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**Per Carlsson's response to questions on priorities in health care**

1. Priorities of health care became a political subject of debate because demands and expectations on health care are steadily growing. This is a result of several long term trends in society. The elderly population is growing in numbers, changes in social structure are increasing the number of people living alone and development of health innovations appear to be steadily accelerating. At the same time the opportunities to finance public services via taxes are recognized to be limited of a majority.

"There would seem to be general agreement today that the grounds of prioritising in the caring sector must be stated and discussed openly if confidence in health care is to be sustainable" (Swedish parliamentary Priorities Commission, 1995)

The debate on priorities took place in late 1980 which resulted in the initiative to set up the Swedish Parliamentary Priorities Commission in 1992. At that time the health care system was similar to the one we still have today. However Sweden was then in a dramatic transition mode which resulted in a great number of initiatives to reform health care services and public sector in general. Moreover Sweden's public economy was in a deep crises with high budget deficits.

2. Between 1992 and 1995 the parliamentary commission investigated the role of explicit priorities in health care, and looked at which ethical principles should guide priority setting. The commission produced a guideline for priority setting which have had some impact. The Parliament approved the guideline with minor changes. Following ranking of broad categories was proposed:

> Prio1:Treatment of life-threatening acute diseases and diseases which if left untreated will lead to permanent disability or premature death. Treatment of severe chronic diseases. Palliative terminal care. Care of persons with reduced autonomy.
> Prio2:Prevention with a documented benefit. Habilitation/rehabilitation etc as defined in Health and Medical Services Act.
> Prio3:Treatment of less severe acute and chronic diseases.
> Prio4. Care for reasons other than disease or injury.

3. In 1993 the committee presented three major principles to be used within all types of health services. This so-called ethical platform was widely discussed in the political sphere, with some public involvement, and in 1997 resulted in changes in the core section of the Health Care Act. Although people in general are mostly unaware of the ethical platform, the three principles of (i) all people are equal in dignity and value; (ii) resource allocation on the basis of need and (iii) taking into account cost-effectiveness. The three principles are ranked in the order they are presented.

General subordination of the needs of for example the elderly, premature babies, self induced diseases or life style related health problems is a form of discrimination and perceived incompatible with the basic ethical principles. Reference to economic circumstances, social status, positions of responsibility and other aspects of social position is also incompatible with the ethical principles.

The commission rejected the benefit principle in the sense that of priority being given to that which is of most benefit to the greatest number. The demand principle and the lottery principle were also rejected.

4. A health care system is always in transition which mean that responsibilities and power is changing. This is particularly true when new fields of interest are established. In Sweden there is a triangle of power between the central government with its agencies, the county councils and the medical professional groups.

The development of health technology assessment (HTA) is a key for the establishment of systematic and open priority setting. In recent years HTA is being used more in policy making in general and priority setting. The establishment of the new agency for the reimbursement of drugs, the Pharmaceutical Benefit Board, is one good example open priority setting.

Table 1. Actors involved in health technology assessment and priority setting in Sweden and their roles.

| **Macro level** | HTA | Priority setting |
|---|---|---|
| The Swedish Parliament | Takes sometimes initiatives to set up particular HTAs | Decides on basic principles for priority setting |
| Ministry of Health and Social Affairs | Takes initiatives to set up particular HTAs by SBU<br>Decides on budget and mission of government agencies i.e. SBU | Allocation of some government subsidies between different sectors in society and health care sectors by annual budget processes and production of policy documents |
| National Board for Health and Welfare (NBHW) | Produces national guidelines. Recent guidelines are based on systematic reviews made in collaboration with SBU | From 2002, priority setting recommendations are a vital part of national guidelines |
| SBU | Conducts comprehensive systematic reviews and produces brief assessments of new and emerging health technologies | No explicit role |
| Medical Product Agency | Approves marketing of new drugs based on efficacy data.<br>Produces guidelines for drug prescription (workshop series) | No explicit role |
| LFN- Agency for pricing and reimbursement decision of drugs | Assessment of effectiveness, cost-effectiveness and clinical relevance of new drugs | Drug reimbursement decisions |
| Federation of County Councils | Active actor in reforming the system for assessment and distribution of drugs.<br>Supportive to regional and local HTA related activities, particularly those related to drugs | Involved in production and implementation of national guidelines in collaboration with NBHW |
| The Swedish Medical Society | No explicit role | No formal role. Engaged in development of methods for open p riority setting of health services engaging several medical specialities |
| Universities | Produce primary clinical research and primary HTA. Many researchers in medicine and other relevant disciplines are engaged in projects conducted by SBU and other national actors | No explicit role besides work on principles and development of methods |
| Other HTA org e.g. consultants. | Produce primary HTA | No explicit role |
| National patient organisations | Sometimes take initiative to an HTA and to some degree financing of HTAs | Participate in formal decision-making processes as members of committees. Informal role as lobby groups |
| **Meso level** | | |
| County councils | Sometimes take initiatives to HTA. Setting up local HTA units (few examples). To a larger extent consumers of HTAs. Responsible for development of regional and local clinical guidelines | Responsible for financing and production of nearly all public health services. This involves a lot of implicit priority setting. Decide upon major investments in new medical technology. Development of open priority setting of health care is currently taking place in a few county councils |
| Local drug committees | Assessment of effectiveness and cost-effectiveness of drugs | Produce prescription recommendations for effective medical practice |
| Municipalities | No role today | Responsible for financing and production of long term care for the elderly |
| **Micro level** | | |
| Clinicians | Take initiative to HTAs. Involved in studies. Increasingly consumers of HTA | Priority setting of individual patients. Engaged in development of clinical guidelines and moderate investments in new technology |
| Other professional groups | Take initiative to HTAs. Involved in studies. Increasingly consumers of HTA | Priority setting of individual patients |

Source: Carlsson, Int J Tech Ass in Health Care 2004;20:44-54.

Public play no direct role in priority setting. In Sweden public representatives such as elected health care politicians play an active role in decision making in the county councils and municipalities.

5. As Sweden has decentralised health care system it is difficult to answer this question. The Ministry of Health has taken e few initiatives. A committee was set up between 1998-2000 with the mission to support and monitor the implementation of the priority setting principles in the county councils and the municipalities. Secondly, the National Board of Health and Welfare was commissioned to work with development of methodology and support the county councils with treatment guidelines including priority setting for common diseases. Thirdly, in January 2001 the National Centre for Priority Setting in Health Care was established in Linköping. The Centre is to strive for the development of knowledge for priority setting activities across the nation. This shall contribute to an exchange of knowledge between persons in health care research and practice and an exchange of experience between the players in these arenas.

The Centre has focused on the development of transparency in priority setting in health care based greater transparency in both decision-making processes and decisions than we are currently used to. This concerns decisions both on the political level and decisions made by health care staff in health care services.

The overall objective for the Centre is to:

- Pursue research and development of methodologies and processes that can support priority setting in health care and work with medical programmed activities,
- Establish meeting places and mechanisms for the exchange of knowledge and experience, and to
- Provide knowledge about transparency in priority setting and to support local development efforts.

In addition to the activities run by the Centre, an increasing number of projects and trials to establish systems for explicit priority setting are under way in Sweden. Such activities are currently taking place at both the national level (e.g. the National Board of Health and Welfare and the Swedish Society of Medicine), and at the local-regional level (e.g. the Östergötland county council and the West Region (Västra Götalandregionen)).

6. In theory the principles mentioned above (question 3) should be applied in prioritisation decisions. In practice there are of course a great number of values and criteria which influencing the decision.

Development work in several projects on national and regional level has resulted in framework which is kind operationalisation of the ethical principles (below):

**Factors to consider in priority setting**

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

7-9. The county councils are responsible for implementation of the idea of explicit priority setting and implementation of prioritisation decisions taken by the Ministry of Health i.e. expand and improve primary care.

To be able to assess whether or not transparency in priority setting is appropriate and to obtain better knowledge of any possible impediments to open priority setting, the National Priority Setting Centre has evaluated the decision-making process in a the Östergötland County Council that has the intention of working with more transparency in priority setting. The county council had planned for greater transparency for several years in line with the Swedish Parliament decision on priority setting in health care. The immediate cause for this particular transparency in prioritizing with limited service was an expected large deficit in 2004. To avoid a large deficit, the Östergötland County Council, according to budgetary directives, was to cut costs for 2004 by SEK 300 million (the equivalent of four percent of the entire budget). As a first step, county council directors commissioned county council services to draw up lists

of vertical priorities within different categories of illness and to draft a proposal for improved efficiency and structural changes.

Observations and interviews show that the procedure for priority setting that Östergötland has used functions relatively well in relation to theory (Daniels &Sabin), but there are shortcomings. The decision-making process satisfies many conditions for being perceived as fair and legitimate – reasonable and accepted by the majority – while a couple conditions are poorly worked out. Decisions on priority setting were made in a legitimate organisational context that had the mandate to make such decisions. Many interested parties' perspectives were represented in the decision-making while others who could have contributed were missing. The politicians were highly aware of the principles and factors they should take into consideration when making decisions, but they seldom directly referred to individual factors in the prioritising model in their practical discussions. The reasons for decisions, as a rule, rested not on individual factors but on a balance of facts. Even though a great deal of the material was available on the Internet, few people were aware of this and neither could they interpret and understand the meaning of the material. In other words, even if the material was accessible, it was nonetheless "inaccessible" for the general public. Nevertheless, in the first round there is no mechanism for reviewing decisions if new facts or arguments come to light.

Areas with the greatest need for improvement are foremost:

- Representation of professional categories other than physicians to illuminate the issue for the entire health care chain, from prevention to nursing and rehabilitation. Representation or dialogue with the "users", i.e. patients and the general public is needed to a greater extent to obtain their perspective on health care political prioritising and to ensure that the priority setting process is perceived as fair and legitimate. However, this requires identifying suitable problems for discussion.
- An established routine is needed in the decision-making process to ensure that those who take part in the prioritising decisions balance all the components in the county council's established model for priority setting.
- As regards transparency in the decision-making process, we judge that it is important that data for decision-making is obtained through a transparent process that includes health care professionals from many levels to achieve as great internal legitimacy as possible. Therefore, satisfactory information must be given to the organisation; initially about the priority setting process, the division of roles, guidelines and time schedules; and at the end of the priority setting process on what the decisions will entail in practice for the services.
- Guidelines for who is to do what and how it is to be done and when it is to be done must be clear. Information must also be provided to the general public; initially on how the task is being done and at the end of the priority setting process about which decisions have been made accompanied by a description of possible consequences. The information that is disseminated externally should, as far as possible, be well prepared and contain information on actual decisions, or preliminary positions that politicians wish to present for public debate.
- A mechanism for reviewing decisions if new knowledge or new arguments come to light is missing and should be established.
- Above all, transparency must be better as regards decisions and how they are motivated. The potential to assess and discuss decisions made on priority setting increases substantially if decisions are well motivated so that facts, basic values and pros and cons are reported.

10. Not yet.
11. To early to have certain opinion about this.
12-13 I think we have to little experience to be able to answer question 12 and 13.