence each other, and the data collected reflects both individual and collective norms and beliefs (154). This interaction among participants, which enforces exploration, clarification, and different views about the issue in focus is an important value of focus groups (155). Such interaction can make data available that would not be possible to obtain by other methods (154, 220).

The GPs and nurses at each PHCC were in separate groups. The reason for this was that the differences in their perceptions might have diminished if they had participated in the same focus group (153). Homogeneity within each

focus group is recommended especially when a hierarchy like that in health care is involved, otherwise it might affect the data (154, 160).

The quantitative studies (Paper II and III)

Internal validity, generalisability (external validity), and reliability are usually considered as measures of research quality in qualitative studies. Face (or content) validity and criterion validity are different aspects of internal validity.

In Paper II, the first three statements in the questionnaire were used and validated in an earlier Swedish study (150). The last two statements in our questionnaire were constructed for the present study. To strengthen their face validity (content validity, i.e. the accuracy of questionnaires and other measures; that they measure what they are intended to measure) the two statements were discussed in the research group and with others familiar with research on priority setting.

As with all questionnaire studies, we have no guarantee that all respondents understood the questions similarly (223). For instance, they might have thought about priority setting at different levels. Furthermore, two of the statements/questions in the questionnaire consisted of two parts ("Tax-financed health care cannot afford all treatments and some things must be excluded" and "Did you get the impression that staff at the primary health care centre could not fully comply with your requirements and that you were excluded due to a lack of resources?"), which might have made them ambiguous to the patients who answered the questionnaire.

The questionnaires for Paper III were pre-tested at two of the participating health centres to strengthen face validity, and minor adjustments were made before the study.

As mentioned, the criterion validity (consistency with results from studies by others or by other methods) for parts of the quantitative studies was strengthened by corresponding results from our own qualitative studies. As for the qualitative studies, some of my research concerns new areas, but many of the findings are confirmed by similar studies, albeit at times in other settings or with other methods. For example, in Paper II we obtained *quantitative* information about how many patients felt they were subjected to

rationing in connection with their health care contact in PHC. We found one *qualitative* study about patients' reactions after experiencing rationing (associated with morbid obesity or breast cancer care) (212) but no other quantitative studies and no studies from PHC on the same subject, which could have strengthened the criterion validity of our results (154).

Since it is difficult to find objective mathematical or quantitative methods to calculate priority levels, a qualitative estimation was performed instead (98, 225, 226). Paper III used 10- and 3-point scales. The scales were selected to be easy for the staff to fill in directly after each consultation. Their validity for priority setting in Sweden was tested on a national and a regional level. The substantial variance in priority ratings, accounted for by the three ratings on the 3-point scales, also indicates their validity.

The studies were conducted at Swedish PHCCs, which limits their generalisability. PHC is organised differently in other countries. However, in some countries, e.g. the UK, the number of small GP practices is decreasing in favour of PHCCs with salaried GPs. The generalisability of the studies might also be affected by time. However, recent findings from other authors indicate that the results are still relevant (1, 227).

Since responses in our Paper II were similar to those in an earlier paper (150) with some of the same questions, this strengthens the reliability of our results. Further studies on differences in priority setting of staff and patients were not found, but could have strengthened reliability in Paper III.

Drop outs

A response rate of 72% in Paper II was judged to be satisfactory. Similar rates at the four different PHCCs indicated that there was no systematic bias due to particular conditions at any centre. The drop-out rate may have affected the results, but it is not possible to say in which direction since there was no indication of systematic drop-out (Paper II).

The response rate of staff was high (96%) in Paper III, but the response rate of patients was only 56%. However, even this lower response rate from patients was considered to be acceptable. Similar rates have been reported in comparable types of studies. Moreover, response rates in questionnaire studies are generally declining (192, 228). Responders and non-responders did not differ concerning age and gender, but contact by telephone instead of a visit

was more frequent among the non-responders. We do not know if this affected the results (Paper III).

The large number of observations in Paper III is a strength of the study. However, despite over 1800 complete pairs of observations (patient and staff concerning the same consultation), the frequency of each specific health condition and intervention was low due to the wide variation of health problems in PHC (113).

FUTURE RESEARCH

- Additional studies on the additional aspects connected to three priority criteria (viewpoint, timeframe and evidence level) from Paper IV. How could they be integrated in a system of explicit priority setting at an individual level?

- In our study, cost-effectiveness seemed to influence the GPs' day-to-day priority setting to a relatively great extent. Is this also true in other contexts?

- More rationing appears to be taking place than patients know about. How do patients recognise rationing? What kind of preferences do they have?

- Patients gave higher priority to acute/minor health problems than to secondary prevention of chronic diseases. What are their reasons for this? Is this also true in other contexts?

- In Paper IV, two-thirds of health conditions and interventions could not be classified into the groups of acute/minor or chronic stable. Neither could they be merged into other large groups. How can the complexity of PHCs be considered in priority setting?

- What are the consequences regarding priority setting for different patient groups from the new Swedish funding system (*vårdval*) for PHC?

CONCLUSIONS

There appears to be a need for, and the potential to, introduce more consistent priority setting in PHC. The characteristics of PHC, such as the vast array of health problems, the large number of patients with vague symptoms, early stages of diseases, and combinations of diseases induce both special possibilities and challenges.

The process of coping with scarce resources was largely by implicit and ad hoc rationing without guidance of ethical principles or criteria (Paper I). The staff called for political policy statements based on priority setting decisions to help manage the situation (Paper I).

Most of the patients had a negative attitude towards priority setting and rationing. Nearly one patient in ten had experienced some kind of rationing, but the majority were satisfied with the outcome of their contact with PHC (Paper II). The patients preferred that health personnel, not politicians, set priorities (Paper II).

The patients' preferences regarding what should be prioritised differed from the staffs' opinion. Patients, compared to medical staff, gave relatively higher priority to acute/minor conditions than to preventive check-ups for chronic conditions (Paper III).

The three key priority-setting criteria (severity, patient benefit, and cost-effectiveness) largely influenced the overall priorities set by the staff. Cost-effectiveness was the criterion that had the greatest impact on overall priority for GPs, while severity had the greatest impact for nurses (Paper III).

Nurses and GPs perceived the three key priority setting criteria to be valuable for priority setting in primary health care. Three additional aspects were identified: 1) viewpoint (medical or patient's), 2) timeframe (now or later), and 3) evidence level (group or individual). Considering these aspects might improve the usefulness of the criteria for priority setting in routine PHC (Paper IV).

SVENSK SAMMANFATTNING

Begränsade ekonomiska resurser är en realitet i alla hälso- och sjukvårdssystem. Prioritering och ransonering är därför oundvikligt. I den svenska primärvården är det ofta brist på personal, framför allt läkare, vilket gör prioriteringar till ett vardagsproblem. I en nyligen publicerad rapport ansåg endast en femtedel av svenska vårdcentralschefer att de ekonomiska ersättningsprinciperna vid tilldelning av resurser stödjer prioritering av patienter med stora vårdbehov. Två tredjedelar ansåg att de nuvarande ersättningsprinciperna riskerar att leda till en undanträngning av patientgrupper med stora vårdbehov (1). Det dagliga arbetet vid vårdcentralerna består av möten med enskilda patienter. Vid otillräckliga resurser blir prioritering och ransonering av enskilda patienter ett problem men samtidigt en viktig uppgift.

En väl fungerande primärvård är en kostnadseffektiv vårdform som påverkar övriga delar av hälso- och sjukvården (2, 3, 4). Detta gör prioriteringsarbetet i primärvården särskilt angeläget.

Den svenska nationella modellen för prioriteringar bygger på den av riksdagen beslutade etiska plattform med tre principer för prioriteringar. Utifrån dessa principer har man arbetat fram tre prioriteringskriterier (tillståndets svårighetsgrad, nyttan av en planerad åtgärd och åtgärdens kostnadseffektivitet). Tillsammans med evidens för effekt och kostnadseffektivitet ska dessa aspekter vara utgångspunkten för prioriteringsbeslut. Hittills har modellen provats i liten utsträckning inom primärvården.

Primärvården har särdrag som påverkar förutsättningarna för hur prioriteringar kan göras. Många patienter har oklara symptom snarare än definierade sjukdomar. Ofta har en patient flera sjukdomar samtidigt. Detta gör systematiska prioriteringar som bygger på en ranking av hälsotillstånd och åtgärder, så som i den svenska nationella modellen, till en särskild utmaning.

Syfte

Syftet med avhandlingen var att studera förutsättningarna för systematisk prioritering i primärvården i Sverige.

Syftet med delstudierna var:
Studie I: att analysera hur personal i primärvården uppfattar och hanterar resursbrist i sitt dagliga arbete.
Studie II: att få kunskap om patienternas åsikter om prioriteringar och om deras erfarenheter av ransonering i primärvård.
Studie III: att analysera och jämföra patienternas och personalens prioriteringar av enskilda patienter i primärvården.
Studie IV: att undersöka hur personalen uppfattade de tre svenska prioriteringskriterierna vid prioritering av enskilda patienter i sitt dagliga arbete i primärvården och hur kriterierna kunde utvecklas.

Metod

Datamaterialet i studie I består av 64 intervjuer med vårdpersonal representerande olika yrkeskategorier från 17 slumpvis utvalda vårdcentraler i södra Sverige. Intervjuerna var semistrukturerade och handlade om hur personalen uppfattade förväntningar på primärvården, hur man hanterade resursbrist och vad man ansåg om vem borde ha ansvar för att göra prioriteringar. Intervjuerna analyserades kvalitativt i två steg. Först grupperades materialet i kategorier med intervjuguiden som mall. Därefter söktes nya kategorier i inom de nybildade kategorierna.
I både studie II och III användes kvantitativa metoder. För båda studierna användes enkäter som delades ut i samband med alla patientkontakter under två veckor vid fyra olika vårdcentraler. Vårdcentralerna valdes ut för att vara olika med avseende på patientpopulationens storlek, socioekonomiska sammansättning mm.
I studie II besvarade patienterna frågor om ansvar för prioriteringsbeslut och om de upplevde att de fått stå tillbaka på grund av resursbrist samt om de var nöjda med resultatet av sin vårdkontakt.
I studie III besvarade både patienter och personal. För varje patientbesök fick personalen ange patientens hälsotillstånd eller aktuella besvär och en till detta kopplad åtgärd. De uppskattade också svårighetsgraden av besvären samt nyttan och kostnadseffektiviteten av den planerade åtgärden gjorde en övergripande prioritering av patientkontakten. Patienterna gjorde en motsvarande övergipande värdering av angelägenhetsgraden av sitt eget vårdbehov vid den aktuella kontakten.
I studie IV utfördes fokusgruppsintervjuer. Vid var och en av de fyra vårdcentralerna som deltagit i studie II och III genomfördes två fokusgrupper, en med sjuksköterskor och en med läkare. I grupperna diskuterades hur

personalen upplevde de tre prioriteringskriterierna (svårighetsgrad, nytta och kostnadseffektivitet) samt deras tillämpbarhet.

Resultat

Studie I: Personalen upplevde att patienterna hade höga förväntningar på primärvården. De upplevde också en ständig brist på resurser, särskilt brist på specialister i allmänmedicin.
Tre olika sätt att hantera resursbrist kunde urskiljas: att försöka undvika ransonering, ad hoc-ransonering och planerad ransonering. Ad hoc-ransonering medförde oönskade konsekvenser som bristande kontinuitet och svårigheter att planera vården för patienterna. Den typen av ransonering kunde också leda till att vissa patientgrupper trängdes undan, särskilt kroniskt sjuka och äldre. De metoder som användes för att undvika ransonering kunde ibland leda till en omedveten ransonering, framför allt genom kvalitetsförsämring.
Personalen önskade hjälp från politiker i form av stöd och riktlinjer för att bättre kunna hantera situationen.

Studie II
Patienterna i primärvården hade höga förväntningar och liten förståelse för behovet av prioriteringar. De ville att vårdpersonal, och inte politiker, skulle göra prioriteringar. Nästan en av tio hade upplevt någon form av ransonering och bland dessa patienter var 60% nöjda med resultatet av sin kontakt med primärvården.

Studie III
Patienter med akuta/mindre problem prioriterade sig själva högre än de som kom för kontrollbesök för sekundärprevention av kroniska sjukdomar. Läkarna prioriterade tvärt om.
De tre prioriteringskriterierna påverkade i hög grad den övergipande prioriteringen av patienterna. Hälsotillståndets svårighetsgrad var det prioriteringskriterium som hade störst inverkan när läkare och sjuksköterskor analyserades tillsammans. När endast läkarna analyserades var det den förväntade kostnadseffektiviteten av åtgärden som hade störst betydelse.

Studie IV
Både sjuksköterskor och allmänläkare uppfattade de tre prioriteringskriterierna som relevanta, men inte tillräckliga. Tre ytterligare aspekter

identifierades, nämligen *perspektiv* –medicinskt eller patientens, *tidsram* – nu eller senare och *evidensnivå* – grupp eller individ. Perspektiv handlar om vikten av beakta både det medicinska perspektivet och patientens perspektiv vid bedömningen patientnytta och svårighetsgraden av sjukdomen. Tidsram gäller bedömningar av nuvarande symtom och nytta kontra risken för komplikationer i framtiden och eventuella framtida vinster av olika insatser. Evidensgrad handlar om individen kontra gruppen, dvs. svårigheter med att applicera kunskap från vetenskapliga studier om en grupp patienter (t.ex. med en viss diagnos) på en enskild patient.

Slutsatser

Det finns behov av att införa mer systematiska prioriteringar i primärvården. Prioriteringskriterierna från den nationella modellen kan användas i primärvården. De tre funna dimensionerna i studie IV kan utgöra ett komplement till de nuvarande prioriteringskriterierna och bidra till att underlätta prioritering på individnivå och till ökad rättvisa. Resultaten visar på ett behov av att klargöra hur patienternas syn på prioriteringar och personalens bedömning av vårdbehov ska avvägas. Primärvårdens särskilda karaktäristika (den stora variationen av hälsoproblem, det stora antalet patienter med diffusa symtom, tidiga stadier av sjukdomar, och kombinationer av sjukdomar) medför både speciella möjligheter och utmaningar.

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APPENDIXES

Appendix A

Följebrev till patientenkät

Till dig som patient

Vi genomför en undersökning under två veckor i oktober/november om prioriteringar i primärvården. Bakom undersökningen står Landstingsförbundet, Socialstyrelsen och flera landsting. Samma undersökning görs vid tre andra vårdcentraler i sydöstra Sverige. Bland de frågor som skall undersökas är: Hur är fördelningen av svårt sjuka med stora vårdbehov och de som har mindre vårdbehov? Hur sker prioriteringen av patienter i praktiken? På vilket sätt skiljer sig patienternas prioritering från personalens?

För att besvara dessa frågor har personalen redovisat hur de bedömt angelägenhetsgraden för din kontakt/besök. Dessutom ber vi dig fylla i en enkät med frågor om dina egna förväntningar och om vad du anser om prioriteringar i sjukvården.

Vid registrering kommer ett särskilt ID nr användas för att koppla svaret i enkäten med personalens registrering. När datainsamlingen är avslutad skall uppgifterna lagras avidentifierade i ett register vid Linköpings universitet, vilket omöjliggör en koppling mellan registerdata och enskilda personers svar. Resultaten kommer att presenteras på ett sådant sätt att det inte heller går att identifiera uppgifter om enskilda personer. Deltagande är frivilligt och du behöver inte heller ange något skäl om du avstår från deltagande. Studien är godkänd av forskningsetisk kommitté (Dnr 117-04).

Det är vår förhoppning att Du medverkar. Resultatet av undersökningen kommer att publiceras i en rapport som kommer att finnas vid vårdcentralen/mottagningen.

Om du undrar över något är du välkommen att ta kontakt med vårdcentralen/ mottagningen.

Med bästa hälsningar

Per Carlsson, Professor IHS, Linköpings universitet

Eva Arvidsson, Leg läkare koordinator primärvården, Kalmar läns landsting

Lars Borgquist, Professor FoU-enheten Östergötland och IHS, Linköpings universitet

ID-nummer……..

Patientenkät –
Mottagnings eller hembesök

Vi önskar att du svarar på några frågor med anledning av ditt besök. Frågorna gäller hur du uppfattar själva besöket och gäller inte din sjukdom/ dina besvär.

Vi är tacksamma om du fyller i denna sida på enkäten även om du gjort det förut i samband en tidigare vårdkontakt.

Sätt ett kryss i rutan för det svarsalternativ till nedanstående frågor som du tycker passar bäst:

1. Är du nöjd eller missnöjd med ditt besök?

Jag är mycket nöjd ☐
Jag är nöjd ☐
Jag är varken nöjd eller missnöjd ☐
Jag är missnöjd ☐
Jag är mycket missnöjd ☐

2. Uppfattade du att personalen vid vårdcentralen eller på hembesöket inte helt kunde tillmötesgå dina önskemål på grund av brist på resurser och att du fick stå tillbaka till förmån för andra patienter?

Ja ☐ Nej ☐

3. Hur angeläget tycker du att ditt vårdbehov var jämfört med andra patienters behov? Ringa in den siffra som passar bäst.

1 2 3 4 5 6 7 8 9 1

Stor angelägenhetsgrad Liten angelägenhetsgrad

DETTA AVSNITT HANDLAR OM DIN INSTÄLLNING TILL DEN SVENSKA HÄLSO- OCH SJUKVÅRDEN OCH PRIORITERING

Om du svarat på frågorna nedan (4-8) vid ett tidigare tillfälle behöver du inte besvara dem igen

4. Svensk sjukvård är skyldig att alltid erbjuda patienterna bästa tänkbara vård, oavsett vad det kostar.

Instämmer helt ☐ Instämmer delvis ☐ Instämmer inte alls ☐ Vet inte/osäker ☐

5. Varje individ bör ha rätt att få sitt sjukvårdsbehov tillfredsställt, även om besvären är bagatellartade.

Instämmer helt ☐ Instämmer delvis ☐ Instämmer inte alls ☐ Vet inte/osäker ☐

6. Eftersom vi lever längre och det hela tiden kommer nya möjligheter att behandla sjukdomar, räcker inte den skattefinansierade sjukvården till allt och en del saker i vården måste då väljas bort.

Instämmer helt ☐ Instämmer delvis ☐ Instämmer inte alls ☐ Vet inte/osäker ☐

7. När sjukvårdsresurserna inte räcker till allt, är det folkvalda politiker, som efter att ha rådfrågat läkare och annan vårdpersonal, ska besluta om vilka sjukdomar/tillstånd som landstinget inte ska behandla.

Instämmer helt ☐ Instämmer delvis ☐ Instämmer inte alls ☐ Vet inte/osäker ☐

8. Politiker ska aldrig besluta om begränsningar i den skattefinansierade vården utan läkare och annan vårdpersonal ska bedöma vilka sjukdomar/tillstånd som inte ska behandlas när resurserna inte räcker till allt.

Instämmer helt ☐ Instämmer delvis ☐ Instämmer inte alls ☐ Vet inte/osäker ☐

Tack för din medverkan!

Om du fyllt i enkäten **på mottagningen**: Lägg den i lådan vid utgången.
Om du fyllt i enkäten **hemma**: Återsänd den i det bifogade svarskuvertet.

(Svaren sammanställs vid Linköpings universitet)

Appendix B

Patientdata/identifikation……..

Kön: Man ☐ Kvinna ☐ Födelseår……..……..

Diagnos/åtgärd

Välj det sjukdomstillstånd som var huvudskälet till kontakten och den åtgärd som passar bäst från listan under A. Om inget i listan passar fyll i diagnos/symptom/sjukdom och åtgärd under B.

Om patienten söker för flera saker eller flera åtgärder blir aktuella väljer du det som tycker var viktigast.

A Symptom/diagnos + åtgärd nr …….. i listan

B Diagnos/symptom/sjukdom……

Åtgärd……..…

Bedömning/prioritering

Tillståndets/sjukdomens svårighetsgrad (*sympto*m,	Stor	☐
funktionsförmåga, livskvalitet och risken *för förtida*	Måttlig	☐
död, permanent sjukdom/skada och försämrad	Liten	☐
livskvalitet med tanke på sjukdomstillståndet)		
Förväntad patientnytta av planerad/genomförd	Stor	☐
åtgärd för den här patientgruppen	Måttlig	☐
	Liten	☐
Kostnadseffektivitet (*hälsovinst i relation till*	Stor	☐
alla kostnader för den här patientgruppen)	Måttlig	☐
	Liten	☐

Utifrån de tre frågorna ovan – Hur skulle du prioritera patienten på en skala 1-10 där 1 är högst? Ringa in rätt siffra.

1	2	3	4	5	6	7	8	9	1

Högsta prioritet — Lägsta prioritet

Var det andra patientrelaterade faktorer som påverkade prioriteringen av patienten? I så fall, vilka?

.....

Datainsamlaren

..... vårdcentral

Datum …… Yrke…… Namn…….

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