

Medical programs

Horizontal political prioritisation From words to action

Sub-report January 2004

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Preface

The county council's decision to openly report on the medical measures that as from 2004 will not be included in care provision for the citizens of Östergötland has attracted a great deal of interest nationwide. Many people have contributed their points of view and opinions about this matter. Even more have expressed their interest in finding out more about how we have prepared and carried out our prioritisation work. This is the background reason for this report being published at this time.

It is the county council's intention to achieve more openness about how these economic resources are shared among different groups, and to show this division is made fairly according to demand. Further, it is desirable to establish public insight and debate on how medical health care resources are used. This will clarify naturally what public undertakings can be feasibly economically covered and what **cannot** be covered, i.e. - to what extent health care has to be restricted. This increased openness over the distribution of resources and prioritisation is equally important both internally and externally.

This report explains how the county council has prepared and carried out prioritisation work, which during the autumn of 2003 resulted in the decision impose certain restrictions on care provision. What is new about this is that the county council elected to report openly on their decisions. Because openness of this kind is unusual in Swedish medical health care, it can be important to spotlight and provide an account of preparations and procedures associated with these decisions and what we have learnt from this work.

We hope these experiences will prove useful to other county councils.

Linköping, January 2004

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Introduction

Medical and technological developments increase our possibilities of helping increasingly ill patients. In parallel, this increases the demands on health care. Consequently, publicly financed health care will never be able to provide sufficient resources to satisfy these demands, needs and possibilities. Prioritisation therefore, is required for the allocation of resources, both within and between disease groups/areas of operation. This kind of prioritisation has always been present, the difference is now that prioritisation discussions are to be conducted openly and in a developing dialogue between politicians and citizens and between politicians and care providers. This too, is one of the starting points for development in Östergötland.

The word prioritisation means “put before”. This means then, a choice between two or more alternatives. In practice prioritisation means that something that seems more important is put before something that seems less important. A practical example is when patients are prioritised on a waiting list for a certain examination or treatment.

Prioritisation can result measures low on the ranking , in certain cases, being crossed off entirely, e.g. a certain kind of care. From now on this rationing process will be referred to as a care supply restriction.

The overall reflections of the county council on prioritisation principles were explained more thoroughly in an earlier sub-report “Model for knowledge-based prioritisation and allocation of resources”. In this report spotlighted questions include; will open prioritisation, in which the county council openly declares its attitude, be possible in the future? This too, is the question that has formed the premise for continued work.

If prioritisations are to be open it is necessary for

- The prioritisation principles and their bases to be known
- Prioritisation to be the result of a conscious choice
- The consequences of the prioritisation to be known
- Possibilities to be provided for public insight and debate on the prioritisations

The need for open and distinct prioritisations does not reduce in any way the need for people in medical health care to always try to make effective use of economic resources, both within medical health care operations and in cooperation with municipalities and social insurance offices. This work must continue with unabated measure.

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In recent years the county council has tried to equip itself for handling the very complicated prioritisation question. This refers to both vertical prioritisation, (within a certain disease group or within a certain area of operation) and, to a still greater extent, to horizontal prioritisation (between different disease groups or areas of operation).

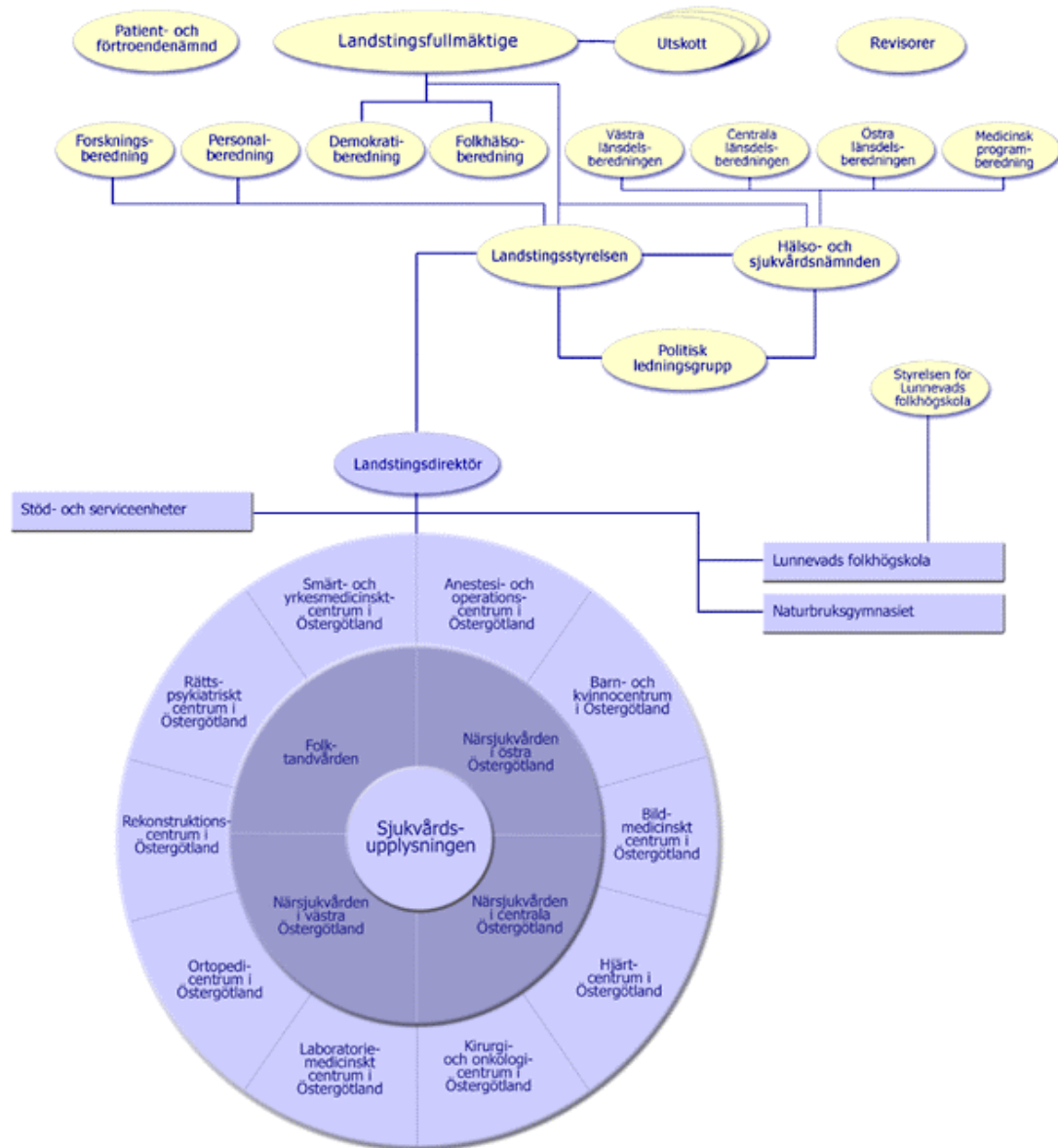
By means of medical health program work, the county council has laid down a satisfactory foundation for a functioning and open prioritisation process. In the citizen dialogue development project it has been found that citizens both can and are prepared to discuss difficult matters. Such talks must be well prepared and respectfully conducted. Further, the purposes of the citizen consultation must be clear.

In the sub-report "Model for knowledge based prioritisation and resources distribution" an account is given of how the medical health program has come about, what matters it provides answers to, the principles for prioritisation that have begun to take shape and thoughts on how the health program could be integrated with the county council management process. Further, the theoretical starting points for ethical aspects, the demand concept, the result concept and cost analysis.

This report recounts partly how work has progressed until now, the reflections we have made along the way, partly the experiences from an initial attempt at transiting from theory to practice by application of the prioritisation model in reality.

The report mentions several political organisations in the county council. An overview of the county council organisation has been provided to simplify the task of the reader.

Figure 1 Organisation diagram, Östergötland county council



Purchasers and providers model forms foundation for operations management.

The county council board has overall responsibility for planning and follow-up of the entire operation and a responsibility for the county council production organisation.

The health and medical care board, which is demand focused, has an expressed responsibility for assuring that assignment descriptions and prioritisations are based on the demands of public health and medical care.

The county council as principal provider of medical health care – responsibilities and tasks

According to the health and medical care act the principal provider of medical health care is responsible for providing inhabitants of the county council region with good medical health care and of planning this according to the requirements of the county population. Also, this planning include private medical care.

According to the county council work report “The county council as a principal provider of medical health care”, the principal provider’s overall responsibility can be seen from the two following perspectives:

Health situation and demand perspective, including:

- Planning, decision making and following up on care.
- Financing of care adopted or that is otherwise dictated by law or other authorized executive undertaking.

Principal care provider producer perspective, including:

- Decision on types of care design, i.e. own operation or through external operation.
- Owning and managing own care resources.

This report touches only on health situation and demand perspective, that is included in the principal provider’s core tasks, and that all principal providers must handle.

The Östergötland county council handle health situation and demand perspective by

- looking after the health and welfare of citizens.
- prioritising between different health and medical care demands in such a way as to assure the provision of care to patient groups/patients with the most need.
- stimulating the improved efficiency and quality both within health and nursing and in cooperation with other operators in society.
- following up and evaluating health and medical care measures from the above perspective.

To look after the health and welfare of the entire population the county council works together with other operators in society, primarily the municipalities, within the framework of the Östergötland public health program. The purpose of this is for all operators in society to work together to create good conditions for bringing

up children and young people, good health and quality of life for adults and good health and life quality for people as they grow older.

County council medical health care has an important task in regard to early diagnoses and treatment or supporting groups/individuals especially vulnerable to developing ill-health and diseases, e.g. children and young people. Health care shall maintain a particularly close eye on groups in which there is a high risk of developing ill health and disease.

Discovering, curing, alleviating, rehabilitating and supporting people stricken by illness is the main task of the county council. In order to assure care is provided to those *patients/patient groups most needy* in the best way possible, the county council needs a structured method to work on planning/documenting the care demand of different disease groups and for prioritisation between these groups. Medical program work, and the prioritisation work that has developed from this, provides an important foundation for this activity.

According to the medical health care act, the county council bears responsibility for attending to the demand for special measures in patient groups with serious diseases, chronic diseases and in groups with deteriorated autonomy or who for other reasons are specially vulnerable. To meet the demand of these groups, cooperation is usually required with other operators in society, such as municipalities and social insurance offices. In many cases this is a matter of improving efficiency and quality of care.

The county council is entrusted with ensuring medical health care – from the overall perspective – is efficient and of good quality. In parallel with prioritisation work, the main focus of this report, the county council runs intensive development and change processes with several other areas such as structural measures, rationalisation and quality work and management development.

Health care quality means “Meeting the demand of those who need service most, at the lowest cost to the organisation, within the limits set by the executive and clients” (Øvretveit, 1992). It is then, necessary at all organisation levels to understand demand, make conscious prioritisation and maintain control of how resources are used.

It is essential to continuously develop quality. I.e. both how the process works in relation to demand and what the result is. A determining success factor is for health care to run quality systems at all levels that support quality development in a systematic manner, that development is based on knowledge, focusing on processes and on the result, with continuous improvement work and learning. Good care must not be prioritised away owing to badly developed quality, i.e. economizing of available resources is not optimal.

Good quality and efficiency entail the population of Östergötland receiving health care according to their needs, at the lowest cost for the organisation, and within determined limits. Health care quality shall be equal throughout the county.

The target is for health care resources to contribute to public health based on effective use of resources, for people to have confidence in health care and find health care to be secure and fairly distributed

Medical program work – a common knowledge base

Medical program work is the collective term for processes that produce and present the knowledge base required for the political management of health care. Information and knowledge shall be adjusted and presented to be accessible and useful for politicians, civil servants and care providers. Further, it shall be based on the entire population, on disease groups and, in certain cases, specific patient groups, and presented both geographically and per group.

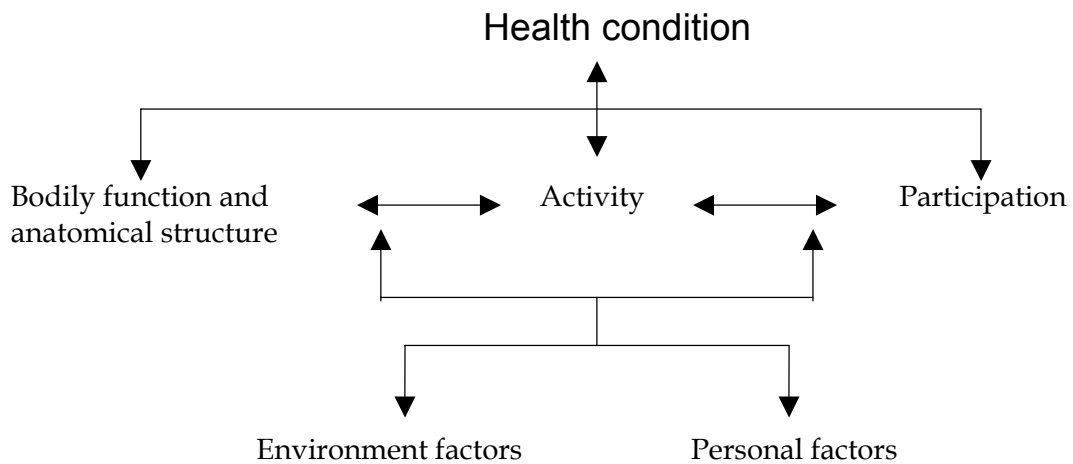
Disease group – requirement group

The medical program and ranking list are based on disease groups to meet the health care requirements of the population in the best possible way. Health care professional skills and work are oriented primarily towards different ways of preventing the negative effects of illness/injury on health. The WHO health model is a starting point for looking at health and the different aspects health care can influence.

Health care is focused on sickness/injury to **organ functions**; e.g. putting a plaster on a broken bone, relieving pain. Work is oriented towards helping the individual to carry out normal **activities**, such as moving about and looking after themselves, **participating** in society and work and maintaining a family and social life.

Factors that affect health include the environment, e.g. social and physical **environment**, while others include **personal** factors such as age, sex, ethnic background, education, degree of autonomy etc. By analysing the latter factors we can **identify vulnerable groups with special needs** within each disease group that health care must take into account when planning and executing of care processes. It is primarily to meet the requirements of these groups that the county council and the municipality need to cooperate over their activities and responsibilities.

Figure 2 WHO classification health model of function condition, function impairment and health



Program work development

During 2004 a comprehensive survey of the medical program was conducted. The purpose was to create a better and more operatively useful information and facts base, containing material for tasks and prioritisation processes.

Program work shall be developed into a natural arena for dialogue between the different parties and their various cooperative partners., e.g. municipalities and social insurance offices. Program work should be firmly based and represent different perspectives, both in health care and about health care.

In future and for each disease group/ medical program there will be a medical expert responsible for medical factual documentation, a political group of representatives and coordination expert in patient and kin perspectives. The medical expert and the patient and kin co-ordinator share responsibility for the compilation process.

As from 2004 the public health centre/ medical program, a county council development group, have overall responsibility for ensuring the medical program develops in accordance with county council executive policy. Work is to be conducted in close cooperation with care provider and county council development units.

Medical facts documentation

The content of this base (the program) shall be developed. The purpose is partly to strengthen patient perspective, partly to improve the content of the medical facts document.

The present section on sickness significance and consequence will be developed to strengthen patient perspective. The purpose is to create conditions for target formulation/tasks that focus more sharply on how patient function and health shall be influenced by health care measures. In 2004 a structured consultation with the disabled persons association consultant organisation was started up within the program work framework. The section on medical measures and effects will be connected to the ranking at an early stage (see page 13).

The intention is to increase accessibility to basic information by presenting basic information/basic data about respective disease groups in a searchable database as a complement to medical documentation. This means all programs as from 2004 will successively be adjusted to the new structure and continuously updated accordingly. The diagram on the following page shows the structure of both the medical documentation and the basic information pertaining to one disease group.

Basic information

There is a quantity of base information, within and outside the county council, that is important to disease groups. A compilation (accessible via the data base) of this information will be made. The information structure is shown on the diagram on the next page. The base-info compilation will comprise:

- direct, compiled data.
- links to compilations, e.g. SCB.
- reference to (written) information, e.g. reports/analyses.

The information and knowledge base produced within the medical program will include both medical facts and other basic facts. On the following page you will find an account of the structure of both the medical facts documentation and the basic information pertaining to one disease group.

Structure and viewable content of medical facts documentation and basic information for one disease group

Medical facts documentation (medical program)

Sickness condition

- Epidemiology
- Aetiology
- Pathogenetics

Sickness consequences

- Affect on bodily functions
- Affect on activities
- Affect on participation
- Circumstantial factors
- Patient groups with special needs

Prevention/treatment of disease

- Preventive measures
- Forms of medical treatment
- Surgical treatment
- Other forms of treatment
- Rehabilitation

Measures results

- Result of specific sickness variables
- Result on function and participation
- Result on general life quality

Basic information (data base info)

Population

- Age/development
- Sex
- Social demography

Ill health among population

- Epidemiological data
- Description of sickness consequence in different stages
- Mortality

Patient/kin demands

- Various forms of quality

Care consumption

- Outpatient/hospital care
- Individual/age/sex
- County area
- Relation to national data

Results

- Various forms of care result

Effects to population

- Registered for sick leave
- Early retirement

Disease group costs

Vertical ranking – a model of principles

In Östergötland work on vertical ranking in patient groups and care measures within an disease group started as part of the medical program work in 1996-97. There was no structured model for ranking . The starting off point was the ethical platform provided by the Priority Commission (ref. difficult care choices (Vårdens svåra val), 1995) with the three ethical principles; human dignity, need and solidarity and cost-efficiency.

During the discussion, in connection with the attempt to arrange patient groups and care measures in ranking , many questions came to the surface: How is demand of a patient group defined? What is the effect of the various interventions? How cost-efficient are these interventions? Is there any scientific documentation? What ethical aspects should be observed?

Later, successive discussions with first and foremost the National Center for Priority Setting in Health Care in Linköping and the National Board of Health and Welfare have resulted in a more structured principals model for use with drawing up ranking lists. Based on the three named principles that have been expanded and put into operation (fig. 3). The principles model is now recommended in Östergötland for continued vertical priority work.

Figure 3 Ranking principles model

PRINCIPLE OF HUMAN DIGNITY			
Need for intervention in health care			
Severity of disease	Patient benefit (effect of intervention)	Cost efficiency	E
Current medical condition symptoms functional capacity quality of life	Effect on current medical condition symptoms functional capacity quality of life	Direct costs medical interventions non-medical interven- tions	V
Risk of premature death permanent disease/injury deteriorated quality of life	Effect on risk of premature death permanent disease/injury quality of life	Indirect costs loss of production intangible costs	I
Deteriorated autonomy	Risk of side effects and seri- ous complications from in- terventions	...in relation to patient benefit	D
			E
Prevention - Diagnostics - Treatment - Rehabilitation			

How to draw up a list of ranking

Disease group oriented work method. We have chosen to start off from disease groups. An advantage is that results and continued work are independent of both current organisation and any future changes to the same. This generates valuable discussion between different care units and care levels during the process itself.

Working group. The target is for the group that establishes the vertical ranking list to include representatives from all care levels and personnel groups involved in the care of the patient group in question. This means e.g. that the municipality too, should be represented, e.g. as a major operator in regard to stroke care.

Restrictions. The task applies only to established medical health care, meaning that research and development are processed elsewhere. As always in these situations, there is a grey zone between the territories. A fact that frequently contributes to the initiation of valuable dialogue.

Obviously, it is not practically possible to cover all sickness conditions or care measures. One objective in the meanwhile is to include at least 75-80% in the ranking list, these to be the most important from various perspectives. As an ex-

ample, pharmaceuticals can be mentioned, where the first to be attended to should be those of the largest volumes, that cost most or are new.

It is important for the entire care chain to be covered, including prevention, diagnostics, treatment and rehabilitation.

How a ranking is drawn up. Ranking parameters comprise symptoms/medical condition paired up in combination with care measures/intervention, e.g. intestinal cancer and surgery.

Each patient must receive an assessment for a new and, for the patient, a worrying symptom. This might take place via contact with health care information, the primary care or the emergency room at the hospital. Only after this assessment can a ranking be made. We have not chosen the Priority Commission method of an approx. division into four priority groups¹. Plainly, the same medical condition (e.g. asthma, diabetes) can be repeated in groups I and II as III. Furthermore, this ranking method fails to take into account the expected effect of different interventions and cost efficiency. Instead, we have divided sickness conditions directly into sub-groups depending on the severity of the condition. *It is important to note that ranking refers to groups of patients.* When actually meeting the patient it might be found that exception from the ranking needs to be made, since special circumstances for this patient may have to be taken into account.

The number of prioritisation levels used¹. The ranking list comprises 10 levels, where level 1 indicates those priority categories assigned the highest priority.

Aspects decisive to ranking. The aspects that should be observed and finally weighed up, when deciding on the level of medical condition/intervention ranking, are *severity of disease* (medical condition severity in regard to symptoms, risk of premature death, affect on quality of life and functional ability), *effect of intervention* on these parameters, including the risk attached to the intervention, plus *cost efficiency* and what scientific *documentation (evidence)* is available for the same (see fig. 4).

The grading of these various parameters has occurred in various ways. In some cases grading of each parameter takes place using a structured description; none, little, modest, major risk of premature death, affected quality of life etc. In other cases points systems are used, or assessment of shares in percentages, cured or retaining certain length of life respectively, etc. Risks have been graded according to a scale relevant to the specific disease group.

Cost efficiency is included to the extent anything is known. The scientific support (evidence) for each parameter is taken into account, although it should be noted that significant scientific support for a certain intervention does not automatically result in this intervention being listed high on the ranking list. Other parameters, e.g. little care need and high cost in relation to the effect of the this intervention, can cause the intervention to be placed relatively low on the ranking list. When the 10 grade scale ranking shall be decided, different methods have been used. In some cases a mathematical/quantitative calculation has been used for establish-

¹ These groups were not intended for sorting different diseases, that can vary in degrees of severity, but were created to give some examples of different demands.

ing the priority level. The risk with this work method is that it furnishes an impression of “false” exactitude. In other cases a more qualitative method is used, with evaluation and weighing-up of all relevant parameters, which is to be preferred. For the final ranking, a comprehensive evaluation of all facts and a discussion between all group participants is required before a general consensus can be attained.

Figure 4 Model for ranking presentation

Medical condition	Severity of the disease and need for intervention	Effect of intervention	Cost per year of life gained/ QALY	Evidence	Ranking
Intervention					1-10

Figure 5 An example of vertical ranking for cardiac care in Östergötland (compare equivalent list of National Board of Health and Welfare guidelines for cardiac care, 2003).

Medical condition Intervention	Severity of the disease and need for intervention	Effect of interven- tion	COST PER YEAR OF LIFE/QALY	Evidence	RANK- ING
New worrying symptoms <i>Health care contact (health care informa- tion/primary care/emergency room)</i>	An initial assess- ment is required to assess health care need, if any, and for ranking.	An initial assess- ment is required of any care demand if it is to be possible to select intervention and assessment of its effect.	Not assess- able	Supported by clinical experience	1
AV-block III (incl congenital condition) <i>Pacemaker implant</i>	Major risk of pre- mature death Major risk of per- manent injury Little-large need for symptom relief Little-large affect on quality of life	Major reduction in risk of premature death Major reduction in risk of permanent injury Little-large symp- tom relief Little-large increase to quality of life	Low (esti- mate)	Supported by clinical experience	1
Acute coronary ar- tery disease and/or recently completed revascularisation <i>Physical training (team based)</i>	Varying risk of premature death and permanent injury Varying need for symptom relief Varying effect on quality of life	Moderate-large re- duction in risk of premature death Moderate-large re- duction in risk of permanent injury Moderate-large symptom relief MODERATE-LARGE INCREASE TO QUALITY OF LIFE	Low	Evidence grade 1 (ef- fect) Good (health eco- nomic evi- dence)	3
Valvular disease in patients with other severe diseases si- multaneously or medical condition entailing expected short survival period <i>Pre-operative assess- ment and if possi- ble/suitable valvular surgery</i>	Major risk of pre- mature death Moderate risk of permanent injury Varied demand for symptom relief Varied effect on quality of life	Small gain in regard to premature death and/or permanent injury owing to such factors as the basic disease Major risk attached to surgery Varied effects of symptom relief Difficult to assess quality of life	Very high (estimate)	Supported by clinical experience	9

Similarities between levels for different ranking lists. Is level 4 for a disease group (e.g. mental disease) entirely comparable with the same level as another disease group (e.g. eye diseases)? Is the care need and the usefulness of care action fully comparable? This is not the case. Obviously, we should try to achieve as much equality as possible. Because ranking lists for different disease groups are generally available, we can examine each other's ranking lists and we can work on them in the interests of improving comparability. But this objective probably cannot be attained within the foreseeable future. One way of reducing the problem is to work on our descriptions of consequences according to a set template. This is described in more detail on page 31. This is especially desirable when necessary to cost reduction, since it might be required to describe the consequences of reduced care at more or fewer levels on our ranking lists, depending on the kind of cost reduction we achieve at each level.

The need to revise. There is no doubt the vertical ranking list has a best before date. It needs regular revision and perhaps radical revision once a year. E.g. for overhauling agreements ready for the following year. Of course, this overhaul is not as labour intensive as the initial establishment of the list. Revision requires only deciding if new knowledge necessitates the ranking being altered. When new methods materialise, these should be assessed as per previous processes used and inserted at the appropriate level on the ranking list.

Experience of work with ranking lists

Problems associated with vertical prioritisation or ranking

One of the largest has been shortage of time. In a tight health care situation and many different tasks of more administrative type, it has been difficult for e.g. care personnel to find commonly available time for this work. Consequently, to a certain extent, this work has been executed during the leisure time of dedicated personnel.

There is a considerable dearth of factual material. This applies to both medical facts and health economics studies. One reason is that sickness conditions have to be divided up into sub-groups. Data for these sub-groups from scientific surveys is lacking because such activity is usually limited to large populations with tens of thousands of patients without division into sex, age or sickness condition severity.

Unfortunately health economics surveys are scarce, or have been conducted in other countries and are thus of doubtful relevance to Swedish conditions. Limited economic and time resources are the rule at local level, and so no structured search process as per SBU methodology is possible.

Ranking is a very delicate task. As said, factual documentation is by no means adequate. A certain pragmatism is required, i.e. using the best available documentation to attain as good an ranking as possible. Doubtless, evaluations are included in the final ranking, but it is probable that a ranking according to the described structure and division of participants would be far sounder than what has previously been possible in patient-doctor relationships.

Positive experiences

The actual process of establishing a ranking list is extremely valuable. It enables constructive discussions between different care levels (e.g. hospital clinic – primary care – municipality) and between different groups of personnel.

Discussions give rise to the possibility of questioning opinions and values and “old routines”. On these occasions cards can be laid out on the table. What scientific support is there for both “old” and more recent work routines and methods? What health gains do they generate? How much does each year of life or QALY (quality adjusted life year) gained cost? Such conversations frequently materialise into ethical discussions.

The meeting between different care levels provides more knowledge about each other’s working conditions. A natural extension of ranking work is the establishment of guidelines or the reviewing of guidelines.

From words to action

During the autumn 2002 county council management decided that prioritisation would be one of the measures used to correct the county council's incipient economic difficulties. The council would in other words, go from discussions to direct action. The prioritisation model, developed within medical program work, was to be tested in reality.

In recent years the county council has, in different ways, been preparing a practical approach. An important guiding star in this work has been the development of work methods, decision making material and other lasting tools.

In this section we report on the preparation work prior to the concrete execution of open political prioritisation within medical health care in Östergötland. We describe in part how concrete execution was conducted, in part the experiences gained from the process.

In preparations for a practical approach the following areas have been processed in recent years:

- Delegation of responsibility for prioritisation work.
- Application of the three ethical principles.
- Assignment and prioritisation processes.
- Documentation for decision making and tools.
- Training seminars subject horizontal prioritisation.
- Dialogue with care providers.
- Dialogue with citizens concerning prioritisation.

Delegation of responsibility for prioritisation work

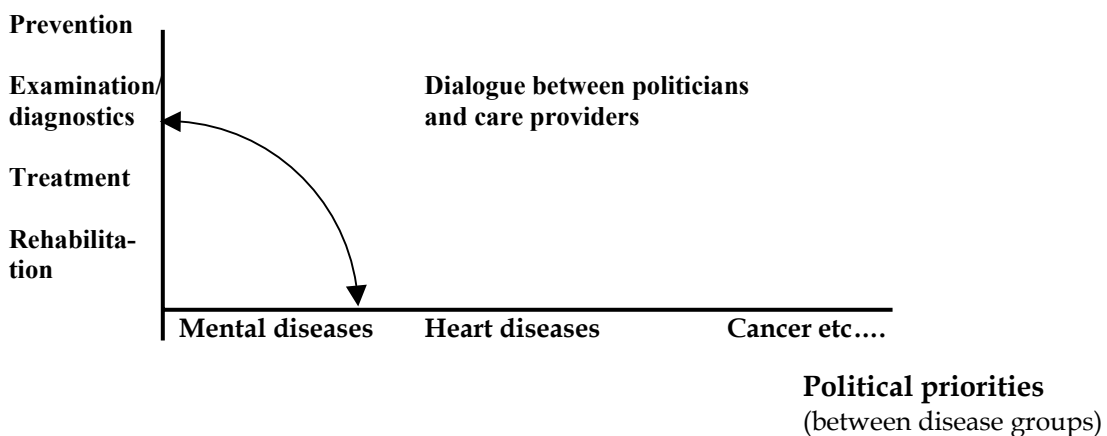
Prioritisation occurs at different levels within health care. At *the political level*, prioritisation decisions are population oriented. This means decisions over division of resources between different operation areas and between large anonymous patient groups, such as between measures directed at kidney diseases and eye diseases. On the other hand, *medically responsible executives* must make decisions in regard to prioritisation between individual patients and patient groups within their own operation area. They must prioritise resources placement in regard to prevention, diagnostics, treatment and rehabilitation.

Prioritisation decisions made at the overall, political level usually have real consequences for individual patients and vice versa. Dialogue and accordance between politicians and the operation in regard to both basics and principles of how prioritisation is to take place are therefore essential. Fig. 6 illustrates the role and delegation of responsibility upon which we base our prioritisation work.

Figure 6 Principle role and delegation of responsibility between politicians and care providers

Care provider priorities

(vertical ranking within disease group)



For prioritisation to be practically possible to execute, starting off points for political priorities, that always have to be population oriented, need to be linked together with the ranking of measures/actions for which care operations have responsibility and that are mainly individual and/or patient group oriented. Therefore the county council has elected to start off from disease groups, which is the "arena" in which both perspectives can meet.

According to the *regulations for the county council in Östergötland*, the county council shall decide upon and adopt prioritisation principles between the health and medical care board and, using factors such as assignment descriptions and consequence descriptions as documentary foundation, prioritise between different needs. This delegation of responsibility forms the starting point for the county council prioritisation process.

The health and medical care board is responsible for the execution of horizontal political prioritisation. This can be caused by lack of resources or the need to share out resources. The health and medical care board decide the areas to be discussed for prioritisation and restricted services. This is based on the weighing up process performed during project work.

It is important to observe the ethical aspects of the prioritisation process.

Application of the three ethical principles

As mentioned, rapid medical – technological development has meant more and sicker patients can now be provided with health care services. This, in itself positive progress, has nevertheless meant that we not always should/are allowed to do everything that we could do from the strictly medical viewpoint. In most cases it is not only the economic reasons that dictate we should refrain from using our resources. Frequently both medical and ethical reasons dictate we should refrain from taking expensive actions and, for example, offer the patient good nursing care and efficient pain relief in the final stages of life instead.

Careful ethical assessments are increasingly important in more and more situations. As care providers there is reason to ask ourselves: “For whom am I making this extra examination or life prolonging action – is it for the sake of the patient, their kin, the disciplinary board or myself?”

There is almost never a simple answer and no obvious right or wrong in these difficult prioritisation situations arising in present care. A patient might have a legitimate right to want to take a chance on an operation entailing major risk of complications and expensive intensive care, even if there is little chance of a cure or improvement. The medically responsible physician has to think of their other patients in the meanwhile, who perhaps, owing to the acceptance of the request of the said patient, will risk being denied a care action that is really more cost efficient and meaningful. When resources are scarce it is perhaps ethically inadequate to meet the demand of the aforesaid patient.

It is a very difficult decision to refuse a strong request from a patient for a certain care action, by which means the patient hopes to be helped. Even if pain relief and other nursing measures are offered, the patient is often very disappointed. A refusal of this kind demands much time to impart thorough information and explanation of the reasons. It is necessary to provide support functions within the care unit and carry on an open and continuous dialogue about ethical matters.

Politically, it is a difficult matter to refuse the strong demands and wishes of patient groups. Although other measures can be offered, this leads to frustration and disappointment. At political level therefore, it is necessary to conduct a clarifying dialogue on ethical values and political ambitions and use these as a basis for the difficult choices that have to be made. The dialogue must, to an increasing extent, be conducted with the people of Östergötland.

In its prioritisation principles, that cover the political level and the clinical level, the county council has taken notice of what is prescribed by the health and medical care act. This states that the following three ethical principles shall provide the basis for prioritisation in health care:

The ethical principles for prioritisation

Human dignity principle as to which all people are equally valuable and have the same rights irrespective of age, sex, ethnic background, personal characteristics or functions in society.

The need and solidarity principle where resources shall be invested in areas (operations, individuals) where the need is greatest.

Cost efficiency principle, in which a reasonable relationship between cost and effects, measured in terms of quality of health and life, ought to be sought when choosing between different operations or measures.

It is important for these three principles to actually be applied in priority work and that they do not merely become prestige words. This should be striven for both when drawing up vertical ranking lists and in horizontal political prioritisation.

In the section covering vertical ranking lists it is clearly stated that the three ethical principles are to be actively applied when producing vertical ranking lists.

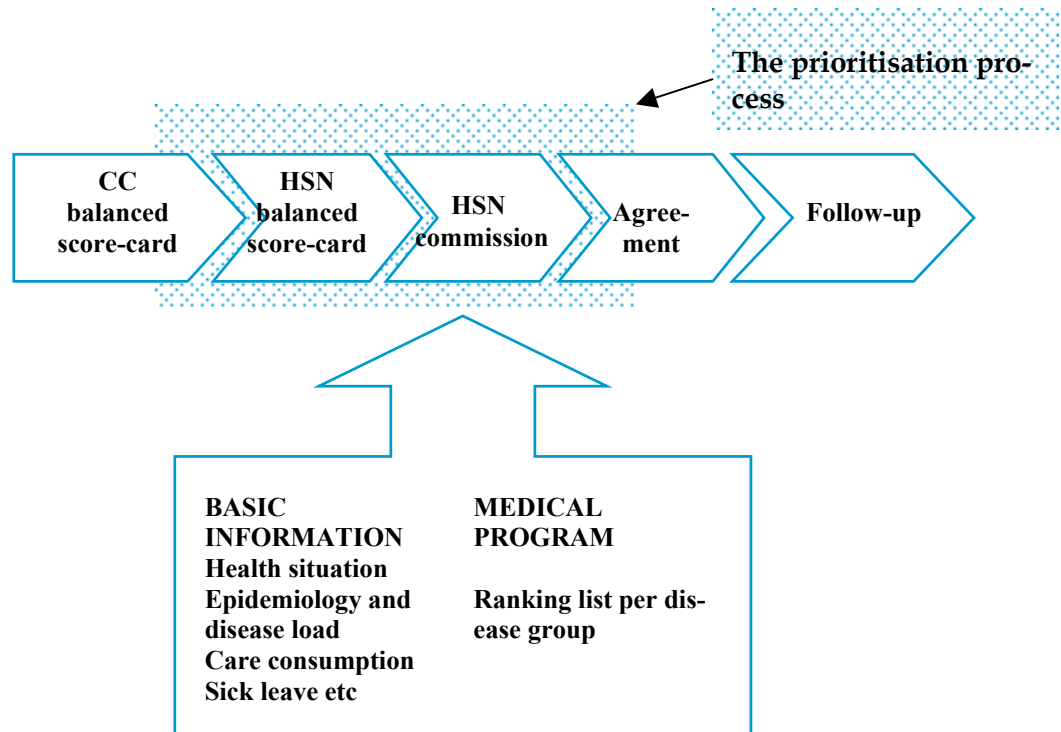
To provide satisfactory support for the politicians in their work with horizontal prioritisation between disease groups, a special checklist has been drawn up. This is based on the three basic ethical principles and the overall political objectives adopted by the county council. The idea is for this to be used when examining, for example, proposals for reprioritisation and care service restrictions (see page 32).

Project and prioritisation process

The project and prioritisation process is the health and medical care board tool in the political control of health care. In recent years these have been successively developed. The primary objective is to ensure that projects assigned to care, and the prioritisations and/or health care service restrictions that follow from this, are an annually repeated process and not just a one off phenomenon. It is important for the preparation and decision process to be thought of as fair, i.e. partly by being well-known, partly by offering participation opportunities.

Fig. 7 on the following page features a principle diagram of the project and prioritisation process position in the health and medical care board management process.

Figure 7 Principles diagram of commission and prioritisation process positions in the health and medical care board management process



What is a commission description and how is this connected to prioritisation?

Because commissions and prioritisations between different demands are intimately connected, in future the commission and prioritisation process will be run as an integral process. The intention is for commissions for overall plans to clarify ambition levels in regard to measures taken for different sickness and patient groups and to ensure a systematic follow-up of how health effects, quality and efficiency develop over time. Commissions make up the foundation for the prioritisation/care supply restrictions that must be made, either in regard to new funds for the county council, a shortage of money or a need to reprioritise between groups.

The health and medical care board cannot act entirely independently in this work, but must unambiguously base activities on the county council overall balanced score-card. This contains the political direction of preference, expressed in overall objectives and prioritisations, and the economic frameworks of the board. In this stage of the process political prioritisations are very much all enveloping. This is mostly about seeing to equal health care conditions for the entire population, and can be achieved by e.g. pointing out the unequal conditions of health care in different population groups, demands for health care not being met or inequality in access to health care. Or it might be a matter of exposing areas in considerable need of improvement, e.g. preventive action, rehabilitation and palliative care.

It remains for the county council and the health and medical care board to realise the overall targets and priorities within their respective areas of responsibility, within the economic frameworks allotted by the assembly.

Commission descriptions indicate how the medical and health care board intend to achieve the overall objectives within the economic frameworks allotted by the assembly. The board draws up a single collected commission description expressed in health effect targets and quality demands for different sickness and patient groups. Work with drawing up commission descriptions includes attitudes to any changes in meeting demand between different groups and, as a consequence of this, changes in the care provided. Such changes have to be reflected in the design of the commission.

Initially the health and medical care board will only be able to make very approximate prioritisations between the different disease groups. As more complete commission descriptions for different disease groups materialise, so the possibilities of politicians to express their objectives levels to be attained for different disease groups increase. One vision is that developing work on long-term target levels will indicate how much health we can afford in different areas (targets to be attained) and how various investments shall be prioritised. Horizontal politics between disease groups/operations areas will develop step-by-step. Commission descriptions provide documentation for agreement dialogues.

Final prioritisation occurs prior to agreement work. As mentioned, this can be caused by lack of resources or politicians with their projects opining that reallocation between groups must be made. This can cause changes/restrictions in the care available, which must be expressed tangibly in care provider undertakings. At this stage of the process this will usually concern restrictions on available care.

Commission descriptions and consequence descriptions drawn up by the operation, based on orders of preference, provide important documentation in this part of the prioritisation process.

The commission and prioritisation process shall be executed in an intimate dialogue between the medical and health care board and its committees, county council management via the director of medical health care and the care providers. The public health science centre/medical program function as coordinators of the process with responsibility for planning, production of knowledge-based documentation and other process support.

The commission and prioritisation process will include the following points as from autumn 2004:

1. The process begins with a run through of the current demand and problem analyses for politicians, county council management and operations. The objective is for these analyses to be presented at total level for the county and at disease group and municipality level.
2. The medical and health care committees provide the orientation for work on respective demand and disease groups starting off partly from the demand and problem analyses and partly from the board balanced score-card (budget). Thereby carrying out the heavy prioritisations between different groups/operations areas.
3. The civil service team works from proposal to assignment in dialogue with the committees and the operations.
4. The medical and health care board and its committees carry on a dialogue with the patient and consumer organisations and with citizens concerning important matters of principle connected to the assignment and prioritisation process.
5. The committees provide target levels for respective groups/operations according to the presiding economic conditions.
6. The final proposals for assignments and the consequences in the shape of reprioritisation/care provision restrictions are discussed with operations and citizens.
7. The presiding committee of the medical health care board draw up a recommendation for reprioritisation/care provision restriction for the board.
8. The hearing of the board prior to the decision taken regarding the project description, including reprioritisation and care supply restrictions.
9. Decision made by the health and medical care board
10. Information to and dialogue with care personnel, patient and consumer organisations and citizens in regard to the decision made.

Assignment descriptions shall then provide a base for agreements between the different production units.

Documentation and tools

In order to convert fact documentation and knowledge from e.g. the medical program work into usable documentation for decision-making we require different tools. To transit from talking to action we have developed the following tools:

Tools for committee and decision work:

- Demand and problem analyses.
- Vertical ranking lists per disease group.
- Consequence descriptions of prioritisation effects.
- Support for horizontal political prioritisation.

Need and problem analysis

The health and medical care board plays an important part in attaining optimum need coverage at group level. As mentioned, the board will initially only be able to make very rough prioritisations in regard to the division of resources between different disease groups. To refine this, more knowledge is needed about e.g. the sickness load division among the population, what health care can do (medical programs and ranking lists), costs of disease groups, etc. This will provide important material for future assignment and prioritisation work.

The production of need and problem analyses is an important development area. These are important premises for both assignment descriptions and prioritisations. They shall be done for disease groups, for predetermined patient groups, e.g. elderly multi-sickness with complex care demands, for a municipality or for the county as a whole. Public health scientific centre/medical program are responsible for demand and problem analyses. These are drawn up in cooperation with medical consultants, medical experts affected, heads of centres affected etc. These shall be completed in good time before assignment and prioritisation processes are begun.

In connection with assignment work 2003 an initial demand and problem analysis was made for the respective disease group. However, these need to be developed.

In 2004 an analytical model will be developed, and will provide support for this work. On the following page you will find some of the questions that could be answered by demand and problem analyses.

The objective is for demand and problem analyses to answer the following questions in the long term:

- What are the economic conditions?
- What risk factors and risk groups must be attended to in a better way and how?
- How many Östergötland people suffer from the sickness covered by the assignment?
- Will demand alter during the assignment period? Trends? Why?
 - Population development.
 - Changed life style.
 - The opportunities provided by medical development.
- Trends regarding larger and/or commonly occurring medical measures executed, e.g. operations for cataracts, on hips etc.?
- Assessment of medical development during the assignment period in regard to;
 - the introduction of new methods and technologies, including pharmaceuticals and equipment,
 - the spread of medical methods and technologies to lower care levels and
 - the removal of methods.
- Security and accessibility – the need for improvement for patient groups
 - with low frequency demand for medical health care,
 - requiring occasional specialised medical measures,
 - with long term and chronic sickness,
 - requiring specialised care owing to serious sickness/injury,
 - with reduced autonomy and complex care needs.
- Other quality problems, e.g.
 - cooperation within medical health care or with municipalities and social insurance offices
- Rationalisation potential
- Assessment of demand coverage prior to assignment and prioritisation work

Vertical ranking lists per disease group

The principles model for ranking has been previously described. This section describes the responsibility and work method of the care providers.

Care providers are responsible for vertical prioritisation within a disease group. An important part of this responsibility is the assurance of operations quality, efficiency and productivity. If quality defects are present in an operation, resources are being used inappropriately and tougher prioritisations than necessary will be obligatory. The main principle therefore, is for care providers to be able to give an account of their quality, efficiency and productivity. This should take place by comparisons with other units in the county/country (e.g. DRG

comparisons), and through accounts of how operational improvement work affects different measurements of quality such as results, costs and other key figures. Additionally, care providers are responsible for continuously discarding ineffective medical methods and technologies.

Care providers are responsible for updating the ranking list. These are used as an operational tool for internal rationalisation and quality work, and provide a basis for consequence descriptions that the health and medical care board call for when there is a need to distribute new resources, reprioritisation between groups and/or care supply restrictions.

Ranking lists shall cover the whole county and be based on disease groups. They shall include in principle all measures taken in primary care, within county medical health care and within highly specialised care, and be based on county council principles for establishing ranking lists.

Sometimes a disease group is treated at one and the same hospital centre, sometimes at different centres. To handle this, one of the country centre managers is appointed to supervise the main process for a disease group, which means that in certain cases staff have to cooperate with other centres over the production and updating of relevant ranking lists. The centre managers are assisted in their work on ranking lists by medical experts and patient and kin perspective co-ordinators, who are appointed for the specific disease group.

Ranking lists require continuous development and improvement. Firstly, the task is a matter of presenting as unified a plan as possible. Next come medicine treatment, treatment and measures performed by other professionals than physicians to be positioned in the order, plus equipment and preventive measures.

Ranking lists shall be updated continuously, perhaps once a year, and especially in connection with new, more costly technologies being introduced into health care routines. The new technology shall then be introduced according to degree of importance on the list before the economic consequences are taken up in the agreement discussions.

To support care providers in their work, the county council is appointing a consultant service in 2004 to develop and apply evidence-based routines when introducing new and expensive methods into medical health care. The service will contain the professional skills required for the task, and the Center for Medical Technology Assessment at the University of Linköping will be playing an important part in this work.

Consequence description of prioritisation effects

Ranking lists for different disease groups are required therefore, as a basis for political prioritisation between different areas of operation/disease groups, although these cannot be the only documents used for decision making. To enable politicians to overview and understand decision consequences, consequence descriptions are required. There are several reasons for this:

- For reasons of space, ranking lists have to be brief and for this reason include certain medical terminology.
- More complete descriptions are required for political decisions, e.g. the social economic consequences, patient volumes, any effects on education and specialist training. The descriptions should be comprehensible to those without medical training.
- Although ranking lists are calibrated as far as possible between different disease groups, no level within an area will ever be entirely congruent with the same level in another area, e.g. between mental illness and eye disease. Consequence descriptions reduce this problem.

It is the job of the care provider to report on consequent descriptions on behalf of the county council, either because the health and medical care board require a reprioritisation between disease groups or because lack of resources mean not all demands can be met. Consequence descriptions shall be drawn up according to special templates and be based on vertical ranking lists, starting from the lowest ranking level. Just how high up the list has to be reached is decided by when the demand for e.g. a certain given cost reduction has been attained. Matters of special interest can be listed on a special checklist for consequence descriptions.

Check-list for consequence descriptions:

1. *Which patient groups are affected and what are the demands of the groups?*

The purpose is to describe the nature, and the seriousness, of the condition/sickness in the disease group. Descriptions shall apply to the typical patient in the group. The description shall contain current sickness situation when treatment was considered (degree of functional disability, pain, mental suffering etc.), risk of premature death, permanent illness/injury, deteriorated quality of life, dependency and assistance requirement.

If patients have impaired autonomy, information about this should be provided.

2. *How many patients?*

The number of patients affected should be stated and preferably how they are divided into age, sex etc.

3. *What medical health care measure/interventions are involved?*

Type of intervention should be described (medicine, surgery etc). If repeated treatment is required, must this be applied in hospital, are special skills required etc.? Are any risks of side effects or complications associated with the treatment?

4. *What patient usefulness/health gain can be expected from the treatment?*

State consequences if treatment not provided; in terms of health loss, lost years of life, risk of permanent injury/illness, impaired quality of life, sick leave, early retirement etc. If possible, state any scientific evidence of such effects.

5. *What does the treatment cost?*

Is anything known about cost efficiency?

6. *Are there alternative forms of care for the patients groups in question?*

Are these more cost efficient?

7. *Will costs, care measures be transferred to the private patient, kin, other care provider, other social sector?*

Support for horizontal political prioritisation

If horizontal political prioritisation is to be credible it is very important for material used for decision making to be of high quality.

If politicians are to assess the consequences of a proposal for reprioritisation of resources or removal of various medical health care measures from the population perspective, the three ethical principles must be carefully observed and political aspects must be allowed for and weighed up.

To provide support for politicians in their work with horizontal prioritisation between disease groups a special checklist has been drawn up (mentioned earlier). This is based on the health and medical care act, including the three basic

principles of ethics. The check-list is complemented by a political checklist, based on the county council's three-year budget/control card and the political orientation decided upon. The two checklists duplicate each other to a certain extent.

Figure 6 Check-list 1 – based on the health and medical care act – for horizontal political prioritisation

1. Basic ethics

	YES	NO
Is the principle of the equal value of people questioned or infringed?		
Are there any obstacles to meeting the needs of the weakest and those with impaired autonomy?		
Does the proposal mean that remaining resources are given to the most needy, those with the most serious illnesses and the lowest qualities of life?		
Has consideration been taken of what effect can be achieved in relation to cost?		

2. Good health care on equal terms according to demand

	YES	NO
Does the proposal affect the basic task of medical health care according to the health and medical care act?		
Is accessibility for groups who might have greater difficulty in having their care demands met than others affected?		
Is patient safety affected? How?		
Is medical quality affected in general? How?		
Is care quality affected in general? How?		
Can care processes work together efficiently in future?		
What part of the care process are affected by the proposal?		
<ul style="list-style-type: none"> • Preventive • Examination and diagnoses • Treatment • Rehabilitation • Palliative care • Follow-up 		
How is care affected generally?		
<ul style="list-style-type: none"> • Dilution (e.g. less frequency) • More limited indication (measures only taken when complaints become more severe) • Measure removed entirely. 		
Is the facility for people to obtain care on equal terms affected? How?		

	YES	NO
Does the proposal mean that coverage of the chronically ill, the disabled and other vulnerable groups' demands is threatened?		
Is the purpose of the proposal for altered patient charges to guide the patient to the correct care level?		
Is the purpose of altered patient charges to increase income?		

Figure 7 Check-list 2 – for political objectives and ambitions – for horizontal political prioritisation.

Does the proposal for reprioritisation/care supply restriction affect	YES	NO
security and quality for the patient?		
attainment of the assignment description targets?		
good accessibility and geographical vicinity for groups dependent on these?		
early measures in the form of diagnostics and treatment for those suffering from illness?		
providing specialised and highly specialised measures for those with serious illness or injury when the care demand or condition requires it?		
providing early and coordinated rehabilitation measures for those who, owing to sickness or injury, suffer from function impairment, with the objective of attaining the highest possible independence of the individual in daily and working life?		
supporting the chronically ill and/or seriously function-impaired person's possibilities of living a satisfactory life?		
providing the elderly and the long-term ailing/ multi-ailing with good and adequate medical care in their own homes or in special residential facilities?		
providing the dying with adequate nursing, symptom control and kin support as required?		
providing well-coordinated support for individuals or groups with increased vulnerability to sickness or ill health, i.e. who live with risk factors of contracting illness or defective psychosocial resources? Especially children and young people.		
contributing to positive health development in individuals and groups, partly by health promotion attitudes based on a comprehensive view of the individual, partly through there being routines for sickness prevention measures? This is especially relevant to smoking, alcohol consumption, diet, physical activity and obesity. Secondary preventive measures should be integrated in the care chain.		

Training seminars

Training seminars focused on horizontal prioritisations have been important in progressing from words to action over the prioritisation question. Seminar purpose has been partly to test the county council prioritisation principles, partly to train in carrying on a dialogue on tangible suggestions for reprioritisation and care supply restrictions. Further, the seminars have provided opportunities for common reflection about the difficulty of prioritisation matters, in which politicians, county council management and operations executives have participated.

In recent years the county council has organised several training seminars, of which one has been video filmed and edited for information and education purposes. Seminars have proven to be valuable elements in the preparation process.

Dialogue with care providers

A continuous and well-prepared dialogue between elected representatives and care providers concerned is necessary to the execution of a good quality prioritisation process. Participation therefore, is an important basic value of control for the county council. This has both an internal and an external perspective and concerns how we can prioritise, make choices and make decisions together.

The execution process as a whole must be carefully planned. Considerable attention must be paid to the cultural conditions present within health care, and this requires an execution process based on trust, common knowledge and cooperation between the various executives. It is important to create common objectives which are felt to be meaningful, because they are related to the requirements of patients and a common set of basic values built on respect for each other's assignments and responsibilities. The dilemma in which health and medical care finds itself – where the measure requirement outstrips the resources available – can be used as an incentive in such development.

The key in this situation is long term, mutual loyalty and a process oriented work method based on constant dialogue.

Good quality project execution and prioritisation processes require the assembly, administrators, experts and operations supervisors, in their capacities as representatives and citizens, to maintain an ongoing and well prepared dialogue. The objective includes attaining a better common point of view in regard to health care demand, what health care does and can do, what proven usefulness is attached to different treatment methods, what results can be attained and the prioritisations that ought to be made.

The ambition is to conduct the project and prioritisation processes in a more structured manner, where care providers are clearly part of the strategic dialogue concerning both projects and prioritisations.

Dialogue with citizens

In a representative democracy the decision making process forms the nuts and bolts of the system. It depends on wholehearted participation of our citizens in voting, following the public political debate, commitment to public movements and political parties and the taking on of political assignments either part of full time.

Interest in developing a systematic dialogue with citizens is about elected representative attitude towards the influence of citizens at all, and to what extent it is considered desirable for citizens to participate in the political debate between elections.

Up until now focus groups, i.e. the direct contact between elected representatives and patients and kin, have formed the dominant arena for dialogue with citizens alongside the dialogue conducted via political parties. The county council has, by means of a project called the citizens dialogue, incorporating the systematic planning, execution and evaluation of debates on this subject, prepared themselves for a dialogue about prioritisation.

The National Center for Priority Setting in Health Care in Linköping has followed and documented this project, using interviews with politicians and content analyses of discussions with citizens. A specific sub project has been evaluated, called the citizens council. The county council too, has reported on the projects and its results in a special report.

What might be unique about this project was that tangible prioritisation matters were discussed with citizens.

Experiences from dialogues with citizens

- The citizens of Östergötland wish to talk with county council politicians about ethics and prioritisation.
- Some forms of meeting forums work better than others regarding prioritisation matters.
- Questions must be carefully thought out and well prepared.
- Citizens are willing to discuss difficult matters.

The planning of this project made use of the Priority Commission argumentation for participant democracy with deliberative qualities with the emphasis on the fundamental importance of argumentation and debate to democracy.

Debates on pharmaceuticals were carried on at all meetings, this being a current subject of interest. The matter was thought to be of general interest and reasonably "hot". So too, it was found to work effectively in practice. The subject was of sufficient interest to provoke the airing of many different opinions.

In this way some 2 300 people living in Östergötland county were reached by various routes during the project.

The people of Östergötland wish to talk with politicians about ethics and prioritisation

Among those spoken to many opined it difficult to influence health and medical care matters outside the election forum. One reason was the apparent lack of any forum for a dialogue with politicians.

Discussions indicated that people wanted to exert influence while simultaneously understanding not everyone can have their own way.

Another important lesson was to find that citizens would prefer discussions with politicians to deal with tangible questions, those which affect people directly in some way or other. During this discussion, tangible matters that citizens regard as being especially important were revealed, such as human values – ethics, prioritisations and the conditions of health and medical care.

Citizens wish to conduct a real dialogue rather than remain passive receivers of information. There are several definitional aspects of what people mean by a real dialogue, these are summarised in the report under the heading "respectful meetings".

Some meeting places work better than others

In principle five different contact methods with citizens were tried out during the project:

- Different types of discussion groups.
- A mini-questionnaire distributed by the politicians themselves at public places and other common ground.
- Use of public arenas such as the county council advice bureau for the disabled and the pensioners' advice bureau.
- Web-survey.
- Citizens advice bureau.

Dialogues on prioritisation require adequate information about matters to be discussed. The citizens advice bureau forum, who worked for two days on producing recommendations to politicians regarding tangible prioritisation questions, was the type of meeting that worked best. Discussion groups and the ad-

vice bureau for the disabled and for pensioners worked fairly well as arenas for prioritisation dialogues. Most importantly, these meetings brought many thoughts and reflections to the surface.

Questions must be carefully thought out and well prepared

Questions taken up with citizens were well prepared and an interactive work form between politicians and experts was used. The starting point was the wish of the politicians to discuss pharmaceuticals with citizens from the prioritisation perspective. The politicians were aided by a communications expert.

Questions were designed to investigate the basic principles of relationships between the individual and society. They were discussed on several occasions with other experts (including pharmaceuticals usage and derivation) and groups of politicians. The principles that finally formed the starting point of the interview guide and survey were as follows:

- ❑ How can we look at the individual's integrity and society's need for control?
- ❑ How can we look at the individual's right to decide over what we receive and how large the demand shall be while remembering social resources are limited?
- ❑ How can we look at the individual's responsibility for their own health?
- ❑ How can we reason in regard to use of resources when these are limited? I.e. there is not enough money to do everything we could do for everyone.

Example: A prioritisation situation with a choice between two different demand situations.

The final shape of the formulation of the questions was decided upon jointly by the supervising experts and the groups of politicians. Participation in the process was extremely important to the legitimacy of the questions; each person had expressed their views while understanding how difficult the matter was.

The questions put to the citizens advice bureau, which were arrived at in similar manner, concerned a tangible prioritisation situation with a choice between two different demand situations, in other words, an extension of question four of the interview guide.

Citizens are willing to discuss difficult matters

When we look at the content of the discussions there are several similarities between the discussions that took place at the citizens advice bureau and in the different discussion groups. However, there is of course a difference in depth because the citizens advice bureau discussions are more multi-faceted and modulated.

Apart from a simplified prioritisation task, the discussion groups talked over questions of individual integrity versus society's need to control pharmaceuticals use, and the individual's right to decide what pharmaceuticals they want to take versus the individual's responsibility for their own health.

The assessment is that citizens are both able and prepared to participate in discussions concerning difficult matters. An important success factor is that debates are well prepared and respectfully conducted, and that there is a clear idea of the purpose of the consultation with the citizen.

The conclusion is that a developed and sustainable citizens dialogue can be an important and perhaps a necessary tool in future work founded on the experiences we have today. Such development would however, need to be well-planned and long term.

Experience from horizontal political prioritisation

In recent years the Östergötland county council has increased health and medical care resources considerably. At the end of 2002 the books showed that the county council, despite this, had run at a deficit amounting to 284 mkr. Counter-measures were taken during 2002 and 2003 to reduce costs by 150 mkr during 2003.

If the county council is to attain economic balance and attained the statutory balance requirement during 2004, then the adopted cost reductions are assessed as being insufficient. Therefore, the assembly has decided to effect further cost reductions during 2004 amounting to 300 mkr in order to obtain a balance between income and costs. All operations were assigned to suggest cost reducing measures within their respective operations equalling 10% of the operation's net costs with effect as from 2004. Cost reductions were, in the first instance, to be achieved by means of rationalisation and better efficiency by county cooperation and structural measures. That which could not be managed by means of such measures would be attained by care supply restrictions preceded by deliberate prioritisations.

One consequence of the decision was that the health and medical health board would conduct their first prioritisation process as part of the 2004 assignments and agreements.

Earlier, in the autumn 2002, the CEO had assigned all clinic heads in the county council to draw up ranking lists for their operations.

In connection with the assembly's decision that the county health and medical care services were to reduce costs by 300 million crowns, the operations were instructed, starting off with orders of preference, to make consequence descriptions equivalent to a reduction of a maximum 10% of county health care provision within their respective areas of operation. How much was finally described depended on how large a part of the total 10% cost reduction it was thought could be achieved through rationalisation or structural changes.

Execution

The prioritisation and care supply restriction process was executed extremely quickly. Furthermore, this was for the first time. To deal with the situation, very careful planning was required of both the drafting and the decision process. The health and medical care CEO was responsible for execution. She was assisted by a preparation group comprising six medical consultants and two administrators. Additionally, economic expertise and secretarial services were used for various stages in the implementation process.

Here follows a general description of the actual implementation.

Autumn 2002

The CEO assigned all heads of centre to draw up ranking lists for their operations according to county council principles of vertical ranking lists.

April 2003

The CEO assigned heads of county health care production units to draw up consequence descriptions corresponding to a cost reduction of a maximum 10% within their respective areas of operation. In addition, various scenarios concerning rationalisations and structural changes by means of increased cooperation with other counties would be worked out. These proposals were expected to bring about a total cost reduction of 300 mkr during 2004.

May 2003

At the end of May all ranking lists reached the secretariat. These were forwarded to the medical consultants for examination.

June 2003

A detailed plan of execution was worked out in June.

August 2003

The county council adopted the prioritisation principles for county council financed health and medical care in Östergötland.

September 2003

The health and medical care board adopted the political drafting and decision process for prioritisation and care supply reduction. The decision means that the board's presiding committee, comprising the chairperson and three vice chairpersons, were assigned to draw up a recommendation to the board in regard to the prioritisations and care supply restrictions that were assessed as being required.

At the beginning of September the secretariat received several scenarios for county cooperation and structural measures plus consequence descriptions associated with care supply restrictions.

The consequence descriptions were examined by six medical consultants, who divided these up between them. They worked primarily in pairs, but afterwards discussed their findings together to achieve broader agreement.

Some bases of assessment were:

- Have the consequence descriptions been adequately based on the ranking lists?
- Are the ranking lists and consequence descriptions applicable to the entire county and are they firmly related to primary care?
- Have the consequences of different courses of action been adequately described?

The consequence descriptions received, mostly clinic based in this instance, were sorted according to disease group.

The board's presiding and preparatory committees presented the results of the conclusions of the medical consultants at a meeting in middle September. These results provided a preliminary idea of the medical consequences of care supply restrictions within respective areas.

During a two day seminar in September, the medical consultants presented the consequence descriptions and their assessment of these to the presiding committee of the health and medical care board. The presentation was attended by the district heads of centres and primary care representatives. This was followed by a question period for politicians to seek clarification and a general dialogue between politicians, civil servants and care providers.

In parallel with this, the final horizontal political prioritisation was prepared. A checklist based on the three ethical principles of the health and medical care board was drawn up, (see page 23). The idea was for the politicians to use this as a support in their prioritisation work, aimed at ensuring the health and medical care act would be observed.

In addition a special protocol was drawn up for use in political prioritisation. This would clarify the medical measures related to prioritisation, a project summary of the political debate, assessed cost reduction and a definite decision motivation for which the checklist named previously was expected to provide support.

October 2003

The presiding committee of the health and medical care board worked for two days in early October on producing a recommendation about care supply restriction for the health and medical care board. The committee was represented by the CEO and one medical consultant. The committee support material included:

- Ranking lists.
- Consequence descriptions.
- The assessment of medical consultants.
- Check-lists for support in the work process.

A special report for each disease group/operation area was made using the templates produced earlier.

The presiding committee proposed some 50 care supply restriction measures representing a value of about 38 mkr.

The health and medical care CEO was assigned to introduce the recommendations of the committee as regards care supply restrictions in association with the final agreement work. The matter was processed by the health and medical care board at the end of October.

The character and content of the political decision

As mentioned earlier, the proposal for care supply restriction, for which the medical executives had drawn up consequence descriptions, were assessed and compiled by the medical consultants. Consequent to consultation with medical executives, consultants and civil servants the politicians assessed the proposed care supply restrictions from the legal and ethical aspects and evaluated the credibility and feasibility of the proposal.

The decision contained three principle characteristics:

- Transfer of sickness condition/measure to another care provider, e.g. primary care.
- More limited indications for certain sickness conditions/measures.
- Purely care supply restriction.

Distribution was about the same between the three groups. In some cases decisions comprised a mixture of the groups.

Examples of transfer to other care provider decisions:

- Surgical care for multi-sickness elderly means that elderly with multi-sickness, after surgical assessment and measure (e.g. constipation or sore), will not be cared for at the operating clinic but a medical clinic or local health care.
- Care supply restriction within children's health care means that mild sickness conditions in children (e.g. obesity, acute, simple urinary infections, head-lice) would not be treated at the paediatric clinic but by the primary care facility.

Example of more limited indication requirements:

- More critical indications required for surgery for eye lid diseases with drooping eyelids means a reduction of 50% in these operations, so that only patients with sight impairment will be operated. Surgery can still be offered should symptoms become more critical.
- Surgery for a hole in the tympanic membrane, means a reduction of 50% of these operations, so that only patients with the greatest need of the tympanic membrane surgery will be offered this service. Surgery can still be offered should symptoms become more critical.
- Surgery for a hernia developed after abdominal surgery means a reduction of 65% of these operations, so that only patients with the greatest need of hernia surgery will be offered this service. Surgery can still be offered should symptoms become more critical.

Examples of care supply restriction:

- Cosmetic surgery for strabismus will not be offered, meaning that adult persons with strabismus not suffering from diplopia and who will not obtain better vision through surgery, will not be referred to an eye specialist for examination or surgery. Children with strabismus are not affected by this restriction.
- In normal cases only one hearing aid device is supplied, meaning that patients with hearing impairment in both ears and with no other disablement and who can manage with just one hearing aid will have this tested and subsidized. A hearing aid for the other ear will be tested by health care but the patient will be required to pay for the hearing aid if further improvement of hearing is desired.
- Surgery for snoring - mild fatigue, meaning that only patients suffering from snoring serious enough to pose a medical risk of injury will be offered this operation.
- The decision not to provide sterilisation for men without medical cause, amniocentesis without medical cause and Caesareans without medical cause can be seen both as acting only on more limited indications and as purely a care supply restriction.

Summary of decision on care supply restriction:

- The political decision to limit care supply was originally proposed by the medical profession.
- Purely care supply restriction covers only a small part of the savings required.
- Care supply restriction ALWAYS means the patient shall receive some kind of MEDICAL ASSESSMENT.

Irrespective of proposed care supply restriction, patients with SPECIAL NEEDS will still receive the necessary assessment, treatment and care paid for by the Östergötland county council.

Routines for reassessment of decisions on care supply restriction

Citizens always have the right to appeal a municipality decision, either based on the municipality act if the decision is to be legislatively examined, or on the administration act if the decision raises objections. These options also apply to decisions concerning care supply restriction.

Care supply restriction means that the county council, in an open and distinct manner, decides on the medical methods that are safe and efficient and that should be included in care supply, and on those which are less efficient and consequently shall not be included. Patients and citizens might have different views on this subject. Care supply restrictions are not entirely static over time.

Because openness regarding care supply restriction is a new phenomenon within health care we should decide if citizens/patients shall have the option of having such a decision reconsidered. Research shows that a basic condition, if citizens are to consider a process as fair, is that they have contributed their opinion and they consider their opinion has been taken seriously.

One possible way of handling this is to build a platform from which citizens can project their opinions as to how decisions have effected them personally. The purpose is not to set up a wailing wall, but to provide the opportunity to uncover new facts that can result in a decision being reconsidered, entirely or partially. However, it must be previously decided as to the grounds upon which the reviews are to be based, so that the process does not become arbitrary. Furthermore, assessment should take place according to a given structure.

Procedure should for example entail that, when a citizen writes to the county council about a decision they would like to be reconsidered and why, on a number of predetermined occasions during the year, such letters are gathered together for perusal and assessment. It would be possible for the county council to transfer this task to external experts, who would make an assessment and conduct a dialogue with the patients concerned.

The introduction of such a routine would require considerable thought and preparation. The county council is currently investigating this matter.

Experiences from the prioritisation process

The county council's economic situation was thought to demand fast solutions and this caused the time schedule for the current prioritisation process to be made far too short. Care personnel were frequently under considerable pressure from their own health care jobs and other work assignments of administrative character. They found it difficult, during such a short space of time, which included the summer vacation period, to find the opportunity to discuss the difficult questions generated by a vertical ranking .

Another problem connected with lack of time was that several jobs/processes were being conducted simultaneously. In addition to prioritisation work within county council health care, both the structural overhaul of health care operations within the county and cost reductions in the areas of highly specialised care and pharmaceuticals were to take place, but in separate processes.

Both vertical ranking lists and consequence descriptions were of fluctuating quality, and hindered fair comparison between different areas. In many cases accounts did not cover the entire county, and were not firmly related to primary care. In most cases however, it was said frankly that care supply restriction effected in one clinic would lead to the transfer of patients and costs to other health care units, e.g. primary care. This open report has to be regarded as a step forward, in comparison to the situation left by previous circumstances.

Additionally, time was too short to establish an adequate dialogue between medical consultants and with the heads of centres who drew up the ranking list and consequence descriptions. No adequate continued processing in cooperation

between heads of centres, program chairpersons and medical consultants could therefore be made.

Politicians were confronted with a particularly comprehensive array of information material. Their time too, must have been far too short to effect a complete process, that should have included an in-depth dialogue with parties and with civil servants and care providers.

The demand for openness to the public was met to the extent that mass media had access to health and medical care board decisions and their motives. Unfortunately, it was not stated if this implied any significant care supply restriction, i.e. that a sickness condition or a care measure would not be paid for with county council resources in future, or if it was only a matter of transferring care measures from a hospital clinic to e.g. primary care or to another hospital clinic. The motives for decisions too, were far too briefly described. These should have been more carefully explained in order to have been understood by the general public. Furthermore, equivalent information to care personnel should have been more substantial.

Opportunities

Although this attempt at an open, political prioritisation was made under difficult conditions with severe lack of time and demand for major cost reductions, the process itself must be considered to be successful so far. The method has not been discarded by either heads of operations, by civil servants or by politicians. The proposals made and adopted have produced a cost reduction of 37 million crowns. Certain disease groups have been spared and it has been possible to refrain from using the previous tactics of gradually slicing away at health care services.

In the meantime everyone should be aware of the difficulty of this process. There is no previous experience to go by. We have to accept this is a question of development in which the current process is the first step. We must learn how the process works and successively refine it, year after year. If we succeed in establishing both a structured vertical and horizontal prioritisation process as described this should help to provide:

- more need oriented health care and more distinct roles and responsibilities between politicians and care providers,
- more openness towards patients and citizens and opportunities for these to participate in discussions about the distribution of tax revenue to the various health care areas, to distribution between county council operations and to other social sectors.

Success factors for horizontal prioritisation

This is a complicated question, previously untried in Sweden; an open prioritisation process that has now been tested in practice. We can pick out several factors of success from experiences gained:

Success factors for horizontal prioritisation

- *Humbleness when faced with a complicated and difficult process.* All those involved (preferably including an informed general public) must be aware of the major complexities entailed by open prioritisation. Everyone must accept that there is no quick solution for prioritisation matters. Long-term thinking and patience are required if the process is to succeed. Everyone must realise this is a learning process lasting many years.
- *Dialogue with the public about the necessity of prioritisation because resources are limited.*
- *Legitimacy and distinct delegation of responsibility.* Representatives participating in prioritisation work must be highly legitimate in their profession and responsibilities between politicians, professions and civil servants need to be lucid.
- *Optimum material for decision making in the shape of ranking lists and consequence descriptions.* To provide comparable material for decision making, these need to be based on uniform templates and encompass all regions and the entire county.
- *Realistic schedule.* Time is needed to establish ranking lists and consequence descriptions. Time must be made for political processing and forming opinions about material.
- *Substantial information to all health care personnel.* If people are to be committed to the task, personnel at all levels need to be informed and understand the purpose (motive) behind prioritisation work.
- *Adequate information to the general public.* This requires a carefully planned and active information strategy.
- *Loyalty to decisions adopted.* The loyalty felt to adopted decisions depends if the decision-making process is thought to be adequate and fair. Lack of time and poor dialogue can have a detrimental effect in this respect.

The reflections of a politician

Health and medical care board chairwoman, Anna-Lena Sörenson (social democratic party), in overall charge of prioritisation work, provides the following reflections over the assignment and prioritisation process completed in 2003.

Background

The changes the part of politicians went through during the Nineties can be described as follows:

- from manager and defender to public representative and purchaser of health care.
- from focus on resources to focus on results.
- to the desire to guide activities to meet prioritised demand and groups.

It soon became apparent that the necessary tools and knowledge were lacking to enable politicians to make decisions from the demand and population perspective. We need instruments to analyse health and needs of the population, as we do knowledge of health care possibilities to make measures, and what results these measures provide and at what cost.

The Priority Commission report *Vårdens svåra val* (The Difficult Choice of Health Care) stimulated debate that provided insight and knowledge. For many, open prioritisation within health and medical care, appeared to be an instrument that could guide resources towards the demand identified and spotlighted in the political guidance documentation.

The medical programs formed the knowledge platform, and the groups of representatives connected to each program functioned as a school for public representation and for the education of health care politicians.

The new political preparatory organisation established in 2000 was a response to the demand for greater participation and assumption of responsibility on the part of elected representatives for the entire decision making process. Preparation work provides opportunities for individual politicians to take on more participation, knowledge and influence.

Parts played by elected representatives, civil servants and the medical profession have clarified. Medical program work became natural arenas for dialogue with various parties. Here, an insight into roles and responsibilities materialised, as did trust in each other and respect for each other's assignments. Soon it became quite natural to talk about operations' vertical- and politicians' horizontal prioritisations.

Program work was positively received by operations, civil servants and politicians. After a few years frustration arose over our inability to progress further. Demands arose for using the prioritisation instrument in the decision making process.

Training seminars

Our training seminars contained questions on the meeting between the vertical and horizontal perspective. Even at this early stage we gained insight into the difficulties, if not the impossibilities, of validating ranking grades and making these comparable.

It became obvious that consequence descriptions should be focused on by the politicians. It is the consequence of measures not taken that have to be put up against legislation, ethical weighing up and overall political prioritisations. At which time new questions arise that need answers. If we can make them, who can answer them? Do we have the knowledge? How do politicians motivate their prioritisation decisions?

Cost reduction process 2003

Reduction principles

In June 2003 the county council assembly adopted the motion to reduce costs by 300 mkr during 2004.

There was a common expressed desire from both politicians and operations to avoid general cost reduction obligations. Instead it was made clear that cost reductions would be achieved by rationalisation, structural changes by cooperation and care supply restriction by means of open prioritisation.

It was clear that the fewer the rationalisation and structural changes, the more the care supply restriction. It is difficult not to get the impression that this understanding served as a driving force for work and decisions on structural changes.

Focus in the debate was on structural changes, while taking care of organisations, our own house and personnel. No proper debate took place over care supply restriction, despite the important decision about the principles of prioritisation taken in August by the health and medical care board and the county council. Mass media and citizens seemed fairly disinterested in the expected care supply restrictions. It probably seemed a distant and abstract measure in comparison to changes to emergency care and the closing down of maternity wards.

Consequence descriptions

The material that arrived at the beginning of September was highly unstructured and found to be difficult to access.

What should we at the health and medical care board really make up our minds about? Would it first be decided what rationalisation and structure changes were to be implemented and the remaining share of the 300 mkr be up to us to find in the form of health care rationing? The answer was we should make up our minds about care supply restriction irrespective of other decisions, and this seemed unsound. What were our circumstances? How should we think? Where were the frameworks? The answer was we should unconditionally work with care supply restriction, with political evaluations and intuition. We found this both positive, because it allowed us more freedom of thought, and negative, because it meant a step away from making "proper" horizontal prioritisations. During this time the

medical consultants worked on the material. That received from the clinics would be put together according to disease group. Additionally, they would decide on such questions as: Were there any consequence descriptions? Were these formulated according to adopted principles? Was it reasonable to reduce measures as described? From my office I could watch the consultants at work, very quiet and very tight-lipped and I noticed that sometimes they looked troubled, which did not make me feel any better.

A week later the medical consultants, civil servants and the presiding committee met for a situation report delivered during an afternoon/evening. We, the politicians, received the material "on the table" and the usual panic about unknown factors took place. We reacted over the fact that we could not form an opinion, as we would have liked to, over a large part of the material, although we understood that certain areas (psychiatry and medicine) are more difficult to describe than others. Nevertheless, courage dwindled somewhat. These were major areas and represented a lot of money.

It was interesting to observe how these two cultures reacted to each other in their discussions over openness towards the general public and media and the assessments of the consultants.

A check-list with a departure point from the ethical principles, legislation and overall political prioritisations was drawn up to help the politicians – the check-list provided good support and structure for thinking things out. We agreed to keep notes on how the presiding committee reasoned when deciding on a proposition for HSN, according to what motives, and to document any reservations.

Dialogue between politicians and professional representatives

The presiding committee and operations representatives met for a two day dialogue over consequence descriptions. Disease groups were examined one by one. It was interesting to listen to the dialogue between the representatives. The matter was discussed, debated and corrected, sometimes with a touch of irritation, but mostly in good humour.

The politicians were given the opportunity to ask questions and we think our thoughts and opinions were given a fair hearing, even though politicians probably felt a need for more knowledge about which groups would be affected, what measures were being talked about, what consequences care supply restriction would have as regards suffering, impaired autonomy, participation ability and about a possible passing on of the costs. It might have been that the forum was somewhat too large for everyone to feel they could ask all their questions. There is a large respect for the profession and politicians have to be brave to ask the "naïve" questions we all usually are dying to ask. Simultaneously it is important to point out, that all opportunities for dialogue provide a place for getting to know each other and learn respect for respective professions. The medical professionals were found to be attentive and interested in the aspects and questions relating to consequence descriptions raised by the elected representatives. This is something to be built upon when we develop and improve political professional skills.

The presiding committee finished off the respective days with a summary of their reflections. Here, much frustration was aired about matters that were felt to be diffuse, the material that was too thin to use for decision-making, and we discussed how we were to progress further. At the same time the ambience was light-hearted, and included a good deal of joking and amusement. After the second day we accelerated proceedings and decided on the disease groups to be considered in regard to the quality of the material received. Despite much uncertainty, it felt satisfying to be able to say what we could take political responsibility for and what material was unusable.

Further examination and anchorage

The politicians worked on in their respective parties and coalition groups. Work was laborious, despite all help received from operations representatives and medical consultants. Responsibility was felt to be extremely comprehensive and there was no prejudicial work to use as support. And all the while, time was running short. Proposals were to be worked out and rooted in parties and groups. Check-lists came in useful. They provided support and structure. The check-lists provided a reference for answering such questions as: How did the consequences of care supply restriction compare with the health and medical care act and to earlier decisions? How could our prioritised demand groups be defended? After the event we can wonder if we should not have made more and more efficient use of these.

The proposal to reduce or take away mammography examinations, like the proposal to raise patient charges, could be thrown out by referral to care supply restriction and the decisions of the elected representatives about Vision, Objectives and Strategies. A good example of how we could rest easy on decisions made earlier, based on very thorough consensus work.

The medical consultants were asked once again for advice over certain descriptions, and hindsight showed this to be a very sensible precaution. We wanted to be sure we were making decisions based on correct premises.

Anchorage work probably occurred in different ways in the different parties. Hearsay tells us the proposals were received both positively and negatively within the different groups. In our party group (social democrat) we conducted a satisfactory debate and the proposals were accepted positively. We had worked a good deal with prioritisation earlier on in the group, and so group members had presumably already become acquainted within these matters.

The presiding committee's proposal to the health and medical care board

It took two days for the board's presiding committee to draw up the final proposition for care supply restriction – yet another laborious process. New questions arose pertaining to consequence descriptions and some earlier questions were resurrected. A medical consultant was on hand to provide support, and this was necessary. We could have done with more help in formulating the proposition, and information could have been drawn up in parallel.

We were largely agreed over the party political boundaries and we found that we had all been thinking along similar lines in our separate territories.

The proposition was presented at a well-attended press conference. All local media were represented. Despite our precautionary measures, we did not really succeed in getting the media representatives to understand what was unique and controversial about this question. We were given plenty of space, but no significant reactions were forthcoming, either from the editorial columns or from the general public. The focus remained on the restrictions imposed on emergency clinics and maternity wards.

The decision of the health and medical care board

At the end of October 2003 the health and medical care board decided to limit care supply in some 50 care supply measures at a cost reduction of some 38 mkr. No debate preceded the decision and it was felt to be important to be able to make this decision with as much accord as possible.

Media storm

A media storm broke out at the same time as the health and medical care board adopted the proposition on care supply restriction. This was caused by the radio programme Dagens Eko running a story about the decision that same morning. The information failed to attract much interest within the county, but awoke enormous interest in the nation-wide media.

Many people got in touch or expressed their support for our decision in other ways. Most of the support came from established care institutions in Sweden, and this felt satisfactory; a confirmation that we had done the right thing. At the same time it bothers me that the reaction from the general public, and others with insufficient information about how our prioritisation work had taken place, was so strong and expressed so much anxiety and fear.

Work continues

The prioritisation work process has to be developed and improved. From the purely administrative point of view, we can say that secretarial support has to be reinforced. This will probably be best achieved in cooperation with information support. We learnt that our decision-making formulations, sometimes of home-made character, had been distributed to the media and given rise to much unnecessary misunderstanding and unnecessary concern. Similarly, we should not allow the medical consultants to release the process to its own devices so early. The experts should have been included during the drafting stage, not the political but the medical, because these are often taken up by the mass media. Similarly it should have been them, not us, who explained and informed. Here too, it became obvious that politicians must develop decision-making material for the purely political stand points. On what ideological base values are we making our decisions? How do these correspond with our promises to the voters?

The task of drawing up ranking lists and consequence descriptions must in future be outsourced to county cooperation and, as far as possible, disease group-wise.

In future it will be important to try and focus on the entire care chain and to have more care professionals join in the ranking for all care measures. In the medical programs and assignment descriptions we must be sure that prevention, rehabilitation and palliative care do not finish up at the bottom of the lists.

In the long term we need a discussion on overall prioritisation at care level between health measures, curative and nursing measures and also at social level between the different sectors.

We need to continue to develop and improve our knowledge base and our instrument for prioritisations. The medical program will be of great importance, as will the work carried out at national level with the ranking of medical measures for different disease groups (the National Board of Health and Welfare and the Swedish Medical Association). We need to continue to develop our decision making material in regard to demand/health, care measure capabilities, results and quality of measures and their costs.

Last but not least: The long term dialogue with citizens must be prioritised. This is a matter of public education work, to create awareness concerning difficult questions and to defend democratic values.