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Priority-setting in the Netherlands:
A Case for Public Participation and Against Proportional Shortfall

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INTRODUCTION

Healthcare priority-setting concerns decisions regarding the allocation of scarce healthcare resources (Bognar and Hirose, 2014, p. 1; Williams, Robinson and Dickinson, 2012, p. 6). When a priority decision is made, it means that the provision of some healthcare resources, e.g. medicines, are prioritised over others. Depending on the health system of the respective country, priority-setting decisions are generally made at the macro, meso and micro-level (Williamson, Robinson and Dickinson, Ibid). For example, at the macro-level, governments may decide the number of resources it allocates to its health budget. At the meso-level, governmental advisory bodies like the Dutch health institute may advise the government which health interventions it should collectively finance. At the micro-level, clinical professionals may prioritize patients in need of organ transplantations. Different priority decisions lead to a different distribution of burdens and benefits within a society. It is therefore important to understand that the prioritisation of healthcare resources is inevitable and raises questions concerning distributive justice.

There are many reasons why healthcare priority-setting is inevitable (Bognar and Hirose, 2014, p. 14-18). Limited healthcare budgets and rising healthcare costs require policy-makers to prioritize some health resources over others. Two of the main causes of rising healthcare costs are advances in healthcare technologies and rising life expectancies (Ibid, p. 14-15). Concerning the former, due to the introduction of new technologies, it becomes increasingly possible to cure more diseases that were previously fatal and to stabilize chronic conditions that were untreatable before. Concerning the latter, life expectancies across the world are rising and with fewer children being born, societies are ageing. As older people usually require more care than younger people, it is easy to predict that healthcare costs will rise. Now, one could object that both causes do not necessarily lead to scarcity in healthcare as one could keep increasing the healthcare budget. Even though that might be true, it does imply that healthcare budgets

need to be raised constantly to keep up with the technological advances and increasing life expectancies. Moreover, other forms of scarcity remain which cannot be resolved with financial resources. One of these factors is time (Ibid, p. 17). Policy-makers cannot provide everything, everywhere at the same time.

Naturally, priority-setting falls within the realm of distributive justice as different priority-decisions lead to different distributions of health burdens and benefits in society (Williamson, Dickinson and Robinson, 2012, p. 14-15). For instance, deciding to collectively finance a cancer intervention may be at the expense of financing treatment for migraine. It is therefore important that healthcare resources are distributed fairly and efficiently. To achieve a fair and efficient distribution of healthcare resources, many countries make use of priority-setting criteria and implement decision-making frameworks within which priority decisions have to be made (Clarke and Weale, 2012, p. 293-294).

Priority-setting criteria are used to guide priority decisions and the use of particular criteria leads to a specific distribution of healthcare resources. To ensure efficiency by maximizing health benefits, many countries make use of the cost-effectiveness criterion (Williamson, Dickinson and Robinson, 2012, p. 17). However, many countries have also implemented additional criteria to incorporate other distributive objectives such as a concern for equality. In the case of the Netherlands, the Dutch health institute has chosen to adopt proportional shortfall to incorporate a concern for the worse off. Proportional shortfall purportedly reflects and balances three important ethical principles: Fair innings, the rule of rescue and severity of illness (ZiN, 2018). Simply put, the fair innings view states that policy-makers should equalize life-time health between individuals with respect to some threshold (Williams, 1997). The rule of rescue dictates that policy-makers should give special weight to those facing imminent death (Mckie and Richardson, 2003). When adopting severity of illness, policy-makers prioritize those who are more severely ill (Nord, 2005). Moreover, the Dutch health institute also values

public support for its chosen priority-setting criteria as it claims that public support leads the criteria and the content of the basic health insurance substantively just (ZiN, 2017).

This thesis is concerned with healthcare priority-setting as done by the Dutch health institute (hereafter referred to as ZiN, Zorginstituut Nederland) who advises the Minister of Public Health, Well-being and Sport on which healthcare interventions it should collectively finance (ZiN, 2020). Specifically, the objective of this thesis is twofold. (1) Scrutinizing ZiN's claim that public support for the priority-setting criteria it uses, makes the content of the basic health insurance package substantively just and offering different reasons as to why public participation in determining priority-setting criteria is important. (2) Scrutinizing the normative justification of proportional shortfall as priority-setting criterion.

The main argument is as follows. First, although I agree that the public should participate in determining the appropriate priority-setting criteria, it is not for ZiN's stated reason. Instead, I will argue that the public has a normative right to participate. Moreover, public participation increases the legitimacy of the adopted priority-setting criteria and public participation has beneficial instrumental effects. I also provide a proposal for public participation, that is, the public should participate deliberately by employing the method of reflective equilibrium. Second, I will argue that ZiN should abandon proportional shortfall as a priority-setting criterion as proportional shortfall lacks theoretical as well as empirical support.

In **Chapter 1**, I will provide the contextual background for the remainder of this thesis. Specifically, I briefly discuss the utilitarian approach to priority-setting and explain that it falls short in some cases as policy-makers may also have a plausible concern with those worse off. I proceed by giving an overview of the Dutch healthcare sector, the role of ZiN and the history of Dutch priority-setting. In the last section, I set the stage for later chapters by taking issue with ZiN's commitment to public participation as well as its support for proportional shortfall.

In **Chapter 2**, I provide my first argument. First, I present a taxonomy for public participation and determine to what extent the public has participated in Dutch priority-setting with respect to this taxonomy. From this, I conclude that the public participates in evaluating healthcare interventions within the decision-making framework adopted by ZiN. However, the public has not participated in the development of the priority-setting criteria. I then continue by arguing that the public should participate in establishing these criteria. This claim rests on three arguments. First, the public has a moral right to participate which exceeds their right to vote in a liberal democracy. Second, public participation increases the legitimacy of the chosen priority-setting criteria. Finally, public participation has instrumental beneficial effects as demonstrated by the relevant empirical evidence. In the final section, I make a suggestion for public participation in determining priority-setting criteria. I propose that the public should participate deliberately by employing the method of reflective equilibrium which seeks coherence amongst individuals' considered moral judgements and broader moral principles.

In **Chapter 3**, I will explain fair innings, the rule of rescue and severity of illness which proportional shortfall purportedly reflects and balances. Moreover, I critically examine ZiN's (2018) understanding of these ethical concepts and motivation for adopting these. In the last section, I proceed by explaining in which manner proportional shortfall supposedly balances these principles and outline two alleged merits of proportional shortfall.

In **Chapter 4**, I will reject proportional shortfall as a priority-setting criterion. This rejection consists of four parts. First, I highlight normative shortcomings related to fair innings, the rule of rescue and severity of illness, which leads me to reject all three as acceptable priority-setting criteria. Second, I examine to what extent proportional shortfall reflects and balances fair innings, the rule of rescue and severity of illness. From this, I conclude that proportional shortfall does not reflect the rule of rescue and fair innings and, in fact, goes against fair innings. Instead, proportional shortfall may be best seen as an operationalisation of severity of illness.

Third, proportional shortfall could be judged as an acceptable criterion were it to address the shortcomings of the ethical concepts on which it is purportedly based. I conclude that it does not and, more problematically, proportional shortfall suffers from its unique shortcoming. Finally, I conclude that proportional shortfall does not best align with people's distributive preferences as demonstrated by the empirical evidence.

CHAPTER 1: HEALTHCARE PRIORITY-SETTING IN THE NETHERLANDS

This chapter provides the contextual background for the following chapters. In the first section, I will describe the relation between priority-setting and distributive justice. Specifically, I will explain that even though policy-makers may have a plausible concern with maximizing health-related well-being by using cost-effectiveness analysis, in some cases this yields counterintuitive priority decisions. This is because policy-makers may also have a plausible concern with improving health-related well-being in those judged worse off (Nord, 2005).

In the second section, I offer a brief overview of the healthcare system in the Netherlands. In short, the Dutch healthcare system can best be characterized as one of regulated market competition where some healthcare interventions are collectively financed by the basic health insurance package (Boot, 2013). Moreover, I will examine a specific kind of priority-setting problem that this thesis is concerned with. Namely, deciding which healthcare interventions should be included in the basic health insurance package. This decision is primarily based on the Dutch health institute's (ZiN) evaluation of interventions. ZiN's concern for efficiency is reflected in its usage of the cost-effectiveness criterion and its concern for the worse off in its adoption of the necessity criterion defined in terms of burden of illness and operationalised with proportional shortfall.

In the third section, I examine the history of the necessity criterion. Discussions about priority-setting were already prominent in 1991 with the publication of the Dunning report. Since its publication, necessity has been used as the appropriate priority-setting criterion to incorporate a concern for the worse off, but much discussion has resulted about its particular definition and operationalisation. Only in 2018, a consensus was reached that the necessity criterion should be defined as burden of illness and operationalised with the proportional shortfall method. This is because it is purported that proportional shortfall prevents age-discrimination and reflects and balances three important priority-setting principles: Fair

innings, the rule of rescue and severity of illness (Stolk, Goes, Kok and Busschach, 2001; Stolk, Poley, Brouwer and Bussbach, 2002; Stolk, van Donselaar, Brouwer and Busschbach, 2004).

In the final section of this chapter, I lay the grounds for the remainder of this thesis. I will explain that I take issue with Dutch priority-setting for two reasons. First, ZiN values public support for its priority-setting criteria as it claims that this support makes these criteria and consequently, the content of the basic health insurance, substantively just (ZiN, 2017, p. 6). I argue that this is mistaken as the public may be wrong about what constitutes just priority-setting criteria. Second, proportional shortfall lacks sound theoretical support. That is, even though proportional shortfall purportedly reflects and balances fair innings, the rule of rescue and severity of illness, it does not follow that it combining these leads to better priority decisions. In fact, to this date, no sound normative justification has been provided for proportional shortfall. These two problems form the basis for later chapters.

1.1 Healthcare Priority-setting and Distributive Justice

To integrate distributive concerns in priority-setting, policy-makers make use of priority-setting criteria. In this section, I outline two main distributive approaches to the prioritisation of a specific healthcare resource, namely, that of healthcare interventions.[1]

1.1.1 Cost-effectiveness and the Utilitarian Approach

A widely adopted priority-setting criterion to integrate efficiency in priority-setting when prioritising healthcare interventions[2] is cost-effectiveness analysis (CEA) (Bognar and Hirose, 2014, p. 53). CEA can be represented with the following formula:

$$CEA = \frac{cost}{unit\ of\ benefit}$$

Costs are expressed in the appropriate monetary terms. The unit of benefit is often expressed in terms of quality-adjusted life-years (QALYs) (Ibid, p. 43). 1 QALY represents a life-year in

[1] In section *1.2.2 Dutch Priority-setting*, it becomes clear why I focus on healthcare interventions specifically.
[2] A healthcare intervention "…is an act performed for, with or on behalf of a person or population whose purpose is to assess, improve, maintain, promote or modify health, functioning or health conditions" (WHO, 2021).

full health and 0 QALYs represent death. Unbearable health conditions can be represented with negative QALYs. QALY measures are derived from preference-elicitation methods such as the standard gamble, where respondents evaluate health states by making trade-offs between different health outcomes.[3] CEA allows policy-makers to rank-order different interventions on a priority list and may establish a cut-off point on the list. Subsequently, interventions above the cut-off point will be financed (Ibid, p. 54).

Only using CEA when it comes to prioritising interventions while simultaneously assuming that QALYs contribute to well-being, implies that policy-makers adopt a utilitarian approach to priority-setting. [4] In the most basic utilitarian approach, priority-setting decisions are just if they maximise aggregate health-related well-being in society (Hoedemaekers and Dekkers, 2003, p. 328). The objective of the policy-maker who adopts this approach is to identify and finance cost-effective interventions. For this policy-maker, it is only rational to finance cost-effective interventions since, with a limited budget, health gains are maximised if the policy-maker first finances the most cost-effective intervention, then the second most, and so forth until the budget runs out. However, this approach to healthcare priority-setting leads us astray in some situations. To illustrate this, consider the following real-life example (Voorhoeve, 2018, p. 125-127).

In 1990, a state commission in Oregon US proposed to prioritise interventions with CEA, resulting in a priority list where interventions for tooth capping were prioritised over treatments for terminal appendicitis as the former was judged to be more cost-effective. The implication of this would be that, with a finite budget, tooth capping would be publicly financed but life-saving interventions for terminal appendicitis would not be. This implication caused public outrage and led Oregon to reject a priority-setting approach only based on CEA.

[3] For a detailed explanation of measuring health states, see Bognar and Hirose (2014, p. 33-41)

[4] Throughout this thesis, I assume that the QALY measure accurately reflects the valuation of health states while being aware, but leaving aside, philosophical issues related to QALY measures in particular and whether health contributes or is constitutive of well-being in general.

This example demonstrates that healthcare priority-setting solely based on CEA and implicitly the utilitarian approach, may lead to the wrong priority judgments. Not simply because the priority-list caused public outrage, but because the utilitarian approach fails to consider distributional objectives besides maximising health-related well-being. Indeed, policy-makers may have a special interest in improving health gains in the worse off members of society (Nord, 2005, p. 257).

1.1.2 A Concern for the Worse Off

There are roughly two ideas of distributive justice that capture this concern for the worse off in healthcare priority-setting (Barra et al., 2020, p. 36). First, being worse off may be considered important in and of itself which gives rise to a special entitlement to healthcare resources (Ibid). This notion is captured by two specific theories of distributive justice. One is the prioritarian view which holds that benefiting an individual should be valued more the worse off that individual is (Barra et al., 2020, p. 36; Bognar and Hirose, 2014, p. 72). This view dictates that policy-makers should attach greater value to QALY gains in those worse off. The other is the so-called sufficientarian view (Barra et al., 2020, p. 36). Sufficientarianism dictates that policy-makers should attach greater value to QALY gains in those who are below some pre-defined threshold of health.

Second, it may be considered bad if one is worse off than others as this gives rise to inequality. On this view, improving the situation of the worse off should be valued more because it reduces inequality. Many specific egalitarian theories capture this idea. Some egalitarians may hold the position that inequality in health-related well-being is intrinsically bad, while others argue that inequality is bad as it, amongst other things, threatens the democratic equality of citizens within a country (Anderson, 1999; Barra et al., 2020, p. 36). However, I deem that egalitarians can be pluralist in their reasons. That is, they are not required to have equality as their only objective in healthcare priority-setting as they may also care about

maximising health-related well-being (Gosepath, 202). On this view, the pluralist egalitarian attributes greater value to QALY gains in those worse off because it reduces inequality and increases health-related well-being (Otsuka and Voorhoeve, 2018, p. 4).

There are two ways to incorporate a concern for the worse off in priority-setting. One way is to incorporate such concerns within CEA with equity-weights (Bognar and Hirose, 2014, p. 70). By doing this, policy-makers assign more weight to QALY improvements for those worse off. For instance, they could multiply the number of QALY gains with a value greater than one for those health interventions that target individuals considered to be worse off. Alternatively, policy-makers could use an independent priority-setting criterion that captures their concern for the worse off by relating this to different cost-effectiveness thresholds. Such an approach is adopted by ZiN (2018) which I will explain in greater detail in the following sections. [5]

1.2 Priority-setting in the Netherlands

1.2.1 The Dutch Healthcare System

Before explaining Dutch priority-setting, I briefly give an outline of the healthcare system in the Netherlands to understand the context in which priority decisions are made.

The current Dutch healthcare system was created with the enactment of the health insurance law, the market arrangement law and the accessibility of health institutions law in 2006 (van Kleef, Schut and van de Ven, 2014, p. 5). These laws ensured that the Dutch healthcare system would be based on competitive, but regulated, market principles. The idea behind this system is to stimulate and reward efficient and cost-reducing behaviour of the three main participants in the Dutch healthcare market: Health consumers, health insurers and health providers (Boot, 2013, p. 425). The crucial factor that leads to efficient and cost-reducing behaviour is that of competition between each of the three market participants. An example of

[5] Note that that the described reasons in this section for being concerned with the worse off do not yet tell us who is in fact considered to be worse off.

such competition is between health insurance agencies over patients/health consumers. Health insurance agencies compete through price competition of their health insurance packages to attract as many health consumers as possible.

However, the Dutch healthcare system is one of regulated competition. This is because the Dutch government recognized that while introducing market elements in the healthcare sector increases efficiency and cost-reduction, it does not by itself ensure other objectives important to public health, such as solidarity, accessibility and fairness (Ibid). Furthermore, the nature of the health sector makes it particularly vulnerable to market failures.[6] Therefore, the Dutch government implemented the aforementioned laws to provide the legal and institutional framework to safeguard objectives such as solidarity and to remedy market failures. Important to understand is the functioning of the health insurance law which I turn to now.

The health insurance law ensures that every Dutch citizen is entitled to health interventions belonging to the basic health insurance package which each health insurance agency is obligated to offer (ZiN, 2019). This law has several important characteristics:

1. Dutch citizens are obligated to have a basic health insurance.
2. The content of the basic health insurance package is determined by the law and is the same for everyone regardless of the insurance agency one is insured at.
3. Dutch citizens are free to choose their health insurance agency, all of which offer the same basic health care package but differ in packages that cover costs not covered by the basic insurance.

[6] According to Arrow (1978, p. 946), many, if not all, market failures in the healthcare sector stem from the prevalence of uncertainty. An example of such market failure is adverse selection. In short, there exists an informational asymmetry between the individual and the health insurer about the individual's expected illness profile. This results in higher premiums and leads healthier individuals to drop out of the market. This process continues till there is a breakdown of the health insurance market. See Akerlof (1970, p. 492-494) for a more comprehensive explanation of adverse selection.

4. Health insurers are obliged to accept every person for the basic health insurance package regardless of the person's health-related risk profile. Additionally, health insurers cannot adjust prices based on the characteristics of the insured.

Not only does this mandatory insurance prevent a breakdown from the insurance market due to informational asymmetry between insurers and the insured, but it also ensures solidarity between Dutch citizens as everybody contributes to this basic insurance package via taxes as well as out of personal means (ZiN, 2019).

1.2.2 Dutch Priority-setting

Even though many healthcare resources require priority-setting, I am concerned with a specific kind of priority-setting problem in the Netherlands. Namely, the problem of deciding which health interventions should be included in the basic health insurance package.

Ultimately, the Dutch Minister of Medical Care decides which health interventions are to be included in the basic insurance package (ZiN, 2020). However, in her decision-making, the Minister considers advice and recommendations from Zorginstituut Nederland (ZiN), an independent governmental advisory body. In its recommendations to the Minister, ZiN (2017, p. 6) pays special attention to ensuring that the priority-setting decisions reflect solidarity and justice. ZiN considers this important as every Dutch citizen is obligated to financially contribute to the basic health insurance package regardless of whether they make use of it (Ibid). As such, ZiN's objective is to ensure that the financial contribution of Dutch citizens to the basic insurance package, is spent well and in a just manner (Ibid). According to ZiN (Ibid), this is achieved when:

a) Dutch citizens support the priority-setting criteria that ZiN uses to determine whether interventions are eligible for the basic health insurance package.
b) Dutch citizens support the process of deliberation that underlies the evaluation of interventions by applying the priority-setting criteria.

Moreover, ZiN (Ibid) states that a) is fundamentally a concern about substantive justice and b) about procedural justice.[7] When it comes to b), ZiN uses an extensive deliberation process to judge whether interventions fulfill the priority-setting criteria (Ibid, p. 9-12). This deliberative process passes four different phases which are based on Daniels and Sabin's (2002) leading framework for legitimate priority-setting.[8] Concerning a), the priority-setting criteria that ZiN (2015a, p. 15-17) uses to judge the eligibility of interventions for the basic insurance package are: Effectiveness, cost-effectiveness, practical feasibility and necessity.

The most important criterion is effectiveness. To be included in the insurance package, an intervention should be successful in curing or remedying the health problem that the intervention targets. If the intervention does not pass this criterion, ZiN does not further evaluate the intervention with respect to the other three criteria and consequently advises to not include the intervention in the insurance package (Ibid, p. 15).

The second criterion is cost-effectiveness and examines to what extent the effectiveness of the intervention stands in proportion to its costs (Ibid). ZiN uses this to incorporate a concern for efficiency in its priority decisions.

The practical feasibility criterion evaluates whether it is practically feasible to include the intervention in the basic health insurance package and whether individuals can pay for the intervention themselves (Ibid, p. 17). Obstacles to including interventions in the insurance package are administrative difficulties and costs.

Finally, the necessity criterion is used to incorporate a concern for the worse off in priority-setting. On this criterion, those individuals who have a high burden of illness as determined by proportional shortfall are worse off (ZiN, 2018, p. 3-4). This criterion, therefore, dictates that

[7] Roughly, substantive justice refers to the justice of the final allocation of the burdens and benefits of various kinds distributed amongst people. Procedural justice refers to the justice of the procedures used to determine the final allocation (Miller, 2017).

[8] For a detailed explanation of these phases, see ZiN (2017, p. 7). See **Chapter 2** section *2.3.3 Public Participation as Condition for Legitimacy* for an explanation of Daniel and Sabins' (2002) accountability for reasonableness framework.

those interventions which treat individuals with a high burden of illness are judged more necessary and should be prioritised.

1.3 The History of Dutch Priority-setting

In this section, I examine the historical development of the four priority-setting criteria. I will pay special attention to the necessity criterion as I will scrutinize its operationalisation in terms of proportional shortfall in **chapters 3** and **4**.

1.3.1 The Dunning Report

Discussions about what should be financed by the collective health insurance were already prominent in the 1990s when the committee Dunning was tasked with investigating which criteria were appropriate in determining which interventions should be collectively financed (Stolk et al., 2001, p. 8). In 1991, the committee published their report and introduced the Funnel of Dunning (Trechter van Dunning). This funnel consisted of four criteria in the following order: Necessity, effectiveness, efficiency and personal responsibility and ability to pay.

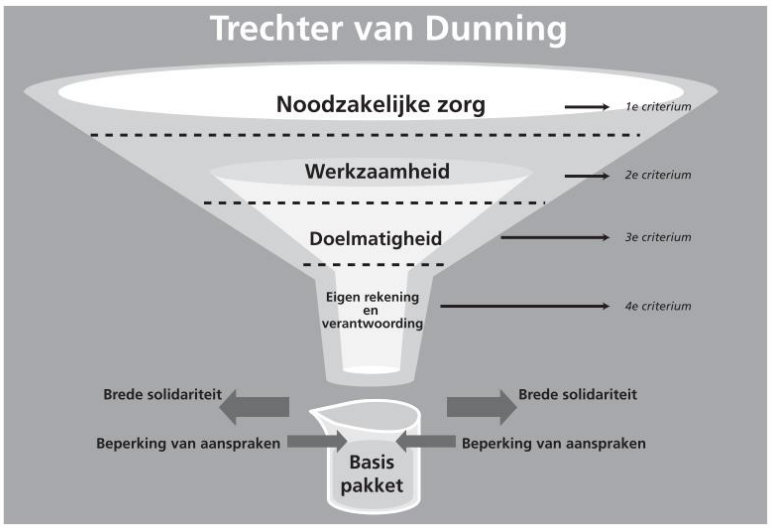

Figure 1: The Funnel of Dunning (Brouwer, 2009, p. 13).

According to the Funnel, any intervention that does not pass a sieve is not eligible for reimbursement. Although the Dunning committee proposed clear criteria, ambiguity existed as

to how the funnel should be applied in practice. Especially when it came to the necessity criterion (Stolk and Poley, 2005, p. 4). Namely, an intervention was considered necessary if it guarantees a person's normal functioning in society or if it restores a person's ability to normally participate in society (Stolk et al., 2001, p. 66). However, the practical implementation of this criterion turned out to be problematic for two reasons. First, normal functioning and participation are contested normative concepts which the Dunning committee did not specify (Ibid). This threatened the relevancy of this criterion as it was not difficult to make a reasonable argument that a new intervention contributed to the normal functioning and participation of individuals in society (Ibid). Second, policy-makers used the necessity criterion as a binary criterion (Stolk and Poley, 2004, p. 4). This raised issues of fairness as the definition of the criterion does not lend itself to such binary use (Ibid). This because it is difficult to justify excluding some interventions from the insurance package based on vague concepts as normal function and participation, especially when this has great financial consequences for individuals in need of those interventions (Ibid).

Therefore, the Ministry of public health, well-being and sport asked the college for health insurances (College voor zorgverzekeringen, CVZ)[9] for recommendations to adjust the necessity criterion. As a response, CVZ requested the institute for Medical Technology Assessment (iMTA) at the Erasmus University, to investigate in which manner the necessity criterion could be operationalised to ease its use in practice (Ibid, p. 7).[10]

1.3.2 The iMTA Recommendation: Proportional Shortfall

One of the primary problems Stolk et al. (2001, p. 19), authors of the iMTA report, identified with the necessity criterion, is that it does not lend itself for relative use. They reasoned that policy-makers not only want to determine whether an intervention is necessary

[9] CVZ was succeeded by ZiN in 2014.

[10] The iMTA was also asked to evaluate whether personal responsibility and individual ability to pay should be used as a criterion. The iMTA concluded that personal responsibility should not be included as a priority-setting criterion. For a detailed explanation of this recommendation, see Stolk et al. (2001, p. 39-40).

or not, but they also want to determine whether one intervention can be judged more necessary than another. To allow for such relative use, the necessity criterion needs to be able to rank-order interventions from more necessary to less necessary depending on the illness it treats. Therefore, Stolk et al. (Ibid) decided to define necessity in terms of burden of illness which is based on the quality-adjusted life-year method[11]. This approach prioritizes interventions for ill individuals based on the burden of their illness as determined with the QALY method. Stolk et al. (Ibid, p. 19-22) offered two reasons for this approach. First, the QALY method had emerged as a reliable method in determining individuals' quality of life when suffering from a particular illness. Second, the QALY method, by numerically representing health states, lends itself for relative use. That is, policy-makers can rank-order interventions based on individuals' burden of illness as determined with the QALY method (Ibid).

However, Stolk et al. (Ibid) argued that individuals' burden of illness should not simply be determined with the QALY method as one has to take the future development of the illness into account. To illustrate this, imagine that you can only finance an intervention for one of the following two individuals and assume all other things being equal:

1. Individual X suffers from a severe illness leading him to be located at 0.1 on the QALY scale, but his condition improves over time.
2. Individual Y suffers from a mild illness leading him to be located at 0.8 on the QALY scale, but his condition worsens over time leading to premature death.

The necessity criterion in terms of burden of illness would prioritize an intervention treating individual X as he presently, has a higher burden of illness than individual Y. However, doing this would overlook relevant information as it fails to take the future development of the illness into account. Therefore, the burden of illness approach should also incorporate information about future health prospects (Ibid, p. 23). However, Stolk et al. (Ibid) worried that this, in turn,

[11] Remember the QALY method represents each health state on a scale of 0-1, 1 indicating a perfect healthy life-year and 0 indicating a severe health condition or even death.

could lead to a potential problem of age-discrimination, especially when relating burden of illness to individuals' life expectancies. To illustrate this, imagine that you can offer a life-saving intervention to:

1. Individual A is 20 years old who faces imminent death.
2. Individual B is 70 years old who faces imminent death.

Even though individuals A and B have an equal burden of illness as both are located at the zero points on the QALY scale, one could argue that the intervention is more necessary for individual A as he will lose a greater amount of QALYs compared to individual B. Indeed, when assuming a life expectancy of 80, this would be the case. Stolk et al. (Ibid, p. 24) argued that this would represent an unacceptable priority decision as the Dutch healthcare system is one based, amongst other things, solidarity between the young and old. Thus, such priority-decision could be seen as age-discrimination.

Therefore, in a subsequent report, Stolk et al. (2002, p. 4), decided to operationalise burden of illness as follows and formerly called this method proportional shortfall (Stolk et al., 2004).

$$\frac{Remaining\ QALYs\ without\ illness - Remaining\ QALYs\ with\ the\ illness\ without\ the\ intervention}{Remaining\ QALYs\ without\ the\ illness}$$

Expressed in words, proportional shortfall prioritizes those individuals who proportionally stand to lose the greatest number of QALYs due to an illness, in relation to the QALYs they would have were they not ill. To illustrate proportional shortfall with an example. Imagine an individual who is 60 years old who suffers from an illness leading him to lose 0.5 QALYs each year without intervention. Furthermore, assume that the average life expectancy is 80 years. By using these numbers, one gets the following result:

$$\frac{20\ (remaining\ QALYs\ without\ illness) - 10\ (with\ illness\ without\ intervention)}{20\ (remaining\ QALYs\ without\ intervention)}$$

This leads to a proportional shortfall of 0.5. It is straightforward to see that with this formula, individuals' proportional shortfall can maximally be 1 and minimally be 0, where 0 indicates

no proportional shortfall and 1 amount to death. There are three purported merits when operationalising burden of illness in this way. First, it takes the future development of an illness into account as it incorporates future QALY information in the calculation. Second, it prevents age-discrimination as the burden of illness is the same for individuals with a similar illness.[12] Furthermore, it is claimed that this operationalisation balances and reflects three well-known ethical principles for priority-setting: Fair innings, the rule of rescue and severity of illness (Stolk et al., 2002, p. 122; Stolk et al., 2004, p. 1100). In short, fair innings dictates that policy-makers should equalize life-time QALYs between individuals with respect to a QALY threshold. The rule of rescue says that policy-makers should prioritize individuals facing imminent death. On severity of illness, policy-makers should prioritize those individuals who are more severely ill.[13]

After this iMTA recommendation, burden of illness and its specific operationalisation in terms of proportional shortfall, was referred to as the proper conceptualisation of the necessity criterion (CVZ, 2006; CVZ, 2009; CVZ, 2013). Surprising is that, even though policy documents referred to proportional shortfall as the proper operationalisation of burden of illness and the necessity criterion, it remained ambiguous to what extent proportional shortfall was used in practice by ZiN (Reckers-Droog, van Exel and Brouwer, 2018, p. 5-7). This changed however with the publication of ZiN's[14] latest report about the use of burden of illness in practice (ZiN, 2018). In this report, ZiN made a clear commitment to the use of proportional shortfall. Moreover, ZiN (2018) proposed that proportional shortfall should be related to the cost-effectiveness criterion. ZiN (2018, p. 3-4) argued that the cost-effectiveness evaluation of interventions should be different when treating individuals with a higher burden of illness as determined by proportional shortfall. In other words, for those individuals with a higher burden

[12] I will explain this in greater detail in **chapter 3** section *3.2.1 Purported Merits of Proportional Shortfall*.
[13] In **Chapters 3** and **4**, I explain these concepts in greater detail.
[14] As a reminder, ZiN succeeded CVZ in 2014.

of illness, society should be willing to pay more to achieve QALY gains. Specifically, ZiN (Ibid) created three burden of illness categories with associated monetary threshold values.

Burden of illness	Monetary threshold value for 1 QALY gain
0.10-0.40	€20,000
0.41-0.70	€50,000
0.71-1.00	€80,000

Table 1: Relation of burden of illness and monetary threshold values (ZiN, 2018, p. 4)

To give an interpretation. This table indicates that ZiN is willing to include an intervention in the basic health insurance package if it can treat individuals with a burden of illness between 0.1 and 0.4 at a cost of no more than €20,000 for an additional QALY gain.[15] It has to be noted that the monetary threshold values are not set in stone. Rather, ZiN argued that it uses these values as an indication when evaluating interventions and that the Dutch government should use these as reference values when engaging in price negations with pharmaceutical companies (Reckers-Droog, van Exel and Brouwer, 2018, p. 3).

To briefly summarize this section, in 1991, the Dunning report proposed that interventions should be evaluated with respect to four criteria before they could be collectively financed. It turned out that, of these criteria, the necessity criterion was particularly difficult to use in practice. Therefore, in 2001, the CVZ was tasked to evaluate and reconceptualize this criterion. Based on recommendations by the iMTA, CVZ proposed to define the necessity criterion in terms of burden of illness and specifically operationalise it in terms of proportional shortfall.

1.4 Two Problems Related to Dutch Priority-setting

Up till now, I have presented a concise overview of the healthcare system and a short history concerning priority-setting in the Netherlands. Regarding the latter, I focused on the

[15] Assuming that the intervention also passes the other priority-setting criteria.

conceptualisation of the necessity criterion in terms of burden of illness operationalised with proportional shortfall.

In this section, I outline two problems that I identify with Dutch priority-setting which paves the way for the following chapters. The first problem is related to ZiN's commitment to public support for its priority-setting criteria. The second problem is related to ZiN's use of proportional shortfall to incorporate a concern for the worse off.

1.4.1 ZiN's Commitment to Public Support

Recall from section *1.2.2 Dutch Priority-setting*, that one of ZiN's (2017, p. 6) primary objectives is to ensure that the financial contribution of Dutch citizens to the basic health insurance package is spent well and in a just manner. According to ZiN (Ibid), a just basic health insurance package is achieved when Dutch citizens support the priority-setting criteria on which the content of the basic health insurance is based. On a strict interpretation, this implies the following:

(a) Public support for the priority-setting criteria on which the content of the basic health insurance package is based, is a sufficient condition to regard the package as substantively just.

However, I take issue with this position for two reasons. First, ZiN is mistaken in believing that public support for the priority-setting criteria makes these criteria and consequently, the basic health insurance package, substantively just. To see this, consider Pettit's (2012a, p. 59) distinction between justice and legitimacy. According to Pettit (Ibid, p. 60), justice is concerned with the social order imposed by the coercive state and whether this social order is justifiable. Legitimacy is about the imposition of the particular social order and its acceptability. This distinction implies that a just social order does not imply legitimacy and vice versa (Pettit, 2012b, p. 130) For instance, imagine a highly racialized society where the majority deems it just to deny health interventions for those belonging to the marginalized group. In this society,

the majority of people have voted to adopt priority-setting criteria which exclude interventions for illnesses that occur mainly amongst members of this group.

When assuming that democratic voting is a condition for legitimacy irrespective of the exact concept of legitimacy, it can be said that the imposition of this social order is legitimate. However, it cannot be said this social order is substantively just as, in this case, the public is clearly wrong about what constitutes a just social order (Ibid). This implies that ZiN's adoption of position (a) is mistaken. Public acceptance of the priority-setting criteria may plausibly make the criteria legitimate, but it does not necessarily make them just. Now, I do not assume that ZiN would indeed consider such priority-setting criteria as described in the above example as just simply because the public supports these criteria. However, this is an implication of how ZiN outlined its current commitment to public support. Moreover, it is the sole reason ZiN offers as to why it is committed to public support for its priority-setting criteria.

Second, leaving the above problem aside for the moment, a problem that remains is that ZiN has not defined what this public support exactly entails. ZiN fails to specify its conception of "the public", the way this public support is estimated and is consequently decisive in ZiN's adoption of particular priority-setting criteria.

Therefore, in **Chapter 2**, I will address both problems. That is, similar to ZiN, I claim that the public should participate in determining the priority-setting criteria although for different reasons and I will make a suggestion for a specific type of participation.

1.4.2 ZiN's Use of Proportional Shortfall

To incorporate a concern for the worse off in priority-setting, ZiN (2018) has chosen to adopt proportional shortfall as operationalisation of burden of illness. This is because proportional shortfall is purported to reflect and balance three important priority-setting principles: Fair innings, the rule of rescue and severity of illness (Stolk et al., 2004; ZiN, 2018).

Moreover, it is alleged that proportional shortfall prevents age-discrimination (Stolk et al., 2001).

Surprisingly, even though proportional shortfall is claimed to have these purported merits and is used in Dutch priority-setting, it lacks sound normative justification. The fact that proportional shortfall seems to balance widely discussed ethical principles for priority-setting does not constitute a sound normative defense. It moreover appears that the original motivation for proportional shortfall was also based on the pragmatic reason that the QALY method was easy to use in practice. Although important, this hardly represents a strong normative argument in favour of proportional shortfall. To this date, no independent normative justification for proportional has been formulated and it remains questionable whether it is normatively more acceptable than any of its underlying principles used independently. Therefore, in **chapters 3** and **4**, I will examine and scrutinize whether proportional shortfall is an acceptable priority-setting criterion.

1.5 Conclusion

In this chapter, I provided the contextual background for the following chapters. In the first section, I explained healthcare priority-setting and its relation to distributive justice. The utilitarian approach, which underlies cost-effectiveness analysis, aims to maximize health-related well-being by only financing those interventions which lead to the greatest QALY gain given a constraint budget. However, policy-makers may have a plausible concern with those worse off either because this is judge as bad in and of itself or because it leads to inequality.

I proceeded by outlining the Dutch healthcare system to understand the context in which priority decisions are made. Even though priority-setting concerns many different resources, I explained that this thesis focuses on priority-setting as done by ZiN. ZiN's function is to advise the Dutch Minister of Medical care which health interventions should be included in the basic health insurance package. To incorporate a concern for efficiency, ZiN evaluates interventions

with respect to the cost-effectiveness criterion and to incorporate a concern for the worse off, ZiN uses the necessity criterion.

In the third section, I examined the history of the necessity criterion. At first, necessity was defined in terms of contested concepts such as normal functioning and participation which made the criterion difficult to implement in practice. Therefore, it was proposed that the necessity criterion should make use of the QALY method as this would ease its use in practice. Specifically, the necessity criterion was defined in terms of burden of illness and operationalised with proportional shortfall. This is because proportional shortfall takes the future development of an illness into account, prevents age-discrimination and purportedly balances and reflects three important ethical principles.

In the last section, I paved the way for the following chapters. That is, I outlined two problems related to Dutch priority-setting. First, I take issue with ZiN's commitment to public support concerning the priority-setting criteria it uses. Second, ZiN's adoption of proportional shortfall is problematic as it lacks any sound normative justification. Addressing both these problems is the objective of the next chapters.

CHAPTER 2: PUBLIC PARTICIPATION IN DETERMINING HEALTHCARE PRIORITY-SETTING CRITERIA

In its report, *Package advice in practice: Deliberation about a fair package in healthcare (Pakketadvies in de praktijk: wikken en wegen in de zorg voor een rechtvaardig pakket)*, the Dutch health institute (Zorginstituut Nederland, ZiN) stated the following (ZiN, 2017, p. 6). The extent to which Dutch citizens' financial contributions to the basic health insurance package are spent in a just manner, depends on two things: (1) whether Dutch citizens support the priority-setting criteria that are used when evaluating healthcare interventions and (2) whether Dutch citizens support the deliberation process in which the interventions are evaluated with respect to the four criteria. According to ZiN (Ibid), (1) is about distributive justice and (2) concerns procedural justice.

In the last section of the previous chapter, I specified ZiN's first claim by stating that (1) is concern with a particular type of distributive justice, that of substantive justice. Moreover, on a strict interpretation, this implies the following:

(1) Public support for the priority-setting criteria on which the content of the basic health insurance package is based, is a sufficient condition to regard the package as substantively just.

I argued that (1) should be rejected for the simple reason that the public may be incorrect about what constitutes a substantively just basic insurance package. Moreover, I argued that ZiN fails to explain what it means by public support and when it assumes to have public support for the priority-setting criteria.

In this chapter, I take the position that public participation is important in healthcare priority-setting. Similar to ZiN, I claim that the public should participate in determining the priority-setting criteria although for different reasons. In order to argue for this claim, I will first offer a clear conception of public participation in determining priority-setting criteria. That

is, I will define public participation, how the public can participate, a notion of the public and the decision power that can be assigned to the public. Then, I will shed more light on ZiN's commitment to public participation by examining to what extent the public has participated in determining the criteria given my described framework for public participation. From this examination, I conclude that the public participates in evaluating healthcare interventions with respect to the priority-setting criteria, but that the public has not participated in the development of the criteria.

In the third section, I will offer three reasons as to why the public should participate in determining the criteria. These differ from ZiN's (2017) stated reason that public participation makes the basic health insurance package substantively just. First, the public has a moral right to participate in a manner that exceeds their right to vote in a liberal democracy. Second, I argue that public participation confers legitimacy to the priority-setting criteria. Drawing on Daniels and Sabin's (2002) framework for legitimate priority-setting, I argue that public participation is a necessary condition for legitimacy. Third, I present several instrumental arguments that suggest that public participation in healthcare priority-setting decisions has positive effects. This is confirmed when reviewing the relevant empirical evidence.

In the final section of this chapter, I will provide a suggestion for public participation. I argue that the public should participate by employing the method of reflective equilibrium which seeks coherence amongst individuals' moral judgements about similar cases and broader moral principles (Daniels, 2016).

2.1 Public Participation: Definition and Typology

2.1.1 Definition

First, I offer a general definition of public participation which applies to democratic societies. Here I follow an adapted definition of Weale et al (2016, p. 739) and Williams, Robinson and Dickinson (2012, p. 28) regarding public participation in healthcare priority-setting. That is, public participation refers to participation in the process of *developing*, *accepting* and *applying* the priority-setting criteria which are ultimately decided upon by public representatives and officials. This definition is general where the methods of participation, the particular conception of "the public" and decision-making power assigned to the public remains undefined.

2.1.2 Typology

To clarify the methods of participation and the conception of the "the public", I use the typology of Bal and van Lindeloof (2005). They base their typology on Charles and DeMaio's (1993) conceptual framework regarding lay participation in healthcare decision-making and on methods of participation where participants have been explicitly asked to participate in decisions about the eligibility of interventions that are to be collectively financed. This typology distinguishes between three dimensions of public participation: (1) the methods of participation, (2) the role of the participants and (3) the decision-making power assigned to participants.

Bal and van Lindeloof (2005, p. 180-181) differentiate between deliberative and non-deliberative methods of participation. With the former method, participants engage in dialogue with each other and sometimes with experts. This deliberation has two functions. First, deliberation activates and fosters the sharing of knowledge between participants and experts. Second, it may lead to the formation of new opinions amongst participants when confronted with different arguments and value judgements of others. The aim of deliberative methods is therefore not necessarily to obtain a consensus but to gain new insights and a deeper

understanding of the rationales held by participants. Examples of deliberative methods are citizen panels or consensus conferences (Williams, Robinson and Dickinson, 2012, p. 33-34). The primary aim of non-deliberative participation is to estimate the preferences held by the participants. Participants do not engage in dialogue with one another and experts. There is no exchange of arguments and participants do not change their opinions or value judgments. Examples of non-deliberative methods are population surveys or interviews inquiring about the public's experience. An often used non-deliberative method in the healthcare priority-setting literature is that of preference-elicitation studies which try to estimate the public's preferences concerning priority-setting criteria (Whitty, Lancsar, Rixon, Golenko and Ratcliffe, 2014, p. 366).

The second dimension of public participation clarifies the notion of "the public". The public may either refer to citizens or patients who are entitled to benefits from the Dutch basic health insurance package. Citizens may be asked to assume the role of patients and vice versa when participating (Bal and van Lindeloof, 2005, p. 181). A reason for involving patients is that they are often directly affected by priority-setting decisions and have experience with interventions (Clark and Weale, 2012, p. 302). At the same time, it is reasonable to assume that patients hold a narrow and self-interested position. This is because patients often have an interest in receiving an intervention that may conflict with other long-term interests of Dutch citizens generally (Bal and van Lindeloof, 2005, p.181; Clark and Weale, 2012, p. 302). Therefore, it is assumed that citizens are more suited to represent these long-term interests of which two can be identified (Bal and van Lindeloof, 2005, p.181; Clark and Weale, 2012, p. 302; Williams, Robinson and Dickinson, 2012, p. 28). First, citizens as taxpayers are concerned with the way interventions are financed. Second, citizens as collective decision-makers are concerned with the range of interventions available for themselves, family, friends and neighbours.

The last distinction that can be made is the degree to which the public, by participating, determines the priority-setting criteria (Bal and van Lindeloof, 2005, p. 181). Three types of decision-making power are identified: Consulting, partnering and dominating decision-power. When consulted, participants may share their knowledge and opinion without the guarantee that this will be incorporated in the actual decision-making. Second, participants can be seen as a partner. In this case, the decision-making authorities will share their decision-making authority with participants by, for example, being members of the same committee. Lastly, participants may have full decision-making power. In this instance, outcomes of public participation will be directly reflected in the adopted priority-setting criteria.

2.2 Public Participation in the Netherlands

With the above framework for public participation in mind, I will assess in which manner the Dutch public has participated in determining the priority-setting criteria.

Recall from the definition of public participation that the public can partake in the *development*, *acceptance* or *application* of priority-setting criteria. In the case of the Netherlands, I identify that the public, as patients, participates in the *application* of the criteria (CVZ, 2006; CVZ, 2009; CVZ, 2013; ZiN, 2017; ZiN, 2018). To specify, patients may participate in the decision-making process concerning the inclusion of an intervention in the basic insurance package by means of evaluating the intervention with respect to the priority-setting criteria (ZiN, 2017, p. 9). However, it is unclear as to what extent the input of patients is decisive in ZiN's recommendation to include the intervention in the basic insurance package.

Moreover, ZiN could claim that the public has been involved in the *development* and *acceptance* of the necessity criterion operationalised with proportional shortfall. This is because public support for proportional shortfall has been assessed with several preference-elicitation studies (ZiN, 2018, p. 9). However, I reject this claim. First, it is unclear to what extent the results of these studies are decisive in ZiN's decision to adopt proportional shortfall. Second,

for the public to either participate in the *development* or *acceptance* of priority-setting criteria, the public needs to be involved before proportional shortfall is used. This has not been the case as ZiN refers to these studies after proportional shortfall was already in use.

Concerning the methods of participation, ZiN's (2018, p. 9) reference to preference-elicitation studies seems to suggest that ZiN relies on non-deliberative methods for participation, but here again ZiN does not make this commitment explicit.

Therefore, I conclude that, after having reviewed the relevant policy documents, the public has not participated in the *development* and *acceptance*, but is involved in the *application* of the priority-setting criteria.

2.3 A Case for Public Participation

In this section, I argue why the public should participate in determining priority-setting criteria. I distinguish between normative and instrumental arguments that can be put forward. To illustrate this distinction, one might argue that public participation is a necessary criterion for some ideal conception of procedural justice or one may hold the position that public participation is only valuable insofar as it leads to better decisions. First, I will provide two normative arguments. Then I will present instrumental arguments of which their merit can be tested with the relevant empirical evidence. These instrumental arguments and associated evidence suggest that deliberative public participation has beneficial effects.

2.3.1 A Moral Right to Participate

I argue that the public has a right to participate because different priority-setting criteria lead to different distributions of health burdens and benefits in society and affects citizens and, in particular, patients directly (Bal and van Lindeloof, 2005, p. 178; Clark and Weale, 2012, p. 294; Kieslich et al., 2016, p. 739). Therefore, the public has a moral right to participate in determining these criteria. However, having this right does not necessarily imply that the public has a right to participate beyond their democratic right to vote in a liberal democracy. With this

right to vote, the public participates insofar as their elected representatives determine the priority-setting criteria or delegate these decisions to institutes like ZiN in the Netherlands. Therefore, to successfully argue that the public has a moral right to participate, requires me to argue that the democratic right to vote does not constitute sufficient public participation. In order to do so, I will first clarify the meaning of democratic voting.

Voting is a key feature of aggregative conceptions of democracy (Gutman and Thompson, 2004, p. 13). These theories have in common that preferences of the public are aggregated by voting and these theories are indifferent to the underlying rationales for the preferences. They only seek to combine preferences efficiently and fairly (Ibid). Furthermore, democratic voting, by aggregating preferences, gives equal consideration to everyone's interests by placing equal weight on each vote (Cohen, 1997, 411). It can thus be claimed that the public has participated in determining the priority-setting criteria in the Netherlands because the public has voted to resolve disputes and problems about priority-setting decisions at the political level. In turn, Dutch politicians have partly delegated this to ZiN. However, in the following, I argue that democratic voting is an insufficient form of public participation in deciding upon particular priority-setting criteria.

First, it is implausible to assume that considerations regarding specific priority-setting criteria figure into Dutch citizens' voting decisions. When voting in the four-yearly elections, Dutch voters have to take a position concerning all kinds of matters. It is unlikely that priority-setting criteria are part of voters' considerations. Moreover, even if these criteria do figure into voters' considerations, it is unlikely that political parties offer a position concerning specific priority-setting criteria. This implies that Dutch citizens cannot decide upon different priority-setting criteria even if they want to do so. Indeed, a brief review of the electoral programs of the three biggest parties in the latest election reveals that none of them mentioned any endorsement of particular priority-setting criteria (VVD, 2021; D66, 2021; PVV, 2021).

Second, voting is insensitive to the nature of disputes that are cast to a vote and the underlying preferences of the voters (Daniels and Sabin, 2002, p. 35). For instance, in voting, it makes no difference whether preferences for different flavours of ice cream or preferences for different priority-setting criteria are aggregated (Ibid). When considering voting for ice cream, imagine a group of people with the option of buying either vanilla or chocolate ice cream. If a majority vote leads the group to buy vanilla, it could leave the minority frustrated as their preference is not satisfied (Ibid). Now imagine the same group voting on priority-setting criteria, whereby one criterion gives priority to a life-saving intervention for a child and another criterion gives priority to curing a substantial number of children who are moderately impaired. Solving this dilemma with a majority vote[16] would not only leave the minority frustrated as in the ice cream case but would also force them to accept a decision that goes against their fundamental moral judgements (Ibid). I claim that in situations where much is at stake, e.g. life or death situation, and where some individuals will be greatly affected by the decision, one should not only arrive at a decision efficiently by aggregation, but one should also pay attention to the quality of reasons underlying the decision. This is to ensure that the decision is not based on ill-informed or inconsistent preferences and to ensure that one can justify the decision to a minority that may be greatly affected by the decision (Baker, Mason, McHugh and Donaldson, 2021, p. 3). I view that deciding upon specific priority-setting criteria can be justifiably regarded as such a decision where a lot is at stake as these criteria determine which healthcare interventions are financed and, consequently, which individuals receive treatment for their illnesses.

Now, one could object to this second argument by stating that merely noting that in priority-setting disputes a lot is at stake, it does not follow that Dutch citizens have a right to participate beyond voting. After all, in a democracy, citizens decide on many fundamental issues such as

[16] This argument is not conditional on the majority vote method, one could use a different method when aggregating votes.

going to war, whether to continue lockdowns, etc, by means of voting. Even though this is indeed true, I argue that this does not constitute an objection, but rather hints at an implication when accepting my argument. That is, when accepting my argument, it implies that one may no longer resolve such fundamental decisions only by means of voting. I recognize that delineating cases that can be resolved by voting alone is difficult. Therefore, I respond to this in two ways.

First, I accept this implication as I take the position that in cases where a lot is at stake, one cannot solely rely on aggregating votes to settle the matter. In those cases, one should pay attention to the underlying arguments for various positions and being able to justify the decision to those disagreeing. Second, one manner in which voting on priority-setting criteria is different from other issues that Dutch citizens vote about is that Dutch citizens have to pay for the basic insurance package not only via taxes but also out of personal means. The fact that Dutch citizens are obliged to pay for the basic health insurance out of personal means represents a relevant difference from other issues that Dutch citizens vote about.

Therefore, I conclude that the public has a moral right to participate which exceeds their democratic right to vote. This is not to say that one should abandon voting altogether as a means of settling disputes regarding priority-setting criteria. Rather, voting may complement other democratic methods in determining priority-setting criteria.[17]

2.3.2 Public Participation as a Condition for Legitimacy

Whether public participation is a normative condition for legitimacy in priority-setting depends on the particular conception and sources of legitimacy put forward (Bærøe and Baltussen, 2014, p. 100). Besides normative accounts of legitimacy, there are also empirical accounts of legitimacy which, for example, define legitimacy as "the belief that authorities, institutions, and social arrangement are appropriate, proper and just" (Tyler, 2006, p. 376).

[17] I present a suggestion for this in section **2.3 A Proposal for Public Participation.**

When an institution or authority has said legitimacy, people voluntarily defer to its decisions (Ibid). Naturally, an institute or authority may be perceived as legitimate but perhaps not for the right theoretically justified reasons. Clearly, people can be manipulated or made to believe that an authority is legitimate even without good normative reasons. An example would be an authoritarian dictator who, through propaganda and fake elections, leads his subjects to believe that he was elected democratically thereby leading the public to accept his decisions voluntarily.

Even though it is relevant to determine whether public participation is an empirical condition for the legitimacy of priority-setting criteria, I focus the discussion on public participation as a normative condition. Specifically, I examine whether public participation is a normative condition for legitimacy when scrutinizing Daniels and Sabin's (2002) leading framework for legitimate decision-making in healthcare priority-setting.[18] Daniels and Sabin (Ibid) developed the accountability for reasonableness framework (A4R) to address the legitimacy problem in healthcare priority-setting. The legitimacy problem poses the following question: "under what conditions do decision-makers have the *moral authority* [emphasis added] to set the limits they impose?" (Daniels, 2007, p. 103). Daniels and Sabin's (Ibid, p. 45) answer this question by formulating four conditions in which priority decisions should be made:[19]

1. Publicity: Decisions regarding both direct and indirect limits to care and their rationales must be publicly accessible.
2. Relevance: The rationales for limit-setting decisions should aim to provide a reasonable explanation of how the organization seeks to provide "value for money" in meeting the varied health needs of a defined population under reasonable resource constraints. Specifically, a rationale will be reasonable if it appeals to evidence, reasons, and

[18] In its evaluation of interventions with respect to its adopted priority-setting criteria, ZiN (2017) also makes use of this framework.
[19] The conditions and their descriptions are directly taken from Daniels and Sabin (2002, p. 45).

principles that are accepted as relevant by fair-minded people who are disposed to finding mutually justifiable terms of cooperation.

3. Revision and appeals: There must be mechanisms for challenge and dispute resolution regarding limit-setting decisions, and, more broadly, opportunities for revision and improvement of policies in the light of new evidence or arguments.
4. Regulative: There is either voluntary or public regulation of the process to ensure that conditions 1–3 are met.

In the A4R framework, a decision-maker has the moral authority and thereby makes a legitimate decision if the decision-making process adheres to these four conditions. Important to note is that Daniels and Sabin (2002) developed the framework not to determine priority-setting criteria, but to prioritise healthcare resources directly. This is because, according to Daniels and Sabin (Ibid, p. 3-4), there is no consensus about appropriate priority-setting criteria that could guide priority-setting and they believe that such consensus will not be achieved soon. Therefore, they reasoned that people, instead of agreeing on principles, can agree on a framework in which priority-setting decisions should be made. [20] However, I will discuss Daniels and Sabin's framework in relation to deciding about priority-setting criteria. Even though not meant for this purpose, I believe that I am justified in doing so. This is because there is no a priori reason to assume that the framework can only be applied to prioritising resources. Indeed, the legitimacy problem[21] Daniels and Sabin intend to solve with the framework is formulated in general terms. Where I take it that adopting specific priority-setting criteria is part of "imposing limits" on healthcare resources. Therefore, I scrutinize if indeed public participation can render priority-setting criteria legitimate by analysing whether public participation should be part of the A4R framework.

[20] This implies that, according to Daniels and Sabin (2002), ZiN could have decided to not use any priority-setting criteria at all and only use the A4R framework to make priority decisions about healthcare interventions. However, ZiN has chosen to use both (ZiN, 2018; ZiN, 2017).
[21] See previous page.

What is evident is that public participation is not an independent condition in the framework and also not an explicit element of any of the four conditions. Indeed, this exclusion is also explicitly argued for by Daniels and Sabin (2002, p. 61-63). They claim that public participation is neither a necessary nor sufficient condition for legitimacy. They reject two common arguments that have been put forward in favour of public participation as necessary condition for legitimacy (Ibid).

The first argument states that public participation is necessary because the participants represent the public as a whole. Through this representation, healthcare priority-setting decisions are democratized. The second argument states that public participation is a form of proxy-consent. Participants' consent to priority decisions, on behalf of others, substitutes the actual consent of those not participating. Daniels and Sabin (Ibid, p. 61-62) reject both the representation as well as the proxy-consent argument as they claim that there is no plausible mechanism in which participants selected can represent the broader public and provide consent on their behalf. According to Daniels and Sabin (Ibid, p. 62), the absence of such mechanism "constitutes a decisive objection" to the claim that public participation contributes to legitimacy. Therefore, they deliberately excluded public participation from the A4R framework.

I reject Daniels and Sabin's (2002) conclusion that public participation only instrumentally addresses the legitimacy problem as formulated by them. First, both the representation and proxy-consent argument reflect what is known as the scale problem of deliberative democracy which states that it is impossible to involve all people subject to the decision to participate in the decision-making (Parkinson, 2003, p. 5). However, many theoretical solutions have been provided that address this issue (Ibid, p. 26-28). For instance, Urbinati (as cited in Parkinson, 2003, p. 26) proposes that not all participants have to take part in the exchange of reasons, but can participate in deliberation through listening. Second, even when the theoretical solutions

prove insufficient or impractical, Daniels and Sabin (2002) too quickly reject public participation as they mistakenly believe that it either fully contributes to legitimacy or not. As Friedman (2008, p. 103) argues, the mere fact that actual public participation neither fits with an ideal conception of representation or consent does not imply the rejection of participation altogether. Rather, it provides reason to experiment with different types of participation and to not overestimate the effect of participation on the legitimacy of the decision-making (Ibid). In other words, a departure from an ideal conception of public participation can still directly address the legitimacy problem albeit imperfectly as legitimacy is not all or nothing but rather a matter of degree.

From these two arguments, I conclude that Daniels and Sabin's (2002, p. 62) rejection of the representation and proxy-consent argument does not "constitute a decisive objection" against the notion that public participation is not necessary for legitimacy.

More importantly, however, as it stands now, I argue that the A4R framework actually does not confer theoretically justified legitimacy to decisions about healthcare resources directly as well as priority-setting criteria because it excludes public participation. This is because of a problem related to the relevance condition. The relevance condition ensures that disagreement about priority-setting problems is restricted to disagreements between fair-minded people, inclined to find justifiable terms of cooperation about rationales that are considered reasonable (Ibid, p. 44-45). I argue that this restriction on the deliberation process threatens the A4R framework's ability to legitimize priority decisions about healthcare resources and priority-setting criteria. In particular, I take issue with the notion of reasonable and unreasonable rationales.

The relevance condition aims to filter out reasons about that what is important in priority-setting, that is, to distinguish good philosophical reasons from for instance faulty religious ones (Ibid, p. 109). According to Daniels and Sabin (2002, p. 53), religion-based reasons are not

convincing to people who do not hold these views (Ibid, 110). Therefore, individuals relying on faith-based reasoning cannot expect others to find these reasons relevant and compelling for priority-setting. An implication of this view in determining priority-setting criteria is that one needs to distinguish between irrelevant and relevant reasons before one starts deliberating about the appropriate criteria. This requires a clear formulation of the type of reasons that can be deemed relevant and will lead to an exclusion of those fair-minded individuals from the deliberation process whose reasons are judged unreasonable. However, the problem I identify is that there is no uncontroversial way to discriminate between reasonable and unreasonable rationales. Especially when considering that deliberation about appropriate priority-setting criteria takes place in a democratic society where a plurality of ethical views exists. Indeed, which rationales can be considered reasonable and unreasonable? As Friedman (2008, p. 109) rightfully points out, can Daniels and Sabin's (2002, p. 53) judgement of the unreasonableness of religious-based views also not apply to Utilitarian, Kantian or Libertarian views about priority-setting? Opponents of these ethical theories often consider these ethical views as misguided and confused and find them as uncompelling as faith-based reasoning (Ibid). Additionally, as Friedman (Ibid, 110) argues, even when granting that some reasons can be judged more reasonable than others, it does seem appropriate that a fair-minded person's own judgement of what constitute appropriate priority-setting criteria is at least to some extent influenced by reasons he deems relevant. Therefore, as I hold that there is no uncontroversial way to a priori discriminate between reasonable and unreasonable reasons, I conclude that those fair-minded people whose reasons are a priori excluded, have no justified normative reason to view priority decisions in general and about priority-setting criteria as legitimate.

The above threatens the A4R framework's ability to confer theoretically justified legitimacy to priority-setting criteria. However, I believe that making public participation integral to the A4R framework addresses this problem. Evidently, the degree to which public

participation increases legitimacy is dependent on the type of participation. As I will make a specific recommendation in section **2.4 A Proposal for Public Participation**, I will remain brief about this in this section. First, those individuals participating need to be representative of the Dutch public to the greatest degree possible. In particular, they need to be representative in terms of their ethical views. Second, participation needs to be deliberative instead of non-deliberative. Rather than relying on some a priori defined concept of reasonableness as envisioned by Daniels and Sabin, participants need to actively argue for the reasonableness of their ethical perspectives and why some perspectives may be judged unreasonable. Such deliberation can only be accommodated by adopting deliberative forms of public participation. By integrating such a type of public participation in the A4R framework, one that is representative and deliberative, the legitimacy of outcomes of the framework increases.

To conclude, even though the leading framework to achieve legitimate outcomes in healthcare priority-setting does not deem public participation as a necessary or sufficient condition for legitimacy, I argued that outcomes of the framework lack legitimacy because it does not incorporate public participation. Thus, public participation should be integrated into the A4R framework to obtain legitimate priority-setting criteria.

2.3.3 Instrumental Arguments

Besides normative reasons for public participation, several instrumental arguments have been put forward that advocate public participation in healthcare priority-setting.

First, public participation may increase the quality of these decisions. By not only considering expert opinion but also the opinion and especially the experience of lay-people who are affected by the decisions, it is assumed that priority-setting decisions will be improved (Bal and van Lindeloof, 2005, p. 176; Clark and Weale, 2012, p. 302). Second, greater public involvement may lead to more public support for the decisions, in other words, public participation is believed to be an empirical condition for legitimacy. Namely, it is believed to

increase trust between the public and the decision-making authorities as it would lessen a presupposed gap between the two (Bal and van Lindeloof, 2005, p. 176). Some tentative evidence exists that there is a lack of trust and support concerning priority-setting in the Netherlands. For instance, in 2012, CVZ[22] recommended the Minister to no longer collectively finance medicines treating the illnesses Pompe and Fabry[23] as both medicines were not cost-effective and cost Dutch society approximately €500.000 and €200.000 a year per patient respectively for only a limited increment in quality of life (NOS, 2013). This, however, sparked public outrage which led CVZ to retract its recommendation. While I recognize that it is premature to assume from this example alone that the Dutch public does not support priority decisions, it does show that at least in this instance support was lacking. Third, it is assumed that public participation has educational benefits as the public would gain knowledge about the dilemmas underlying priority-setting, resulting in more understanding (Ibid; Williams, Robinson and Dickinson, 2012, p. 32).

There are also several instrumental arguments against public participation. First, some question the ability of the public to adequately participate in the decision-making. It is assumed that the public lacks the relevant knowledge required for adequate participation (Bal and van Lindeloof, 2005, p. 178). Second, public participation could be a method by which officials delay the decision-making, as developing priority-setting criteria and making priority decisions is a complex and difficult task. Additionally, officials could conceal their reasons behind the decisions made by the public (Ibid; Hunter et al., 2016, p. 801). This since they may use the majority's opinion to their advantage when making a preferred priority-setting decision by simply stating that it is the choice of the majority without giving a detailed rationale for their

[22] To recall, CVZ was succeeded by ZiN in 2014.
[23] Fabry disease causes lipids to build up in the autonomic nervous system, cardiovascular system, eyes and kidney (NIHa, 2021). Pompe disease is an inherited and fatal disorder that damages the heart and skeletal muscles (NIHb, 2021). Individuals with either one of the diseases dies prematurely.

position (Bal and van Lindeloof, p. 2005, p. 178). In other words, officials may use public participation only to foster the belief among the public that the decisions are legitimate.

One way of weighing the merits of these instrumental arguments is by reviewing the relevant empirical evidence which I turn to now. Dryzek et al. (2019, p. 1145) argue that experimentation conducted with deliberative methods refutes many of the arguments against public participation. Their review of empirical literature shows that people are capable of high-quality deliberation about difficult topics. Moreover, deliberation overcomes polarization between different groups and leads to considered judgements where participants find their judgements more consistent with the values they hold after deliberation. This is supported by Bal and van Lindeloof's (2005, p. 215-218) earlier review of international experience[24] with public participation in priority-setting. They conclude that participants were able to understand and discuss complex technical issues and made substantive contributions to the discussion. Moreover, participants valued the fact that they could contribute to priority-setting decisions. However, Bal and van Lindeloof (Ibid) stress that the quality of the contribution depended on the method of deliberation whereby deliberative methods seemed to give the best results. Additionally, a recent experimental study regarding public deliberation in the Netherlands showed positive results (Baltussen et al., 2018). In 2017, 24 Dutch citizens were selected to participate in a citizens forum to gain insight into their preferences for priority-setting criteria. These participants identified 16 criteria that should guide this evaluation (Ibid, p. 3). From this experiment, Bijlmakers et al. (2020, p. 36) conclude that the participants (1) were capable of articulating their preferences and viewpoints, (2) discussed a broad spectrum of opinions and considerations and (3) cultivated their opinions by challenging each other in a structured

[24] Bal and van Lindeloof (2005, p. 184-208) analysed public involvement with priority decisions in Oregon (Health service commission), The United Kingdom (Citizens Council), New-Zealand (National Health Committee), Israel (Health Parliament), Canada and Sweden.

deliberation. Although the deliberation resulted in the 16 criteria, it did prove to be difficult to reach a shared recommendation (Baltussen et al., 2018, p. 50).

This review of the empirical evidence suggests that public participation has positive effects. However, one needs to keep in mind is that all evidence presented primarily concerns deliberative methods of participation.

2.4 A Proposal for Public Participation

While it is increasingly recognized that good healthcare priority-setting requires public deliberative participation, I notice that recommendations as to how participants should deliberate remain general (Baltussen et al., 2016; Bærøe and Baltussen, 2014; Jansen, Baltussen and Bærøe, 2018; Daniels and Sabin, 2002; Dryzek et al., 2019).

Therefore, in this section, I present a proposal for public deliberative participation in determining the priority-setting criteria which should be integrated into the A4R framework. I will do this by briefly outlining three shortcomings of the commonly used, non-deliberative method, of preference-elicitation studies for estimating public preferences' for priority-setting criteria. From this, I conclude that policy-makers should not solely rely on preference-elicitation studies for measuring preferences about priority-setting criteria. I then argue that these shortcomings are overcome if the public can participate deliberately by employing the method of reflective equilibrium (RE) in moral inquiry.

2.4.1 The Shortcomings of Non-deliberative Participation

The aim of non-deliberative public participation in general and in the form of preference-elicitation studies in particular is to measure people's preferences regarding priority-setting criteria (Whitty et al., 2014, p. 366). Whitty et al. (Ibid, p. 375) identify three broad approaches to eliciting these preferences: Discrete-choice, contingent-valuation and person trade-off experiments. To illustrate one of these approaches, consider the following hypothetical example which the public might be faced with when taking part in a person trade-off experiment.

Assume that you can finance intervention A or B. Intervention A restores people facing immediate death to full health and intervention B restores people who are moderately ill to full health. Is there an X number of people that can be treated by B that would outweigh the number of people that can be treated by A so that you would finance treatment B?

The assumption is that such person trade-off studies uncover people's value judgements in priority-setting dilemmas provided they receive the relevant information about health states and outcomes.

I identify several shortcomings related to preference-elicitation studies which threaten the normative conclusions that can be derived from its results. First, preference-elicitation studies rest on the assumptions of rational choice theory. However, psychological and behavioural economic research has demonstrated that people's choices often deviate from the choices predicted by rational choice theory (Tversky and Kahneman, 1974). Therefore, there is a concern that subjects when making these moral choices, base their decisions on heuristics and mental shortcuts which violate the assumptions of rational choice theory (Sunstein, 2005, p. 531). Indeed, this has been demonstrated in a person trade-off study conducted by Voorhoeve, Stéfanson and Wallace (2019) where research subjects' choices not only violated the transitivity condition but also did not align with standard theories of distributive justice. This indicates that the moral value judgements in these experiments are untrustworthy (Ibid, p. 3).

The second limitation of preference-elicitation studies is similar to the shortcoming of voting. That is, do researchers uncover ice-cream like tastes when eliciting the trade-offs people are willing to make or do they truly reflect people's moral value judgments? In priority-setting, it is the latter that policy-makers should be interested in. While developments in methodology seem to resolve this issue, these methods prove to be complex and may exacerbate the methodological concerns outlined above (Daniels, 2007, p. 115-116).

The last shortcoming is captured by the anthropological objection which reads as follows (Daniels and Sabin, 2002, p. 38; Daniels, 2007, p. 116). When assuming the above methodological worries not to exist and that the results of such person trade-off experiments truly represent subjects' moral value judgements, researchers are still left with the question of whether people should make those value judgements and whether priority-setting criteria should be based on them. For instance, the fact that the majority of people make the same moral value judgements in these experiments does not necessarily imply that these are the right judgements to make. In effect, this normative problem is similar to the criticism I raised against ZiN when I argued that public support is insufficient to regard the basic insurance package as substantively just. This is because people's moral judgements regarding what they perceive as a substantively just allocation of health interventions may be wrong.

This is not to say that preference-elicitation studies and non-deliberative methods should be rejected altogether. An obvious benefit of non-deliberative methods compared to deliberative methods is the fact that the former is scalable. It is relatively easy and cheap to administer these experiments amongst a wide range of people compared to deliberative methods. Therefore, the upshot of this discussion is that policy-makers should not solely rely on non-deliberative methods when valuing public participation.

2.4.2 Deliberative Participation: The Method of Reflective Equilibrium

I propose that the public should participate in a deliberative way and policy-makers should formulate priority-setting criteria which are the result of participants employing a particular method for moral reasoning, namely, the method of reflective equilibrium (RE). Additionally, this deliberative participation should abide by a set of rules which ensure representative, fair and high-quality deliberation.[25] This type of participation overcomes two out of the three

[25] For suggested guidelines for high-quality and representative deliberation, see for instance Williamson, Dickinson and Robinson (2012, p. 44-45), Jansen, Baltussen and Bærøe (2018, p. 975), or Norheim et al. (2021, p. 11). I do not explain theses guidelines any further as my main concern in this section is about the manner in which the public should deliberate, not how this deliberation can, for instance, be considered representative.

shortcomings that non-deliberative participation is subject to. (1) It side-steps the methodological concerns related to preference-elicitation studies and (2) it allows the eventual policy-maker to identify the participants' underlying reasons for supporting particular priority-setting criteria.

As a reminder, the objective of deliberative participation is to engage in dialogue with the public where participants exchange arguments and reasons when having to decide about priority-setting problems (Bal and van Lindeloof, 2005, p. 180). The goal is not necessarily to reach a consensus amongst participants but to identify the relevant reasons put forward. In light of the different reasons, participants can change their minds during deliberation. Moreover, in my proposal, when combined with the method of RE, participants are forced to actively engage in moral reasoning.

In brief, the method of RE, which originates in the writings of Rawls (1971), is a form of moral deliberation. During this deliberation, a constant reflection takes place between an individual's considered moral judgements about specific cases and principles, developed to fit with these considered judgements (Arras, 2017, p. 178-179). If the developed principles cohere with each other and with the considered judgements and can provide a rationale for the considered judgements, then the individual is in RE. If not, then the individual has to amend either his considered judgements or his moral principles (Arras, 2017, p. 179; Scanlon, 2002, p. 140-141). Once individuals reach equilibrium, the justification of their moral outlook is not based on some unchangeable foundational theory, but on the coherence of their endorsed moral principles and considered judgements and the ability of the endorsed principles to provide a rationale for the judgements (Arras, 2017, p. 179).

To illustrate this method with an example. Imagine you can provide an intervention that results in a 1 QALY gain in either a 40-year-old sick person or an equally sick 41 year old, or that this may be decided by a flip of a fair coin. Let us assume that you decide to settle this

decision with a flip of the fair coin reasoning that, all other things being equal, age is not a relevant moral consideration. From this considered judgement, you adopt the non-discrimination principle which dictates that one should not discriminate between individuals based on their age.

Now consider a slightly different case, where you are presented with the same decision. You can either provide an intervention resulting in a 1 QALY gain for a sick 41-year-old or an equally sick 20-year-old or again decide the matter with the flip of a fair coin. Applying the non-discrimination principle dictates that you should decide with the coin flip, since all other things being equal, age is an irrelevant moral factor. However, applying this principle goes against your considered judgement in this particular case, because you believe it would be morally better to treat the 20-year-old. This means that your case judgements and the non-discrimination principle are not in reflective equilibrium. The method of RE then dictates that you should either amend your judgements to fit the non-discrimination principle or amend or abandon the non-discrimination principle as age is deemed relevant, at least, in some cases.

I submit that deliberating in this way is less subject to at least two of the shortcomings of the preference-elicitation approach. In the first instance, it allows participants to spot inconsistencies in their reasoning and violations of rationality that threaten the trustworthiness of their judgements in preference-elicitation studies. When participants have to actively discuss different priority-setting criteria by making considered judgements and by reflecting these judgements to endorsed moral principles, I assume that participants will be less subject to the heuristics and mental shortcuts that undermine their rational decision-making. This is because the method of RE demands coherence between a person's moral principles and judgements and because my proposal includes the fact that the method should be employed in a deliberative context with other participants. This allows participants to spot violations of rationality in each other's reasoning.

Second, while in non-deliberative methods one cannot be sure whether people's choices reflect taste-like preferences or deeper held moral convictions, the method of RE allows policy-makers to identify the underlying reasons for the moral choices of participants as participants have to provide a rationale for their endorsed principles and considered judgments.

Finally, this proposal allows and demands that participants provide reasons for their endorsed views and consider and judge the reasonableness of different viewpoints. This solves the problem I identified with Daniels and Sabin's A4R framework in section *2.3.2 Public Participation as a Condition for Legitimacy*.

Naturally, many assumptions are underlying the method of RE and it is therefore not without dispute.[26] As such, I will address two objections that seem to undermine my purpose in using the method.

2.4.3 Considering Two Objections

First, Arras (Ibid, p. 197-200) argues that coherence as a source of moral justification is insufficient. To illustrate this point, consider the case of a teenager with a mediocre intellectual capacity, narrow moral vision and who emerges himself in orthodox-religious chatrooms and readings. From this inquiry, the teenager emerges as a devoutly orthodox-religious person who views homosexuality as a sin and therefore endorses conversation therapy. This teenager's moral outlook is perfectly coherent and can be said to be in reflective equilibrium. Despite this, the fact that his moral views are in equilibrium is not a sufficient justification for his moral outlook.

Now, one could object to this example by arguing that the teenager is not justified in making his claims as he is not well-educated and is morally not cultivated. However, Arras (2017, p. 198) rejects this objection as determining whether the person holds the correct

[26] For a detailed overview of the concerns regarding the method of reflective equilibrium, see Arras (2017, p. 185-201).

epistemological beliefs when being in reflective equilibrium is not within the objective of the method.

Moreover, a similar but even more powerful objection against coherence as justification for a person's moral outlook is Arras' (Ibid) illustration of an early 20th century hypothetical young woman. This woman is smart, well-educated, progressive and she is well-versed in social Darwinist political theory. Moreover, she believes her race to be superior and supports the sterilization of the unfit. Unlike the hypothetical teenager, one cannot reject her views on the grounds of not being well-educated or short-sighted. Even when assuming she has reflected her views against other moral considerations prevailing at the time, one would still reject her moral views. Not only because her views rest on, currently established, inaccurate Darwinist social theory, but also because today's society places more value on individual autonomy and bodily integrity than people did in the early 20th century. Taken together, these two examples demonstrate that coherence in a person's system of moral beliefs fails as a sufficient justification for having those beliefs.

Turning to the second objection against the method of RE, Arras (Ibid, p. 192-196) claims that it is unlikely that the method of RE results in consensus between people when applying the method. When relying on considered judgements as a starting point for moral reasoning, Arras (Ibid) argues that in a pluralistic democratic society, different people will make different judgements. Even though throughout deliberation, these judgements are amendable, they still significantly influence the eventual moral principles that people will accept. For instance, one can reasonably expect a cosmopolitan progressive Dutch citizen to make radically different judgements when compared to an orthodox Dutch Christian leading both to end up in different equilibria.

2.4.4 A Response to the Objections

The above two objections can be restated as follows. (a) The method of RE cannot justify the resulting moral views of people using the method even when assuming that people have the relevant epistemic beliefs and (b) it is unlikely that the method of RE leads to a consensus in moral views.

Objection (a) undermines my purpose in two ways. It raises a concern to what extent participants who do not have the relevant epistemic beliefs about the complexity of priority-setting problems and who are not well-versed in the plurality of moral theories and principles, can reach a justifiable equilibrium. Second, even if participants have the relevant epistemic beliefs, coherence, as a criterion for the justification of moral views in reflective equilibrium, is not sufficient to justify these views. It is thus unclear whether priority-setting criteria based on the outcome of such deliberation are normatively justified.

To objection (a) I respond by stating that one can impose requirements on belief formation when participants employ the method of RE. In fact, this was originally argued by Rawls (as cited in Scanlon, 2002, p. 143) who states that considered judgements are judgements made by people who are (1) aware of the relevant facts, (2) able to concentrate on the question and (3) have nothing to gain or lose by their judgement. The empirical evidence outlined in section *2.3.3 Instrumental Arguments* already demonstrates that people can understand the complexity surrounding priority-setting. Thus, to ensure (1) and (2), I suggest that experts are present or have provided the participants with relevant information about the technicalities related to priority-setting problems and that deliberation occurs in an environment that gives participants time to reflect. Furthermore, to ensure that condition (3) is met, I propose that the participants are actively reminded of the principle of depersonalisation. This principle states that participants should take as much as possible the interest of the general population into account

instead of their personal interest when deliberating (Baker, Mason, McHugh and Donaldson, 2021, p. 2; Williamson, Robinson and Dickinson, 2012, p. 30).

To answer the second part of objection (a), stating that coherence between principles and judgements cannot justify the resulting moral views, I argue that this objection reflects a much deeper problem not restricted to the method of RE but to the philosophical inquiry of what would constitute acceptable moral principles in general. For instance, one could take the position that only abstract moral theorizing could lead to acceptable priority-setting criteria and see no purpose for practical moral reasoning in the manner of RE. However, I remain convinced that the method of RE has justificatory force when distinguishing between "narrow" and "wide" reflective equilibrium.

Seeking narrow reflective equilibrium (NRE) refers to the example about age and the non-discrimination principle discussed earlier. To reach NRE, individuals only focus on a group of principles and particular cases. These principles are not reflected against abstract moral theories (Daniels, 2016). It is particularly NRE that is subject to the described criticism that only seeking NRE cannot justify the resulting moral views when being in equilibrium. Wide reflective equilibrium (WRE) on the other hand, is less subject to this criticism. When seeking WRE participants' judgements and principles are not restricted to the particular cases but are reflected against a broader range of foundational ethical theories such as Utilitarianism or Kantianism (Ibid). Having reflected considered judgements with broader moral principles and foundational ethical theories in WRE, WRE has greater justificatory force compared to NRE.

Despite this advantage, one could argue that the method of WRE is too demanding for the purpose I have in mind. It seems unreasonable to demand of participants that they reflect their considered judgements and principles with all the currently existing moral theories (Arras, 2017, p. 185-186). My response, while recognizing that this solution is imperfect, is that

philosophers and ethicists could inform participants about the leading ethical theories relevant for determining priority-setting criteria.

To objection (b), which says that it is unlikely that the method of RE leads to a consensus in moral views in a pluralist democracy, I respond by arguing that this is first and foremost an empirical question. Even though I agree that it is reasonable to assume that such a consensus cannot be reached with RE, I claim that we first have to run the experiment. Second, even if a consensus cannot be reached, policy-makers may in the end still rely on voting. The advantage of first applying the method of WRE followed by voting is that those individuals who hold the minority view have a better reason to accept the final decision. In my proposal, those holding the majority view have to give reasons and arguments as to why their perspective should determine the priority-setting criteria. They cannot simply rely on the power of the majority vote to push their preferred priority-setting criteria. An alternative way of settling the matter would be by complementing the deliberation with preference-elicitation studies. In that case, policy-makers could determine whether the majority view in deliberation also represents the majority view in preference-elicitation studies (Baker et al., 2021, p. 6).

2.5 Conclusion

In this chapter, I scrutinized ZiN's commitment to public support for the priority-setting criteria it uses. As ZiN is unclear about its conception of the public and public support, I provided a framework for public participation in determining priority-setting criteria. I concluded that the public has not taken part in the development and acceptance of the priority-setting criteria, but patients do participate in the application of the criteria. Moreover, I argued that ZiN cannot conclude that the priority-setting criteria are based on public support.

Furthermore, as ZiN also relies on the wrong justification for public participation, I provided three different arguments as to why the public should participate. First, the public has a moral right to participate which exceeds their right to vote. Second, I argued that public

participation is a necessary condition for legitimacy when scrutinizing the leading framework for legitimate decision-making in healthcare priority-setting. Lastly, I considered instrumental arguments in favour and against participation and examined empirical evidence which suggests that deliberative public participation has beneficial effects.

In the last section of this chapter, I made a suggestion for public participation by first highlighting shortcomings of a particular type of non-deliberative participation, i.e. preference-elicitation studies. I then argued that the public should participate in a deliberative manner by applying the method of RE in moral inquiry within the A4R framework.

CHAPTER 3: EXAMINING PROPORTIONAL SHORTFALL

To integrate a concern for the worse off in priority-setting, ZiN (2018) has chosen to adopt the necessity criterion which it defines in terms of burden of illness and operationalises with proportional shortfall. In **chapter 1**, I explained ZiN's motivations for operationalising the necessity criterion with proportional shortfall. Namely, one of the primary reasons is that proportional shortfall purportedly reflects and balances the fair innings view, the rule of rescue and severity of illness and prevents age-discrimination (Stolk et al., 2001; Stolk et al., 2002; Stolk et al., 2004; ZiN, 2018).

Much ambiguity exists regarding the fair innings view, the rule of rescue and severity of illness as priority-setting principles. What I mean by this is that, in the healthcare priority-setting literature, different authors have described and understood these concepts in different ways. Moreover, these principles have not been derived from and systematically discussed in reference to the broader perspectives of distributive justice I explained in **chapter 1** section *1.1.2 A Concern for the Worse Off*. Therefore, in this chapter, I will clarify how these concepts have been commonly described. This allows me to scrutinize how ZiN (2018) understands these concepts and motivates its position for adopting these concepts by balancing and reflecting them in proportional shortfall. Additionally, in this chapter, I will explain proportional shortfall in greater detail. This provides the groundwork for the next chapter in which I will criticize fair innings, severity of illness and the rule of rescue and proportional shortfall in detail. This chapter is structured as follows.

First, I will explain the fair innings view, severity of illness and the rule of rescue. Fair innings refers roughly to the view that everybody is entitled to the same amount of health over their lifetime with respect to a threshold. Fair innings thus reflects a lifetime perspective whereby those individuals who enjoyed less health, are considered worse off (Ottersen, 2013). Severity of illness states that priority should be given to those who are more severely ill (Barra

et al., 2019). Naturally, severity may be operationalised in different ways. For instance, severity of illness may refer to an individual's illness at the moment an intervention would be implemented or may include an individual's future health as well. The rule of rescue reflects the perspective that priority should be given to those who face imminent death without regard to the opportunity cost of doing so. After each explanation, I will examine ZiN's motivation for adopting these concepts and examine to what extent ZiN's (2018) account of these concepts corresponds to their theoretical description. From this examination, I conclude that ZiN's motivation for adopting these concepts is ambiguous as their adoption follows from ZiN's perspective of distributive justice which it does not outline.

In the second and last section, I will explain proportional shortfall and present two purported merits of it. Proportional shortfall seems to make a trade-off between fair innings and severity of illness and seems to prevent age-discrimination.

3.1 Fair Innings, Severity of Illness and the Rule of Rescue

3.1.1 Fair Innings

The fair innings view was first argued for in Harris' (1985) book *the Value of Life*. This view is a response to what Harris (Ibid, p. 88-90) calls the anti-ageist argument which denies the moral relevance of age when deciding between saving the life of a young or old person assuming all other things to be equal. The anti-ageist argument rests on the assumption that the remainder of people's lives are equally valuable regardless of their life expectancies, as long as both persons deem it worth living. Therefore, individuals who want to go on living suffer the same injustice when their life is cut short regardless of their age. This implies that advocates of the anti-ageist argument would consider it wrong to prioritize a younger over an older person when both have an equal desire to live because the former has a longer life expectancy when being saved.

In response to this, Harris (Ibid, p. 90-94) develops the fair innings view. The fair innings view says that there is a span of life years that society considers as reasonable, i.e. the fair innings, for instance, 80 years. Those who reach 80 or older are considered to have received a bonus as they received some life-years beyond that which they could reasonably expect (Ibid, p. 91). Those who do not live to be 80 have been cut short and therefore suffer an injustice (Ibid). The fair innings view rests on the intuition that it is always a *misfortune* [emphasis added] to die when one desires to keep on living but not a *tragedy* [emphasis added] to die in old age, whereas it is both a *misfortune* and a *tragedy* when one dies young (Ibid, p. 93). Harris (Ibid, p. 93) recognizes that the concept of misfortune and tragedy are vague. Therefore, he argues that the fair innings view only applies to those cases where the life of an individual who has not reached its fair innings can only be extended at the expense of a life of an individual who has reached its fair innings, as judged by reasonable people (Ibid, p. 93-94). Moreover, according to Harris (Ibid, 94), the fair innings view should uphold the anti-ageist argument as he argues that everyone below the fair innings threshold should have an equal chance of reaching the fair innings.

The fair innings view was further developed by Williams (1997). He highlights four key features of Harris' (1985) fair innings view. First, it is an outcome-based concern with equality as one judges the number of life-years enjoyed by the individual. Second, it is concerned with an individual's total lifetime experience and not restricted to an individual's current situation. Third, it rests on an aversion to inequality in health because those who have not reached their fair innings are prioritised over those who have. Lastly, it is easily quantifiable as it uses age to determine the fair innings. However, Williams (Ibid, p. 119) then continues by arguing that this last feature of the fair innings view is insufficient as age is only an approximation for an individual to have reached the fair innings. According to Williams (Ibid), what policy-makers

should be concerned with is not only the length of an individual's life but also its quality. To see this, consider the following example.

Vignette 1: Imagine that individuals reach the fair innings at 80 years and you can either save the life of.

(a) An 81-year old individual facing imminent death who has suffered from a chronic illness throughout his life and who gets 1 QALY when being treated.

(b) A 75-year old individual facing imminent death who has been healthy throughout his life and who gets 1 QALY when being treated.

On Harris' (1985) fair innings view, individual (b) should be prioritised as this patient has not reached the fair innings compared to individual (a). However, this view fails to capture the fact that the 81-year old individual has been chronically ill. When assuming that the 81-year old individual effectively enjoyed 74 QALYs and the 75-year old 75 QALYs, Williams (1997) would claim that the 81-year old should be given priority. The fair innings view should be concerned with the quality as well as the number of life-years (Ibid, p. 121).

Nord (2005) further specified the fair innings view put forward by Williams (1997). Nord (Ibid, p. 259) argues that the fair innings view can be understood in two ways. He differentiated between the *equal innings* and the *sufficient innings view* [emphasis added]. The equal innings view says that everybody is entitled to the same number of QALYs over their lifetime with respect to a fair innings threshold whereas the sufficient innings view says that health gains should be valued less for those above the fair innings threshold. Concerning the former, Nord (Ibid) argues that policy-makers could, for example, adopt the position that QALY gains should be weighted proportionally to the difference between the individual's quality-adjusted life expectancy with the illness and the fair innings threshold in terms of QALYs. Concerning the latter, an example of adopting the sufficient innings view would be to assign a weight of less than 1 or even 0 to QALY gains for individuals above the fair innings threshold and equal

weight to QALY gains for individuals below the threshold. In that sense, the sufficient innings view remains most faithful to the original fair innings view of Harris (1985) who argued that decision-makers should be anti-ageist below the fair innings threshold.

Noteworthy is that neither Harris (1985), Williams (1997) nor Nord (2005) has justified or related fair innings to a particular conception of distributive justice. As stated at the beginning of this section, the fair innings view has been Harris' (1985) response to the anti-ageist argument and has subsequently not been related to any broader distributive perspective.

This brings me to ZiN's (2018) understanding of the fair innings view. ZiN's (Ibid, p. 11) describes the fair innings view as follows: Justice is achieved when everybody is able to reach a certain number of life-years X, e.g. 80 years in good health, where this is measured in terms of QALYs. ZiN thus adopts William's (1997) perspective of the fair innings view in that it should be concerned both with the quantity and quality of life-years. However, it is unclear which conception of justice motivates ZiN's adoption of the fair innings view. That is, it is unclear as to why ZiN considers it just when everybody can reach the same QALY threshold. Moreover, it remains ambiguous which priority decisions ZiN would endorse with respect to the threshold of 80 years. Specifically, it is unclear which decision ZiN would make when individuals have surpassed the threshold.

3.1.2 Severity of illness

In healthcare priority-setting, it seems obvious to regard those who are more severely ill as worse off. Indeed, severity of illness figures prominently in the priority-setting literature and in priority-setting in countries like Sweden and Norway. Severity of illness has been operationalised in three ways: Present health, prospective health and absolute shortfall (Barra et al., 2020, p. 28-31; Dolan and Olson, 2001, p. 824; NOU, 2015; p. 2; Norheim et al., 2014, p. 3; Reckers-Droog, van Exel and Brouwer, 2019, p. 1442). Present health determines the severity of illness by measuring the QALY loss due to illness at the moment an intervention

would be implemented. Prospective health is similar to present health, but also takes the future development of the illness into account. Absolute shortfall looks at present and future QALY loss with respect to some QALY reference level.[27]

However, severity of illness as a priority-setting criterion is contested (Barra et al., 2020, p. 26). Much disagreement exists about (a) the justification which should underly severity of illness and (b) the manner in which severity of illness should be operationalised specifically (Barra et al., p. 26; Hausman, 2019). Addressing concerns with respect to (a) and (b) is crucial before severity of illness can justifiably be used in priority-setting. This is because policy-makers' motivation for adopting severity of illness determines their specific operationalisation of the concept. Moreover, regardless of the specific operationalisation, Barra et al. (2020) outline several technicalities related to severity of illness that influence which interventions are eventually prioritised. Therefore, in this section, I will first examine how severity of illness has commonly been justified and describe ZiN's motivation for adopting severity of illness. Then, I will examine some of the technicalities associated with severity of illness and how ZiN addresses these.

Several reasons have been put forward to ground severity of illness. First, the needs of those currently severely ill may be assumed to be more urgent (Barra et al., 2020, p. 38; Sandman and Hofmann, 2018). Therefore, they may be considered to have a greater claim on healthcare resources (Barra et al., 2020, p. 38).

Second, given one's particular conception of distributive justice, those severely ill can be considered worse off and therefore should receive priority. For instance, policy-makers could adopt the prioritarian view which dictates that one should prioritize those worse off as health improvements in those worse off should be valued more (Barra et al., 2020, p. 36).

[27] $Absolute\ shortfall = Remaining\ QALYs\ without\ illness - Remaining\ QALYs\ with\ illness\ without\ intervention$

Third, Nord (2005, p. 261) reasons that people place more weight on the current and future suffering of others. A possible reason is that present and future suffering may elicit feelings of solidarity as well as a duty to help those suffering. This concern for present and future suffering in others may be further supported by the fact that people also have a bias towards the future when it concerns personal suffering. To see this, consider Parfit's (1986, p. 54) illustration of this point.

Imagine that you are in a hospital and will undergo surgery. As the procedure is without risk and always successful you are not worried about its outcome. However, during the surgery you cannot have anaesthetics because you need to give the surgeon feedback, causing the surgery to be extremely painful. Due to this, patients are given a drug that erases their memory of the operation. Now imagine that you have just woken up in the hospital with no recollection of the immediate past, causing you to ask when your surgery will take place and how long it will take. Your nurse answers that she is not sure if you had surgery yesterday, a long 10-hour operation with associated suffering, or that you are the patient who will have surgery later today, which, she is certain, will take 9 hours. The nurse is going to find out which one is true.

Parfit (Ibid) is clear which scenario he would prefer to be true if he were the patient and assumes that most people would have that preference. That scenario is the one in which he has already had the surgery. Parfit (Ibid) argues that this rests on people's preference to prefer having had negative experiences in the past and looking forward to positive experiences in the future.[28] This could imply that people also place a higher weight on present and future suffering in others when sympathetically take up each others' position. Therefore, both a concern with present and future suffering in oneself and others may motivate severity of illness in priority-setting.

[28] For a detailed explication of this argument, see Parfit (1986, p. 53-57).

Finally, Nord (Ibid) hypothesizes that past suffering may be considered a sunk cost as the past cannot be changed. As it is only the present and the future one can influence, policy-makers may plausibly focus on the present and future in priority-setting.

Turning to ZiN's motivation for severity of illness. ZiN (2018, p. 11) bases its commitment to severity of illness in terms of a concern for distributive justice as it deems it just that people with the worse health prospects are given priority. However, ZiN (Ibid) is silent regarding its particular conception of distributive justice that motivates its position. Moreover, ZiN (2018, p. 11) refers to absolute shortfall in its description of severity of illness. On this operationalisation, individuals who stand to lose the greatest number of QALYs with respect to a QALY threshold should receive priority. However, as ZiN is silent about its motivation for adopting severity of illness, it is unclear why ZiN views absolute shortfall as the appropriate operationalisation.

With this in mind, I now examine several practical technicalities associated with severity of illness. This is relevant as policy-makers' way of dealing with these technicalities further determine which interventions are prioritised over others when using severity of illness. This discussion is structured by answering a sub-set of questions posed by Barra et al. (2020) as different answers to these questions lead to different practical implications when using severity of illness.

(2a) Should disease-severity or condition-severity be assessed?

Disease-severity refers to the severity of the illness in absence of any intervention whereas condition-severity refers to the severity of the illness when taking existing interventions or intervention options into account (Reckers-Droog, van Exel and Brouwer, 2018, p. 3; Sanman and Hofmann, 2019, p. 28). Naturally, assessing the severity of illness in terms of either disease-severity or condition-severity leads to different results as the former would indicate that an individual is in a worse health state on any of the three operationalisations of severity of illness.

In their examination of both concepts, Sandman and Hofmann (2019, p. 29-34) argued that condition-severity best conforms to their considered judgements when prioritising between different interventions in different cases as condition-severity estimates the actual health loss an individual suffers from the illness.

ZiN (2018) is not clear about whether it uses condition-severity or disease-severity. In its discussion of absolute shortfall, ZiN (Ibid, p. 11) repeatedly refers to "QALYs without the intervention" without specifying whether this concerns severity in the absence of any treatment or concerns existing interventions. However, in an earlier report, ZiN does state that for an "add on" intervention, which is an intervention that complements an existing intervention, condition-severity should be calculated (CVZ, 2013, Appendix 3 p. 6).

(2b) Should severity be operationalised by including co-morbidity factors?

Co-morbidity factors refer to the presence of one or multiple conditions besides the primary condition which the health intervention targets. For instance, an individual may suffer from breast cancer while also having a heart condition. Gustavsson (2019) argues that policy-makers should give priority to those who are worse off by taking all co-morbidity factors into account. This is supported by Barra et al. (2020, p. 33) who see no moral justification in only focussing on a specific condition when determining who is worse off when prioritising based on severity of illness. While ZiN (2018, p. 21) does determine the presence of co-morbidity factors, it is unclear to what extent these are included in its identification of those who are worse off.

(2c) Should death be an independent dimension of severity?

ZiN (2018, p. 8) looks at death independently. This perspective is informed by the ethical principle "the rule of rescue" which I will describe in the next section.

(2d) Should severity be related to the individual's context?

This question addresses whether indirect health effects on third parties, e.g. family, should be included when determining the severity of illness. For instance, two individuals who suffer

from two distinct illnesses with an equal QALY loss but where one individual requires informal care could be judged worse off when considering the demands it places on informal caregivers. This question hints at a broader debate in bioethics regarding whether direct non-health and indirect benefits should be taken into account in priority-setting (Brock, 2003; Du-Toit and Millum, 2016). An example of the former would be accounting for the direct effect of the intervention on an individual's economic productivity and of the latter, the earlier described effect on informal caregivers.

In its description of absolute shortfall, ZiN (2018) takes the position that only direct health benefits should be taken into account as it only looks at the QALY loss of those individuals that are targeted by the intervention. However, it does this without explicit argument.

(2e) What should be the relation between severity and age?

Here it is important to make a distinction between two cases. First, assuming all other things being equal, one could judge that younger individuals should receive priority over older individuals because they are younger in case of equal illness. In that case, age is judged to be a morally relevant factor. Second, assuming all other things being equal, one could operationalise severity of illness in such a way that it gives priority to the young over the old. However, in this case, it is not by virtue of age that the young receive priority. Rather it is a consequence of the operationalisation that younger individuals happen to receive priority. It is only the former situation that plausibly leads to the objection of age-discrimination as it could be considered unfair to prioritize some individuals simply because they are younger. This anti-ageist position is adopted by ZiN (2018, p. 4) who deems age a morally irrelevant factor in priority-setting. In fact, as I have shown in **chapter 1** section *1.3.2 The iMTA Recommendation: Proportional Shortfall*, an important motivation for adopting proportional shortfall was to prevent age-discrimination.

3.1.3 The Rule of Rescue

The Rule of Rescue (RR) in relation to healthcare priority-setting was first discussed by Jonsen (1986, p. 174). Jonsen (Ibid) described the RR as a moral imperative which demands that one should try to save those individuals who face immediate death. Mckie and Richardson (2003, p. 2407) further specified Jonsen's (1986) description and refer to RR as "the imperative to rescue identifiable individuals facing avoidable death, without giving too much thought to the opportunity cost of doing so". Furthermore, Mckie and Richardson (2003) and Schöne-Seifert (2009) discuss two key features of the RR as priority-setting criterion and the underlying ethical and psychological motivations that may ground the RR.

First, the RR disregards opportunity costs. That is, the RR demands that a life should be saved of someone facing immediate death by prioritising a life-saving intervention determining its opportunity cost (Mckie and Richardson, 2003 p. 2408; Schöne-Seifert, 2009, p. 427-428). Another important feature is the RR's concern with identifiable individuals. According to the RR, an intervention is more valuable when it can save the life of an individual(s) who is, by virtue of facing imminent death, identifiable to those who can help. This is different from other priority-setting criteria such as fair innings or severity of illness as in those cases "the worse off" refers to a category of anonymous worse off individuals (Mckie and Richardson, 2003, p. 2409; Schöne-Seifert, 2009, p. 424-425). Thus, as priority-setting criterion, the RR regards those who face imminent death as worse off. These individuals can be clearly identified by them facing imminent death and should be prioritised without consideration to opportunity costs.

Mckie and Richardson (2003, p. 2410) argue that the RR may be grounded in both a moral duty or obligation to save a life when possible as well as a non-moral motive related to psychological feelings of compassion, shock and horror. Indeed, those situations, outside priority-setting, that seem to trigger the RR are usually unexpected and dramatic, where eye-

witnesses usually have no time to psychologically prepare for what is coming thereby triggering a shock and horror response. Examples that trigger such responses could be a person suddenly suffering from a heart attack or a child on a cruise ship falling overboard. While this suggests that the RR only applies to situations of impending death, it may also apply to situations where a life is not at risk, but where similar shock-horror responses may be elicited (Ibid, 2410). Mckie and Richardson (Ibid) present an example of children with physical deformities that are sometimes flown from poor to rich countries for treatment. If indeed the shock-horror response grounds the RR, then Mckie and Richardson (Ibid) argue that RR does not necessarily have to give added weight to all life-saving interventions. For instance, where witnesses are horrified when a child on a cruise ship falls overboard, they probably feel less shock compared with a cancer patient who dies after a long period of sickness. Therefore, this could indicate that not all cases of death trigger the RR in priority-setting.

When looking at ZiN's (2018, p. 11) conception of the rule of rescue, ZiN (Ibid) formulates the RR in terms of a concern with distributive justice similar to fair innings and severity of illness. That is, ZiN (Ibid) deems it just that those people who face imminent death or stand to lose a substantial number of QALYs should be prioritised. However, this description deviates from the motives that Mckie and Richardson (2003, p. 2410) outline for why the RR is used in priority-setting. The motivation for using the RR in priority-setting is that it reflects the ethical imperative to save a life when being able to do so. ZiN's motivation for using the RR deviates from this as ZiN's description suggests that it views the RR not as ethical imperative, but as a principle of distributive justice. This is problematic because the fact that, on a personal level, individuals may indeed have and feel the obligation or the duty to save another's life if they can do so, does not imply that this grounds the RR as a principle of distributive justice as well.

3.2 Proportional Shortfall

According to ZiN (2018, p. 8-9), as the fair innings view, severity of illness and the rule of rescue independently have merit, it argues that a proportional priority-setting criterion may balance these considerations. To see how proportional shortfall[29] purportedly balances these considerations, consider the following graph of Stolk et al. (2004, p. 1100).

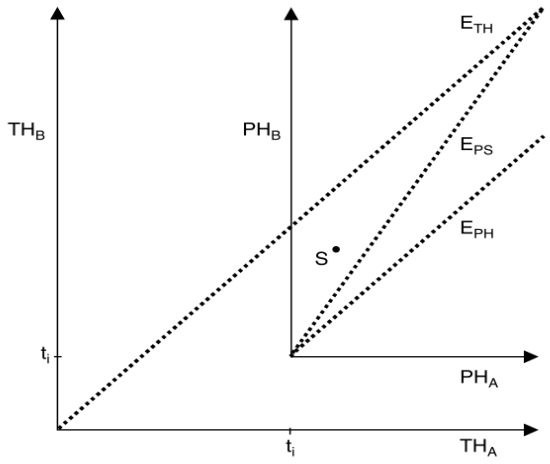

Figure 2: Graphic representation of proportional shortfall, severity of illness and fair innings of individuals A and B suffering from an illness.

The horizontal axis represents the experienced QALYs of individual A and the vertical axis that of individual B. The axis PH_A and PH_B delineate the future health space of A and B at the moment of intervention t_i. Point S represents the final allocation of QALYs in case both individuals do not get any intervention. Assume all other things being equal, a fixed QALY reference level and only one individual can receive the intervention.

According to Stolk et al. (Ibid), the fair innings view dictates that an equal distribution of QALYs exists when A and B are located on the E_{TH} line at any point in time.[30] Furthermore,

[29] As a reminder, proportional shortfall is calculated as:

$$\frac{Remaining\ QALYs\ without\ illness - Remaining\ QALYs\ with\ ilness\ without\ intervention}{Remaining\ QALYs\ without\ illness}$$

[30] More specifically, according to the equal innings view there is an equal distribution of QALYs when both A and B are located on the E_{TH} line in any point in time. Note that Stolk et al. (2004, p. 1100) do not make this specification.

Stolk et al. (Ibid) state that, according to severity of illness[31], an equal distribution of QALYs exists when A and B are located on the $E_{PH\ line}$ from t_i onwards. Finally, according to proportional shortfall, equality exists when both individuals are on the E_{PS} line. With that in mind, consider how proportional shortfall purportedly balances fair innings, i.e. equal innings, with severity of illness with respect to point S. At point S, individual A experienced more QALYs than individual B, therefore, the equal innings view dictates that individual B should receive the treatment. On severity of illness, individual A loses a greater amount of QALYs with no intervention considered from t_i.[32] Therefore, individual A should be prioritised. Proportional shortfall purportedly takes a middle position. From t_i, individual A proportionally loses the greatest expected amount of QALYs compared to B and therefore should receive priority, which, in this case, is similar to severity of illness.[33] To make this purported balance clearer, consider the following numerical example.

Vignette 2: Assume a fixed threshold of 80 QALYs and that you can offer an intervention resulting in a 1 QALY gain in either:

(a) Individual A, 30 years, who experienced 30 QALYs who now suffers from an illness leading him to experience 20 more QALYs after which he dies.

(b) Individual B, 20 years, who experienced 20 QALYs who now suffers from an illness leading him to experience 25 more QALYs after which he dies.

On the equal innings view, individual B should be prioritised as he will, without intervention, experience only 45 out of 80 QALYs whereas individual A 50 out of 80 QALYs. On severity of illness, individual A should be prioritised as he will experience only 20 QALYs in absence of the intervention whereas individual B 25 QALYs. On proportional shortfall, individual A could have expected to experience 50 QALYs but loses 30 QALYs leading to a proportional

[31] Stolk et al. (Ibid) do not specify which operationalisation of severity of illness they have in mind.
[32] Formally, because S is above the E_{PH} line.
[33] Formally, because S is above the E_{PS} line.

shortfall of 0.6.[34] Individual B could have expected to experience 60 QALYs but loses 35 QALYs leading to a proportional shortfall of 0.58.[35] As individual A proportionally loses more QALYs, he receives priority.

3.2.1 Purported Merits of Proportional Shortfall

If indeed proportional shortfall successfully represents an acceptable trade-off between severity of illness and fair innings, it solves Nord's (2005, p. 261) concern regarding how severity of illness should be traded-off against the equal innings view. What is this trade-off exactly? Severity of illness is forward-looking, that is, it considers only present and future QALYs while the fair innings view is backward as well as forward-looking as it considers past, present and future QALYs. Therefore, if policy-makers see merit in both priority-setting criteria, they will have to make a trade-off between their concern for present and future suffering as dictated by severity of illness on the one hand, and their concern with equality in lifetime QALYs as dictated by the equal innings view on the other hand. It is purported that proportional shortfall satisfactorily makes this trade-off (Stolk et al., 2004, p. 1100; ZiN, 2018, p. 8-9).

Another alleged merit of proportional shortfall and one of its original motivations to adopt it is that it is not subject to the objection of age-discrimination (ZiN, 2018, p. 9). To see this consider vignette 3.

Vignette 3: Assume a fixed threshold of 80 QALYs and that you can offer an intervention resulting in a 1 QALY gain in either:

(c) An until now perfectly healthy 20 year old who faces imminent death.

(d) An until now perfectly healthy 60 year old who faces imminent death.

[34] $\frac{50-20}{50} = 0.6$

[35] $\frac{60-25}{60} = 0.58$

On proportional shortfall, both individuals receive equal priority as both their proportional shortfall is equal to one.[36] In general, regardless of their age, individuals receive equal priority if they suffer from an illness which results in an equal proportional QALY loss. Given this, it is said that proportional shortfall prevents age-discrimination. Additionally, **vignette 3** also demonstrates how proportional shortfall purportedly reflects the RR. According to ZiN (Ibid, p. 11), proportional shortfall reflects the RR as it gives the highest priority to anyone facing imminent death regardless of their age.

3.3 Conclusion

The purpose of this chapter was to examine fair innings, severity of illness and the rule of rescue which proportional shortfall purportedly balances and reflects and to criticize ZiN's motivation and description of these concepts. What becomes clear from my discussion is that ZiN's motivation for adopting these concepts is unclear. That is, ZiN repeatedly states that it considers it just when priority-decisions are made based on fair innings, severity of illness and the rule of rescue without specifying the perspective of distributive justice that motivates its claims. Moreover, ZiN insufficiently addresses several technicalities related to severity of illness. This is problematic as the manner in which policy-makers address these questions influences priority decisions based on severity of illness.

In the second section, I explained proportional shortfall in more detail. Proportional shortfall takes a relative perspective by determining individuals' QALY loss due to illness in relative terms. By doing this, it is claimed that proportional shortfall makes a trade-off between fair innings and severity of illness. Moreover, by assigning equal weight to individuals with a similar proportional QALY loss, it reflects the RR in cases of imminent death and it is not subject to the objection of age-discrimination.

[36] $\frac{20-0}{20} = 1, \frac{40-0}{40} = 1$

CHAPTER 4: CRITICIZING PROPORTIONAL SHORTFALL

In **Chapter 3**, I explained proportional shortfall and its underlying ethical considerations in greater detail. In this section, I continue my criticism by scrutinising the priority-setting criterion ZiN (2018) has chosen to adopt, proportional shortfall. This ultimately leads me to reject proportional shortfall as acceptable operationalisation of the necessity criterion.

My rejection is based on four parts. First, I will assess whether fair innings, the rule of rescue and severity of illness are acceptable priority-setting criteria when used independently. That is, I examine their normative and some of their practical shortcomings. I do this to determine whether balancing and combining these concepts has merit. From this examination, I conclude that all three suffer from shortcomings leading me to reject all three as appropriate priority-setting criteria.

Second, I will scrutinise proportional shortfall. Contrary to its advocates' claims, I conclude that proportional shortfall does not adequately reflect fair innings and the rule of rescue. In fact, it goes against fair innings. Moreover, proportional shortfall may be best seen as a distinct operationalisation of severity of illness.

Third, despite proportional shortfall not reflecting the ethical considerations on which it is purportedly based, proportional shortfall could still be judged an acceptable priority-setting criterion. To assess whether this is the case, I will determine whether proportional shortfall addresses and solves the shortcomings to which fair innings, the rule of rescue and the operationalisations of severity of illness are subject to. I conclude that proportional shortfall is unsuccessful in this regard. Moreover, I will show that proportional shortfall's deliberative attempt to avoid age-discrimination leads to priority-setting decisions which go against considered case judgement.

Finally, a last defence advocates could give in favour of proportional shortfall is that it rests on empirical support, as estimated by preference-elicitation studies. However, after reviewing

the relevant empirical evidence I conclude that proportional shortfall does not best align with societal preferences.

However, before offering my criticism, I briefly describe the argumentative strategy which I will employ in this chapter.

4.1 Argumentative Strategy

As I already did in **chapters 1** and **3**, I will make use of hypothetical two-person cases to illustrate shortcomings in fair innings, the rule of rescue and severity of illness. Two-person cases are commonly deployed in healthcare priority-setting literature and relate to the method of reflective equilibrium as I described in **chapter 2** (Herlitz, 2018, p. 520). In such two-person cases, one has to make a priority decision between two individuals who usually differ from each other on one dimension. Although these cases only describe the health situations of two individuals, they can be considered reflective of priority decisions between groups and, subsequently, between interventions (Ibid). Furthermore, I regard priority judgements in these two-person cases as the result of making a considered judgement.[37]

Second, I assume that inequalities in health matter. That is, I take it that policy-makers need to be concerned with maximizing QALYs as well reducing inequalities in QALYs. This position rests on the pluralist egalitarian view as described in **chapter 1** section *1.1.2 A Concern for the Worse Off*. Recall that the pluralist egalitarian view cares about equality as well as maximizing health-related well-being (Gosepath, 2021). On this view, prioritising the worse off is more valuable as it not only improves their situation but also reduces inequality. Many reasons can be put forward as to why equality matters and consequently which individuals can be regarded as worse off. However, throughout my criticism, I do not commit to specific egalitarian reasons as this is not necessary for my criticism. Moreover, I exclusively focus on

[37] As a reminder, see **chapter 2** section *2.3.4 A Response to Objections* for an explanation of considered judgements.

health-related well-being as measured in terms of QALYs. Whether one is allowed to exclusively focus on inequalities in QALYs only in healthcare priority-setting is subject to debate (Brock, 2003; Du Toit and Millum, 2016). As already mentioned in **chapter 3** section *3.1.2 Severity of Illness*, much discussion exists whether direct non-health benefits and indirect benefits should be taken into account. One could for instance argue that policy-makers should not exclusively focus on inequalities in health but should focus on inequalities in well-being generally in priority-setting. As the priority-setting criteria under scrutiny as well as ZiN (2018) exclusively focus on QALYs, I also focus on QALYs as the relevant distribuendum.

4.2 Scrutinising Fair Innings

To recall, the fair innings view aims to equalize lifetime QALYs between individuals with respect to a QALY threshold, i.e. the fair innings. In the following, I will outline three problems that policy-makers need to contend with when adopting the fair innings view: (i) Operationalising and justifying the fair innings threshold, (ii) priority-setting with respect to the fair innings threshold (iii) balancing past with present and future health.

4.2.1 The Fair Innings Threshold

There are three ways to operationalise the fair innings threshold. (a) The threshold could be determined by life expectancy, (b) the threshold could be based on the quality-adjusted life expectancy and (c) the threshold could be determined by the natural life span (Farrant, 2009, p. 53-53; Tsuchiya, 2000, p. 59-60). In the following, I will argue that all three operationalisations lack sound normative justification and cannot be set in a non-arbitrary manner.

First, the original justification for the fair innings threshold in terms of (a) life expectancy was based on the judgement that it is both a tragedy and misfortune when a young person is denied a life-saving intervention and only a misfortune when an old person is denied such an intervention (Harris, 1985). However, concepts such as misfortune and tragedy are inherently

vague and are unable to justify the notion of a threshold, let alone a particular threshold (Rivlin, 2000, p. 6).

Second, the subsequent rephrasing of the fair innings threshold by Williams (1997) that everybody is entitled to a certain number of (b) quality-adjusted life-years does not resolve this issue. One is still left with the question about what constitutes an appropriate quality-adjusted life span.

Moreover, operationalising the threshold in either (a) or (b) is problematic as these vary per birth cohort. Improvements in socio-economic conditions, as well as medical innovations, have increased life expectancies per birth cohort over time. For instance, the average life expectancy for men in the Netherlands in 1981 was 72,71 years and in 2019 80,46 (CBS, 2021). As the fair innings view makes a normative claim on who should be prioritised, Farrant (2009, p. 54) argues that it should be grounded on some fact or facts about people which is stable across people to ensure fairness. The variation in (a) and (b) between birth cohorts does not provide this stability. From a fairness perspective, it is unfair if one were to increase the fair innings threshold for those born later and under better conditions because they have a higher (quality-adjusted) life expectancy. What further complicates this is that (a) and (b) not only differ per birth cohort but also increase over time during a person's lifetime. For those older, the (quality-adjusted) life expectancy is greater than for those younger. Again, it is unfair if one were to increase the threshold for those who have already enjoyed more life-years or healthy life-years. When adjusting for this, one implicitly takes the position that someone who has had more health in the past is entitled to more health in the future (Ottersen, 2013, p. 176). Therefore, operationalising the fair innings threshold in terms of (a) or (b) requires a fixed threshold to ensure fairness and be normatively justifiable, but this threshold cannot be set in a non-arbitrary way.

On the surface, (c), the natural lifespan, seems to be able to provide a non-arbitrary, normatively justifiable fair innings threshold. The notion of natural life span or biographical life span refers to the idea that human beings have a natural finite life span (Farrant, 2009, 54; Tsuchiya, 2000, p. 60). Basing the fair innings threshold on this notion seems to be a non-arbitrary way of doing so as this limit is set by human biology. However, I identify several problems with this approach. First, assuming that an objective natural life span exists, does not necessarily mean that it is unfair when individuals do not reach it. That is, the notion of natural life span may ground the fair innings threshold in a non-arbitrary way, but it cannot justify it. Second, it assumes that each individual has the same natural life span even though it is plausible to assume that, since the biological composition of each individual is different, their natural life span will differ. Third, it is unclear which life span can be considered natural. Evidence indicates that people can live up to approximately 120 years, but this evidence is based on observational data and not on biological evidence indicating that a clear upper limit exists (Farrant, 2009, p. 54). Lastly, the invention of new health interventions might be able to increase the natural life span. If this is indeed the case, the idea of natural life span loses its merit as it would no longer be non-arbitrary but dependent on medical advancement. One would be confronted with the same problem as (a) and (b) as the natural life span would be different between birth cohorts as well.

To sum up, all three operationalisations of the fair innings threshold suffer from similar shortcomings. The choice for any threshold lacks normative justification and the threshold cannot be set in a non-arbitrary manner.

4.2.2 Priority-setting in Relation to the Threshold

For the sake of argument, let us assume that a non-arbitrary normatively justified fair innings threshold in terms of QALYs has been successfully established. Policy-makers now have to decide how to make priority decisions with respect to the threshold. This decision

depends on the type of fair innings view one endorses, the equal innings or sufficient innings view (Nord, 2005, p. 259). As a reminder, the equal innings view says that everybody is entitled to the same number of QALYs throughout their lifetime with respect to some threshold. Therefore, the objective of priority-setting is to equalize lifetime QALYs between individuals. The sufficient innings view states that QALY gains above the threshold should hardly be taken into account or should not count at all.

The sufficient innings view is most faithful to the original fair innings view. As argued by Harris (1985, p. 94), policy-makers should be anti-ageist below the threshold, only when a decision between someone below and someone above the threshold has to be made, the former should be prioritised.[38] However, Bognar (2014, p. 255) identifies a shortcoming with the sufficient innings argument which its advocates need to address. From a fairness perspective, if a person's claim to an intervention diminishes or becomes non-existent when reaching the threshold, then the following question arises (Ibid). Why does a person's claim as he gets closer to reaching the threshold not diminish as well? To illustrate this problem, consider the following.

Vignette 4: Assume a fixed threshold of 80 QALYs and that you can offer an intervention resulting in a 1 QALY gain in either:

(a) A 50-year-old who experienced 50 QALYs facing imminent death.

(b) A 30-year-old who experienced 30 QALYs facing imminent death.

On the sufficient innings view, policy-makers should neither prefer (a) to (b) nor (b) to (a) as both have not reached the threshold. Two defences have been put forward to support this judgement.

The first defence is offered by Harris (1985, p. 92) himself who appeals to the following analogy. Imagine that one mile can be run in seven minutes and two people are allowed to

[38] Assuming all other things being equal.

demonstrate that they can run a mile in that time. However, one runner is given four minutes to run and the other three. As both runners are unable to run the mile in either the four or three minutes, Harris (Ibid) argues that four minutes is not a fairer threshold than three minutes as neither runner can run the mile in seven minutes. In other words, the unfairness to the runner allotted three minutes is not greater than the other.

Bognar (2014, p. 255) rejects this analogy as defence as it merely restates differently that the fair innings is a threshold. More importantly, according to Bognar (Ibid), the runners may not only be concerned about finishing the mile but also about how much distance they have covered. If this is true, the sufficient innings view is wrong as it judges the number of QALYs experienced below the threshold irrelevant when comparing any two individuals below the threshold.

A possibly stronger defence for the sufficient innings view is given by Bognar (Ibid) which he also later rejects. He argues that advocates of sufficient innings could argue that running part of the mile is not of value in itself, finishing the mile is what counts as this is an achievement. When applying this reasoning to priority-setting, advocates could argue that the value of undertaking important life projects is only derived when one completes these projects (Ibid). For instance, when writing a thesis the value of the thesis is only obtained once the thesis is finished and cannot be distributed amongst the various stages of the project. As such, only a complete life as determined by reaching the fair innings threshold is valuable. Those achieving the threshold derived the full value whereas those below have not obtained any value yet.

Now, one can levy many objections against this analogy. For instance, one could reject the assumptions that the value of completing a project is only derived once the project is completed or that life can be regarded as a single projected to be completed. However, even when granting the point that value is derived once something is completed, Bognar (Ibid) levies a strong

objection to this version of the sufficient innings view which its defenders need to contend with. To see this, consider the following.

Vignette 5: Assume a fixed threshold of 80 QALYs and that you can offer an intervention resulting in a 10 QALY gain in either:

(c) A 70-year-old who experienced 70 QALYs facing imminent death.

(d) A 30-year-old who experienced 30 QALYs facing imminent death.

Faced with this situation, Bognar (Ibid) would argue that defenders of the sufficient innings view face a dilemma. In this case, the 70-year-old could appeal to the sufficient innings view by arguing that even though the 30 year old and he are below the threshold, he will be able to reach the threshold when treated, thereby deriving the full value. However, the sufficient innings view would reject this reasoning as it dictates that one should neither prefer (c) nor (d) as they are both below the threshold.

Perhaps this need not be an unsolvable dilemma for the sufficient innings view. Defenders could simply argue that, when all things are equal except for the number of QALYs experienced, no one should be prioritised below the threshold except when a person can reach the threshold when prioritised. However, I argue that adopting this position requires defenders to deal with a problem related to uncertainty. To understand this, consider a slightly adapted version of **vignette 5** where everything else is the same except that the benefit of the intervention to individual (c) is uncertain. That is, there is a 50% chance that the intervention results in a 10 QALY gain and a 50% chance that the intervention has no effect. In this case, adopting the sufficient innings view with the caveat that those below the threshold should be prioritised if that means that they can reach the threshold, leads to a result that goes against considered judgement. On this sufficient innings view, I claim that it follows that (c) should be prioritised because (c) at least has the chance to reach the threshold whereas (d) will never reach the threshold despite the certainty of receiving 10 QALYs. This conclusion, however, would

go against considered judgement in this case as it not only implies that one forgoes a certain 10 QALY gain for an uncertain 10 QALY gain but also seems unfair from the perspective of the 30-year-old who dies at the expense of someone *possibly* achieving the threshold.

The equal innings view is not subject to the above objections as it holds that everybody is entitled to the same number of QALYs over their lifetime with respect to some threshold (Nord, 2005, p. 259). On this view, one could for instance assign more weight to QALY gains to those individuals below and further away from the equal innings threshold. However, the problem I identify with this approach is that, if one is concerned with equalizing lifetime QALYs between individuals, why bother with first establishing a particular QALY threshold and equalizing with respect to that threshold. One can just as well assign more weight to QALY gains to people who experienced fewer QALYs without reference to a threshold which, as shown, is difficult to justify.

One issue not yet discussed for both the sufficient and equal innings view is what policy-makers should do once individuals have surpassed the threshold. It is unclear on both the equal innings and sufficient innings view whether QALY gains for those individuals above the threshold should count only a little or not at all.

4.2.3 Past Health

Let us turn to the issue of past health. There are two issues related to taking past health into account which supporters of the fair innings view and in particular, the equal innings version, have to address.

First, adopting the equal innings view may lead to the prioritisation of a currently slightly ill individual compared to a currently severely ill individual because the former experienced fewer QALYs in the past. An extreme case would be when one individual faces imminent death and another only a slight illness, but the latter is prioritised because he has been severely ill in

the past, causing him to have fewer QALYs over his lifetime.[39] Naturally, whether this represents an acceptable priority decision depends on policy-makers' underlying reason for adopting the equal innings view. When adopting the equal innings view one, by assumption, adopts the perspective that past, present and future QALYs should be valued equally. However, since there are plausible reasons for having a concern with present and future suffering as I demonstrated in **chapter 3** section *3.1.2 Severity of Illness*, I adopt the position that treating past, present and future QALY loss as similar requires additional, explicit justification which the equal innings view does not provide.

Second, in actual priority-setting, it may prove to be difficult in practice, to accurately determine individuals' past health. For instance, it may be costly and time-consuming to obtain information about past health when evaluating an intervention. Although such a practical argument is not morally decisive in adopting the equal innings view, it remains something that policy-makers need to contend with.

To summarize, I demonstrated that policy-makers who adopt the fair innings view are faced with, at least, three problems. First, they need to operationalise and justify a particular fair innings threshold. All three operationalisations discussed are difficult to justify and are impossible to set in a non-arbitrary manner. Second, policy-makers can set priorities with respect to the threshold by either adopting the sufficient or equal innings version of the fair innings view, but, as I have shown, both suffer from shortcomings. Last, the fair innings view, specifically the equal innings version, treats past, present and future health as equally valuable. However, policy-makers may have a justified concern with the present and future when setting priorities. The equal innings view provides no explicit justification for treating past, present and future QALYs similarly. Moreover, there may be practical difficulties when taking past

[39] Assuming the benefit of the intervention to be the same.

health into account. Therefore, without addressing these shortcomings, policy-makers are not justified in adopting either the equal or sufficient innings view as priority-setting criteria.

4.3 Scrutinising the Rule of Rescue

Turning to the rule of rescue (RR), I will argue that the RR should not be used in determining the worse off in healthcare priority-setting. In other words, I completely reject the RR as priority-setting criterion. As a reminder, Mckie and Richardson (2003, p. 2407) refer to the rule of rescue (RR) as "the imperative to rescue identifiable individuals facing avoidable death, without giving too much thought to the opportunity costs of doing so". Schöne-Seifert (2009, p. 423) identifies five key features in cases, outside healthcare priority-setting, in which the RR is usually and rightly invoked:[40]

1. Individuals' identifiability and visibility.
2. The imminence of death.
3. Reasonable chance of effective rescue.
4. Insensitivity to the costs to the rescuers.
5. The exceptionality of the occurrence.

An example of a paradigm case in which these characteristics can be regarded as present is one where miners are trapped due to the collapse of a tunnel.

I claim that although these five features may justifiably trigger the RR in such cases, they are not always present in priority-setting. More importantly, as ZiN is a public body, it should not make priority decisions based on the RR even in priority-setting situations where the above features are deemed present. This is because prioritising based on the RR violates fair, impartial and dispassionate decision-making (Cookson, McCabe and Tsuchiya, 2008, p. 543; Miller, 2017; Schöne-Seifert, 2009, p. 424). Therefore, the RR should not be used in healthcare

[40] Schöne-Seifert (2009, p. 424) states that it is unclear from the literature whether these characteristics are seen as necessary or sufficient to trigger the rule of rescue.

priority-setting. I will argue for this claim by demonstrating that all five characteristics are either not present in priority-setting or, when present, violate fair and impartial decision-making.

First, individuals' identifiability is morally irrelevant in priority-setting even in situations where individuals are identifiable because they face something as severe as death. According to Mckie and Richardson (2003, p. 2415), this violates justice as justice demands that one should not discriminate between individuals on morally irrelevant grounds, where being identifiable cannot be regarded as a morally relevant characteristic in priority-setting. Cookson, McCabe and Tsuchiya (2008, p. 542) take a similar position. They argue that partiality towards identifiable individuals should not figure into priority-setting as this is unfair and discriminates individuals who are not identified. This unfairness is even greater when identifiable individuals are made visible by media coverage (Schöne-Seifert, 2009, p. 425). Indeed, in the Netherlands, patients who faced imminent death have been given "a face" by the media as the case of Pompe and Fabry demonstrate (NOS, 2013). This while others, perhaps also suffering from a severe but not deadly illness, have not been made visible. Thus, being identifiable and being visible in the media are unjust grounds for priority-setting.

Second, at first glance, the presence of imminent death seems to justify not taking opportunity costs in priority-setting into account (Mckie and Richardson, 2003, p. 2408; Schöne-Seifert, 2009, p. 425). According to Schöne-Seifert (2009, p. 425) and Mckie and Richardson (2003, p. 2409), outside priority-setting, this justification rests on the urgency of situations where death is near and the fact that great benefits can be obtained in such situations. To illustrate this with the case of the trapped miners. Each delay in their rescue significantly decreases the chances of their survival. Moreover, except for those who were injured during the accident, when successfully rescued, most miners will return to living their lives in full health. However, I argue that the urgency and benefit in situations that trigger the RR are not present

in priority-setting. First, in priority-setting, there is no sense of said urgency as priority decisions are usually made before individuals need the actual interventions (Schöne-Seifert, 2009, p. 425) Therefore, there is time to calculate costs and benefits, weigh risks and take opportunity costs into account. Moreover, even when the urgency is present, not weighing risks and opportunity costs would violate impartial decision-making because financing a life-saving intervention goes at the expense of other interventions. Second, usually, the life of individuals who suffer from a severe illness can only be extended at reduced quality of life (Ibid). Only in rare cases are individuals restored to full health. This is in stark contrast to the miner situation in which the benefits of saving the miners, in terms of QALYs, are great.

Turning to characteristic three, the reasonable chance of effective rescue. In the miner case, the chances of successfully rescuing them and also in a good state of health are uncertain. Schöne-Seifert (Ibid, p. 427) argues that specifically, this uncertainty triggers the RR because it is felt that the miners have a right to be rescued unless proven that the rescue is a futile exercise. This is contrary to priority-setting, where policy-makers know, albeit imperfectly, the health state of individuals and the health benefits that accrue to individuals receiving an intervention, before deciding to save their lives.

Fourth, in cases outside priority-setting, the RR does not take absolute as well as opportunity costs into account when trying to save those facing imminent death (Ibid, p. 428). As already mentioned, considering the costs of interventions should figure in priority-setting as financing one intervention goes at the expense of another.

Lastly, the last feature of cases outside priority-setting where the RR is invoked, is that these cases do not occur regularly (Ibid). They are exceptional events that often trigger a shock-horror response due to their tragic nature (Mckie and Richardson, 2003, p. 2409; Schöne-Sefeirt, 2009, p. 428). However, regarding cases of imminent death in priority-setting as exceptional and giving life-saving interventions more priority based on this feature, is

problematic. As humans are mortal, everyone will experience a stage where death is imminent and need medical care. Therefore, Cookson, McCabe and Tsuchiya (2008, p. 543) argue that the imminence of death cannot be considered exceptional and should not give rise to special consideration in priority-setting. Doing so could, for instance, lead to the prioritisation of frail elderly people facing imminent death due to old age, over severely ill children although not facing death. To avoid such priority decisions, using the RR in priority-setting requires policy-makers to denote exceptional situations not only in terms of the imminence of death but other factors as well that further restrict the cases where the RR applies. For example, this has been done by the Pharmaceutical Benefits Advisory Committee in Australia which only applies the RR to cases where individuals with a progressive and severe illness face premature death and where the number of individuals suffering from the illness is small (PBAC, 2021). However, I argue that precisely such further restrictions lead to unfair priority-setting as it would imply that some individuals do not receive priority if they happen to suffer from a more common but deadly illness.

Thus, I conclude that the RR should not be used in priority-setting as the features of particular situations that trigger the RR are not always present in priority-setting and, when present, violate principles of dispassionate, fair and impartial priority-setting.

4.4 Scrutinising Severity of Illness

Severity of illness dictates that those individuals who are more severely ill should be considered worse off and be prioritised. Severity of illness has been operationalised in three ways: (1) Present health, (2) prospective health and (3) absolute shortfall (Dolan and Olson, 2001, p. 824; NOU, 2015; p. 2; Norheim et al., 2014, p. 3; Reckers-Droog, van Exel and Brouwer, 2019, p. 1442). In the following, I will demonstrate that all three suffer from shortcomings leading me to reject them as appropriate priority-setting criteria. First, I highlight

problems unique to each operationalisation, then I will discuss the shortcomings which all three are subject to.

4.4.1 Present Health

Present health simply refers to severity of illness measured in QALYs, at the moment when an intervention would be implemented. When only looking at the present health, those individuals who are located lower on the quality-adjusted life-year scale are prioritised. Evidently, only looking at present health in terms of QALYs suffers from a major shortcoming as it overlooks future health prospects. For instance, even though individual X is worse off now, his health prospects in terms of QALYs may be better than that of another individual Y. This is the case when Y suffers from an illness that will become worse as it progresses possibly leading to premature death, whereas X might suffer from a severe illness that improves over time. Given this major shortcoming, I reject present health status as an appropriate operationalisation of severity of illness.

4.4.2 Prospective Health

Contrary to present health status, prospective health does take present and future health prospects into account. Prospective health refers to the number of remaining QALYs in presence of the illness, or the number of QALYs in absence of the intervention (Dolan and Olson, 2001, p. 824; NOU, 2015, p. 3). This operationalisation, therefore, considers the progression and duration of the illness whereby it gives priority to those individuals who face the worst current and future health prospects. Where present health would prioritise individual X, prospective health would prioritise individual Y. Evidently, prospective health leads to the better priority-decision compared to present health as it takes the entire consequence of the illness into account when determining the worse off.

However, prospective health can be criticized on the grounds that it does not account for the considered judgement that one would like to take the future loss of healthy life years into account. To illustrate this, consider vignette 6.

Vignette 6: You can offer an intervention that results in a 1 QALY gain in either:

(e) A 50-year-old with a health prospect of only 3 QALYs.

(f) A 20-year-old with a health prospect of only 3 QALYs.

On prospective health, both individual (e) and (f) receive equal priority as their prospective health is similar. As a tie-breaker, policy-makers could randomize the priority decision. However, instead of randomizing, a morally relevant difference between individual (e) and (f) can be identified which would lead to the prioritisation of (f). That is, a health prospect of 3 QALYs can be considered a greater future health loss for individual (f) than individual (e). This is because one can reasonably expect individual (f) to experience more QALYs were he not ill. Therefore, individual (f) suffers from a greater health loss which makes him worse off. Such a judgement was, for example, made by a working group in Norway tasked with advising the health Minister on priority-setting (NOU, 2015, p. 3). They argued that an equal health prospect between individuals can be regarded as more severe for those individuals further away from the quality-adjusted life expectancy for that patient group (Ibid). Therefore, Norway operationalised severity of illness in terms of absolute shortfall (NOU, 2015, p. 3; Reckers-Droog, van Exel and Brouwer, 2019, p. 1442; Reckers-Droog, van Exel and Brouwer, 2018, p. 2).

4.4.3 Absolute Shortfall

Absolute shortfall does take future health loss into account. Absolute shortfall is operationalised by subtracting the remaining QALYs with an illness in absence of the intervention from the remaining QALYs an individual would have had in absence of the illness (Reckers-Droog, van Exel and Brouwer, 2019, p. 1442). To illustrate this consider again

vignette 6 and assume a reference level of 80 QALYs. In that case, individual (e) has an absolute shortfall of 27 QALYs and individual (f) 57 QALYs, thus individual (f) is prioritised.[41] Absolute shortfall thus accounts for the judgement that healthy life-years lost matter.

However, a shortcoming of absolute shortfall is that it suffers from the same problem as the fair innings view. Similar to fair innings, absolute shortfall relies on a QALY reference level with respect to which individuals' absolute shortfall is calculated. Yet, as demonstrated, determining such a level in a non-arbitrary and normatively justifiable manner is difficult. For instance, the way in which Norway determines the threshold is unfair as it increases the threshold with the age of the patient group for which it evaluates an intervention (NOU, 2015, p. 4).

To recap, up till now, I have shown that each operationalisation of severity of illness suffers from shortcomings that threaten their normative justifiability. I now turn to an issue all three operationalisations are subject to.

4.4.4 General Limitation Severity of Illness

The general limitation of all three operationalisations of severity of illness is that they ignore past health. At first glance, this seems to contradict my criticism of equal innings as I criticized equal innings based on the fact that it values past QALYs similar to present and future QALYs. However, there is no such contradiction. The relevant point I am trying to make is that either valuing past, present and future QALYs the same or differently requires explicit justification. Where fair innings assumes the former, severity assumes the latter by completely ignoring past QALYs, both do this without justification. So, why does past health matter?

First, when assuming all other things to be equal and you have to either prioritize an ill individual who had 20 QALYs in the past or an ill individual who had 30 QALYs, both with identical future health prospects, I regard this difference in past health as morally relevant in

[41] Individual (e): $30 - 3 = 27$, Individual (f) $60 - 3 = 57$.

priority-setting. This can be justified based on my assumed pluralist egalitarian perspective of distributive justice. Although I remained silent as to why inequalities in health matter in section *4.1 Argumentative Strategy*, many different reasons can motivate this perspective. For instance, that individual who experienced fewer QALYs in the past may have had fewer opportunities to pursue its conception of the good life and can therefore be regarded as worse off.

Second, failing to consider past health may lead to a case of double jeopardy (Altmann, 2018, p. 308-309). This refers to the situation where someone will be disadvantaged in the future because they have been disadvantaged in the past (Ibid). According to Altmann (Ibid), these situations can be regarded as unfair and therefore should be avoided. Let me illustrate this with the following example.[42]

Vignette 7: Imagine that you can offer a life-saving intervention that extends the life of the following two individuals by 15 years and it cures the illness that causes death. You can either prioritize:

(g) A 65-year-old who experienced 65 QALYs and who faces instant death.

(h) A 65-year-old who experienced 60 QALYs as he turned blind at the age of 55 and who faces instant death.

By ignoring past health, every operationalisation of severity of illness assigns equal weight to individual (g) and (h). Both face instant death and lose the same number of QALYs in relation to a reference level of 80 QALYs considered from the moment in time the intervention would be implemented. Therefore, as a tie-breaker one may either prioritize one of two individuals at random or prioritize based on a relevant factor on which the two individuals differ. In this case, a relevant difference is the health benefit that would be obtained when treating either individual (g) or (h). As both individuals live for another 15 years, one can see that treating individual (g) results in 15 QALYs and treating individual (h) results in 7.5 QALYs.[43] As ZiN balances a

[42] Example taken from Altmann (2018, p. 306).
[43] Assuming that individual (b)'s blindness persist after him being saved.

concern for justice with efficiency by its adoption of the cost-effectiveness criterion, the efficiency consideration would likely lead to the treatment of individual (g). It is this priority decision based on maximizing QALYs and ignoring past health that would lead to a case of double jeopardy as individual (h)'s disadvantage in the past, i.e. being blind, leads him to be disadvantaged in the present. This is not to say that the maximization of QALYs may sometimes outweigh possible cases of double jeopardy, however, the upshot is that policy-makers, when ignoring past health, cannot account for and weigh cases of double jeopardy.

To summarize, in this section I discussed three common operationalisations of severity of illness and their unique as well as general shortcomings. Given these shortcomings, I conclude that policy-makers are not justified in adopting severity of illness as priority-setting criterion.

4.5 Proportional Shortfall: Accept or Reject?

I have offered a detailed overview of the shortcomings of the three ethical perspectives on which proportional shortfall, purportedly, is based. These shortcomings already indicate that proportional shortfall, by combining fair innings, the RR and severity of illness, rests on questionable theoretical grounds. In this section, I continue by scrutinising proportional shortfall by answering the following two questions: (1) Does proportional shortfall combine and reflect the fair innings view, the rule of rescue and severity of illness? (2) Is proportional shortfall an acceptable priority-setting criterion?

4.5.1 Does Proportional Shortfall Combine Fair Innings, Rule of Rescue and Severity of Illness?

It is purported that proportional shortfall reflects and balances fair innings, the RR and severity of illness[44] (Reckers-Droog, van Exel and Brouwer, 2018, p. 3; Stolk et al., 2002, p. 122; Stolk et al., 2004, p. 1100; Stolk et al., 2005, p. 344; van de Wetering et al., 2013, p. 111; ZiN, 2018, p. 11-13). However, I will argue that proportional shortfall insufficiently does so. I

[44] Specifically, absolute shortfall.

do this by offering the reasons that have been given as to why proportional shortfall reflects and balances the RR, fair innings and severity of illness and then show that this is mistaken.

First, starting with the RR. As shown in **chapter 3** section *3.2.1 Purported Merits of Proportional Shortfall*, proportional shortfall gives equal weight to anyone facing immediate death, regardless of their age. Based on this, it is claimed that proportional shortfall reflects the RR (Stolk et al., 2002, p. 122). While assigning equal weight to everyone facing imminent death might be considered to be in the spirit of the RR, I argue that it does not constitute a correct reflection of the RR. Namely, the RR is appropriately invoked in exceptional cases of imminent death which elicit shock-horror responses where ignoring opportunity costs may be justified (Mckie and Richardson, 2003; Schöne-Seifert, 2009). In my view, if one wants to do justice to the RR in priority-setting, it implies that, rather than subsuming cases of death in a systematic operationalisation of the worse off, cases of death should be given special attention where the usual priority-setting procedures do not apply or may be deviated from. For instance, in those cases, the usual cost-effectiveness considerations may be abandoned. As proportional shortfall does not give special consideration to cases of death, it does not reflect the RR.

Second, let us turn to fair innings. One reason has been given as to why proportional shortfall reflects fair innings. Similar to fair innings, proportional shortfall assumes a QALY threshold which constitutes the fair innings (Stolk et al., 2004, p. 1100). I argue that this reason does not lend support to the claim that proportional shortfall reflects fair innings. Moreover, I will demonstrate that proportional shortfall goes against fair innings. First, the fair innings view presupposes that everybody is entitled to the same number of QALYs over their lifetime with respect to a threshold. However, the mere fact that proportional shortfall assumes a QALY threshold similar to the fair innings view, does not mean that it reflects this underlying consideration. Second, doing justice to the idea that everybody is entitled to the same number of QALYs over their lifetime with respect to a threshold also requires an explicit consideration

of past health. Proportional shortfall completely ignores past health. More problematically, I claim that proportional shortfall goes against the fair innings view. To see this, consider again *figure 2* in **chapter 3**, **3.2 Proportional Shortfall**. On proportional shortfall, equality exists when the relative distance between individual A and B to the common health target is the same. However, it is precisely this objective of equality in relative terms sought by proportional shortfall that violates the objective of the fair innings view. That is, the fair innings view, in particular the equal innings view, aims to equalize individuals' lifetime QALYs with respect to a common health target in absolute terms. In taking a relative, purely forward-looking perspective proportional shortfall abandons the notion that everybody is entitled to the same number of QALYs. Therefore, proportional shortfall does not adequately reflect the fair innings view and, in fact, goes against the objective of the fair innings view.

Finally, rather than reflecting any of the three operationalisation of severity of illness, I believe, similar to others, that proportional shortfall may be best seen as fourth distinct operationalisation of severity of illness (NOU, 2015, p. 3; Sandman and Hofmann, 2018, p. 29). Contrary to present health, prospective health and absolute shortfall, proportional shortfall determines an individual's severity of illness in relative terms instead of absolute terms.

4.5.2 Is Proportional Shortfall an Acceptable Priority-setting Criterion?

Despite the fact that proportional shortfall does not appropriately reflect the ethical considerations which it is purported to, one may still regard proportional shortfall as an acceptable priority-setting criterion. In this section, I will argue that this is not so. I will demonstrate that proportional shortfall does not address any of the shortcomings I identified related to fair innings, the RR and severity of illness. Moreover, proportional shortfall's deliberative objective to avoid age-discrimination leads to priority-setting decisions which go against considered judgement.

Regarding the shortcomings that proportional shortfall could have addressed, I can be brief. First, it assumes similar to fair innings, a QALY reference level. As discussed at length, setting a non-arbitrary normatively justified target is difficult and proportional shortfall fails to do. Second, proportional shortfall fails to weigh past health with present and future health thereby it fails to successfully make a trade-off between severity of illness and fair innings. Explicit justification is required when one adopts the perspective that past health can be ignored. Proportional shortfall does not offer such explicit justification and, similar to severity of illness, completely ignores past health. Moreover, ignoring past health can lead to cases of double jeopardy which is unfair. Third, similar to fair innings, proportional shortfall offers no solution about what policy-makers should do when individuals have surpassed the common health target. It is unclear whether these individuals should receive little priority or no priority at all. Finally, proportional shortfall's deliberate attempt to avoid age-discrimination goes against considered judgement. Let me illustrate this.

Vignette 8: Assume a fixed threshold of 80 QALYs and you can offer an intervention resulting in a 10 QALY gain in either:

(i) A 70-year-old who faces instant death.

(j) A 20-year-old who is severely ill experiencing only 0.1 QALYs each year till he dies at the age of 80.

In this case, proportional shortfall prioritizes individual (i) as his proportional shortfall is equal to one whereas that of individual (j) is equal to 0.9.[45] This decision, however, goes against considered judgement. In this case, I take it that many would prioritize individual (j) as he not only experiences fewer QALYs over his lifetime (i), but he will also lose more QALYs even when ignoring past health. This demonstrates that proportional shortfall's avoidance of age-discrimination severely goes astray. This is especially problematic as it is unclear which

[45] Individual (i): $\frac{10-0}{10} = 1$, individual (j): $\frac{60-6}{60} = 0.9$.

problem related to age-discrimination proportional shortfall exactly tries to solve. Recall from **chapter 3** section *3.1.2 Severity of Illness*, that a priority-setting criterion may be subject to the objection of age-discrimination if it prioritizes individuals because they are younger than others. However, any of the priority-setting criteria discussed, do not prioritize on this basis. Even though fair innings and absolute shortfall in most cases happen to prioritize younger individuals as these have, on average, experienced fewer QALYs and are further away from a QALY threshold, it is not by virtue of their age that they receive priority when applying these priority-setting criteria. Rather, in many cases, age is simply highly correlated with the number of QALYs individuals have experienced or can expect to experience in the future. However, this does not amount to age-discrimination as both fair innings and absolute shortfall do not view age as a morally relevant characteristic for priority-setting.

From this discussion, I conclude that proportional shortfall should be rejected as priority-setting criterion. First, it does not satisfactorily reflect fair innings and the RR. Second, it is subject to the same shortcomings of fair innings and severity of illness. Lastly, its objective to avoid a mischaracterized problem of age-discrimination leads to unacceptable priority-decisions.

4.6 Empirical Support for Proportional Shortfall

As proportional shortfall lacks theoretical justification, defenders of proportional shortfall could still argue that it does rest on empirical support. In this section, I will refute this claim. I will show that proportional shortfall does not best reflect individuals' distributional preferences regarding priority-setting criteria as examined in the following preference-elicitation studies.

Stolk, Pickee, Ament and Busschbach (2005) asked 25 health science students, 24 health researchers and 17 health policy-makers (N = 65) in the Netherlands, to rank-order 10 different health conditions using a pairwise comparison technique. In each comparison, the research subjects needed to indicate which patient should receive treatment and thereby be restored to

full health. From the results of these pairwise comparisons, Stolk et al. (2005, p. 350-351) constructed a priority-list and compared this to priority-lists based on (1) the fair innings view approximated by QALYs foregone given a predetermined age-related target and assuming equality in past health, (2) severity of illness in terms of prospective health and (3) proportional shortfall. Stolk et al.'s (Ibid, p. 353-354) findings indicate that the observed priority-list was best predicted by the priority-list based on fair innings, followed by proportional shortfall and severity of illness.

In a second study by Olsen (2013), 503 adults representative of the Norwegian population also had to make pairwise choices by prioritising patients who differed in terms of age, remaining life-time in absence of treatment and increase in lifetime with treatment. His findings indicate that the research subjects preferred fair innings over prospective health, where both fair innings and prospective health were measured in life years and not adjusted for quality of life (Ibid, p. 1063-1064). Furthermore, Olsen (Ibid, p. 1065) concluded that the research subjects valued absolute rather than relative health loss, indicating a lack of support for proportional shortfall.

The inability of proportional shortfall to explain distributional preferences has been further confirmed by Richardson, Iezzi, Maxwell and Chen (2018) in a representative sample of 606 Australian adults. The research subjects had to allocate 100 votes between a standard scenario and 13 other scenarios in pairwise comparisons (Ibid, 797). The 13 scenarios differed in terms of the life-year gain due to treatment, age, years until death without treatment and the age of death with and without treatment (Ibid, p. 798). Based on their findings, Richardson et al. (2018) stated that proportional shortfall is less able to explain societal preferences compared to, for instance, fair innings and in some scenarios, proportional shortfall even suggested a prioritisation of patients strongly rejected by the research subjects. Richardson et al. (2018) concluded that proportional shortfall is unlikely to explain distributional preferences.

Unlike the previous studies, Reckers-Droog, van Exel and Brouwer (2019, p. 1443) conducted a discrete-choice and person-trade-off experiment to investigate the relative strength of societal preferences for age and severity levels measured by disease-related QALY loss. In a Dutch population of 1014 adults, Reckers-Droog, van Exel and Brouwer (Ibid) let their research subjects' indicate which group, A or B, they prioritised given different severity levels while keeping age constant and vice versa. When both groups differed either in terms of age or severity, on average, most research subjects prioritised that group with a higher severity level or lower age. However, when both severity and age differed between both groups, on average, more priority was given to that group with younger age levels regardless of the level of severity.

Furthermore, they found that severity, as measured by absolute shortfall, prospective health and proportional shortfall, were consistent with societal preferences when patients differed in terms of severity of illness levels only. When patients differed both in terms of age and severity of illness levels, absolute shortfall was most consistent with societal preferences followed by proportional shortfall and prospective health (Ibid, p. 1447). According to Reckers-Droog, van Exel and Brouwer (Ibid), these findings are consistent with those of Stolk et al. (2005).

Now, one should be careful when interpreting the results of these preference-elicitation studies. First, they may suffer from the methodological shortcomings outlined in **chapter 2** which threatens the normative conclusions that can be derived from their results. Second, only two out of the four studies reviewed were conducted in the Netherlands. As it is likely that different societies have different distributional preferences regarding priority-setting decisions, one cannot assume that preferences in one society are similar to that of another. Nonetheless, I believe that one can draw the following conclusion. There exists evidence that proportional shortfall does not best align with societal preferences as demonstrated by preference-elicitation studies.

4.7 Conclusion

In this chapter, I scrutinised proportional shortfall as well as the three underlying ethical considerations on which it is based. I identified several shortcomings related to fair innings, the rule of rescue and severity of illness. This led me to reject them as priority-setting criteria and indicates that combining them may not have any merit.

Then, I continued by scrutinising proportional shortfall. First, I assessed to what extent proportional shortfall reflects fair innings, the RR and severity of illness. I argued that proportional shortfall does not reflect the RR and fair innings and, in fact, goes against the objective of the latter. Moreover, proportional shortfall can be seen as a fourth operationalisation of severity of illness. Second, I examined whether proportional shortfall addresses the normative shortcomings of fair innings and severity of illness and concluded that it does not. More problematically, proportional shortfall suffers from its unique shortcoming as its deliberative avoidance of age-discrimination leads to priority-setting outcomes which go against considered judgement.

In the last section, I reviewed empirical evidence regarding the support for proportional shortfall as investigated in preference-elicitation studies. These studies indicate that proportional shortfall does not best align with societal preferences.

Therefore, I conclude that proportional shortfall does not constitute an acceptable operationalisation of the necessity criterion and ZiN should rethink the manner in which it wants to incorporate a concern for the worse off in evaluating the eligibility of healthcare interventions for the basic health insurance package.

CONCLUSION

The Covid-19 pandemic has demonstrated the importance of a well-functioning healthcare system. Although it may be impossible to be entirely prepared for such a rare event, it should at least be possible for societies to ensure that their healthcare systems are functioning well under normal circumstances thereby possibly minimizing a pandemic's negative effect on medical care. One way of doing this is to adequately deal with a problem all societies need to contend with, namely, the prioritisation of healthcare interventions. Given the existence of limited financial and non-financial resources, interventions need to be prioritised efficiently and fairly.

This thesis aimed to critically examine the prioritisation of healthcare interventions as done by the Dutch health institute (ZiN). ZiN advises the Dutch Minster which interventions should be included in the basic health insurance package, collectively financed by all Dutch citizens. When considering the eligibility of an intervention, ZiN makes use of priority-setting criteria to guide its evaluation and recommendation. In this thesis, I have been concerned with two aspects of Dutch priority-setting. First, I scrutinized ZiN's claim that public support for the priority-setting criteria is important as this makes the content of the basic health insurance substantively just. Second, I critically analysed ZiN's adoption of proportional shortfall to integrate a concern for the worse off in its priority decisions. On proportional shortfall, those interventions that treat individuals who proportionally stand to lose the greatest number of QALYs should be prioritised. From my analysis, I concluded that (1) the public should participate in determining the priority-setting criteria which exceeds their moral right to vote in a liberal democracy and (2) proportional shortfall should be rejected as it does not rest on sound theoretical justification.

In **chapter 1**, I provided the contextual background for my thesis. I discussed priority-setting from the perspective of distributive justice. Furthermore, I gave an overview of the

Dutch healthcare system to understand the context in which priority decisions are made. Moreover, I discussed the necessity criterion and the resulting discussions about its definition and operationalisation that ultimately led to the adoption of proportional shortfall. In the final section, I set the stage for the following chapters by outlining the two problems I identified with Dutch priority-setting.

In **Chapter 2**, I presented my first argument. I argued that the public should participate in determining the priority-setting criteria although not for ZiN's stated reason that it makes the content of the basic health insurance substantively just. Instead, I argued that (1) the public should participate because they have a moral right to participate which exceeds their right to vote, (2) public participation increases the legitimacy of priority-setting criteria and (3) public participation has beneficial instrumental effects. Moreover, I made a positive contribution with a specific suggestion for public participation when I proposed that the public should participate deliberately by employing the method of reflective equilibrium.

I continued in **chapter 3** by examining proportional shortfall in greater detail. I discussed the theoretical descriptions of the fair innings view, the rule of rescue and severity of illness and related these descriptions to ZiN's understanding and motivation for adopting these concepts. Moreover, I also examined proportional shortfall and its purported merits in detail. By taking a relative perspective, advocates claim that it makes a trade-off between severity of illness and the fair innings view and it prevents age-discrimination as individuals with the same relative QALY loss receive equal priority.

My detailed discussion of fair innings, the rule of rescue and severity of illness allowed me to extensively scrutinize proportional shortfall in **chapter 4**. In this chapter, I rejected proportional shortfall because of four reasons. First, the three ethical concepts on which it is based, suffer from serious shortcomings which led me to reject them as appropriate priority-setting criteria. Second, I demonstrated that, contrary to its proponents' claims, proportional

shortfall does not adequately balance and reflect fair innings, the rule of rescue and severity of illness. Third, despite proportional shortfall not reflecting the above principles, one could argue that it still has merit. However, I also rejected this as proportional shortfall does not address any of the normative shortcomings I identified with fair innings, the rule of rescue and severity of illness and because its deliberative avoidance of age-discrimination leads to priority decisions that go against considered judgement. Finally, my review of the relevant empirical studies shows that proportional shortfall does not best align with people's distributive preferences.

Although this thesis comprehensively scrutinized Dutch priority-setting and made a positive contribution by making a suggestion for public participation, one limitation and topic for future research remains. Namely, I did make a recommendation as to which priority-setting criterion should replace proportional shortfall. However, I can offer a brief suggestion in this regard. From my adopted pluralist egalitarian perspective, I believe that ZiN needs to be concerned with equalizing lifetime QALYs between individuals. At the same time, I recognize that ZiN may have a justifiable concern with severe present and future suffering. This is because ZiN not only aims to ensure that the basic health insurance package is substantively just, but also that it reflects solidarity between Dutch citizens. To safeguard this solidarity, I believe that ZiN should place special weight on present and future health loss as people not only have bias towards personal future suffering but are also affected by the suffering of others when sympathetically taking up each others' positions.

Therefore, a priority-setting criterion should balance these two objectives. This requires that a priority-setting criterion needs to take past, present and future QALY loss into account while simultaneously placing more weight on present and future QALY loss. One solution could be to assign somewhat more weight to QALY losses in the present and the future but possible other alternatives exist as well. I will explore and make a specific suggestion for such a priority-setting criterion in a policy-report that is forthcoming.

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