Open Priorities in Östergötland

Part I. The Political Decision Making process

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FOREWORD

The commissioning bodies for the National Centre for Priority Setting in Health Care are the Swedish Ministry of Health and Social Affairs, the Swedish Federation of County Councils and the Swedish Association of Local Authorities. The Centre is managed by the County Council of Östergötland. Our task is to spread information and conduct research about priority setting as a phenomenon and as a process, as well as to support and contribute to development of methods that can be used in open priorities. This is done by following and documenting practical work with priority setting that is of common interest.

Since representatives from the National Centre for Priority Setting in Health Care have been involved on different occasions in recent years in the County Council's developmental work concerning priority setting, we can hardly claim to be totally independent analysts. Nor has it been our objective to evaluate the process in terms of an external "marking" against a norm, but instead to document a course of events and convey the lessons participants in the process convey. To avoid being excessively influenced by our own preunderstanding and participation we have striven for an approach with a high degree of systematisation in data collection, analysis and reporting of results. This does not prevent us from having drawn our own conclusions concerning different phenomena. We have reported both what we consider to have worked well and that which has worked poorly. Our interpretations are based on the idea that development of new ways of working with open political priorities requires a long-range approach.

Karin Bäckman (project manager) and Anna Andersson at the National Centre for Priority Setting in Health Care, with degrees in public administration and health informatics, respectively, were responsible for data collection. This was accomplished through observations at different meetings using a detailed observation form, and through interviews with a sample of individuals who took part in the work with priority setting. In addition, a study is underway of reactions in the daily press toward the decision/priority setting process.

This report is addressed to persons who are interested in how politicians in Östergötland reasoned when they made decisions about priorities and service limitations and how they worked together with other actors. We also report on how the participants themselves experienced the process.

We want to thank the Presidium of the Public Health and Medical Services Committee (PHMSC) and the medical advisors who generously allowed us to participate in their meetings, and the politicians, public officials, medical

advisors and health professionals who took time to be interviewed. We also want to thank Gunvor Rundqvist, who followed the two priority setting exercises that were held during the spring of 2003. In addition, we are grateful to Olga Sandlund and other co-workers at the National Centre for Priority Setting in Health Care who participated in the focus groups at the citizens' meeting that was carried out in January 2004, and to Jane Wigertz who translated this report into English.

For information about the Swedish democratic system, see "Levels of local democracy in Sweden" on the homepage of the Swedish Association of Local Authorities and the Federation of Swedish County Councils (www.lf.svekom.se).

Linköping, Sweden
April 2004
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SUMMARY

In the autumn of 2003 the County Council of Östergötland went all the way in terms of working with open horizontal priorities, and was the first county council in the country to do so. Preparations had then been underway for a number of years.

The aim of this report is to describe the political decision making process during the work with priority setting in Östergötland in 2003, and to analyse the process based on a condition that is of importance if a decision making process is to be considered fair and legitimate.

Some of the questions we initially had were:

- Are the politicians going to set any open priorities?
- What is the process like?
- What actors take part in the decisions?
- How do the politicians reason in order to arrive at decisions?
- What do the politicians take into account when making decisions?
- What are the obstacles to open priorities?
- What are the success factors?

Our method is based on acquiring information from many sources:

1. Direct observation at the Public Health and Medical Services Committee's (PHMSC) two practical priority setting exercises in March and in May 2003
2. Direct observation at the PHMSC's information meetings, working meetings and conferences, and the medical advisors' meetings during September - October 2003.
3. Interviews with participating politicians, medical advisors, public officials, the Health Care Director, and health professionals during December 2003 - January 2004.
4. Examination of directives, background material, supporting documents for the decisions, and internal and external documents from the county council.
5. Focus groups and a before-after questionnaire at the citizens' meeting in January 2004.

An additional study focuses on how the priority setting process was reflected in daily newspapers during the autumn of 2003. The results of this study will be reported in an upcoming report.

Our observations and interviews show that the procedure for priority setting used in Östergötland functioned relatively well but that there were also shortcomings. In addition, we found that with respect to many points the decision making process fulfilled the required conditions for a decision making process to be considered fair and legitimate — reasonable and accepted by the majority — while several conditions were poorly dealt with.

1. *The institution where the decisions are made*
   In accordance with current regulations for the County Council, decisions are made by the PHMSC following recommendations from its Presidium. *The priority setting decisions were made in a legitimate organisational context with a mandate to make this type of decision.*

2. *The persons who participated in the decisions*
   Only politicians on the PHMSC took part in formal decision making, but during the preparatory phase with development of proposals for decisions, the Presidium of the PHMSC had the support of medical advisors, public officials, the Health Care Director, as well as administrative assistance. When making decisions, the politicians' behaviour was consistently supportive. This contributed to making a joint political decision possible despite differences in political views and different opinions. Supporting documents in the form of vertical ranking lists and descriptions of consequences were furnished by the health professionals. When developing these documents for use in decision making, however, representation of professional groups other than physicians was often missing, as was that of "users", i.e. patients and citizens. *The perspectives of many interested parties were represented, while others that could have contributed were missing.*

3. *Factors considered in the decisions*
   Different individual factors that shaped the decisions are found in the priority setting model that was established in the County Council. The priority setting model is based on ethical principles established by the Swedish Parliament and contains components that are important to consider in priority setting. *The politicians had a high level of awareness concerning principles and factors they should consider in their decisions, but in practical discussions they seldom referred directly to individual factors in the model for priority setting.*

4. *Reasons for the decisions*
   The politicians had not written down their reasons and motives at an early stage, which made open discussion difficult concerning both results and their underlying motives. The individual factors the politicians considered during their discussions were weighed together into different composite pictures,

clusters of facts, that formed the reasons and motivations for the decisions. *As a rule, reasons for decisions did not rest on individual factors, but on a total appraisal of facts.*

5. *The decision making process*
   The work fulfilled a number of conditions for the decision making process itself within a decision making group that contribute to fairness. *We consider that there was great openness within the decision making group, while there was less openness toward other politicians and toward other actors in the priority setting process.* There was also relatively great outward openness toward the public. The supporting documents and the final document were published on the Internet. *Although a large part of the material was available on the Internet, few knew that it was there and could interpret and understand its content. In other words, although the material was accessible it was nevertheless "inaccessible" to the public.*

6. *Mechanisms for appealing decisions*
   The intention of the County Council was that it would be possible for its first decisions to be appealed if new facts and arguments emerged. *In this first round, however, there was no prepared mechanism for appealing decisions if new facts or arguments emerged.*

The areas where we think there is the greatest need for improvement:

- Representation of groups other than physicians is needed in order to elucidate problems regarding the entire care chain, from prevention to care to rehabilitation. Greater representation or dialogue with "the users", i.e. patients and citizens, is needed to obtain their perspective regarding health care policy priority setting and to assure that the priority setting procedure is considered to be fair and legitimate. However, it is necessary to identify appropriate problems about which to carry on a dialogue.
- An established routine in the decision making process is needed to assure that those who take part in the decisions consider all the components in the County Council's model for priority setting.
- Concerning openness in the decision making process, we consider it important for supporting documents to be developed by means of an open internal process that includes health care staff at many levels in order to attain as high internal legitimacy as possible. Sound information must therefore be given to participants' own organisation: initially concerning the priority setting process, differentiation of roles, guidelines and timeframe; and at the conclusion of the priority setting process concerning what decisions mean in practice for the clinical areas. Guidelines for who should do what, how it should be done, and when it should be done must be clear. Information also needs to be given to the public: initially

concerning how the work is carried out, and at the conclusion of the priority setting process concerning the decisions that have been made and a description of possible consequences. The information that is dispersed externally should as far as possible be well adapted and contain information about actual decisions, or preliminary positions the politicians want to convey for public debate.

- A mechanism for appealing decisions if new knowledge or new arguments emerge is lacking and should be created.
- Above all, openness must increase with respect to decisions and reasons for decisions. The possibility of assessing and discussing priority setting decisions increases greatly if the decisions are well-motivated so that facts, values and the weighing of pros and cons are reported.

CONTENTS

1. INTRODUCTION

1.1 Background

In its final report in 2001 the Priorities Commission noted that "there is a tendency to shift responsibility for priority setting to groups other than the group one represents" (SOU 2001:8 p 93). The Commission saw many reasons why different actors avoid taking responsibility for the priority setting process or defend themselves against making difficult decisions. For politicians, a natural explanation can be that priority setting in health care is not always amenable with the desire to meet all the demands of the public. For groups of health care professionals, the explanation can be that it is difficult to reconcile open priorities with professional ethics and the focus on the individual patient as principles of care. The National Centre for Priority Setting in Health Care has conducted a number of interview studies with decision makers and health care staff in municipalities and county councils[1]. To summarize, these studies show that there is both great ignorance concerning what is meant by open priorities, as well as a series of obstacles to establishing increased openness. To assess whether open priorities are suitable and to get better knowledge about possible obstacles so as to be able to work them through in the long run, it is of great interest to follow a political decision making process in a county council where the aim is to work more with open priorities. When in the spring and autumn of 2003 the possibility arose to follow the political decision making process in the County Council of Östergötland at close range, this study got underway.

The County Council had planned for increased openness for many years, in line with the Swedish Parliament's decision on priory setting in health care. The immediate reason for this open priority setting regarding service limitations was an expected large financial deficit in 2004. In order to avoid this large financial deficit, the County Council of Östergötland was to decrease costs for 2004, in accordance with the budget directive, by 300 million kronor (corresponding to 4 percent of the entire budget). As a first step the county council leadership commissioned health professionals to draw up vertical lists of priorities in the different groups of diseases, and prepare proposals for streamlining and structural changes. Initially, it was not known how large the cutbacks brought about through streamlining and structural changes would be, nor how much could be saved through rationing or through total elimination, so-called service limitations.

[1] See reports in the National Centre for Priority Setting in Health Care report series: 2004:1 Lämås and Jacobsson, 2003:7 Höglund, and 2003:5 Lund.

1.2 Aims and questions at issue

Liss defined the concept of open priorities as follows[2]:

> *"Priority setting is open to the extent that the priority setting decisions, the bases, and the reasoning (including expected consequences) are accessible to all who want to acquaint themselves with this information." (Liss 2002)*

The aim of this study was to follow the County Council's process of working with horizontal open priority setting during the autumn of 2003. The focus was on the way in which the politicians worked with and reasoned concerning open priority setting, and on whether the decision making could be considered fair and legitimate based on the theoretical model we used. In addition, the aim was to acquire better knowledge about possible obstacles and success factors regarding open priorities in this type of decision making.

By way of introduction we formulated the following questions:

- Are the politicians going to make any open priorities?
- What is the decision making process like and how open is it?
- What actors participate in the decisions?
- How do the politicians reason in order to reach decisions?
- What do the politicians take into account in making decisions?
- What are the obstacles to open priorities?
- What are the success factors?
- What do citizens think of the county council's work with priority setting?

The National Centre for Priority Setting in Health Care also intends to examine the media's actions during the priority setting process in Östergötland. The results of this study will be presented in a later report.

1.3 Methods and limitations

From a long perspective, the priority setting procedure in Östergötland started during the autumn of 2002 when the County Council leadership gave health professionals the task of developing vertical ranking lists of their activities on a clinic by clinic basis, while from a short perspective it started after the summer of 2003 when supporting documents were drafted and the political decision making process began. Our study is limited to the political decision making process in the autumn of 2003.

[2] For a concept analysis see Liss 2002.

The theoretical frame of reference for the study is comprised of the conditions for a fair and legitimate procedure for priority setting in health care proposed by Daniels and Sabin (Daniels and Sabin 1997). Singer and co-workers used these in the development of a model with factors of importance for considering decision making as fair and legitimate (Singer and co-workers 2000). These two theories are described in more detail in Chapter 2. We based our analysis of the political decision making process in Östergötland on the model of Singer and co-workers in order to see how well it fulfilled the criteria for a fair and legitimate procedure. With regard to which factors politicians take into account in their decision making, we used both the Östergötland guidelines as well as national guidelines (see Appendix 2).

Our method is based on information collected from a number of sources:

1. Direct observation at the PHMSC's two practical priority setting exercises in March and in May 2003.
2. Direct observation at the PHMSC's information meetings, work meetings and conferences, and the medical advisors' meetings during September - October 2003.
3. Interviews with participating politicians, medical advisors, public officials, the Health Care Director and health professionals during December 2003 - January 2004.
4. Examination of directives, background material, supporting documents, and internal and external documents from the County Council.
5. Focus groups and a before-after questionnaire at a citizens' meeting in January 2004.

Gunvor Rundqvist from the National Centre for Priority Setting in Health Care collected data from the two *priority setting exercises* that the County Council conducted in the spring of 2003, using both direct observation at the two exercises as well as direct observation at a group meeting of the PHMSC Presidium after the first exercise. In addition, three interviews with medical advisors who took part in the work were conducted after the first exercise. See Chapter 4.

The reasoning of the politicians — and also that of the medical advisors and health professionals — was followed by means of *direct (non-participant) observation* (Adler and Adler 1998) at formal meetings during the drafting and decision making parts of the process in September - October 2003. This involved *systematic observations* where certain parameters that had been established beforehand were studied and registered by two observers (Karin Bäckman and Anna Andersson). Three observation forms containing a total of 77 points/questions were developed, and these were filled in at the time of the observations (see Appendix 1). Throughout, examples and quotations were

noted for the different points. A summary of the observers' individual impressions of the observation occasion was made after almost every occasion. The notes taken at the observations were then analysed in a number of steps. The individual observation occasions were then summarized in a single document separately by each of the observers. Thereafter, the documents and impressions of both observers were joined together in one document. In the report of findings, the observations were divided according to the different actors involved (politicians, public officials, the Health Care Director, medical advisors and health professionals).

Two investigators (Karin Bäckman and Anna Andersson) conducted *interviews* with a sample of politicians, medical advisors, public officials, the Health Care Director, and health professionals who took part in the priority setting process. A total of 13 persons were interviewed during December 2003 - January 2004: five politicians, two public officials, one Health Care Director, two medical advisors, and three health professionals. The interviewees were selected so as to represent the entire county based on a number of established criteria such as position, role in the priority setting process, participation in the process, sex, political affiliation, and based on impressions acquired during the observation study concerning activity during the work process. The interviews were semi-structured (Frey and Fontana 2000) and followed a question guide that had been prepared in advance with about 25-35 questions. Tape-recording and notations were done in parallel. An outside transcribing agency transcribed the interviews consecutively and the transcripts were analysed by both interviewers. Any gaps in the transcriptions were filled in using the tapes and notes.

Archive data (Drury 2002), i.e. the directives, background material, supporting documents, memos, internal and official documents, etc., produced by the county council and that derived from the priority setting process under study were collected and analysed.

To obtain a picture of how the county council's work with open priorities was perceived by the public, 400 randomly selected residents aged 18-74 years from the whole county of Östergötland were invited to a *citizens' meeting* in Linköping. At that meeting, information was presented about the priority setting process carried out in the County Council, and there was an opportunity to pose questions to politicians and medical advisors. Three focus groups were conducted, and a questionnaire was administered at the beginning and the end of the meeting. See Chapter 7.

2. THEORETICAL FRAME OF REFERENCE

2.1 Fair and legitimate procedures

Daniels and Sabin developed an account of how priority setting should be done within the framework of the American health care system, which is largely based on subsidization via private health insurance (Daniels and Sabin 1997)[3]. Their views are, however, also of relevance to publicly financed health care systems such as in Sweden. Two issues in the priority setting process in health care are identified: *legitimacy* and *fairness*[4] . The problem of legitimacy is expressed by them as follows: *"Under what conditions should authority over priority setting decisions be placed in the hands of a particular organization, group or person?"*; while the problem of fairness is expressed in the question: *"When does a patient or clinician have sufficient reason to accept priority setting decisions as fair?"* (Gibson 2002).

The bases of Daniels and Sabin's framework are a discursive theory of fairness and that decisions about which treatments should be financed by a publicly financed health care system should be public since they are moral in character. Fair procedures are needed in order to solve this type of moral conflict. Furthermore, they contend that since we cannot expect to reach a consensus within the foreseeable future concerning which principles should direct priority setting decisions, fair procedures therefore constitute a better basis than abstract and general principles.

They present four conditions that must be met in order for decision making procedures concerning subsidization of health care to be considered fair, and together these comprise what they term "accountability for reasonableness". These conditions can be described briefly as follows:

1. *Publicity*: The bases for priority setting decisions must be public.
2. *Relevance*: These rationales (evidence, positive arguments and principles) must be considered relevant for priority setting decisions by fair-minded people.
3. *Appeals*: There must be mechanisms for challenging decisions and revising them in light of new evidence and arguments.
4. *Enforcement*: There must be either voluntary or public regulation of decision making processes to ensure that the first three conditions are met.

[3] For a Swedish summary of Daniels and Sabin's perspective, see Melin 2003.
[4] Fairness and legitimacy in this sense refer to whether the procedure itself (not the results) can be perceived as reasonable and fair and thereby become legitimate (accepted by the majority), rather than the more juridical meaning of legitimacy, i.e. being in accord with the legal system in question.

Daniels and Sabin think that the reason rational bases for subsidization decisions ought to be public is to show that consistent assessments are made from case to case and that this is being done fairly. Judgements made in earlier decisions should be the starting point for future decisions, but earlier judgements can also need revision. By clarifying the reasons for their decisions, an organization can improve its decision making. If a decision is inconsistent with earlier judgements this then becomes obvious, and by striving for agreement in the reasons for priority setting decisions made at different times, fairer decisions will be reached, which will also result in more thoughtful judgements.

Clarifying that good economic management of health care resources is of mutual importance for all actors in health care is not sufficient. Arguments concerning how such a system should be must also fulfil the requirement that the reasons presented can be accepted by everyone. This reasoning is anchored in the idea of a "deliberative democracy", which means that democratic decisions should be preceded by open debates and not be justified only by means of voting. Further, Daniels and Sabin think that an open debate where arguments are sought that can be unifying is an appropriate approach for justifying decisions when morally controversial questions are to be decided upon. In accordance with a deliberative view of democracy, decisions should be preceded by a search for arguments everyone can agree upon.

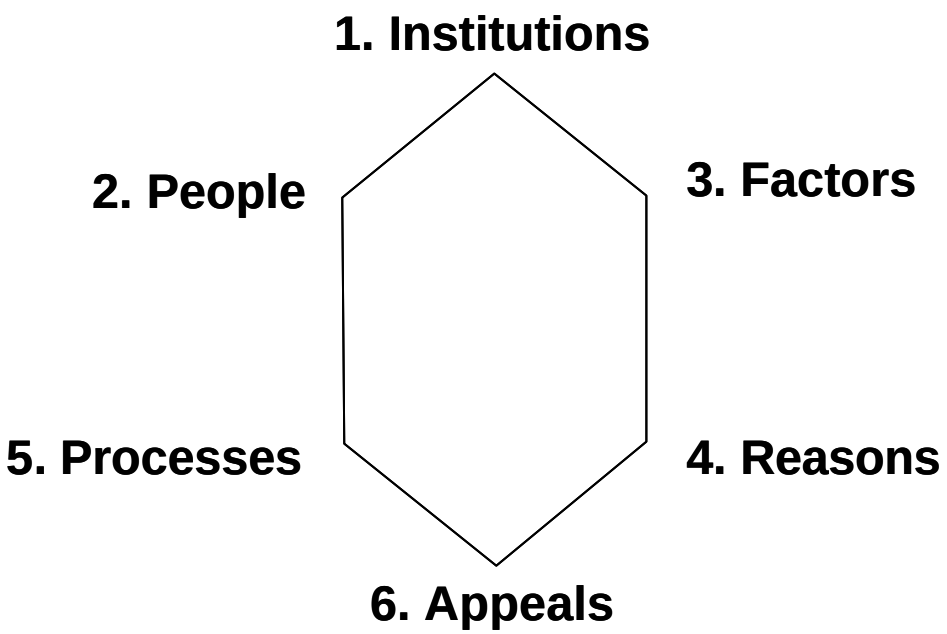
Further, there must be mechanisms for questioning decisions and revising them in light of new information or new arguments. Participants who were excluded from the decision making thereby get the chance to make their voices heard, and even if challenging a decision does not lead to a change in the decision, Daniels and Sabin contend that the procedure for resolving conflicts leads to increased legitimacy if it forces a new judgement of the original decision. Procedures for conflict resolution make possible a public examination of the decision and its underlying policy, and can reduce patients' need to take their case to court.

To ensure that the first three conditions are met, there must also be either voluntary or public regulation of the decision making processes. Daniels and Sabin maintain that if the institution itself does not ensure that these conditions are met, then public regulation is necessary.

Further, they write that accountability for reasonableness provides the opportunity to educate all stakeholders about the substance of deliberation about fair decisions under resource constraints. This enables social learning about limitations and connects decision making in health care to broader, more basic democratic deliberative processes, which should result in increased possibilities for agreement about a fair allocation of resources (Daniels 2000).

2.2 Models with components of importance for decision making

Singer and co-workers conducted a qualitative study (field studies and grounded theory (generation of theories on empirical bases)) focusing on procedures when deciding about subsidization of new medical technologies in cancer care and cardiac care in Canada (Singer et al 2000). They defined six elements/areas they consider of importance so that priority setting decisions are perceived as fair and legitimate, and they combined these in a "diamond model" (See Figure 1).



1. the institution where priority setting occurs
2. the people who are involved in priority setting
3. the factors taken into consideration in priority setting decisions
4. the reasons for the decisions
5. the process for decision making
6. mechanisms for appealing decisions

Figure 1. The diamond model of priority setting (Gibson 2002).

Each of the six facets in the model influences the others in a reciprocal way. They can be more or less perfect and contribute to how perfect/complete the totality will be.

The authors emphasize that priority setting decisions must be made in a legitimate organizational context with the mandate to make priority setting decisions. This can apply to the exercise of public authority or to groups with democratically selected representatives.

A key element regarding fairness is that the perspectives of important parties are represented in the decision making. Singer and co-workers state that a certain decisive number, a critical mass, of lay members is needed to attain a successful decision making process in priority setting in health care.

Further, they found that a number of individual factors shape the decisions: benefit, evidence, harm, costs, cost-effectiveness, and pattern of death. The expected benefit of an intervention was found to be of greatest importance. Evidence represents the degree of certainty with which the benefit is known, and sometimes the benefit must be weighed against the evidence. Discussions about the total costs for a certain disease group can lead to discussion about access and fairness. Facts about cost-effectiveness are available for only a small number of interventions, but in those cases they can be used to support decisions based primarily on benefit and evidence. The pattern of death in relation to that in other diseases can influence deliberations. The possibility of "saving" patients' lives, even in the future, tends to influence the allocation of resources.

The underlying reasons (the motivations) for the decisions do not rest on individual factors; the decisions are based on information taken together, clusters of facts. These clusters can have different appearances/combinations from decision to decision. For example, functional ability and quality of life in the present health state plus the risk for permanent injury and deteriorated quality of life can be of most importance in one decision, while the risk for untimely death plus patient benefit from the intervention for the condition plus existing evidence for this can be of most importance in another decision. Further, decisions and the rationales concerning them are compared with earlier decisions and rationales, which provides guidance in making the next decision, and so on. According to Singer and co-workers, in the long run this ought to result in well-founded decisions.

Transparency in decisions is a key element in the decision making process in the priority setting group. Other aspects of the process that contribute to fairness are: disclosure of conflicts of interest; providing the opportunity for everyone to express their views; ensuring that all committee members understand the deliberations/debate; maintaining honesty; building a consensus; ensuring access to consultation with external expertise; ensuring an appropriate agenda; maintaining an effective leadership/presidium; and ensuring the right time point for health budget decisions (for giving new, effective technologies to patients).

Finally, both Singer and co-workers as well as Daniels and Sabin conclude that in order for a procedure to be perceived as fair and legitimate there must be a mechanism for appeal, or in other words it must be possible to revise decisions if new arguments or new facts emerge.

2.3 What behaviour occurs in groups engaged in problem solving?

Previous studies of the behaviour of persons in small groups who are engaged in problem solving show that the nature of the problem and the atmosphere where this is taking place determine which forms of interaction will be predominant (Swedner 1961). Bales classified participants' behaviour and developed an observation form (Bales 1950), see Figure 2. Participants' behaviour is classified by Bales into the main categories of positive reactions, attempted answers, questions, and negative reactions, after which they are broken down into the smaller subcategories of problems of orientation, evaluation, control, decision, tension-management and integration.

We found that Bales' chart was useful as support in our own observation study and worked it into our own observation form for our systematic observations, see Appendix 1. The aim was an attempt to find a subcomponent that could explain a possible failure or a successful process.

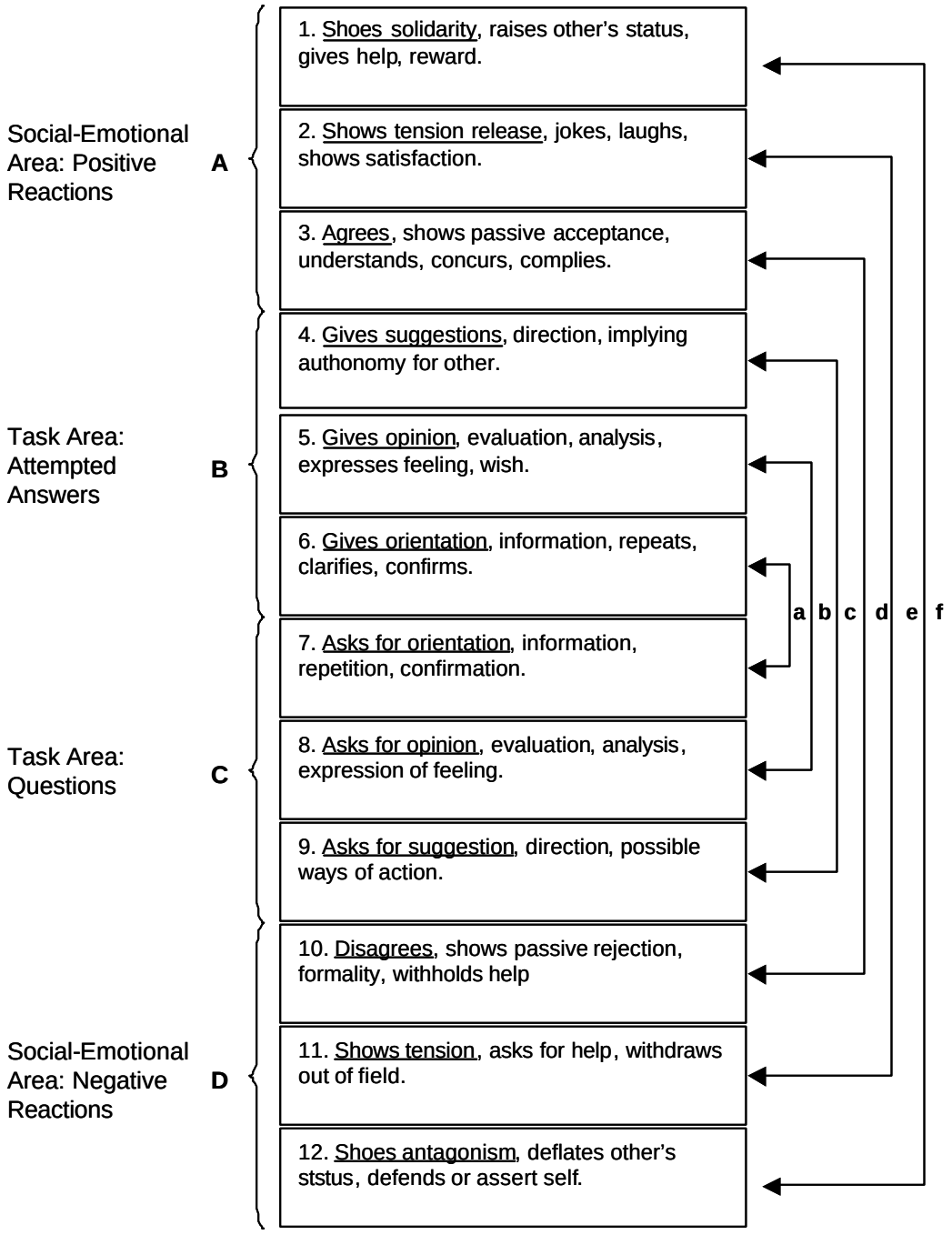


Figure 2. Robert Bales' system of categories used for classification of behaviour in small groups engaged in problem solving.

3. WHAT WAS THE COUNTY COUNCIL'S WORK WITH PRIORITY SETTING LIKE ?

In early 2003 the County Council of Östergötland predicted an economic deficit of approximately 300 million SEK (33 million euros) for 2004. The ways by which County Council management thought this deficit could be handled were working with structural changes[5], efficiency measures, and priority setting that would result in decisions concerning service limitations in care[6][7]. Efficiency measures and structural changes were to be utilised first of all, and thereafter there would be descriptions of consequences for patient groups/care for which services must be limited.

A so-called *Public Official Advisory Board* (the Health Care Director, medical advisors and public officials as support persons) and a so-called *Politician Advisory Board* (the Presidium of the PHMSC) were established for the work with priority setting. The task of the Public Official Advisory Board was to analyse vertical ranking lists and descriptions of consequences and present the results to the politicians, while the politicians' task was to consider the results and supporting documents and present a proposed decision to the PHMSC. The whole procedure is described in a report by participants in this work (County Council of Östergötland 2004a). The report describes the development of ranking lists and the subsequent work with priority setting, how the political priority setting process was carried out, and experiences regarding this. Details concerning the process are presented in this report. In addition, published articles are presented on the County Council's homepage [8] "Change in the county council – county co-operation" (County Council of Östergötland 2004b). The County Council's news articles about the process and reports on the work of groups of health professionals are also on the homepage. In addition, there is information about service limitations decided upon for different groups of diseases and a more easily read compilation of the priority setting list. There is also a compilation of questions and answers concerning changes in services and structural changes.

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[5] Development of proposals for structural changes was handled by a smaller group of five to six persons (consisting of County Council public officials at the highest level and physicians at the highest level), and this work proceeded in parallel with priority setting.

[6] By *structural changes* the County Council means organizational changes such as the concentration of certain types of care in one department or one hospital. *Efficiency measures* refers to requirements for improved work processes to reach the goal of more adequate care with unchanged or decreased resources. The County Council of Östergötland chose to use the concept of "service limitations" to mean care that will no longer be financed by the County Council. These decisions were preceded by a priority setting procedure.

[7] We have tried to the best of our ability to focus our study on the part dealing with priority setting.

[8] The County Council of Östergötland's home page: www.lio.se.

3.1 The procedure for priority setting

Preparations for this work began in the *autumn of 2002* when the County Council Director gave clinical department heads the task of developing vertical *ranking lists* for county health care. The lists were to cover the whole county and to have the support of primary health care, and were to be submitted by December 31st at the latest. Since 1997 there have, however, been preliminary vertical ranking lists for many disease areas. These were developed as part of the County Council's Medical Programme work[9].

Ranking of diseases/conditions in combination with health care interventions was aimed at comparing the care needs of patient groups, patient benefits from health care interventions, and the cost-effectiveness of the interventions (County Council of Östergötland 2004c). The ranking lists were to be disease group-based and to comprise 10 levels. There can be a number of health states/health care interventions on each level, just as one and the same health state can be found on several levels depending on the intervention that is involved. The ranking was also to be a weighing of external facts: ethical principles, care needs (degree of severity of the disease), the effects of the intervention, cost-effectiveness and evidence (scientific support).

In *March 2003* the first training seminar on priority setting was arranged for politicians. See Chapter 4.

Since the ranking lists were not designed for direct use by politicians in making decisions regarding resource allocation among disease groups (horizontal priority setting), in *April* clinical department heads were given the task of formulating *descriptions of consequences* for the 10 percent of county health care that was ranked lowest on their lists and that health professionals judged could not be handled with structural changes or efficiency measures. The descriptions of consequences were to be submitted by September 5th at the latest and to be formulated so that they could be read and understood by those without medical training. A plan for carrying out the priority setting process was also drawn up by the Public Official Advisory Board (County Council of Östergötland 2003a).

Seven questions were to be answered in the descriptions of consequences (County Council of Östergötland 2003g):

1. Which patient group(s) are affected?
2. Which health care intervention is involved?
3. Size of the patient group?

[9] For more information about this form of work see Kernell-Tolf et al. (2003) and Östergötland County Council (1999).

4. What will be the consequences if the intervention in question is not forthcoming? (survival, functional ability, health-related quality of life, sick-listing, retirement, risk for permanent injury)
5. What are the costs for the treatment? What is known about the cost-effectiveness?
6. Are there any other alternative care forms for this patient group? Which alternative, less resource-demanding interventions can be considered and what would be the effects on the above parameters?
7. Will costs and care/interventions be shifted over to the individual patient, relatives, other care providers or other sectors of society?

The second training seminar on priority setting for politicians was held in *May*.

In *June* the ranking lists were received at the County Council office and a verbal presentation per disease group was made at an opening meeting for contract negotiations for 2004. The plan for implementation was now presented in more detail (County Council of Östergötland 2003k).

In *August* the County Council Executive Board established "The principles for priority setting in county council-financed health care in Östergötland" (County Council of Östergötland 2003j). The PHMSC stipulated how the drafting and decision making process should be carried out and the public officials formulated protocols and check-lists for the politicians' horizontal priority setting.

In *September* the descriptions of consequences were received at the County Council office. During a two-week period the medical advisors compiled and examined the ranking lists and descriptions of consequences per disease group.

The medical advisors evaluated the descriptions of consequences based on a form with six questions:

1. Is there a vertical ranking list?
2. Is the ranking list county-wide and supported by primary care?
3. Is the description of consequences based on the ranking list? In that case is it consistent and in the right order?
4. Does the description of consequences concern county-wide health care?
5. Are costs or patient responsibility transferred?
6. Are the questions in the description of consequences answered?

The advisors presented the results to the Presidia[10] of the PHMSC on one day and to the PHMSC Presidia together with the health professionals during two full days at the end of September.

As help in their decision making the politicians received forms on which to make their own notations for each disease group, the medical advisors' compilations and comments per disease group concerning the descriptions of consequences, as well as a check-list to use for their political examination of proposals for structural changes and proposals for priority setting (County Council of Östergötland 2003i,h,b).

On *October* 1st and 2nd the Presidium of the PHMSC formulated a proposal on priority setting for the Committee. The decisions consisted of over 60 points, of which about 40 concerned transfer of patients to another department or care level. The savings for county health care were estimated at around 38 million SEK (4.2 million euros) (County Council of Östergötland 2003m). The Health Care Director and one of the medical advisors also took part in the decision making process. To assist them, the politicians had a protocol form containing headings like Summary of the discussion; Recommendations to the PHMSC; Expected cost decreases and Motivations for positions taken (County Council of Östergötland 2003l). A press conference was held on October 2nd where the Presidium of the PHMSC and a medical advisor presented the proposals to journalists and a press release was sent out (County Council of Östergötland 2003n).

On October 29th the PHMSC adopted the resolution "Changes in services and structure in health care in 2004" (County Council of Östergötland 2003c), which includes the decisions on service limitations. Reservations were entered by the Moderate Party, the Christian Democratic Party, and the Centre Party.

In March 2003 the National Centre for Priority Setting in Health Care was asked if we were interested in following and documenting the political priority setting process. Our work began by observing and documenting experiences from the political priority setting exercises during the spring, and continued during the autumn with observations of the decision making process at meetings, and during the winter interviews were conducted with actors involved in the priority setting process.

[10] The Presidium of the Public Health and Medical Services Committee, the Presidia of the West, East and Central drafting committees, and the Presidium of the Medical Programme drafting committee. There are representatives from the following parties in the presidia: the Social Democratic Party, the Green Party, the Left Party, and the Moderate Party. Representatives from the Christian Democratic Party, the Centre Party, and the Liberal Party also participated.

4. PRIORITY SETTING EXERCISES

On two occasions during the spring of 2003 the County Council arranged practical priority setting exercises for four politicians in the PHMSC Presidium. Also invited were politicians from the Central, East and West County drafting committees, public officials from the County Council office, medical advisors, and a selection of physicians from the County's hospitals. A total of 28 persons were invited to the first practice session and 43 persons were invited to the second session. The aim of the practice exercises was expressed in the invitation as follows:

> *"In a number of Programme areas there are now preliminary vertical priority setting lists (ranking lists). We now want to test how these would work in practice, as support in so-called horizontal priority setting prior to decisions on resource allocation among different disease groups/health care areas. More specifically, we want to examine how a dialogue between politicians, care providers and leading public officials would take shape and function."*
> *(County Council of Östergötland 2003e)*

At the first priority setting exercise three different disease areas were presented to a Politician Advisory board comprised of the Presidium of the PHMSC and the Health Care Director. The areas were cancer, musculoskeletal diseases and heart disease. The pre-conditions were that all possibilities to increase efficiency had been fully utilised. After presentations, followed by time for questions, the politicians met in private to make their decisions. The politicians conveyed their decisions and commented on them. Thereafter, discussions took place in small groups comprising politicians, medical advisors and members of the public concerning difficulties, misgivings and their wishes prior to a real situation.

Some brief lessons from the first priority setting exercise were that:

- The dialogue between politicians and health professionals is important in understanding the roles and problems of one another.
- The descriptions of consequences should be more detailed, have a clearer user perspective, and be more comparable to one another.
- The descriptions of consequences should be examined and possibly supplemented by a professional board before politicians can take a stand on them.

The second session of priority setting exercises was arranged the same way as the first. More people were invited to the exercises, but the audience was somewhat smaller. This priority setting exercise focused on eye disorders and vascular disease.

Some new lessons from the second priority setting exercise were that:

- The meaning of priority setting for the patient at the functional level, the activity level and the societal level needs to be described more clearly in order to provide guidance for the politicians.
- Health professionals want a clear model according to which they can work and training in using the model.
- There were more problems in this second session, which caused the politicians to experience decision making as more difficult.

Based on our experiences from the exercises a protocol (see Appendix 1) was formulated so as to be able to follow and document the political decision making process that got underway in September 2003. The task of the National Centre for Priority Setting in Health Care did not comprise other parts of the County Council's work with efficiency measures and structural changes, but was limited to the priority setting process.

5. CAN THE DECISION MAKING PROCESS IN ÖSTERGÖTLAND BE CONSIDERED AS FAIR AND LEGITIMATE?

The work with priority setting in the County Council was carried out in two dimensions. In the first, *vertical priority setting* was done in different disease groups, and care providers and managers with medical responsibility were responsible for this. The focus here is on priority setting between patient groups/care efforts, or between resources for prevention, investigations/diagnostics, treatment and rehabilitation. On the second dimension *horizontal priority setting* was done between different groups of needs and groups of diseases, and this was mainly the responsibility of the politicians. The latter are population-based decisions and concern resource allocations between different areas of health care, disease groups or large patient groups.

We studied mainly the work with horizontal priority setting – which was done during the autumn of 2003. As mentioned earlier, the analysis was based on the Diamond Model of Singer and co-workers, with six components that are important to take into account so that decision making concerning resource allocation in health care will be considered fair and legitimate [11].

1. The institution where the decisions are made.
2. The people who are involved in decision making.
3. The factors taken into consideration in the decision making.
4. The reasons for the decisions.
5. The process for decision making.
6. Mechanisms for appealing decisions.

What should be kept in mind is that each one of these six components can in and of itself be more or less perfectly fulfilled. This naturally contributes to how perfect/complete (fair and legitimate) the procedure as a whole is considered to be.

5.1 Decisions made in a legitimate organisational context with a mandate to make priority setting decisions

According to current "County Council Regulations", the County Council Executive Board decides upon and establishes principles for priority setting, while the (PHMSC), based on task specifications, is charged with priority

[11] What these components comprise was presented in more detail in Chapter 2.

setting concerning different needs (County Council of Östergötland 2003j). Further, it is the Presidium of the PHMSC that is responsible for developing recommendations to the Committee regarding which priorities it should set. The PHMSC has the political responsibility for drafting decisions concerning priority setting and service limitations, while the Director of Health Care is responsible for drafting at the public official level and is assisted by the County Council's medical advisors, who act by order of the Director of Health Care (County Council of Östergötland 2003d). The Director of Health Care also has the task of incorporating the recommendations for service limitations made by the PHMSC Presidium in the final contract negotiations with care providers. This delineation of responsibilities is the basis for the County Council's work with priority setting.

The PHMSC Presidium conferred and made a decision that then was the basis for (and became) the decision that was formally made by the entire PHMSC .

The work in the autumn was preceded by two preliminary exercises during the spring of 2003 where the politicians had the opportunity to prepare themselves for this new type of decision making, which is considered difficult. In our interviews it was found that those who were not present at these two exercises felt that it was generally somewhat difficult to discuss priority setting issues. Politicians we interviewed thought that a greater number of politicians needed to obtain more information and ought to get the chance to practice, and not just those politicians who are going to make the actual priority setting decisions later on.

5.2 The perspectives of a greater number of interested parties should be represented in the decision making

The central actors who participated most during the decision making process were:

- *politicians* — four women in the Presidium of the PHMSC; they developed proposals for the priority setting decisions
- *health professionals ¾* from the four hospitals in the county; they provided supporting documents in the form of ranking lists and descriptions of consequences
- *medical advisors* — six in all, five men and one women; they prepared supporting documents and gave the politicians their recommendations and advice
- *public officials* — two women; they supported the politicians and developed guidelines for both politicians and health professionals in order to advance the process

- *Health Care Director* — a woman; she was responsible for drafting at the public official level and assisted the politicians

These actors had different tasks in accordance with the time plan, see Figure 3. The different phases of the work succeeded one another and the respective actors were dependent on what emerged (the product) from the actors in the previous phases.

- *The politicians* in the PHMSC Presidium constituted the central group during the entire priority setting process and acted chiefly during the drafting and decision making phases.
- *The public officials and the Health Care Director* played an important role at an early stage, in the planning and development of guidelines for the work, as support during the drafting phase, and in the final stages of decision making and the final revision of the results.
- *The medical advisors* acted in the middle of the priority setting process, in drafting and decision making.
- *The health professionals* acted in the beginning and in the middle of the priority setting process, in the development of supporting documents and drafting, and afterwards when the results were to be implemented.
- There was also access to administrative assistance, and to the finance department and the information department.

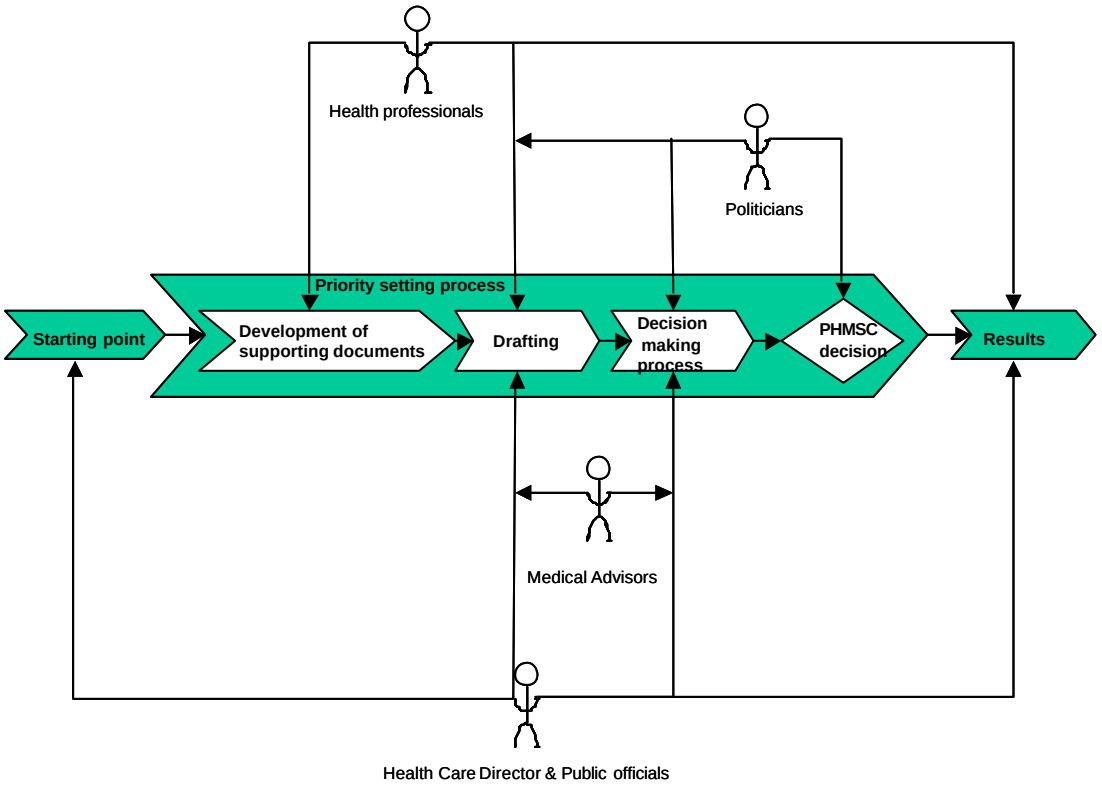


Figure 3. The roles of central actors during the priority setting process.

Joint decisions were made by the entire PHMSC based on the proposals presented by the Presidium of the Committee (with full-time politicians from the Social Democratic Party (s), the Green Party (mp) and the Moderate Party (m)). Discussions had taken place both within the different parties and within the majority group ((s), (mp) and (v)) and the opposition group ((m), the Liberal Party (fp), the Christian Democratic Party (kd), and the Centre Party (c)).

In the interviews the politicians commented that it was difficult to judge how the different steps in the "care chain" were affected by their decisions, and they considered this a problem. It therefore became important for them to be able to communicate in the future with professional groups other than physicians so that their perspectives would also be included.

All those we interviewed thought that involved actors contributed valuable knowledge and that the open dialogue resulted in increased discussion about priority setting – on the part of all actors and even among different actors. *Trustful participation by the politicians* was emphasized in the interviews. All the politicians respected the process and stuck together, and there did not appear to be any political manoeuvring.

5.3 The individual factors that shaped the decisions

All those interviewed emphasized that the two whole days in the autumn when the politicians and health professionals met constituted the single most important element regarding the formation of priority setting decisions. According to the interviewees, those days provided the opportunity for communication and clarification and made it possible for the politicians to pose questions about things they did not understand or where information in supporting documents was missing. The politicians could also clarify what information they thought they needed in order to make decisions. The health professionals could in turn clarify their reasoning for the politicians, obtain clarification regarding aspects of the guidelines, and pose questions and get insight into the reasoning of other health professionals when they combined their ranking lists and descriptions of consequences.

Important factors that shape priority setting decisions are those found in the model for priority setting that was established and is used not only in the County Council but also nationally (see Appendix 2). The model consists of components that are important to consider in priority setting, based on the ethical principles established by the Swedish Parliament: the principle of all people being equal in dignity and value, the principle of need and solidarity, and the principle of cost-effectiveness.

These guidelines specify which aspects are of most importance to take into account and to form the basis for development of vertical ranking lists with ten levels by the health professionals (County Council of Östergötland 2003j). Those interviewed reported being already familiar with the model for priority setting, and it was accepted by all actors.

In our observations it was noted that *the politicians* were highly aware of principles and the factors they *ought to* take into account in their decisions, but in their discussions they seldom directly referred to the model for priority setting. An example of going back to reasoning based on principles was when they discussed where a particular intervention should take place — if it should be done at one department or another, in primary care or in municipal care. However, the discussions mostly concerned what *reasonable service limitations* were based, for example, on how they would affect individual patients and the amount of resources that could be freed. Concepts from the model could emerge in the discussion as isolated phenomena, but when motivating service limitations there was no immediate association to the model in the wording of the decision.

In their discussions the politicians pointed out that the ethical principles constitute the ground they stand upon and that they were going to specify that in their final document. They also said they defended the operation of health care according to need and that they would not make decisions based on an organizational perspective concerning where patients should be cared for. The politicians posed questions to the advisors concerning the meaning of diseases and health care interventions. The cost-effectiveness of interventions was almost never mentioned, but the politicians sometimes wondered about the shifting of costs to other actors in society such as the municipalities, and how cooperation with them could be improved. At the same time, they pointed out that it was not in their power to oversee the allocation of society's total economic resources to different actors in society. Now and then they touched upon the question of available evidence that they should consider when taking a position regarding different factors. One example was the statement that if there were no scientific facts indicating any positive effects, there was actually no reason to carry out that particular surgical procedure.

Many politicians pointed out at the interviews that the supporting documents — the descriptions of consequences — were not of sufficient quality to allow them to make well-grounded decisions. The inadequacies they referred to were that the descriptions were very different for the different disease areas (Some were considered good and others very poor); that all the facts that were to be included according to the directive were not included; that the descriptions of consequences did not cover the county as a whole and were not supported by

primary care, and they were sometimes difficult to understand (the names of diseases and medical terms were written in Latin instead of Swedish).

The medical advisors made use of the model for priority setting in their points of view and recommendations, and based on its components they contributed views on what they considered to be *medically and practically feasible*. For example, their reasoning was based on how priority setting is done today and how different patient groups function in their everyday environment, and what the practical consequences would be for these groups if services limitations were enacted. The degree of severity of diseases and the benefits of health care interventions were found in the advisors' presentation of the ranking lists for the different disease areas. The advisors explained the individual diseases and interventions. Information about the cost-effectiveness of the interventions was seldom touched upon, but they pointed out that studies on this are lacking today for many diseases and interventions.

The public officials strived to have the ethical principles permeate the entire priority setting discussion. They posed questions to the politicians (and sometimes forced them to answer) with the idea that the politicians should take the principles into consideration. This was an advisor role, both to provide support as well as to act as moderator in order to hold the process together during the course of decision making. The public officials could also pressure the politicians by assuming the role of devil's advocate in order to make them think through their position one more time before making a definitive decision.

The Health Care Director focused on which supporting documents seemed most adequate for the purpose of making a decision and on where reasonable service limitations could be made. The importance of following laws and ethical principles was pointed out.

The health professionals should have made use of the model when developing the supporting documents. Those we interviewed reported being familiar with the model and that they felt positive toward priority setting. However, in the whole-day presentations we observed that some of the health professionals were somewhat sceptical about whether service limitations would result in any cost savings at all. They implied that there is a risk for activities simply to be moved around in the health care system. In these discussions, however, an association to the model on priority setting was missing, as was a line of argument about where they thought these health care interventions should be carried out and by whom. Many of the health professionals emphasized that because of this process a discussion could now begin — in Östergötland and in Swedish health care as a whole — concerning whether all patients should really get all the care that can be given despite the fact that the benefits are sometimes low, and concerning

when patients could be denied care, i.e. even the serious health states/disease groups emerged in the discussion.

5.4 The reasons for decisions were based on a total appraisal of facts

The preliminary work for the politicians' decision making process was done by the medical advisors, who divided the disease groups among themselves and first worked individually with their own areas and then in pairs in order to discuss and get support for their positions. Finally, they reported their recommendations to the politicians together for each disease group. The different factors that were deliberated upon during the politicians' discussions were then compiled into different combinations/clusters of facts that comprised the motivations for the decisions. Sometimes certain facts weighed heavier than others and the motivations could differ, have different emphases, from decision to decision. If or how the politicians took all the points in the model of priority setting into account in each separate decision was not commented upon. During the discussions the politicians sometimes compared decisions and the lines of reasoning concerning them with earlier decisions and their reasoning in order to validate their own reasoning. In the interviews it was also found that during the decision making situation the politicians pondered over what a decision involved in relation to decisions made earlier. Here the public officials and the health care director acted as support for the politicians and functioned as a uniting link throughout the line of reasoning and helped to "bring it into line".

An example where it was obvious that many factors were considered at the same time was surgery for a one-sided cataract with good sight in the "other" eye. Here the politicians discussed how these patients functioned today (regarding stereoscopic vision and driving, for example), the risk that patients would injure themselves, and the quality of life of the patients. Further, regarding the benefit of a cataract operation on the "first" eye they reasoned that the patients would get good sight in both eyes, that they could keep their driver's license, and that they would have better quality of life. The risks with not doing the operation were judged as small and the cost was considered low in relation to patient benefit. The decision was to retain cataract operations on the "first" eye as a health care intervention in the County Council's services.

The politicians had thoughts about whether certain interventions, such as those based on non-medical indications, should instead be charged a fee for, but they noted that this line of argument was outside the scope of questions concerning service limitations, which were to be decided upon on this occasion, and that such decisions should be taken up in a separate discussion at a later time.

5.5 The process of decision making

The priority setting procedure in Östergötland can be characterized as long or short, depending on how one chooses to define when it started[12]. In *the long perspective*, the work started during the autumn of 2002 with the urgent request of county council leadership for the health professionals to develop clinical department-wise ranking lists of their activities (covering the whole county and supported by primary care), and during the spring of 2003 two practice sessions were arranged. The priority setting procedure would hardly have been possible without the preliminary work that started as early as 1994 with introduction of the so-called ”Medical Programme work” in the County Council in connection with the new purchaser-provider organization (Kernell-Tolf and co-workers 2003). There have been vertical ranking lists for certain disease groups since 1997 via the Medical Programme work. In *the short perspective*, the work began after the summer of 2003 when the descriptions of consequences for that part of the stipulated savings that could not be achieved through structural changes or efficiency measures were submitted to the County Council by the health professionals. The supporting documents underwent a drafting process and proposals for service limitations were presented to the politicians in the PHMSC, which then made decisions about service limitations. Figure 4 illustrates the political process and outward openness.

[12] For a more detailed description of the different steps in the process see Chapter 3 and County Council of Östergötland 2004.

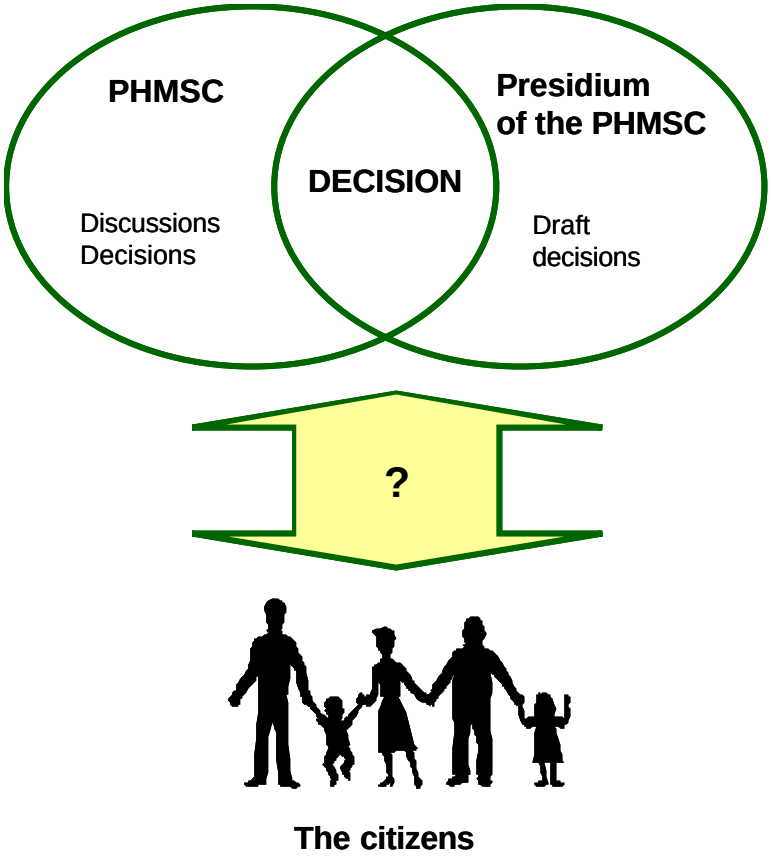


Figure 4. The drafting and decision making process and outward openness.

The process can be divided into two components, the political process within the group, i.e. within the entire PHMSC and within the subgroup of the PHMSC Presidium, and the process outside the group, i.e. how outwardly open the process is toward the public.

5.5.1 Cooperation and roles in the inner core

All the different parties represented in the PHMSC ((s), (mp), (v), (c), (kd), (fp), and (m)) were present at the two full-day meetings during the autumn when the health professionals and politicians met. All those present had access to the material and information given on those days and had the opportunity to convey their views. The public officials had prepared an agenda both for the process from May until October as well as for days of extra importance during the process. During the two full days when the politicians and health professionals met, the agenda and allocation of time for speakers were strictly adhered to both during presentations and in the following group discussions. After going through the disease groups each day, the politicians then discussed those that had been presented that day.

Throughout the whole process the medical advisors, public officials and the health care director were available for consultation. *The medical advisors* tried to give the politicians a nuanced picture of why some of the supporting documents had not been as good as they had wished. They tried to uphold a feeling of confidence between health professionals and politicians and said that the politicians must have trust in the material provided by the health professionals. They also advised the politicians to avoid unnecessary "wear and tear" in how they acted in relation to the different areas of health care. As an example, they considered a substantial stipulated savings to be better than many small savings at short intervals. Further, the advisors pointed out that they did not want the method to be condemned because some parts of the priority setting procedure were not carried out in an optimal way this first time.

The politicians were well aware of the fact that not all of their fellow party members or their colleagues in the County Council Parliament[13] necessarily agreed that politicians should make decisions based on lists of priorities compiled by health professionals. Or that politicians could work together on priority setting across party bloc lines, and based on these discussions produce supporting documents on which to base decisions. The politicians thought this was considered an unorthodox way of working that differed from the traditional method with interpellations and debates concerning decisions. The politicians wanted it made clear that their decisions were based on supporting documents developed by the health professionals, and for that reason they were irritated by documents that were of poor quality or of no use at all.

The health professionals were open about pointing out conflicts and inconsistencies in the descriptions of consequences. Inconsistencies could exist between different professional and specialist affiliations, but they contended that there were also geographical inconsistencies. One of the health professionals believed that the work had received support at the management level only, which is a shortcoming and can be a problem when decisions are implemented.

The public officials strove to hold the different actors together and tried to give advice to the politicians and support to the medical advisors in the work involved in arriving at decisions. They asked the politicians why they made decisions the way they did and on what grounds, which resulted in small confrontations but in the end facilitated the work for both the medical advisors and the politicians themselves. The *Health Care Director* worked openly at getting as good a decision as possible from the politicians so that contract

[13] The County Council Parliament is the Council's top-level decision making body. It consists of 101 elected members who are responsible for the allocation of County Council resources.

negotiations with care providers (which are to be based on the decision) would go as well as possible.

5.5.2 Interaction among the participants during the critical phase

One of the methods we chose was to study the behaviour of participating actors during the critical phase of the decision making process based on Bales' observation form for classification of behaviour in small groups engaged in problem solving (Swedner 1961, Bales 1950)), see Figure 2 in Chapter 2.3. The aim was to try to explain a possible failure or a successful process. The participants' behaviour was observed in terms of if they showed positive emotional reactions, made neutral factual statements, or showed negative emotional reactions. The behaviour could then be classified as involving orientation, evaluation, control, decisions, tension-management or integration.

In our observations we noted that *neutral factual statements* in the form of questions and answers dominated the discussions – and recurred on the part of most of the actors. These were statements concerning *orientation, evaluation and control*.

- The *politicians asked for orientation and information*, for example they often wanted additional information when the medical advisors gave their presentations of the disease groups. They *asked for repetition and confirmation* that they had understood something correctly and sometimes wanted orientation from the health care director. They *evaluated and analysed* the medical advisors' conclusions and what was said by the health professionals. They *expressed the wish* that supporting documents were better and that certain health care areas could have provided better material to enable politicians to make good political decisions. They seldom *asked for evaluation or analysis* from someone else. They frequently *gave suggestions,* such as regarding how they would work further on in the process, what their attitude would be toward supporting documents, what decisions they would make, and what should be thought about "next time". They essentially never *asked for suggestions or guidance*.
- *The medical advisors asked for orientation and information,* for example how the process and work would proceed from then on, and they *provided orientation and information* about the different disease groups. They *asked for confirmation* that they had understood the work process correctly and that they had understood the supporting documents correctly when they had read them. One of their main tasks was to *give their opinions* and *evaluate* the supporting documents. They *expressed feeling* about their quality and content and *expressed their wishes* concerning what they should have been like. They could also *ask for evaluation*, for example concerning how they should handle a particularly problematic

disease area and *express feelings* (that it was discouraging when supporting documents did not fulfil requirements). Sometimes *suggestions were made* regarding what their own opinions would be toward the material and the process, and how the decisions would be reported, but they could also *ask for suggestions*, for example concerning how they should handle unclear supporting documents, effects of shifting responsibility, and so on.

- *The public officials and the Health Care Director gave orientation, clarification and confirmation* concerning how the priority setting process could be perceived and how the work would proceed from then on. They seldom *asked for orientation or information.* They sometimes *gave their opinions* and *expressed feelings and wishes*, for example initially concerning what the decision making process would be like later on, and later concerning the effects they thought different alternative actions would have (how the role of politician would be perceived by the public and health care areas, the reasoning of health professionals in the next step). They could also *give suggestions or direction*, but seldom asked for them.

There were also quite a few *positive emotional reactions* that concerned *decisions, tension-management and integration* — primarily on the part of politicians and medical advisors (who were the main actors in the meetings during the decision making process).

- *The politicians showed solidarity* toward one another in their views (for the most part) and *contributed toward raising the other's status* by emphasizing, for example, that they thought the medical advisors did "a great job", and that a particular politician was skilled in relating to one of the county's daily newspapers. They exhibited *tension-managing* behaviour, and despite the seriousness of their task there were *jokes and laughing* in the separate group discussions. They *showed satisfaction* by saying, for example, that against the background of what the medical advisors said the work felt satisfying. On the other hand, they were not satisfied with the quality of the supporting documents. The politicians were largely in agreement, *understood and concurred with* the medical advisors' discussions and conclusions, and *supported* one another's viewpoints (for the most part).
- *The medical advisors* also demonstrated a relatively easy-going form of social intercourse with *laughter and jokes*, and saw their own roles and persons in perspective (for example, "I'm a fired centre boss" and "Don't you say hello to everybody?" "No, we've know each other for so long!"). The advisors *supported* one another's views, interpretations and proposals, and *understood* one another and what they meant during

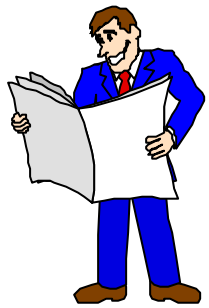
discussions. They *agreed with* the public officials' reasoning regarding the process.

Negative emotional reactions, that also concerned *decisions, tension-management, and integration,* occurred to a very small extent in the discussions.

- Different politicians *sometimes expressed a view that differed* from that of the group (for example, public access to supporting documents and what attitude politicians should take regarding the media). They could *be firm* concerning their opinion on a particular question, and could on rare occasion *deflate the other's status* (for example, by expressing themselves in negative terms about a health care area or about persons/personnel groups).
- *The medical advisors* could also *be firm* in their opinions (either as individuals or as a group).

5.5.3 Possibilities for others to acquaint themselves with the decision making

Questions that can be asked regarding the County Council's priority setting are:



¾ How open was the priority setting process?

¾ Were the decisions, the bases and the reasoning (including the consequences) accessible to all who wanted to acquaint themselves with them?

Obtaining support for the PHMSC Presidium's positions outside of the Presidium occurred in different ways according the politicians who were interviewed. The politicians first got the support of their own party group and then that of the majority group. It was reported that support was also obtained in the county-wide party groups. Some politicians wrote debate articles for the county's daily newspapers, but the newspapers sometimes chose not to publish them. One politician pointed out the importance of learning to utilise the whole organisation, and that the best messengers are care personnel. Further, in their everyday encounters, part-time politicians should be able to contribute more in the dialogue with the public. The politicians also received many questions and reactions (both positive and negative) from party members in other parts of the country.

All those interviewed thought it was good that openness had resulted in discussion concerning the role of health care on the whole, what publicly-financed health care and other actors in society should devote themselves to, and in an increased dialogue between different parties. One health professional was of the opinion that everyone should know what can be expected of publicly-financed health care in the future:

> *"The goal of this work we have begun is to increase awareness on the part of everyone." (health professional)*

One politician pointed out that openness placed greater demands on how they express themselves and that they had to be much more precise and careful in their choice of words.

The decisions were in principle accessible to all who wished to become acquainted with them in that they were published on the Internet[14]. Political decisions made in the PHMSC are public documents and can be accessed in the same way as all public documents (for example, via the County Council's official register). Afterwards, a more easily read compilation was prepared concerning what the different service limitations mean, and this is also accessible on the County Council's homepage[15]. In the present case, reports by the media contributed to making the majority of the public aware of the decisions.

The reasoning of the health professionals (including the consequences to the extent it was possible to predict them) was in principle accessible in that all the descriptions of consequences were also published on the Internet. When they compiled and provided the supporting documents, the health professionals were not informed of the fact that the material would be made this public, something that aroused irritation on the part of some health professionals and medical advisors. On the other hand, we do not know how many persons have actually visited the homepage and read the underlying material.

The reasoning of the medical advisors, i.e. their comments on the supporting documents and the positions they took, was not accessible to the public, and is instead considered working material. A document concerning their compilations was given to politicians at a meeting with the PHMSC's extended presidium[16]. The advisors pointed out that it is important for the type of priority setting that was done, and the reason for this, to be made very clear in the documentation communicated outward, so that those not directly involved can understand the

[14] The County Council's home page: www.lio.se
[15] PM 2003-12-10: "Priority setting in plain language" (in Swedish: Enklare om prioriteringar).
[16] The PHMSC's presidium and the Central, East and West Subarea Drafting Committees and the Medical Programme Drafting Committee.

reasoning and the decisions. On the other hand, they did not want documents developed as internal working material to be made public, since these lack explanations and can easily be misunderstood.

The politicians' reasoning during the course of the work was not accessible to the public. Meetings and discussions were not public and any notations made during the course of the work were considered working material. The public officials and the health care director tried to find methods for relating the decisions to the supporting documents in a pedagogic way and in that way support the politicians in formulating the documentation.

The information division published their own articles on the County Council's homepage while the process was underway, although not to any great extent with respect to service limitations (but more concerning structural changes in the County Council). There is also a compilation of questions from the public as well as answers to those questions, material from information meetings in the form of video broadcasts, and presentation material in the form of overheads[17].

5.6 Is it possible to appeal decisions if new information emerges?

No mechanism is reported here, this first time, for appealing decisions if new facts or arguments emerge. Discussions about this and about appealing decisions from a citizen perspective have, however, been conducted. On the other hand, it was possible to appeal proposed decisions during the entire course of the decision making process, up until the decision was formally made by the PHMSC on October 29th.

[17] The County Council's homepage can be found at www.lio.se. Information on the work with priority setting is found under Press, Information and Register. County-wide cooperation is underway (in Swedish: Press, info och diarium, På gang: länssamverkan), but the extent to which the County Council maintains its part of this is not known.

6. Experiences from Östergötland's priority setting

6.1 Increased openness ¾ a development with no turning back

The priority setting process studied in Östergötland – the most intensive part of which took place in the autumn of 2003 – was the first of its kind not only in the County Council but in Sweden as a whole. This work was considered a learning process by the participants, during which they learned from both successes and mistakes. The intention is for this to be a routine way of working in the County Council in the future.

One of the *politicians* was of the opinion that if we believe in democracy and have confidence that citizens can actually take in something difficult, then we cannot have hidden priority setting, and once we start down this road there is no turning back. If we have taken the first step toward increased openness, then we have taken a step toward a democratic way of working. Many of the politicians thought that the traditional way of arriving at political decisions and queues in health care cannot be considered an alternative.

One politician believed that in the future there will be open priorities on many different levels and in different contexts. For example, development of new methods for priority setting among different sectors of society and between municipal care and County Council health care. This politician thought that we must begin thinking about resource allocation between municipal activities and County Council activities and illustrated this by saying that if extensive resources are directed toward outpatient treatments, more effective methods of treatment, and so on, so that people advance more quickly in the chain of care, then we must be prepared to allocate much more money to care activities so that people also have dignified lives after treatment.

One politician stressed that the new role of the politician is a part of future developments, and that new politicians must receive training in order to assume a partially different role than previously (which this politician thought had happened in Östergötland). Further, this politician thought that our new society will require politicians other than the traditional ones who are used to allocating, establishing regulations, and so on, and that we need to influence public opinion to a much greater extent, and that public officials often lead the way. Another politician thought that we must now begin discussions and decide what should be included in the public undertaking.

The public officials also said they saw no alternative to the work that was done. One official thought that if citizens feel secure and satisfied with having someone else decide about and handle priority setting questions so that they do

not have to take active interest in all of that, then they do not have to get involved. But *if* they want to, then it must be possible for them to do so.

One public official thought that when this way of working becomes an integrated part of the County Council's process of governance it will not result in big headlines and general commotion. In addition, this official thought that the atmosphere had been extra hostile this time in that structural changes in the County Council had occurred at the same time.

> *"Now that we've taken the plunge, we know what it's like, so now maybe we can take things easier next time." (public official)*

The public officials also expressed their appreciation concerning the political stability and the similarity in views among the different political parties:

> *"we've been so enormously spoiled in this County Council, and I don't even think we understand that" (public official)*

They thought this was due to the fact that politicians had been involved right from the start in representative groups within the framework for Medical Programme development. Priority setting has been a logical consequence of the Medical Programmes with their build-up of knowledge and being viewed as a way of governing health care in order to continue working with descriptions of tasks. Being able to work for this many years with a line of development that started in 1995 was seen by the public officials as unique in the county council world [18].

The medical advisors gave two examples of alternatives to the work in question. One was for the County Council to engage consultants to do the work, which was considered a poor alternative. Another advisor said that the County Council could order X number of deliveries, Y number of operations, etc., but this was not experienced as a good alternative either. The advisors thought that even care that was of high priority according to the Priorities Commission, and that by tradition has been seen as "protected" (cancer care and paediatric care, for example), might now be the object of discussions, questioning and priority setting.

One *health professional* thought that the alternative to discussing limitations in public commitments would be to "get the wheels rolling" so that society would get more money for health care (for example, revise allocations to different sectors of society and increase the number of births), but at the same time this person realized that with medical-technical development as it is today (as rapid

[18] For more on Medical Programme work: Kernell-Tolf et al. (2003) and County Council of Östergötland (1999).

as it is), society will still be unable to offer all care to everyone, but that more can be given to a greater number of people with more money in the system. It was the belief of another health professional that in the future politicians will work more with comprehensive priority setting issues rather than with such detailed questions as was the case this time.

6.2 What are the possibilities for increased openness and what are the success factors?

What possibilities and advantages were seen by those who took part in an open priority setting process? Based on their experiences, what factors did they see that would contribute to the success of work with open priorities? In this regard the different actors had similar views.

The *politicians* thought that openness was important in itself. That we have succeeded in clarifying which principles are at issue and that we have a base from which to continue working makes it possible for many actors to be involved. One politician thought openness would also result in greater confidence in politicians in the future since the public would see that politicians can stand by their decisions. Now they all had a way of thinking about what they should primarily devote themselves to, and discussion has begun concerning the public commitment.

> *"I see great possibilities in that we have finally found a good tool, an instrument, for governing health care." (politician)*

One of the *public officials* reported viewing health care as an organisation aiming at competence and it is not easily changed by means of different regulations. Furthermore, the work largely concerns dialogue, having knowledge in common and respect for one another's roles, and a feeling of being a part of things and of participating, and that it seems fair in different ways — both from the perspective of health care areas as well as from the perspective of the public. According to this official, the challenge is in establishing a good, well-thought-out priority setting procedure.

> *"This is opening up something that has been closed." (public official)*

The *health professionals* thought that priority setting clarifies what should and should not be focused on and that perhaps health care can no longer do everything for everyone. One of the health professionals pointed out that we live in a would where resources are not in accord with our possibilities in health care and that priority setting is a way of making this clear:

> *"This system of financing we have now is not valid. I'm convinced of that, so that's why I think this is good." (health professional)*

One health professional thought that the priority setting process provides greater clarity in that things are placed in opposition to one another, and that with this method most causes are given consideration as compared with previously, when large groups were looked at one at a time.

The *medical advisors* thought this was such a new process that certain parts of it must be allowed to be unsuccessful. They thought it was important to adhere to the original idea and to obtain support for the priority setting process and not change its structure, and that now it should simply be adapted.

> *"We haven't seen any of its effects yet. We haven't seen whether there are any economic effects, or if there are any societal effects, or if it has any effect on people working in the area of health care production, we haven't seen any such effects. Then you should be careful about making changes." (medical advisor)*

A summary of the success factors seen by the participating actors:

- Politicians who work together and do not try to win political points.
- A well worked-out plan for the process with a clear differentiation of roles among the actors and the insight that everyone's knowledge is needed.
- Much dialogue, cooperation and open discussions among the participants
- Similar views and loyalty on the part of the participants.
- A good process for obtaining support for the priority setting procedure in their own organization.
- Clarity about where the work fits into the political process of governance and how it fits in with other activities.
- Good supporting documents in the form of vertical ranking lists and detailed descriptions of consequences.
- Good support for the politicians in the form of documents, presentations and advisors.
- An advanced information strategy.
- Good dialogue with the public.

7. REFLECTIONS OF CITIZENS

A citizens' meeting was arranged by the National Centre for Priority Setting in Health Care on the evening of January 19th, 2004 at a central location in Linköping. Four hundred randomly selected Östergötland residents, aged 18-74 years, from the entire county were invited. The first invitation — with a programme for the evening, information about the Centre, and a response form and envelope — was mailed in mid December, and a reminder was sent in the beginning of January. Twenty people came, six of whom were accompanying relatives. This outcome is low, but international studies show that it is not abnormally low for this type of meeting to which it can be difficult to attract participants (Hansen 2000). The meeting began with information (presented by a medical advisor in the County Council) concerning how the County Council had gone about making its priority setting decisions. In order to answer questions, politicians and medical advisors (physicians) who had participated in the work were at the meeting. Thereafter, the participants were divided into three focus groups, each of which had a discussion leader and a person who wrote minutes, and they led the discussion based on a question guide (See Appendix 3). A questionnaire in which the participants were to respond to a number of statements about Swedish health care and about priority setting was also tested. However, the number of participants was too small to draw any conclusions from the results.

7.1 What pictures did the citizens have?

Following the introductory information and the question period, the participants were divided into three focus groups for a discussion about the priority setting that had been done in Östergötland and thoughts about "ideal" priority setting. The summary below is not claimed in any way to portray a consistent reflection of what citizens in general think about these issues, but can simply be seen as an expression of the thoughts of this small group of 20 persons. It was, however, a mixed group with respect to sex and age.

7.1.1 Was there a need for better information?

New information

Information about the County Council priority setting had been acquired mainly from county newspapers, but also via TV news. The information presented during the evening concerning details of the County Council's priority setting was new to the participants. Their reaction was especially positive toward the large amount of work — by many different actors — that they learned lay behind the decisions.

Different pictures

The information the participants had taken in (read in newspapers, seen on TV, or via acquaintances) had resulted in their having different pictures. On the one hand they felt the information consisted of *distorted pictures* that were pure errors, such as that the politicians themselves had made the medical judgements about the diseases and the health care interventions that would no longer be included. On the other hand they had experienced *disaster pictures* painted by the media of security in Swedish health care being in jeopardy and that there was reason for anxiety about the future. The need emerged for a more balanced message in the media. There was also a *conflict perspective* where the media were experienced as creating a picture where those who are financially well off and able to pay for the care they want were placed in opposition to those not thought to have this possibility.

Need for a personal message

There was a strong wish in the group for more information. The participants reported that they had come mainly in order to get more information about what happened in the County Council and what the consequences would be for them personally. They pointed out that the picture portrayed in the media had not been totally clear, and that getting clearer information directly from the County Council would be better than getting it through the media. They wanted a clear conveyor of information about priority setting in health care with whom they could have a dialogue.

7.1.2 How did the participants experience the decision making process?

A need for context

The participants discussed why priority setting was done at all, why the County Council was doing this right now, and why there was such a hurry. They wondered if it was because the County Council had failed to carry out proper economic planning and had used its money for the wrong things, and where funds were lacking (for staff, premises, or what?). Some of them pondered the question of whether today's health care is as effective as it could be, for example against the background of news that physicians see too few patients per day and that administrative duties (which they thought should be handled by other professional groups) take up too much of their time.

Acceptance of priority setting

The participants did not express any direct objections to the fact that priority setting was being done. There were some reservations, however: that this should be done at a national level and not by individual County Councils; if priority setting is to be done then the County Council must really have insufficient resources and the demand for care (needs) must really exceed available services.

Seriousness
Many participants expressed appreciation that so many different actors had been involved in the County Council's priority setting process, and they thought they had received increased insight during the evening's meeting concerning the fact that much more work lay behind the decisions than they had thought was the case before the meeting.

Participation
The importance of and wish for a dialogue with patients (whom participants at the meeting thought had knowledge about what it is like to have different diseases) was stressed. One participant wondered if there was some other way to decrease the need for care other than by setting priorities (for example, by concentrating on preventive work, health maintenance and eating habits).

The political role
The role of party politics and the lack of political opposition to the decisions in Östergötland were pointed out by some. In addition, the participants wondered about the complexity of this issue and how priority setting can be fair.

7.1.3 How did the participants experience the decisions and their consequences?

The view toward the function of health care
The participants conveyed the view that the all-embracing role of health care is to maintain a good quality of life in the population. Many had thoughts about what constitutes needs and about the population's high expectations regarding care ("Does everyone who gets the flu have to go to the doctor?") Further, they discussed how needs can be judged and how health is measured. Some participants thought the only available alternative in the future would be to pay privately for the care that will not be offered through tax-financed health care. They thought that those who could afford it could do so, while they were very doubtful about how things would be for all the others.

The individual need for security
The individual need to feel secure despite the decisions that had been made was stressed as important. Feeling confidence in one's doctor was also important as was the understanding that if I am sick then I will get help. Some participants were worried that in this connection older patients would be discriminated against.

Observance of the decisions
The participants discussed how things would actually be in the encounter between doctor and patient and if the decisions mean that now things will be the same for everybody, or if this would depend on which doctor you go to and if

you as a patient can "influence" the doctor, and they thought it was important that this would not be arbitrary.

Acceptance of the bases for priority setting

There was also a discussion about the bases for priority setting. For example, if the elderly will be given priority because they have only a short time left and they should be able to maintain a good quality of life for as long as possible, or if young people will get health care first so they can return faster to working life and be able to pay taxes to support the health care system.

7.1.4 How did the participants experience the public accessibility of the decisions?

Security

Without exception, the participants were strongly supportive of openness with respect to this type of decision. They thought it created opportunities for debate and examination of the care provided. Many participants thought that increased public accessibility engendered security, while others were more evasive and thought the dialogue between doctor and patient was important and that one must be able to trust that doctors would set the right priorities.

Need for objective information

The participants also pondered how, as a citizen, one can understand the information that is given and how to seek information oneself, and the degree to which citizens bother to familiarize themselves with important social issues. Some of them thought that on the whole, people did not make use of available opportunities for getting information and that they did not care about events in society until they resulted in personal consequences.

Personal involvement

The actions of the media in general were discussed and questioned, and the participants thought that headlines were of great significance (the concept of the "black list" became a negative message). Further, they thought the County Council itself must try to influence the media and make sure that facts in the articles are correct. A distorted picture can otherwise have negative consequences, such as creating unnecessary opposition.

7.2 Our experience of the citizens' meeting

There is scientific support from both Swedish and international studies showing that groups of citizens who obtain information about a factual matter can change their opinions and that a group with an "informed" opinion thinks differently than a group with an "uninformed " opinion (Fishkin 1995). There are also clear

indications that attitudes in the population are rather unstable, and that moderate amounts of information are sufficient to cause individuals to be unsure about an issue or to change their opinions. However, this does not apply to fundamental questions concerning values, where opinions can be considered stable.

The results from this limited citizens' meeting provide some support for the idea that the opinions of citizens regarding priority setting issues can be influenced through information. The fact that opinions changed during the meeting is not unreasonable considering that most of those who participated in the discussion explained that much of the information they received during the meeting was totally new to them.

We experienced that in the discussion in this small group, increased understanding and acceptance emerged that priority setting must be done and that it has always been done in health care.

Earlier studies of citizen dialogues and citizen juries in Östergötland also show that the people in this county are interested in opportunities for dialogue with County Council politicians[19]. However, the weak interest in participating shown by the citizens may indicate a lack of familiarity with actively taking part in discussions not directly concerning themselves. We think that the limited endeavour reported here has provided valuable information about this type of inquiry, in preparation for similar studies in the future.

[19] See reports in the report series of the National Centre for Priority Setting in Health Care: 2002:2 Brokvist M, and 2002:3 Garpenby P.

8. CONCLUSIONS

8.1 Can the decision making process in Östergötland be considered fair and legitimate?

A question in this study involved studying if horizontal priority setting in Östergötland during the autumn of 2003 can be considered as fair and legitimate based on our theoretical model. Based on the results of our observations and interviews that were described in this report we can state the following:

1. *The institution where the decisions were made*
   The politicians' priority setting decisions, based on ranking lists and descriptions of consequences, were made as determined initially, i.e. a delegation to the PHMSC to make these decisions. The decisions were made by the PHMSC, following the recommendation of the PHMSC Presidium, in accordance with applicable County Council regulations. *We found that priority setting decisions in Östergötland were made in a legitimate organisational context with a mandate to make such decisions.*

2. *The people who took part in the decisions*
   During the priority setting process there was an exchange — an interaction — between the politicians in the PHMSC Presidium and both the health care director and the health professionals. The public officials and the medical advisors were there to give advice and to support the politicians. The public officials contributed to advancing the process itself, and they refrained from pursuing their own organisational interests. See Figure 5.

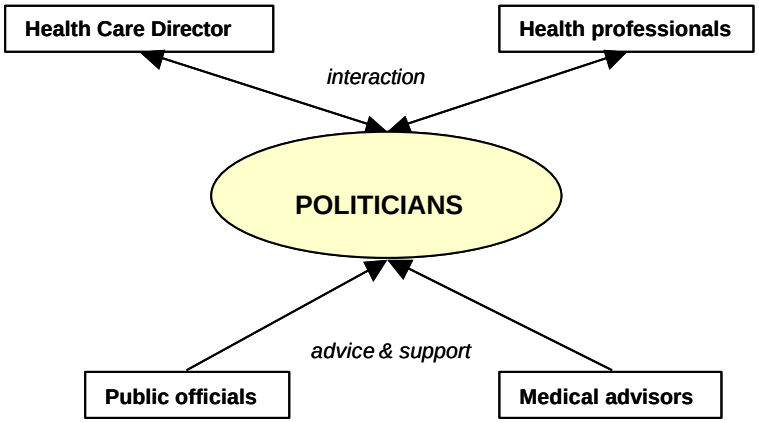


Figure 5. Categories of persons taking part in the priority setting process by means of interaction or giving advice and support.

The politicians' behaviour was supportive throughout the decision making process. This contributed to the fact that a joint political decision could be made despite differences in political views and opinions. Without exception, only persons in leadership positions were represented in the priority setting process, both with respect to politicians who developed the positions that were taken and the health professionals who provided the supporting documents. In the preparation of supporting documents, members of professional groups other than physicians were hardly represented. Likewise, there was no representation on the part of the "users", i.e. patients or citizens. *The perspectives of many interested parties were represented, while others that could have contributed were missing.*

3. *Factors that were considered/taken into account in the decisions*
   The model for priority setting that was established in the County Council, as well as nationally, comprises components that are important to take into account in priority setting and that are based on the ethical principles stipulated by the Swedish Parliament. *The politicians had a high level of awareness concerning principles and factors they should consider in their decisions, but in practical discussions they seldom referred directly to individual factors in the model of priority setting.*

4. *Reasons for the decisions*
   The politicians had not written down their reasons and motives at an early stage, which made open discussion difficult concerning both results and the underlying motives. The individual factors the politicians considered during their discussions were weighed together into a composite picture, a cluster of facts, that shaped the reasons and motivations for the decisions. This composite picture differed from decision to decision. Decisions and reasoning were compared with one another in order to validate the reasoning. *As a rule, reasons for decisions did not rest on individual factors, but on a total appraisal of facts.*

5. *The decision making process*
   The discussion that followed the politicians two whole-day meetings with the health professionals resulted in principle in a consensus between representatives of the different parties and between the majority and the opposition groups. In practice, what was said at these meetings later became the bases for the decisions. However, there were some reservations at the formal decision making in the PHMSC, both regarding parts of the decisions (by (m) and (c)), as well as the whole decision (by (kd), which proposed a temporary tax increase instead). In other words, the PHMSC followed what had been had been arrived at in the

discussions, both by the political parties as well as by politicians and health professionals. *We think that openness in the decision making group was good, but there was somewhat of an information gap regarding other politicians and other actors in the priority setting process.*

Regarding openness outward toward the public we found that the decisions were accessible, in principle, to everyone who wanted acquaint themselves them since documents concerning the decisions were published on the Internet. However, these documents were not suitable for external use as they were brief and, in principle, without motivations for the decisions. The lines of reasoning of the health professionals were also accessible in principle, in that they were published on the Internet, which can be considered a questionable manoeuvre considering the variable quality and poor adaptation to external use. The medical advisors' positions and the politicians' lines of reasoning during the course of the decision making process were not accessible to the public as they were considered to be working material. *We found that although a large part of the material was accessible on the Internet, it was relatively unknown and difficult to interpret.*

Previous studies (Garpenby 2003) have shown that the priority setting process can be seen as two processes: one regarding *internal legitimacy*, which is characterised by the ability to find a knowledge base and arguments on which to base priority setting; the other regarding *external legitimacy*, which concerns the public's opinions and confidence in the arrangement. It is clear that in this first round the County Council concentrated mainly on developing internal legitimacy, while external legitimacy remained in the background.

6. *Mechanisms for appealing decisions*
   This first round lacked a mechanism for appealing decisions if new facts or arguments emerged. However, discussions concerning this and concerning the appeal of decisions from a citizen perspective have been conducted. Since this was the first time the County Council of Östergötland carried out priority setting, we know nothing about the position of politicians with respect to appealing their decisions. Would politicians consider revising their earlier decisions, or are they firmly resolved? Will the politicians take new facts and arguments into account that emerge after these first decisions? These questions cannot be answered until the County Council carries out this work again, which will be done in the spring of 2004, and priority setting becomes an established part of County Council's process of governance.

8.2 Overall conclusions from Östergötland's priority setting

It is our judgement that the way in which the County Council worked seems to have functioned as expected. An important weakness pointed out by many of those interviewed was that the decisions were mixtures of pure service limitations, tightening up of indications, and transfers to other care providers/care levels. Of the decisions that were made, pure service limitations constituted only a small part of the total stipulated savings. Transfers of patients/health care interventions to other care providers/care levels constituted approximately one third of the calculated cost reductions. This became an information problem, as in the media's presentation of what they came to call "the black list" it was impossible for the public to see the distinction, and anxiety easily arose that none of the items on the list would be available in the future.

There was a common view among the involved actors that the work should be seen as a learning process in which participants acquire experience, learn from their mistakes, and where the form of working must change over time. After this first round we see the greatest potential for improvement with respect to:

- *Quality of the supporting documents*:
  - Ranking lists and descriptions of consequences must follow established guidelines.
  - Ranking lists and descriptions of consequences should be similar in terms of form in the different disease areas in order to allow for comparisons.
  - More support can be enlisted for ranking lists and descriptions of consequences.
- *Motivations for the decisions*:
  - Motivations with respect to what the decisions are based on and what effects they will have can be more exhaustive.
  - The text should be better adapted for external use so that everyone can understand and interpret its meaning.
- *Information to the participants' own organisation:*
  - Information initially about the priority setting process, differentiation of roles, guidelines and time plan, and at the end of the process concerning what the decisions mean in practice for the different areas, can be improved.
  - The guidelines for who should do what, how it should be done, and when it should be done can be made clearer.
- *Information to the public:*

- Information should be given to the public initially and at the end of the priority setting process concerning what the decisions mean for them.

Further, we can note that it is important not to set up unrealistic goals — that in the short run it can be better to limit the number of decisions to a few firmly based, well-motivated decisions.

The behaviour of the politicians was supportive throughout the decision making process. We noted that *neutral factual statements* in the form of questions and answers dominated the discussions and recurred in most of the actors. These concern *orientation, evaluation and control.* There were also a large number of *positive emotional reactions* that concerned *decisions, tension-management and integration*, primarily seen in politicians and medical advisors, who were the main actors during the decision making process. *Negative emotional reactions*, which also concerned *decisions, tension-management and integration*, seldom occurred.

Since the prerequisites for starting to work with open horizontal priority setting differ in different county councils, it is important to keep in mind that each and every county council in Sweden must "do it's own thing", and that the method of one county council cannot be directly applied to another county council. Naturally, however, they ought to learn from one another regarding both successes and mistakes. A number of county councils and national bodies have started working with vertical ranking of diseases in combination with health care interventions, which is one of the first steps along the way. However, no county council has progressed as far as Östergötland, which now has also tested horizontal priority setting among disease groups. We can conclude that the prerequisites for open priority setting have improved in Östergötland, but that a significant amount of developmental work remains.

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Appendix 1

Observation Forms

A. Singer's model, expanded version

Give examples

Time: - -	**Place:**
Event:	
Present: ❑ politicians ❑ public officials ❑ medical advisors ❑ directors ❑ others:	
Notes:	

1.The institution:

Are the decisions being made in a legitimate organisational context?	

2. The persons:

Are the perspectives of a number of interested parties represented?	

3. The factors:

1. Is the **principle of all people being equal in dignity and value** considered?	
Degree of severity of the disease 2.1.1. Are the **symptoms** of the present health state considered?	
Degree of severity of the disease 2.1.2. Is **functional ability** considered for the present health state?	
Degree of severity of the disease 2.1.3. Is **quality of life** considered for the present health state?	
Degree of severity of the disease 2.2.1. Is the risk for **untimely death** considered?	
Degree of severity of the disease 2.2.2. Is the risk for **permanent illness/injury** considered?	
Degree of severity of the disease 2.2.3. Is the risk for **deteriorated life quality** considered?	
Degree of severity of the disease 2.3 Is **reduced autonomy** considered?	

Patient benefit (effect of health care intervention) 3.1.1. Is the effect on **symptoms** considered for the present health state?	
Patient benefit (effect of health care intervention) 3.1.2 Is the effect on **functional ability** considered for the present health state?	
Patient benefit (effect of health care intervention) 3.1.3. Is the effect on **quality of life** considered for the present health state?	
Patient benefit (effect of health care intervention) 3.2.1. Is the effect on risk for **untimely death** considered?	
Patient benefit (effect of health care intervention) 3.2.2. Is the effect on risk for **permanent illness/injury** considered?	
Patient benefit (effect of health care intervention) 3.2.3. Is the effect on risk for **poorer quality of life** considered?	
Patient benefit (effect of health care intervention) 3.3. Are the risks for **side effects and serious complications** from the intervention considered?	

Cost effectiveness 4.1. Are direct costs of **medical interventions** considered?	
Cost effectiveness 4.2 Are direct costs of **non-medical interventions** considered?	
Cost effectiveness 4.3. Are indirect costs of a **loss in production** considered?	
Cost effectiveness 4.4. Are indirect costs of **other time costs** (patients, relatives, others) considered?	
Cost effectiveness 4.5. Is cost effectiveness considered **in relation to patient benefit?**	
4.6 Are **total costs** considered (budget effect)?	

5. Is **evidence** (the degree of certainty concerning effects, risks, benefit, cost-effectiveness) considered? Which aspects are emphasized?	

4. Reasons:

Are the decisions based on **individual factors**? Predominant reason?	
Are the decisions based on **clusters of factors**? Predominant reason?	

5.1 Within the group:
The process:

1. Is there transparency in the process (is the line of reasoning known)?	
2. Are conflicts of interest acknowledged?	
3. Is it possible for everyone to express their views?	
4. Do participants reveal what they think?	
5. Do all committee members understand the deliberations/debate?	
6. Is honesty maintained?	
7. Is a consensus built?	
8. Is access to consultation with external experts guaranteed?	
9. Is an appropriate agenda guaranteed?	
10. Is an effective chairmanship/presidium maintained?	
11. Is the right time point for giving new, effective technologies to patients guaranteed in health budget decisions?	
12. Is there knowledge about what has preceded/is occurring in parallel with this work?	
13. Is there discussion about dissemination of the decisions?	
14. Was only priority setting discussed (service limitations, rationing, vertical lists)? (Did they stick to the subject?)	

5.2 Outside the group:
How open is the process?

Is **the line of reasoning** (including the consequences) accessible to all who are interested?	Within the County Council of Östergötland: The public:
Are **the decisions** accessible to all who are interested?	Within the County Council of Östergötland: The public:
Are the **reasons** accessible to all who are interested?	Within the County Council of Östergötland: The public:

6. Appeal

Is there a possibility to appeal decisions? (in a clearly expressed way)	

7. What are the obstacles?

Insufficient knowledge on the part of? ❑ politicians ❑ public officials ❑ medical advisors ❑ directors ❑ others:	
Problems in the dialogue between politicians – public officials – health professionals? ❑ politicians ❑ public officials ❑ medical advisors ❑ directors ❑ others:	
Problems in understanding one another's roles and areas of responsibility? ❑ politicians ❑ public officials ❑ medical advisors ❑ directors ❑ others:	
Formulation of the **vertical lists** (supporting documents)? ❑ politicians ❑ public officials ❑ medical advisors ❑ directors ❑ others:	Too complicated Have deficiencies Are incomplete

Formulation of **descriptions of consequences** (supporting documents)? ❑ politicians ❑ public officials ❑ medical advisors ❑ directors ❑ others:	Too complicated Have deficiencies Are incomplete
Are the politicians themselves not good at communicating what kind of supporting documents they want?	
Political reasons (opinions, recipients' reaction, etc.)?	
Other:	

8. Do they refer to the ethical guidelines?

Principle of all people being equal in dignity and value?	
Principle of need and solidarity?	
Principle of cost-effectiveness?	

B. Bales' model

		Behaviour	***Give examples***
f	A.1.	<u>Shows solidarity</u> raises other's status gives help gives reward	
e	A.2.	<u>Shows tension release</u> jokes laughs shows satisfaction	
d	A.3.	<u>Agrees</u> shows passive acceptance understands concurs complies	
c	B.4.	<u>Gives suggestion</u> direction implying autonomy for other	
b	B.5.	<u>Gives opinion</u> evaluation analysis expresses feeling expresses wish	

a	B.6.	Gives orientation information repeats clarifies confirms	
a	C.7.	Asks for orientation information repetition confirmation	
b	C.8.	Asks for opinion evaluation analysis expression of feeling	
c	C.9.	Asks for suggestion direction possible ways of action	
d	D.10.	Disagrees shows passive rejection formality withholds help	
e	D.11.	Shows tension asks for help withdraws out of field	
f	D.12.	Shows antagonism deflates other's status defends self asserts self	

Appendix 2.

Underlying principles for priority setting of health care interventions

Model of Priority Setting in the County Council of Östergötland, spring/autumn 2003.

The principle of all people being equal in dignity and value			
Need for interventions in health care			
Severity of the disease	**Patient benefit (effect of the health care intervention)**	**Cost-effectiveness**	
*** Present health state** - sympthoms - functional ability - quality of life *** Risk for** - untimely death - permanent illness/injury - deteriorated quality of life *** Reduced autonomy**	*** Effect on present health state** - symptoms - functional ability - quality of life *** Effect on risk** - untimely death - permanent illness/injury - deteriorated quality of life *** Risk for side effects and serious complications from the intervention**	*** Direct costs** - medical costs - non-medical costs *** Indirect costs** - loss of production - other time costs **…in relation to patient benefit of intervention.**	**E** **V** **I** **D** **E** **N** **C** **E**
Prevention - Diagnostics - Treatment - Rehabilitation			

Appendix 3

The citizens' view of the priority setting process in the County Council of Östergötland

Guide for discussion leaders in the focus groups conducted at the citizens' meeting arranged by the National Centre for Priority Setting in Health Care on January 19th, 2004

Information

- Were you already familiar with the information you got this evening, or was some of the information new to you?
- In that case, what was it that was new?

Decisions and consequences

- As we heard, the County Council has decided that certain conditions/interventions that were ranked low will no longer be offered by tax-supported health care; what do you think about this?

Publicity

- Did the politicians in Östergötland do the right thing by openly reporting what will not be offered in publicly financed health care?
- Why is it the "right" thing or the "wrong" thing?
- (In general, what do you believe people want to know regarding priority setting and service limitations in health care?)

The decision making process and thoughts about ideal priority setting

- What do you think is most important to think about when doing priority setting as they have tried to do in Östergötland? In other words, how should priority setting in health care be done?
- (Who should decide what?)
- (How can you know which patients have the greatest need and need to be given priority regarding health care?)
- What then has been good and what has been bad about the way things have been done in this County Council?
- In case of confusion about concepts during the discussion, the participants can be asked what they think priority setting in health care really means.

If time allows

- What do you think now about the information you had before coming here today?
- How did you get it?
- Why do you think the politicians thought that priority setting and service limitations in health care were necessary?
- Why do you think it was decided as it was here in Östergötland to place these particular conditions and interventions outside of publicly financed health care?
- (Do you think it was wrong that a particular condition/intervention had low priority and was taken away?)
- (Are there other conditions or interventions you think could have had lower priority in health care?)

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