Resolving Health Care’s Difficult Choices

Survey of Priority Setting in Sweden and an Analysis of Principles and Guidelines on Priorities in Health Care

National Centre for Priority Setting in Health Care
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This project report is the product of an extensive survey and analysis by Sweden’s National Centre for Priority Setting in Health Care. The project was commissioned by the National Board of Health and Welfare, which shall report to the Swedish Government on the priority setting activities of local governments (e.g., county councils and municipalities) and assess how well they comply with the intent of Sweden’s Health and Medical Services Act and the Riksdag’s (Swedish parliament) resolutions on priority setting. We were also assigned to analyse problems in applying the guidelines on priority setting and to propose changes and clarification.

The National Centre for Priority Setting in Health Care has been engaged in the complexities of prioritisation issues for many years. We welcomed the Government’s initiative and gladly accepted this assignment. Our ambition has been to describe the situation throughout Sweden from multiple perspectives. We reviewed the literature on studies and follow-ups related to the Riksdag’s guidelines. In studying the experiences of local governments in establishing healthcare priorities we focused on county council leaders, but complemented the study by interviewing representatives of major personnel categories. We also interviewed a smaller sample representing Swedish municipalities. Based on over 150 interviews, we describe current activities, plans for priority setting, and perceptions towards the current guidelines. Karin Bäckman served as coordinator for this part of the project. Other contributors from the National Centre for Priority Setting in Health Care included: Mari Broqvist, Per Carlsson, Peter Garpenby, Catrine Jacobsson, Per Johansson, Erling Karlsson, Sven Larsson, Karin Lund, Per-Erik Liss, and Ann-Charlotte Nedlund.

In addition to the interview study, and under the leadership of Per-Erik Liss of the National Centre for Priority Setting in Health Care, we conducted an ethical analysis of principles and guidelines in priority setting. Anders Melin reviewed international ethical guidelines and principles in priority setting. A separate chapter presents a summary of this work. The ethical analysis also includes proposals for improvement, e.g., reinterpretation and description of the ethical principles in the current platform, the addition of another ethical principle, and suggestions concerning the role of health services. Preliminary versions of the analysis were discussed at seminars with ethicists and individuals experienced in transparent priority setting and representing the National Board of Health and Welfare, the Pharmaceutical Benefits Board, the Swedish Association of Health Professionals, the Swedish Association of Registered Physiotherapists, the Swedish Federation of Occupational Therapists, and the Swedish Medical Association.
Katrin Lindroth conducted literature reviews and edited the report. Elisabeth Furberg, Gustav Tinghög, Niklas Ekerstad, and Peter Wahlberg from the National Centre for Priority Setting in Health Care also contributed valuable perspectives. Appendix 3 presents the staff of the National Centre for Priority Setting in Health Care.

Preliminary versions were discussed with the Board of Directors of the National Centre for Priority Setting in Health Care, who offered many constructive viewpoints.

I would like to express my sincere appreciation to all who contributed valuable input and perspectives throughout the process. It is my hope that our collective effort will lead to improvement in regulations and work methods and will generate greater understanding for the importance of transparent priority setting in health care.

*Linköping, Sweden*
*March 2007*

*Professor Per Carlsson*
*Director of the National Centre for Priority Setting in Health Care*
SUMMARY

The Swedish National Board of Health and Welfare commissioned the National Centre for Priority Setting in Health Care to survey the methods that healthcare providers and other central bodies use in priority setting and to assess how this work complies with the intent of the resolutions on prioritisation by the Riksdag (Swedish Parliament). We also analysed the content and application of the Riksdag’s guidelines for priority setting in health care. This was done through ethical analysis, against the background of a large body of interviews with representatives of local government (politicians, administrators, and healthcare professionals), state agencies, and professional organisations, and by reviewing findings from previous studies. In this report, we propose several changes and clarifications relative to the guidelines.

We can report that the methods used by local governments (county councils and municipalities) to set priorities do not differ substantially from those used when the Priorities Delegation presented a similar study in 2001. Still today there is little transparency in decisions concerning the distribution and prioritisation of resources, given the assumption that decision makers should consciously consider several alternatives and that the grounds for decisions should be accessible to anyone who wants to know.

In situations where available resources are not in parity with ambitions, staff must bear the heaviest burden in deciding how to distribute and ration health services. Except at the executive level, healthcare personnel still appear to be relatively unaware of the ethical principles established by the Riksdag to guide the prioritisation of health services. Few were aware of the ethical platform and the three ethical principles. Local models or documents to facilitate the priority setting process are uncommon. Necessary conditions are not in place to implement the Riksdag’s principles on prioritisation. Likewise, there are no apparent strategies within the county councils to create such conditions.

Municipal health and social services still do not see themselves as being particularly affected by the ethical platform and prioritisation principles. Joint priority setting efforts among providers are rare.

Citizens have little involvement in the prioritisation process. Greater transparency for users often means that some information on priorities is disseminated via traditional channels, eg, patient organisations and associations of pensioners and disabled persons. Some opinions are collected through general patient surveys, while complaints are handled by committees that represent patients.
We also found distinct differences in how the priority setting process is managed today compared to six years ago. The central government, via the National Board of Health and Welfare and the Pharmaceutical Benefits Board, has taken the lead in showing how to set priorities by systematic and transparent means. This work has clearly led to advancements in methodology. We can point to several concrete examples of development efforts and collaboration among providers concerning the broad concept of evidence based health care, to which systematic priority setting is closely associated. We can also point to various initiatives aimed at vertical ranking of priorities in organisations. These primarily involve the physician community, but also include isolated attempts at systematic, political priority setting. Furthermore, we found several promising pilot projects in priority setting that were initiated and implemented by healthcare staff, both locally and nationally. Professional associations have also become more active in disseminating information on priority setting in health care.

**Ethical Platform**
The priority setting principles in the ethical platform, and the guidelines for their application, are important starting points for discussions on prioritisation. Efforts are still under way to systematically implement the principles. The three principles – the human dignity principle, the needs and solidarity principle, and the cost-effectiveness principle – are known to leaders in the county councils, but are perceived as being difficult to apply. Some of these difficulties can be attributed to deficiencies in the guidelines, which are considered vague and contradictory.

Our ethical analysis also points to problems associated with the formulation of the ethical platform. Hence, we propose clarifications and improvements that include reinterpretation and greater definition of the ethical principles comprising the current platform, and the addition of another ethical principle – the responsibility principle. Although many questions, discussions, and decisions remain before potential changes in the current ethical platform can be achieved, we believe it is important to discuss the roles of different principles and their relative rank order.

As regards the *human dignity* principle, we should study the possibilities to enhance its clarity and suitability by more exactly specifying the things to which people have an equal right, hence also clarifying the goals and duties of health services. This is important to further define the principles of need and cost-effectiveness.
We believe it would be valuable if the guidelines clarified and distinguished between the principles of *need* and *solidarity* since they express several different ethical considerations that, at times, may be in conflict with each other. For example, the needs principle addresses care needs that have already been expressed, while the solidarity principle also encompasses the identification of unexpressed care needs. By separating the principles, the conflicts between the two ethical considerations will become more distinct.

In our preliminary proposal, the needs principle indicates that resources should be distributed according to need, and that care needs should be ranked according to their level of severity. Three components comprise the concept of need – actual situation, desired situation (goal), and necessary action. In assessing need, it is important to differentiate between need as the gap between the actual and desired situation and need as a necessary action. Need that refers to the gap itself is a *health-related need* while need in terms of action is an *intervention (service) need*. Health-related needs are ranked according to the impact of undelivered care on the individual’s health or ability to act (degree of severity). Care needs are ranked according to the impact of undelivered care on the individual’s health or ability to act, but also consider the interventions to meet these needs.

Briefly, the solidarity principle means there should be equal access to care and that, to the extent possible, inequities in the conditions that enable a good life should be levelled out. Solidarity also means giving high priority to measures for assessing needs among people who cannot express their own needs. For example, one should see to that children, people with dementia or severe mental illness, and those who are unconscious or disoriented should have their needs assessed since they are less able than others to express these needs. The solidarity principle implies that the *assessment* of need is generally given a high ranking.

We believe there are several reasons to clarify the *cost-effectiveness* principle. Briefly, this principle can be formulated as follows: In choosing among interventions, services, or disease groups, primarily one should select the most cost-effective option. It is important to clarify that the principle may be applied in choosing among treatments and care needs when prioritising at a group level. Effects should be assessed mainly by the impact that the interventions have on the health or quality of life of patients and their family. In certain situations it could also be important to assess the external effects on other people. Different perspectives can be used in assessing the costs of an intervention or service. Primarily we need to consider costs that burden health care and other public services. Other relevant costs may also be important to include in the assessment, and they too should be transparent.
We see good reasons to study the motives for adding the *responsibility* principle to the ethical platform since people have a responsibility for their health and self care within the context of their own individual situations. This responsibility includes avoiding ill health and regaining lost health to the extent possible. It also involves delivering, maintaining, and financing one’s care. Since much of the care delivered in society today already falls within the framework of self-care, it is essential to develop generally accepted and recognised criteria to determine when the conditions for self-care are met. In a resource distribution context, the responsibility principle means that needs arising from neglecting one’s responsibilities can be given lower priority in relation to other needs when resources are scarce. However, applying this principle requires satisfying several conditions, which we seldom find to be the case.

We suggest there are reasons to discuss the rank order of different prioritisation principles. The human dignity principle appears to convincingly override the other principles. Then there are several good arguments why the same ethical status should be allocated to the other principles – the so-called *prima facie* principles (see section on the role of principles). This means they are not ranked at the outset. Any conflict between principles must be resolved by ranking them from case-to-case. In a conflict situation, eg, between the need and cost-effectiveness principles, decision-makers must take a position on which of the principles in this situation should take precedence over the others. Decision-makers are expected present their position in a transparent way so it can be reviewed, and possibly accepted, by others.

*We propose that the formulation of the current ethical principles in priority setting be clarified and that the need to add a responsibility principle be studied. Furthermore, the rank order of the ethical principles should be reassessed.*

The function of the so-called priority groups to provide guidance in making priority decisions must be viewed as weak at all levels. They appear to serve as more of a reminder that certain groups of disease, groups of people, or types of interventions should not be forgotten – eg, chronic diseases, people with limited autonomy, or population-oriented prevention. Simply highlighting certain diseases, groups of people, or types of interventions offers far too little guidance for setting priorities. Rather, this only creates misunderstanding that could lead to priorities that directly conflict with the intent of the ethical platform.

*We propose that the priority groups be eliminated or substantially revised.*

Our survey and analysis of the general guidelines for priority setting show that these guidelines need to be clarified or re-examined, and perhaps eliminated completely in some instances.
Needs related to health and quality of life
In disease and injury, needs related to quality of life carry, in principle, weight equal to health-related needs. A health-related need indicates that sick people primarily have a need to be cured of their disease, and a need related to quality of life indicates that if the disease cannot be cured the patient has a need for care and relief from symptoms.

We propose revising the guidelines to be more precise since how one interprets the concept of need in relation to quality of life has consequences for how one should define the scope of responsibility for health services.

Prioritising all effective interventions
When a disease or diagnostic group has high priority, in principle it encompasses all effective interventions, ie, diagnostics, treatment, care, habilitation/rehabilitation, and prevention. Secondarily, a determination can be made among the different interventions.

We propose that this guideline be eliminated or substantially revised. Rigorous application of the ethical platform implies that every element in a continuum of care should be assessed independently.

Limited autonomy and special consideration
People, who because of disease or injury have a limited capacity for self-determination or are unable to clearly express their needs, and children without responsible guardians, deserve special consideration. However, the degree and duration of limited autonomy varies, as does the importance of different care needs. Hence, the recommendation to prioritise people with limited autonomy should be modified to consider the circumstances in each individual case.

We propose further clarification of this guideline as regards the prioritisation of need. The guideline should not be interpreted to mean that the need for care by people with limited autonomy is ranked differently from the same need in other people since this, eg, would conflict with the human dignity principle.

Self-care
Opportunities to promote, teach, and support self-care should be utilised among all groups.

We propose that this guideline be clarified and further defined. There is reason to consider incorporation of the guideline into a prioritisation principle that addresses responsibility.
Non-beneficial interventions
Non-beneficial care interventions should not be used and should not be included among the priority options in health care.

_We propose further clarification of this guideline, particularly the concept of non-beneficial interventions._

Care regulated by special legislation
Health services regulated under special legislation could be viewed as guaranteed resources, eg, legal abortions and services covered by the Communicable Diseases Act, the Compulsory Mental Care Act, and the Forensic Mental Care Act. The same applies to the legislated requirements to establish cause of death and to perform forensic medical and psychiatric investigations and issue certified statements regarding the findings.

_We propose that this guideline be subject to critical appraisal in relation to the ethical principles and possibly be subject to revision. Of greatest importance is to clarify how services regulated under special legislation relate to other activities from a prioritisation standpoint. Primarily, services motivated from a societal perspective should be discussed._

Transparency, democracy, and the opportunity for patients to monitor and influence the priority setting process
Among other topics, the preliminary work behind the priority setting principles addresses whether patients should have the opportunity to monitor and influence health services. If so, they should have access to information revealing the findings used to set priorities, the options available to influence these findings, and the way to proceed when dissatisfied with the priorities proposed. Furthermore, the health services are obliged to develop methods to make this information accessible to the public and to assure that patients’ views are routinely solicited and followed up.

If people are to have a high level of trust in health services, the grounds for prioritisation must be openly discussed. Also, to be perceived as reasonable and just, the values that guide decisions on access to care and prioritisation must be shared by most of the population. To promote public understanding about priorities, people working in health care have a duty to inform others about the discussions on prioritisation.
We propose that this guideline be clarified. The underlying motive behind the guideline should be made clear. Furthermore, the distribution of responsibility should be specified as regards who should discuss the grounds for prioritisation with citizens and the patients. Presumably, more research and development is required before this guideline can be more widely applied than it is today.

Standards and criteria
Individual patients cannot be prioritised according to pre-established models or criteria that give some diseases general priority over others. Each case is unique and must be assessed based on the individual patient’s needs and the unique situation at hand, but guided by carefully thought-out ethical principles.

We propose that this guideline be revised to indicate that individual patients should be prioritised based on their unique situation, but with support from standards and criteria. Such standards and criteria could include prioritisation at the group level, eg, ranking lists.

Responsibility for resource allocation
In allocating resources, providers (eg, county councils and municipalities) are free to decide that certain needs cannot be prioritised, and can thereby avoid budgeting the necessary resources. Although such decisions determine the direction of clinical practice, the medical staff can make exceptions if there are strong reasons to do so. According to the Health and Medical Services Act, the choice of treatment method is determined by the attending staff in collaboration with the patient, while the resources are determined at the higher political level.

We propose that the guideline be further defined with regard to its application and that the need for a complementary responsibility principle be analysed.

Priority setting in general social welfare
The same principles that guide prioritisation in health services should also guide prioritisation in general social welfare, which means that need, not demand, should be the driving force and that understanding should be created among the population for difficult political choices. Requirements are placed on the different actors to collaborate.

We propose that this guideline be clarified to define the responsibilities that different actors in society have to apply the prioritisation principles and to co-operate.
Other measures
We believe that only part of the difficulties that politicians, administrators, and healthcare staff experience when they attempt to implement the Riksdag’s resolutions on prioritisation can be attributed to the content of the principles and guidelines. A major problem is that the current principles and guidelines are generally unknown among healthcare providers. Hence, it would not be sufficient to improve the content of the guidelines, but a series of other changes are probably required. In some cases, the problem can be attributed to a lack of systematic knowledge, in other cases to vague responsibilities or the inability to utilise existing knowledge.

It is important to develop the competence among different actors to strengthen their abilities to implement more transparent prioritisation. This means developing information, education, knowledge, and other resources and making them assessable to decisions-makers at various levels in the healthcare system. One approach would be to compile the current guidelines into an overview. Another would be to show how guidelines at the national level relate to the values and realities of various actors. In this case it concerns, eg, actively involving healthcare professions and employee groups in the work of finding practical ways to set priorities. Efforts are already under way among several professional associations and should be intensified, nationally and locally. There is strong interest in ethical issues throughout the health services. This should be used as a foundation in approaching other issues that might be more difficult to understand, eg, how cost-effectiveness should be interpreted and used as a basis for setting priorities.

Our survey suggests that the issue of transparency in priority setting is cause for major concern among many county councils and municipalities. There is considerable uncertainty about goals and means in communicating with the public about priorities. Although many research projects focus on democratic participation, the results are inconsistent, and there is no given strategy for implementing prioritisation that the public would view as legitimate. A potential approach would be for the governing bodies to conduct their own development projects that are more systematic and would transfer knowledge more systematically than is presently the case. Our experience shows that learning through the organisation’s own development projects, and systematically transferring knowledge, is a cornerstone for successful implementation of the prioritisation guidelines.
CONTENTS

PART I. ASSIGNMENT AND BACKGROUND

1. BACKGROUND: ASSIGNMENT FROM THE SWEDISH GOVERNMENT ......................................................................................................................... 3

1.1 HISTORY OF THE GOVERNMENT’S ASSIGNMENT ..................................................... 4
1.2 ESTABLISHMENT OF THE COMMISSION BY THE GOVERNMENT AND Riksdag .................................................................................................................... 6
1.3 FOLLOW-UP OF THE RIKSDAG’S RESOLUTION BY THE PRIORITY COMMISSION ............................................................................................................. 7
1.4 SWEDISH NATIONAL AUDIT OFFICE MONITORS THE RIKSDAG’S RESOLUTIONS .................................................................................................. 10

2. APPROACH USED BY THE NATIONAL CENTRE FOR PRIORITY SETTING IN HEALTH CARE .......................................................... 12

2.1 WHAT IS THE RIKSDAG’S INTENT? ........................................................................ 12
2.2 LITERATURE REVIEW .......................................................................................... 13
2.3 INTERVIEW STUDY .............................................................................................. 13
  2.3.1 Sample ......................................................................................................... 14
  2.3.2 Consequences of the sample ....................................................................... 15
  2.3.3 Contacts ...................................................................................................... 15
  2.3.4 Analysis of the interviews ......................................................................... 16
2.4 ETHICAL ANALYSIS ............................................................................................ 17
2.5 DESCRIPTION OF KEY CONCEPTS ...................................................................... 18
  2.5.1 Allocation .................................................................................................... 19
  2.5.2 Prioritisation ............................................................................................... 19
  2.5.3 Rationing .................................................................................................... 20
  2.5.4 Vertical and horizontal prioritisation ......................................................... 21

3. FOLLOWING THE RIKSDAG’S GUIDELINES FOR PRIORITY SETTING – WHAT HAS BEEN DONE? .......................................................... 23

3.1 NATIONAL LEVEL – APPLICATIONS AND ACTIVITIES ........................................... 23
  3.1.1 National Board of Health and Welfare ......................................................... 23
  3.1.2 Pharmaceutical Benefits Board ................................................................. 24
  3.1.3 Swedish National Institute of Public Health ............................................. 25
  3.1.4 National Centre on Priority Setting in Health Care ................................... 25
3.2 REGIONAL AND COUNTY LEVELS – APPLICATIONS AND ACTIVITIES .......... 26
  3.2.1 Follow-up by the National Board of Health and Welfare ......................... 26
  3.2.2 Review by auditors ...................................................................................... 28
  3.2.3 Other follow-ups ......................................................................................... 30
3.3 MUNICIPAL LEVEL – APPLICATIONS AND ACTIVITIES .................................. 31
3.4 VOLUNTARY ASSOCIATION LEVEL – APPLICATIONS AND ACTIVITIES...... 33
3.4.1 Swedish Society of Medicine .............................................................. 33
3.4.2 Swedish Society of Nursing and Swedish Association of Health Professionals ................................................................. 34
3.4.3 Swedish Federation of Occupational Therapists and the Swedish Association of Registered Physiotherapists .......................... 35
3.4.4 Swedish Municipal Workers’ Union .................................................. 36
3.4.5 Swedish Disability Federation ........................................................... 36

4. HOW DO HEALTHCARE STAFF PERCEIVE THE RIKSDAG’S INTENT IN PRIORITISATION? ........................................................................ 37

PART II. SURVEY OF PRIORITISATION ACTIVITIES AND APPLICATION OF PRINCIPLES AND GUIDELINES FOR PRIORITY SETTING AT THE LOCAL/REGIONAL LEVEL

1. INTRODUCTION .......................................................................................... 43

2. HOW ARE PRIORITIES SET, AND HOW WELL ARE NEW METHODS PROGRESSING? ................................................................. 43

  2.1 WITHIN REGIONS AND COUNTY COUNCILS ........................................ 43
    2.1.1 How do the different county council health services deal with resource shortages? .......................................................... 45
    2.1.2 How are new methods introduced in county council health services? ............................................................................ 46
    2.1.3 How do county councils prioritise systematically? ....................... 47
    2.1.4 Examples of county councils that have started a systematic, priority setting process .......................................................... 48

  2.2 MUNICIPALITIES AND SYSTEMATIC PRIORITY SETTING .................... 50
    2.2.1 How do different municipal care units deal with resource shortage? .................................................................................. 51

3. AWARENESS, ACCEPTANCE, AND APPLICATION OF PRIORITISATION PRINCIPLES AND GUIDELINES .............................................. 52

  3.1 THREE ETHICAL PRINCIPLES ................................................................. 53
    3.1.1 Awareness ....................................................................................... 53
    3.1.2 Human Dignity Principle ................................................................. 54
    3.1.3 Needs and Solidarity Principle ......................................................... 56
    3.1.4 Cost-Effectiveness Principle ............................................................ 58
    3.1.5 Municipalities ................................................................................ 61
    3.1.6 Summary ....................................................................................... 62

  3.2 GUIDELINES ON PRIORITY GROUPS AND INDIVIDUAL ASSESSMENT .... 63
    3.2.1 Awareness ....................................................................................... 63
    3.2.2 Application ..................................................................................... 64
    3.2.3 Reported problems ........................................................................ 64
3.2.4 Respondents’ suggestions for change ................................................ 65
3.2.5 Municipalities ..................................................................................... 66
3.3 GENERAL GUIDELINES IN PRIORITY SETTING ............................................. 67
  3.3.1 Guideline on needs related to quality of life and health .................... 67
  3.3.2 Guideline on prioritisation of all effective interventions .................. 69
  3.3.3 Guideline on limited autonomy and special attention ....................... 71
  3.3.4 Guideline on self-care ....................................................................... 74
  3.3.5 Guideline on non-beneficial interventions ......................................... 76
  3.3.6 Guideline on care regulated by special legislation ........................... 79
3.4 OTHER GUIDELINES .................................................................................... 80
  3.4.1 Guideline on the opportunity of patients to monitor and influence the priority setting process (patient perspective), and on transparency and democracy (citizen perspective) ................................. 80
  3.4.1.a Patient perspective .......................................................................... 80
  3.4.1.b Citizen perspectives ......................................................................... 82
  3.4.2 Guideline on standards and criteria ................................................. 86
  3.4.3 Guideline on responsibility for resource allocation ......................... 88
  3.4.4 Guideline on priority setting in general social welfare ...................... 90

PART III. PROPOSED CLARIFICATION AND ADDITIONS TO THE ETHICS PLATFORM

1. BACKGROUND........................................................................................................ 97
2. FUNCTION OF ETHICAL PRINCIPLES ................................................................ 99
3. CRITICS OF THE CURRENT ETHICS PLATFORM .............................................. 101
4. ETHICAL GUIDELINES AND PRINCIPLES FOR PRIORITY SETTING IN HEALTH CARE IN OTHER COUNTRIES ........................................ 108
  4.2 DENMARK ........................................................................................................ 109
  4.3 FINLAND ........................................................................................................ 110
  4.4 THE NETHERLANDS ....................................................................................... 110
  4.5 NEW ZEALAND .................................................................................................. 111
  4.6 GREAT BRITAIN ............................................................................................... 112
  4.7 CANADA ........................................................................................................... 113
  4.8 PRINCIPLES AND GUIDELINES IN OTHER COUNTRIES ........................ 113
  4.9 COMPARING PRINCIPLES BETWEEN SWEDEN AND OTHER COUNTRIES .... 114
    4.9.1 Conclusions ............................................................................................... 115
5. PROPOSED CHANGES IN THE PRIORITISATION PRINCIPLES .................................................................................................................. 117
  5.1 HUMAN DIGNITY PRINCIPLE ........................................................................ 117
    5.1.1 The Commission’s interpretation of the human dignity principle ......... 117
5.1.2 Proposed alternative interpretation of the human dignity principle ................................................................. 118
5.1.3 Operationalising the human dignity principle ................................................................. 120
5.1.4 Human dignity principle as a guide in resource allocation decisions ..................................................... 122
5.1.5 Human dignity principle – concluding comments ............................................................................. 123

5.2 MISSION OF HEALTH SERVICES ............................................................................................................ 125
5.2.1 Goal concept ...................................................................................................................................... 125
5.2.2 Goals, domains, and mission of health services .................................................................................. 127

5.3 CONCEPT OF HEALTH .......................................................................................................................... 128
5.3.1 Disease-based health concept ............................................................................................................ 128
5.3.2 Activity-based health concept ............................................................................................................ 128
5.3.3 Health concept – final comments ....................................................................................................... 129

5.4 NEEDS PRINCIPLE ................................................................................................................................. 130
5.4.1 Concept of need .................................................................................................................................. 130
5.4.2 Ranking needs .................................................................................................................................... 135
5.4.3 Concluding comments about the needs principle ................................................................................ 136

5.5 SOLIDARITY PRINCIPLE ......................................................................................................................... 137
5.5.1 Summary of the solidarity principle ................................................................................................. 138

5.6 COST-EFFECTIVENESS PRINCIPLE ..................................................................................................... 138

5.7 RESPONSIBILITY PRINCIPLE .................................................................................................................... 142
5.7.1 Concept of responsibility .................................................................................................................. 144
5.7.2 Principle of responsibility for one’s own care .................................................................................. 144
5.7.3 Principle of self-responsibility for health ......................................................................................... 147

5.8 RANKING THE PRINCIPLES ....................................................................................................................... 152

PART IV. CONCLUSIONS AND PROPOSED ACTIONS

1. IS THE CARE GAP AN ILLUSION? ............................................................................................................ 155

2. PROGRESS SINCE THE PRIORITIES DELEGATION CONCLUDED ITS WORK ............................................................................. 159

2.1 WHAT HAS HAPPENED, OR NOT HAPPENED, UP TO NOW? ............................................................................. 159

3. CLARIFICATION AND ADDITIONS TO THE PRINCIPLES AND GUIDELINES ON PRIORITISATION ............................................................................. 163

3.1 ETHICAL PRINCIPLES ............................................................................................................................... 163
3.1.1 Human dignity principle ...................................................................................................................... 164
3.1.2 Needs and solidarity principle ............................................................................................................ 164
3.1.3 Cost-effectiveness principle ............................................................................................................... 165
3.1.4 Responsibility principle ...................................................................................................................... 166
3.1.5 Ranking .............................................................................................................................................. 167

3.2 GENERAL GUIDELINES FOR PRIORITY SETTING .................................................................................... 167
3.2.1 Four priority groups and individual assessment ......................... 167
3.2.2 Guideline on quality-of-life-related and health-related needs ......... 169
3.2.3 Guideline on prioritisation of all effective interventions .............. 170
3.2.4 Guideline on limited autonomy and special attention ................. 171
3.2.5 Guideline on self-care ................................................................ 172
3.2.6 Guideline on non-beneficial care interventions ........................... 173
3.2.7 Guideline on care regulated by special legislation ....................... 173
3.3 OTHER GUIDELINES ....................................................................... 174
   3.3.1 Guidelines on patient opportunities to monitor and influence priority setting, and on transparency and democratic support .......... 174
   3.3.2 Guideline on standards and criteria ......................................... 177
   3.3.3 Guideline on responsibility for resource distribution ............... 178
   3.3.4 Guideline on priority setting in social welfare generally .......... 178

4. DEVELOPING A FAIR PRIORITISATION PROCESS;
   OBSTACLES AND ACTIONS ............................................................. 180
   4.1 REASONS FOR PROBLEMS IN IMPLEMENTING THE RIKS DAG’S
       GUIDELINES ................................................................................. 182
         D) Actors view the situation to be uncertain since the problem is unclear .............................................................................. 186

REFERENCES ......................................................................................... 190
Part I.

Assignment and Background
1. BACKGROUND: ASSIGNMENT FROM THE SWEDISH GOVERNMENT

In December 2005, the Swedish Government assigned the National Board of Health and Welfare to survey how healthcare providers (ie, county councils and municipalities) prioritise health services. Part of the assignment was to assess the extent to which these prioritisation efforts complied with the intent of the Swedish Parliament’s resolutions on priority setting in health care and prioritisation as addressed in the Health and Medical Services Act. Based on this survey, the National Board of Health and Welfare was to analyse whether problems existed in applying the Riksdag’s guidelines for priority setting in health care and, if so, consider the need to change and clarify the guidelines. The National Board of Health and Welfare was also asked to determine whether the priority setting activities of the providers needed to be monitored continuously and, if so, to present a proposal regarding how to implement this type of monitoring. (Socialdepartementet 2005)

As part of this effort, the National Centre for Priority Setting in Health Care was commissioned to:

- conduct a survey on the ways that healthcare providers (ie, county councils and municipalities) and other central actors work with priority setting and assess how well this work complies with the intent of the Riksdag’s resolutions on priority setting in health care.
- use the above survey and other relevant material to analyse whether problems exist in applying the guidelines for priority setting in health care and, if so, propose changes and clarifications in the guidelines. (Socialstyrelsen 2006)

The results were to be reported to the National Board of Health and Welfare no later than March 15, 2007. In turn, the National Board of Health and Welfare was to report to the Government no later than May 1, 2007.

The assignment to the National Centre for Priority Setting in Health Care did not include studying how healthcare providers, and primarily their staff, actually prioritise at a general level or between individual patients. Hence, we cannot answer the questions of how “fair” health care is today, or how the Riksdag’s resolution regarding an ethical platform has actually affected resource distribution in Swedish health services.
1.1 History of the Government’s Assignment

In 1992, the Swedish Government called for a parliamentary commission to discuss the role of health services in a welfare society, emphasising the basic ethical principles that should guide necessary prioritisation of health resources. Part of the assignment was to specify values that should guide those who must make prioritisation decisions, both at the political/administrative level and in daily clinical practice. The inquiry was called the Priorities Commission, and was chaired by Jerzy Einhorn. In March 1995, the Priorities Commission presented its final report “Health Care’s Difficult Choices”, SOU 1995:5 (Ministry of Health and Social Affairs, 1995). The introduction stated: “It is the requirement to set priorities among scarce resources that generates debate, raises difficult ethical problems, and is the main reason for this inquiry.” And “If confidence in health services is to be maintained, it is essential to openly present and discuss the grounds on which priorities are set and actions taken. This report aims to initiate a process to achieve:

- clearer definition of the role of health services in society
- clearer demarcation of the responsibilities of health services
- comprehensive, generally accepted principles and guidelines for setting priorities.” (Socialdepartementet 1995)

The primary outcome of the Commission’s work was briefly formulated in the ethical platform, crystallised in the principles of human dignity, needs and solidarity, and cost-effectiveness. The Commission described these principles as follows:

**Human dignity principle:** all humans have equal value and equal rights, irrespective of their personal characteristics and function in society. The human dignity principle is fundamental, but alone it is insufficient grounds for prioritisation. When resources are limited, everyone cannot receive everything that they actually have a right to.

**Needs and solidarity principle:** resources should be expended in the areas where the need is greatest. Solidarity also means attending to the needs of groups that may be unaware of their human worth and have less opportunity than others to make their voices heard or exercise their rights.

**Cost-effectiveness principle:** in selecting among different interventions or areas of activity, one should aim for a reasonable relationship between cost and effect, as measured by improved health and quality of life. The cost-effectiveness principle should be applied only to compare methods for treating the same disease. Among different diseases, the effects cannot be justly compared.
The proposed ranking of the three principles placed the human dignity principle first, followed by the needs and solidarity principle, followed by the cost-effectiveness principle. Since the needs and solidarity principle precedes the cost-effectiveness principle, severe diseases and substantial deterioration in quality of life should take priority over the less severe, even though treating severe conditions may cost substantially more. Hence, the cost-effectiveness principle cannot be used to deny care or offer a lower quality of care, eg, to the dying, severely and chronically ill, elderly, developmentally disabled, severely handicapped, or others for whom delivering care would not be “profitable”.

The Commission also identified several ethically unacceptable prioritisation principles. High age per se cannot be grounds for prioritisation, nor can premature, low birth weight infants be subject to any form of general limitations on care. Self-inflicted injuries should not lead to negative, special treatment since at the outset the individual might not have known about the harmful consequences of a behaviour; it is not possible to distinguish between causes rooted in lifestyle versus inherited factors; harmful behaviour is generally acquired early in life and has a complex history; a boundary between harmful lifestyle and self-inflicted injury is at risk of being capricious.

Further, it was suggested that anyone with suspected injury or disease should have a right to medical evaluation. Based on the medical evaluation, the patient may be offered appropriate care, although self-care may be fully adequate in some cases. The Commission also proposed guidelines for priority setting in health care. These guidelines were structured into five priority groups, each under a political/administrative or clinical level. The guidelines aimed to support healthcare providers and clinical staff in safeguarding resources for the most urgent needs.

According to the directive, the Commission should also consider the appropriateness of establishing a minimum level of health care that should be offered to everyone, and what collectively financed care would cover. The conclusion was that it should cover diagnostics and subsequent medical evaluation, care due to disease or injury, habilitation/rehabilitation, and prevention. Care delivered for reasons other than disease or injury should not be collectively financed.

Regarding practical application of the guidelines for priority setting, the Commission found that; “The priority setting guidelines can help health care providers (eg, county councils and municipalities) and clinicians safeguard resources for the most urgent needs while maintaining quality of care, and not satisfying less-motivated needs, preferences, and demands.”

(Socialdepartementet 1995)
Furthermore, it stated that local providers could decide which needs should not be prioritised, and thereby not budget resources for them.

The Commission also discussed where the responsibility of health services ends, and called for better interaction among the different social service areas in society: “The Priorities Commission finds that the ethical principles proposed in the prioritisation of health services should be able to guide the prioritisation of all social services.” (Socialdepartementet 1995)

### 1.2 Establishment of the Commission by the Government and Riksdag

In Government Bill 1996/97:60, Priority Setting in Health Care (Socialdepartementet 1996/97), the Government presented general guidelines for priority setting in health care. These were based on the ethical principles that the Priorities Commission had proposed: the human dignity principle, the needs and solidarity principle, and the cost-effectiveness principle. The latter should be used only after the needs principle has been applied. Four broad priority groups exemplify the guidelines for prioritisation, based on the ethical principles:

**Priority Group I**
- Care of acute, life-threatening disease
- Care of diseases that, if left untreated, lead to permanent disability or premature death
- Care of severe chronic illnesses
- Palliative care and care of the terminally ill
- Care of people with limited autonomy

**Priority Group II**
- Prevention
- Habilitation/rehabilitation

**Priority Group III**
- Care of less-severe acute and chronic diseases

**Priority Group IV**
- Care for reasons other than disease or injury

The Government chose not to separate the political/administrative and the clinical levels as proposed by the Commission, and instead proposed a unified approach as described above.
The intent was to make the guidelines useful for decision-makers in different contexts when prioritising health services, and to serve as a departure point for further reflection and discussion. The bill established that it is a form of discrimination, and contrary to the ethical principles, to generally allow needs to be circumvented by age, birth weight, lifestyle, or economic and social conditions. The bill also proposed amending several items in the Health and Medical Services Act. One amendment provided for care to be distributed according to need and delivered with respect to the equal worth of all humans and the dignity of every individual. Health services were also made responsible to rapidly assess the care needs of those seeking care. Furthermore, the bill called for a commission to be established to disseminate knowledge about the prioritisation principles. (Socialdepartementet 1996/97)

The bill was then included in the Riksdag’s report 1996/97:SOU14 Priority Setting in Health Care. (Socialutskottet 1996/97) After the submission period for motions had elapsed, the Committee agreed to both the proposal on principles and the guidelines for priority setting. The guidelines should be based on the ethical principles and exemplified by four broad groups. According to the Committee, a determination of the need for care in each individual case must be based on the conditions specific to that case. Both acute and chronic diseases can vary in severity from time to time in the same patient. Hence so can the need for care. Consequently, the Committee’s view was that care for a particular disease could be categorised under different groups during different phases. The Committee also supported the proposed amendment to the Health and Medical Services Act (1982:763), which would, eg, confirm the ethical principles by law. The amendment to Section 2 then stated; “Care shall be delivered with respect to the equal worth of all humans and the dignity of every individual. The person with the greatest need for health care shall be given priority by the health services”. Section 2 § was also amended, “Every patient who seeks health services, unless they are obviously without need, shall receive a medical evaluation of their health condition as quickly as possible”. (Socialdepartementet 1982)

1.3 Follow-up of the Riksdag’s Resolution by the Priorities Commission

A Government decision on October 23, 1997 ratified the directive calling for a commission to follow up the guidelines for priority setting in health care. The primary task of the Priorities Commission was to disseminate information and knowledge about the guidelines and the ethical values upon which they are based.
The Commission focused on external activities, where Committee members, experts, and secretariats participated in numerous conferences, seminars, and meetings, but also arranged conferences and seminars. The report, “Priorities in Health Care – Perspectives for Politicians, Professionals, and the Public”, SOU 2001:8 (Socialdepartementet 2001) presented the findings and conclusions of the Commission.

The Commission found that healthcare executives and staff were relatively unaware of the proposition and the Riksdag’s resolution. This was particularly apparent in the municipalities. Through a questionnaire survey (autumn of 2000) of all county councils, municipalities, private providers, and those directly involved in delivering care, the Commission found that the Riksdag’s resolution had the broadest impact in the county councils, but a lesser impact in the municipalities. Nevertheless, the survey indicated that discussions, study circles, and various forms of public dialogue on ethics and priorities were taking place to some extent. It also indicated that some providers were incorporating the ethical platform and guidelines into decisions and target documents. Research and development efforts had also been initiated. “After nearly three years of work, the Priorities Commission can report that the Riksdag’s resolution has had an impact on practical and policy efforts at the national, regional, and local levels, although wide variations exist among providers. To a large extent, this is due to the rapid development in health services leading to growing understanding among those responsible for and working in health care that long-term needs will exceed available resources.” (Socialdepartementet 2001)

The general perception was that much remained to be accomplished, which the Commission summarised under the following points:

- Ultimately, it is the Riksdag and the Government that should oversee that the guidelines for priority setting in health care are followed.

- The main responsibility for moving the prioritisation process forward rests with the health care providers (eg, county councils and municipalities).

- As part of its supervisory role, the National Board of Health and Welfare has the responsibility to monitor compliance with the Riksdag’s resolution and to assure that the prioritisation process is intensified.
• Associations at the national level, eg, the Federation of Swedish County Councils (FCC) and the Swedish Association of Local Authorities (SALA) – which later merged under the name, the Swedish Association of Local Authorities and Regions (SALAR) – play key roles in the ongoing work of priority setting.

• Development efforts must be intensified to acquire relevant and comparable measures and follow-up data.

• New demands will be placed on the role of policy-makers. Political parties have an important responsibility to develop this role and reinforce political representatives.

• In-depth discussion is needed concerning the extent to which the boundaries of public commitment in health care should change. The responsibility for initiating such a discussion rests primarily with the political parties, the Riksdag, and the Government.

• The Östergötland County Council joined with Linköping University to form a knowledge centre (National Centre for Priority Setting in Health Care) aimed at organising a national effort to develop priority setting in health care and social services. This knowledge centre should also become a resource for local efforts.

• Local and regional committees should be formed to anchor the practical application of the priority setting guidelines.

• Prioritisation issues should be emphasised and openly discussed already during basic education for the different care professions.

• Information and knowledge should be made easily assessable so that user organisations – associations representing the disabled, patients, family groups, and pensioners – have opportunities to become more involved in the debate and acquire a broader knowledge base.
1.4 Swedish National Audit Office Monitors the Riksdag’s Resolutions

In 2003, the Swedish National Audit Office decided to review whether national authorities and the Government had met their responsibilities to solidify broad national goals, and the extent to which they created the conditions for healthcare providers to apply the Riksdag’s resolution on guidelines for priority setting in health care. (Riksrevisionen 2004) The questions forming the basis for the review were:

- Have national authorities and the Government solidified the Riksdag’s guidelines for transparent priority setting in health care so they can be applied in practice?
- Has the implementation of the guidelines been followed up?

This review was motivated because previous reviews of state management in health services had revealed problems in the practical implementation of various management mechanisms. The Swedish National Audit Office found it important to review the guidelines for priority setting in health care since the guidelines address management and distribution of enormous public resources intended to reach those in greatest need.

In addition to reviewing the Government’s contributions, the Swedish National Audit Office also reviewed how the National Board of Health and Welfare and the Pharmaceutical Benefits Board addressed the issue. The Audit Office did not, however, review how the individual providers, ie, county councils and municipalities, applied the Riksdag’s guidelines. The review revealed that the goal for transparent priority setting (in the national implementation plan for development of health services) had not been concretely addressed in the appropriations contracts, or in any other manner. The Government had neither followed up nor requested information that would enable it to evaluate goal achievement. “Hence, it is not possible to know whether the guidelines have been applied generally in practice.” (Riksrevisionen 2004)

Furthermore, the Swedish National Audit Office found that the Government had not clarified for healthcare providers where the prioritisation guidelines stood in relation to the initiatives to enhance accessibility. The goals on accessibility were concrete, and the follow-up requirements were clear, but there was no follow-up of the guidelines for priority setting. According to the Swedish National Audit Office, this indicates that the guidelines for priority setting play an “obscure role among the national policies for health services.” (Riksrevisionen 2004)
The final recommendations by the Swedish National Audit Office were:

- that the Government should take steps to develop the guidelines
- that the Government should revise the National Board of Health and Welfare’s instructions to public agencies so that they also cover the duties and responsibilities concerning cost-effectiveness and needs-based health care.
- that the Government should clarify for the parties concerned how the initiatives for increased accessibility stand in relation to the Riksdag’s guidelines for priority setting in health care.

The Committee on Health and Welfare addressed the findings from the Swedish National Audit Office in Report 2004/05:SoU10 and proposed that the Riksdag notify the Government about “the need for improved control and follow-up of the Riksdag’s guidelines for priority setting in health care, and the need to develop feedback reporting of operational results to the Riksdag” (Socialutskottet 2004/05)
2. APPROACH USED BY THE NATIONAL CENTRE FOR PRIORITY SETTING IN HEALTH CARE

The Swedish National Board of Health and Welfare commissioned the National Centre for Priority Setting in Health Care to survey the involvement of healthcare providers and other central actors in priority setting and to assess whether their efforts complied with the intent of the Riksdag’s guidelines on prioritisation in health care. To fulfil this assignment we conducted an extensive interview study and a literature review of other studies. In particular, we attempted to study the awareness of the principles and guidelines and the actions taken by providers in response to these.

Our assignment included analysing whether problems existed in applying the Riksdag’s guidelines for priority setting in health care and, if so, propose changes and clarification of the guidelines. Hence, parallel to the interview study we conducted an ethical analysis of the principles and guidelines for setting priorities and a literature review of ethical principles used in other countries. Based on the survey mentioned above, and the ethical analysis, we discuss the implementation of the guidelines for priority setting in health care and propose changes and clarification of the guidelines.

2.1 What Is the Riksdag’s Intent?

The Government’s assignment to the National Board of Health and Welfare states that the priority setting efforts by healthcare providers shall be assessed to determine the extent to which they comply with the intent of the Riksdag’s resolutions on priority setting in health care (1996/97:SOU14, rskr 1996/97:186) and provisions in the Health and Medical Services Act (1982:763) regarding prioritisation in health services. We used the following documents in determining “the Riksdag’s intent”:

- Final report of the Priorities Commission; SOU 1995:5 “Health Care’s Difficult Choices”.
- Government bill 1996/97:60 ”Priority Setting in Health Care”.
- Report by the Committee on Health and Welfare; 1996/97: SOU 14 ”Priority Setting in Health Care”.
- Health and Medical Services Act; SFS 1982:763.

We believe that the ethical principles form the core of the Riksdag’s intent behind the guidelines for priority setting in health care.
This is clearly indicated by the incorporation of these principles into the Health and Medical Services Act. Furthermore, the Riksdag’s resolution contains other guidelines, some of which address the application of ethical principles and other supportive functions in prioritising health services, eg, democratic mandate and a division of responsibility among the actors within provider organisations (policy level – care level). The latter guidelines are not included in the Health and Medical Services Act. Rather, they are more an indication by the central government as to what providers should consider in setting priorities. Part II presents the guidelines and the results from the interview survey.

2.2 Literature Review

The literature was reviewed to identify other studies and follow-ups published since 1997 that address the Riksdag’s guidelines. We began by searching the literature database on prioritisation and other resources available at the National Centre for Priority Setting in Health Care (http://e.lio.se/prioriteringscentrum). Several earlier interview studies conducted or supported by the National Centre for Priority Setting in Health Care examined the views of healthcare staff (in county councils and municipalities) towards prioritisation of health services. These studies are published in the Centre’s series of reports. The literature review also includes other research and several audit reports. Part I presents the results from the literature review.

2.3 Interview Study

We interviewed a sample of individuals from county councils, municipalities, and national organisations, including elected officials, public executives, departmental directors in medicine, rehabilitation, habilitation, and nursing, and various other categories of caregivers. Nine individuals associated with National Centre for Priority Setting in Health Care conducted the interviews. On eleven occasions they conducted group interviews. With one exception, these interviews were with nursing and rehabilitation staff. Two interviews were conducted by telephone due to problems in finding a suitable time for a personal interview. Interviews were conducted from June through October 2006. Hence, the survey describes the situation in county councils, municipalities, and other organisations during spring/autumn 2006. We were unable to address any changes that might have occurred after the autumn election in 2006.

We used semi-structured interviews and followed a predetermined guide in asking the questions.
Twelve blocks of text summarising the intent of the Riksdag’s guidelines were presented to the interviewees, and several questions were asked in conjunction with each statement. Each interview lasted between one and two hours. All interviews were electronically recorded, and a summary of the response to each question was written after the interview. The nature of the assignment did not require a verbatim transcript of the interviews. Various documents acquired from the interviewees or county council websites provided complementary information.

2.3.1 Sample
The following categories of respondents were interviewed in each region/county council:

- elected politicians from the political majority
- administrators, eg, county council directors, health service directors, or administrators in charge of prioritisation matters
- healthcare executives at various levels, eg, directors (or equivalent) of hospitals, clinical centres, divisions, departments, and community health centres.

Six municipalities were selected primarily on criteria that the municipality was engaged in ongoing activities concerning prioritisation, or demonstrated interest in prioritisation issues. However, sample also considered geographic location and population size. The following municipalities were chosen: Östersund, Uppsala, Gotland, Kävlinge, Borlänge, and Trollhättan (Table 1). Respondents represented the same job categories as those interviewed in the county councils.

Table 1. Selected municipalities.

<table>
<thead>
<tr>
<th>Municipality</th>
<th>County Council</th>
<th>Population</th>
</tr>
</thead>
<tbody>
<tr>
<td>Östersund</td>
<td>Jämtlands läns landsting</td>
<td>58 600</td>
</tr>
<tr>
<td>Borlänge</td>
<td>Landstinget Dalarna</td>
<td>47 300</td>
</tr>
<tr>
<td>Uppsala</td>
<td>Landstinget i Uppsala län</td>
<td>185 200</td>
</tr>
<tr>
<td>Trollhättan</td>
<td>Västra Götalandsregionen</td>
<td>53 800</td>
</tr>
<tr>
<td>Gotland</td>
<td>Gotlands kommun</td>
<td>57 300</td>
</tr>
<tr>
<td>Kävlinge</td>
<td>Region Skåne</td>
<td>27 300</td>
</tr>
</tbody>
</table>


In total, we interviewed 155 individuals from the county councils, (n=102), municipalities (n=24), and other organisations (n=29).
Within each job category the interviewees were selected by the chair of the county council board of directors or the executive director of the county council and the chair of the municipal board or director of municipal social services. The Swedish Federation of Occupational Therapists (FSA) and the Swedish Association of Registered Physiotherapists (LSR) helped in selecting interviewees in the field of rehabilitation services. Also, interviews were conducted with individuals in rehabilitation services from the following municipalities: Vellinge, Örebro, Hallsberg, Kumla, and Lekeberg.

2.3.2 Consequences of the sample
The survey included representatives of the selected categories from all county councils and from the municipalities. Generally, the opinions presented in the report, eg, concerning interpretation of the Riksdag’s intent, the importance of the various documents, and the problems experienced, are the perceptions of the respondents and do not necessarily coincide with the official policies of the county councils, municipalities, or organisations. Certainly there are more examples of activities, interpretations, and problems than we have been able to identify in this report. Hence, we present this information with the reservation that the survey might not have captured all opinions and ongoing county council activities.

A small number of municipalities were surveyed, and the sample is based on narrow criteria. Hence, as regards the municipalities, we cannot claim to present a comprehensive view of municipal representatives’ interpretation of the Riksdag’s intent in priority setting, or that we convey all examples of prioritisation activities under way in Sweden. Certainly, there are many good examples beyond those we present in this report. The examples described, however, provide an overview of current activities in several of Sweden’s municipalities that have worked with prioritisation issues for some time, or have an interest in discussing the issues. Due mainly to time constraints, we did not have the opportunity to conduct a comprehensive study of all municipalities in Sweden. However, we have no reason to believe that general awareness of the Riksdag’s guidelines would be higher in the municipalities we did not select (probably it would be lower).

2.3.3 Contacts
A letter was sent to the board chairs of the county councils and a small sample of municipalities, with copies to the executive directors of the county councils and the directors of municipal social services, respectively. The letter informed the reader about the Government’s assignment to the National Board of Health and Welfare and subsequently to the National Centre for Priority Setting in Health Care. We requested assistance in identifying three or four suitable interviewees, or a contact person that we could ask for help.
The second step was to contact (by phone or e-mail) the interviewees selected by the county councils and municipalities, requesting their participation in an interview. This letter also provided information about the assignment.

Using a similar letter, the Swedish Federation of Occupational Therapists and the Swedish Association of Registered Physiotherapists asked several individuals (representing the widest possible geographic distribution in Sweden) to participate in the survey. Those interested in participating in the interview then contacted us. The final selection aimed at a distribution across Sweden. Interviews were also conducted in conjunction with an educational programme on priority setting at a habilitation unit and a rehabilitation unit. Finally, a group interview was conducted with those holding the medical responsibility for rehabilitation in some municipalities.

In similar fashion, group interviews with representatives from professional nursing organisations (the Swedish Society of Nursing and the Swedish Association of Health Professionals) were conducted in conjunction with a one-day educational programme on prioritisation. An invitation and a programme were sent from the organisations’ headquarters to those responsible in the sections/networks and departments around Sweden. The organisations covered the participants’ expenses for the day, and thereby funded the interviews. For other interviews with leaders of nursing organisations, the contacts and selections were made via letters and personal contacts.

With few exceptions, we did not experience any accessibility problems or other special restrictions as regards the interviews. We were able to address all areas that we wanted to address. All interviewees consented to electronic recording of the interviews. In conjunction with the interviews, respondents were informed that their answers would be treated in a manner that would not reveal how a particular individual had responded. The interviewees are listed by name in Appendix I.

2.3.4 Analysis of the interviews
Analysis of the interviews and editing of the text involved the following steps:

- **Step 1**
  The interviewer summarised, in writing, the responses to the respective questions.

- **Step 2**
  Interviewee responses were entered in a collective document structured in line with the questions in the interviewer’s guide.
The text was categorised by: politicians, administrators, and health service directors, irrespective of provider affiliation (ie, county council or municipality).

- **Step 3**
  One person analysed the material assembled in Step 2 and summarised it into a collective document of findings for all county councils and municipalities. The job categories were the same as before, and the text was categorised under the headings:
  I. Awareness, understandability, reasonableness, respondent’s interpretation
  II. Application
  III. Problems, obstacles, shortcomings
  IV. Respondents’ suggestions for improvement
  V. Our conclusions.

- **Step 4**
  Results of the analysis were approved and discussed by the project group. Two individuals then edited the text. Further discussions were held within the project group on several occasions.

- **Step 5**
  The Board of the National Centre for Priority Setting in Health Care discussed the content and results of the full report.

- **Step 6**
  The interviewees were allowed to review and comment on Part I and Part II.

- **Step 7**
  Comments were incorporated and further discussions were held within the project group, whereupon the final disposition and writing of Part II was completed.

### 2.4 Ethical Analysis

Initially, a preliminary ethical analysis of the ethical platform and the prioritisation principles that comprise it was developed. We used a form of maieutics; an approach to research that has its roots in the works of Socrates and Plato. Briefly, the method involves using current moral assumptions to develop proposals to solve ethical problems. These proposals are then subjected to critical reflection, revision, new proposals are presented, etc.
An important aspect of the critical review is the possibility to take various perspectives. A manuscript was discussed at various stages in a seminar with ethicists, representatives from the National Board of Health and Welfare, the Swedish Medical Association, the Swedish Association of Health Professionals, Swedish Federation of Occupational Therapists, the Swedish Association of Registered Physiotherapists, and the Pharmaceutical Benefits Board (see Appendix 2 for list of participants). In addition, the project group of the National Centre for Priority Setting in Health Care discussed several drafts of the proposal. Many constructive ideas arose in the seminar discussions, and new insights emerged that led to changes in the text. However, it has not been possible to incorporate all viewpoints, and we are keenly aware of the need for continued discussion in this area.

2.5 Description of Key Concepts

Several key concepts presented in the report are presented below. The information in this section is based on an earlier report from National Centre for Priority Setting in Health Care. (Liss 2004) However, whether or not the interviewees used the concepts in precisely the same way as described below is uncertain, which we tried to remain aware of in our analysis.

Decisions on resource distribution are taken at different levels. Some decisions address the individual level, eg, when nurses allocate their scarce time among patients in the ward. Other decisions address the group level, eg, when elected officials allocate economic resources among different groups of disease. Still others address the population level, eg, when elected officials allocate resources among various geographic areas.

When resources are scarce, it is common to consider ethical aspects in allocation decisions. However, prioritisation might also be necessary in surplus situations, hence, even in these situations, decisions should be guided by ethical considerations. The ethical principles are intended to provide guidance for decisions in allocating, prioritising, or rationing at all levels regardless of groupings or classifications. However, the ethical principles might not be applicable to all healthcare decisions, and therefore it may be necessary to remember what is contained in the concepts of “allocation”, “prioritisation”, and “rationing”.
2.5.1 Allocation
Allocation usually involves a conscious decision to divide and distribute the things to be allocated (eg, resources) to two or more recipients. Resources in health care and social services can be allocated among geographic areas, types of residence, healthcare facilities, patients/user categories, etc.

*The standard form of allocation means that something is consciously divided between two or more recipients and the respective shares are distributed to the recipients.*

To consciously consider options is a decisive criterion. To characterise something as an allocation process it must involve a conscious choice among alternatives. Simply distributing a given resource to a particular recipient should not be viewed as allocation. Within health care and social services, political committees can decide to invest in a particular area, eg, to build facilities for assisted living and to allocate extra resources for that purpose. Before we can call this “allocation”, the committee must have considered other options.

*Allocation as authorisation*, however, refers to something quite different. The authorisation we consider from an allocation standpoint can be a consequence of conscious decisions intended to achieve a given distribution, ie, the result of a planned process, but it does not need to be so. Actual distribution of resources could be the result of a process that involves chance, unconscious actions, and conscious actions with another intent, ie, the result of an unplanned process. When we evaluate allocation as authorisation, we look only at what the recipients have in relation to each other.

2.5.2 Prioritisation
Let us consider a standard case of prioritisation. A hospital ward has five patients, all of whom need care. The nurse cannot care for all five patients simultaneously, but must determine the order in which to treat them.

Prioritisation can be used to determine the rank order. Prioritisation can also be used to determine the rank order of diseases within a particular disease group, indicating which of these diseases should be viewed as more important or less important. We can express the content of the prioritisation concept in a brief statement:

*To prioritise means to place in rank order and choose.*

Rank order can be determined at different levels and can involve two or more options. At the political level it could deal with ranking needs among various population groups, ranking care needs within a department, or ranking various treatment alternatives for an individual patient.
The prioritisation concept also involves using the rank order to determine, eg, the option to be allocated resources or the option to be rationed.

All types of ranking or all methods of decision-making cannot, however, be viewed as prioritisation. For instance, rejecting a type of treatment or an intervention because it is ethically problematic or because it does not benefit the patient cannot be considered as prioritisation. Before a rank order or a choice can be viewed as prioritisation it must meet certain requirements. First, the alternatives must be considered. Second, these alternatives must be viable options that could actually be considered.

2.5.3 Rationing

The term “rationing” is not used as frequently as “prioritisation” in discussions on allocating resources in health care and social services. Yet, in practice, rationing is not uncommon. Rationing aims to bridge the gap between need and available resources by limiting the possibilities to fully meet the need. For instance, rationing could involve spreading out the number of dialysis treatments for patients already receiving care, thereby creating space for another dialysis patient, or extending the waiting time for cataract surgery, or limiting the number of physiotherapy hours in rehabilitation following an injury. Handling a resource shortage by diluting resources or limiting the supply impairs the possibility to satisfy a care need. Hence, this is a matter of rationing care and social services. The concept of rationing is used as follows:

Rationing involves limiting the possibilities to optimally satisfy needs for health care or social services.

Rationing of health services involves limiting the possibilities to address needs in some way. These limitations differ in character, depending on the situation. We can divide rationing methods into five categories:

- Goal rationing – limitation in goals that address need, ie, the needs for health care and social services are only partly met, and optimum health or quality of life (ie, potential health/quality of life achievable based on current knowledge) cannot be attained
- Exclusion – some problems, diseases, or conditions that limit the quality of life are not addressed
- Time rationing – the goal cannot be achieved within a reasonable time
- Dilution – limitation in quality
- Changed indications – further deterioration before the need is addressed.
Rationing can take different forms. *Goal rationing* can be carried out by not fully addressing care needs. For instance, rehabilitation after an injury requires 15 hours of physiotherapist time for full recovery, but patients are given only 10 hours and must continue rehabilitation on their own.

*Exclusion* involves decisions not to address certain needs via publicly financed activities. An example would be the decision to exclude publicly financed health measures intended to promote individual participation in recreational activities. This move would require the patients themselves to cover the costs for recreational equipment or other expenses for participating in such activities. Decisions not to provide certain home care services (eg, washing windows or taking a walk) are other examples of rationing by exclusion, assuming there is a need for such services. The decision not to provide ritualistic circumcision, male sterilisation, or treatment for minor varicose veins are examples of other services that have been excluded from health care in some regions.

*Time rationing* results in delays – needs are not met within a reasonable timeframe. This may occur when the user or patient must wait an unreasonably long period before the intervention or treatment begins. It can also occur by choosing treatment methods that take an unreasonably long time. *Dilution* is a collective term for different interventions, none of which address need at a reasonable level of quality. This might involve, eg, longer intervals for follow-up visits, lower-quality prostheses, less-qualified staff, or less-expensive drugs that are less effective or have more side effects than the more expensive options. Finally, *changed indications* refers to changes in the criteria regarding the needs addressed. This could involve a further deterioration in health or quality of life before the need meets the criteria for intervention. The decision to perform eye surgery only after vision has deteriorated beyond a given level would be an example of this type of rationing.

### 2.5.4 Vertical and horizontal prioritisation

This report refers to two types of prioritisation. *Vertical prioritisation* refers mainly to priority setting within a disease group, clinic, or professional group. The reasons for developing vertical priorities (ie, rank order) in health services can vary. The aim might be to provide support and guidance in clinical care and to better understand the reasoning behind the priorities set. Another might be to distribute scarce resources more fairly. *Horizontal prioritisation*, on the other hand, distinguishes between disease groups, organisational areas, community health centres, hospital departments, etc and mainly involves politicians. However, the boundary separating vertical and horizontal priorities is not distinct. As a rule, political priorities deal more with allocating resources to general areas of activity than to specific activities.
In some situations, however, even political priorities can be quite detailed, addressing specific inputs in health care – for instance, when attempting to clearly define the limits of public activities, such as when politicians participate in decisions on indications for treatment, or decide on fees for certain medical interventions.
3. FOLLOWING THE RIKSDAG’S GUIDELINES FOR PRIORITY SETTING – WHAT HAS BEEN DONE?

This section presents relevant studies conducted since 1997 regarding what has transpired since the Riksdag resolution became effective, and the ways that healthcare providers and other key actors are working to set priorities.

3.1 National Level – Applications and Activities

State activities mainly involve efforts by the National Board of Health and Welfare and the Pharmaceutical Benefits Board (LFN) to establish new approaches towards setting priorities in health care. The Pharmaceutical Benefits Board directly decides on priorities, while the main role of the National Board of Health and Welfare has been to develop informational support for decision-making by local governing bodies (eg, county councils and municipalities) in health care. In this context, the Swedish Council on Technology Assessment in Health Care (SBU) and the Medical Products Agency (MPA) play indirect but important roles – SBU by systematically reviewing the scientific literature and MPA by issuing guidelines on treatment practices.

3.1.1 National Board of Health and Welfare

In 1999, the National Board of Health and Welfare began a long-range effort to develop methods to apply the Riksdag’s resolution on priority setting in health care. Their aim complies with the goals expressed by the Government in its bill for a national action plan to develop in health services. (Socialdepartementet 1999/2000) Among other things, the bill states that the National Board of Health and Welfare should help attain the long-term goal of integrating prioritisation issues in the health planning efforts by governing bodies at all levels, resulting in deliberate and transparent priority setting processes. The prioritisation work of the National Board focuses on producing information to support decision-making that concerns patients with common diseases. The guidelines for common diseases are intended to lend national support to local/regional governing bodies in their work with medical programmes and priority setting. (www.socialstyrelsen.se) Four guidelines have been published to date, ie, cardiac care (2004), asthma and chronic obstructive pulmonary disease (COPD) (2004), venous thromboembolism (2004), and stroke care (2006). Guidelines on cancer care (breast, colorectal, and prostate cancer) have been reviewed and are scheduled for publication in 2007. In addition, work is under way to update the cardiac care guidelines and to develop new guidelines for dementia, depression and anxiety, diabetes, and methods to prevent disease by influencing lifestyle factors.
New guidelines that were released after 2003 differ from the earlier ones by the National Board of Health and Welfare in that the sections on medicine and health economics systematically present current scientific evidence on the effects and cost-effectiveness of various interventions. Furthermore, interventions are now ranked more clearly and systematically than before, based on scientific evidence and clinical experience. Conclusions about priorities, ranked on a scale from 1 to 10, are based on collective decisions that consider the ethical principles in the Riksdag’s resolution on priority setting.

Methodology for this type of vertical prioritisation has developed successively. Collective experiences in applying a priority-setting model were recently discussed in a broad-based working group initiated by the National Board of Health and Welfare and the National Centre on Priority Setting in Health Care. These discussions have resulted in broad agreement on a national model for vertical prioritisation that largely coincides with the approach of the National Board of Health and Welfare. (Carlsson et al 2007) In recent years, the National Board has joined with healthcare providers (local authorities) to arrange conferences on the new guidelines. Furthermore, the National Centre on Priority Setting in Health Care, on assignment from the National Board, is studying how the county councils are applying the cardiac care guidelines. (Garpenby et al 2005, Rahmqvist and Levin 2005) A similar study was conducted in 2007.

3.1.2 Pharmaceutical Benefits Board
The Pharmaceutical Benefits Board (LFN) became operational in October 2002. Its primary mission is to determine which drugs will be reimbursed under Sweden’s universal health insurance plan. LFN’s priorities are grounded in the three principles of the ethical platform, and its assessments take a broad socioeconomic perspective. The assessments are based on documentation compiled by the pharmaceutical corporations. In Sweden, LFN is currently the agency that most clearly bases its decisions on health economic assessments. From October 2002 to June 2005, LFN rendered decisions on 107 cases involving new drugs. In 13 of these cases, LFN denied reimbursement. Of the remaining 94 cases, 12 were approved for limited or conditional reimbursement. (Carlsson et al 2006) All decisions to approve or deny reimbursement are a matter of public record and are published, eg, on the LFN website. However, corporations also have the option to withdraw their applications, which are then no longer available to the public. In 2005, several applicants withdrew their applications for new drug reimbursement after they became aware that reimbursement would not be approved.

In changing over to the new system for drug reimbursement, it was not feasible to simultaneously test the 2000 or more drugs already reimbursed under the previous regulations that placed a ceiling on patients’ out-of-pocket expenses.
Hence, these drugs will continue to be reimbursed until further notice. According to the new regulations, which became effective in October 2002, LFN should also evaluate these drugs for reimbursement. The order of review is based on sales revenue during 2003 in the respective drug groups. By January 2010, all 49 groups should have been reviewed. The Pharmaceutical Benefits Board has completed its review of drugs for migraine and drugs for diseases caused by increased gastric acidity. (www.lfn.se)

3.1.3 Swedish National Institute of Public Health
Since 2003, when the Riksdag passed the bill “Goals for Public Health” (Government Bill 2002/2003:35), Sweden has had a cross-sectoral and coordinated public health policy. The Swedish National Institute of Public Health (FHI) is responsible for coordinating and developing indicators to monitor and assess work related to public health policy. The report (Public Health Policy Report 2005:5) presents nearly 400 development issues and proposals for action. These address policy, infrastructure, and public health practices. Forty-two of the proposals submitted were prioritised as particularly urgent. Grounds for prioritisation include: a) areas that present particular threats to public health and where interventions can have effects far into the future, and b) issues found to be most important for increasing the capacity and quality of public health services. In contrast to the agencies mentioned above, the work of FHI is not rooted in the ethical platform for priority setting in health care (Statens Folkhälsoinstitut 2005)

3.1.4 National Centre on Priority Setting in Health Care
A national knowledge centre for priority setting in health care and social services (ie, The National Centre on Priority Setting in Health Care - PrioriteringsCentrum) was formed in 2001 on the initiative of the National Council on Health Policy – a coordinating body comprised of the Ministry of Health and Social Affairs, the Federation of Swedish County Councils, and the Association of Local Authorities. Östergötland County Council serves as the governing body for the Centre. Although the National Centre on Priority Setting in Health Care is the first knowledge centre of its type, there have been plans to establish similar national centres to address strategic issues affecting health services. The Centre has focused on developing transparent prioritisation processes in health care and social services, and has contributed towards this through its own initiatives and by participating in development efforts by other bodies. Here, the Centre has worked mainly to develop vertical priorities in collaboration with the National Board of Health and Welfare, professional associations, and county councils.
The National Centre on Priority Setting in Health Care has also provided county councils and municipalities with consultancy and educational services, primarily lectures or one-day conferences on priority setting.

To date, several hundred consultations of this type have been offered throughout Sweden. Every second year the Centre arranges a national conference, which is an important arena for sharing information. This conference is arranged jointly with county councils/municipalities in various parts of Sweden and in collaboration with several national healthcare organisations. During 2001, the National Centre on Priority Setting in Health Care also initiated a network called PrioNet. Using this network, interested representatives from municipalities, county councils, and other bodies have an opportunity to share knowledge and experiences. Information on prioritisation activities by the Centre and other organisations is also disseminated via the Centre’s website.

3.2 Regional and County Levels – Applications and Activities

3.2.1 Follow-up by the National Board of Health and Welfare
Several follow-up studies have examined how the regions and county councils have applied the Riksdag’s resolution on priority setting in health care, e.g., a report by the National Board of Health and Welfare in 1999, “Setting Priorities in Health Care – Resolutions and Applications” (In Swedish: Prioritering i sjukvården – Beslut och tillämpning). (Socialstyrelsen 1999) The report aimed to present and discuss the implementation methods used by the county councils and the conditions for deliberate and transparent priority setting. Findings were based mainly on interviews with leading administrators in Sweden’s county councils, complemented by written documentation. Three county councils (Östergötland, Västerbotten, and Jönköping) were studied in greater detail.

According to the report, certain conditions are required for successful priority setting:

- Persistence and a coherent work process.
- Scientific evidence and the ability to use relevant information.
- Policy-makers must be more active.
- Policy-makers and administrators must “safeguard” the long-range perspective.
- Professional education/training.

Among other findings, the National Board of Health and Welfare found that county councils seldom had documentation and reports describing how they intend to set priorities.
The Board also reported that: “the deliberate promotion of various management systems during the early 1990s (the Dala model, followed closely by the Bohus, Stockholm, and Sörmland models) contributed towards competition of ideas among institutions. In practice, the focus was more on how to produce health services as efficiently as possible than on how to manage health services to achieve more systematic, needs-based resource distribution”. (Socialstyrelsen 1999)

The Board also concluded that county councils often have access to considerable information on ill health and its distribution in the population. However, there appears to be deficiencies in the capacity to transform this information into a needs profile that can serve as a basis for discussing how resources should be distributed among different health services or patient groups. The study also showed that county council executives believed there were deficiencies in dealing with prioritisation issues from a political standpoint. They also thought that stronger scientific evidence, eg, from economic assessments of medical interventions, was needed to make transparent, well-balanced prioritisation decisions, and that such assessments and subsequent recommendations would give strong support to political decisions.

Furthermore, the respondents indicated that the Riksdag’s resolution on priority setting did not clearly define the limits of responsibility for publicly financed health services. However, the attempt to identify these limits at least clarified the difficulties associated with rationing and prioritising. Respondents thought it would be difficult to gain political support for limiting coverage of certain health services that the population believes should be publicly financed.

“But the predominate view is that few guidelines exist at the county council level to support political/administrative and clinical priorities. The priorities in Swedish health services remain – as in most comparable countries – largely hidden and unexpressed.” (Socialstyrelsen 1999)

In summary, the National Board of Health and Welfare identified the following deficiencies in the prioritisation efforts among county councils at the time:

- Deficiencies in unified strategies and consistent working methods.
- Policy-makers and administrators have not created the conditions needed to apply the resolution on priority setting.
- Insufficient education/training – the ability to produce data is generally greater than the ability to benefit from this data by managing health services through analysis, monitoring, and improvement.
- The potential for involving physicians and other staff in efforts to develop information for political decisions on priorities and on guidelines in clinical priority setting is not always utilised.
• Many of the most urgent areas for prioritisation involve both the county councils and the municipalities; collaborative priority setting among different governing bodies occurs only sporadically.

3.2.2 Review by auditors
A summary of results from follow-up studies on priority setting in different regions and counties shows similarities to the findings by the Swedish National Audit Office and the National Board of Health and Welfare. The authors of an audit in Blekinge and Kronoberg county councils report that both have far to go regarding transparent priority setting for different needs groups. (Endrédi, Axelsson, 2002) By analysing the views of care producers (providers) and county council managers towards prioritisation, and the interaction among the different actors (operational plans), the auditors found that comprehensive strategies and implementation plans were lacking and that scientific evidence was weak. A transparent, systematic priority setting process was not in place, and the perception was that horizontal prioritisation had been shifted to the operational level. “In the budget, politicians emphasise the groups given a high priority, while nothing is said about those given a low priority.” Vertical prioritisation of referrals and treatment interventions at the clinical level did, however, occur to some extent. The Riksdag’s resolution on priority setting was thought to support this work.

In Västra Götaland Region, a study in 2001 by the region’s auditors concluded that purchasers had set priorities in their budgets, purchasing contracts, and agreements with producers (providers). (Olsen et al 2001) The nature of these decisions, however, focused on certain groups, not on excluding or ranking groups. Purchasers’ general prioritisation of certain needs/groups had only minor effects. The auditors noted that purchasing dialogues needed to be refined so that producer commitments coincided better with purchaser assignments and priorities. According to the auditors, the region’s prioritisation strategy to require the sectoral councils to first list their vertical priorities seemed to be reasonable. (See more about Västra Götaland in Part II, section 2.1.4)

“Despite dividing up the organisation into purchasers and producers, it is still goal and framework management that dominate. Hence, when purchasers reach agreements with the various producers, horizontal prioritisation is shifted largely onto the producers…”(Olsen et al 2001)

In 2004, an audit in Västmanland focused on the following questions:
• How are priorities in health care managed, given the changes in legislation?
• What effect has the development of clinical guidelines had on certain diagnostic groups?
• How have changes in the legislation affected the patients and the management of health services? (Elmersjö et al 2004)

The auditors noted that some groundwork had been done at the political and administrative levels, aimed at resuming more active development work in priority setting during the autumn of 2004. Leading politicians and the administrators concerned were both hesitant to fully commit to this path as, eg, Östergötland County Council had done. (See more about Östergötland in Part II, section 2.1.4)

“Generally, it appears that priority setting in health care is being managed largely in compliance with the legislation. Prerequisites for this, eg, information and productive dialogues, appear to have been established more through external influence and contacts than through actions within the county council.” (Elmersjö et al 2004)

In summary, the auditors drew the following conclusions:
• Physicians and other staff appeared to be aware of the ethical platform.
• Co-ordination related to the principles was problematic.
• The main principles from the Commission, eg, prohibiting prioritisation based on age, were well known. (Elmersjö et al 2004)

In 2005, auditors in Halland studied the question: Based on the guidelines from the Prioritisation Commission, how are priorities set at the political/administrative levels in health care that address the chronically ill and people with limited autonomy? The auditors soon discovered that visible prioritisation efforts were limited among these groups so they expanded the study to include priority setting in general. They found good prerequisites in Halland County Council for working more actively with transparent prioritisation, given the ongoing work with clinical guidelines, vertical prioritisation, and data describing care needs in the population. Political prioritisation involved the expansion of resources, while prioritisation of existing health services was shifted primarily to top administrators and departmental directors. (Eriksson and Odgaard 2005)

An audit in Östergötland (2005-2006) including document studies and interviews investigated whether or not the priority setting efforts by the board of health had affected the organisation. (Ogensjö et al 2006)

“Priority setting is a long process, where the county council has taken the first step. In our judgement, the prioritisation process is beginning to have effects in the organisation that coincide with the aims of the board of health.”
Nevertheless, the auditors found that knowledge about the aims of prioritisation had not spread throughout the organisation to a sufficient extent. They found that the work initiated by the board of health was valued highly in the organisation. Also, they found that the greatest impact of the prioritisation process was that priorities were being discussed more and that a new way of thinking was beginning to spread among the staff. The auditors proposed, eg, that follow-up should improve as regards the needs groups prioritised by the county council. Furthermore, the outcome reports upon which the prioritisation findings are based should be improved. (Ogensjö et al 2006)

At the request of Jönköping County Council, auditors studied the consequences of the deficiencies in central, systematic prioritisation in the county council. The auditors expressed criticism, stating that:

“Actual priorities at the county council level are based largely on measuring accessibility and waiting times, which receive systematic attention by county council leaders. Corresponding attention is lacking as regards how care needs are met in relation to their medical priority. Hence, the county council does not have the possibility to monitor whether resources for the horizontal priorities expressed in the budget are distributed according to the general national guidelines on priority setting.” (Roland and Gjesteby 2006)

According to the auditors, there is a risk that supplemental, centrally prioritised resources will mainly target care needs identified by monitoring waiting times, while other care needs might be neglected, even if they have a higher medical priority. The county council was advised to complement its accessibility initiatives by including methods that focus on needs, and hence aim to assure care in accordance with general guidelines even for groups that have not received attention either from the media or from monitoring waiting times. (Roland and Gjesteby 2006)

3.2.3 Other follow-ups
An interview study on transparent and legitimate priority setting processes was conducted in 2005 within four specialties in Region Skåne. The questions were:

- To what extent do the organisation’s representatives live up to the Riksdag’s position that prioritisation in health care should be transparent?
- How are prioritisation discussions conducted in relation to cost-reduction projects at the departmental level?
- What support do the organisation’s representatives receive from centrally established decisions or documents?
- What support do the organisation’s representatives want from the region in their prioritisation efforts?
The degree of transparency was found to be relatively low. One conclusion drawn from this study was that a regionally shared vision is necessary to develop more transparent and legitimate prioritisation processes. (Anell et al 2005)

The National Centre on Priority Setting in Health Care studied various aspects of Östergötland’s first priority setting process. Three sub-studies have been published. (Bäckman et al 2004, 2005, 2006) The first investigated the political decision-making process and was based on several questions and conditions that are important if a prioritisation process is to be perceived as being fair and legitimate, ie, that most people find it reasonable and acceptable. The second study investigated how the media have reported on the priority setting process, and how media surveillance might have helped create interest in and understanding for the priority setting process in particular and prioritisation in general. The third study attempted to describe and explain the content of the political resolution and, based on the perceptions of executive staff, follow up the resolution’s impact on health services in the county’s hospitals. The study also investigated whether it is possible to confirm these perceptions through the county council’s usual system for statistical monitoring. Generally, the executive staff and administrators interviewed were positive towards the county council’s approach towards prioritisation procedures. In addition to being perceived as important in development of health services management in the county council, the approach also promoted greater understanding for the conditions facing health services and policy-makers. Respondents said it had also increased transparency among specialties and stimulated ethical reflection through discussions about scientific evidence for various care interventions and routines. Another follow-up study was conducted during 2007.

3.3 Municipal Level – Applications and Activities

A report, “Transparent Priority Setting in Municipal Health and Social Services” suggests that the municipalities have not adopted the principles for transparent prioritisation stipulated in the Riksdag’s resolution on priority setting in health care. (Lund 2003) A possible explanation could be that, for various reasons, representatives of municipal health services have not viewed the resolution as pertaining to them, another is that the municipalities – through legislation in the Social Services Act and the act to provide service and support for certain functionally disabled groups – have several prioritisation regulations to follow and that some uncertainty exists regarding which needs should receive greatest emphasis, social service or healthcare needs.
A common reaction from municipal representatives, as reflected in the interviews, was that the Riksdag’s resolution is oriented more towards county councils/hospitals. Hence, the municipalities found it difficult to see how useful the ethical platform would be for them. Another common reaction was that all patient groups under municipal jurisdiction are in priority group I – hence, given the intended groupings it is not possible to prioritise in a deliberate and transparent way. Interviewees were asked whether the municipalities were aware of the Riksdag’s resolution on prioritisation in health care and the concept of transparent priority setting. Most of the respondents were aware of the Riksdag’s resolution, even if they did not follow it directly. Respondents found it difficult to see how the principles would fit into their own organisations, and thought they lacked the tools and strategies to set priorities in accordance with the resolution. The authors concluded that transparent priority setting was largely an unknown concept in the municipalities they visited. While all municipalities use some type of guidelines for assessing needs of the elderly and functionally disabled, public documentation was often unavailable to patients/clients and their families.

In October 2004, a joint project was launched in Skåne concerning transparent priority setting in municipal services for the elderly. (Rosén 2005) The project involved the collaboration of the Skåne Association of Local Authorities, R&D Skåne, the National Centre on Priority Setting in Health Care, and seven municipalities (Hässleholm, Hörby, Kävlinge, Skurup, Svedala, Tomelilla, and Vellinge). The aim of the pilot project was:

- to test the possibility of developing a model for transparent priority setting within municipal services for the elderly that includes horizontal and vertical ranking lists (similar to those used by the Östergötland County Council) to identify needs and interventions in municipal services for the elderly, and
- to raise awareness of employees and users concerning prioritisation in day-to-day work.

A conclusion drawn in this project was that it is essential to develop municipal ranking lists for educational purposes. Such lists offer opportunities to overview the situation and generate discussion about the values that steer resource allocation. However, both current legislation and the desire for more user-directed resource planning may conflict with more general guidelines on priority setting.
The reports “Perspectives on Priority Setting for Services for the Elderly” and “Why Is Transparent Priority Setting Difficult in Services for the Elderly?” analysed priorities in the care of the elderly. (Svensson and Rosén 2004a,b) An interview study of various professional groups involved in elder care and a survey of, eg, politicians and the public found that views towards elder care differ substantially among the various groups interviewed. In general, politicians and case managers gave a more positive profile of services for the elderly than did the care staff. This reflects differences in the roles played by politicians and administrators on one hand and care staff on the other, deficiencies in communication, and differences in expectations on organisational performance. According to the authors, the difference in perceptions between formal decision-makers and care staff can result in decisions that are more generous than what the organisation can actually deliver. Hence, the growing gap between needs and resources leads to a stressful situation for those who “distribute the shortages”, namely the case-managers and care staff. If the responsibility for priority setting is pushed downward in the organisation there is clearly a risk for hidden and unreported priorities.

3.4 Voluntary Association Level – Applications and Activities

Several professional organisations in health care have been informing people about the ethical platform and developing methods for transparent, systematic priority setting. This section describes activities by the Swedish Society of Medicine, the Swedish Society of Nursing, the Swedish Association of Health Professionals, the Swedish Municipal Workers’ Union, the Swedish Federation of Occupational Therapists, the Swedish Association of Registered Physiotherapists, and the Swedish Disability Federation.

3.4.1 Swedish Society of Medicine

The Swedish Society of Medicine has indicated that, in principle, development of methods for transparent priority setting is an important issue, and the medical profession has a responsibility to develop information for politicians who make decisions on allocating resources among different disease groups and service areas. In the spring of 2000, the Swedish Society of Medicine appointed a committee on priority setting to study the conditions – in the sections of the Swedish Society of Medicine – for working with transparent prioritisation and to develop and propose a working model for vertical priority setting.

Eight sections were invited to participate in the first phase. Seven sections – general medicine, internal medicine, surgery, neurology, obstetrics and gynaecology, oncology, and otorhinolaryngology – presented preliminary results at the end of this phase in 2003.
During the first phase, the sections had relatively free reign to form their own working methods even though the committee had proposed a preliminary model.

Based on experiences from the working models used by the various sections, and from the experiences in priority setting described by other organisations in Sweden (eg, the National Board of Health and Welfare, the Pharmaceutical Benefits Board, and county councils/regions), a working model for vertical priority setting was presented. (Swedish Society of Medicine 2004)

After this initial phase (2001-2003) to address the prioritisation process, they entered a second phase aimed at continuing the process across all sections of the Swedish Society of Medicine. The Society also participates in the so-called “maximum waiting time guarantee” project of the Swedish Association of Local Authorities and Regions where around ten sections are developing common national indicators for various diagnoses/interventions. This work aims to survey practice, evidence, and vertical priorities. The Swedish Society of Medicine has also joined with the National Centre on Priority Setting in Health Care, the National Board of Health and Welfare, and several county councils/regions to develop a common national model for vertical priority setting.

3.4.2 Swedish Society of Nursing and Swedish Association of Health Professionals

Transparent priority setting is of major interest to professional organisations involved mainly in patient care. These organisations disseminate knowledge about transparent priority setting at conferences and when members meet to discuss the potential to integrate priority setting in labour union and professional activities. Most of this work takes place at the national level, but some activities are local (eg, in joint groups). The Ethics Advisory Committee of the Swedish Society of Nursing regularly discusses ethical positions and the ethical platform in relation to the professional code of ethics. Close collaboration has also been established with the Swedish Federation of Occupational Therapists and the Swedish Association of Registered Physiotherapists.

To study the possibility of setting priorities in nursing, the Swedish Society of Nursing, the Swedish Association of Health Professionals (SAHP), and the Swedish Society of Medicine began collaborating in the autumn of 2002. This resulted in the document “Priority Setting in Nursing: A discussion paper based on interventions for stroke”, presented in 2004. This project aimed to study whether it would be feasible to develop guidelines for transparent prioritisation of nursing interventions. The scope of the project was confined to nursing care for stroke.
It found that several specific basic criteria could be used in prioritisation of nursing interventions for stroke victims, but also found a lack of scientific publications, nationally and internationally, addressing nursing methods and priority setting. “A system with transparent priority setting should be able to reduce the risk for arbitrary and unintended allocation of resources.”

In 2005, a similar model project was launched, which also addressed priority setting in nursing for stroke. (Jacobsson 2006) This project showed that the working model for vertical priority setting that had been tested, eg, by the Swedish Society of Medicine, was a good guide for concrete discussions on setting priorities in nursing. It was also shown that transparent priority setting could promote clarification and description of nursing interventions and a uniform nursing practices. A development project was planned jointly by the Swedish Federation of Occupational Therapists and the Swedish Association of Registered Physiotherapists that will also include interventions for stroke. The work will be based both on the national guidelines from the National Board of Health and Welfare and on the experience gained from other priority setting projects.

Examples of other activities
- At the central level, the Swedish Association of Health Professionals develops documents/information on priority setting, management, and finance.
- The association works actively at the national level to influence and participate in developing guidelines in various diagnostic areas.
- Annual conferences present national projects concerning leadership and priorities.
- The Swedish Society of Nursing works to disseminate knowledge about evidence-based nursing and gender and their importance in delivering safe patient care, eg, collaboration with SBU and SBU Alert by proposing nursing methods in need of assessment.

3.4.3 Swedish Federation of Occupational Therapists and the Swedish Association of Registered Physiotherapists
Two professional organisations in the rehabilitation field, the Swedish Federation of Occupational Therapists (FSA) and the Swedish Association of Registered Physiotherapists (LSR), have shown a strong interest in transparent priority setting and are actively working to support their members in the priority setting process. Intra-professional development is viewed as an important foundation for engaging in inter-professional priority setting. Both associations, in collaboration with the National Centre on Priority Setting in Health Care, have conducted projects to assess a model for vertical prioritisation. (Broqvist 2006)
Their findings from the project have been incorporated in developing a national model for vertical priority setting. (Carlsson et al 2007) This model is being systematically tested in a project encompassing all rehabilitation services in Kalmar County Council.

The associations are collaborating on producing material for a study circle based on the model project. Their aim is to promote discussion among rehabilitation services in county councils and municipalities as a means to support priority-setting methodology. The Swedish Society of Nursing, the Swedish Association of Health Professionals, the Swedish Federation of Occupational Therapists, and the Swedish Association of Registered Physiotherapists are jointly planning a project to enhance nursing and rehabilitation in the national guidelines for stroke (National Board of Health and Welfare). Priority setting has been a major topic on the agenda of the associations’ two most recent national conferences. Both associations have established a close working relationship with the National Centre on Priority Setting in Health Care.

3.4.4 Swedish Municipal Workers’ Union
The Swedish Municipal Workers’ Union has actively worked towards creating understanding for and developing the process of priority setting, primarily in direct patient care. For instance, the union has actively participated in a series of projects with the Swedish Association of Health Professionals and has promoted the issue within its own organisation via various educational activities. (Karlsson and Lyrén 2005)

3.4.5 Swedish Disability Federation
Since April 2004, the Swedish Disability Federation has been working on the project “Participation of Disability Organisations in Health Care Priority Setting”. The project aims to involve disability organisations in efforts to assure that priority setting in the county councils complies with the 1997 resolution on guidelines for priority setting in health care. A project goal has been to increase awareness among central and regional representatives of disability organisations regarding the Riksdag’s resolutions on priority setting and to encourage their participation in the priority setting process of local governments. Discussion material has been developed on the potential for disability organisations to promote prioritisation issues. (HSO 2004)
4. HOW DO HEALTHCARE STAFF PERCEIVE THE RIKSDAG’S INTENT IN PRIORITISATION?

Several published studies have addressed perceptions, awareness, and interpretations among healthcare staff concerning the Riksdag’s intent in prioritising health services. For instance, Anna T. Höglund at Uppsala University conducted an interview study showing that awareness of the prioritisation guidelines was low among healthcare staff and was strongly associated with professional category. (Höglund 2003) Nevertheless, the author observed that the staff generally appeared to act in accordance with the guidelines, even without reflecting on whether their ethical actions concurred with the national ethics principles. Among the respondents, some acceptance was found for considering age in priority setting – to a higher degree than indicated by the guidelines. This finding suggests that a gap exists between the national ethics guidelines and moral practice at the clinical level. A conclusion that can be drawn, according to the author, is that staff competence in ethics should increase.

“The results of my study indicate that the guidelines for priority setting in health care are general and vague, and hence difficult for caregivers at the clinical level to interpret. Also, there are inherent conflicts between the principles of human dignity, need, and cost-effectiveness. To implement the principles in practice, the staff must be better informed about the existence of the guidelines and their content, and there should be greater clarity and transparency in the decision-making process on prioritisation.” (Höglund 2003)

A study of nurses (20 interviews) in the Västerbotten and Norrbotten county councils showed similar results. (Lämås et al 2004) The absence of political support in the priority setting process was described as a problem, and there was a description of how administrative decisions negatively affected nursing care. Transparent priority setting was described as a possible means of support, but the risks were also discussed; transparent priority setting can provide support in the prioritisation process if the workload is high, or if staff is inexperienced. Risks were described as: transparency in priority setting can be too controlling, and necessary flexibility can be lost so as to negatively affect the individual patient. Another perceived risk was that guidelines could potentially increase the stress on staff in special situations where they cannot comply with the guidelines.

The priority setting principles appeared to be accepted, but there was a need for discussion on how the general principles should be applied in practice within health services.
Some respondents understood cost-effectiveness to be a purely economic concept, and suspicion (and in some cases resistance) was aimed at calculating cost-effectiveness in health services. The conclusion was that a substantial need exists to discuss concrete prioritisation in day-to-day work and to develop common principles. This should increase the potential for setting patient-oriented priorities based more firmly on well-considered and well-developed grounds.

“\textit{The study also suggests that there is some uncertainty in understanding the ethical principles in the Health Services Act, particularly as regards the principle of cost-effectiveness. Hence, there is reason to raise and discuss the key ethical principles in more concrete terms.}” (Lämås et al 2004)

A study with similar aims addressed occupational and physiotherapy. (Broqvist 2004) Eight occupational therapists and eight physiotherapists were interviewed to determine perceptions about transparency in priority setting. The author found that the results supported the findings of the Priorities commission (Socialdepartementet 2001), ie, that occupational therapists and physiotherapists do not participate to any great extent in organised prioritisation efforts, neither in a multidisciplinary context nor with politicians. The study also showed that:

- There is a lack of awareness about the priorities one actually sets as an individual practitioner and the distribution of responsibility for priority setting.
- Many factors influence the priorities set by occupational therapists and physiotherapists (eg, their own interests, the culture and traditions of the workplace, and other factors such as access to facilities), which at times conflict with the Riksdag’s guidelines.

Only a few of the respondents were aware of the ethical principles in the Riksdag’s resolution on priority setting. Hence, this calls for continued dissemination of information on prioritisation efforts and further development of methodology.

Mårtensson et al published a study in 2006 on setting priorities in primary care. They interviewed 62 physicians, nurses/district nurse, and physio/occupational therapists at 17 community health centres. The interviews showed that primary care staff mainly thought that healthcare priorities should be based on medical need, and in most cases resource shortages were caused by the lack of staff, mainly physicians. Half of the respondents said it was difficult to implement prioritisation, and that it was uncommon to have written, local guidelines. (Mårtensson et al 2006)
“A small percentage of those interviewed felt there was transparency in priority setting at their community health centre or in the county council, but at times transparent priori- tisation had preceded rationing decisions that involved cutbacks in issuing certain medical authorisations/certificates, health examinations, and vaccinations for foreign travel.” (Mårtensson et al 2006)

The authors found that few respondents were aware of any efforts to promote more transparency in priority setting in primary care. Most, however, called for greater transparency in prioritisation and thought it was important to create greater public understanding, especially among citizens and patients, for what underlies prioritisation decisions and what can be expected from primary care. Several emphasised the importance of the politicians’ role in setting priorities, and that it was essential to agree on the role of primary care in facilitating greater transparency in priority setting.

“A question one can ask oneself is whether prioritisation studies are actually relevant? Is there a problem with priority setting and rationing in primary care? To a high degree, the responses confirm our view of the way things are. There is a general perception that primary care suffers from a major lack of resources, mainly a shortage of staff, which is reflected by the lack of appointment times available for patients seeking care. This resource shortage is managed through various types of rationing...” (Mårtensson et al 2006)
Part II.

Survey of Prioritisation Activities and Application of Principles and Guidelines for Priority Setting at the Local/Regional Level
1. INTRODUCTION

Part II presents the results of our interviews in county councils, municipalities, and other organisations regarding issues of awareness, interpretation, and application of the Riksdag’s guidelines. We begin with a brief description of how regions, county councils, and municipalities work with priority setting on a general level. This is followed by a presentation of findings from the interviews on principles and guidelines related to priority setting, and ends with our conclusions.

2. HOW ARE PRIORITIES SET, AND HOW WELL ARE NEW METHODS PROGRESSING?

This chapter presents our findings from the interview survey on priority setting at the broader level, ie, allocation of resources and management of resource shortages in county councils and municipalities.

2.1 Within Regions and County Councils

The survey revealed fairly similar views among politicians, central administrators, and department representatives as regards how far the county councils have progressed, how responsibility is distributed, and what information is important in allocating resources.

Although the county councils have shaped their organisations and management systems in different ways, they use a somewhat similar process to distribute resources, ie, establishing the size of the budget. Respondents reported that resource allocations were based largely on past budgets, with some adjustments for recent or expected organisational changes. Furthermore, special investments were made when particular needs received attention, or new options appeared for medical care and treatment. Establishment of a new clinic for treating obesity was given as one such example. Examples of other factors that can serve as a basis for resource distribution included population composition (age structure, number of inhabitants), national comparisons, local geographic factors, and the previous year’s production, eg, number of admissions, clinic visits, or operations. As a rule, respondents said that the background information was comprehensive, but the consequences of decisions rendered, or the potential consequences of alternative allocations, were discussed only briefly.

In their details, the approaches towards allocation vary according to the management system used by the county council/region.
Generally, the respondents reported that overall resource distribution was decided at the political level (horizontal distribution) through more or less well-developed information by staff. The political decisions almost always deal with adding resources to various areas of activity. Political decisions to cut back or eliminate activities were thought to be uncommon. Politicians in many county councils described resource allocation based on goal-oriented management and objectives from a county council plan that could include the Riksdag’s priority groups. Some county councils have made more systematic attempts to use identified, but unmet, care needs in the population as a basis for setting priorities. To support this, a special approach has been used – so called “disease-oriented policy programmes” (described in Bäckman et al 2003). Several respondents referred to disease-oriented policy programmes as a means to make the discussions on prioritisation more comprehensive and evidence based.

Most county councils are discussing how the national guidelines issued by the National Board of Health and Welfare should be linked more closely to the counties’ own management processes. This includes, eg, the national guidelines for cancer care. In the northern health services region, the aim behind this approach was to create broad awareness of the content of these guidelines (including prioritisation methods and results) and to involve decision-makers in decisions on implementing them. In addition to the clinical protocol groups for each type of cancer, a special regional group on palliation was formed to highlight palliative issues. These issues receive high priority in the guidelines, but are at risk of being overshadowed, eg, by new, effective, but less prioritised drugs and other forms of cancer treatment. Using consequence analyses, the process aimed to create a clear basis for decision-making linked to the ranking list in the guidelines. This approach has been promoted at the local level, aiming to develop local information for decision-making in the respective county councils and the region.

In principle, the politicians based their positions on facts from population/needs analysis, but in practice much of the information on unmet needs actually comes from organisation representatives and national comparisons (eg, staffing in primary care). Initiatives by professional networks and the work of speciality societies are viewed to be important grounds for the county councils’ priority setting efforts. The interviews also revealed that media campaigns could provide impetus for special initiatives without any in-depth analysis of needs and priorities.

Resource allocation at the clinical level can also differ. As a rule, respondents believed that allocations were based on the previous year’s budget, adjusted for changes in the organisation.
In some county councils, administrative staff or politicians have influence over resource distribution even at the clinical level, while other county councils have clearly separated the political level from the clinical level. It was perceived that hospital and clinical directors had increasingly independent control over resource distribution within their budgetary frameworks. The dominant perception was that priorities are set unsystematically and behind closed doors. Generally, the public is not aware of the grounds for decisions. Seldom are distinct alternative investments compared against each other in transparent discourse about priorities. County council leaders were viewed as consciously trying to stay outside of discussions on resource distribution for as long as possible, and thereby avoid rationing scarce resources at the clinical level in hospitals and community health centres.

However, there are some examples of development towards greater systematic and transparent prioritisation. In Östergötland County Council, ranking lists are used to help allocate resources in a hospital or clinic/community health centre. Several other county councils participate in regional collaboration on developing decision-support for vertical priority setting, eg, Uppsala-Örebro Region and county councils in the southern health services region.

2.1.1 How do the different county council health services deal with resource shortages?
When economic shortages or deficient capacity (staff or other) arise, the county councils deal with this through economisation or various forms of rationing. Several respondents said that although they were forced to make cuts, they were careful not to “draw a cut-off line”, eg, as was done in Östergötland County Council. Resource shortages at the county council level are usually managed by requiring percentage reductions for all services, except for some health services that have been exempted for various reasons, eg, less cost cutting in primary care. Each care unit is expected to solve its’ own problems with cost cuts or resource shortages. Hence, the responsibility is placed on those in charge of the unit, who must redistribute, economise, ration, or cut back. One county council respondent described tax increases as one alternative for maintaining quality when demand increases.

Some discussions concern redistribution within hospitals, requiring changes in resource needs for different departments, eg, redistribution from general surgery to oncology, or between hospital services and primary care. Several respondents referred to current needs for redistribution due to major cost increases for cancer drugs or drugs for treating rheumatoid arthritis. Structural changes in health care have also been used to manage resource shortages. Politicians usually make these decisions.
A county council respondent mentioned that resource deficiencies were managed by tightening indications, conservatively introducing new methods, or discretely rationing certain services (e.g., cosmetic surgery, writing medical authorisations for sick leave, etc. or rationing resources by extending waiting times for services). The national effort on medical indications is also being monitored, but leaders find it difficult to gain acceptance for this.

Generally, respondents found it difficult to receive political support to address resource shortages by openly excluding certain interventions/patient groups. The same applies to introducing or raising user fees for health services. As a rule, the department heads, not the politicians, make decisions to exclude services, or not to introduce new methods. Some respondents said that politicians should give department heads as much autonomy as possible to deal with changes and shortages by redistributing resources within their respective departments. There were, however, exceptions. Some county councils have appointed advisory groups to address these issues. Our impression is that the advisory groups are still in a development phase. Hence, it is unclear how services are actually excluded in practice.

2.1.2 How are new methods introduced in county council health services?
County councils introduce new methods or technologies in different ways. Various efforts are under way to introduce new methods in a more organised fashion than previously. Leaders in one county council require old methods to be phased out when new methods are introduced, which the health services are often disinclined to do. Therefore, this county council requires a health services committee to review any new method prior to making a decision on whether to introduce it. An example would be thrombolytic treatment for stroke. Usually, political decisions are not necessary to introduce new methods. Exceptions include major capital expenditures for equipment, or methods that involve larger groups or substantial additional resources, e.g., screening methods that may require studies prior to a political decision (for instance, analysis of consequences, displaced services, health benefits, or scientific evidence). It should be possible to present satisfactory evidence of clinical effects, but respondents reported it was more difficult to produce documentation on cost-effectiveness. Generally, decisions at the regional or the local levels did not resolve questions regarding consequences (i.e., Where will the resources be taken from? Will some other health service need to be rationed or excluded?)

In some county councils, decisions to introduce new methods are made indirectly by politicians, e.g., in Östergötland County Council where each service unit places new methods on a ranking list. If the new methods require new resources and thereby affect some other activity that then cannot be carried out, the consequences should be described for the board of health.
If needed, clinical directors or other leaders can receive assistance from the Health Technology Review Committee. In addition to the Östergötland County Council, representatives of Region Skåne, the Västra Götaland Region, Värmland, Kronoberg, Jämtland, Halland, and Gävleborg also mentioned that they have advisory committees to critically review the evidence and provide additional facts for proposals to introduce new health methods/technologies. Review committees take a position and give recommendations concerning whether or not a method should be introduced, based on the scientific evidence. However, the review committees do not take a position on whether new resources should be injected since other ways are used to set relative priorities. The interviews indicated that the health technology review committees are still developing, and in fact many new methods are introduced without being discussed by such a committee. In several county councils, professional groups discuss and deal with introducing new methods. This creates de facto prioritisation of new methods, but only within the respective specialities.

A general perception was that the politicians become involved in decisions on new methods only when a department cannot afford the method within the framework of its economic resources. Then representatives of the department and/or other interests lobby politicians and administrators. Patient groups or industry representatives are also involved in lobbying according to the respondents. For instance, one county council found that male sterilisation could not be motivated given a shortage of resources so they stopped offering the procedure. However, the politicians decided to reinstate this service after it received attention in the media. Some methods that attract media attention might become political and must then be addressed separately. Politicians can demand that these services be introduced, but managed within the existing framework of the department, implying economisation or rationing. An example would be screening of hearing in newborns, which was recently introduced in Uppsala County Council and other county councils.

2.1.3 How do county councils prioritise systematically?
Systematic priority setting has reached different stages of development around Sweden. Some county councils use short guidebooks on general priority setting. (Östergötland County Council 2003, Östergötland County Council 2004, Blekinge County Council 2001, Halland County Council 2004, Västra Götaland Region 2003 and 2004, Sörmland County Council 2005, Värmland County Council 2006, Västerbotten County Council 2003 and 2004, Gävleborg County Council 2005) However, the effect of these manuals in the practical process of prioritisation, or in routine health care, is uncertain. Several county councils have no general manuals or local guidelines on priority setting. Discussions about priorities in these county councils usually consist of special meetings between different parties to deal with a single matter.
Prioritisation issues might be touched on in these contexts, but not as a rule. Several county councils have chosen to use other types of systematic quality improvement processes, eg, aimed at increasing accessibility, quality, safety, efficiency, and patient benefit from interventions. This was reported, for instance, from Norrbotten and Jönköping county councils. Such improvement efforts do not specifically target priority setting.

2.1.4 Examples of county councils that have started a systematic, priority setting process

Some county councils/regions are engaged in developing systematic priority setting processes. Östergötland County Council and Västra Götaland Region appear to have the longest experience in this respect.

*Västra Götaland Region* (VG Region) has been developing a working model for prioritisation since 2001. Councils representing medical sectors are responsible for developing vertical ranking lists (per medical speciality). This has been taking place since 2002. Previously, the VG Region had a committee for ethics, prioritisation, and maximum waiting time issues, and in 2005 a special prioritisation council was formed to coordinate and develop regional prioritisation efforts. Among other initiatives, it proposed methods for horizontal policy prioritisation, and commented on strategic changes related to implementing medical technologies (including drugs). A working model for horizontal priority setting is being developed (Västra Götaland Region 2002 and 2005).

*Östergötland County Council*, in contrast to Västra Götaland, has already established an active priority setting process at the policy level, which is integrated with the work of describing assignments and commitments prior to formulating agreements. Vertical ranking lists have existed for a relatively long time in several areas – in many cases, ranking lists had been created within disease groups via the earlier “disease-oriented policy programmes” used by the county council since 1997. Health service directors are responsible for updating the vertical ranking lists for disease groups and for describing the consequences if all medical conditions cannot be addressed with the resources allocated. Medical advisors assisted the politicians and administrators and reviewed data from the centres/clinics, etc.

Before politicians made prioritisation decisions, discussions were arranged with representatives from all major disease groups, administrators, and policy-makers. In 2003, the politicians made their first transparent political decisions on prioritisation. They presented a list of interventions that would no longer be included among the health services offered by the county council (ie, limitation of supply). At the time, this received considerable attention.
Since then, however, transparent political decisions have been presented annually. Decisions have not addressed only service cutbacks; in recent years new resources have been injected into various areas. (Östergötland County Council 2004, Bäckman et al 2004, 2005, and 2006)

Other county councils that have initiated some type of systematic priority setting process include:

- Värmland County Council has developed a priority-setting programme adopted by the county council assembly. (Värmland County Council 2006) At the time of the interviews, a prioritisation committee existed under the assembly. This committee was decommissioned following the shift in political power after the 2006 election. A central prioritisation council has been established with representation from the seven divisions of health service and the county council ethics group.
- Örebro County Council has developed a policy programme for transparent priority setting that has yet to be formally adopted, but its principles are included in directives for the budget and should be included in assignments and agreements.
- During 2005/2006, the ethics committee of Jämtland County Council was expanded to include a group of administrators and staff representatives from the municipalities in the county. The committee mainly addresses prioritisation issues, and together they developed a model for countywide prioritisation of health-related needs.
- Several county councils have joint advisory groups with the municipalities. Prioritisation is one of the areas for collaboration. In Västmanland, the joint advisory groups address cooperation and distribution of responsibility as regards assistive devices, home care, and efficiency in the continuum of care.
- Since 1995, the Västerbotten County Council has had a tradition of working with prioritisation and ethical issues. Västerbotten conducted a central project (2001-2003) aimed at proposing a management organisation for priority setting. It included a range of activities such as limited prioritisation projects, seminars, and formation of central guidelines for priority setting. Follow-up questionnaires (the most recent in 2005) were aimed at the unit level and concern priority setting, indication definition, and quality improvement. A group on ethical issues in health care has existed in the county since 1997, and ethics representatives are found in several care units. In 2006, a central working group on priority setting was established at the request of the county council executive group.
Work is also under way concerning citizen dialogues in the form of public health committees where politicians regularly meet with citizens and, based on study material, discuss issues concerning priority setting. (Västerbotten County Council 2005)

- In Norrbotten, a three-year, countywide ethics project began in 2006, “Ethics in Practice”. This project was based on work in Arvidsjaur from 2001 to 2004, which led to a countywide project now involving 25 of 33 units. The project addresses priority setting and ethics, from relationships to performance. Feedback of experiences gained from using the new knowledge is then given to the countywide project group.

- During 2003 to 2005, the Stockholm County Council developed a basis for vertical priority setting that is used in prioritisation at the departmental, administrative, and political levels. The goal included developing 15 reports (at least one from each disease-oriented policy programme council) and testing the work methods against a manual developed for the purpose. An assessment following the test period recommended that the county council’s administrative and political leaders adopt the project, and that work should continue through collaboration with other county councils – aiming towards a common national ethics platform for prioritisation issues. (Karolinska Institutet 2005)

- Regional collaboration on vertical priority setting is found in the Uppsala-Örebro Region where 23 specialised committees have been formed with department heads and other representatives. The ranking is intended to serve as a basis for decision-making, but such a list should not be obligatory and should not prescribe what cannot be done.

- Collaboration is also under way to develop vertical priority setting in the southern health services region, encompassing Region Skåne, Blekinge County Council, Halland County Council, and Kronoberg County Council.

- In 1990, a special prioritisation group in Gävleborg County Council developed what were described as simple priority lists of different medical conditions in various clinical areas. How, and the degree to which, these are applied in current practice is uncertain.

### 2.2 Municipalities and Systematic Priority Setting

In principle, there are two expressed ways to allocate funds to elder care and other care-related services provided by municipalities. The first is to construct a one- to three-year plan, based largely on historical conditions, previous costs, and demographic change. Four of the six municipalities surveyed distributed resources based on such plans.
Briefly, this means that the budget is formed partly by estimating the percentage of the fixed resources needed for salary increases, etc and partly by assessing activities and determining resource needs accordingly.

The second principle used to distribute resources builds more on key indicators (such as the number of children or elderly in different age groups) to estimate resource needs, ie, determine the cost for various interventions (eg, cost per child at different levels in school, or per diem cost for special housing for the elderly). “Previously, this work involved calculating the estimated budget increases, but we have now introduced a reimbursement system instead. Now one cannot say there is too little money in the agency, the sum is established according to the decisions on resource distribution.”

2.2.1 How do different municipal care units deal with resource shortage?
Most of the municipalities studied have had large budget deficits in recent years and have dealt with this shortage mainly through organisational and structural changes. “In 2004, we had a deficit of 60 million Swedish kronor. We changed our organisation by consolidating two boards and two agencies. We have fewer administrators, more uniform regulations for determining subsidies, and have established several criteria for home services.” “We discontinued all rehabilitation activities except those mandated by law, and we converted the assisted living units to senior residences.” Another approach involves rationing by changing the benefits. “We have stopped offering snow removal and window washing, while assistance with showering is now needs-based.” The determination of need is related more to the family situation than to the individual’s economic situation. Several municipalities have prioritised care and services in the individual’s own home, while in recent years others have changed the orientation and are again expanding the assisted living option. “Previously we spent a lot on home services, but we were able to show that in some cases this is very expensive, more expensive than institution-based living. In last year’s budget discussions the politicians reconsidered, and now we are going to build a living facility for people with dementia.”
3. AWARENESS, ACCEPTANCE, AND APPLICATION OF PRIORITISATION PRINCIPLES AND GUIDELINES

What we perceive to be the main intent of the Riksdag resolution – based on the final report from the Priorities Commission, “Health Care’s Difficult Choices” in 1995, the government bill, “Priority Setting in Health Care” in 1996, and a committee report under the same name from the Committee on Health and Welfare in 1997 – we have summarised into several points. The same text was presented to the interviewees in our survey, and several questions were asked in conjunction with each statement. Most of the text is cited directly from one of the above sources, but could also have been taken from other sources. Abbreviations used to refer to the sources are PC for Priorities Commission, GB for government bill, and CR for committee report. We mainly refer to the Priorities Commission and the government bill; the committee report is referenced where it provides complementary information. The reader is referred to pages in the source documents (available in Swedish only) where the citation or summarised text can be found.

First, we present the responses from the county council interviews, followed by responses from interviews in the municipalities. In addition to interviewing leading individuals in the county councils, in hospitals and departments, and in the municipalities, we also interviewed nursing and rehabilitation staff and a representative of the Swedish Medical Association. These responses are integrated with the discussion regarding the county councils. If viewpoints diverge, or other aspects of a question arise in these groups, this was also reported.
3.1 Three Ethical Principles

The three ethical principles
The principles that serve as a basis for setting priorities are the human dignity principle, the needs and solidarity principle, and the cost-effectiveness principle (PC p 115, chapter10-11, GB p 18)

- **Human dignity principle**: every individual should have equal value and equal rights regardless of personal characteristics and functions in society.
- **Needs and solidarity principle**: resources should be committed to the people or activities having the greatest need.
- **Cost-effectiveness principle**: in choosing among different activities or interventions, a reasonable relationship should be attained between costs and effects, measured as improvement in health and increased quality of life. (PCI p 115, GB p 18)

Greater needs should take precedence over lesser needs (PC p 153), and more of health care’s resources should be given to those in greatest need, those with the most severe diseases, and those having the poorest quality of life. (PI p 118, GB p 20)
The weakest people, eg, those who are unaware of their human dignity, have fewer possibilities than others to make their needs and voices heard or exercise their rights. This should receive particular attention. (PC p 118, GB p 20)
In choosing between different services or interventions, a reasonable relationship should be attained between costs in terms of resources committed and effects measured as improved health and increased quality of life. (PC p 119, GB p 21)
The cost-effectiveness principle should be applied only when comparing treatment methods for the same disease. (PC p 120, GB p 21)
It is inconsistent with the ethical principles to allow needs to be pushed aside because of chronological age, birth weight, lifestyle, or economic and social circumstances. (PC p 127, GB p 24) It is the overall assessment of a patient’s needs and how the patient can benefit from care that should determine the intervention. (PC p 128, GB p 25)

3.1.1 Awareness
All respondents were aware of the main thrust of the three ethical principles and viewed them as reasonable. The principles were viewed to be important standpoints in Swedish health services. However, there was uncertainty concerning how the three principles should be applied. The respondents did not think that the guidelines provided sufficient direction, eg, regarding how to assess needs or determine a reasonable relationship between costs and effects.
3.1.2 Human Dignity Principle

Application

Although most respondents claimed to use the human dignity principle and said its importance was obvious, they thought the principle was complicated and difficult to apply in principle and in practice. In shortage situations, the principle can face difficulties. When intensive care beds are in short supply, for example, then several patients with major medical needs must compete for these beds. When patients differ widely in age, it leads to a real test whether priority is given solely on need and treatability and not on age. The respondents were of the opinion that discussions about the ethical platform had raised awareness that old age *per se* was not grounds for assigning lower priority.

In no county council did respondents report any official decisions to introduce special age limits, or any special priority for the patients absent from work. Nevertheless, they gave examples of political decisions about interventions that could indirectly affect priorities based on age. One example would be the directive to reduce the sick-leave rate among the employed below 65 years of age. Also, medical reasons can motivate certain age limitations. According to the respondents, any care cutbacks that include age limits are based only on medical judgment, eg, age limits for various types of screening, IVF, or amniocenteses. In other words, these decisions involve balancing benefit against risk. At times, determinations of benefit appeared to be based on uncertain grounds since the effects of intervention on different age groups were not always evident, eg, restricting certain rehabilitation services to people of working age. More explicitly, age limits are applied in relation to user fees, eg, charging little or nothing for children and subsidising dental care and influenza vaccination for the elderly.

Reported problems

Despite agreement on the human dignity principle, several respondents believed or suspected that some patient groups nevertheless received special treatment, for better or worse, in health care. We did not have the opportunity to investigate whether or not this is actually the case. Groups reported to receive discriminatory, special treatment include those under the influence of alcohol, the mentally ill, non-Nordic immigrants, disorderly people, those seeking asylum, patients with complex needs, people in special housing, the elderly, the terminally ill, those on sick leave, the unemployed, or even the employed. Examples were also given of groups thought to receive special treatment in a positive sense, eg, “those who shout the loudest”, or premature babies, children in general, employed, or even those on sick leave.
Special treatment based on gender was also reported. Language and functional disabilities can also block access to care. Preferably, patients should be sufficiently well informed to seek appropriate health services. Likewise, patients’ social situation regarding support and custody can affect the way they are received by health services. One respondent was concerned about free health services for children – if everyone is supposed to have equal access to care regardless of age, then how can we defend outpatient services that are more accessible to children by being free of charge.

Interventions aimed at reducing the sick-leave rate in society actually give priority to people with a particular social function, eg, the gainfully employed. At times, socioeconomic benefits are used to motivate this.

Work-related needs such as receiving a hearing aid or cataract surgery to enable continued employment were viewed by some to be a greater need than if the same interventions were provided to improve someone’s social life. Joint projects involving the Swedish Social Insurance Agency (Försäkringskassan), targeted specifically at those on sick leave, are under way in several locations throughout Sweden. In one county council the Swedish Social Insurance Agency tried to purchase health services to reduce sick leave, but the county council denied the request to avoid prioritising those on sick leave ahead of other patients.

A rehabilitation-related example given was that the non-working elderly have less access to rehabilitation services than others do, which is viewed to be unreasonable “younger people have access to complete multidisciplinary teams, while the elderly are channelled to incomplete municipal teams.” Others reported the opposite, ie, that age prioritisation can be warranted so that younger people have an opportunity to live a full life, something that the elderly have already experienced. Further ethical principles were mentioned as grounds for prioritisation, but were dismissed, eg, self-inflicted injury where some argue that people responsible for their own disease or injury should be given lower priority. Establishing the boundaries for such a principle would be too difficult to enable the principle to be applied in practice.

**Respondents’ suggestions for change**

Most respondents indicated that it was essential to retain the human dignity principle as the overriding principle. Several respondents suggested how to improve implementation of the guidelines, eg, address gender equality by reporting health statistics by gender and educating staff about equality in care.
Several aspects of the guidelines need to be clarified. These include clarifying how to interpret and apply the Riksdag’s guidelines with respect to evaluating return-to-work, home care, and other costs and benefits linked to social benefits in relation to the human dignity principle.

Another perception was that age *per se* should play a role in actual shortage situations; “*who should receive priority, children who can benefit longer from interventions, or the elderly?*” Respondents holding this view suggested that the guidelines should be open to such interpretation.

**3.1.3 Needs and Solidarity Principle**

*Application*

Given the current resource distribution – which is largely influenced by historic reasons or strength of demand – we can seriously question the extent to which distribution is based on need, according to several respondents. Despite high awareness about the needs principle, the respondents pointed to many other factors that influence the priorities set in health care. Not least, this concerns patient demand for care and the competence and interests of the staff. There is a perception that many resources are invested in minor disorders, while, eg, psychiatry – which lacks strong pressure groups – actually receives a lower priority. Those with the loudest voices tend to be heard and receive more care than, eg, patients with greater needs but lower autonomy.

Staff usually assess the needs of individual patients without having access to a systematic needs assessment at the group/organisational level. On the one hand, some respondents perceived needs assessment to be somewhat obvious, “*use your head, common sense, and weigh these matters*”. Others viewed it as more problematic since without guidelines, assessment tends to be arbitrary. They pointed to the lack of a systematic effort at the local level to determine greater and lesser needs – rather, we are referred to policy decisions such as the National Board of Health and Welfare’s national guidelines or regional protocols. Some, however, reported active discussion in health care about the definition of greater versus lesser needs. Respondents recognised the educational challenge of explaining to people who believe they need health care that judgements are always being made with consideration to the care needs of others.

Some county councils are assessing needs more systematically at a general level. Östergötland County Council developed annual needs analyses for all disease categories, which were intended to help politicians assign work to care providers. However, the county council found this approach to be too broad and impractical.
Since care needs in the population change gradually, and needs analyses do not require updating every year, a new approach analyses four disease or needs groups in depth per year. Politicians use these findings in assigning duties to care delivery organisations. Another example is Örebro County Council, which systematically uses epidemiological and health services data to analyse care needs in the population. In several other county councils, community medicine units are involved in discussing needs concepts and using public health reports and health services data to develop evidence for prioritisation.

**Reported problems**

Many respondents expressed uncertainty about the definition of “needs” and who should define which patients have the greatest needs. The grounds for needs assessment were generally perceived as being vague. For example, why did breast cancer appear to be managed more quickly than other forms of cancer? Similar problems arise with other comparisons, eg, the need for physiotherapy versus the need for surgical intervention. Another question concerned primary prevention and whether it should be viewed generally as a major need. It was mentioned that there is also a psychological need that determines how quickly patients receive care, since naturally it is extra stressful to wait for an intervention after having been informed that one has a life-threatening disease.

The maximum waiting time guarantee was also reported to create problems in applying the needs principle. The concerted effort to increase accessibility jeopardises the needs principle, eg, when policy-makers decide that no one should wait more than two hours in the emergency room. Demands and increased pressure from assertive patients and the media have too great an influence on politicians. The difference between need and demand also has a tendency to become vague. The geographic catchment area for primary care was also viewed to be in conflict with the needs principle: all health disorders within an area should be addressed within certain time limits, while at the same time patients with the most severe conditions should be given priority.

Politicians who were interviewed mentioned a negative aspect of adhering to the needs principle, namely that it is politically delicate to exclude any group with minor needs. It is difficult to compare, eg, a person with one major health problem against another person with many small disorders that combined add up to a major health problem. Another respondent pointed out that the need for care must be continuously reassessed in pace with medical advancements, and that the more specialised the practitioner, the more difficult it is to have a holistic view of need, “the perspective determines the opinion”. Hence, one’s area of expertise tends to dominate.
Representatives of community medicine indicated that they provide information for decision-making, but do not currently participate in ongoing needs analysis.

**Respondents’ suggestions for change**

The needs principle is viewed to be an important ethical principle in Swedish health services. To effectively address the difficulties in applying the principle, one respondent highlighted the importance of working with disease groups and using needs analysis to acquire extensive knowledge about needs in the population from many different sources. Several health service directors expressed the need for a lively, ongoing dialogue concerning the groups of patients that should, in principle, receive priority. Forums for such discussions were called for. One respondent thought that greater progress could be made by establishing more stringent criteria for ranking conditions and interventions. One unit director called for clearer guidelines on what to include in a needs assessment. Another respondent raised the question of whether external factors, eg, access to family, should be considered in assessing the magnitude of care needs.

Several indicated that the political will to increase transparency would make it easier to clarify vertical priorities and to work more systematically than what is currently the case. They indicated that many healthcare employees are already prepared to work on this, but that unified, local prioritisation efforts require official backing from politicians. Needs analyses at the group level also require a clear description of patient experiences, eg, level of severity of various conditions and the benefits of various interventions. Several respondents indicated that the concept of “need” needed to be further clarified for people working in health care.

**3.1.4 Cost-Effectiveness Principle**

**Application**

Respondents were divided in their views of the cost-effectiveness principle. One view is that cost-effectiveness commands too much attention in Swedish health care. Many felt that a short length of stay and a balanced budget appeared to be the overriding goals. Another view is that organisations continue to have a low level of cost awareness, and some health staff still seem to believe that resources are infinite. These respondents would like cost-effectiveness to have greater importance.

The principle seems to be applied more broadly than prescribed by the guideline since it is used not only to compare treatment methods at the same hospital— it is also used to compare the cost-effectiveness of treatments for various conditions.
In contrast, it was less common to compare interventions within an area such as rehabilitation versus curative or preventive interventions, eg, exercise versus medication. In pace with growing medical options, many of the respondents expected the cost-effectiveness principle to increase in importance, “shouldn’t there be limits on what an intervention can cost?” They also said that knowledge about the costs and benefits of interventions could be helpful in situations where politicians are uncertain and divided. Extremely expensive technologies and methods that benefit few patients are appearing more frequently. How to deal with this in relation to inexpensive interventions for many patients with minor care needs is a question that arose in the interviews. The principle appeared to be difficult to apply consistently. It is used where the data exist and someone has the courage to raise questions. There is strong opposition against thinking in terms of cost-effectiveness, both within the health services and externally, and public pressure to introduce new methods. Nevertheless, most respondents agreed with the basic premise of cost-effectiveness; that a reasonable relationship should exist between costs and effects of an intervention or service.

Politicians appeared to find difficulty in deciding not to use a method due to poor cost-effectiveness. Hence, several respondents suggested this is mainly a question for physicians to struggle with in the future. Administrators thought it was reasonable to factor in cost-effectiveness, but this made consistent application more difficult to achieve. “Long delivery times” were viewed to be especially difficult in this context, ie, most preventive interventions require a long time between the expenditure for an intervention and its effects.

A common example of the discussion around the cost-effectiveness principle concerns drugs and the recommendations in selecting them. “Regarding cancer treatment drugs, what is reasonable to pay for another six months of life?” Another example from the interviews concerns a new, but expensive, medication used in rheumatology, which appears to effectively relieve symptoms. If the point of departure for priority setting concerns only the patient’s health, then the choice is easy. But to what degree does this type of decision relate to society at large? If every patient who could benefit from this medication had access to it, then probably other major and urgent needs would be pushed aside.

One county council is taking a more systematic approach towards reviewing the scientific evidence for the methods used, including evidence of cost-effectiveness. Another county council has a policy stipulating that if any service provider is considering introducing a new drug or method, that provider is obligated to raise the issue for general public debate on costs and benefits. In Örebro, Sweden a special research and development centre for health technology assessment works to help assemble evidence.
County councils that develop lists to rank priorities are forced to take a position on what constitutes a reasonable relationship between costs and benefits.

There is an expressed aim to follow recommendations and decisions from the Swedish Council on Technology Assessment in Health Care (SBU) and from the Pharmaceutical Benefits Board (LFN), which is giving greater attention to cost-effectiveness. Local drug committees are also considered to be important in addressing issues regarding the cost-effectiveness of drugs.

**Reported problems**

Several respondents expressed the need for a debate about defining the boundaries for costs and effects. A concern is, however, which leaders would want and dare to participate in such a debate. However, a debate like this would clarify for patients why decisions are made in different ways in health care. One problem expressed was that a “reasonable relationship” between cost and effect is ultimately a judgment call. Also, the principle was thought to be difficult to apply if used in the limited context prescribed by the Commission and government bill, ie, that it only may be used in comparing methods addressing the same disease.

The frequent absence of health economic assessments was mentioned as a problem. Another question was: From which perspective should “benefit” be judged – from a patient perspective, a societal perspective, or a professional perspective? The perception was that indirect benefit for society, for better or worse, is a strong driving force within care and a common argument, eg, in rehabilitation. Several respondents expressed uncertainty concerning how they should address costs that fall outside of health services. Should the costs for sick leave or municipal social services be included in cost-effectiveness analyses?

Some respondents felt that cost-effectiveness was applied incorrectly at times when used as grounds to evaluate the organisation’s own budget rather than the guideline, “improved health and increased quality of life”. A perception among politicians was that they, to a greater extent than health staff, must monitor the benefits to society and, eg, consider regional policy. The interview responses, however, strongly indicate that societal benefits – if they are to be considered – should not outweigh the human dignity principle. Another risk perceived by the respondents was that if a patient is unfortunate enough to have a disorder whose effects or costs are poorly documented then perhaps that patient would fall far down the priority list only because strong evidence was not available, not because of a lack of urgency to treat the problem.
Respondents’ suggestions for change
Several respondents said that physicians, as a group, did not want to decide on what is or is not cost effective because they wanted to have that support from policy-makers. Following a dialogue among the public, politicians, and healthcare directors it is essential to decide what costs are reasonable for various types of health benefits.

The human dignity principle had broad support as “an overriding, core principle”. As regards ranking the principles, a rather split image emerged. The view that the cost-effectiveness principle should be subordinate to the other principles was thought to be incorrect by some respondents and reasonable by others. The reason why some found it reasonable is because they placed greater importance on the severity of conditions than on cost-effectiveness. Hence, people with more severe conditions are allowed to receive more of healthcare’s resources. In other words, if the patient experiences severe suffering, less consideration should be given to the cost-effectiveness of treatment than if the patient experiences minor suffering. Several share the view that no single principle should be in control, but that different principles should be balanced against each other. Those who indicated that the current ranking of principles was incorrect did so based on the notion that unreasonable consequences could result from a literal interpretation of the ranking.

3.1.5 Municipalities
All respondents knew of the three principles in the ethical platform, but the pervasive opinion was that they are not expressly included in the work of the municipalities. “We do not use the concepts as they appear in the law. The humanistic view corresponds to the human dignity principle, we constantly discuss cost-effectiveness, and the needs principle is the basis for determining assistance.” The principle that everyone is equal is said to be obvious, but it appears to be more problematic for those closest to the action. “I hope that it is applied, but perhaps in reality it is not always fully implemented.”

Everyone was aware of the needs principle, but several indicated that its application was not complicated. “It is a reasonable principle, but we have no system for identifying those in greatest need, just common sense and experience.” Several municipalities have guidelines, established politically, to assess need when evaluating the right of the elderly to receive assistance. One municipality is working to establish the need for rehabilitation based on a ranking of different interventions. “It’s difficult, in rehabilitation we have worked on a ranking of interventions that we believe should be appropriate even in care of the elderly. The next step is to develop a ranking there.”
The cost-effectiveness principle is not used in the way intended, but all respondents were actively trying to control costs. Östersund was reported to be actively addressing the cost-effectiveness principle through investing heavily in home rehabilitation. “The entire range of activities in home rehabilitation represents an example of applying the cost-effectiveness principle. The committee said that we invest money now, and we believe we’ll see a return on this investment.”

3.1.6 Summary
We found that respondents throughout Sweden were familiar with the three ethical principles. The human dignity principle held a particularly strong position, and several examples were given of daily inequalities/injustices in care. In principle, we found no formal decisions on age limits. Examples of decisions that encompass age limits were generally motivated by medical or organisational factors. However, there were examples of age limits in some rehabilitation activities where retirement age represents such a limit, but the association of benefit from investment is unclear. Some executive staff, however, indicated that age should play a greater role than it does today in setting priorities.

The needs principle is viewed to be reasonable, but is difficult to apply since the needs concept is found to be complicated and the basis for needs assessment is viewed to be much too vague. The focus of patients and politicians on accessibility, and the growing demand for care, create a risk for displacing patients with major needs.

The cost-effectiveness principle appears to be gaining increasingly greater acceptance, but applying the principle is difficult, eg, due to insufficient evidence. Some respondents were critical towards its increased importance since they thought that economic considerations already weigh heavily. Likewise, physicians do not want to be alone in deciding on priorities based on cost-effectiveness, but prefer greater collaboration with policy-makers.

Human dignity was regarded as the overriding principle, but opinions differed concerning the appropriate ranking of the other principles. No single principle alone should be in control.
3.2 Guidelines on Priority Groups and Individual Assessment

Guidelines on priority setting are based on the three ethical principles and exemplified by four priority groups (PC chapter 13, GB chapter 7.3, p 31)

**Priority Group I:**
- Care of acute, life-threatening disease
- Care of diseases that, if left untreated, lead to permanent disability or premature death
- Care of severe chronic illnesses
- Palliative care and care of the terminally ill
- Care of people with limited autonomy

**Priority Group II:**
- Prevention
- Habilitation/rehabilitation

**Priority Group III:**
- Care of less-severe acute and chronic diseases

**Priority Group IV:**
- Care for reasons other than disease or injury
- In each individual case, the need for care should be based on conditions specific to that case since diseases can vary in severity over time in the same patient. Hence, the care of a given patient can fall into different priority groups at different stages. (PC p 158, GB p 32) The condition and the care needs at each individual point in time are the important factors, not the diagnosis or the disease. Coverage of needs should be greater in the higher priority groups than in the lower ones. (PC p 163, GB p 39)

3.2.1 Awareness
Respondents were familiar with the four priority groups exemplified by the three ethical principles. For example, “it feels like the priority groups are recognised today”. Whether the groups are viewed to be understandable and reasonable depends on how the interviewees interpret them. When interpreted as guidelines for resource distribution at a general political level, or as a means to highlight unmet needs, the guidelines were viewed to be reasonable. However, as guidelines at the clinical level they were viewed to be less useful.
3.2.2 Application
When it comes to practical application of the four priority groups, we found two distinct camps – those who thought the four priority groups were functional and used them actively, and those who rejected the groups, found them to be unworkable, and thought they contradicted other guidelines and should be eliminated. Some suggested that the groups played a role when the Riksdag’s resolution was new, but no longer do so.

The county councils that reported using the priority groups included them in various planning and prioritisation documents. According to some, the groups provide support in budgetary discussions, eg, interventions in Group IV that are subject to elimination. Several examples were given where the priority groups consciously affected resource distribution. Respondents in one county council saw a risk associated with the guidelines – that patients belonging to Group I will always have their needs met ahead of groups with lower priority, and therefore resources were intentionally earmarked for the lower priority groups. Several respondents mentioned that the groups have drawn greater attention to palliative care, care of dementia patients, and rehabilitation in the resource allocation process.

The interviews also showed the opposite view: that the priority groups were not being used in practice. Less-severe diseases were being allocated resources at the expense of more-severe chronic diseases, “many with colds go first”, and in real terms resources for e.g rehabilitation have not been prioritised. Some reported that various actors were using the priority groups in an over-simplified way as an argument to acquire more resources.

3.2.3 Reported problems
The concept of “needs coverage” in the guidelines generated some concern among respondents. Several said that it leads to problems in applying this guideline. An interpretation was that all care needs in Group I must be met first; all care needs should be met for patients in Group I, most care needs in Group II, a minor share in Group III, and in Group IV when time, resources, and opportunities are available.

Another way to interpret the concept of needs coverage is that needs should be covered, to varying degrees, on a declining scale from Group I and downward; one should address all needs, but in a declining scale from Group I and downward (one cannot meet all needs in Group I before Group II, etc).

Those reporting that they used the four priority groups have had problems with interpretation.
Several respondents viewed Priority Group II as another dimension since it includes interventions in contrast to diseases, as in the other groups. The controlling effect that the priority groups have was questioned by a politician who stated that politicians are struggling to upgrade basic preventive services aimed at alcohol and smoking, but in practice the staff ranked this low, “I don’t know how many decisions we made without having anything happen”. From community medicine, which should be a supportive resource with expertise in prevention methodology, it was said that the placement of prevention into Group II has made it easier to emphasise this area in budgetary work and resource distribution. This is most apparent in the general political process where, eg, in cost cutting situations money earmarked for prevention has been set aside and clearly noted that the area should receive attention in the objectives targeted at primary care. Group III covers a large share of the services in health care, making it difficult to apply. Another problem reported was that the groups are too general to be useful in routine practice. A problem with these groups is that disease severity can vary over time, and the interventions are not factored in “there is no treatment to offer so it is meaningless to prioritise”. Several politicians called for a definition of the difference between chronic illness and severe chronic illness. For example, a patient can have episodes of severe chronic illness, but otherwise be chronically ill. Hence, the patient vacillates between the two categories.

The groups are not useful at all, according to some: “the groups are useless, we have never paid attention to them”. The priority setting model developed by the Swedish Society of Medicine was viewed to be substantially better, replacing to some extent the Riksdag’s guidelines. The groups served their purpose until the National Board of Health and Welfare issued the national guidelines and presented ranking lists. Respondents found it difficult, however, to see the link between the priority ranking and the four priority groups. Many respondents said that the national guidelines issued by the National Board of Health and Welfare were more useful as a basis for prioritising.

3.2.4 Respondents’ suggestions for change
Two more or less conflicting suggestions were given regarding application. One was to delete the priority groups from the Riksdag’s guidelines. Here, there was a suggestion to replace the groups with more specific directions, eg, the working model proposed by the Swedish Society of Medicine or the model for national guidelines proposed by the National Board of Health and Welfare, which describes what should be considered in assessing needs. The second suggestion was to maintain, but clarify, the priority groups.
Respondents who said that the priority groups needed further clarification indicated, eg, that Group II should be eliminated and that habilitation/rehabilitation should be included within the other groups just as any other intervention. Legislated services should be managed in a particular way. Several of the respondents thought that interventions under Priority Group IV were no longer a part of health services, or that health services should not provide them. In other words, they did not believe that Group IV plays a role in the prioritisation discussion. In one county council a director in primary care expressed the need for a “priority group 0” that would include patients yet to be evaluated.

### 3.2.5 Municipalities

Most were familiar with the priority groups, but associated them mainly with health services. Views were divided on the extent to which people used prioritisation that placed some groups and health services ahead of others. A clear perception was, however, that health services “prioritise themselves”, they always go first. Some respondents indicated that the Social Services Act does not make it possible to place emphasis on groups in the same way that the Health and Medical Services Act does, while others saw clear parallels. Most were unfamiliar with the concept of needs coverage, and therefore it was not used. Nevertheless, palliative care and terminal care were areas emphasised in conjunction with the needs coverage concept, and where most said that they allocated substantial resources in collaboration with county councils, indicating that these health services were highlighted in the Priorities Commission’s report.
3.3 General Guidelines in Priority Setting

3.3.1 Guideline on needs related to quality of life and health

Several general guidelines also exist for setting priorities, regardless of the level on which this is done.

In disease and injury, needs related to quality of life carry the same weight, in principle, as needs related to health. (PC p 153, GB p 18)

By a health-related need, the Commission refers to sick people who primarily have a need to be cured from their disease, and quality-of-life-related need refers to the need for symptom relief and nursing services if the patient's disease cannot be cured. (PC p 109, GB p 17)

Awareness
A similar share of respondents were aware of and unaware of the guideline stating that, in cases of disease or injury, quality-of-life-related needs should carry, in principle, as much weight as health-related needs. However, most respondents understood the guideline and found it to be reasonable. Also, most respondents indicated it was important for the Riksdag to emphasise quality-of-life-related needs.

Application
Healthcare professionals, administrators, and politicians, comparing present versus past health services, described a major change in awareness about the importance of improving the quality of life for patients who cannot be offered suitably curative treatment. Today, for instance, there is more discussion about the cut-off points when the attending physician realises that it is best for the patient to receive adequate pain relief and be allowed to die with dignity. Curative interventions do not necessarily have to rank highest on the list. Several mentioned that an important motto in this context is “occasionally cure, always ameliorate, and continually comfort”.

A question was raised about the extent to which health services are obliged to console, and who else would be willing to assume that role. In contrast to the increased awareness of the importance of palliative intervention was the opinion that care today is strongly oriented towards cure, and that there are deficiencies in services such as cardiac rehabilitation in relation to life-saving measures. Another example would be the life-saving measures taken for premature infants versus the resources allocated for care later in life.
Quality-of-life issues are less likely to influence decisions on need than are issues associated with survival, eg, prolapse incontinence in women has a major impact on quality of life, but is given a lower priority than treatment of cancer that is already under good control, mentioned one respondent.

**Reported problems**

Although the guideline was viewed to be reasonable, some respondents thought the writing was vague and difficult to interpret. “Quality of life” varies widely in content, as does “health-related need”. Rather, the importance of viewing health and quality of life as a part of experienced health was emphasised; “Can you imagine health without quality of life?”

A problem that a politician noted in this context is that much of what can be called quality-of-life-related need is uninteresting to the mass media, eg, palliative care and psychiatry. Rather, the media picks up on very different issues, eg, waiting time for surgery, thereby pressuring politicians into addressing problems that are actually not of the highest priority.

Another issue raised was that the medical profession is not always so good at informing people that not every health problem can be cured. There is a tradition in health care to focus on cure until all options have been exhausted. Some respondents mentioned that staff is not sufficiently trained to handle the difficult discussions required when there is nothing left do but inform about effective pain relief and death with dignity. Another problem mentioned was the tendency to allow other health service organisations, rather than one’s own organisation, deal with interventions related to quality of life, eg, providing effective pain relief to dying patients. Some shortcomings were also reported in coordination between hospitals and primary care. Several respondents said they believe that if cure is not possible, then in any case it is possible to comfort patients, and in this context staff are obligated to refer to others, eg, social services or patient associations.

**Respondents’ suggestions for change**

Issues concerning care of health-related and quality-of-life-related needs, eg, for the elderly, must be discussed more with the municipalities to improve application of the guidelines, said several respondents. The county councils must also become better at establishing contact with the Swedish Social Insurance Agency and social services. Patients notice the boundaries between providers, which is perceived as a problem. Respondents indicated that greater knowledge of each other’s situation and duties would facilitate better collaboration than we see today.
Administrators believed that quality-of-life-related needs probably need to be emphasised more in the management process, and that politicians also need to be more explicit about what levels are reasonable for healthcare expenditures when it comes to perceived quality of life.

**Municipalities**

Concepts such as those addressed in the guidelines for priority setting are not used in municipal services since they are viewed to be more medically related, while municipal health services tend to prioritise nursing care above other interventions. Both types of intervention impact on the care recipient’s quality of life. “*Medical interventions always take precedence, they are prioritised and they are obvious. What we discuss in relation to quality of life is, eg, that everyone should be able to get out-of-doors, no one should need to sit inside an assisted living unit all the time.*”

### 3.3.2 Guideline on prioritisation of all effective interventions

When a disease or diagnostic group is given high priority, this covers, in principle, all effective interventions: diagnostics, treatment, nursing care, habilitation/rehabilitation, and prevention. Secondarily, a balance may be reached among the different interventions. (PC p 153)

**Awareness**

More respondents were aware of this guideline than were unaware of it. Nevertheless, many indicated that they had problems understanding how to apply it.

**Application**

Proficiency in managing the full continuum of care varies around Sweden. Several respondents reported deficiencies in application, so that some interventions in a disease course might be prioritised, but not necessarily all effective measures. Primarily, there is a risk for minimising prevention, rehabilitation/habilitation, and even nursing care. An example would be that diagnostics for neuropsychiatric disorders might have high priority while treatment interventions for the same group might have low priority. Some respondents noted deficiencies in establishing holistic clinical protocols that cut across organisational boundaries, since there are often gaps. There was also a perception that different care levels must focus on different things to be effective, “*prevention cannot be the primary purpose of surgery*”.
Reported problems
Many of the respondents were uncertain of the meaning of “Secondarily, a balance may be reached among the different interventions.” Should diagnostics, treatment, etc be weighed against each other, or should this balance be reached, eg, among different diagnostic procedures? Or should it include a little of each? Does “secondarily” apply to resource shortages, and how should the balance be reached? Should a disease be treated “to the maximum”, or can one and the same condition have different levels of priority depending on the intervention in question? Another, somewhat different, interpretation was that primarily the severity level of the condition should determine the priority, and only then should the benefit of various interventions be considered.

Some respondents thought this guideline contradicted other guidelines; here it states that a particular priority applies to all effective healthcare interventions while other documents, eg, the four priority groups, address only needs groups. Several respondents expressed doubt that an entire diagnostic group would be prioritised the same way. Furthermore, some diagnostic groups were currently perceived generally to have high priority on uncertain grounds. “It is fashionable to have a blood clot in the heart, but not equally fashionable to have one in the brain, and it is least fashionable to be in a confused state due to a urinary tract infection.” Priorities should not be linked to a particular diagnosis, but to a condition, according to the administrators and health service directors interviewed. Setting priorities based on disease/diagnostic groups is difficult, eg, in rehabilitation/habilitation where priorities are determined by impairments in function and activity, and “it is an oversimplification to think in terms of diagnoses”.

Various interpretations of the guideline were expressed. One respondent commented on the part of the text that says “the patient has priority I for all of his/her interventions”, mentioning that health services do not work that way, “in emergency situations the patient has priority I, but when she needs rehabilitation she might have priority II for a particular treatment”. Another respondent suggested it was unreasonable to think that if diagnostics, treatment, and rehabilitation are good, but there are no preventive interventions, then the ranking should be lowered for the entire diagnostic group, and consequently all interventions.

Respondents’ suggestions for change
One way mentioned to solve the problem in applying this guideline was to use the fundamental idea that priority setting should start by linking every need to an intervention in every given instance.
In other words, cancer would not be automatically given highest priority since at times there is no effective treatment, and then health services should quite simply do something else instead. Greater knowledge was called for in certain areas to be able to assess the effectiveness of interventions, eg, prevention. Also mentioned as important was the inclusion of several professional groups with different experiences in the internal priority setting process. Having stronger evidence should make it easier to navigate between treatments, nursing care etc, commented several politicians, and suggested there are reasons to pursue this. Formulating guidelines that are less categorical at steering priorities towards certain diagnostic/disease groups was called for.

**Municipalities**

The guidelines were unknown to the representatives from the municipalities, but all immediately turned to the question concerning collaboration with county councils. Healthcare intervention, however, always seemed to take precedence, which was perceived as a problem. “Since medical needs prioritise themselves we should find a method or process whereby all needs can be weighed in the same way, so that all needs are included and considered, not just medical needs”.

### 3.3.3 Guideline on limited autonomy and special attention

People, who because of disease or injury have a limited capacity for self-determination or are unable to clearly express their needs, and children without responsible guardians, deserve special attention. However, the degree and duration of limited autonomy varies, as does the importance of different care needs. Hence, the Commission’s prioritisation of people with limited autonomy should be modified to consider the circumstances in each individual case. (PC p 153)

**Awareness**

Most respondents reported they were aware of the guideline concerning people with limited autonomy, although several were not; “I didn’t know that, but it is obvious”. Generally, the principle was considered to be very important as a “safeguard”.

**Application**

Some respondents interpreted the guideline to mean that people with limited autonomy always receive high priority, while others interpreted it to mean that health services should assure that those who cannot speak for themselves are not discriminated against. Another interpretation was that there must be some type of guarantee, ie, “to do that which the person would have done had they been able to manage on their own”.
Yet another interpretation was that people with limited autonomy are those with the greatest need for good continuity. The guideline was also interpreted to mean that people with limited autonomy should be evaluated on equal grounds as other patients, but they also have a need for visibility so that they can benefit from the interventions they need.

The respondents expressed different views regarding application of the guidelines. Many linked the text to the interaction between patients and health services – rather than to the priority-setting situation itself – and indicated that this way of thinking should be obvious in health care, but that it not always is. To what extent should a representative serve as the interpreter for another person, eg, parents of children, family of a functionally disabled person? One perception was that currently it makes a major difference if a family member accompanies the patient in health services, and those with limited autonomy who have no representative probably receive less favourable treatment. There appears to be variation in how well the supportive functions are constructed to identify the needs of people with limited autonomy. Special policies, eg, for children or the functionally disabled, have been established in some places around Sweden, as have personal advocates for certain patient groups with limited autonomy. Other examples involve utilising special expertise, such as targeted resource centres or acute geriatric teams in emergency departments. Even in the financing system, special consideration can be given to groups with limited autonomy, eg, when primary care allocates more time (and hence more financing) to treating certain groups.

Politicians in particular thought it was difficult to specify how the guidelines are actually applied; largely it is left to the health services to assure compliance. One politician, however, noted “I think it is our duty to give a voice to groups that do not have their own voice”. This could involve, eg, politicians asking how the needs of these people are met by health services through, eg, quality improvement processes. Another perception among politicians was that the guideline must exist to create the security that everyone in society has accessible health care.

Reported problems
Problems related to interpreting the guideline involved how to interpret the concept of “special attention”. Special attention should not be misunderstood to mean that people with limited autonomy are given priority regardless of medical need, or that they should receive much more care, commented some respondents. Others indicated that people with limited autonomy should belong to Priority Group I, and thereby be guaranteed high priority regardless of need. Respondents also said it was difficult to know who should be covered by the guideline.
For example, does it include people with mental disorders that make it difficult to express their needs, immigrants with language and cultural difficulties, or the elderly who do not make demands but are more passive recipients of care? An interpretation in the rehabilitation field was that limited autonomy is equivalent to limited independence, which means that most patients in rehabilitation/habilitation are covered by the concept.

Regarding application problems, several emphasised the potential risk that health services might treat assertive people in a more positive way, and that knowledge and “nagging” could be helpful in getting ahead, which these respondents perceived to be wrong.

The historic and demand-based orientation of health service organisations can also lead to discrimination against groups with limited autonomy. The opposite was also reported as we noted earlier; that those with limited autonomy, such as people with dementia, received more attention in health care today than they did previously. Hidden needs are also difficult to notice since they go undetected, and health services do not work enough with case finding. One example of a service that should be increased is targeted vision examination of people with developmental disabilities.

**Respondents’ suggestions for change**

The respondents called for more discussion and clarification in interpreting the guideline, which they viewed to be important. To be better able to apply the guideline, politicians said that health services must improve at defining groups with limited autonomy, acquire greater knowledge of their needs, and learn what the health services can do to reach them. As regards the composition of the guideline, it was noted that patients with limited autonomy should not only be given special attention in evaluation, but also in receiving the services that can effectively meet their needs.

**Municipalities**

All respondents from the municipalities reported that they frequently worked with people with limited autonomy, but people do not express themselves in the way indicated by the guideline. People with dementia and mental illness were mentioned as groups given particular emphasis. Someone also noted that, by law, social services have an expressed obligation for case finding, “but whether we get to this is a little hit-or-miss”. Several also noted that the difficulties therefore do not lie with assessing the need among those lacking autonomy, but in reaching these groups in the first place.
3.3.4 Guideline on self-care

Opportunities to promote, teach, and support self-care should be pursued in all groups. (PC p 154, GB p 27)

Awareness
Several respondents reported that they were aware of the guideline on self-care, while others were not. From the responses, it is uncertain whether the interviewees reporting they knew of the guideline were actually aware of the link between self-care and prioritisation, and not simply that self-care should be promoted in general. Several indicated that the link to prioritisation was unclear, self-care was associated more with rationing even though in many instances it is an adequate healthcare intervention.

Application
Many reported that self-care in conjunction with prioritisation was a matter of solidarity. They said that people with good knowledge who can manage their own health problems thereby free resources for people who actually require health services. Hence, it is important to promote self-care and not over-treat patients. The boundary separating public services versus self-responsibility was viewed to be a key issue in the prioritisation context, and self-care was identified as one of the areas with the greatest potential for development in health services.

Several mentioned empowerment, ie, living a more healthy life despite one’s disease, and taking advantage of the patient’s capacity for self-care. “It can be a matter of what I can do for myself in my health situation before I become a patient.” Examples of areas where self-care is developing include earlier discharge from hospital to the home, and pelvic training after childbirth. There was a general perception that considerable time is spent informing patients about self-care. For example, nurses teach patients to carry out some tests themselves, eg, for asthma, diabetes, and heart failure. Prescribed exercise was also mentioned as a self-care activity. Several respondents, however, held the opposite opinion; that self-care does not receive a low priority.

Among politicians, there was the view that rationing is already being discussed, and must be discussed to a greater extent in the future. An example of self-care as rationing that arose in the interviews concerned rehabilitation, where items that were previously covered by health services, but are now defined as self-care, have been subject to fees or have been completely excluded (eg, health promotion groups and some assistive devices).
Greater accessibility to information on self-care, eg, via pharmacies and the health hotline (telephone nurse) was viewed as positive. Some county councils include information on their websites, distribute printed information on self-care, or have established patient forums in collaboration with patient associations, which helps health services with information material. Collaboration with sports associations concerning self-care is also found throughout Sweden.

**Reported problems**
The respondents did not express any major problems concerning the guideline on self-care. Some found it difficult to know what the concept of self-care included – “*is it when you buy nasal drops yourself?*” In other words, the absence of criteria for defining self-care was perceived as a problem.

Regarding implementation of the guideline, some found it difficult to place clear demands on patients to participate in treatment. At times, patients become disappointed in their physician if they have to be active themselves. Changing the public’s expectations that health services should take care of all health problems was viewed to be a difficult task.

**Respondents’ suggestions for change**
Regarding practical application, most agreed that the potential for self-care should receive more attention. Where they exist, political public health committees should take responsibility for promoting a public dialogue on self-care issues. Some administrators mentioned the option of raising self-responsibility to its own ethical principle. A more contemporary definition of self-care was called for, as was the development of generally accepted criteria concerning what are appropriate self-care activities.

**Municipalities**
Self-care as a concept was not used in the municipalities interviewed, even though it concerns much of their activity. Some perceived self-care to be purely a healthcare concept. Others did not directly recognise self-care as part of the priority setting process. Rather the concept used was “*help for self-help*” or “*a rehabilitative approach towards work*”, but the content appears to be the same as for self-care in the health services. “*We are trying to work with hands on our hips – to encourage self-activity in others. Of course, this is a better way to use resources in the long term.*”
3.3.5 Guideline on non-beneficial interventions

Non-beneficial care interventions should not be used and should not be included among the priority options. (PC p 154, GB p 11, 39)

**Awareness**
Excluding non-beneficial interventions from the prioritisation options was viewed to be self-evident. But determining what is non-beneficial, and who is responsible for determining this, was not as self-evident to respondents from the county councils and municipalities. The extent to which respondents were aware of this guideline is uncertain.

**Application**
The responsibility clearly rests with the departmental directors to determine which interventions are beneficial and which ones are not. Some politicians indicated that this engages the cost-effectiveness principle, and is, in principle, self-regulating. None of the respondents were aware of any political decisions they had taken to discontinue an intervention shown to have no benefit. In Östergötland, where ranking lists were established for health services, new interventions were added to the list and obsolete ones were removed. The respondents indicated that when ranking lists are established, non-beneficial interventions should not be included in the first place, they should be eliminated through the usual quality improvement process, “an intervention that does not provide any benefit should render itself obsolete”. Respondents gave examples of interventions used previously, but which have been phased out since they apparently provided no benefits. These include eye pressure testing, certain types of orthopaedic procedures for ankle and whiplash injuries, several preoperative examinations, cauterisation in abdominal endometriosis, and antibiotics for uncomplicated ear inflammation.

Many reflected that introducing new methods in health care appears to be easier than phasing out traditional working routines, and that the extent of phasing things out should be greater than it is now – “force of habit is difficult to break”. Representatives of several county councils gave examples of how they address this issue:

- Department heads place a requirement on themselves to phase out obsolete methods when they introduce new technology. (Jönköping)

- A council on evidence-based medicine has been established to disseminate new findings. (Halland)
• One physician works half time with evidence-based medicine. (Blekinge)

• A physician will be employed to work with evidence-based medicine and promote material from SBU (Swedish Council on Technology Assessment in Health Care). (Västernorrland)

• The Medical Council discusses the benefits of various methods. (Kronoberg)

• A medical council will be established to work with both the introduction and phase-out of methods. (Gävleborg)

• A technology council has been established to inventory the state of knowledge concerning methods that can potentially be introduced or phased out as routines in health services, and to provide recommendations to decision-makers. (Östergötland)

• The Centre for Assessment of Medical Technology in Örebro (CAMTÖ) provides the healthcare sector with knowledge and information on methods, helps to implement material from SBU, and performs studies in collaboration with healthcare organisations. (Örebro)

Apart from these examples, the absence of routines for introducing methods appears to be common. Many factors influence whether or not a method is phased out from publicly financed health services. One administrator held the opinion that forms of reimbursement have an effect in the sense that interventions that provide revenue continue to be used even though the effects are questionable. The patients’ perceptions towards benefit are another influential factor. Health service directors mentioned that it is easy to distinguish services that obviously have no benefit, but those on the borderline can be difficult to phase out when patients request them. They also indicated that occasionally the care staff do things which they know are non-beneficial when there are no other options, i.e., in situations where they cannot do anything, for the purpose of calming the patient or feeling that they do “everything in our power – it is as if we must offer something”. In other words, substitution appears to have an effect since when there is no other alternative, staff tend to continue with a method despite uncertain benefits. A less active method may be perceived to provide health on other levels than the one intended, and staff continue to use it instead of perhaps engaging other health professions or other more adequate interventions, according to some of the interviews. The fact that patients are increasingly more knowledgeable about various treatment options was perceived to make it more difficult to deny an intervention.
Occasionally, care staff wants to stop providing a certain intervention, but politicians are opposed. One health service director gave an example where health services were forced to introduce a method they believed to be non-beneficial because the politicians demanded it. Another perception among health service directors was that methods are phased out due to economic factors or because the special skills required are no longer available in a department, which seemed to carry more weight than scientific evidence supporting the same outcome.

Reported problems
As with many of the other guidelines, there was a call for clearer definitions – in this instance, the meaning of “non-beneficial”. Does medical benefit, quality of life mean that the patient experiences benefit or something else? Benefit for whom? Should this judgment consider the effects on people other than patients themselves? These were some of the issues that arose.

One problem mentioned was the absence of evidence in studies in all areas, and that only a small proportion of all healthcare interventions have been scientifically assessed. However, SBU reports and other scientific assessments were reportedly followed to the extent possible, as were the national guidelines from the National Board of Health and Welfare. Health service directors also wondered how much evidence should be required for an intervention to be “allowed” in practice, and suggested that at times standard practice was sufficient grounds.

Respondents’ suggestions for change
A desire was expressed to acquire a better knowledge base that would enable one to withstand the pressure of demands and media campaigns. Better support and loyalty from politicians was also sought. Likewise, the importance of establishing “don’t do lists” was mentioned. To further ensure the application of the guidelines, respondents called for national decision processes and collaboration within regions, eg, where one or more hospitals test new methods under controlled circumstances before the methods are widely disseminated. Respondents thought that the text of the guideline could be written more clearly.

Municipalities
The extent to which interventions are, or are not, beneficial is an issue discussed in the municipalities, and respondents were aware of the deficiencies in knowledge and the lack of a systematic approach. “Unfortunately, the reality of working in the municipality is that we have too little time to keep up with what’s going on in the world and read reports. We have little time to be far-sighted.”
Kävlinge municipality has developed a working collaboration with the school of nursing, mainly to help nurses think more systematically about what is beneficial. Östersund municipality is considering more actively searching for scientific evidence on various interventions.

3.3.6 Guideline on care regulated by special legislation

**Awareness**
This guideline was viewed to be both understandable and reasonable.

**Application**
The guideline affected most of the respondents in one way or another, directly or indirectly depending on their position.

**Reported problems**
The greatest problem with this guideline, which many stressed emphatically, was that the central government makes decisions that occasionally affect the economy of the county council. For example, the central government, via the courts, can increase the county councils’ costs for forensic mental care without the county councils being able to influence the decision. Several respondents said that if the central government passes judgment in a court then the central government must also assume obligation for the costs, then the county councils can manage the services.

There are problems in applying this guideline. One concerns the demand that the legislated services are at risk of directly displacing patients with other needs. The other is that issuing medical opinions/statements/certifications was said to be time-consuming and has a different priority among different health service employees. One county council, for example, noted that some employees in primary care give high priority to medical certificates for driver’s licenses, referring to legislative requirements, while others place this is in the lowest priority group.

Generally, it is reasonable that if a law supports certain services, then resources should also be provided. But the question was raised in the interviews: “Why should this type of care not be questioned while other types are?”

| Health services regulated under special legislation could be viewed as guaranteed resources. Such legislation includes the Communicable Diseases Act, Compulsory Mental Care, Forensic Mental Care, and legal abortions. The same applies to the legal requirements to establish cause of death and to perform forensic medical and psychiatric investigations, and thereupon issue a statement of findings. (PC p 154) |

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**Health services regulated under special legislation**

- Communicable Diseases Act
- Compulsory Mental Care
- Forensic Mental Care
- Legal abortions
- Establish cause of death
- Forensic medical and psychiatric investigations
- Statement of findings

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**Reported problems**

- Central government makes decisions that affect county council's economy
  - Via courts
  - Increases costs for forensic mental care
  - County councils have no influence

- If central government passes judgment in court, they must assume obligation for costs

- Demand of legislated services risks displacing patients with other needs

- Issuing medical opinions/statements/certifications is time-consuming
- Priorities among health service employees vary

- It is reasonable that laws supporting certain services should also provide resources
Here again, transparency was viewed to be important as regards the basis for this priority. One administrator said that even if these areas are guaranteed resources, care cannot be delivered in just any way, it must be cost-effective. These areas “draw resources first”, commented one health service director.

**Respondents’ suggestions for change**
Some respondents discussed the issue that resources should not be guaranteed to too many areas since this could have negative consequences for the rest of health care. In contrast, other respondents wondered if even other interventions should be legislated, eg, life-saving interventions or childhood vaccinations.

### 3.4 Other Guidelines

#### 3.4.1 Guideline on the opportunity of patients to monitor and influence the priority setting process (patient perspective), and on transparency and democracy (citizen perspective)

<table>
<thead>
<tr>
<th>Patient in focus</th>
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<tbody>
<tr>
<td>Patients should have the opportunity to monitor and influence health services. They should have access to information about the findings on which priorities are set, the opportunities available to influence these, and the steps one can take if dissatisfied with the priorities set. Furthermore, health services are obliged to develop methods to make this information accessible to the public and assure that patients’ views are routinely solicited and followed up. (GB p 13)</td>
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<tr>
<th>Transparency and democratic acceptance</th>
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<tr>
<td>For the population to have high level of trust in health services, the grounds for prioritisation must be openly discussed (PI p 47), and the values that guide both access to care and prioritisation decisions must be shared by most of the population and perceived to be reasonable and just. To promote public understanding about priorities, people working in health care have a duty to inform others about the discussions on prioritisation. (GB p 14)</td>
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#### 3.4.1.a Patient perspective

**Application**
We did not identify any county council that had a developed process to specifically solicit patients’ opinions about priorities in health care. Many respondents, however, mentioned that patients had the opportunity through other channels, eg, via patient questionnaires.
Other ways to acquire patients’ opinions about health services in general that were mentioned included, eg, a direct channel between patients and citizens to the politicians and hospitals.

This has been established in some county councils. “Speak out on Health Services” in Halland and “Patients’ Direct Channel” in Jönköping are two such initiatives. Värmland offers another example of the contact approach, where the county council established a unit for patient and citizen services (centrally placed in the county council secretariat) that handles complaints, service issues, freedom of choice issues, citizen contacts, and some formal issues such as patient rights, etc. However, this unit does not replace the patients’ committee. Other types of patient contacts and acquisition of information can take place via the so-called “disease-oriented policy programmes”. During the process of developing disease-oriented policy programmes in Östergötland, politicians met with over 700 patients and their relatives during the course of a year. General meetings were also held with various organised groups, eg, patient associations and councils representing consumers and the disabled. Voluntary associations can also be invited to various political committee meetings.

Patients are regularly informed that they can turn to the patients’ committee (patient representatives) if they are not satisfied with the priorities set. This information is disseminated in various ways, eg, in meetings between patients and caregivers and via county council websites, catalogues, and brochures. Administrative and medical directors are also key contacts. Increasingly, county councils are establishing special functions to manage accessibility issues and the so-called maximum waiting time guarantee, eg, a “gatekeeper” in Örebro and Norrbotten, a “care guide” in Kronoberg, a “patient ombudsman” in Jämtland and Stockholm, and a “maximum waiting time guarantee unit” in Uppsala County Council.

**Reported problems**

Nearly all respondents reported shortcomings in implementing this guideline. Directors of rehabilitation services reported major deficiencies in paying adequate attention to patient perceptions regarding what should be prioritised. Likewise, the possibilities of influencing health services depends on the assertiveness of patients or their relatives. Reasons for the shortcomings in implementation were reported to be:

- few priorities are set consciously on evidence, hence communication between healthcare staff and patients about priorities is perceived to be a problem
- inadequate support for prioritisation by politicians makes communication difficult between patients and physicians or other healthcare staff.
• insufficient transparency in healthcare delivery limits patients’ opportunities to demand relevant interventions.

Other problems concerned the fact that the responsibility for transparency rests at several levels that are poorly coordinated.

Hence, there is uncertainty about who should be responsible for what. There was a perception that the responsibility for transparency rests with the politicians (at least as concerns communication of political decisions), while health service employees, particularly organisational directors, must take responsibility for transparency concerning practical prioritisation in health services and capturing patient viewpoints about the decisions.

Another obstacle mentioned concerns the uncertainty of who is responsible for collecting patients’ opinions. Should it be considered an administrative duty or a duty of politicians? For example, hospital executives in one county council attempted to conduct several meetings with patients in the county to discuss how well the hospital did its job, eg, concerning referrals. The politicians also wanted to participate in the meeting, but the hospital leaders thought it was inappropriate and proposed that the politicians arrange a similar meeting of their own.

3.4.1.b Citizen perspectives

Application
Nearly all respondents thought that the intentions concerning transparency and democracy were understandable. The rule that the basis for setting priorities must be openly discussed was interpreted to mean, eg, that health services should openly present the grounds on which various choices are made, and that it concerns an attempt to tell the public how health services work to assure good quality. “Decisions that cannot withstand the spotlight should not be made.”

There are, however, few examples of prioritisation decisions at the group level that have been reported or discussed openly with the public (we define public as all citizens, not only those who are patients, in contrast to the preceding section). In some instances, discussions on priority setting have been held on a general level. When the report from the Priorities Commission was released, several county councils, eg, Västerbotten, Sörmland, Kalmar, and Örebro, or council meetings in, eg, Uppsala County Council, arranged study circles. Citizen dialogues, which can include prioritisation issues even if they are not the main theme, are an example. Västra Götaland adopted a communication plan in the county council that included more structured arenas for communication. In Halland, citizen dialogues were held in each municipality, but public interest in
participating was weak. Citizen dialogues to specifically discuss priorities with the population have been held in Östergötland and in the northwest health services district in Skåne. The dialogues consisted of a combination of questionnaires to one percent of the population and extensive discourse with citizens who expressed interest. In Skåne, the first programme was held during 2002 and annually thereafter. In Östergötland, the project was implemented in 2005. (Rosén 2006 a,b)

Some of the respondents indicated that an open discussion on prioritisation already takes place through media coverage, including press releases, debates, and letters to the editor. They also refer to transparency in decision-making via, eg.,

- county council websites, including discussion forums
- county council newspapers or newsletters
- public dialogues
- committees working with various disease groups
- meetings with organised citizens, eg, organisations representing pensioners or the disabled, or other voluntary associations
- meetings with temporary patient advisory groups, eg, consisting of people within the catchment area of a community health centre
- discussions within and via the political parties
- public county council plans for the forthcoming year, and annual reports
- open meetings with media participation.

**Reported problems**

Many respondents had concerns about the reasonableness of the intentions concerning transparency since priority setting was viewed to be a difficult issue to discuss with citizens. At the same time, people thought that transparency in prioritising services could create acceptance for holding off on the greater needs. Some respondents suggested that the general public has many inaccurate assumptions about priority setting and its foundation.

Several health service directors said they felt it was unreasonable to subject necessary priorities to public discussion. They believed it placed too great a responsibility on citizens since it is difficult to take a position on prioritisation questions. There is little discussion in society concerning neglected care needs, about what we can afford, and what we should primarily invest in. The public is not ready for such a discussion because: “People don’t want to hear that there is too little money to do everything, it is not possible to carry on a discussion no one wants” and that “the Riksdag should make decisions as the people have mandated, not decide that people should carry on a debate if they don’t want to”. Since not even those working in health care openly admit that they cannot
do everything, some health service professionals did not view transparency towards citizens as reasonable. Other health service directors felt that transparency is exceptionally important, and should be greater in decisions on rationing that are actually being made today.

Politicians were also split in their opinions on transparency. On one hand they viewed it as important to openly present various options, medical experts’ appraisals, and decision timeframes and show that prioritisation/rationing is economically necessary, medically safe, and politically feasible, eg, to prevent situations that would foster parties of discontent. On the other hand, there is some doubt as to whether citizens are interested – they seem to be mainly interested in accessibility. “It’s our major problem, so it’s important to meet the needs of the population.” Politicians seem to find it easier to talk about positive topics, eg, on free choice, than about limitations in what health services can provide. One politician said that needs-based management is difficult to communicate in a short period. But after more lengthy discussion most people understand and appreciate the opportunity to participate in the debate. Another said that, of course, politicians can have an impact with clear, public guidelines, but in practical politics it is difficult to influence opinion since it appears to have strong control. There were also politicians who questioned transparency about things that could not be done, and said they had not yet seen any positive effects from this, particularly not based on the political experience in Östergötland. The first transparent decisions on priorities in 2003, and the major media attention it received, has discouraged politicians from being more open. It is doubtful that politicians are ready for total transparency, responded some administrators.

Citizens were viewed as being uninterested in prioritisation until they themselves became patients. “It’s easy to discuss prioritisation and ethical values at a general level, but when it gets down to the personal level, wondering why my own needs should wait, then it is not as easy”. A perceived problem was that the public seldom has an overview of the needs of others. Another comment was that citizens find it difficult to understand how health services are divided between the county councils and the municipalities, and that each has different areas of expertise and decision-making rules.

Many respondents pointed to a lack in systematic transparency and dialogue with citizens, or even methods established to do this. A problem is that citizens who participate in a dialogue are seldom representative of the population as a whole.

Respondents’ suggestions for change
Suggestions were given on how to increase transparency in priority setting. By emphasising and clarifying collaboration among the different actors in a county
council, it can be shown that politicians take responsibility for priority setting, that decisions are based on scientific evidence, and that this occurred through dialogue with healthcare staff. Acceptance must also be gained within the health services that politicians use more than just medical reasons when setting priorities.

First, some suggested, there needs to be transparent, uniform procedures for prioritisation and rationing within the organisation before external transparency and dialogues are possible.

There is also room for greater clarity in the guidelines as regards the responsibility for transparency in prioritisation, not least concerning the responsibility of politicians, said some respondents. Other suggested that the guideline on transparency needs to be reformulated to more clearly show that it applies both to health services within the organisation and towards the public.

**Municipalities**

Municipal representatives reported that methods are available to collect user opinions about services. In most cases this involves questionnaires or user advisory committees. Much of this input comes from committees representing pensioners or the disabled that solicit opinions concerning how well the organisation functions, but also supports suggestions and ideas for change. Direct contact with politicians is one common form of communication “the municipality is not so large that people don’t know who you are”. Another formal process involved handling of complaints or outliers. Complaints are logged and addressed in accordance with formal procedures. Nearly all respondents representing municipalities believed that transparent decision-making and dialogues with citizens were reasonable and important, even if it did not always seem effective. One administrator, however, stated that transparency in priority setting was nearly impossible to accomplish. “We and the politicians try to solicit opinions and information during the process, but when decisions are finally made it is difficult to know what was said, or who said what, and to show the reasons why things turned out as they did.”

Many municipalities did not engage in dialogues with citizens in more organised fashion. Rather, the municipal websites were used for more general information; decisions, decision-making information, and studies were presented on the Internet, but it appeared as if no one worked with this information in a more systematic way. Again, respondents mentioned contact and consultation with user organisations.

Interviews conducted in one of the municipalities indicated that a more systematic process was under way. “The board specifically assigned us to
develop contact with the public. Each year we have had three or four dialogues with citizens, using a model that we tested with user organisations. In some cases, dialogues were set up even before we in administration were assigned to do the investigation, for instance, the idea to convert assisted living to independent living for seniors. Changes in food production and distribution are other examples, and led to the board changing its programme on food services.”

3.4.2. Guideline on standards and criteria

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<tr>
<th>Standards and criteria</th>
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<td>Individual patients can never be prioritised according to pre-established standards or criteria (GB p 12) that give some diseases general priority over others (CR chapter Priority Group I). Each case is unique and must be assessed based on the individual patient’s needs and the unique situation at hand, but guided by carefully thought-out ethical principles. (GB p 12)</td>
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Awareness
Most respondents seemed to be aware of this guideline. Opinions concerning its reasonableness differed. Many suggested that this guideline contradicts several of the other guidelines.

Application
Most shared the opinion that the guideline concurs with the dominant view in health care, ie, primarily to consider individual patients needs and make an individual assessment, but that general standards and criteria must be available to provide a basic structure in decision-making and even serve as a basis for individual decisions.

“When face-to-face with a patient we can use rankings and other criteria to support a clinical decision, and based on the individual can present a wise proposal on how to address the problem. Age, comorbidities, interventions, medications, etc must be factored in, and together with the patient we need to arrive at the wisest decision.”

Some respondents thought that the guideline did not allow prioritisation at the group level, ie, establishment of ranking lists, etc.

Reported problems
The guideline is not in agreement with the guideline calling for some groups to always receive high priority. Hence, some respondents said that the four priority groups should not be included as part of the guidelines on priority setting.
In contrast, some respondents said it was desirable to use standards and criteria in health care to assure good care on equal terms, so that delivery of patient care was not random.

It was equally apparent to consider individual factors in determining care and treatment. “Otherwise, why do we talk so much about care on equal terms, quality registers, and transparent comparisons, or why do we have SBU reports?” “It’s a double-edged sword – I want to be treated as a unique individual, but I don’t want anyone to forget anything.”

Also noted was that most healthcare staff actually use some types of standards and criteria for guidance at a group level, eg, clinical protocols and decision models by the health hotline. Assuring the best quality and the most equitable health service was thought to be particularly important during resource shortages. Some were concerned that resource shortages would lead to general actions instead of individual decisions, eg, that hip patients would receive assistive devices instead of knee surgery, even though needs vary widely among individuals in both groups.

**Respondents’ suggestions for change**

Politicians indicated a risk for becoming paralysed in decision-making unless there was a system to support assessment and weighing of differences among groups. Such evidence must be developed together with the health services. Then, the politicians’ role is to be loyal to this system, not to the organisation representatives, if conflicts appear. Things are different at the clinical level, since the needs of individual patients must be weighed. Caution was called for in not going too far to the other extreme, ie, considering everything to be unique. Several department heads requested more standards and criteria to use as support in setting priorities for individual patients. They said that much more standardisation should be possible in health care, and health services can certainly use more standards to assure that equal care can be delivered year round for all patients. SBU reports and the national guidelines from the National Board of Health and Welfare were considered to be valuable and useful in the priority setting process.

**Municipalities**

All agreed with the guideline as presented, and recognised that guidelines were important to health services. All municipalities have established policy guidelines to determine financial assistance, but the respondents also emphasised that the needs of the individual should be paramount. “The Social Services Act is designed so that the law requires us to consider the needs of the individual, irrespective of the guidelines. If these needs cannot be met in any other way then we must individually adapt the support, this is fundamental in the
In some instances, deviating from the guidelines requires a decision at a higher level.

One municipality considered eliminating detailed standards. Rather it would widen the scope of services and allow individuals themselves to determine how they want to use available resources. They pointed to the risk that guidelines can become too confining, ie, if it says that one may not or cannot use a particular service then one doesn’t, one stops thinking. In contrast, a healthcare professional noted that the work requires even more concrete support. “It would be a good tool for the staff. It would also support the de-prioritising of interventions for lesser needs in some shortage situations.”

3.4.3 Guideline on responsibility for resource allocation

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<th>Responsibility</th>
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<td>In allocating resources, providers (eg, county councils and municipalities) are free to decide that certain needs cannot be prioritised, and can thereby avoid budgeting the necessary resources. Although such decisions determine the direction of clinical practice, the medical staff can make exceptions if there are strong reasons to do so. (PC p 167) According to the Health and Medical Services Act, the choice of treatment method is determined by the attending staff in collaboration with the patient, while the resources are determined at the higher political level. (GB p 30)</td>
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Awareness

All respondents recognised their situation in the description of resource allocation given in this guideline. However, most did not realise it was connected to priority setting. Respondents thought it was reasonable that, given strong reasons, clinical judgment could motivate exceptions to political priorities. This freedom was perceived to give healthcare staff some latitude, but it also makes political control of health services more difficult.

Application

The politicians interviewed thought that the politicians’ role in priority setting should be limited to the general (horizontal) level, and that vertical priorities were best managed by experts in the organisation. The political priorities should be based on structured evidence from the medical profession along with political values. Redistribution of resources between different health service activities, eg, introduction of new treatment options such as new and often expensive cancer drugs was also seen as a political responsibility. Some politicians felt an obligation to report on the needs that were not prioritised when allocating resources, not least in regard to transparency.
Several administrators and health service directors said that regardless of the reimbursement system used by the county council, the politicians are the ones that must set limits on healthcare costs.

They must actively decide which services are not affordable when they allocate resources and explain why they chose the solution they did.

**Reported problems**

Nearly every respondent asked for a definition of “higher political level”. Does this refer to the national, regional, or local level? Administrators describe the political priority setting process as unclear, and indicated that politicians often failed to explain their reasoning. “*We dare to say which needs should be addressed, but we do not dare to say which needs shouldn’t be addressed.*” Politicians indicated that they lack the knowledge about which needs should be addressed and in what order. It is difficult to be specific in the context of health services. They felt they did not have the total picture, and that it is difficult to determine whether resources have been allocated correctly. A structured priority setting process is necessary to support greater political freedom of action, said several politicians. On one occasion in Sörmland, the department heads asked the county politicians to set horizontal priorities between cancer services and psychiatry. The result was that the politicians did not turn down anything, but yet wanted to provide extra resources to psychiatry.

At times, there are reasons for politicians to intervene in resource decisions within the framework of resources that have already been allocated to health services. This happens every time that cases of individual patients are raised for political discussion. Pressure from, eg, the media and patient organisations, forces them to intervene in the organisation’s budget, or earmark resources. An example would be hearing screening of newborns, cochlear implants for deaf people, and PSA testing to detect prostate cancer.

Physicians find it to be problematic when politicians become involved in cases of individual patients, but here opinions diverge concerning what should be done. Several called for clearer control while others only asked for general decisions. There is a substantial need to improve communication between politicians and healthcare staff.

**Respondents’ suggestions for change**

Respondents called for political decisions that specify the limits for healthcare costs and describe the public’s role. This should, however, be combined with decentralised decision-making that gives the organisation an opportunity to make prudent decisions that best address the situation, regardless of one’s position in the organisation.
Municipalities
Given the description of responsibility in the guideline, most respondents indicated that it functioned. Roles are clear and collaboration with the political board functions well. The politicians’ role is to address overall goals, to show the way, while it is up to administration to build the highway. Several representatives of the executive staff noted, however, that the division between the political role and the operational role is not always clear. There is a grey zone where both the politicians and the health service providers can make decisions.

On one point there was unity among the administrative respondents; political responsibility has not included decisions indicating what should not be prioritised. “I think that the organisation would be better off if the board more clearly defined what we should do and what we should not do. If we have a clearly defined assignment it supports what we can do, it also makes it possible to choose not to do certain things.” Some respondents noted that the guidelines for case management in some instances indicate when assistance should not be granted. Two administrative directors noted that social services are controlled by two pieces of legislation, the Social Services Act and Health and Medical Services Act. “The Social Services Act is a little different here. There are aspects of service where politicians can never refer to available resources in deciding to intervene or not, and that is when it concerns help for individuals.” Furthermore, social services have no directly licensed staff, it is not possible to fall back on professional responsibility in the same way as one does in health care.

3.4.4 Guideline on priority setting in general social welfare

The same principles that guide prioritisation in health services should also guide prioritisation in general social welfare 1, which means that need, not demand, should be the driving force and that understanding should be created among the population for difficult political choices. 2 (PI p 173,174) Requirements are placed on the different actors to collaborate. 3 (PI p 177, GB p 8)

1) Verbatim in the report: “The Commission concurs that the ethical principles proposed for priority setting in health care should have the potential to guide priority setting in all social welfare”.
2) Verbatim in the report: “The Commission concurs that one should aim to use need and not demand to guide the prioritisation of resources among different welfare areas”, and “a generally accepted ethical platform should also contribute to the public’s understanding for priorities chosen in difficult situations and perhaps facilitate broad political solutions.”
3) “Collaboration must therefore be developed, particularly between health services, social services, and the Swedish Social Insurance Agency, so that those seeking assistance can be quickly and appropriately served.”
Application
Collaboration with other county councils in the region has been established for some time (Sweden is divided into six health service regions). The respondents indicated that discussions in these forums mainly concerned working methods, eg, concerning what services should be handled at the national level, regional level, and the county level and the introduction of national guidelines – rather than priority setting. Some regions have established regional, disease-oriented policy programmes, eg, the southeast health services region, where priority setting can be discussed. Concrete collaboration in and discussions about specific priorities are under way in several locations throughout Sweden:

- The southern health services region is working with vertical priority setting. Joint medical councils have also been established. Free choice of care has been offered for 15 years within the region, which has led to the perception that one must aim for similar judgments.
- Halland collaborates with both Västra Götaland and Skåne in regional efforts at priority setting.
- A regional speciality committee in priority setting has been formed in the Uppsala-Örebro region. The committee includes organisational representatives only, but the politicians support this effort. Regional collaboration at the political level is being established (2006).
- Uppsala County Council reported that prioritisation for efficient resource utilisation was also being discussed in the regional planning group.

County councils and municipalities have collaborated, but not concerning prioritisation issues. Rather, they have focused more on how to avoid problems for patients that arise due to jurisdictions, eg, services for the elderly, home services, assisted living, assistive devices, and early intervention for children and adolescents.

As care providers, municipalities often participated in work involving clinical protocols and continuity of care. For several years, a collaborative project, Life Force Skåne, has been under way in Skåne in southern Sweden. When patients are transferred from a county council to a municipal jurisdiction and perhaps have a life-long need for assistive devices, there are effects in terms of prioritisation since the county council remains responsible for the cost. Västmanland has formed a collaborative body, “The Joint Board”, with politicians from the county council and all municipalities. Staffing includes county council administrators and municipal directors of social services. Collaboration and distribution of responsibility concerning assistive devices, home health care, and elder care are discussed, but not directly in terms of priorities, although that is possible. In Dalarna the county council and the county’s 15 municipalities formed a body referred to as KLIW.
Here too, the discussions have not centred on prioritisation, but on, eg, home health services. In Norrbotten, a shared employee serves as a coordinator between the county council and the municipalities. Gävleborg holds several joint forums between the county council and the municipalities to discuss, eg, reports on outliers related to transfer of patients between the two jurisdictions.

Collaboration, with some exceptions, addresses questions of prioritisation. Jämtland has formalised collaboration between the county council and the municipalities concerning ethics and priority setting. Collaboration with the municipalities concerning the introduction of national guidelines for stroke was initiated in Östergötland in the autumn of 2006. Seminars addressing priority setting have been held in Uppsala with participation from the county council and the municipalities, where representatives from the municipalities presented difficult ethical questions for discussion.

Various forms of collaboration with other actors have also been reported, eg, with the Swedish Social Insurance Agency and the county labour board, but not concerning prioritisation. Collaboration across jurisdictions reportedly led to discussions where each one wanted to prioritise in their own way. Several county councils were engaged in working together with the National Board of Health and Welfare and the National Centre for Priority Setting in Health Care to produce a common national working model for vertical priority setting. Several of the respondents viewed this to be particularly valuable and desirable. Collaboration involving the speciality sections of the Swedish Society of Medicine was viewed to be important, particularly for the smaller specialties. Likewise, the drug review committees were viewed to be important in discussions concerning drug costs, selection, and prioritisation.

**Reported problems**

Several respondents expressed a need to develop shared prioritisation principles among providers (county councils and municipalities), which is currently lacking. Different providers set different priorities, which can mean that they do not use all effective care interventions. Rehabilitation was given as an example. In cases where collaboration was lacking, the reasons were unclear. One county council politician remarked that thinking in terms of need had not taken hold in the municipalities, and that even many county council politicians found it difficult to understand what need means, and what actually differentiates need from demand. Other reasons for insufficient collaboration on prioritisation included the lack of routines or disinterest by both parties.
Respondents’ suggestions for change
Some respondents said that the ethical principles upon which healthcare priorities are based should apply to society in general. For example, they referred to the principle addressing people with limited autonomy.

Municipalities
Collaboration with the county council is the topic that arose immediately when the guidelines were mentioned. “The need for collaboration is great, we are two providers, we have to create and maintain a process that offers security for the public.” Collaboration with the county councils was reported to be working better. Nevertheless several mentioned that common principles for priority setting within the entire welfare sector were necessary even if greater collaboration with the county councils and health services successively leads to a shared vision. Several mentioned that more discussion was necessary regarding the municipalities’ role and what should be expected of them. “I fear that the Health and Medical Services Act will take over all activities at the expenses of the Social Services Act, that health services and treatment will take over.”
PART III

Proposed Clarification and Additions to the Ethics Platform
1. BACKGROUND

Part III presents the results from an ethics analysis that was conducted and discussed with representatives from the university, public agencies, and professional organisations. Discussed below are several ethical problems associated with the current ethics platform for priority setting, followed by proposals for change.

Decisions to allocate resources in health care have an impact on people. Therefore, it is important for these decisions to be well founded. We should not accept arbitrary decisions on prioritisation, or allow special interests to control the allocation of healthcare resources. To the extent possible, decisions should be based on fact to avoid arbitrary allocation or distortion of the allocation process by special interests. But using just any facts is not defensible. The selection of facts must be defensible based on ethical principles. Hence, an important issue concerns how we should proceed in choosing these important facts. Our assignment here does not include developing a theory to manage the selection of facts upon which to base prioritisation and rationing decisions in health care. However, we can state that the principle foundation for resource allocation includes three components: facts, concepts, and values.

Figure 1. Three basic components with examples of content.

Values: expressed as ethical principles.

Concepts: eg, “need” and “cost-effectiveness”.

Facts: eg, severity of ill health or cost of intervention in relation to effect.
Our interests determine the facts we ought to search for, but we do not know which facts to start from before we have analysed the conceptual component. For instance, if we apply the needs principle in allocating healthcare resources, facts about needs in health care become interesting. Exactly which facts we should use, however, is not certain before we fully analyse the concept of “care needs”. Likewise, we do not know if it is important to analyse the “care needs” concept, or other concepts that could be of interest, before establishing core values. The concept of need is only interesting if the needs principle is included in the core values or the ethics platform. The same applies to the concept of “cost-effectiveness”. We do not know exactly which facts concerning costs and effects are interesting before we have analysed the concept of cost-effectiveness. Likewise, we do not know if cost-effectiveness should steer decisions on resource allocation before the core values have been clarified. In other words, values that are expressed as ethical principles, and which form the foundation for allocation decisions, comprise the most fundamental components.

One reason why the Swedish Government established the Priorities Commission was to determine which fundamental principles should form the basis for necessary priorities in health care. The ethical principles that the Commission presented, and which the Riksdag later approved, have been subject to discussion in conjunction with various attempts to apply them in routine health care. Discussions have focused on alternative interpretations of the three principles that form the core values and on the rank order of the principles. Furthermore, demand for greater transparency in rationing of health services has increased the interest in issues about central duties of health services in a welfare society, and about self-care, personal responsibility for health, and age criteria.

The term core values is used here in referring to the ethical considerations – formulated as ethical principles – that should guide decisions on resource distribution within publicly financed services. These principles are often referred to as the ethics platform. Since this expression tends to imply a static state, it might not be the best option from a pedagogic standpoint. It gives an impression that the ethical principles are set in stone. A premise of this report, however, is that core values should be always subject to reflection and discussion. We also find support for this in the government bill. (Socialdepartementet 1996/97) It states “it is necessary to view the discussion on prioritisation in health care as a long-range and continually ongoing process. Previously established guidelines may need to be re-assessed as demographic patterns change, resource availability shifts, and technical advances in treatment and drugs lead to new treatment methods, etc”. Since the “ethics platform” expression is widely used, and the risk for misinterpreting its meaning is minor, we continue to use this expression here.
2. FUNCTION OF ETHICAL PRINCIPLES

An important issue to address is the function that ethical principles ought to have. Three functions are conceivable – symbolic, motivating, or guidance functions. Having a *symbolic function* means that the ethics platform will be used to generate support for the activity from external actors, eg, the general public. Services that have established ethical principles that most people accept can instil confidence. For instance, a corporation may have adopted a code of ethics as an important aspect of marketing. Early medical ethics codes may have played a symbolic role. For example, in times when physicians were not yet licensed, adherence to a code of ethics could instil confidence among the public. (Porter 1999)

The *motivating function* can be aimed at internal actors. For instance, it might involve creation of a positive attitude towards an activity among staff, or to motivate staff to fulfil the purpose or goals of the activity. Ethics codes provide an example where, in addition to guidance, the function may be to create professional identity.

The three functions are important, and ideally an ethics platform would fulfil all three. Difficulties in fulfilling all three functions concurrently relate to the degree of precision. To fulfil the symbolic and motivating functions, the principles should have a high rhetorical profile. They should be formulated in general and vague terms and in terms that the public perceives as positive, eg, “justice” and “human equality”. A *guidance function* may well contain principles with positively charged terms, but these terms should be defined or specified clearly enough to provide adequate guidance. Experience shows that agreement tends to decrease when vague principles are more precisely defined. In this report, the ethics platform is addressed mainly in the context of its guidance/advisory function.

The ethical principles included in the platform could also be viewed as ethical imperatives. This is the common way to view ethical principles. Here they functions as ethical criteria, and deviation from the principles can mean unethical decisions or actions. Ethics principles can, however, be more or less imperative (see below). Legal interpretations are the most imperative form of guidance since the ethical principles are backed up by legislation. The current ethics platform has been ratified by the Riksdag and enjoys this legal status.

Here, the ethical principles are considered to be ethical criteria, which is most common. They do not have an absolute status, but rather a so-called *prima facie* status. Absolute status means that the ethical principles must be adhered to without exception.
Prima facie status means, however, that one can circumvent the ethical principle without overstepping an ethics boundary – but only for a strong reason. The most common type of strong reason is when one principle gives way to another that is considered to be more important in the situation. We find such a situation, for instance, when the needs principle conflicts with the cost-effectiveness principle. The principle that should give way is not predetermined, but decisions must be made from case to case. Here we find a difference. The government bill gives the needs and solidarity principle higher status than the cost-effectiveness principle. Hence, the former always takes precedence over the latter. In ethical principles, the idea of prima facie status is rooted in moral philosophy and is now applied in standards, eg, in medical ethics. (Beauchamp and Childress 2001) Furthermore, it is usually applied in research ethics where the expected benefits of research should be weighed against potential risks to the research subjects.

Two important questions must be resolved when studying the guidance function of the ethics platform. The first is: What should the ethics platform guide? What should the decision concern? The second question is: Who should receive guidance? Which actors does the platform target?

From our perception, the ethical principles presented here are intended to provide guidance for decisions involving resource allocation. This part of the report focuses on allocation of resources in health care. Health care in this context refers to interventions aimed at preventing, diagnosing, and treating ill health. Also included in health care are dental services, medical transportation, and caring for the deceased.

The principles are ethical in nature and contain the core values that should guide decisions on resource allocation, prioritisation, and rationing. They are not intended to guide other decisions that require ethical consideration and reflection, eg, concerning foetal diagnostics or euthanasia.

The question concerning which actors the ethics platform should guide can be answered only in principle. It should guide all actors in health care, in its broadest sense. This means it should not only guide various care professions, policy-makers, and administrators, but also, eg, actors linked to the Swedish National Institute of Public Health, the Swedish Institute for Infectious Disease Control, the Swedish Work Environment Authority, the National Board of Health and Welfare, and Apoteket. The platform should also guide actors within the municipal care and social services sectors.
3. CRITICS OF THE CURRENT ETHICS PLATFORM

In Part II, we presented problems that respondents experienced concerning the ethics platform. Below we add the viewpoints that arose in discussions about the ethical principles in other contexts.

The Riksdag accepted (with minor revisions that did not affect the ethical principles) the ethical principles for priority setting as proposed by the Priorities commission. The principles are ranked in the order mentioned. The human dignity principle always outweighs the other two principles, and the needs and solidarity principle always outweighs the cost-effectiveness principle. Is this categorical ranking of principles ethically defensible? Opinions vary. There appears to be agreement concerning opinions that the human dignity principle outweighs the other principles, but not regarding the relationship between the other two principles (see previous section). In many cases it should be easy to agree that the needs and solidarity principle should rank ahead of the cost-effectiveness principle. But is it reasonable to automatically apply this ranking? We achieve a more flexible ethics platform if, at the outset, we give equal weight to the two principles and rank them from case to case. Several reviewers also expressed the opinion that in practice the cost-effectiveness principle could be given greater weight than what was foreseen by the Commission. (Socialdepartementet 1996/1997) Criticism that can be directed towards the current platform concerns the categorical ranking between the principles, which places necessary flexibility at risk.

The human dignity principle gives equal value and equal rights to all individuals irrespective of personal characteristics and function in society. The principle is considered a framework principle. Primarily, it indicates what we should not take into consideration in decisions on resource allocation. We should not base decisions on personal characteristics such as talent, age, or gender. Nor should we base decisions on functions in society, eg, social position or social responsibility. The Commission did not, however, specify the things that everyone has a right to. Hence, the principle does not fully describe what we should consider in allocating scarce resources. What does it mean when everyone has equal rights, but resources are insufficient to address everyone’s care needs? The right discussed here is not an absolute right, only a right (equal right) to the care available. The human dignity principle should be further defined to provide guidance regarding, eg, health service goals and duties.

The needs and solidarity principle indicates that resources should be invested in the areas, activities, or individuals where need is the greatest. This means that more of the resources in health and social services should go to those in greatest need, those with the most severe diseases, and the poorest quality of life.
According to the Priorities Commission, the principle should be applied even if the outcome does not meet everyone’s needs.

The Commission links the concept of care needs to both disease (ill health) and quality of life. Health-related needs mean that health services are needed to address (prevent, treat, and rehabilitate) diseases while quality-of-life-related needs mean that health services are needed to influence quality of life. The Commission, however, expresses a limited view of quality-of-life-related needs. It is possible to interpret the concept of quality-of-life-related needs in two ways

1. The need for interventions to influence quality of life is determined within the framework of disease or injury. “If the disease cannot be cured, the patient needs relief from symptoms and nursing care. This is a quality-of-life-related need.” (Ministry of Health and Social Affairs 1995) Here it concerns quality of life that is influenced by, or is at risk to be influenced by, disease or injury. Poor quality of life (or the risk of it) concerning something other than disease or injury (e.g., appearance, sexual inadequacy, or infertility) does not constitute care need. (2) In the alternative interpretation, the need for intervention by health services is determined in part by the degree of life quality (or risk of becoming worse) and in part by the degree to which health services can potentially affect life quality. The latter requirement is logical in nature. There cannot be a need for something that is of no benefit. If the patient receives no benefit from a drug, then the patient does not need the drug. In interpretation (2) of the concept “quality-of-life-related need” it is not necessary for disease or injury (or the risk of it) to be present.

Which alternative should we use to further define the needs and solidarity principle? The Commission clearly chooses alternative (1). A quality-of-life-related need exists only when quality of life is affected by disease or injury (or the risk of it). However, it appears that the subsequent government bill is not equally clear, but leaves room for either interpretation. (The National Board of Health and Welfare 1996/1997) The section about needs states: “Primarily, sick people need to be cured from a disease. If the disease cannot be cured, the patient needs symptom relief and nursing care. This is a quality-of-life-related need”. (Ministry of Health and Social Affairs 1996/1997) Here the focus is on interpretation (1) where quality-of-life-related need is assessed within the framework of disease or injury. Later in the discussion of Priority Group III it states: “The Commission found that many couples who are involuntarily childless report a lower quality of life. Hence, these couples have a quality-of-life-related need that is well motivated. Where a biological disorder can be found in the man or woman there is also a health related need.” (Socialdepartementet 1996/1997) In other words, health-related needs are linked conceptionally to biological disorders (sickness or disease) while quality-of-life-related needs are not. Here the bill expresses interpretation (2).
This interpretation reappears in the discussion on short stature (Socialdepartementet 1996/1997) “In some cases, however, we also see that where short stature probably cannot be explained by a direct hormone deficiency, the suffering and lower quality of life that short stature causes can be sufficient grounds for medical intervention.”

The interpretation by which we choose to assess quality-of-life-related needs has consequences in the rationing of health services. If we choose interpretation (1), this means that suffering or poor quality of life (or the risk of it) not caused by disease or injury will receive low priority regardless how great the suffering or how poor the quality of life. If we choose interpretation (2), this means that we broaden the area of responsibility for health services. Here they are not limited to disease or injury, but also cover all suffering or low-grade quality of life that health services can remedy by effective methods.

The needs principle means that care needs alone should determine the extent and character of the intervention. The principle says nothing per se about how the care needs should be ranked. A study shows that it is possible to choose among several ranking methods (Liss 2003) In this context, the needs principle provides a means to rank care needs – the greatest need should be addressed first. The severity level of disease or injury should, according to the Commission, determine need, which in turn should be determined by the parameters of suffering experienced, medical prognosis, functional impairment, and existential need.

Are there other factors that should also determine the magnitude of need, ie, ranking of care needs? For instance, should the duration of need play a role? Duration refers to the time that a care need will go unmet if not treated. In considering duration it could be possible that a care need of a younger individual is ranked higher than that of an older one when the degree of severity and cost-effectiveness are the same. The government bill offers a vague answer to this question: “The magnitude of need probably also depends on its duration.” (Socialdepartementet 1996/1997)

Hence, needs should be ranked according to the level severity. The question then becomes severe for whom? For the patient, family, health services staff, corporation, community, or public welfare? Here, we have a problem of boundaries. Should we draw the boundary with the patient, or should we also include family and friends in determining the severity level of needs? If we include the suffering of family members should the severity level of needs in patients with many relatives be rated higher than the severity level of patients with few or no relatives? According to the human dignity principle we should not consider the public welfare in allocating healthcare resources.
But at times it can be necessary to consider the publics’ need for protection, eg, from infectious disease epidemics or psychiatrically disturbed individuals.

Should the replaceability of care needs influence their ranking? Assume that we have two health disorders, A and B. Health disorder A can be treated by surgery or psychotherapy (eg, perceived problem of undersized breasts). Health disorder B can be treated only by surgery. Considering replaceability in the case of surgical treatment, then B should be ranked ahead of A since the severity level and cost-effectiveness are the same. As regards the importance of replaceability in ranking, the Commission or government bill provide no answers. The background documentation leaves room for different definitions of care need. The need and solidarity principle is also unclear about other points. What should be included in assessing the severity level of need – the patient alone or also other individuals affected? Should the duration of need and its replaceability be considered in ranking care needs?

In addition to equal opportunity for care, the idea of solidarity suggests that the outcome of care should be as equal as possible, ie, everyone should achieve the best possible health and quality of life. Solidarity also means that the needs of the weakest should receive particular attention. For instance, children, people suffering from dementia, coma, disorientation, or severe mental illness should have their needs assessed since they have fewer possibilities than others to express or communicate their needs. This special consideration refers, however, only to the assessment of care needs. Subsequent ranking should then be based on the ethical principles. The vague language in the Commission and the government bill creates a risk for misunderstanding on this point (eg, “The needs of people with impaired autonomy should receive special attention.” (Socialdepartementet 1966/1997) The solidarity principle supports a high priority for needs assessment or diagnostics. However, nothing is said about how to rank needs assessment or diagnostics in relation to other interventions. Likewise, nothing is said about the ranking that should be given to revised medical assessments. Also, it is unclear whether solidarity means that health services should try to capture care needs that have not yet caused symptoms in everyone – even autonomic. If so, this would mean that screening, for instance, has a high priority (if the solidarity concept alone serves as the foundation for prioritisation). The solidarity idea includes vague descriptions that can lead to misunderstanding. It is uncertain how actions to detect unidentified care needs should be ranked in relation to interventions that target identified care needs.

The cost-effectiveness principle indicates that in choosing between different areas of intervention or activity one should aim for a reasonable relationship between costs and effects, measured by improvements in health and quality of life.
The Commission concluded that the cost-effectiveness principle should be applied only in comparing treatment methods for the same disease. This means that it should be applied only in setting priorities among treatments – not in setting priorities among diseases, health conditions, or individuals. Effects can be interpreted in terms of whether the intervention or treatment goals are better met, or if side effects and risks for complications decrease. We can also note that here the Commission suggests organisational goals. The effects of treatment or intervention should be measured in terms of health and quality of life.

Does the cost-effectiveness principle, formulated in this way, provide sufficient guidance? The principle could be further defined in several different ways, as regards both the cost and the effectiveness aspects. Which costs should be included in estimates, and which should be excluded? Should costs for patients, family, and others, or other payers (eg, county councils) be included? Should cost calculations include only the resources used by health services? Questions related to scope are further addressed in the definition of effects. Should calculations of treatment effects be limited to the patient? Should the effects on family, other people, or institutions also be included? Would treatment effects be influenced if needs could be met through self-care? According to the government bill on priority setting in health care they could.

(Socialdepartementet 1996/1997)

The definition of cost-effectiveness is far from uniform, and it is difficult to reach consensus on how cost-effectiveness is defined in the bill. (Socialdepartementet 1996/1997) Application of the cost-effectiveness principle is also much too limited. The Commission stated it should only be applied in choosing among treatments for the same disease. This means that care needs should be ranked without considering the cost of intervening in relation to the outcome. Wider application would allow the principle to be applied even in choosing among diseases or disease groups. Here the Riksdag later took a position on the cost-effectiveness principle in guidelines issued for the Pharmaceutical Benefits Board in legislation concerning drug benefits. (Socialdepartementet 2002) The guidelines state that drug reimbursement (prioritisation) decisions by the Pharmaceutical Benefits Board should always consider cost-effectiveness from a societal perspective.

Should the cost-effectiveness principle be used in the same way when setting priorities at the individual level and at the group level? This question should also be investigated. The responsibility for self-care receives little attention in the Commission and the subsequent bill. Nevertheless, the bill emphasises the importance of self-care. “Opportunities for promoting, instructing, and supporting self-care should be used within all priority groups. Self-care is also an important component in treating many chronic diseases.”
However, nothing is said about the ranking of self-care in relation to care delivered by health services. Likewise, the bill does not indicate the ethical considerations that support self-care as an alternative to professional care. A principle to support the choice of self-care in priority setting decisions is lacking.

Generally, the ethics platform indicates the factors that should, or should not, serve as a foundation for decisions on resource allocation in health care and social services. The human dignity principle indicates that we should not consider factors involving personal characteristics or functions in society. The needs and solidarity principle indicates that we should consider facts related to need, and that we should particularly consider the needs of the weakest. In using the cost-effectiveness principle we should consider facts about the cost of intervention and the outcomes measured in improved health or quality of life, and the relationship between these components.

The review presented above reveals the uncertainties concerning interpretation of the principles and the potential for further clarification. We can summarise the criticism of the current ethics platform as follows:

- The human dignity principle implies that all people have equal rights, but the current ethics platform does not adequately specify what it is that people have a right to. The goals and duties of health services are not given.
- The ranking of the needs and solidarity principle and the cost-effectiveness principle is too categorical, i.e., that ranking of interventions should be based solely on need. Hence, a treatment aimed at meeting a need can, in practice, be ranked higher despite a high cost per health benefit.
- The Commission defines the concept of care needs in a limited way. Care is needed primarily when ill health or poor quality of life is related to or caused by disease or injury. Thereby, the cause of suffering and not its severity becomes decisive in prioritisation decisions. The government bill also expresses a broader view of care need. Hence, suffering not caused by disease or injury can also give rise to care needs. Various definitions of care needs are expressed in the background documentation. The needs and solidarity principle is even unclear regarding other points. What should be included in judging the severity level of need? Should the duration of need and its replaceability be included in ranking care needs?
- The solidarity principle contains vague statements that can foster misunderstanding. It is not clear how actions to capture unexpressed care needs should be ranked in relation to interventions intended to meet needs already identified.
• The application of the cost-effectiveness principle is too limited. According to the Commission, it should only be applied in choosing between treatments for one and the same disease. Hence, care needs caused by different diseases are ranked without considering what they cost to treat in relation to the treatment outcomes. A broader application implies that the principle could also be applied in choosing between diseases or disease groups. However, the formulation of the principle is much too vague in terms of costs and effects. This gives rise to different interpretations that can lower the confidence in using the principle, making comparisons between different measurements impossible. Presumably, it is important to distinguish between applying the principles in prioritisation of individual patients versus prioritisation of groups (policy level).

• Except for a few lines of text that encourage self-care, the Commission says little about individuals’ own responsibilities. It lacks a prioritisation principle that would support the choice that patients/citizens themselves have a responsibility to practice and maintain care.
4. ETHICAL GUIDELINES AND PRINCIPLES FOR PRIORITY SETTING IN HEALTH CARE IN OTHER COUNTRIES

This section summarises a report that Anders Melin compiled at the request of the National Centre for Priority Setting In Health Care. It addresses ethical guidelines and principles on priority setting in other countries. (Melin 2007) The report primarily contains analyses of ethical guidelines from Norway, Denmark, Finland, the Netherlands, and New Zealand. Great Britain and Canada are also included in the study since these countries have been intensively engaged in a debate on priority setting, although they have yet to establish national ethical guidelines.

The presentation is based mainly on public reports from the different countries. Regarding Norway, this includes two public inquiries from 1987 and 1997 (NOU 1987:23 and NOU 1997:18). For Denmark, the Ethics Council’s report on priority setting (1996) was reviewed. The Finish report, From Values to Choices (1995), the Dutch report “Choices in Health Care” (1992), and the New Zealand report “The Best of Health 2” (1993) were also included in the study.

Norway conducted two state inquiries on priority setting (Lönning I and Lönning II). The Lönning I inquiry discussed the following five principles or dimensions for prioritisation: level of severity, equal opportunity for treatment, waiting time, economic aspects, and patients’ self-responsibility. The inquiry concluded that the severity level must be viewed as the most important prioritisation principle. The equity principle is interpreted to mean that health services should be offered in a way that everyone should be able to be as healthy as their prerequisites allow. Services offered should be equally independent of social, geographic, and age-related differences. Furthermore, the inquiry concluded that it is important to develop more uniform criteria to administer waiting lists. Regarding economic aspects, the inquiry found that economic considerations alone cannot comprise a prioritisation principle. It is obvious that resources need to be used in the most efficient way, but this would conflict with the severity criteria based only on the principle that one should achieve “most health for the money”. Finally, the inquiry is sceptical towards giving lower priority of patients assumed to be responsible for their own health disorders.

The Lönning II inquiry mainly addressed three principles for priority setting: the severity level of the condition, expected benefits, and cost-effectiveness, all of which the inquiry found to be important. It is reasonable to first treat patients with serious diseases, but one must also consider the expected benefits of treatment. Those who can be helped most by a treatment should be prioritised, but treatment costs must also be considered. Likewise, cost-effectiveness must also be considered. Within the health sector, allocated resources should be used...
for those patients who collectively receive the greatest health benefit. The inquiry also discusses how to achieve a balance between principles, but does not establish an absolute rank order. Regarding the relationship between the severity principle and the benefit principle, they found that one cannot always prioritise patients with the poorest health despite a strong moralistic intuition to attend to the sickest. They also found that the principle of cost-effectiveness must be balanced against the principle of fair allocation. One must consider allocating health services in a fair way, not only to those who can benefit most. Relative to Lönning I, the principles of benefit and cost-effectiveness are considered somewhat more important in Lönning II.

Lönning II is generally sceptical towards prioritisation based on age, lifestyle and health behaviour, productivity, and social needs. These factors can be considered only under special circumstances in decision-making at the clinical level.

4.2 Denmark

In Denmark, an ethics council, established by the Danish parliament in 1987, addressed issues on priority setting in health care. The council’s task is to discuss ethical issues that arise within the health sector and in research and utilisation of bio- and genetic technology. In December 1996, this ethics council issued a report, “Priority Setting in the Health Sector – A Presentation”.

At the outset, the ethics council said that from a political standpoint one should avoid developing a Danish model of priority setting modelled on the Norwegian, Dutch, or Swedish models. It could be valuable to discuss the principles and criteria, but the concrete decisions at both the political, administrative, and clinical levels must be based on a comprehensive assessment of many specific conditions. Certain core values, overriding health sector goals, and objectives aimed to operationalise the core values must be established as a basis for priority setting in Danish health services. The ethics council presented four core values in society: equality of human worth, solidarity, security, and safety, and freedom and self-determination. The overriding goal of the health sector is described as promoting health and preventing disease and thereby securing the potential for development of life among all citizens regardless of their social background and economic status. The report defines four important objectives: social and geographic equity, quality, cost-effectiveness, and democracy and user influence.

The ethics council also discusses several different prioritisation criteria. A central criterion is need, particularly at the political and administrative levels,
110
despite the difficulty in determining who actually has the greatest need for a care intervention. Some exceptions are possible at the clinical level, mainly when patients cannot get treatment for themselves due to age-related weakness. The council generally distances itself from giving lower priority to patients having lower social status, eg, the unemployed, and those perceived to be responsible for their own disorders because of a harmful lifestyle.

4.3 Finland

In the early 1990s, Finland slipped into a major economic recession. At this time, the local authorities were given greater decision-making power over funds allocated by the state for health care. Because of reduced funding, the municipalities were forced to decide where they should cut back on resources. To help the municipalities manage the ethical dilemmas the Finnish Government formed a working group to propose ethical guidelines for prioritisation. (Working Group for Prioritisation in Health Care 1995)

According to the report, human equality served as the point of departure for prioritisation. Patients in the same situation should be treated equally, and there should not be regional differences in access to care. The working group indicated that patients with the greatest need should receive priority, particularly patients threatened with death or disability if not treated. Need is defined based on what is required to restore the patients age-specific functional capacity. Furthermore, the most cost-effective treatments should be given priority. Health services should be evidence-based, ie, based on scientific research of treatment outcomes. The working group mentioned age and lifestyle as examples of factors that should not form a basis for prioritisation. They are only of importance if they impact on the effectiveness of treatment. The working group also hesitated to set priorities based on social conditions.

4.4 The Netherlands

During the late 1980s and early 1990s an intensive discussion developed in the Netherlands regarding the prerequisites for transparency in priority setting. The discussion resulted from a weakness in the economy and a concurrent, sharp rise in health service expenditures. A committee, named the Dunning Committee, was commissioned to present a proposal for prioritisation. The committee completed its report, “Choices in Health Care”, by the end of 1999.

Defining what comprises necessary health services was the point of departure for the Dunning Committee’s proposed guidelines for priority setting. Since health was defined as the ability to function normally, needed health services
were those that restored normal functional capacity. According to the investigation, normal function should be established from a societal perspective. Needed care is the care necessary for patients to function normally as a member of society. Furthermore, the Dunning Committee found that compulsory solidarity is an important characteristic of the Dutch insurance system. It can be motivated based on human equality and equal opportunity to participate in society. According to the committee, limits should not be placed on compulsory solidarity based on factors such as age, lifestyle, personal choice, or reciprocity.

The Dunning Committee reported that it was necessary to limit the health services included in the base package covered by compulsory insurance. The only services that should be included are those that are necessary, have documented effects, are cost-effective, and cannot be converted to an individual responsibility. Based on these criteria, the committee found that in vitro fertilisation, homeopathic medicines, and dental care for adults should not be included in the base package.

However, treatment of sports injuries should be included, as should nursing home care for individuals who cannot care for themselves and cannot afford this service.

4.5 New Zealand

By international comparison, New Zealand was early to openly discuss priority setting in health care. In 1992, “The National Advisory Committee on Core Health and Disability Support Services” abbreviated as “The Core Services Committee” was appointed. The aim was to attempt to contain rising healthcare costs while concurrently guaranteeing good access to necessary services. The committee was directed to annually define the core health services that should be covered under publicly financed health care. A report, “The Best of Health 2”, presented the ethical point of departure for prioritisation.

According to the report, the treatments to be prioritised should have clear benefits, be worth the investment, be fair, and coincide with the values of society. First and foremost, treatments should be prioritised that are documented to have greater positive than negative effects. A treatment’s cost-effectiveness should also be assessed. For every type of treatment, it is necessary to consider whether it is fair to use the resources in this way instead of some other way. Finally, public values should be considered.
4.6 Great Britain

The National Institute for Clinical Excellence (NICE) was established in 1999 in Great Britain to promote assessments to identify treatments that are most cost-effective. NICE has independent status within the National Health Service (NHS) to be able to fulfil its charge to submit recommendations on the use of medical methods and treatments for various disease groups. During the autumn of 2002, NICE appointed a Citizen’s Council to secure public influence in the decision-making process. The Citizen’s Council aims to provide proposals to NICE regarding how to address issues related to values. It includes up to 30 members of different age, gender, social class, and ethnic background.

At the local level, the Clinical Ethics Committees has begun to discuss prioritisation issues concerning patient care. The committees are active within various primary care organisations. To date, no ethical principles have been presented by these ethics committees. Some primary care organisations have also established prioritisation forums to present proposals regarding how priorities among different patient groups should be set at the local level.

The Oxfordshire Priorities Forum is the forum that has progressed farthest in their prioritisation efforts. They have developed an ethical framework that provides the basis for their decisions (see website for UK Clinical Ethics Network).

The NICE Citizen’s Council has also discussed questions on determining clinical needs and on age differentiation in determining the cost-effectiveness of treatment. In conjunction with the former issue, the panel concluded that the characteristics of illness that should influence the judgment of clinical need are those that determine the level of severity and the benefits of treatment. They emphasise that there should be no discrimination based on ethnic background, gender, or housing situation. As regards age differentiation, a majority found it to be legitimate if age influences disease risk or clinical effectiveness. However a majority opposed any age differentiation for reasons that different age groups often play different social roles or that different age groups have had different opportunities to experience life.

The Oxfordshire Priorities Forum developed an ethical framework including three principles: effectiveness, equal treatment, and patient choice. In deciding which treatments or drugs should be financed, one should consider whether the effects have been scientifically documented. Furthermore, all patients should be treated equally, irrespective of age, gender, and social status. It is also important to consider patient choice.
4.7 Canada

According to Martin and Singer (Martin and Singer 2003) no general guidelines for priority setting have been formulated in Canada at either the national or regional levels. It is also difficult to present a general profile of prioritisation in Canadian health services since priorities are set at national, regional, and local levels via many different methods, processes, and techniques. Priority setting takes place through a relatively well-developed system for technology assessment, analysis of cost-effectiveness, and waiting-list management. No national authorities are responsible for prioritisation, so decisions of this type are left to leaders at the regional and local levels.

Often the theoretical discussion and research on priority setting has been based on the concept of “responsibility for reasonableness” – which means that the grounds for fair prioritisation should be certain discursive procedures rather than universal and substantive principles.

The outcome of the procedures can be characterised as fair if they fulfil the following criteria: public access, relevance, appeals, and regulation. In a general review of Canadian health services, Martin and Singer conclude that these four conditions are seldom fulfilled.

4.8 Principles and Guidelines in Other Countries

Countries that have formulated national ethical guidelines and principles for priority setting, ie, Norway, Denmark, Finland, the Netherlands, and New Zealand, share many similarities. In all countries, need or severity levels are key prioritisation principles.

Treatment benefits or effects are also important grounds for priority setting in other countries. Inquiries in Norway, Denmark, Finland, the Netherlands, and New Zealand concluded that treatments with documented benefits should receive priority. All of these inquiries also found cost-effectiveness to be an important principle in setting priorities. One should select the treatments that have the greatest effects in relation to their costs. Since the principles of severity level, benefit, and cost-effectiveness are found in each of the countries, perhaps these can be interpreted to be fundamental and obvious starting-points for prioritisation. Another explanation can be that the authors of the different reports were aware of what had been presented elsewhere.

Another key point of departure for priority setting is justice or equal treatment. The most recent Norwegian inquiry (NOU 1997:18) states that if a particular
patient is offered a health service, then all patients in the same situation should receive the same offer. Denmark and Finland hold the same view, where people in the same situation should be given equal access to the supply of health services. Some of the inquiries also describe self-responsibility as a basis for prioritisation. Authors of the report in the Netherlands wrote that treatments that patients can perform themselves could be excluded from the base package. The most recent Norwegian inquiry addressed how one should choose among different prioritisation principles. It avoids strictly ranking principles based on severity level, expected benefit, and cost-effectiveness. The report suggests it is not reasonable to prioritise the most ill, regardless of treatment benefit, in all cases. This would involve too great a sacrifice for those with less severe disorders, but who could be helped considerably more by treatment. Nor can a strict ranking be performed among severity levels and cost-effectiveness.

Major similarities also exist among the descriptions of the criteria that should not form a basis for priority setting.

The reports from Norway, Denmark, Finland, the Netherlands, and New Zealand are generally sceptical towards setting priorities based on age. They suggest that age can only be a relevant criterion in certain instances in prioritisation at the clinical level, eg, when patients cannot access a treatment due to age-related weakness. According to the Norwegian, Danish, Finnish, and Dutch reports, it is also problematic to give lower priority to patients with a lifestyle that endangers health. Lowering priorities in this way can only be reasonable when a lifestyle change is necessary for treatment to take effect.

Similar to the reports in other countries, the NICE Citizen’s Council describes the severity of disease and benefit of treatment as important departure points in prioritisation. Furthermore, they suggest that age differentiation can be reasonable when age influences the risk for disease, or the effectiveness of a treatment. Treatment benefit is an important basis for setting priorities, according to the ethical framework established by the Oxfordshire Priorities Forum. This framework also includes the principle on equal treatment.

4.9 Comparing Principles Between Sweden and Other Countries

The human dignity principle in the Swedish Priorities Commission report corresponds to the equal treatment principles in Denmark, Finland, and Norway. Self-responsibility or personal responsibility that appears in the report from the Netherlands is not included in the Swedish ethics platform. In contrast to the Swedish Commission, the reports from other countries do not strictly rank the
various prioritisation principles. In fact, the Norwegian inquiry expressly distances itself from such a strict ranking.

Major similarities are also found between the Swedish Priorities commission and other countries as regards the description of what should not be grounds for prioritisation. The Swedish report particularly distances itself from the idea of denying priority to very elderly patients. According to the Commission, it is necessary to consider which medical interventions older patients can tolerate and benefit from. (Socialdepartementet 1995) A similar view towards prioritisation based on age is found in the reports from Denmark, Finland, the Netherlands, and New Zealand and in the guidelines presented by the NICE Citizen’s Council in Great Britain.

Likewise, the Swedish Commission indicates that people with self-inflicted injuries should not be subjected to negative, special treatment. One reason given is that it can be difficult to determine the extent to which some diseases result from genetic factors or from a particular lifestyle.

Furthermore, some harmful behaviours such as drug abuse often deteriorate relatively early in life and are more frequent among individuals with lower education and social status. Denmark, Finland, the Netherlands, and Norway take a similar stance as regards self-inflicted injuries.

In contrast to the other countries, benefits or effects are not expressed principles in the Swedish Commission. A specific feature of the Swedish Commission, however, is that it rejects the benefit principle, ie, interventions that provide the greatest benefit for the most people should be selected. According to the Swedish Commission, eg, we should not give mild problems high priority, even if they are inexpensive to treat. (Ministry of Health and Social Affairs 1995)

One of the most important differences between the Swedish guidelines and those in other countries is the strict ranking between the different prioritisation principles in Sweden. The debate in other countries indicates that strict ranking between the needs and solidarity principle and the cost-effectiveness principle can be problematic. The most recent Norwegian report states, eg, if priority should always be given to the most severely ill regardless of treatment benefit, it would lead to unreasonable hardship for people with mild illness who could improve substantially with treatment.

4.9.1 Conclusions
• The three prioritisation principles approved by the Riksdag are also common in the guidelines in other countries.
• In contrast to the Swedish Priorities Commission, the reports from other countries do not strictly rank the different prioritisation principles. The Norwegian report expressly dismisses any such ranking.
• Treatment benefits or effects comprise an important basis for prioritisation in other countries. A specific feature of the Swedish guidelines that it dismisses the benefit principle, ie, that interventions yielding the greatest collective benefit should be chosen.
• There are major differences between the Swedish Commission and reports from other countries as regards what should not be used as a basis for setting priorities.
• Some of the reports include personal responsibility as a basis for prioritisation. The report from the Netherlands suggests that treatments which patients can manage themselves could be excluded from public health services.
5. PROPOSED CHANGES IN THE PRIORITISATION PRINCIPLES

5.1 Human Dignity Principle

The idea that all humans are of equal worth is, as discussed earlier, strongly anchored in Sweden and internationally. This is expressed in the Swedish constitution and in the UN Declaration of Human Rights. The idea has achieved strong symbolic value. It implies that people should be treated with respect and from the standpoint of a humanistic view of mankind. It also implies that people should not be discriminated against, or given special treatment, without legitimate reasons. It is easy to understand the unity on, and the widespread adoption of, the fundamental values expressed in the idea of equal human worth. However, the idea must be further defined to give sufficient guidance for decisions on resource allocation. Presumably this will probably reduce unity. What are the consequences when everyone has equal value, or should be treated with respect, in a situation where everyone’s care needs cannot be fully met, and some form of special treatment becomes necessary? What reasons for special treatment are ethically defensible and simultaneously concur with the idea of equal human worth?

5.1.1 The Commission’s interpretation of the human dignity principle

The Priorities Commission interprets the human dignity principle to mean that everyone has equal worth and equal rights, regardless of personal characteristics and functions in society. The expression “equal rights” is an incomplete expression and must be fully formulated to offer guidance. People not only have the same rights, they also have rights to something. Hence, the question is: Equal rights to what? The response of the Priorities Commission is: “equal rights to:

- have their care needs assessed
- have their care needs addressed in relation to the level of severity of the disease/injury.

Furthermore, the Commission proposes further definition of the principle. We should not consider personal characteristics such as talent, age, or gender – nor should we consider economic capacity or function in society, eg, social position or social responsibility.

When resources are scarce, it is impossible from a practical standpoint for health services to strictly adhere to the standard that everyone has equal rights – since everyone cannot have their needs fully met.
Hence, people must be treated differently. According to the Commission, the magnitude of need is an ethically defensible reason for special treatment – people with greater needs should receive priority over people with lesser needs. The magnitude of need should be judged on the severity level of the *disease or injury*. In other words, needs resulting from disease and injury comprise an ethically defensible reason for special treatment, according to the Commission.

The idea that people should not receive special treatment (positive or negative) based solely on personal characteristics or function in society is common in our culture. Hence, it is easy to reach agreement that the magnitude of need should comprise an important basis for resource allocation. Therefore, agreement or unity probably decreases as the needs principle becomes more specifically defined in terms of how magnitude is determined. The Commission’s proposal implies, as mentioned earlier, that the magnitude of need should be determined according to the severity level of the disease or injury. Suffering that cannot be attributed to such causes (e.g., involuntary childlessness or aesthetically stigmatising appearance), and can be treated only via health services, automatically implies a lower care need regardless of how much suffering is involved.

Neither the Commission nor the subsequent government bill provide any explanation why treating people differently based on the *cause* of their suffering is consistent with the human dignity principle. An alternative that we believe should be considered involves basing special treatment on the degree of suffering. Hence, it would not matter if disease or injury caused the suffering. The decisive factors would be the severity level of suffering and the availability of effective treatment.

Presented below is an alternative proposal for further defining the human dignity principle. It discusses other ethically defensible reasons for treating people differently.

**5.1.2 Proposed alternative interpretation of the human dignity principle**

Equality of human worth is also the point of departure in the alternative interpretation. All humans have self-worth, and they have the *same* self-worth. However, it is a trivial concern that people are more or less valuable to society, to the labour market, or to other people. Some people have key positions in society and are therefore more valuable in these respects. Differences in income might be an expression that people are perceived to have different value in the labour market. For parents, their own children are more valuable than the children of others. *Human dignity*, however, is associated only with the characteristic of being human, and since we are humans to the same degree, no human life has greater intrinsic worth than any other.
We believe that the concept of equal human dignity should be expressed as a general working principle and a general attitude towards people. As in the Priorities Commission, the expression “equal worth” is interpreted to mean “equal rights”. However, the expression “equal rights” will be given an alternative interpretation as regards what the rights refer to.

Operational principle: *The human dignity principle implies that everyone has an equal right to the necessities for living a good life.*

The nature of the prerequisites implied here can vary. For instance, they can involve material conditions such as income and housing, or education and knowledge, or upbringing and health.

The general operational principle that follows from the alternative interpretation of the human dignity principle means – expressed in terms of obligations – that society, health services, or people in general have an obligation to respect this right. The principle is general and is applicable to all conceivable human actors. To provide guidance for decisions in the public sector it must be operationalised to adapt to different areas and actors. Operationalisation can vary. For instance, it is not intended that health services should create or influence all prerequisites. Health care should only influence the things it has the expertise to influence. Primarily, it should focus on the health or quality-of-life components for a good life. This will be developed further in a later section addressing healthcare goals and what constitutes a good life.

A general attitude among people is also advocated – respect for human worth means that we should respect human dignity. We should show respect for people’s integrity. Hence, from the outset we should consider people to be capable agents who can take responsibility for their own actions. It involves showing respect by adopting a particular attitude. We should avoid, eg, viewing people to be victims with no will of their own. A common way to avoid showing respect for someone’s integrity is to ‘victimise’ them – eg, to explain their situation based only on external causes. Obviously, many people are affected by external or internal situations for which they cannot be held accountable – eg, accidents and genetic predisposition. Victimisation automatically releases people from the responsibility for a difficult situation without further awareness about the conditions.

General attitude: *The human dignity principle implies equal rights for respect concerning one’s dignity.*
The general attitude implies that, from the outset, people are considered to be autonomous individuals given their individual situations, ie, with capacity for different levels of responsibility. Individuals are considered as free and capable beings that can take responsibility for the consequences of their actions based on their individual prerequisites.

In decisions on resource allocation, the general attitude implies that we should use a responsibility principle. This principle means that individuals must take responsibility for their situation both in regard to their health and in regard to their care (a responsibility principle is discussed later).

5.1.3 Operationalising the human dignity principle
The specification of the human dignity principle that we propose is that people have equal rights to the conditions for living a good life. Hence, society, health services, or other institutions have an obligation to create such conditions. To more precisely describe the obligations involved, the “good life” concept must be defined along with what it means for everyone to have equal rights.

**Concept of “good life”**
A good life means having an optimally long life with a reasonable degree of quality and respect for integrity. The good life concept includes three fundamental components – length of life, quality of life, and integrity. Hence, a good life varies with the degree of length, quality, and integrity.

Length of life varies among people and is influenced by many factors. We can influence several of these factors, others we cannot. How good a life has been is not affected by what has shortened it. Only length is of importance if the other components are constant. The second fundamental component concerns a person’s quality of life. A life with poor quality implies a life that is less favourable, everything else being equal. Quality of life as addressed here involves a combination of living conditions and well-being. Living conditions are comprised of health-related, psychological, social, or material conditions while well-being concerns a person’s psychological state. It concerns how a person feels physically or mentally. Living conditions and well-being are related – good living conditions often generate good well-being. However, the two components can also take opposite directions. A person might have good living conditions, but nevertheless experience poor well-being. Assessment of the quality of life must therefore consider both components – not how they are combined mathematically, but how they are balanced.

The third component in the good life concept concerns a person’s integrity. The higher the degree of integrity in a person’s life, the better that person’s life is.
Someone’s integrity is influenced in part by other people and in part by the person themselves. We can violate someone’s integrity by not treating that person as an independent and capable individual. Treating a normally talented adult as a small child is an example of violating and diminishing that person’s integrity. Another example would be a lack of respect for an individual’s autonomy, which can involve withholding or distorting important information and manipulating or forcing someone into a particular type of behaviour.

We can even affect our integrity through our own behaviour. At times, we say that someone demonstrates high integrity. Perhaps it is someone who does not yield to inappropriate pressure. A high level of integrity often characterises a person who foregoes personal gain in favour of other values. Moral integrity implies, eg, that the individual places moral actions ahead of personal gain. High integrity is usually associated with traits such as honesty, loyalty, and fairness.

In determining the degree of good life, the three components (length of life, quality of life, and integrity) are not consolidated into a common measure. In other words, we have no uniform or index-like measure for a good life. Rather, we can address different aspects of a good life. Someone who dies at an early age may have lived a good life in terms of quality and integrity, but not in terms on length.

What is meant by equal conditions for a good life?
That which comprises the conditions for a good life varies by individual since different individuals have different interests. Some of the conditions we cannot change, while others can be changed, eg, by health services. Some individuals have a genetic predisposition for a long life – others do not. Material and economic conditions are examples of other factors that can be influenced. Health services can influence human health through, eg, prevention, cure, or rehabilitation. Even those things that create integrity can vary with the individual’s situation. For instance, some people find it more important than others to be treated as an independent individual. This individualisation means that the same type of condition (certain education, certain material conditions, etc) can have different contributions towards a good life. Hence, the expression “equal conditions for a good life” does not refer to identical conditions, but to the conditions required for a good life in the individual case.

The idea of a right to equal conditions for a good life includes an equality aspect. Equality does not concern the conditions per se, but the level of the good life. Ideally, everyone could achieve a maximum level of the good life. Since this is not possible, it involves aiming for an optimum level.
Therefore, we should be able to formulate the operational principle in another way: Everyone has an equal right to the necessities for achieving their optimum degree of a good life.

5.1.4 Human dignity principle as a guide in resource allocation decisions

Even in this alternative interpretation, the human dignity principle indicates what we should not consider in distributing scarce resources. We should not consider personal characteristics such as chronological age. However, we should consider biological age, and thereby avoid harming patients who cannot survive a medical intervention due to weak physiology. However, at times it could be practical at a group level to use chronological age as an indicator of biological age.

The equality aspect of the concept “equal right to the conditions for a good life” means that, eg, health services are obligated to help everyone to the extent possible have the opportunity to live a good life. A consequence of applying the human dignity principle could be that a young person who is at risk of losing the opportunity to live a good life, eg, due to disease or injury, will be ranked ahead of someone who has already lived a good life. The consequences are similar to those that would arise from prioritisation based on chronological age. But application is not based on evaluating age, degree of health benefit, or social benefit, but on the requirement for equal opportunity to live a good life. The above ranking between young and old also finds support from the concept of solidarity. According to this idea, people should show solidarity with each other. In a situation where none of the other principles offer guidance, it would appear to be more reasonable for the older to show solidarity towards the younger, and step aside, than the other way around.

According to the human dignity principle we should not consider general functions in society in allocating resources. However, in particular situations, it could be in line with the principle to consider that certain people provide special functions that involve helping others. For instance, in a threatening influenza epidemic it would be in line with the human dignity principle to prioritise people whose task it is to help other people. Therefore, administering vaccine to health services personnel could be viewed as a way to enable staff to maintain sufficient health to continue providing care to patients suffering from influenza.

The human dignity principle also suggests goals for health services. In this report, the human dignity principle will be operationalised in terms of those obligations generated by the right to the conditions for a good life.

An initial step towards the general operationalisation principle can be to limit the scope of obligation.
All of society’s resources should not be allocated to health services even if this would be required to meet all care needs. Other sectors must also be assured of resources that contribute towards conditions for a good life. Furthermore, demands on the individual to contribute towards conditions for other people should not be so high as to negatively affect the individual’s own opportunity to create the conditions for a good life.

The human dignity principle also suggests the role of health services. It will be described here in terms of two components, ie, goal and domain. The goal indicates what should be achieved, how much and when it should be achieved. The domain, on the other hand, deals with means or types of actions to realise the goal (see section on goal concept). Several institutions in society in addition to health services, eg, schools and social services, have the goal (according to the human dignity principle) to create the conditions for a good life. They operate, however, within different domains dependent on separate types of activities. The domain is defined by the collective expertise within each institution. Hence, the domain of health services will be limited by its expertise in relation to other actors. The most cost-effective interventions should be used to address needs regardless of the social institution involved. Hence, the obligation of health services is to contribute to a good life through using its expertise in a cost-effective way. A domain’s boundaries will vary with the cost-effectiveness of the actions involved.

This reasoning leads towards a more defined operational principle and an operational goal for health services.

Defined operational principle: Health services are obligated to contribute in an equal and cost-effective manner towards what people need to live a good life.

Operationalised goals for health services: Fight ill health or low quality of life.

5.1.5 Human dignity principle – concluding comments
The human dignity principle covers everyone – including refugees and illegal immigrants. Hence, it is contrary to the human dignity principle to deny these groups access to needed care.

The obligation to contribute in an equal way to conditions for a life with dignity means that age cannot be used as a basis for prioritisation. It would be contrary to the human dignity principle to consider chronological age in priority setting and rationing. However, consideration should be given to biological age since it relates to an individual’s ability to survive or benefit from an intervention. Exposing patients to excessive risk in pursuing health conditions for living a good life would conflict with the human dignity principle.
Applying the human dignity principle places an emphasis on preventive activities, which helps people take responsibility for their health and care. The principle does not involve an obligation to create a good life, but the *conditions* for such a life. Maintaining these conditions is then a matter of individual responsibility. The conditions could involve information and knowledge about risk factors or health factors affecting sickness and health. But they can also involve improving – or preventing deterioration of – general living conditions (eg, income, employment, housing, social relationships). What exactly comprises the domain of health care as regards prevention depends on the extent to which it can employ the most cost-effective methods. To succeed, prevention often requires collaboration among several major actors on a broad front.

In the difficult choice between, eg, preventive, curative, and rehabilitative activities, the human dignity principle does not provide sufficient guidance as an operational principle. Creating the conditions for a good life involves, on one hand, preventing a poor life. But on the other hand, this involves restoring a life that has deteriorated because of ill health. Hence, health services and other institutions must set aside resources for all of these areas.

The human dignity principle also concerns an attitude that, from the outset, considers people to be autonomous individuals. Given their individual abilities, they are considered capable of taking responsibility for their own lives. This attitude provides incentive to give high priority to preventive activities – assuming effective methods are available. For people to be able to take this responsibility they must have, eg, the educational and environmental prerequisites. If society withholds important knowledge, or consciously avoids improving living conditions, this does not create the conditions for a good life.

We propose the following general statement to describe the human dignity principle: *Everyone has equal rights to what is necessary for a good life and respect for their dignity.*

We also propose a more specific operational principle and an operational goal for health services: *Health services are obligated to contribute equally and cost-effectively to what people need to live a good life. The operational goal for health services is to combat ill health or poor quality of life.*

The interpretation of the human dignity principle in this modified version is similar to the Priorities Commission’s version in the way it considers personal characteristics and functions in society. According to both interpretations, we should not consider these factors in allocating resources within health services. The interpretation of the human dignity principle expressed in this report differs, however, from the previous interpretation on the following points:
• The principle more specifically indicates what people have a right to, namely equal conditions for living a good life.
• The principle provides goals and objectives for health services.
• The principle refers to a general attitude – we should respect the dignity of people by showing respect for human integrity. This in turn means, eg, that at the outset we should consider people to be capable agents who can take responsibility for their own actions.
• The principle emphasises the objective of preventive interventions to increase opportunities for people to exercise responsibility for their own health and care.

5.2 Mission of Health Services

The mission of health services is important in further defining both the needs principle and the cost-effectiveness principle. Having a need means not only needing something, but also needing this something for some purpose. We need preventive services to reduce the risk for ill health. We need health services to achieve health. The structure of the needs concept is that whatever we need, we need it to achieve a goal. This goal plays a decisive role in determining need. To further define the needs principle, we need to answer the question: What are health services are actually for?

Judging the effects of an intervention involves choosing an effect measure (endpoint). The point of departure in this proposal is to select an effect measure relating to the healthcare goal. The better the goal attainment, the greater the effectiveness of the intervention.

5.2.1 Goal concept
A goal can be discussed and described in three dimensions – qualitative, quantitative, and temporal. The qualitative dimension addresses what should be achieved. This dimension is most common in goal descriptions. Goals described in the qualitative dimension would include health, quality of life, or freedom from disease.

The quantitative dimension of a goal addresses how much should be achieved by that which comprises the qualitative dimension. This could include the level of health (if health is the qualitative dimension) that the individual should have (full health, optimal health, or a threshold value of health), how long they should remain in the qualitative state (eg, throughout life or only throughout working life) and how this state is distributed among individuals (eg, distribution of health in the population).
The temporal dimension concerns the *time frame* in which the goal should be achieved. For instance, we can speak in terms of immediate, medium-term, and long-term goals.

**Goal hierarchy**

Complex organisations commonly present their goals in a structured hierarchy, showing how different types of goals relate to each other. In this section we discuss the distinction between final goals, operational goals, and domain.

The reasons why we try to achieve a goal can vary. We can attempt to achieve goals for their own sake, or to achieve other goals. At times, we might have a sequence of goals that follow a hierarchical order. A goal we try to achieve for its own sake will be called a *final goal*. A goal that we attempt to achieve in order to reach another goal will be called an *operational goal*.

Many processes in health care and social services include some form of operational plan. This plan might contain several operational goals in addition to the final goal. The final goal, operational goals, and what will be called the organisation’s *domain* comprise the components in an interrelated goal structure.

**Difference between goal and domain**

An organisation’s domain is related to the organisations goal, but concerns mainly the area of activity or approaches used to achieve the goal. The difference between goal and domain can be illustrated by an example involving national defence. The army, air force, and navy all have the goal of defending their country. However, they have different domains and different operational goals. The army defends the land, the navy defends the sea, and the air force defends the skies. Hence, domain is not defined by a geographic boundary, but by the type of action or field of operation. The special expertise of the actors determines the area within which it is rational to operate.

In similar fashion, the domains of different professions in health care and social services can be defined by the rational use of the expertise in the respective professions. Politicians, administrators, and people working in health care and social services might all have the health of the individual as their goal. But since their expertise varies, it is logical for them to take different pathways towards the goal. Politicians might focus on economic conditions, administrators on organisational aspects, and healthcare staff on various treatment methods or interventions, to mention a few examples.

A domain relates not only to a final goal, but also, and primarily, to an operational goal. The goals we discuss here concern conditions that we should, or want to, achieve.
In some situations we try to achieve a goal for its own sake. These goals are called *final goals*. Achieving a final goal could require numerous actions in several domains. In certain situations, carrying out all actions in a particular domain might only partially reach the final goal. Fully achieving the final goal in such a situation requires completing all actions in every domain. The *operational goal* is achieved by completing all actions within a specific domain. Assume that health education comprises most of the domain of a particular health profession – the profession will then work towards reaching the final goal by operating within this domain. In this instance, knowledge and health are the operational goals.

### 5.2.2 Goals, domains, and mission of health services

The point of departure in this report is that healthcare goals should be ethically grounded. The human dignity principle is the ethical principle that addresses both goals and mission. The principle holds that all people have the same right to the conditions for a good life. The final goal is then equal conditions for a good life. The final goal should be realised through health services using their competence in a cost-effective way. This requirement leads to domains, (medical methods, nursing, etc) and operational goals (to combat ill health or poor quality of life). Together, domains and operational goals form the mission of health services.

We propose the following goal, domain, and mission of health services:

**Final goal of health services:** *contribute towards creating equal conditions for a good life.*

**Operational goal:** *combat ill health or poor quality of life, which also includes equalisation of differences in health or quality of life.*

**Domain of health care:** *use cost-effective means, based on appropriate expertise, to combat ill health or poor quality of life.*

**Mission:** *based on its collective expertise and in an equal and cost-effective way, prevent, investigate, treat, restore, and ameliorate the effects of ill health so people are able to live a good life.*
5.3 Concept of Health

Health and quality of life form the operational goal for health services. This means that the concepts need and effectiveness are defined in relation to this operational goal. Interventions are needed to restore or maintain health and quality of life. The effects of an intervention should be judged in relation to the degree of health or quality of life achieved. To further define the operational goal, it may be helpful to briefly introduce the concept of health. (For an introduction of the concept “quality of life” see under the heading “good life”.)

The health concept can be analysed in several ways. Generally, we can divide health theorists into two groups. One group analyses the concept of health in terms of the absence of disease, while the other group analyses the concept of health in terms of the ability to act.

5.3.1 Disease-based health concept

American medical philosopher Christofer Boorses uses the term “subnormality” as a keyword in his characterisation of disease. A disease is something that impairs normal function in some organ or organ function. The sign that disease is present is observed when functions deviate in a subnormal way from what is typical for the human species. Normality, therefore, is statistical normality. (Boorse 1977) In this approach, disease is the fundamental concept. Health is characterised in terms of disease. A person is sick or has ill health if he or she has at least one illness. Here we have an example of the popular idea that health is the absence of disease.

5.3.2 Activity-based health concept

According to the World Health Organisation (WHO), health is “a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity”. Here we have a concept of health that we could call maximally holistic. According to this perspective, health is something other than the absence of disease. The WHO health concept moves us away from a disease-orientation and closer to the existential side of the human state. Since health is equivalent to well-being, the concept tends to be very inclusive. Someone who has a poor level of well-being then automatically (per definition) also has a poor level of health.

A key term among the health concepts grounded in a more limited holistic perspective is ability to act. This gives rise to the expression “activity-based health concept”. This holistic approach is characterised by its emphasis on three factors. First, the individual as a whole person and his/her relationship to his/her environment is key. Mainly, it emphasises the key role of activity in a person’s life.
Second, health is the fundamental concept, and the concept of disease is defined in terms of health. Third, health is not the same as well-being, but something that tends to contribute to well-being.

Several types of activity-based health concepts have been presented. (Nordenfelt 1987) According to an oft-cited analysis, health consists of having the ability to do that which is important for the individual. More precisely, health is the ability, under standard circumstances, to achieve one’s vital goals.

5.3.3 Health concept – final comments

We propose that an activity-based concept of health should be used as the operational goal for health services.

What does it mean to use a concept of health grounded in activity-based theory? For example, will it be less interesting to combat diseases? No, obviously not, for the simple explanation that most diseases attack the basic abilities of the individual. Regardless of which of these abilities to act are important to the individual, most diseases will limit these abilities.

The use of an activity-based health concept can therefore place certain demands on the relationship between health services and individuals in a society. Every individual has a unique set of vital goals. Since these vital goals determine the individual’s health conditions, the concept of health is individual-related. However, this point should not be exaggerated – certainly there is substantial similarity in the vital goals of humans.

Consequences of resource distribution in health services

Using an activity-based health concept as a goal for health services has major consequences when compared to using a diseased-based concept. First, it broadens the mission of health services. It is no longer simply about combating disease or injury. Everything that influences the ability to act, and which health services can effectively address, will be included in the mission. This does not automatically mean that all services need to be reimbursed by state funds. Second, the needs principle will be defined differently. An improved or maintained ability to act now comprises the needs goal. In other words, the intervention is needed to affect the individual’s ability to act. Third, the definition of the cost-effectiveness principle has an impact. Endpoints should be chosen in relation to the effects of the ability to act. The more positive the effects on the ability to act, the greater the intervention’s effectiveness. In this context, the ability to act refers not only to physical ability, but also to mental ability.
The health concept proposed in the report is an individual related-concept. Having health means that individuals have the ability to realise their goals – hence, the lower the ability the higher the degree of ill health. This means that the severity level of the need per se is not determined by the type of disease or injury or degree of functional impairment, but by the consequences for a person’s ability to do that which is important to him/her. The same level of functional disability can therefore cause different levels of difficulty for different people. A mild impairment in one hand might have little practical effect on one individual, while it would cause severe consequences for another (e.g., pianist or artist). In a social culture where salaried employment and self-sufficiency is considered important, the application of an individual-related health concept could mean that it is more important for an employed person to quickly regain their ability compared to, e.g., an elderly pensioner. In this case, the employee should be ranked ahead of the pensioner – not because of the public welfare, but because of the severity of need. In prioritising at the group level, where it is difficult to consider the individual, this means that people in the workforce should be ranked ahead of people who are not.

5.4 Needs Principle

The Priorities Commission and the subsequent government bill combined the needs principle and the solidarity principle. We recommend separating these principles. The advantage of separation is that it is more apparent when the two principles are in conflict. The needs principle could be formulated as follows:

*Resources should be distributed according to health-related needs, and needs with a high level of severity should take priority over needs with a low level of severity.*

The severity level of need should be determined based on the level of ability to act – the lower the ability to act, the higher the level of severity.

This statement, however, must be further defined. What does it mean to distribute according to need? It partly involves defining the needs concept and partly involves ranking the needs. An important question is “What is care needed for?” Here we tie into the reasoning behind the goal of health services.

5.4.1 Concept of need

Two traditions appear in the literature concerning the concept of need. One looks at need as internal tension or disequilibrium in the individual. Having a need based on this tradition, means finding oneself in a psychological state. It might deal with the individual’s desire or motives.
The second tradition looks at need as something instrumental or goal-related. A descriptive statement of this perception would be: “P needs X to the extent that X is necessary to realise a particular state or goal”. Need as internal tension cannot be applied to health services since, eg, even unconscious people have needs. Here we follow the Priorities Commission and adopt the goal-related tradition. (Liss 2003)

A goal-related need is by nature a relation, or gap, between an actual state concerning the individual and a norm that prescribes something desirable, or a goal. The gap is what comprises the need. From this perspective, when someone has a need it means that a gap affects the individual. This applies to all types of needs. The actual and desired state, or goal, in question is determined by which type of need is present in the particular situation. In the example of economic assistance it involves economic conditions. In other contexts other conditions can be involved. For instance, a person who is starving and needs nutrition is affected by a gap between the person’s actual nutritional state and the desired nutritional state.

Concerning the need for care, we speak about a gap between an actual state of health and a desired state of health, or goal. This gap involves not only the current condition, ie, how one feels today, but also the risk for future ill health. It is about a health gap or a health-related need (Figure 2). For instance, someone who needs antihypertensive medication has a gap between current blood pressure and desired blood pressure. In social services, the gap might involve quality of life – a gap between current quality of life and desired quality of life. A population that needs preventive interventions could have a gap between current risk levels for ill health and desired risk levels. Generally, if someone or something has a need, there is a gap between the current and the desired state. In this context, the current and desired states should be understood from a broad perspective. Not only statistical conditions are involved, but also changes or processes. A person’s current state could be described as a slow deterioration in health status, or the desired state could be described as an improvement in the person’s health.

To clarify the idea of need as a gap between current and desired states, we might consider a situation where there does not appear to be a gap expressed in current health. A person with poor living habits from a health perspective, but who is otherwise healthy, is advised that he/she needs a better diet and more exercise. Here there does not appear to be a gap between the health dimensions at the time, but there is a risk for ill health in the future, ie, a gap between current risk and desired risk.
In the above example, the goal (the desired state) was a lower risk for deterioration of health. The goal could also have been to minimise deterioration. Perhaps it is not possible to completely stop the deterioration in the person’s health. In such a situation the goal becomes to achieve as little deterioration as possible. In other words there is a gap between the current state (major health deterioration) and the desired state (minor health deterioration). Hence, the person has a need for an intervention that leads to as little deterioration as possible.

To facilitate this presentation, the discussion will continue in terms of care needs and health. We can consider the gap between actual state and desired state to lie along a health dimension. In principle, the same reasoning is appropriate for other dimensions, eg, quality-of-life dimension that can be used to assess quality-of-life-related needs or social service needs.

*When someone needs care: (a) there is a gap between the current state of health, and desired state of health, (b) care is necessary to achieve the desired state of health.*

The Figure below presents a graphic illustration of the definition.

**Figure 2 Health-related need.**

![Health-related need diagram](image-url)
Usually, a needs assessment does not conclude with stating that a need exists, ie, a gap between the current and desired states (current state and desired state describe not only how a person feels at the time, but also the risk for future ill health). The next step in the assessment concerns the question of what a person or population has a need for. Hence, this involves the intervention need, ie, the agents, interventions, or treatments necessary to eliminate the gap. In the case of an application for economic assistance, the social worker must determine the appropriate amount of aid after receiving confirmation that a gap exists between the current economic situation and the prescribed welfare norm. The physician must determine necessary interventions to achieve correct blood pressure, thereby lowering the risk for poor health in the future. Those working with health promotion must propose necessary steps to reduce the risk for disease or injury in the population. In determining whether a care need exists, this line of reasoning requires two conditions to be met:
1. A gap exists between a current state of health and desired state of health.
2. Care is necessary to eliminate this gap.

To determine the presence of an intervention need, it is necessary to answer two fundamental questions:
1. Is there a gap between the current state of health and the desired state of health?
2. If yes, is care necessary to bridge this gap?

To answer these questions we need information about the three fundamental components:
- actual state
- desired state
- interventions needed to achieve the desired state.

Information about the first two components is necessary to be able to judge the health-related need, while information about the third component is necessary to be able to judge necessary interventions (intervention need). Information about the current state should be sufficiently specific and comprehensive to enable one to determine necessary interventions.

Exactly what information is important will be determined by the purpose of the needs assessment, the desired state, and health- or disease-specific factors. In our proposal, health and quality of life comprise the operational goal for health services, which means that need should be judged according to the consequences for the individual’s state of health or quality of life. Hence, pain or functional impairment per se are not what is important, but rather the consequences that pain or functional impairment have for the individual’s health or quality of life.
The desired state is an important, but often underestimated, component in the concept of need. It is the state we intend to achieve by satisfying the need. Hence, it can appropriately be considered a goal. The goal can be decisive as regards the dimension that will be appropriate for describing the current state. If the goal is to be pain-free, it could be appropriate to describe the current state in levels of pain. If the goal involves mobility, then functional impairment could be suitable for describing the current state. In determining intervention needs, the operational goals of health services comprise the desired state.

Secondly, the goal is necessary for determining needed interventions. The goal that the individual should be able to manage at home may require entirely different interventions than the goal to be pain-free at rest. The goal to reduce falls among the elderly by 20% within ten years might require substantially more intervention than the goal to reduce falls among the elderly by 10% within the same time frame. The choice of goal influences the character of the gap, which in turn affects the scope and direction of the intervention necessary to achieve the goal. As discussed earlier, health or quality of life are operational goals in health care.

Several steps can be involved in determining the necessary interventions or the intervention needs for attaining the goal (desired state) given the current state. The first step could involve determining which health-related needs should not be addressed by health services. These might be needs that require intervention only by actors outside of the health services sector, eg, social services.

The second step involves determining the character and scope of the health interventions necessary to address the needs that should be addressed within the framework of health services. This involves judging which type of intervention or investment is required to achieve the goal, given the current state of health. Hence, this decision requires more specific information about the current state and the operational goal.

Furthermore, information is necessary about characteristics of the necessary interventions. For an intervention to be necessary it must be effective. Hence, there can be no need for an intervention that is not effective in some way. In certain situations, only one type of intervention works. In other situations, many types might work. In these situations, an appropriateness criterion must be used to choose among them. Patient preference, cost-effectiveness, and interventions that meet several needs are examples of potential appropriateness criteria. According to the Health and Medical Services Act, if needs assessment is the basis for prioritisation, then cost-effectiveness should play a decisive role in choosing among appropriate interventions for a particular health-related need.
**Who should determine need?**

This is a difficult question to answer generally. Giving a reasonable answer requires that we consider multiple aspects of different types, eg, political and organisational. However, in principle, those with responsibility for allocating resources should also have ultimate responsibility for the needs assessment.

**5.4.2 Ranking needs**

To *rank* needs we need to place a given number of needs in a particular order. To do this in a rational way we must compare the different needs in a particular context. In this context, different needs will then be given different values. To *grade* needs means to assign a measure or value to a need.

A particular grading of needs, however, does not necessarily yield a particular ranking. A need can be graded in several ways, and the choice of grading does not determine the ranking to be used. However, we have decided what this ranking should be based on. Assume that we decide to use suffering as a grading dimension. This decision does not mean that we have also determined whether the need that involves the greatest suffering should be ranked higher than the need that involves less suffering. It is natural to assume that greater suffering ranks ahead of lesser suffering. However, there may be situations where the opposite is plausible, eg, when no methods are available to treat the need involving the higher degree of suffering.

**Different ways to grade need**

As mentioned earlier, a health-related need is a gap between an actual state of health and a desired state of health. It is this gap that should be graded and used as a basis for ranking and prioritisation. Health-related needs can be graded in different ways: the magnitude of the gap can be graded simply by measuring the distance between the grades of the actual state and the desired state, or by measuring the cost to eliminate the gap (meet the need). The possibility to eliminate the gap can be determined by simply determining the degree of elimination, or by determining the replaceability of the intervention need (ie, if there are other options). Furthermore, the gap can be graded simply by grading the needs goal, grading the actual state, or grading the consequences of not closing the gap. The duration of need is also important. (Liss 2003)

Here, it is unnecessary to present all seven ways to grade needs. We recommend the same methods as proposed in the Priorities Commission. The proposal concerns the consequences of not addressing the gap or the need. Ill health often involves a process. A sick person’s state of health can only improve spontaneously, remain the same, or become worse. Not addressing a need can lead to a new situation involving another need or gap.
This gives us the opportunity to grade an existing gap by grading a potential gap. The appearance of a potential gap is a consequence of not addressing the original gap.

Three aspects are important in grading need in line with the consequences of not providing interventions or inputs – consequences for the individual’s future health (or quality of life), time available for treatment, and the duration of need. Time available refers to how quickly it is necessary to address the need to avoid severe consequences. Grading of the consequences of not providing care should be done by grading the state of health, or the quality of life. The lower the expected state of health, the greater the need. But we should also consider the risks for ill health – the greater the risk, the greater the need. Duration of need should also be included in grading. Grading of severity is influenced by how long the need lasts. If need A is expected to last longer than need B, need A has a higher level of severity than need B, assuming everything else is equal.

In ranking a health-related need we should also consider the characteristics of the intervention need. If several interventions work for the same health-related need, we should choose the most appropriate intervention (eg, the most cost-effective one). If no interventions works, this too should affect the ranking of need. Furthermore, in some cases the intervention’s replaceability is important. By replaceability we mean a possible intervention can be replaced by an alternative intervention that also works. Considering replaceability can mean, eg, that if one health-related need can only be treated with surgery while another can be treated with either surgery or pharmacotherapy, the need for surgery in the former health-related need is given a higher priority than the latter health-related need, since the latter can also be treated with pharmacotherapy.

5.4.3 Concluding comments about the needs principle
We propose that the needs principle be formulated as follows:

*Resources should be allocated according to health-related need, and need should be ranked according to level of severity.*

The concept of need includes three components – current state, desired state (goal), and necessary intervention. In determining need it is important to distinguish between need as a gap between current and desired states and need as necessary intervention. Need as a gap is known as *health-related need* while need as an intervention is known as *intervention need*. The combination of health-related need and intervention need, ie, the ability to assimilate a treatment, can be called care need. In prioritisation, consideration should also be given to other principles, such as the intervention’s cost-effectiveness.
We also propose that needs should be graded based on the consequences for health (ability to act) if care is not provided. It is the degree of health or ill health (or risk for ill health) that shapes the parameters for determining the severity level.

5.5 Solidarity Principle

Below we discuss the solidarity principle, separate from the needs principle. The advantage of separating these principles is that any conflicts that arise between the different ethical considerations prescribed by the principles become clearer. Here, the solidarity principle is interpreted roughly the same as described in the Riksdag resolution. (Socialdepartementet 1996/97) The principle prescribes several different ethical considerations. It prescribes equal opportunities for health care and that inequalities in the conditions for living a good life should be equalised to the extent possible. Solidarity also means that the needs of the weakest should be given particular consideration. For example, children and people with dementia, coma, disorientation, or severe mentally ill should have their needs assessed. They have fewer options than others to express their needs. Giving needs special attention does not necessarily mean they are automatically ranked high. It only means that the requirement to identify needs of those who cannot express their needs should be ranked high. After the needs have been assessed, ranking is based on level of severity and cost-effectiveness. The principle also prescribes a high ranking for the assessment of need in everyone, regardless of their level of autonomy. If the severity level and benefit/cost-effectiveness of the care need determines the ranking, it is essential for health services to adequately evaluate care needs in patients. Lastly, solidarity means giving a high ranking to efforts to capture asymptomatic needs in the general population. This may involve inviting people to participate in active screening programmes, or home visits to elderly ill people.

Requirements of the solidarity principle might come into conflict with the needs principle. The needs principle means that we should spend resources to address already known care needs, while the solidarity principle means that we should spend resources to capture unknown care needs. We propose that the principles be given equal weight. Hence, conflicts that arise between them must be resolved from case to case.

The idea of solidarity among people is anchored strongly in our culture and represented in most of the ethical principles that we discuss here. According to this idea, those with lesser needs give way to those with greater needs, which is expressed in the needs principle.
The idea of solidarity also includes the thought that those who have already lived a good life should give way in health services for those who have not had the opportunity to live a good life. Solidarity can also be expressed when people avoid taking unnecessary risks with their health, or practice self-care, thereby giving way for those with greater needs for care (linked to the responsibility principle).

5.5.1 Summary of the solidarity principle
We propose formulating the solidarity principle so that it prescribes:
• equal opportunity for care
• equalise, to the extent possible, the opportunities for living a good life
• give high ranking to interventions to assess needs of those who cannot express their own needs
• give high priority to effective interventions for assessing needs, even asymptomatic needs, of everyone.

5.6 Cost-Effectiveness Principle

Determining the cost-effectiveness of an intervention (synonymous with treatment or service) involves looking at the cost in relation to the effects of the intervention. Consideration to cost-effectiveness is an important ethical requirement in a situation with scarce resources. Choosing the most cost-effective intervention or investment means utilising resources in a way that provides the most health. Not selecting the most cost-effective treatment means that we cannot treat as much suffering as we otherwise could have. It is ethically irresponsible to allow people to suffer unnecessarily. Hence, the cost-effectiveness principle is an important ethical principle in allocating resources. In this report, the cost-effectiveness principle is formulated as follows:

In choosing among interventions for different types of ill health, one should primarily choose the one that is most cost-effective.

Cost-effectiveness is a relative concept – an intervention can be more or less cost-effective in relation to another intervention. Considering cost-effectiveness could mean choosing a more expensive intervention (and its cost impact over the entire disease course) if the more expensive one provides a proportionally better effect than the less expensive option. The opposite is also possible. A cheaper intervention can be preferred if the effects of the more expensive treatment are not proportional to the effects of the cheaper option. Cost-effectiveness analysis assumes that effects and costs of at least two relevant options can be compared. Primarily, we are interested in both the difference in effects and costs between the alternatives.
The relevant information in a cost-effectiveness analysis is a ratio concerning the added cost to achieve an extra health benefit over the course of disease. In chronic diseases, the course might include the remainder of the patient’s life. Usually this is expressed in monitory units (SEK, USD) per life-year gained, or units per quality-adjusted life-year.

Hence, the question becomes: Which cost concept or effectiveness concept should be used? Several different suggestions are conceivable. The minimalistic suggestion for calculating costs includes only the cost for health services. The moderate suggestion calculates only the costs that burden the public budget. The maximalistic approach takes a societal perspective, also including the costs outside the public sector.

The maximalistic proposal is applied by the Pharmaceutical Benefits Board in accordance with legislation on pharmaceutical benefits. (Ministry of Health and Social Affairs 2002) In decisions to subsidise (prioritise) a drug, the authorities should, eg, determine if it is cost effective from a societal perspective. Different countries can take different perspectives, and the scientific debate includes divergent views on what is most appropriate. There are reasonable arguments for all three methods of analysis. The basic alternative recommended by NICE, the leading state assessment authority in Great Britain, is that the cost of health care (ie, National Health Service) and the cost for personal social service should be limited. (The latter generally corresponds to the expenditures by municipalities for care and social services in Sweden.) In cases where substantial costs arise in other sectors, these should also be presented separately.

“For the reference case, the perspective on outcomes should be direct health effects whether for patients or, where relevant, other individuals (principally carers). The perspective adopted on costs should be that of the NHS and PHS [Personal Social Services]. If inclusion of a wider set of costs or outcomes is expected to influence the result significantly, such analyses should be presented in addition to the reference case analysis.” (NICE 2004)

We propose that this question be further studied, but tentatively we prefer an alternative in line with the NICE recommendation, which uses the distribution of scarce public resources as the starting point for discussing the ethics platform. Hence, the cost for an intervention or service should be judged mainly on the degree to which it burdens public expenditures. In other words, the cost estimate for a treatment should include not only costs to the health service, but also costs to other publicly financed institutions. Problems that patients experience from treatment side effects are suggested for inclusion in assessing treatment outcomes, while financial effects (eg, expenses for travel or drugs) for patients are not included in the main alternative.
However, substantial effects and costs can arise in society outside of that sphere. It would be inappropriate to withhold such information from those who should be setting priorities. An example might include comparisons of different treatment strategies whereby under one strategy the patient must make repeated trips to health services each week for injections, while the other strategy is available as a single treatment that is more costly, but has equal effect. Even other effects and costs, eg, enabling patients to return to work sooner, outside of the public sector can be relevant and included in a separate analysis.

The effects of interventions or activities should be assessed in relation to the organisation’s goal, ultimately to the overall goal, but operationally to the operational objective. In this case, it means that effects should be judged based on the intervention’s impact on the health and quality of life of individuals and their family members. Increased effect could mean a decline in the risk for ill health, achieving a higher level of health, or a decrease in side effects and risks for complications. In special situations, it might be necessary to consider the effects on others. Similar to costs, they should be separately reported and motivated.

An important issue concerns the type of decision to which the principle should be applied; choice between treatments for the same type of ill health or care need, choice between different types of ill health or care needs, or choice between people? The latter would be contrary to the human dignity principle if it allows choices based on personal characteristics. As before, the human dignity principle in this report overrides other principles. Applying the cost-effectiveness principle in choosing among individuals is therefore excluded. However, it does not conflict with the human dignity principle to rank care needs by cost-effectiveness for a group of people. Using such a ranking, care needs that can be met with a high degree of cost-effectiveness receive higher priority than care needs that can be met with a low degree of cost-effectiveness. Hence, the cost-effectiveness principle can be in conflict with the needs principle. Such a situation, as we mentioned earlier, requires consideration of the principles from case to case. Even when considering the needs principle (those with greater health needs should take precedence over those with lesser needs), it should mean that groups with major health-related needs could reasonably cost more per health benefit compared to those with minor needs.

We believe that this interpretation largely agrees with the Government’s thinking on the bill – ie, the cost-effectiveness principle should be applied only in comparing methods for treating the same disease, since otherwise the outcomes cannot be compared fairly.
The Government, however, states it is essential to distinguish a cost-effectiveness principle that applies to choice between different interventions for the individual patient (where the principle can be applied as the Commission proposes), and the aim of health care for high-level cost-effectiveness as regards health services in general. "We believe, however, it is essential to differentiate between cost-effectiveness as it concerns treatment of individual patients and as it concerns health services in general. A cost-effectiveness principle that involves choices between different interventions for the individual patient must be applied as the Commission proposes and be subordinate to the human dignity principle and the needs and solidarity principle. However, it is essential that health care strive for high-level cost-effectiveness as regards health services in general. Such cost-effectiveness for health services in general can be achieved, eg, through better coordination between different units, changes in the staffing schedule, or increased occupancy of facilities." (Socialdepartementet 1996/97)

How the Government interprets the cost-effectiveness principle at the operational level is not presented in detail, but it likely intended comparison of cost-effectiveness among different types of interventions at the group level. Here to we refer to the Riksdag’s directive to the Pharmaceutical Benefits Board. According to Government Bill 2001/02:63 “New Pharmaceutical Benefits”, the Pharmaceutical Benefits Board shall consider the cost-effectiveness principle when determining drug subsidies and observe the needs and solidarity principle and the human dignity principle.

The Priorities Commission mentions a conceivable allocation principle that it later rejects – the utility principle. Here the Commission has a type of utilitarian principle in mind – that which provides the greatest total benefit, regardless of who receives the benefit, should be chosen in priority setting situations. Adhering to this principle would, eg, mean that patients receiving priority are those who have the most important tasks or are most profitable for society. The principle emphasises social benefits. Applying the utility principle, according to the Commission, would conflict with the human dignity principle, which asserts that everyone has equal worth.

The utility principle and the cost-effectiveness principle are similar, but this report addresses them as two distinct principles. They differ on at least two points. The first concerns the endpoint. According to the utility principle, the endpoint should be judged in terms of total benefit, ie, effects on the national economy or the collective life quality of the population. If many patients receive small benefits, the total benefit to society can be large. According to the cost-effectiveness principle, as formulated here, the effects should be judged in terms of health or quality of life for an average individual regardless of the size of the patient group.
The second point concerns the cost of an intervention. In contrast to the cost-effectiveness principle, the utility principle does not consider cost. The utility principle is not included in the revised proposal.

We propose that the cost-effectiveness principle should be formulated as follows: *In choosing between interventions for different types of ill health, one’s first choice should be the option that is most cost-effective.*

Regarding the perspective to use in calculating costs, our preliminarily recommendation is the option that uses distribution of scarce public resources as the starting point for discussing the ethics platform. The cost of an intervention or service should therefore be judged primarily on the degree to which it burdens public expenditures. Secondarily, other costs of importance should be reported. We also propose that the outcomes of interventions or services be judged in relation to their goals, ultimately to the overall goal, but operationally in relation to operational objectives. In this instance, it means that effects should be judged on the impact an intervention has on the health or quality of life of individuals and their family members. Finally, we propose that the principle should be applied in choosing among treatments for the same type of ill health or care need, and in choosing among different types of ill health or care needs. However, the principle should not be applied in choosing among people.

### 5.7 Responsibility Principle

The responsibility principle means that we should respect people by making them responsible for their actions and responsible for the consequences of their actions based on individual prerequisites. Three reasons motivate placing the responsibility principle on an ethics platform to guide decisions on resource allocation. First, it is a consequence of the human dignity principle as formulated. This principle asserts that we should respect people by considering them to be free and capable individuals who can take responsibility for their own, and to some extent for other’s, life and the consequences of their actions, with consideration to individual prerequisites.

Secondly, it is a consequence of the increased consideration for patient autonomy in health care, eg, greater patient empowerment. This is expressed, eg, in the guidelines supporting patient insight and influence concerning prioritisation, and on transparency and democratic authorisation (Part II, section 3.4.1), but also in report SOU 1996:133: “*Patients should be in empowered.*” (Ministry of Health and Social Affairs 1996) Greater influence also carries greater responsibility.
Respect for an individual’s dignity requires both respect for the individual’s right to decide over their own life (autonomy principle) and assignment of responsibility based on individual prerequisites.

The third reason is symbolic in nature and deals with the individual’s relation to health services. In a distanced relationship, patients are a passive object in health services. Patients turn themselves over to health services and do not participate in care more than to accept (carry out) that which they are told. This contrasts with a participatory relationship where patients are a subject and actively participate in health care by acquiring information about different interventions, or by helping to select appropriate interventions. The public in general can also be active through engaging in discussions on transparent prioritisation. If we look at the relationship between the patient/citizen and health services from a participatory perspective it seems natural to give patients/citizens greater responsibility for their health and care. Ethics platforms of other countries include similar principles on individual responsibility.

In applying the responsibility principle is it appropriate to limit what the individual has responsibility for? Where is the boundary for individual responsibility? Do individuals have responsibility not only for their own life but also for lives of family and others? If individuals have broader responsibility, how should they exercise this responsibility? Is it sufficient for people to contribute merely through taxes for public health services, or should they participate actively in care, through, eg, care of family? These are complicated questions that require substantial discussion. This report limits the principle mainly to responsibility for oneself and for one’s own health, referred to here as self-responsibility. It concerns being responsible for one’s own health and care. Here it is appropriate to mention that application of the responsibility principle in health care must be subject to strict limitations (Section 5.7.1-5.7.3). Furthermore, the responsibility principle is only one of several principles with the same ethical status – which means that the responsibility principle can be overshadowed, eg, by the needs principle when the two are in conflict. Elisabeth Furberg presents discussion in ethics theory, which we do not discuss in detail here, concerning the responsibility that individuals have for their own health, and the role of the responsibility principle in health care. (Furberg 2007) Before we further define the principle, it may be helpful to examine the concept of responsibility. What do we mean when we say that a person has responsibility for something?
5.7.1 Concept of responsibility
The concept of responsibility will be analysed in terms of obligations. Having a responsibility for something means having obligations vis-à-vis that something. A politician who has responsibility for a particular area thereby has obligations regarding that area. A member of the medical staff who has responsibility for a patient has obligations towards that patient. When we assign someone or something responsibility, it is the same as assigning obligations. An individual or activity can assume a responsibility, which means the same as assuming certain obligations.

Fulfilling the obligations that follow with responsibility generally requires the responsible party to be active in some way, or be consciously passive and not act. Generally, clinics have attending physicians who are directly responsible for assuring that patients receive adequate medical attention. Parents are responsible for their children, which means having the obligation to assure the children are raised well.

The examples suggest that we are not only responsible in some respect, but that responsibility always implies being responsible for something – here we are talking about a responsibility object. We can be responsible for a home, a child, an association’s economy, for material possessions, etc. Different professional roles involve different types of responsibility, eg, responsibility for patients. In this report two responsibility objects will be emphasised – health and care. The first involves responsibility for our own health. The second involves responsibility for our own care.

Someone who does not take responsibility, ie, meet his/her obligations, can be blamed in the same way as when someone breaks a moral or ethical rule in principle. But here it is important to observe the distinction between performing an unethical act and being blamed for it. There may be cases where a person performs an unethical act, eg, does not fulfil their obligations, but at the same time should not be blamed for this. The person may have, eg, been prevented from fulfilling the obligations due to external circumstances. Hence, two questions must be answered when we determine the degree to which responsibility is met – are the obligations met, and if not, should we blame the responsible party?

5.7.2 Principle of responsibility for one’s own care
The principle of responsibility for one’s own care means that the individual has obligations to assure that he or she receives the care needed. Here we will not, as mentioned earlier, discuss, eg, parents’ responsibility for care of their children or an adult child’s responsibility for care of their aging parents.
The principle implies that individuals themselves, to the extent possible, carry out, maintain (with or without the help of family), or pay for their care. The concept of *caring for one’s self* includes three different activities: to carry out care oneself, at times with support from others, ie, usually referred to as “*self-care*”; to *manage one’s own care*, eg, to assure that it is provided by others, and *self-financing* of care regardless of who delivers it.

Applying the principle depends on the extent to which the individual has the practical opportunities to carry out the responsibility. People who lack the ability (mental or physical) should not be assigned responsibility. The principle of self-responsibility should therefore be described only to capable or autonomous individuals. Care of non-capable individuals should be the responsibility of social institutions. Responsibility assumes that external circumstances allow one to take responsibility. This might involve contributions by family or other people towards a person’s care, or that the person has economic options.

The principle of self-responsibility is based in part on the human dignity principle and in part on the idea of solidarity among people. The former indicates, as mentioned earlier, that we should consider people to be responsible for their actions and the consequences of their actions – including their health. The idea of solidarity includes a requirement to be generally careful with public resources. Those who waste common resources subject others to problems when resource supply becomes insufficient. Being careful with public resources applies to all situations. For instance, it can be expressed in the use of pharmaceuticals. The responsibility principle places an obligation on the individual not to waste pharmaceuticals by taking out cost-free prescriptions that go unused, but also to take medications in compliance with recommendations so they are beneficial.

Applying this principle in resource allocation in health care can mean, eg, that individuals must pay for certain types of care themselves regardless of whether it is delivered by public services or private services. The principle can be applied through different forms of rationing. For instance, reaching rationing goals does not allow all care needs to be fully met – but patients may continue to seek care on their own. An example would be in vitro fertilisation. Another approach involves rejection – choosing not to pay for certain interventions within the publicly financed system. Examples would include cosmetic surgery, normal eyeglasses, adult dentistry, vaccinations for foreign travel, and some assistive devices. But the extent to which rationing is a result of tradition or thoughtful selection based on ethical principles is unclear. There are various motives for these limitations.
One motive could be that some health services, from an effectiveness and fairness standpoint, are probably better distributed via the marketplace. Another is they fall outside of the traditional area of expertise for health services.

Applying the principle of responsibility for one’s own care can be a consequence of applying the principle of responsibility for one’s health, ie, individuals are responsible for their own ill health therefore need to manage or finance it on their own. Efficiency constitutes the second reason for applying the principle of responsibility for one’s own care, ie, care is delivered most cost-effectively by individuals themselves. A third motive is based on shortage of resources in health services. Shortage of resources requires solidarity; everyone must take responsibility to avoid wasting resources. This may involve individual self-care for easily managed care needs. Easily managed care needs are those that do not cost too much to address, that are easily addressed outside of the public system, or can be addressed by individuals themselves.

Certain conditions must be fulfilled for the principle of responsibility for one’s care to be applied within the public health sector. The first condition involves situations where individuals themselves should pay for all, or part, of their care. Self-financing requires that:

- the individual has the ability to exercise responsibility (a sufficient degree of autonomy)
- the individual has information, or can acquire information about the characteristics of the intervention (eg, the ability to assess benefits and risks)
- little risk for serious side-effects for the individual and others, eg, family members should not be burdened in a way that risks their health or quality of life
- costs are manageable for most in the target group.

The other condition concerns self-care. This requires that:

- the individual has the ability to perform self-care
- the individual has sufficient knowledge and skills
- the individual has the practical opportunity (eg, suitable housing or access to help from others)
- little risk for side effects for the individual and others, eg, family members should not be burdened in a way that risks their health or quality of life.

These conditions regarding the application of the responsibility principle in publicly financed health services means that rationing should be applied only if these conditions are met.
For instance, the requirement to take self-responsibility for care at home, which is a reality for many chronically ill people, should be evaluated against these criteria. Rationing decisions should also be followed by decisions to assure that the conditions are met through, eg, informing people. Hence, it may require resources to equip the individual or the general public to take responsibility that will enable rationing. An issue for discussion concerns the degree to which health services should attempt to motivate citizens to take responsibility for their own health or health care.

### 5.7.3 Principle of self-responsibility for health

Responsibility for one’s health involves an obligation to preserve or improve one’s health. The obligation can be met by preventing ill health. It can involve, eg, choosing a healthy lifestyle or avoiding unnecessary health risks. The obligation may also involve protective measures of various types, such as vaccinations and the use of safety devices, eg, in the workplace or in traffic. The obligation to improve one’s health can involve, eg, following the instructions of healthcare staff or seeking necessary care. This is most obvious for individuals with severe infectious diseases.

The responsibility principle concerns individuals’ responsibility for their own health. The important question now becomes how should health services relate to this principle in allocating scarce resources. Should we consider the individual’s responsibility at all? If so, in what way? The point of departure in this report is to consider the individual’s responsibility in an ethical context since the human dignity principle requires us to view humans as responsible for their actions (based on individual conditions). However, we can consider this in many different ways. Several suggestions regarding application of the responsibility principle in health care are mentioned below.

The principle of self-responsibility for health, used as a guide in resource distribution in health services, can be formulated at the individual level as follows:

*If P’s state of health is a result of P taking conscious, unnecessary health risks, P should be given a lower ranking than someone who has not taken unnecessary risks.*

At the group level, the principle of self-responsibility for health can be formulated as follows:

*Health states that are a typical result of unnecessary and conscious risk taking should be given a lower ranking compared to other health states.*
A person who has not taken appropriate responsibility in other contexts is subject to blame or various degrees of penalty. However, this should *not* apply to the responsibility principle in health services since consideration for fairness comprises the basis to apply the principle of responsibility for one’s health.

The important issue here concerns the degree to which health services should care for someone who consciously mismanages their own health, i.e., has not taken responsibility for it. We can choose between two main alternatives: (1) Do not take deficient self-responsibility into consideration in allocating health resources. (2) Take deficient self-responsibility into consideration. In this report, where we do not include political considerations, the second alternative (2) is proposed. Applying the principle of self-responsibility for health should have consequences for prioritisation and rationing decisions. People who do not take sufficient responsibility for their health, e.g., if they consciously take risks, should for *reasons of fairness* be treated differently compared to people who take responsibility for their health, e.g., by giving them a lower ranking. However, this applies only in situations where choices are necessary due to insufficient resources. It is not a matter of blaming or punishing individuals, but to consider what is fair.

Lower ranking can be followed by different types of rationing. The low ranking can mean that when resources are insufficient, the irresponsible person must stand aside (in terms of waiting time) for the responsible one. In other words, the care need that resulted from conscious and unnecessary risk taking is treated later in relation to other care needs. This involves time rationing for self-inflicted care needs. Lower priority can also mean rationing by deciding not to treat a particular care need. These individuals must then manage or pay for care on their own. The form of rationing applied in various instances is subject to special decisions.

Here it may be appropriate to recall that the responsibility principle is one of several principles of equal weight in the ethics platform. It should not have a higher status than the needs, solidarity, or cost-effectiveness principles. In conflicts among the four principles, decisions must be made from case to case. Decision-makers are then forced to take positions concerning which principle is important or less important. There is nothing from an ethics standpoint that would prevent decisions-makers from giving the responsibility principle a lower priority in relation to other principles in a conflict situation. This principle can be considered in the special situations where it might be appropriate. Presumably there are such situations, but they appear very seldom.

To apply the principle of self-responsibility for health in allocating resources, the following conditions must be fulfilled:
1. Ranking is necessary. It is not a matter of special treatment merely because someone consciously risks their health, but concerns situations where it is necessary to determine a ranking due to a shortage of resources.

2. The causal association between a person’s behaviour and state of health must be sufficiently clear. It is about the possibility and reasonability of assigning a person responsibility for their ill health. Responsibility implies causality, and it is notoriously difficult to establish a causal association with sufficient accuracy between, eg, behaviour and ill health.

3. The behaviour must be conscious and voluntary. Prerequisites for taking responsibility for one’s own health involve, eg, material (economic), psychosocial, or intellectual conditions. Hence, the prerequisites vary among people. For that reason, assigning responsibility should consider the individual prerequisites. The same applies to freedom from responsibility. We should avoid victimisation of individuals, ie, automatically free people from a responsibility for their difficult situation without adequate knowledge about the conditions.

4. It must involve unnecessary risk. This concerns the reasons why individuals risk their health. Living a good life requires activities of various types in work, recreation, social relationships, etc. The activities can contribute towards reducing the risks for ill health. But they involve risks of different types and degrees. This may involve risks for traffic accidents in commuting to work, or risks for injury in recreational activities. Damaging one’s health in relation to activities that are important to maintain a good life should not influence decisions on resource allocation, assuming that the individual has not taken unnecessary risks. However, if the individual has taken unnecessarily high risks, or damages their health through other activities that are not important for a good life, this should influence ranking decisions.

5. The individual should be aware that the responsibility principle is applied in health services. Hence, the principle should not be applied retroactively.

Rigorous demands will be placed on decisions concerning the degree to which the conditions are fulfilled. This involves defining the conditions, eg, what is meant by unnecessary risks. It also involves determining if the conditions are met. Is there a causal relationship between behaviour and ill health? If so, is the person responsible or was the behaviour a result of ignorance, or was the behaviour involuntary? We easily recognise the difficulties in answering such questions. Here we should apply the principle, rather free than condemn. This means that, in practice, consideration to self-inflicted ill health will play a minor role in resource allocation. The Priorities Commission also drew the same conclusion.
The Priorities Commission categorically rejected the principle of self-inflicted ill health as a basis for resource allocation, with the following, practical motivations: the relationship between behaviour and disease is not generally understood, genetic factors have importance for the onset of certain diseases, behaviour harmful to health is usually acquired early in life, and defining that which comprises a harmful lifestyle or self-inflicted disease is at risk of being arbitrary. The conditions in this report generally agree with the Commission’s reasoning, but the principle of responsibility for one’s health is not rejected in the same categorical way. The potential to determine if the conditions are met will be the decisive factor. In cases where they are clearly met it would be reasonable to apply the principle.

The responsibility principle has been discussed at several seminars. Some have said that the principle could be interpreted to mean that those who consciously take unnecessary risks with their health no longer have a right to receive care. **This is a misinterpretation.** Everyone has the same right to receive care according to the human dignity principle. Those with minor care needs have the same rights as those with major care needs. Likewise, those who have taken unnecessary risks with their health have the same right as those who have not. It is only in situations of forced choice that we should consider the magnitude of need, the cost-effectiveness of the intervention, or the responsibility for ill health.

The strict conditions mean that health services should apply the responsibility principle restrictively. We should not, for example, make individuals responsible for their own health based only on knowledge about the person’s lifestyle, eg, smoking and alcohol consumption, since we cannot be sufficiently certain that lifestyle caused the disease. But this does not completely exclude application of the principle. It could be applied on a small scale to support difficult decisions to establish limits. For example, the principle could be applied through, eg, clearly informing people in advance that ill health caused by various activities requires individuals to take responsibility themselves by paying or arranging for their care. Examples of such activities might include allowing oneself to be tattooed or pierced. But even extreme sports such as mountain climbing, parachuting, or diving, or dangerous hobbies such as keeping poisonous snakes could also be considered. This does not necessarily deal with excluding care but with self-financing – eg, decompression treatment for the bends, where the risk for the disorder and its treatment are relatively well known and defined. Hence, it could be the financial responsibility of the individual, eg, through compulsory insurance.
Individuals also have responsibilities in restoring health. Examples include following instructions for necessary actions such as pharmacotherapy, exercise, or refraining from activities that limit the benefits of treatment. Even in these cases, the above criteria should be applied in special cases of resource distribution. Here there is another factor that concerns the benefits of treatment. In those cases where poor patient’s compliance reduces the benefits of treatment, this should affect the ranking of the treatment (when we apply the cost-effectiveness principle).

**Further application of the responsibility principle**

Applying the responsibility principle in allocating healthcare resources also means that health care should create conditions for individuals to be able to take responsibility for their health. This involves every phase in the process – prevention, treatment, nursing care, and rehabilitation. Here we are referring to intellectual, material, and social prerequisites. For example, to be able to choose a healthy lifestyle, the individual must be knowledgeable about the association between lifestyle and health. Likewise, the individual must have the psychological and practical prerequisites. This could involve economic conditions, the psychological strength to overcome dependence, practical opportunities for recreation or exercise, or social conditions. Health service personnel of all categories should give patients the resources to increase control over their ill health. Healthcare advice, self-care manuals, or self-dialysis in hospital are examples of interventions to equip both patients and other people with greater responsibility.

Applying the responsibility principle means that health services have an obligation to create prerequisites for facilitating individual responsibility for their own health. To a greater extent, health services should aim to empower individuals (see Liss 2004b for an analysis of empowerment). Health services, however, are not alone in this obligation. It concerns all social institutions, but health services should contribute with their special expertise in the health field. This report does not discuss which methods for health promotion are ethically defensible. Applying the human dignity principle means, however, that we should treat people as capable individuals based on their individual prerequisites. This leaves less room for paternalistic actions (acting on behalf of the individual without their permission).

*We propose investigating the potential inclusion of a principle of responsibility for self-care in the ethics platform with the limitations mentioned. We also propose further study on applying the principle of responsibility for one’s own health as regards the exact conditions for its application and the potential practical and political effects thereof.*
5.8 Ranking the Principles

The Priorities Commission and the government bill propose an ethics platform encompassing three principles. The ethical principles express different ethical considerations that apply in allocating resources and which occasionally are in conflict with each other. The Commission and the bill propose a hierarchy among the principles. On this point, Sweden differs from other countries with prioritisation guidelines. We propose another model that is common in modern medical ethics, where the various ethical considerations have the same status from the outset. If they conflict, they are ranked from case to case. This model can be applied regardless of the principles proposed for inclusion in the ethics platform. However, we recommend that one of the principles be exempt – namely the human dignity principle. This principle is so fundamental that it should be given higher status than the other principles. In any conflict among the principles, the human dignity principle always takes precedence over the other principles. Our proposal involves revising the principles in the Riksdag’s platform and including yet another principle. The ethical principles we address in our analysis are as follows: the human dignity principle, the needs principle, the solidarity principle, the cost-effectiveness principle, and the responsibility principle.

We propose that in any future revisions of the platform, the human dignity principle should take precedence over the other principles. These however should have the same ethical status – they are so-called *prima facie* principles (see section on the function on principles). Hence, at the outset these are not ranked. If they are in conflict they must be balanced by ranking them from case to case. In a situation where two are in conflict, decision-makers must decide which of the principles should take precedence in that particular situation. It is expected that this process will be transparent.
Part IV

Conclusions and Proposed Actions
1. IS THE CARE GAP AN ILLUSION?

In conjunction with the work on this report, we joined with others in questioning the relevance of developing principles and guidelines for priority setting. The Priorities Commission was active during a period when the Swedish economy was weak. This probably influenced the public’s frame of mind at the time and subsequently affected the Commission. The weak economic trend probably also affected a state inquiry (HSU 2000), which in the mid 1990s attempted to project the future needs for health services. According to its 1996 report: “Trends after 2000 will be determined largely by growth in the national economy and decisions by the Government and Riksdag concerning economic conditions in the municipalities and county councils. Demographic trends will result in financial problems that, in the long run, are substantially greater in municipal care of the elderly than in health and medical services financed by county councils”. (Socialdepartementet 1996)

Since economic growth has been surprisingly strong for several years, and tax revenues in the county councils and municipalities are increasing, the focus has shifted towards planning, development, and expansion and away from cost cutting, budgetary shortages, and projected future care needs. Is prioritisation still necessary? If not, why should one invest a great amount of effort in this endeavour? Periods of economic growth facilitate the work of allocating public resources since it is easier to distribute surplus resources to the services needing them than to redistribute scarce resources, or to cut costs across the board. We believe that even when economic growth in the public sector is good it is essential to distribute surplus resources as effectively and fairly as possible. The same requirements for systematic, transparent processes should apply as when the resource framework is unchanged or smaller. As long as the public sector alone does not address all care needs there will always be a need to define the boundary between publicly financed care and the private sphere.

Are resources sufficient, and can all essential needs in health care be met? The question is too comprehensive to be answered in this context. Also, the circumstances vary in different parts of the country and by sector. We can point to several situations.

The major challenges to Swedish health care in the future concern more than economic growth alone – future resource needs are heavily influenced by a combination of factors. Several key factors are addressed in the report “Health Services Until 2030”. (Sveriges Kommuner och Landsting 2005)
Demographic factors are important; an aging population increases the need for care, which can differ from current needs, eg, due to the social trend of the growing number of single people. Work and lifestyle affect health, and care needs can change as physically hazardous jobs decrease while the mental working environment may create more problems. Other changes involve social trends, eg, a decreasing number of smokers and an increasing number of overweight or obese people, or people with stress-related disorders.

The disease panorama will also change, eg, new and old communicable diseases resulting from greater internationalisation. Changing attitudes and shifting human values are other factors that indirectly affect care needs through greater demand. When is one healthy/sick? When should treatment be started, or when should we ‘wait and see’? Increasingly more well-informed and articulate patients are demanding greater accessibility, more complete information, and input in deciding on care content and choosing among different options. The organisation and management of health care can affect both supply and demand in different directions. New medical advances increase the opportunities to treat more disorders and patients than previously. The form and pace at which this will occur is impossible to predict. We only know that the prerequisites for financing health services, and the ability to meet all care needs in society, will be continuously changing.

What actually occurs in the complex systems that comprise health care must be followed up and analysed in detail. The status report of primary care in 2006 by the National Board of Health and Welfare exemplifies this type of follow-up. It reported that the many of the cutbacks that affected the county councils during the first half of the 1900s did not really impact on primary care. (Socialstyrelsen 2007a) Hence, primary care’s share of total healthcare resources has increased somewhat. In 2005, primary care accounted for 16% of the county councils’ total net costs for health care. Further, it was noted that the National Board of Health and Welfare’s assessment of the national action plan shows: “There is uncertainty about the extent to which the extra state resources have benefited primary care, and to what extent the action plan’s goal to enhance opportunities for the population to establish a long-term relationship with their own physician has actually been realised.” (Socialstyrelsen 2007a) Regarding equality and equity in care, greater inequality has been observed in primary care. People with higher education visit the doctor more than people with lower education do, even though morbidity is higher among those with less education.

The National Board of Health and Welfare’s latest status report on elder care verifies the increased demands on elder services and on the municipalities that HSU 2000 warned about. (Socialstyrelsen 2007b)
The number of places/beds available for care of the elderly has decreased in recent years, as have the costs for these programmes. Slightly over 2500 hospital beds have been decommissioned during the same period, and the number of people receiving home services and municipal home health services has increased (135 000 people received home care services in 2005, which is just over 14 000 more than in 2000). However, those older than 80 years who receive help of some type decreased by 1.9% between 2000 and 2005. The supply of resources decreased by nearly 5%, while the percentage of people aged 80 years and older in the population increased by just over 7%.

Swedish municipalities differ widely as regards the supply and cost of care for the elderly. In 2005, the cost per person receiving home care services was five times higher in the municipality with the highest cost compared to the municipality with the lowest cost, while the same comparison for an individual in assisted living yielded a three-fold higher difference. According to the National Board of Health and Welfare, tradition and historical conditions are responsible for the design of social services. (Socialstyrelsen 2007b) This type of comparison between geographic areas is valuable for identifying inequities in health and the supply of care services. The increased interest in transparent comparisons regarding quality of care and outcomes, and the increased interest in evidence-based medicine, are expressions of the aim to improve health services. Greater transparency can also contribute towards strengthening the position of patients and citizens, and increase their influence over decisions. This can contribute to greater efficiency, but is also valuable per se. In this context, it can be mentioned that quality improvement, transparent comparisons, evidence-based medicine, and knowledge management are concepts closely associated with transparent prioritisation.

If we look a few years into the future, will the current gaps between the demand and supply of health care and social services in the public sector continue to persist? To answer this question we refer primarily to a study from 2005, by the Swedish Association of Local Authorities and Regions, that addresses the total long-term resource needs of health care (Sveriges Kommuner och Landsting 2005)

The report by the Swedish Association of Local Authorities and Regions (SALAR) predicts that if the trend from the past 25 years continues unchanged, by 2030 the resource needs of health services will increase by 50%. Furthermore, it predicts a gap between resource needs and financing that will correspond to an increase from 9% to 12% in the health services’ share of GNP. This projection assumes that tax rates remain constant, and that the need for health services by different age groups in 2030 remains the same as when the report was written.
However, resource needs are expected to increase at a faster rate than the demographic trend. The rate of increase is due mainly to the introduction of new medical technologies and the public’s increasing expectations regarding their health. The report also indicates that the challenges in health care are not limited to financial issues – the supply of staff can also be problematic. A general conclusion is that health care must draw on its potential to utilise resources more efficiently, and a discussion must be promoted on how we should finance health services in the future. The SALAR report concludes that the healthcare system faces major challenges in the future, but there are opportunities to influence the trends. Maintaining the current system will require several parallel changes, such as improving resource utilisation in health services and tighter limits regarding the content of the publicly financed health services. The potential to solve financial problems through tax increases and resource redistribution in the public sector at large is viewed to be limited.

In summary, we believe that the need for prioritisation and the importance of the ethics platform will not decrease over the long term, or the short term, as a result of better economic growth. Politicians and other decision-makers might perceive priority setting to be somewhat easier during periods of strong economic growth. We argue, however, that even when economic growth is strong, in the public sector it is essential to distribute additional new resources as efficiently and fairly as possible. We should set the same standards on systems and transparency in such periods as when the resource framework is unchanged or becomes tighter. In the long run, prognoses point towards a need for substantial redistribution of resources in the public health sector. Now would be a good time to develop new working methods – presumably, in times of crisis there would be less latitude for this type of thinking.
2. PROGRESS SINCE THE PRIORITIES DELEGATION CONCLUDED ITS WORK

The Priorities Delegation, assigned by the Government to monitor the implementation of the Riksdag resolution on priority setting in health care, concluded its work in 2001. (Socialdepartementet 2001) The Delegation’s general impression was that both the government bill and the Riksdag resolution were relatively unknown to the executives and healthcare staff. This was particularly noticeable in the municipalities. A survey showed that discussions and study circles on prioritisation, and various forms of public dialogue, were under way. A limited development project had begun.

The Delegation contributed by clarifying that the Riksdag and Government have the responsibility to assure compliance with the guidelines on priority setting in health care, while health service providers must develop the prioritisation process. Interest groups at the national level, eg, SALAR, should play key roles in ongoing prioritisation efforts. Further discussion is needed concerning whether the boundaries of public involvement in health care should change. The responsibility for initiating such a discussion rests mainly with the political parties, the Riksdag, and the Government. Local/regional committees should be formed to anchor the prioritisation guidelines in practice and to include this topic in the basic education of various care professions. Information and knowledge should be easily accessible for user organisations – disability associations, patient organisations, family groups, and pensioner associations.

Shortly before the Priorities Delegation presented its final report, the National Board of Health and Welfare presented similar results from a survey. (Socialstyrelsen 1999) They found a lack of coordinated strategies and consistent methods among the provider organisations. Politicians and administrators had not created the necessary prerequisites for applying the prioritisation resolution, or exploiting the potential available to engage physicians and other health care staff in developing a basis for setting priorities. Collaboration among providers, and between county councils and municipalities, occurred only sporadically.

2.1 What has happened, or not happened, up to now?

Based on the interview study and other studies we found that little has changed in priority setting today compared to the most recent national studies by the Prioritisation Commission and the National Board of Health and Welfare. It would be inaccurate to claim that no progress has been made. We found several examples of practical applications of the Riksdag’s principles and guidelines for
priority setting, both at the local (county council) level and the national level. Development of methodology for vertical prioritisation has shown the most progress. Below, we summarise our conclusions regarding how the central government, county councils, and municipalities are currently managing the prioritisation process. First, we present the areas that remain relatively unchanged relative to the conclusions of the Prioritisation Delegation and the National Board of Health and Welfare six years ago.

- There are still no clear strategies or consistent working methods for prioritisation in county councils and municipalities. One explanation could be that politicians and administrators have not created the necessary prerequisites for applying the principles for priority setting. Local rules usually do not exist.

- Political decisions to reduce or exclude services remain uncommon, and priority setting is generally not transparent. Healthcare staff must assume the greatest responsibility, and politicians participate only marginally in prioritisation discussions and/or decisions. Mainly, politicians are uncertain about their role and their intentions in prioritisation.

- Healthcare staff, with the possible exception of persons in leading positions, still appear to be relatively unaware of the ethical principles intended to guide priority setting in care, and a few are aware of the so-called priorities groups. There is no longer the active level of discussion on the ethics platform that was found the mid 1990s. Nevertheless, it appears that the prioritisation and rationing of care that routinely takes place actually complies with the intent of the legislation, with the possible exception of the cost-effectiveness principle, eg, social services staff are unfamiliar with this.

- Citizens and patients continue to be only marginally involved in priority setting. There is considerable uncertainty about how to address this.

- The review of resource allocation principles in the municipalities concluded that deliberate prioritisation, based on established principles, is generally lacking. To deal with persistent budget shortages, county councils and municipalities attempt to increase efficiency through structural and organisational change, more rigorous resource allocation systems, uniform application of various regulations, and in some cases by direct reduction of benefits through fewer and less frequent home care services, eg, cleaning, window washing, and assistance with personal hygiene.
• Municipal care and social services still view themselves to be basically unaffected by the ethics platform and the prioritisation principles.

• Many municipal respondents mentioned that the principles for prioritisation in municipal services, like those in the Health and Medical Services Act, could be useful. They called for greater specificity and clarity in discussing the mission of the municipalities, and greater reliance on municipal legislation.

• Several of the most urgent areas for prioritisation, eg, care of the elderly, affect both the county councils and the municipalities, but joint prioritisation efforts rarely take place between these governing bodies.

We also observed several positive changes related to priority setting today compared to six years ago:

• The National Board of Health and Welfare and the Pharmaceutical Benefits Board actively support systematic and transparent prioritisation. This work has resulted in considerable development of methodology.

• Some signs point to the introduction of more systematic methods for resource allocation, priority setting, and rationing in municipalities and county councils. It is becoming increasingly common for politicians to make resource allocation decisions based on goals and mission statements of the various health services, and there are isolated attempts at systematic political prioritisation. Several county councils have used a systematic approach towards resource allocation, based on unmet care needs in the population.

• Several promising development projects in priority setting have been initiated and are being implemented by healthcare staff locally and nationally. The potential to engage physicians and other healthcare staff in the effort to develop a foundation for political prioritisation decisions and guidelines for clinical priorities is better utilised today than it was previously.

• Professional associations are considerably more active today than they were previously as regards dissemination of knowledge and participation in development projects. We identified several examples of collaboration between different groups. Associations representing the disabled are also working to strengthen their capacity for transparent priority setting.
• Important actors in health services support the national working model for vertical prioritisation.

• Advancements in prioritisation are closely associated with other areas of evidence-based health care. We note that regions and county councils have begun to collaborate much more in recent years.

Several regions have assigned groups of medical experts to address and develop new methods to better implement national guidelines for treatment of common diseases.

• More county councils have adopted new methods to introduce new, expensive health technologies or investments in new services that require additional new resources. In this respect, politicians are often ‘forced’ to act. One way is to take a more evidence-based approach. Toward this end, several county councils have established advisory bodies intended to critically assess scientific evidence and provide additional facts.

• The so-called maximum waiting time guarantee, as currently formulated and implemented, focuses on the need for transparent prioritisation in a way that did not exist previously.

• The National Centre for Priority Setting in Health Care (PrioriteringsCentrum) has been established to support the various actors in the health services.
3. CLARIFICATION AND ADDITIONS TO THE PRINCIPLES AND GUIDELINES ON PRIORITISATION

In summary, politicians, administrators, and clinicians viewed the Riksdag principles and guidelines on priority setting in health care to be useful and of considerable importance in formulating the discussion on prioritisation. The respondents considered much of the text in the guidelines to be self-evident for health care and thought that most people would agree with the main focus. The guidelines were mainly perceived to be supportive and something that one keeps in mind. A major benefit is that health services now have the terminology, concepts, and a clear ethical foundation to facilitate a debate on prioritisation.

Many of the details in the guidelines are vague, and the various concepts used in the guidelines are interpreted in different ways. Clearly, all concepts and definitions need to be scrutinised. Even the concept of prioritisation was found to be problematic since it is used in many different ways. The general public perceives “to prioritise” and “to exclude” as synonymous concepts, not that the prioritisation can involve both excluding things and “raising priorities” or adding resources.

Although many questions, discussions, and decisions remain before the current ethical principles can be changed, we believe it is valuable to discuss the content of the various principles, their mutual ranking, and complementary guidelines. We conducted an ethical analysis (Part III), which together with the empirical study (Part II) shows a need for clarification and modification of the current principles.

We begin by presenting our views concerning the ethical principles for priority setting in health care and propose several clarifications and additions. These viewpoints are based largely on the ethical analysis, and to some extent on observations from the interview study. Then we discuss the guidelines in the Riksdag’s resolution that aim to support the application of the ethical principles, or serve to support the county councils in their prioritisation efforts. We highlight the need for clarifications and additions regarding the guidelines. Here we mainly refer to the responses to our interview study of the various parties engaged in priority setting in county councils, municipalities, and other organisations.

3.1 Ethical Principles

The ethical analysis and interviews in our survey show a need to clarify certain aspects of the current principles.
3.1.1 Human dignity principle
Unquestionably, the human dignity principle is strongly anchored in Swedish health care. Not providing special treatment based on personal characteristics and function in society is perceived to be highly important. Nevertheless, questions arise in the interpretation of the principle. The current ethics platform does not adequately define what people have a right to, or what the goals and mission of health services are exactly. When health care is insufficient, the standard of equal rights might be impossible to uphold without allowing some type of special treatment. Currently, the level of need determines the rights for special treatment, ie, those with greater needs take precedence over those with lesser needs. The level of need is determined, in turn, by the level of severity attributed to the disease or injury. We believe it would be difficult to find ethically defensible grounds for special treatment based on the cause of suffering.

A modified interpretation of the human dignity principle, in its most general form, implies that people have equal rights. It should be possible to further define the principle as an operational principle and a general attitude. The operational principle implies that everyone has equal rights to the conditions for living a good life. It means that health services, within their sphere of responsibility, have an obligation to contribute equitably and cost-effectively towards what people need to live a good life. The concept of good life encompasses length of life, quality of life, and integrity. Here, special treatment is based on the degree of suffering (not its cause) and whether effective interventions are available. The general attitude refers to the equal right for respect regarding the dignity of each and every person. It means that, from the outset, people should be considered as autonomous individuals with individual prerequisites and the capacity for responsibility. In resource allocation decisions a responsibility principle could be applied advantageously in conjunction with the human dignity principle. We have outlined how such a responsibility principle could be formulated, and suggest that it does not conflict with the other principles (see below).

3.1.2 Needs and solidarity principle
The needs principle is also widely accepted among the representatives of health services. However, the needs concept is perceived as unclear and to some extent contradictory, both in routine practice and in how the principle is interpreted. What should affect the level of need? In addition to the severity level, should duration and replaceability also affect this determination? Drawing the boundaries is also problematic, ie, who should be included within a condition’s severity – only the patient, or even others (eg, family members)? We believe it
would be valuable for the guidelines to clarify and separate the needs and solidarity principle for the following reason: both principles express several different ethical considerations that could, at times, be in conflict with each other. For example, the needs principle implies that we should address existing health needs while the solidarity principle implies that we should also attempt to capture unexpressed care needs. Separating the two principles would make it easier to identify any conflicts between the different ethical considerations.

An alternative interpretation of the needs principle would imply that resources should be allocated according to need. The greatest need should receive the highest ranking. The needs concept has three components: current state, desired state (goal), and necessary intervention. Two questions must be answered to assess the presence of a care need. Is there a gap between current and desired states? Such health-related needs should be ranked based on the consequences of excluded care, and the severity level is graded considering the level of ill health. An assessment also includes the risk for ill health, the time available (ie, acuteness level), and the duration of need. The second question concern whether care is necessary for equalising this gap.

The intervention need is ranked based on the consequences that the exclusion of care would have on the individual’s health or ability to act, and also considers the availability of effective interventions, ie, if an effective intervention is not available it would influence the ranking of the care need.

A proposal for a separate solidarity principle implies, in brief, that people should have equal opportunities for care and that inequities in the prerequisites for living a good life should be equalised to the extent possible. Solidarity also means giving a high ranking to interventions to determine needs among those who cannot express their own needs. For example, children, people suffering from dementia, unconsciousness, disorientation, or severe mental illness should have their needs assessed since they have fewer opportunities than others to express them. Finally, the solidarity principle implies that the assessment of need generally receives a high ranking, simply to be able to identify the care needs that exist.

3.1.3 Cost-effectiveness principle
We see several reasons to further clarify the cost-effectiveness principle. Current application of the principle is limited to the choice between treatments for one and the same disease, which can be interpreted to mean that costs for different diseases can vary extremely without being compared and ranked in relation to cost and benefits of various inputs. The principle is also vaguely formulated in terms of the costs and effects that should be included: Which costs should be
included, and which ones should be excluded? Applications of the principle at the individual and group levels also need to be clarified.

In summary, a cost-effectiveness principle could be formulated: In choosing among interventions, services, or disease groups the primary choice should be the one that is most cost-effective. It is important to clarify that the cost-effectiveness principle should be applied in setting priorities among treatments and care needs at the group level, but not at the individual level. Effects should be judged primarily on the impact that the interventions have on the health or quality of life of patients and their families. It can also be important to evaluate the external effects on other people in special situations (eg, to prevent spread of communicable disease). Different perspectives can be used to evaluate the costs of an intervention or service. According to our preliminary findings, the primary focus should be on costs that burden health services, and other public expenditures. Other costs could also be relevant and included in a separate analysis. The issue should be further investigated.

We propose further discussion of the cost-effectiveness principle to clarify its area of application, and the concepts of cost and benefit, in a way that would facilitate the application of the principle.

3.1.4 Responsibility principle
We find good reason to study the motive for complementing the ethics platform with a responsibility principle. Health services require ethically solid criteria for what is referred to as self-care. To automatically relieve people of responsibility can be viewed ethically as an infringement on the human dignity principle, just as it would be an infringement to place responsibility on those who do not have the prerequisites to take responsibility. A responsibility principle is based on the assumption that all people are responsible for both their health and care commensurate with their individual prerequisites. Being responsible for one’s health implies, in part, avoiding ill health to the extent possible, and in part, restoring health to the extent possible when health fails. Responsibility for one’s own care should include delivery, maintenance, and financing. Since much of the care provided in society falls within the framework of self-care, it is essential to develop generally accepted and recognised criteria that indicate when the prerequisites for self-care are met. In distributing resources, the principle of self-responsibility for one’s health should imply that needs which arise from irresponsibility could be ranked lower in relation to other needs when resources are inadequate (the solidarity principle implies a requirement not to use public resources if unnecessary). However, it is important to point out that applying this principle requires several strict conditions to be fulfilled (eg, a clearly causal relationship between behaviour and state of health). Except in certain, clearly defined situations, the principle would be seldom applied in practice.
Likewise, several conditions must be met in applying the responsibility principle to self-care in publicly financed health services. Self-financing means that the individual must have the ability to exercise responsibility, that effective interventions are available, that the individual is informed about the quality of interventions, and that costs are affordable. Other conditions concern self-delivered care, eg, the individual must be able to handle responsibility, sufficient knowledge and skills, and the practical potential to assume responsibility. Also, the risk for side effects or failure should be small.

3.1.5 Ranking
We find reason to discuss the ranking between different principles for prioritisation. The human dignity principle appears to take convincing precedence over the other principles. We have presented several reasons suggesting that the other principles should have equal ethical status – they should be considered prima facie principles (see section on function of principles). Hence, they are not ranked at the outset. If they conflict, they would need to be balanced through case-by-case ranking. In conflict situations, eg, between the needs and cost-effectiveness principles, decisions-makers must decide which of the principles should take precedence in that situation. Decision-makers are expected to present their positions in a way that is transparent, permitting evaluation and, potentially, acceptance by others.

We propose that the text of the current ethical principles on prioritisation be clarified, and that the need for a complementary responsibility principle be investigated. Further, the ranking of the ethical principles should be re-assessed.

3.2 General Guidelines for Priority Setting

Having discussed the possibilities to clarify and complement the current ethical principles (the ethics platform) we now address the guidelines in the Riksdag resolution aimed at supporting priority setting efforts by the governing bodies in health care (county councils and municipalities). Again, we propose certain clarifications or modifications.

3.2.1 Four priority groups and individual assessment
Respondents were uncertain about the idea behind the four priority groups, and called for further study of the content and mutual relationship of the groups. The function of the priority groups in guiding prioritisation decisions is weak at all levels. They serve more as a reminder not to neglect certain disease groups, groups of people, or types of interventions – eg, chronic disease, people with
impaired autonomy, or population-oriented prevention. We find support for this assumption in the government bill, which states: “We agree with the Commission and many of the reviews thereof, that it is essential for health services to place an emphasis on severe chronic diseases”. (Ministry of Health and Social Affairs 1996/1997) However, a general emphasis on certain diseases, groups of people, or types of interventions is far from adequate guidance for prioritisation decisions. Rather, it creates misunderstanding that can contribute towards setting priorities that directly conflict with the intent of the ethics platform.

The need for care – not the character of the disease – should be the determining factor. The bill emphasises that in each individual case it is the conditions of the case that determine the care needs. Both acute and chronic diseases can vary in severity over time in the same patient. Hence, care for the same disease can fall into different priority groups during different stages.

The government bill, like the Priorities Commission emphasises that the initial medical assessment is of greatest importance. It is a prerequisite for adequate prioritisation.

Hence, according to the bill, diagnostics lie outside of the priority groups, and it is unclear how to rank medical assessment in relation to preventive, curative, or rehabilitative activities. Should assessments of different conditions be graded on the degree of urgency in accordance with placement of the disease? Or should all assessments be considered equally urgent? The government bill provides no answers, while the Priorities Commission calls for grading of urgency in assessing suspected disease or injury. The Commission also suggests that diagnostic interventions should be consistent with the therapeutic options. This assumes that the therapeutic options can be determined prior to completing the diagnostics.

According to the government bill, the ethics platform is used as a basis to assign diseases to the various priority groups. At the same time, the severity level of the need appears to be the determining factor. The degree to which one considers the principle of cost-effectiveness is not apparent in either the government bill or the Priorities Commission. Population-oriented prevention and habilitation/rehabilitation have been assigned to Group II. Neither the bill nor the Commission discuss the ethical considerations that led to this result. Here, it is no longer about ranking diseases, but types of interventions. The important characteristics of interventions concern benefits and the cost-effectiveness. Subsequently, the government bill also calls for the documented value of the preventive interventions. However, no connection is drawn to the severity level of needs. If prioritisation among different preventive measures, or between
prevention and other measures, is based on the value of the interventions alone, this represents a departure from the idea of considering the severity level of need in decision-making.

We concluded from our interviews that the priority groups are widely recognised, which per se can be problematic since concurrently their utility is being questioned. Our interviews revealed growing criticism concerning application, uncertainty, risk for misinterpretation, and inconsistencies. Most mentioned that the priority groups should be removed from the guidelines, or be further developed to be more specific.

We propose that the priority groups be removed or substantially revised.

3.2.2 Guideline on quality-of-life-related and health-related needs
The Priorities Commission links the concept of “care need” to both disease (ill health/malady) and quality of life. Health-related need implies that care is needed to address disease or injury, while quality-of-life-related need implies that care is needed to address the quality of human life. The Commission, however, expresses a limit on quality-of-life-related needs.

It is possible to interpret the concept “quality-of-life-related need” in two ways:
1) The need for interventions to affect quality of life is determined within the framework for disease or injury. “If the disease cannot be cured, the patient has a need for symptom relief and nursing care. This is a quality-of-life-related need.” (Socialdepartementet 1995) This concerns quality of life that is influenced by, or is at risk of being influenced by, disease or injury. Poor quality of life (or the risk thereof) caused by something other than disease or injury (e.g., appearance, sexual inadequacy, or involuntary childlessness) does not constitute a care need.

2) The alternative interpretation bases the need for healthcare interventions partly on the level of life quality (or risk for deterioration) and partly on the potential of health services to affect quality of life. The latter is logical – there can be no need for an intervention that yields no benefit. If a patient receives no benefit from a drug, the patient has no need for the drug. In the second interpretation of the concept “quality-of-life-related need” the presence of, or risk for, disease or injury is not necessary.

Which alternative should we choose to further define the needs and solidarity principle? The Commission clearly chooses alternative (1). A quality-of-life-related need then exists only if the quality of life is affected by disease or injury (or a risk thereof). However, the subsequent government bill is not as clear; it provides leeway for either interpretation. (Socialdepartementet 1996/1997)
According to the section on need: “Sick people have a primary need to be cured from a disease. If the disease cannot be cured, the patient needs symptom relief and nursing care. It is a quality-of-life-related need”. This addresses interpretation (1) where quality-of-life-related needs are assessed within the framework of disease or injury. Later, in the discussion of Priority Group III, it states, “Many involuntarily childless couples experience a poor quality of life, according to the Priorities Commission. Hence, they have a well-motivated quality-of-life-related need. When a biological disorder can be demonstrated in the male or female, there is also a health-related need.” In other words, a health-related need is conceptually linked to a biological disorder (disease or injury), while a quality-of-life-related need is not. Here, the government bill expresses interpretation (2). This interpretation appears again in the discussion on short stature. “We also believe, however, that in certain cases where short stature probably cannot be explained by direct hormonal deficiency, suffering and the lower quality of life caused by short stature may be sufficient grounds for medical treatment”.

The interpretation by which we choose to assess quality-of-life-related needs has an impact on rationing of health services. If we choose interpretation (1), it implies that suffering or poor quality of life (or risk thereof) not caused by disease or injury will receive lower priority regardless of how great the suffering or how poor the quality of life. If we choose interpretation (2), it means that we broaden the area of responsibility for health services. Hence, it is not limited only to disease or injury, but also includes suffering or poor quality of life that health services can affect via effective methods.

Our interviews suggest that quality-of-life-related needs, alongside of health-related needs, appear to be receiving increasing attention. It appears that health care still has a strong primary orientation towards cure. In other words, the practical application of the guideline remains uncertain. The concepts of quality-of-life-related and health-related needs are difficult to interpret uniformly, which can affect their practical application.

We propose that the guideline be further defined since the interpretation of the concept “quality-of-life-related need” has consequences for how one defines the sphere of responsibility for health services.

3.2.3 Guideline on prioritisation of all effective interventions
A continuum of care consists of several phases, including prevention, diagnostics, treatment, nursing, and habilitation/rehabilitation. Should each of these different phases be ranked the same, or should they be ranked individually? The former would involve ranking all phases in accordance with, eg, the severity level of need of the disease itself. The latter would involve
ranking each phase individually based on the combination of the severity level of need and the cost-effectiveness of the intervention. The former alternative appears to conflict with other perspectives in the government bill. Strict application of the ethics platform would mean that each phase should be assessed individually. We cannot assume that consideration of, eg, cost-effectiveness of prevention or rehabilitation coincides with the ranking of the disease groups. The severity level of need in regard to all phases of the continuum of care does not necessarily follow the severity level of need regarding the disease itself. For instance, the need for rehabilitation could be greater in a disease with lower priority than a disease with higher priority. To generally assign equal importance to every phase in the continuum of care would deviate from the idea that the needs and solidarity principle together with the cost-effectiveness principle should guide the prioritisation decision. This contradiction can lead to confusion in health services at the practical level.

Based on our interviews, we found that this aspect of the guidelines was relatively unknown for most, and was perceived to be both questionable and illogical. It is difficult to apply, since it contradicts the idea that the patient’s condition should be the determinant and not the patient’s diagnosis. Giving high priority an entire diagnostic group was therefore found to be inappropriate. The same type of criticism was directed towards the priority groups. In the context of applying the guidelines, the needs in rehabilitation and prevention were not as well served as other interventions.

*We propose that this guideline be withdrawn or substantially revised. A strict application of the ethics platform would mean that each phase/intervention in the continuum of care should be evaluated independently.*

### 3.2.4 Guideline on limited autonomy and special attention

The risk for misinterpretation of this guideline is amplified by the guideline that people with limited autonomy should be placed in Priority Group I. Here, the nature of disease does not determine the ranking but rather, personal characteristics. This can be interpreted to mean that limited autonomy automatically leads to higher priority regardless of the severity level of the need. In such a case, the care of children, for example, should be given the highest priority regardless of the severity level of the care need. Prioritisation based only on personal characteristics conflicts with the human dignity principle. A reasonable interpretation of this guideline is therefore that the determination of need in people with limited autonomy should be given high priority. Once the care need has been determined, ranking can be performed in the same way as with other care needs. This, in turn, should not be interpreted to mean that needs assessment in people with limited autonomy should receive a higher ranking
than needs assessment among others, but that it should be done so that people with limited autonomy are assessed in an adequate and equitable way.

Our interviews showed that respondents perceived the guideline to be reasonable, and one of the most important principles. It appears to have been accepted and applied in care settings. However, the guideline is interpreted in different ways. Some interpret it to mean that everyone with limited autonomy should always be given priority for care, regardless of the severity level of need. Others interpret it to mean that people with limited autonomy should be given high priority in the assessment of care needs, but not that their care needs in general should be prioritised higher than those of others. For this reason, the guideline should be clarified to better define the attitude of health services towards these individuals.

*We propose that this guideline be clarified as regards the prioritisation of needs. The guideline should not be interpreted to mean that the intervention need of people with limited autonomy should be ranked differently for that reason alone. Among other concerns, this would conflict with the human dignity principle.*

### 3.2.5 Guideline on self-care

What is the position of self-care in prioritisation decisions? The government bill views health services to be inefficient when self-care is a viable option. This should be interpreted to mean that if self-care is an adequate method, it should be prioritised ahead of professional health services. However, the severity level of need is not factored in and could limit the role of self-care in prioritisation decisions. The preamble to the guideline states that health services should utilise opportunities to promote self-care among all priority groups, but the assumption here is that self-care is associated with low risk.

The ethical grounds on which self-care should be prioritised are, however, not addressed. None of the three ethical principles that comprise the ethics platform currently provide support for high prioritisation of self-care generally. Adding a responsibility principle would provide the ethical support for special decisions on self-care.

The guideline on self-care was relatively unknown among our interview respondents, but after being informed they perceived it to be reasonable. In general, the respondents indicated that self-care is often an underutilised option. Increased accessibility to information in society about self-care was therefore viewed to be positive, and an idea that was presented involved elevating the self-care responsibility to its own ethical principle. The guideline on self-care should be more widely disseminated, and how it could be applied in practice through
prioritisation should be clarified. The self-care concept must also be further defined.

*We propose that this guideline be clarified and further defined. There is reason to consider whether the guideline should be incorporated into a prioritisation principle on responsibility.*

### 3.2.6 Guideline on non-beneficial care interventions

In assessing the degree to which special care interventions are needed, consideration should also be given to the benefits of intervention. Logically, there cannot be a need for an intervention that does not fulfil even the smallest care need. Hence, such interventions should not be included among the options for prioritisation. Given this standard, it is important to clarify what is meant by benefit.

We should start from the character of the need itself, since the intervention is needed to fulfil a need. A single situation may generate many needs. A disease, for instance, can involve medical needs, nursing needs, comfort needs, or needs to have one’s dignity respected. Which needs should we consider in assessing the benefit of, eg, a medical intervention – only the medical needs, or all needs? If we consider all needs, can a medical intervention that has no medical benefit still sufficiently meet one or more of the other needs?

Among those interviewed, the guideline on non-beneficial care interventions was easy to understand and received strong support. But respondents reported that it was far from being applied in the way that should be possible. Obstacles that prevent more comprehensive application include the force of habit, the lack of evidence and expertise, time pressure, demand from patients, and media reports. Routines for introducing and phasing out methods are largely inadequate, but are developing. This requires new, national decision-making bodies and better regional collaboration. The definition of what is implied by non-beneficial care interventions needs to be further clarified.

*We propose that this guideline be clarified, especially the concept of non-beneficial care interventions.*

### 3.2.7 Guideline on care regulated by special legislation

Through special allocation decisions, resources have been earmarked for health services regulated by special legislation. The government bill makes no provision for what should be done if these resources are inadequate. What ranking should this area of health care have in relation to activities that are not regulated in the same way? The government bill does not address the ethical considerations leading to these decisions. It is doubtful that they are grounded in
the three ethical principles of the ethics platform. Implementation of the Communicable Diseases Act, for example, is generally justified based on public welfare considerations. According to the Riksdag’s guidelines we should not apply the utility principle, ie, public welfare in prioritisation decisions. Here, there is an obvious conflict between principles.

Respondents perceived the guideline to be understandable and reasonable, even if not everyone linked it to the Riksdag resolution on priority setting in health care. The greatest problem was perceived to be that county councils cannot alter the scope of the services based on court orders, but must nevertheless assure that they are carried out. Other problems mentioned included compliance, eg, staff shortages (in psychiatry), and that certain services are given low priority, eg, issuing medical authorisations/statements. Concurrently, it was suspected that the health services within the legally regulated framework are displacing other psychiatric services. 

*We propose that this guideline be subject to critical review in relation to the ethical principles, and potentially be subject to revision. Of greatest importance is to clarify how services regulated under special legislation relate to the rest of the organisation from a prioritisation perspective. Primarily, services that are motivated from a public welfare perspective should be discussed.*

### 3.3 Other Guidelines

#### 3.3.1 Guidelines on patient opportunities to monitor and influence priority setting, and on transparency and democratic support

Guidelines on transparency and the public’s perspective have broad support, but are problematic from standpoints of principles and practicality. The the preamble to the guideline states that prerequisites for democratic discourse and public acceptance of necessary priorities include; knowledge about the grounds on which priorities are developed, the options available for input, and how to proceed if one is dissatisfied with the priorities set. It also mentions that health services have an obligation to develop methods for making such information accessible to those who are patients today and those expected to be patients in the future. (Socialdepartementet 1996/97) The government bill on prioritisation briefly mentions the knowledge and information required for patients to participate more in decisions concerning their own care: knowledge about accessibility, queues, and waiting times to various providers. Furthermore, patients must have knowledge about clinical protocols and the content of care for different diseases. Such information should also be accessible to the public at large. The government bill mentions nothing about the methods that should be used to disseminate knowledge and information. It mentions only that health services have obligation to develop methods.
Our survey found that transparency in priority setting is uncommon at a general level. Contact with citizens – eg, through public dialogues and meetings with various user organisations – was perceived to be increasingly common, but it focused on issues other than prioritisation. Patients have input regarding issues of accessibility, quality, and patient rights. The interviews in the municipalities showed a clear ambition to acquire both positive and negative opinions from users and citizens, and several municipalities are attempting to develop new methods for this type of communication. Some transparency in priority setting probably takes place via providers’ own channels, or through traditional media reporting on county council decisions.

If it is desirable to increase transparency for patients and citizens (which not all respondents agreed with), a range of practical obstacles in achieving this were mentioned.

Furthermore, methods have not been established to systematically acquire patient opinions about prioritisation. Some hesitancy was also voiced concerning the ability of citizens to take an informed position on priorities.

Results from the interviews show that the guidelines provide poor support since they are vague about how to inform and engage patients and citizens. The distribution of responsibility concerning transparency was also perceived to be unclear. Difficulties facing county councils in developing new methods to inform patients and citizens about priorities were exacerbated by the divided opinion concerning transparent discussions. Is greater transparency worthwhile if the public does not call for it? Transparency is viewed to be important – but there is uncertainty about how to manage it. We see several good reasons to continue working in this direction. The first reason is based on a democratic ideal and relates to values. The second reason is empirical. It assumes that knowledge and information about health care is necessary for public acceptance in the long run. The government bill does not indicate whether knowledge and information are sufficient for acceptance. Greater transparency and opportunities for input from people other than health services staff are expected to provide a stronger basis for decision-making. The bill does not indicate what “better” actually refers to – eg, more rational, more ethical, or more acceptable.

A more fundamental argument for increasing transparency concerns respect for human integrity. The human dignity principle requires that we treat people as capable individuals based on their individual prerequisites, ie, to respect integrity.
Patients’ input regarding their own treatment is ethically grounded in the autonomy principle. According to this principle, patients have a right to be informed about their condition, the treatment options offered by different care providers, and the accessibility of these services. Generally, patients have a right to all information of relevance for decisions concerning their health. Patients have a right to choose among the options offered, or to refuse an offer for care. However, the autonomy principle does not give patients the right to demand care. Hence, patients should not be responsible for a decision concerning resource allocation, but can participate in the decision process at various levels by communicating their unique knowledge and preferences.

We can also show respect for human integrity in the role of citizen, by allowing people to have access to and participate in decisions that affect, or will affect, them. Citizens may be able to participate directly in decisions through some type of voting process, eg, via citizen panels or through representative democracy where voters select representatives of political bodies to make the decisions.

If such a system functions properly, and if people in general have confidence in their institutions, there is probably no need for specially designed methods of public participation in order to respect human integrity.

A range of issues needs to be addressed by research and development activities. One such issue concerns the potential conflict between participatory democracy and traditional representative democracy (voting). Direct participation from citizens can create problems for decision-makers. How should a political body manage situations where citizen recommendations conflict with the ethics platform, eg, when a strong vocal majority discriminates against a weaker minority? But there are also other forms of participation that have recently received considerable attention, eg, deliberative democracy where influence is not exercised through voting, but through arguments in open discussions.

If the primary purposes of patient and citizen participation in allocation decisions are acceptance, confidence, or better basis for decision-making, the following questions must be answered:

- What knowledge or information is necessary for this purpose?
- Is the knowledge and information adequate?
- What degree or type of influence is suitable to achieve the purpose?
- Is the sense of participating in the process important?
- What methods are appropriate for dialogue?
- When is a form of representative democracy sufficient, and in what situations can more direct participation from the citizens be needed?
In such a case, who should represent them?

_We propose that this guideline be clarified. The underlying motives of the guideline should be clarified. Furthermore, the distribution of responsibility needs to be further defined as regards who should discuss the grounds for prioritisation with citizens and patients. Further research and development is needed to be able to apply it more widely than is presently the case._

3.3.2 Guideline on standards and criteria

On the whole, the guidelines may be perceived to be inconsistent. For example, the guideline on standards and criteria implies that predetermined standards or criteria cannot be used in prioritising individual patients. This creates confusion concerning the role that the Riksdag’s criteria (in the guidelines for priority setting in health care) should actually play.

The government bill emphasises the importance of the individual assessment in priority setting.

Every case is unique and must be assessed based on the individual patients’ needs and the unique conditions of a particular situation, but guided by well-thought-out ethical principles. Individual assessment places high standards on individual interaction. What patients need depends, in part, on what they value as important. Hence, it is essential to clarify how much attention should be given to individual considerations in priority setting. The patient’s actual condition naturally plays a major role. But to what extent should patients have the opportunity to determine the goal of treatment?

It is also necessary to make prioritisation decisions at other levels, eg, at the group level. How should individual priority decisions be united with the priority decisions at the group level where no individual consideration can be given? To what degree may individual prioritisation decisions deviate from prioritisation decisions at the group level?

The interview study shows that this guideline has strong support _per se_, but raises problems of interpretation. Several department directors called for additional standards and criteria, eg, guidelines or clinical protocols, to support assessment of patients and assure that equal care is provided across the country. This was perceived to be in line with treating each patient case as unique and was assessed based on individual patient needs and the unique conditions of that particular situation. Municipal representatives also expressed a need for guidelines regarding their services. For example, the municipalities have guidelines for determining financial assistance, but the respondents also
emphasised that individual user’s needs should be the decisive factor in decision-making.

*We propose that this guideline be revised so that prioritisation of individual patients should be based on the patient’s unique situation, but supported by standards and criteria. Such standards and criteria can involve prioritisation at the group level, eg, ranking lists.*

### 3.3.3 Guideline on responsibility for resource distribution

The preamble to the guideline states that in allocating resources, governing bodies are free to specify needs that should not receive priority. Hence, they may exclude them when budgeting resources. Such decisions regulate clinical practice, although given compelling reasons; health services staff may make certain exceptions. This approach involves rationing by exclusion. Do the three ethical principles support this type of rationing? Both the needs and solidarity principle and the cost-effectiveness principle may support exclusion. An intervention can only be needed if it provides benefit. Hence, diseases or injury for which there are no effective treatments can be excluded.

In cases where self-care would be more cost effective, the exclusion decision is supported by the cost-effectiveness principle, as are situations where the cost per health benefit is unreasonably high. But the question remains: Is it the intent to cover only such conditions and interventions? There are also needs where more or less cost-effective treatments are available, but where the interventions lie outside of the public sphere. This includes, eg, several over-the-counter drugs, assistive devices, eyeglasses, adult dental care, and cosmetic surgery. It is doubtful that the three ethical principles support each of these examples. Complementing the ethics platform with a responsibility principle would provide ethical support for rationing through exclusion of needs that people can generally manage on their own.

*We propose that the application of the guideline be further defined, and that the need to add a responsibility principle be analysed.*

### 3.3.4 Guideline on priority setting in social welfare generally

Respondents were largely unaware of this guideline, but most perceived it to be reasonable. Collaboration on prioritisation issues has not progressed very far among the different sectors, although some examples can be found. While there is the opportunity to raise prioritisation issues in the current collaboration between county councils and municipalities, this opportunity has not been pursued. The central government needs to place clearer demands on providers (eg, county councils and municipalities) to collaborate in the priority setting process.
We propose that this guideline be further clarified to define the responsibilities of various actors in society to apply the prioritisation principles.
4. DEVELOPING A FAIR PRIORITISATION PROCESS; OBSTACLES AND ACTIONS

Our interview study found that the guidelines on priority setting in health care are generally perceived to be reasonable, and to some degree self-evident. However, applying the guidelines appears to be problematic in various ways. Hence, it is important to understand the character and origin of the problems to be able to overcome obstacles and find ways to facilitate implementation of the Riksdag’s guidelines. In concluding, we discuss the possible reasons for these obstacles and actions to overcome them.

Sweden’s publicly financed health service demonstrates all the features of a complex organisation. Through the decisions and positions taken by the Riksdag and Government, the central government exercises influence by establishing goals concerning how to act or not act, and also controls various types of resources to influence behaviour. The responsibility to effectuate goals and benefit from resources rests with the county councils and municipalities with their own democratic mandate and their own right to levy taxes on the population. Implementing goals and applying resources in direct contact with citizens places considerable responsibility on the personal decisions of healthcare professionals and other staff. In this environment, national goals and purposes should be implemented in line with fundamental principles for fair distribution of and access to public health services. All nations struggle with similar problems – to find effective instruments to move a complex reality in a desired direction. (Peters and Pierre 1998, Howlett 2000) In recent decades, the solution has been to test combinations, so that prescribed means such as legislation are complemented by other means such as strengthening the knowledge and capacity of those who must act, eg, through reorganisation, education, and information.

The Riksdag resolution on priority setting in health care (1997) deals with fundamental principles in the delivery of public health services. In Sweden – in contrast to many other countries – the central government has chosen to use certain ethical principles to guide the governing bodies responsible for organising public health services. These principles form the core of the Riksdag’s guidelines on priority setting. This has been clearly emphasised by including the principles in the Health and Medical Services Act. In addition, the Riksdag resolution contains other guidelines, some concerning application of the ethical principles and others providing a supportive function in prioritising health services, eg, democratic support and division of responsibility among actors within a provider organisation (political level – service delivery level). The latter guidelines are not included in the Act, but rather emphasise what the central government wants the governing bodies to consider in priority setting.
The Riksdag resolution on priority setting in health care aims at influencing actors in health care to do things they otherwise would not have done, or to do these things in a different or better way. Whether the establishment of ethical principles is the best way to get the various actors in health care to act differently or better in prioritising health services is nothing that we can, or want, to assess. We can only say that this is probably a complicated means to use if the intent is to affect behaviour among different categories of actors in Swedish health care. Although guidelines can be difficult to implement, there may be good reasons to establish them. For example, one reason might be that the central government wants to clarify the values that should permeate actions within a particular sector of society, despite the difficulties of applying them in practice. The goal of priority setting in health care should be based on what an authoritative decision-maker believes is the right thing to do, not on what can be implemented easily. (Linder and Peters 1987) Problems can arise when guiding principles are converted into practical actions. The result could be a clarification of the principles, but the problems could also be addressed through other means.

Guidelines like those addressed in this report can only ‘guide’ up to a certain point. They do not comprise a solution to all decision problems facing healthcare decision-makers. Guidelines *per se* can provide better guidance if they become clearer, particularly if they contain elements that can be interpreted differently among the actors in health services, or if they give conflicting information concerning how to act, which does occur to some degree. But similar to what the Prioritisation Delegation reported at the time (and which we referred to earlier), we believe that healthcare providers (e.g., county councils and municipalities) must be the ones to develop the prioritisation process. However, not all of the Riksdag’s guidelines provide guidance concerning how these bodies should assess and motivate resource allocation problems in health care. We have proposed that the ethical principles – except for the overriding human dignity principle – should be given the same ethical status, which means that in conflicting situations, decision-makers must use their own judgement. Hence, decision-makers – whether politicians or healthcare professionals – must have the capacity and sense support from the rest of the organisation in decision-making situations.

But how does this actually relate to the conditions for implementing the Riksdag’s guidelines in practice? Previously, we noted several of the problems we perceived. Now we attempt to take another step towards systematising these problems to show the various reasons why implementation of the guidelines is difficult in practice. Only some of these problems can be attributed to the content of the guideline themselves.
4.1 Reasons for Problems in Implementing the Riksdag’s Guidelines

Problems encountered in the practical implementation of the guidelines are rooted in many different reasons. Ann Schneider and Helen Ingram, American political scientists, (1990) presented five reasons why those who are expected to act do not behave as decision-makers intended. If we use these reasons as categories to systematically classify responses from our interview study of healthcare politicians, administrators, and professions in the county councils and the municipalities, the following profile emerges:

A) The actors do not think that the rules apply to them or give them support for their actions.

A common opinion held by the respondents regardless of whether they are politicians, administrators, or healthcare professionals is that the guidelines provide inadequate guidance. One perception is that the Riksdag’s resolution does not give them strong enough support to act. Primarily, they believe that the key concepts used in conjunction with the ethical principles, or the guidelines based on the principles, are unclear and need to be further developed before they can be applied in practice. This is exemplified by the hesitancy concerning how to assess need and how to relate cost-effectiveness to need. Other examples concern uncertainty about the concepts of “needs coverage”, “non-beneficial interventions”, “self-care” and “special attention” in the context of people with limited ability for self-determination and children without responsible guardians. Some interpret the text to mean that these groups need help to make their needs known, but that their medical needs should not be assessed differently than needs in other groups. In another context the interpretation could be that people falling within this category should receive higher priority regardless of actual needs. But the perspectives can also include uncertainty about what is meant by “overriding political level” in the guideline addressing responsibility for resource allocation.

Among the priority groups – which are perceived to be contradictory in general – group II is viewed as somewhat of a ‘misfit’. Respondents emphasised the importance of prevention and rehabilitation, but since the groups list interventions instead of conditions this leads to questions concerning implementation.

Secondly, the respondents reported indications that some actors choose to neglect the guidelines, possibly because they do not think that the guidelines apply to them. For example, it was suggested that medical decision-makers avoid responsibility for quality-of-life-related needs and, to the extent possible, concentrate on curative interventions. Yet, there is a guideline that equalises needs of different types.
Another example would be the assertion that patient perceptions are not included in prioritisation despite the guideline that gives patients the opportunity for insight and influence. Representatives of municipal services perceive that the guidelines apply to county council services, not to the municipalities.

B) Actors lack the incentive or capacity to act.
The lack of incentive can, in this context, be viewed as an absence of prerequisites in the environment in general to act in line with the guidelines, or to target particular objectives. The absence of incentives can be due to a perceived lack of support from others, or that one interprets factors in the environment to be unfavourable for targeting a particular objective. For example, this could apply to county councils and municipalities (which are democratically ruled organisations) being subject to opinion pressure, not least through intensified mass media coverage of healthcare issues.

An example of the lack of incentive in terms of support is that physicians on the whole do not want to make cost-effectiveness decisions on their own without explicit support from politicians. This problem – that one’s actions are dependent on the actions of others – was mentioned repeatedly in the interviews. This is associated, eg, with uncertainty about responsibility for establishing criteria in resource allocation and who should bear the responsibility for interpreting the ethical principles, eg, regarding what constitutes major and minor needs. Several respondents asserted that problems arise due to the lack of political courage to discuss what health services should not be offered when resources are inadequate. Service providers call for political support in backing up decisions to deny certain treatments.

It was also asserted that problems arise when political decision-makers do not consistently adhere to their previous positions, eg, how the organisation views need. In this context, situations were highlighted where politicians act on perceived “pressure” from interest groups to introduce new methods without a needs analysis, and which conflict with standpoints already taken up at the national level.

If the political will for transparency is lacking, it can negatively influence systematic work with prioritisation in the county councils. Transparency in prioritisation issues requires strong unity within the organisation before external dialogues can be established with the public. Another assertion is that the lack of political support makes communication with patients more difficult. Since decisions may be vague, and a conscious foundation supporting the nature of the decisions is lacking, they cannot be communicated to patients.
Health service staff could also find it difficult to place demands on patients to actively influence their personal health, since the extent of support for such action from the Riksdag’s guidelines and local decision-makers is unclear.

The interviews also suggest why politicians generally hesitate to act, or act in a way perceived to be inconsistent within the organisation. Politicians’ incentives depend somewhat on how the mass media cover various types of needs in health care. Hence, major attention can be directed at needs other than quality-of-life-related needs, which in turn can affect the scope of action by politicians. Another problem affecting the willingness of politicians to make decisions that might guide health services to exclude certain interventions is rooted in the legitimacy of the publicly financed sector. This argument, mentioned in the interviews, assumes that citizens must perceive some benefit from public services before they are motivated to contribute to their financing – politicians might be hesitant to exclude anyone. This can make it politically difficult to recognise and allocate resources to only those groups with major care needs.

Regarding problems that arise due to insufficient capacity, the interviews pointed to deficiencies in “internal legitimacy” – that politicians and health service personnel have different perceptions, eg, in their views towards the needs principle. The situation is exacerbated by the lack of a forum for a dialogue concerning interpretation, eg, of the needs principle. Also noted was the lack of decision-making information in health care, including data and instruments to analyse needs, or evidence for assessing cost-effectiveness and phasing out ineffective methods. Questions raised in this context include: What should be considered a reasonable relationship between cost and effect? How should we deal with costs that fall outside of health services? Evidence to support the proposal to expand self-care is also called for.

Some mentioned a lack of capacity in terms of knowledge about principles, methods, and instruments for horizontal priority setting, ie, prioritisation between different disease groups and service areas.

C) Actors do not share values concerning goals and means.
It is complicated to determine what are goals and means in Swedish health services. A range of various means can be used in reaching various goals, whether primary goals or subordinate goals. If the role of ethical principles is to provide guidance, they can be perceived as means to achieve a well-functioning health service with public financing. But the Riksdag resolution from 1997 also mentions other types of means to support application of the ethical principles. Hence, we can identify means of different importance.
The interviews revealed various types of criticism due to differing opinions concerning means; whether the Riksdag’s guidelines are generally appropriate, or if they carry inappropriate weight compared to other means. The former includes opinions about the guideline calling for transparent prioritisation. Some respondents seriously questioned whether patients and citizens demand transparency about difficult decisions in health care, and consequently whether this is appropriate. The latter is exemplified by the uncertainty about the relationship between the cost-effectiveness principle and the other ethical principles. Opinions differ regarding whether the cost-effectiveness principle should be subordinate to or equal to the other principles.

Another type of criticism concerns the interpretation of the human dignity principle, where values other than those that form the basis for the Riksdag resolution are mentioned. Some respondents believe that if an intervention has “major social benefit”, it should be possible to use this as a basis for prioritisation. An example would be the treatment and rehabilitation of individuals on sick leave who can be expected to return to work.

Perceptions differ on the use of standards and criteria in priority setting as expressed in the guidelines. The critics imply that the restrictive view towards standards and criteria conflicts with other guidelines, eg, the formation of priority groups indicating that some conditions should receive high priority and others low priority. This can be perceived to mean that the Riksdag advocates standards even though standards are not sanctioned. Some respondents claimed the opposite, that standards and criteria are desirable to be able to assure appropriate care, and that standards are encouraged in other contexts, eg, through the emphasis on evidence-based medicine (by SBU) and the national guidelines for treatment of common diseases from the National Board of Health and Welfare.

A problem that many respondents addressed was that the government continually introduces new goals in health care that should be prioritised, but does not place them in relation to the prioritisation principles in the ethics platform or other guidelines. An instrument to deal with this was recently introduced, the so-called maximum waiting-time guarantee. The importance of the maximum waiting-time guarantee in the efficiency and monitoring of health services was emphasised in the interviews, but a common opinion is that conflicts can arise between the rules on applying a maximum waiting-time guarantee and the prioritisation guidelines, ie, a conflict between different means. The respondents did not disapprove of these means per se, but observed a conflict in values between the two means. The concepts of free choice of care and the maximum waiting-time guarantee could be perceived to conflict with the prioritisation principles:
The maximum waiting-time guarantee carries a risk for a displacement effect so that highly prioritised patients with major care needs are at risk for less access to care than lower priority patients with fewer needs, but who are in a certain queue with longer waiting-times. Although politicians have expressly stated that minor problems should not take precedence over more serious ones, decisions that allow exceptions to certain principles in favour of others are often missing. Hence, there is a risk that a demand that creates large volumes of patients would have more influence than actual needs. Ophthalmology is an example of just such an area. People with severe and long-term disease, people with functional impairments, or elderly with multiple disorders may have to stand aside for younger people with recent disorders who can better assert their rights and can utilise opportunities to be treated by providers in other county councils.

D) Actors view the situation to be uncertain since the problem is unclear
An obvious example of uncertainty about the character or scope of the problem relates to whether the county councils fully live up to the ethical principles. Application of the overriding principle, the human dignity principle, can be inadequate, according to some of the people interviewed. They suggest there are indications that the needs of some people, eg, women and immigrants, are prioritised too low while other groups receive positive special treatment, ie, they receive greater attention than what is actually motivated by need. Since the scope of these problems is uncertain, there is also uncertainty about how to address them.

Another example concerns the uncertainty surrounding the approach and role assignments in establishing discourse with patients and citizens about resource shortages, and long-term communication regarding priority setting. There is uncertainty concerning which methods and instruments can be used in communicating with the public as regards priority setting. This is also rooted in the uncertainty about how transparency should be managed, whether lack of transparency is actually a problem, and how responsibility for communicating with the public should be distributed. If the problem profile is ambiguous, or if the problem profiles in an organisation differ, it is not easy to act.

E) Actors are uncertain how to act, or how other associated actors should be motivated to act.
Even if the ethical principles are available to support actions, uncertainty can arise about who should act and how one should act to achieve goals. A familiar problem of this type concerns the boundary between the county councils and the municipalities, determining who should have responsibility in the continuum of care, and how joint priorities can be established.
In this context, it is asserted that representatives for the county councils and the municipalities approach needs differently. The extent to which this can be attributed to differences in legislation (Health and Medical Services Act verses the Social Services Act), or to something else, is uncertain.

The lack of collective responsibility for prioritisation and uniform application and interpretation of the principles, as well as questions about responsibility at different levels, creates uncertainty. Local initiatives to develop more systematic rankings can be found in primary care and in hospitals, eg, that may choose to use the “Västra Götaland Model” or the “Swedish Society of Medicine Model”. But unified action is missing.

Other areas of uncertainty may involve questions like: who within the organisation is responsible for defining which patients have the greatest needs; who is in charge of managing questions about how to view needs versus demands; and who is responsible for transparency regarding patients?

4.2 If problems exist, how do we proceed?
The review presented above suggests that certain problems may originate from the content of the Riksdag’s guidelines, while other problems are of a completely different nature – they relate to the decision-making capacity, scientific evidence, management functions, and different perspectives among the actors assigned to develop a prioritisation process in health care.

Depending on the character of the problems that emerge, different instruments can be used to affect the situation. Often, different combinations of means are possible. (Schneider and Ingram 1990) Some inputs may be grounded in the ethical principles, while others involve supporting the ability of providers to act in line with the Riksdag’s guidelines. In some cases, the problems can be attributed to a deficiency in systematic knowledge, and in other cases to the capacity for using available knowledge. Some of the instruments mentioned by Schneider and Ingram (1990) can be used to increase the potential for county councils and municipalities to comply with the intent of the Riksdag’s guidelines for prioritisation of public health services. In this context, the instruments involve:

1. Clarify the ethical principles and guidelines.
This also includes changing or complementing existing guidelines. If there are problems in interpreting and using the ethical principles, or if they are perceived to be incomplete, they may need to be further developed, clarified, explained, or complemented. An example would be the question of how the cost-effectiveness principle should relate to the needs principle.
Previously, we presented our views on the importance of clarifying the ethical principles and the guidelines that support them.

2. **Increase the capacity of actors to strengthen their decision-making ability.**

   Even in this area we find opportunities to influence the situation. Developing capacity means providing information, education, knowledge, and other resources for decision-makers at different levels in the healthcare system. Additional capacity can be expressed in different ways:

   a) The interviews show that healthcare professionals call for more clarity in policy-making decisions. The capacity for decisions at policy level can be improved by clarifying, and in some cases complementing, the ethical principles. We proposed a responsibility principle aimed at strengthening the foundation for certain political decisions, which in turn can guide decisions in health care. Strengthening this capacity could also improve the acquisition of evidence for needs assessments, or enable more systematic application of the cost-effectiveness principle.

   b) As citizens acquire greater information about the outcomes of health services they may react against the arbitrariness of resource utilisation. Hence, it is important that the representatives of health services contribute towards developing models that yield similar evaluations and similar working methods throughout the country. Currently there is such a national model for vertical prioritisation, which is a first step. Opportunities are available to continue in this direction.

   The interviews revealed uncertainty regarding how needs should be defined and described, and that prevention is perceived to be a ‘misfit’ that is difficult to adapt to health services generally. Possibly these questions can be managed better if the resources of social medicine – with epidemiological knowledge about public health problems and methods of prevention – are more systematically involved in prioritisation efforts.

3. **Show how guidelines at the national level relate to the values and realities of different actors.**

   This concerns, eg, involving the medical profession and other professional groups in efforts to find practical solutions in prioritisation. Although work is already under way within some professional associations it should be intensified nationally and locally. If, as indicated, there is major interest for ethical issues within health services, this could be used as a basis for approaching other issues that can be more difficult to address, eg, how to interpret and apply cost-effectiveness as grounds for prioritisation.
Many respondents suggested it is possible to make the prioritisation process more uniform throughout Sweden and expressed a desire to work towards this. As regards national guidelines and prioritisation, the work of the National Board of Health and Welfare was viewed as a model. More concrete prioritisation discussions, similar to the national guidelines, would be desirable. Some called for a national model for priority setting. It is becoming increasingly difficult to defend the differences among county councils, and more collaboration is needed. Prioritisation is perceived to require hard work and continuous discourse aimed at some type of shared vision.

4. Use the opportunity to learn through quality improvement efforts and the systematic transfer of knowledge.

Our survey suggests that the issue of transparency in prioritisation is a major cause for concern among many healthcare providers. Communication with the public about prioritisation is an area of considerable uncertainty as regards goals and means. Although research is under way on democratic participation (Esaisson and Westholm 2006) and transparency in prioritisation (Daniels and Sabin 2002), the results are somewhat contradictory and do not provide guidance for developing a strategy for priority setting that the public might accept as fair and legitimate. In that context, we emphasised the importance of developing scientific evidence. A potential way forward involves an effort by providers to develop a more systematic approach and a more systematic transfer of knowledge. This work should aim at understanding when one-way information flow is appropriate and when discourse and direct participation by the public are preferable. Even in other areas, the systematic transfer of knowledge has major value, not least as regards the dissemination of practical experiences in priority setting.
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