# Severity of illness and priority setting in Norway

Summary of a report from a working group, November 2015.

Severity of illness has been a criterion for priority setting in the health care sector in Norway since 1987. The selection and weighting of prioritisation criteria have been discussed in three Norwegian Official Reports (NOU 1987: 23, NOU 1997:18, NOU 2014:12). In 2015, the Government appointed a working group with the specific task of determining how to assess severity of illness in practical priority setting in the health care sector. The working group submitted its report to the Ministry of Health in November 2015. Below is a summary of the working group's report.

Priority setting is one of several policy tools to ensure equity in the access to health care services, and thus concerns the distribution of health care services. The key concepts employed by the working group in its approach to the discussion of principles for distribution are *equity* and *need*. The challenge in practice is to define these concepts in a manner that makes them applicable to the design of practical principles for resource allocation.

Priority setting in health care takes place at various levels. There are four types of decisions for which prioritisation is relevant: i) decisions in clinical practice, i.e. decisions that will normally arise in the meeting between the individual patient and the health care services; ii) decisions regarding distribution of a limited budget between different types of health care services; iii) decisions regarding the introduction of new medications, treatment options, diagnostic techniques, public health programmes, and the like, i.e. decisions relating to changes in capacity; iv) political decisions at the societal level regarding allocation of resources among various types of public services, among various types of health care services, and the like.

Assessment of severity is relevant for priority setting at all levels in the health care sector, and the working group concludes that the severity criterion should be provided in two forms: a broad *textual description* primarily for use in clinical practice, and a targeted *operationalised form* for use in decision-making at the group level, such as when introducing new methods, new medications or larger-scale public health measures.

Up to now there has been no precise definition of severity, and the term has been employed in diverse ways. The working group has conducted a simple survey among clinicians, decision-makers and patient organisations to get an idea of how the concept is understood and used in various segments of the health care services. The responses reveal that there is no universal understanding of what severity entails, and no clearly designated usage of the term. Rather, severity is described by means of many elements and these elements are weighted differently. According to the working group, it is important to define a criterion for severity that reflects this range of meaning. A criterion with too narrow a scope will not adequately encompass the full range of relevant intuitions about what makes an illness severe, which will ultimately make the criterion less attractive.

Thus, the working group is proposing two different versions of the severity criterion for use in priority setting in the Norwegian health care services. The *textual version* describes the elements that the working group believes should be included in a severity assessment. The following description is proposed:

> *The priority of an intervention increases in keeping with the severity of the condition. The severity of the condition is to be assessed on the basis of:*
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> - *risk of death or loss of function;*
> - *the degree of loss of physical and mental function;*
> - *pain, physical or mental distress.*
>
> *The present health situation, the duration and the future loss of healthy life years are all of significance for determining the degree of severity. The more urgent the need to start the medical intervention, the higher the degree of severity.*

This textual description will be particularly suitable for priority setting in clinical practice, i.e. in the patient's meeting with the health care services. The working group additionally proposes a more targeted version of the term for use in decision-making at the group level. This version builds on and is in keeping with the textual version, but can also be operationalised to a degree that makes it more suitable for group-level decision-making. This version will be especially applicable to the assessment of new medications, new diagnostic procedures, new treatment methods and larger-scale public health measures.

The working group describes and discusses four different approaches to this more targeted description of severity. The term "healthy life years" is used to describe health gains and health losses in a manner that takes into account both increased life expectancy and improved quality of life with medical intervention. Severity can thus be potentially operationalised through:

*i)* *Prognosis:* The number of healthy life years remaining before a person dies.
*ii)* *Absolute shortfall:* The number of healthy life years lost as a result of premature death and reduced quality of life during the period of illness. Absolute shortfall is equivalent to future loss of healthy life years.
*iii)* *Proportional shortfall:* The number of healthy life years lost as a result of premature death and/or reduced quality of life during the period of illness, as a proportion of the potential number of remaining healthy life years in the absence of the disease.
*iv)* *Absolute shortfall from birth:* The sum of the number of healthy life years lost as a result of premature death and/or reduced quality of life during the period of illness plus the number of healthy life years lost earlier in life.

In all four alternatives, severity is measured in relation to the treatment options currently available to the patient groups. In its consideration of these alternatives, the working group has attached particular importance to:

*Absolute shortfall from birth*

Using the patient group's expected absolute shortfall from birth as the basis for priority setting implies using the health care services in a project in which the objective is that all individuals should be able to experience an equal number of healthy life years over the course of their lifetime. This is often referred to as the "fair innings" argument. The working group argues that there are both practical difficulties and principle concerns in using absolute shortfall from birth as a criterion for assessing new methods/medications. It is the opinion of the working group that the primary task of the health care services is to treat disease and promote health, not to compensate for previous health losses.

According to the working group, loss of health prior to the onset of a disease should not influence the assessment of the severity of the present health situation. Today's health care system is rooted in a value base built on the presumption that access to health care services must be independent of the individual's status. When we meet the health care services we are all in the same position and all have the same right to services – we have *equal rights.* A person's health earlier in life could also be interpreted as part of the "status" in this context. In the view of the working group, severity must thus be linked to future health outcomes related to a given disease, i.e. the health impacts of not making a new form of treatment available.

*The number of remaining healthy life years – prognosis*
Prognosis, understood as the number of remaining healthy life years, captures the present health situation as well as the development and duration of the disease. This alternative is best suited for conditions leading to premature death, and it may perhaps harmonise best with our intuitive understanding of severity. Prognosis does not, however, take into account "future loss of healthy life years". For example, a prognosis of three years implies a larger loss of healthy life years for a patient group with an average age of 30 than for a patient group with an average age of 70. In the case of chronic conditions, the number of remaining healthy life years will necessarily be higher the younger the patients are, and the prognosis will be less representative of the severity of the condition. The same will be true for temporary conditions. The working group believes that *prognosis* alone does not adequately capture the relevant aspects of the term severity.

*Future loss of healthy life years – shortfall*
It is the opinion of the working group that future loss of healthy life years plays a significant role in the assessment of severity. The question is whether this is best captured using a measure of *proportional* or *absolute* shortfall. Both absolute shortfall and proportional shortfall are measures that can partially capture the present health situation, the illness duration and future loss of healthy life years.

In the discussion on the use of severity as a criterion for priority setting, the relationship between the severity criterion and age has been a topic of particular debate. Both proportional shortfall and absolute shortfall may vary according to the average age of the patient group towards which the intervention is targeted. Furthermore, the correspondence between average age and proportional or absolute shortfall will depend on whether the conditions are considered as leading to premature death (fatal), leading to loss of quality but not length of life (chronic), or temporary. Thus, neither absolute shortfall nor proportional shortfall describes severity in a manner independent of age. Proportional shortfall will

truncate the differences between age groups, thereby appearing to be less related to the age of the patient groups. Any ranking of interventions by severity must, however, also be linked to a fixed willingness to pay threshold, and differences between proportional shortfall and absolute shortfall may, if desired, be dealt with through the way severity is weighted into the prioritisation decision. Therefore, it is not possible to conclude with certainty, how a criterion will affect the distribution of services between various age groups when it is applied in actual priority setting situations.

Proportional shortfall differs from absolute shortfall in two ways. Proportional shortfall does not take into account when during life a chronic condition occurs. Thus severity will not depend on the amount of time patients live with a chronic condition. Also, proportional shortfall will assess a temporary loss of healthy life years as being more severe for older patients than for younger patients. Both of these elements lead the working group to prefer absolute shortfall as a better measure of severity. In addition, in the context of proportional shortfall, a small loss of healthy life years late in life may be considered equally serious to a large loss early in life because the small losses may comprise an equivalent *proportion* of expected remaining healthy life years. In the opinion of the working group, it is more serious to lose e.g. 20 of 40 remaining healthy life years than to lose one of two remaining healthy life years.

*Thus, the working group concludes that absolute shortfall incorporates to a greater degree than the other measures the key features of what characterises a condition as severe. The working group therefore recommends that assessments of new medications, new treatment methods and other group-oriented measures such as large-scale public health measures are based on a description of severity as expected absolute shortfall for the patient group towards which the measure is directed. Furthermore, future loss of healthy life years should be calculated based on the anticipated life expectancy of the patient group in question, not on normative figures on average expected healthy life years for the population as a whole.*

The working group believes that as a measure, absolute shortfall fulfils the intentions in the textual description of severity.

The working group discusses the relationship between age and severity. In the patient's meeting with the health care services, age should not, according to established practice, be an independent prioritisation criterion. When services or treatments are established, they should normally be available to all patients that can benefit from them, regardless of age. Prioritisation at the group level is not about individual patients, but rather the types of medical intervention that society wishes to prioritise above others. Severity will be significant in this context, as a high degree of severity provides grounds for giving higher priority to treatments for certain diseases than an assessment of costs and health outcomes alone would indicate. As a measure, the working group's recommendation, *absolute shortfall*, will in many cases be highest for diseases affecting younger age groups. This implies that diseases depriving patients of *many* future healthy life years will be assessed as more severe than diseases depriving patients of *fewer* future healthy life years. This is not an indication of a deprioritisation of elderly patients. The elderly who need medical assistance and care will continue to receive it.

Severity, measured as absolute shortfall, will be one of several criteria applied in priority setting. The working group discusses how a measure of absolute shortfall can be made more specific for use in actual prioritisation decisions at the group level (introduction of new medications, new methods, larger-scale public health measures, etc.). The group has not had the latitude to conduct its own analyses as a basis for quantifying specific thresholds. Thus, the recommendations of the group are based in part on calculations provided in NOU 2014:12.

Severity can be quantified on a continuum or by fewer, broader groups. According to the working group, the first alternative could give a false impression of accuracy. The working group therefore proposes that severity, described as absolute shortfall, is divided into six groups. The lowest group would comprise diseases/conditions where the expected absolute shortfall is less than four healthy life years, while the highest group would comprise diseases/conditions where the expected absolute shortfall is more than 20 healthy life years. There would be no differentiation within each group. As a general rule, an absolute loss of healthy life years of more than 20 years will not be ranked as more severe than the highest group.

The working group stresses that efforts should be launched to establish more reliable Norwegian figures for actual resource use for one healthy life year for those interventions that will be displaced by the introduction of new interventions. Furthermore, the maximum willingness to pay should be the result of a political process. The working group sees its recommendation as a solution that can be employed until more reliable calculations have been made and any political decisions regarding the willingness to pay threshold have been taken.

The working group's proposed solution includes a maximum willingness to pay – a cost ceiling – for the lowest group of NOK 275 000. This is an estimate of resource use for one healthy life year for the interventions that will be displaced by the introduction of new ones. The maximum willingness to pay, i.e. for diseases/conditions with a shortfall of more than 20 years, is set at NOK 825 000 for one healthy life year. This figure is based in part on what is considered established practice and in part on recommendations from corresponding discussions in previous reports.

The working group emphasises that there may be aspects of severity at the group level that are not captured by a targeted, operationalised measure such as absolute shortfall. There may be modifying factors that can lead to acceptance of an intervention with a cost that is higher (or lower) than is commensurate with the measure's degree of severity. The working group points to dignity, uncertainty and the budget impact of the intervention as examples of such modifying factors.

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