Priority Setting: Towards a Dutch Financial Pandemic?

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Content

Introduction

If you wait long enough, a problem will simply disappear. Or, on the contrary, it will present itself. Although numerous articles have pointed out the lack of a workable or generally accepted value framework for setting priorities, a solid substantive discussion on this seemed to have been lacking in recent years. Then suddenly there is a pandemic and setting priorities becomes a hot topic.

In the Netherlands, terms such as 'dry wood' were used for the over-80s to indicate that young people should have priority when ICU capacity was limited. Discussions about who should be vaccinated first, either the elderly because of their vulnerability or young people because of the restrictions that hinder their development and happiness in life.

To have a well-considered, nuanced, meaningful debate on prioritisation, the last thing that is needed is urgency.[1] The subject should have been on the political and societal agenda for a long time. Priority setting should have been discussed publicly, or not? Because of Corona, it suddenly appeared on the agenda with countless overheated and unsubstantiated debates as a result. The assessment frameworks were not always clear, nor who had been consulted about them.

It is time to put the subject of prioritisation on the agenda and to shed light on it from several angles so that it will at least come to everyone's attention when the crises have been calmed down. However, the aim of this essay is not to reflect upon the decision-making process in the Netherlands during the ongoing Covid pandemic. The goal is to examine prioritisation in Dutch healthcare from a broader perspective, specifically with the knowledge that Dutch healthcare[2] will soon become unaffordable. The main question addressed in this essay is as follows: **Should the public be involved in the priority setting?** Since an ethical approach is closely linked to its application in practice, it is important to base it on an adequate description of the current situation.

[1] Raad voor Volksgezondheid en Zorg, 'Rechtvaardige Selectie Bij Een Pandemie', in *Signalering Ethiek en Gezondheid 2012/3,* ed. by Gezondheidsraad/Raad voor de Volksgezondheid en Zorg (Den Haag Centrum voor Ethiek en Gezondheid, 2012). The author writes this essay in 2021, in the midst of the Covid-19 pandemic, and is astonished to discover this very thoughtful 'signal' on fair selection. It addresses the idea that both distributive justice and procedural justice need to be considered before an actual crisis occurs. Astonished as no reference was ever made to this advice during the Covid crisis, to the knowledge of the author.

[2] The terms 'care' and 'healthcare' will be used alternately and interchangeably, as synonyms of each other. Only when a distinction is made between 'care' and 'cure', this will be mentioned explicitly.

The Dutch Healthcare System

For years in a row the Dutch Healthcare system is ranking among the top three European healthcare systems as the yearly 'Euro Health Consumer Index' reports indicate.[3] The latest report covered forty-eight performance indicators and included thirty-five countries.[4] The Netherlands performs remarkably on two indicators of which one is the gatekeeper position of the general practitioner with regard to the access to specialists and the other one being infant mortality.[5] Although the various 'Euro Health Consumer Index' reports identify this gatekeeper system as a negative element, it is also invariably hinted that this limitation may not be a 'despite' but perhaps a 'thanks to' reason for the excellence of the Dutch system over others. The second indicator, the relatively high rates of infant mortality are often attributed to a typically Dutch phenomenon: home births and the lack of adequate care when complications occur. Nonetheless, the quality of the Dutch healthcare is outstanding.

Simultaneously, the Dutch system is also considered as one the most expensive ones. The United States has long been at the top of the list of those who spend the most on healthcare.[6] This while the quality of its healthcare is often criticised. Apparently, the American healthcare system is so expensive due to its inefficiency and lack of transparency. The high costs lead to patients not seeking care, which in turn creates a vicious circle, as avoiding care can lead to poorer health outcomes, which in turn cause higher healthcare costs.[7] Depending on what is

[3] Arne Björnberg, 'Euro Health Consumer Index 2018', in *Euro Health Consumer Index*, ed. by Health Consumer Powerhouse (Marseillan, 2019); Arne Björnberg, 'Euro Health Consumer Index 2017', ed. by Health Consumer Powerhouse (2018), p. 100; Arne Björnberg, 'Euro Health Consumer Index 2016', ed. by Health Consumer Powerhouse (2017), p. 100; Arne Björnberg, 'Euro Health Consumer Index 2015', ed. by Health Consumer Powerhouse (2016), p. 117.

[4] Björnberg (2018), P. 26; (2019), p. 25

[5] The first indicator, concerns the position of the general practitioner (GP). The Netherlands knows a so-called GP system making the GP responsible for referrals to specialists. In other words, the GP is the gatekeeper to specialists. In most other (European) countries patients have direct access to specialists. The Dutch boundaries to specialists frequently cause misunderstanding among temporary or less temporary visitors such as foreign students, expats or migrants.

[6] Roosa Tikkanen, 'Multinational Comparisons of Health Systems Data, 2017', in *Multinational Comparisons of Health Systems Data*, ed. by The Commonwealth Fund (Washington: The Commonwealth Fund, 2017); Roosa Tikkanen, 'Multinational Comparisons of Health Systems Data, 2018', in *Multinational Comparisons of Health Systems Data*, ed. by The Commonwealth Fund (Washington: The Commonwealth Fund, 2018); Roosa Tikkanen, 'Multinational Comparisons of Health Systems Data, 2019', in *Multinational comparisons of health systems data*, ed. by The Commonwealth Fund (Washington: The Commonwealth Fund, 2019).

[7] Investopedia, 'What Country Spends the Most on Healthcare?', in *Economy*, (2020). <https://www.investopedia.com/ask/answers/020915/what-country-spends-most-healthcare.asp> [27 April 2021]

taken into account, the Dutch healthcare system is the eight most expensive in the World.[8,9] For years, at least in 1970, 1985 and even in 2000, the Netherlands held the tenth spot. Since then, there has been a steady rise: in 2005 to ninth place and, as mentioned above, now eighth.[10] This increase in expenditure is a source of concern. To say the least. Some facts about the Dutch healthcare system may elucidate this.

The general image that exists about the Dutch healthcare sector does not entirely match reality. Zorgwijzer has listed the seven biggest misconceptions.[11] First of all, there is the widely held idea that the government systematically cuts spending. A quick glance at the OECD statistics shows that this is categorically not the case.

Secondly, there is a firm belief that more and more people are uninsured or do not pay their health insurance or pay it too late. Both the number of uninsured and the number of defaulters is falling steadily. In the first case, a decrease of more than half can be seen, in the second case of more than thirty-seven percent. Both decreases reflect the state of affairs in 2020 compared to figures from 2011.[12] The author of the seven misconceptions refers also to the above mentioned 'Euro Health Consumer Index' to underpin the quality of the Dutch healthcare system. Hence no repetition of this substantiation is made.

Three out of the other four misconceptions deal with money issues. People tend to think that insurance companies earn extravagantly on the Dutch premium payer. Again, this is not the case as ninety-seven per cent of the premium is spent on healthcare. The insurance companies spend around two and a half per cent on overhead and labour costs. They are not allowed to make a profit and if they do make a profit, they have to reinvest it in healthcare.

Related to this point, misconception five, is the fact that insurance companies have high financial reserves. This is due to European legislation, hence obligatory.

Another money-related misconception, handles the wages of Dutch healthcare employees. It is stated that the Dutch healthcare staff earns specifically less than elsewhere.

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[8] OECD, 'Focus on Public Funding of Health Care', ed. by OECD Health Statistics (Paris: OECD Publishing, 2020). Although not all countries are members of the OECD (e.g. China, India and Russia), the health statistics include their statistics since 2000. OECD, Better Policies for Better Lives, 'Oecd Home About', (Paris: OECD 2021). <https://www.oecd.org/about/> [27 April 2021].

[9] OECD Stat, 'Health Expenditure and Financing', (Paris: OECD 2021). The OECD has a database in which the figures of expenses and costs of the different health systems can be found. In this case is looked at the governance/compulsory schemes. The Netherlands occupies an eighth place in 2019 whereas this was a tenth in 2010. When all schemes are included, including the voluntary health care payment schemes and the household out-of-pocket payment schemes, the Netherlands ranks thirteen.
<https://stats.oecd.org/Index.aspx?DataSetCode=SHA> [27 April 2021].

[10] OECD Stat.

[11] Koen Kuijper, '7 Misvattingen over Ons Zorgstelsel', ed. by Zorgwijzer (Barendrecht: Zorgwijzer, 2020).

[12] Zorgwijzer, 'Cijfers Zorgverzekering', ed. by Zorgwijzer (Barendrecht: Zorgwijzer, 2020).

Figures from the OED countervail this 'fact'. GP's, specialists and nurses, they all earn above the average listed OECD wage.[13]

A yearly research from Motivaction commissioned by the 'Autoriteit Consument & Markt' (ACM),[14] makes it clear that a large majority of the population is reasonably to highly satisfied with their healthcare provider, and thus with the healthcare system as it is currently conceived.

It may be concluded that although the Dutch healthcare system belongs to the most expensive ones in the world, it is certainly not the worst in the world. On the contrary, it ranks by far amongst the best in the world. As the above made clear, it is considered of a very high standard, although quite some Dutch people seem not to be aware of this, take it for granted, or have considerable misunderstandings about it. Nevertheless, now that most of the misconceptions have been cleared up, the affordability of the system remains the main concern. In other words, the predictions that Dutch healthcare will become twice as expensive within twenty years hang like dark clouds over the Dutch head.[15] The question arises of how this will affect issues of prioritisation. By looking at this issue from an ethical stance, a deliberate dialogue can be established.

Priority Setting: Public Engagement and Resources

Two aspects of the discussion on prioritisation will be examined. The first is the debate on resources, the second is the debate on public involvement. Although they are closely intertwined, an attempt will be made to discuss them first separately and then, at some point, to link them together again. Indeed, purely economic considerations will not, cannot and must not suffice to secure public support for complex decision-making issues such as the setting of priorities. Nor will it answer the ethical question that is at the core of this essay.

[13] OECD, *Health at a Glance 2019,* (2019), p. 177 depicts the ratio to average wages of GOP's and specialists, p. 181, the ratio to averaged wages of nurses.

[14] Rebecca Van der Grient and Cecilia Keuchenius, 'Consumentenonderzoek Zorgverzekeringsmarkt 2019', in *Consumentenonderzoek Zorgverzekeringsmarkt,* ed. by Motivaction Research & Strategy (Amsterdam: Motivaction Research & Strategy, 2019); Rebecca Van der Grient and André Kamphuis, 'Consumentenonderzoek Zorgverzekeringsmarkt 2019', in *Consumentenonderzoek Zorgverzekeringsmarkt,* ed. by Motivaction Research & Strategy (Amsterdam: Motivaction Research & Strategy, 2020).

[15] RIVM, 'Trendscenario: Zorguitgaven. Hoe Ontwikkelen Zich De Zoruitgaven in De Toekomst?', (RIVM, 2018). The doubling of expenditure is from the expenditure in 2015. This means an annual growth rate of almost three per cent.

Resources

The plea for a public discussion on prioritisation in the light of a fast-increasing scarcity of resources, is certainly not from yesterday. To say the least. Professor Leenen started this discussion in the 1980s.[16] The priority setting debate in the Netherlands was instigated by the discussion of what would be included and what not in the insurance packages.[17] Already back in 1991, the Netherlands installed the Commission Dunning to study methods and principles of priority setting, resulting in the report 'Kiezen en Delen' [Choosing and Sharing].[18] The report addresses the issues of choice, demarcation and priority that arise when it comes to the fairest possible allocation of scarce resources in healthcare. In addition to the pressing economic issue, social, ethical and legal aspects come into play in an increasingly complex society. Furthermore, to developing various strategies to support the decision-making process at the various levels, the aim was also to instigate a public debate on these complex issues.[19]

Generally spoken, the scarcity problem arises at three levels: micro-, meso-, and macro. The microlevel concerns the individual level of care with regard to patients and caregivers. The mesolevel deals with the distribution of resources to the various sectors and institutions such as hospitals, elderly care institutes, mental healthcare institutes, etc. At the third level, the macrolevel, the scarcity issue is primarily a political problem of priority setting. Here 'political' refers not just to a government or public authority issue, as Leenen subtly implies, but rather to a social issue.[20] The focus in this essay is on the macrolevel. The Dunning commission departed from the definition of health as 'the capacity to function normally in society', and decided that a 'community-oriented' approach would be the most suitable one to make considerations of what is necessary care.[21] According to Ten Have, Ter Meulen & Van Leeuwen[22] the importance

[16] H.D.C. Roscam Abbing, 'Kiezen En Delen; Rapport Van De Commissie Keuzen in De Zorg (Commissie-Dunning)', *Nederlands Tijdschrift voor Geneeskunde*, 135 (1991).
[17] Lindsay M. Sabik and Reidar K. Lie, 'Priority Setting in Health Care: Lessons from the Experiences of Eight Countries', *International Journal for equity in health*, 7 (2008), 1-13.
[18] Commissie Keuzen in de Zorg, 'Kiezen En Delen. Advies in Hoofdzaken', (Rijswijk: Ministerie van Welzijn, Volksgezondheid en Cultuur, 1991).
[19] Roscam Abbing.
[20] H.J.J. Leenen, 'Verdeling Van De Schaarse Middelen in De Gezondheidszorg', *Nederlands Tijdschrift voor Geneeskunde*, 135 (1991), 904-908. In this article Leenen provides some figures which, for the sake of comparability later on, will be expressed in percentages. In 1963 the expenditures on healthcare amounted to 4.3 % of Gross National Product (GNP). By 1989, this had risen to 9.4% GNP. OECD statistics provides figures expressed in GDP (Gross Domestic Product). The first figures date from 1972, where the Dutch healthcare expenditure was 5.58% of GDP, and in 1989, 6.83%. In 2019 this has increased to 9.96% of GDP.
[21] Henk A.M.J. Ten Have, Ruud H.J. Ter Meulen, and Evelien Van Leeuwen, *Medische Ethiek*, vierde herziene druk, edn (Houten Bohn Stafleu Van Loghum, 2013), pp. 128-130. The other two approaches, i.e. individual and professional, were for various reasons not considered useful in determining what should be considered necessary at the macrolevel.
[22] Ten Have, Ter Meulen, and Van Leeuwen, pp. 117-118.

of a description of health is important when it comes to scarcity of resources, and in particular when it comes to necessary care. Ten Have defines necessary care as the care that a society should minimally guarantee to its population and that serves as a starting point in the decision-making process about the distribution of these scarce resources.[23] The first criterium in what became known as the 'Funnel of Dunning' was the necessity or necessary care aspect. The other three criteria or sieves are effectiveness, efficiency, and the self-pay aspect, also described as own responsibility. The sieve 'necessity' proved to be complex to operationalise and did not take into account emotional or ethical aspects, and was eventually replaced the 'disease burden' criterium.[24,25]

Taking a step forward in time, in 2006 another advisory report was produced on what criteria should be used to determine what should be financed from the collective resources. Broadly speaking, the same criteria emerge, with the understanding that they should not be applied sequentially but in conjunction with each other. The operationalisation of 'necessity' as 'disease burden' indicates that this has been given a normative interpretation, which implies that the criteria must be fair.[26] What constitutes justice is open to various interpretations and will be discussed below. Solidarity, the report states, is related to Dunning's fourth criterion: what one can pay oneself, one should pay oneself.[27] The Netherlands applies the principle of solidarity so that everyone has equal access to necessary or basic care.[28] It's 'the 'moral infrastructure' of the Dutch welfare state according to Van der Aa and others.[29] Dunning's 'Funnel' never made it into its original form and mode of operation. There is a certain consensus about the underlying criteria, but how to shape and embed them remains unanswered in the report 'Zinnige en Duurzame Zorg' [Sensible and Sustainable Healthcare].[30]

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[23] Ten Have, Ter Meulen, and Van Leeuwen, p.128.

[24] Elly Stolk and others, 'Uitwerking Criteria Noodzakelijkheid, Eigen Rekening En Verantwoording En Lifestyle', (Rotterdam: Institute for Medical Technology Assessment (iMTA), 2001). It would be going too far to go into the substantiation and further elaboration of this fifth criterion here. The iMTA report from 2001 discusses this in detail. The report defines disease burden as 'the average quality of life of patients with a certain indication during the remaining life expectancy that patients in this group would have without the condition', p.3.

[25] M.J. Poley and others, 'Ziektelast Als Uitwerking Van Het Criterium 'noodzakelijkheid' bij Het Maken Van Keuzen in De Zorg', *Nederlands Tijdschrift voor Geneeskunde*, 146 (2002). Disease burden is defined as 'the percentage of remaining health that a patient is expected to lose if his or her condition is not treated. Health is expressed in quality of life-adjusted life years (QALYs)', p. 2513.

[26] Raad voor de Volksgezondheid en Zorg, 'Zinnige En Duurzame Zorg', (Zoetermeer: Raad voor de Volksgezondheid en Zorg, 2006), p. 6.

[27] Raad voor de Volksgezondheid en Zorg, p. 20.

[28] Ten Have, Ter Meulen, and Van Leeuwen. The authors define solidarity as the subordination of one's own interests to those of the community in the society or group to which one belongs, p.130.

[29] Maartje J. Van der Aa and others, 'Solidarity in Insuring Financial Risks of Illness: A Comparison of the Impact of Dutch Policy Reforms in Health Insurance and Disability Insurance since the 1980s', *Journal of Comparative Policy Analysis: Research and Practice*, 21 (2019), 199-215 (p. 212).

[30] Raad voor de Volksgezondheid en Zorg. In 2010 Henri Plagge and Michael Dutrée state that Dunning's 'Funnel' and the report of the commission has not lost any of its topicality and should be consulted if only for inspiration.

A new report was published in November 2020. This time the title sounds 'Samenwerken aan passende zorg: de toekomst is nú' [Working Together for Appropriate Care: The Future is Now].[31] It sums up that the healthcare in the Netherlands belongs to the best in the world; that it also is one of the most expensive ones, and rapidly becomes even more expensive. It adds that the system is built on solidarity. So far nothing new. It continues that choices have to be made, change is needed, otherwise the borders are reached and the system becomes unaffordable. The report is replete with the word ' together'. A collaborative effort is needed from government, the healthcare sector, health insurers, in short, all public and private stakeholders involved to find appropriate solutions. The tenet of the advisory report is to 'set in motion a process towards the realization of preconditions for the provision of appropriate care that adds value'.[32] Thirty years after the Dunning report, it seems that the Dutch are still in the phase of signaling the problem and giving advice. It does seem clear, however, that it is a joint problem that requires a joint solution. What does this mean for public involvement?

Public Engagement

Also at an early stage, the aforementioned professor Leenen mentioned the ethical side of the scarcity problem in relation to prioritisation.[33,34] He further pointed out that fair distribution also requires population support. This is a recurring element, but there is no formal involvement of the same population, as the scoping review[35] by Mitton and others[36] shows. They observed that much of the existing (academic) literature on public engagement has been primarily

H.W.M. Plagge and M.A. Dutrée, 'Haal Trechter Van Dunning Uit De La', in *Medisch Contact*, (Utrecht: Medisch Contact, 2010), p. 4.

[31] Zorginstituut Nederland and Nederlandse Zorgautoriteit (NZa), 'Samenwerken Aan Passende Zorg: De Toekomst Is Nú. Actieplan Voor Het Behoud Van Goed Een Toegankelijke Gezondheidszorg', (Diemen: Zorginstituut Nederland & Nederlandse Zorgautoriteit (NZa), 2020).

[32] Zorginstituut Nederland and Nederlandse Zorgautoriteit (NZa), p.7

[33] H. J. J. Leenen, 'Verdeling Van De Schaarse Middelen in De Gezondheidszorg, Prioriteiten En Het Gelijkheidsbeginsel', *Tijdschrift voor Gezondheidsrecht*, 14 (1990).

[34] Leenen. Interesting is his following remark: After all, it is not a foregone conclusion that every perceived health problem justifies an ethical claim on society and that every ethically defensible claim must also lead to a legal right, p.904 [Direct translation by the author].

[35] Scoping reviews differ from the known systematic literature reviews. The general purpose of a scoping review is to identify and map of the available research evidence. They often precede systematic reviews when, for example, it is not yet clear what more specific questions can be asked. It is used to inform practitioners in the field about types of evidence that may appeal or can be useful to them and the ways the research has been conducted. Zachary Munn and others, 'Systematic Review or Scoping Review? Guidance for Authors When Choosing between a Systematic or Scoping Review Approach', *BMC medical research methodology*, 18 (2018), 1-7; Sucharew H. and Maurizio Macaluso, 'Methods for Research Evidence Synthesis. The Scoping Review Approach', *Journal of Hospital Medicin*, (2019), 416-418.

[36] Craig Mitton and others, 'Public Participation in Health Care Priority Setting: A Scoping Review', *Health policy*, 91 (2009), 219-228.

conceptual, theoretical or advocacy-oriented, and less on empirical case studies, although the latter was increasing.[37] According to them policy makers are confronted with increasing demands to involve a variety of stakeholders in the debate on priority setting, while on the other hand there is a lack of clear guidance on how to do this.[38] While they remark an increase in involving the public, they observe as well that formal evaluations of this engagement, whenever they do take place, rarely occur. In addition, no effort is made to show how acquired public opinions are taken into account in the decision-making on the priority setting. Their approach is particularly interesting as they do not confine their review on what is known in the health sector but look outwards at other public domains where similar debates have been going on for some time. More on this later.

Despite the fervently expressed desire for public involvement and an increasingly demanding population, this does not seem to have led to a systematic or extensive public engagement in the priority setting process. The contribution by Bal and Van de Lindeloof presents some arguments about the advantages and disadvantages of public engagement.[39] The first argument in favour of citizen participation is that it could increase the quality of the decision-making process. An instrumental argument is that participation increases support, which is necessary for the declining trust in political decision-making; it should close the gap between citizens and politics. Last but not least, normative arguments play a role: in a democratic country, the population should be heard. The 'alleged' lack of capacity of the populations is an argument against involvement. So is the fact that it might slow down the decision-making process. A third argument put forward is the right to 'political laziness'. In their study, they looked at a number of foreign experiences of public participation and concluded that, despite the many examples, the influence on decision-making remains small. To the question whether this also applies to the Netherlands, they give a number of reasons why it might be different here. Without being exhaustive, they mention the high degree of consensus - popularly known as 'poldering' - as a possible reason why public input could lead to different decision-making. The way in which the Dutch insurance system is organised could also be a reason. Notwithstanding the possibilities they see, there are also some disadvantages to citizen participation. In addition, there are challenges, such as organising this participation in the right

[37] Mitton, p. 226.
[38] Mitton, p 220. These stakeholders diverge from decision-makers, academics, the media, funders, other levels of government and some segments of the public itself.
[39] R.A. Bal and A. Van de Lindeloof, 'Publieksparticipatie Bij Pakketbeslissingen. Leren Van Buitenladnse Ervaringen ', in *Zicht Op Zinnige En Duurzame Zorg*, (Den Haag: Raad voor de Volksgezondheid en Zorg, 2006), pp. 169-229. This contribution is part of a background study that addresses specific issues of importance to the aforementioned advisory report 'Sensible and Sustainable Healthcare'.

way and clearly outlining the expectations regarding the role and ultimate influence of the participants.

The progress as predicted by Mitton and others has been made, as becomes obvious by the review of Manafò and others[40] conducted over a ten-year period since 2007. Nevertheless, it seems that practical indications on how to achieve public and patient engagement are still lacking in the literature. Similarly to Bal and Van de Lindeloof, they discuss some models and processes that have been successfully applied in various settings. Leaving the operational details aside, they, as other before, call for attention to the evaluation of the engagement process. In addition, they point out the importance of paying attention to the ethical side of involving the public and/or patients.

The latest report, dating from 2020, again calls for public involvement and stresses the importance of coming to balanced decisions together. Without ignoring the fact that there are apparently also hurdles to overcome, such as gathering sufficient (political) courage[41], the discussion on prioritization will be looked at from an ethical stance in relation to resources and public involvement.

Ethical Deliberation on Priority Setting

In essence, questions of priority setting are about justice, equality, and equity. It refers to the tenth article of the Universal Declaration on Bioethics and Human Rights: 'The fundamental equality of all human beings in dignity and rights is to be respected so that they are treated justly and equitably'.[42] Priority setting includes issues of distribution and inclusion/exclusion. Or as the oft-quoted Professor Leenen described it deals about fair - or least unfair - distribution of available resources.[43] In other words, this refers to distributive justice, the type of justice that departs from the viewpoint that everyone is entitled to a fair share.[44]

[40] Elizabeth Manafò and others, 'Patient and Public Engagement in Priority Setting: A Systematic Rapid Review of the Literature', *PloS one*, 13 (2018), 1-18.
[41] Zorginstituut Nederland & Nederlandse Zorgautoriteit (NZa). Like others before such as Plagge and Dutrée, the report talks about 'courage', in other words the political will to take stringent measures to keep healthcare affordable in the future.
[42] UNESCO, *Universal Declaration on Bioethics and Human Rights*, (Paris UNESCO 2005). http://portal.unesco.org/en/ev.php-URL_ID=31058&URL_DO=DO_TOPIC&URL_SECTION=201.html [Accessed 1 May 2021]. The tenth article deals about Equality, justice an equity.
[43] Leenen, p. 908.
[44] Julian Lamont and Christi Favor, 'Distributive Justice', in *The Stanford Encyclopedia of Philosophy* ed. by Edward N. Zalta (2017).

Distributive Justice

Four important theories or principles of distributive justice are the libertarian, the utilitarian, the egalitarian and the communitarian.[45] The libertarian principle is characterized by the right to personal freedom and private property. One of the best-known proponents is probably Robert Nozick.[46] The libertarian features also apply to healthcare in liberal societies i.e. where the system is based on a free market principle, has no underlying compulsory schemes and helping diseases and handicapped is seen as charity not as justice.

The egalitarian theory departs from idea that people are morally equal hence they should have equal levels of material goods (including burdens) and services. John Rawls has advanced this theory and belongs to the most famous political philosophers of the last century.[47] He is particularly known for his theory of justice as equity, which encompasses a liberty and an equality principle.[48] Applied to healthcare, equalitarianism means equal health status for all, equal use of healthcare services for persons with equal health needs, and equal access to healthcare services. Egalitarian health principles are very much based on equality, both with regard to access and availability, and solidarity with the worst-off.

The main tenet in utilitarianism is to maximize the highest good for the highest number of people, i.e. maximize the benefit or intrinsic value to the most people.[49,50] As it focuses on collective welfare it is perceived as a social theory. Two philosophers of the classical utilitarian theories are Jeremy Bentham and John Stuart Mill.[51] A healthcare system based on utilitarianism aims to maximise its utility, i.e. the maximum contribution to the overall health of the population. In healthcare terms it can also be expressed as striving for a distribution of care that has the most favourable effect on the largest possible number of life years gained or QALYs.[52] Central to this health justice principle are the effectiveness and cost-effectiveness of the healthcare.

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[45] Lamont and Favor. Although this article deals with several types of distributive justice, this essay briefly touches upon the four recognised as the main ones.
[46] Robert Nozick, *Anarchy, State, and Utopia*, (New York: Basic Books, 1974).
[47] Leif Wenar, 'John Rawls', in *The Stanford Encyclopedia of Philosophy* ed. by Edward N. Zalta (2017).
[48] John Rawls, *A Theory of Justice*, (Cambridge, MA: Harvard university press, 1971), p. 60. The First principle reads: 'each person is to have an equal right to the most extensive basic liberty compatible with a similar liberty for others'; the Second: 'social and economic inequalities are to be arranged so that they are both (a) reasonably expected to everyone's advantage, and (b) attached to positions and offices open to all.
[49] John Stuart Mill, 'Utilitarianism (1863)', in *Utilitarianism, Liberty, Representative Government*, (1859).
[50] Anthony Kenny, *An Illustrated Brief History of Western Philosophy* (Oxford, UK: John Wiley & Sons, 2019). See chapter XVIII on The Utilitarians.
[51] John Deigh, 'Utilitarianism', in *An Introduction to Ethics*, (Cambridge: Cambridge University Press, 2010), pp. 93-122.
[52] National Institute for Health and Care Excellence (NICE), 'Quality-Adjusted Life Year', in *Glossary*, ed. by National Institute for Health and Care Excellence (2021). QALY is described as 'A measure of the state of health

The communitarian principle states that liberal freedom is only possible through social relations or constituent communities that are different in nature and that should serve as a basis to inform our moral and political judgements, as well as policies and institutions.[53] Well-known protagonists are amongst others Alasdair MacIntyre[54] and Charles Taylor.[55] In the communitarian approach health is not a goal in itself but is related to society's goals, it is a precondition for a society, to be able to participate in that society. This is in line with communitarian theory of Daniel Callahan of health as a common benefit.[56] The 'community-oriented' approach chosen by the Dunning Commission, is an example of the communitarian principle.

Of course, each of the above principles has its own advantages and disadvantages, especially in priority setting. For example, the libertarian system has little or no concern for the poor, nor does it take environmental factors and genetic dispositions into consideration. Moreover, there is a possibility that in the end collective choices have to be made which impede individual health needs can be met. The egalitarian theory might become very expensive due to the focus on the least advantaged, which will reduce overall healthcare for all. Some consider the principle paternalistic e.g. because of compulsory insurance. While the egalitarian principle is seen as focusing too much on the most disadvantaged, utilitarianism is the opposite, as it focuses on the majority, leaving small groups or rare interventions uncovered. Moreover, it is primarily economically oriented. The criticism of the communitarian principle is that complete consensus is considered unrealistic. In addition, the function of health is interpreted rather narrowly, i.e. as a social function, which collides with the intrinsic value of life.

Solidarity and Equality

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of a person or group in which the benefits, in terms of length of life, are adjusted to reflect the quality of life. One quality-adjusted life year (QALY) is equal to 1 year of life in perfect health'. QALYs are calculated by estimating the years of life remaining for a patient following a particular treatment or intervention and weighting each year with a quality-of-life score (on a 0 to 1 scale). It is often measured in terms of the person's ability to carry out the activities of daily life, and freedom from pain and mental disturbance.

[53] Daniel Bell, 'Communitarianism', in *The Stanford Encyclopedia of Philosophy* ed. by Edward N. Zalta (2020), p.1.

[54] Alasdair C. MacIntyre, *After Virtue: A Study in Moral Theory* (Notre Dame, Ind: University of Notre Dame Press, 1984). Both political philosophers build on the thoughts of Aristotle and Hegel. MacIntyre, for example, recognises that moral rules are based on virtues that are socially embedded and grounded in tradition.

[55] Charles Taylor, 'The Politics of Recognition', in *Multiculturalism. Examining the Politics of Recognition*, ed. by Amy Gutmann (Princeton: Princeton University Press, 1994), pp. 25-73 (p. 26). A central element in Taylor's work is recognition: 'Due recognition is not just a courtesy we owe people. It is a vital human need'.

[56] Ten Have, Ter Meulen, and Van Leeuwen, pp. 117-118.

In the Netherlands, solidarity and equality are fundamental values. As far as healthcare is concerned, this means that there is a basic package of healthcare, regardless of income or risk, which is called risk solidarity and income solidarity. This solidarity is understood broadly and no exceptions are made on the basis of lifestyle or other personal criteria. Ten Have and others distinguish between solidarity as an instrumental value and as an intrinsic value. With regard to ethical discussions, above all the latter is important as intrinsic value means something has worth in itself. Ten Have further mentions the two moral principles that underlie medical action: respect and inviolability. He explains that the sanctity of life can be seen as synonymous with the fundamental value of life: human life has intrinsic value and as intrinsic value it is worth from the beginning, from the way it came into being. That is why human life deserves respect. This has three consequences. Firstly, it calls for equality; secondly, it calls for respecting life as long and as well as possible; finally, it calls life a task. The second principle related to the fundamental value of life is its inviolability.[57]

The fundamental value of equality should lead the healthcare system to base itself on the principle of egalitarian justice, which explicitly seeks to give priority to care for those who are worst off. Rogeer Hoedemaekers and Wim Dekkers have looked into whether this is the case and whether this is the best choice in the long run.[58] They list a number of advantages and disadvantages of collective decision-making with regard to setting priorities. In short, the disadvantages have to do with too little consideration for specific and individual situations. The advantages, on the other hand, have to do with a greater chance of fair distribution and deliberation of healthcare. They propose a normative framework that could support decision-making.[59] This framework looks at which distributive justice principles can be applied per phase, depending on a country's prevailing fundamental principles. In the Netherlands, this means that the principles of solidarity and equality are of paramount importance, whereas in America, for example, the principle of solidarity seems less important. The framework could envigorate a discussion as prompted by the latest report 'Working Together for Appropriate Care: The Future is Now'.

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[57] Ten Have, Ter Meulen, and Van Leeuwen, pp. 62-66. Ten Have and others give a more detailed explanation of the concept of value, the further explication of the philosopher Dworkin, and the related ethical foundations for the medical profession.

[58] Rogeer Hoedemaekers and Wim Dekkers, 'Justice and Solidarity in Priority Setting in Health Care', *Health Care Analysis*, 11 (2003), 325-343.

[59] Hoedemaekers and Dekkers, pp. 332-343. The four stages in brief. Stage one involves an explicit assessment of the severity of a condition. Stage two looks at the effectiveness and cost-effectiveness (appropriateness) of the measure in the benefits package. Minimum thresholds must be set in both phases. Stage three concerns the trade-off between disease burden assessments on the one hand and effectiveness and cost-effectiveness assessments of health services on the other. In stage four there are decisions on (the level of) co-payments.

Two other reports, a Dutch one that has already been mentioned before[60] and one of the World Health Organization[61] are urging a debate on priority setting in the event of a pandemic. Although the advice given is primarily concerned with the possible pandemic outbreak, it is may shed some light on priorisation. Especially since both reports were written well in advance of the ongoing pandemic and were intended to stimulate a debate before a pandemic actually breaks out. More importantly, both reports focus on the ethical considerations in prioritisation. The most important aspects, suitable for a more general priority setting as the subject in this essay, will be examined and translated to the present essay.

Priority setting involves always potentially diverging interests of individuals and community. It would be unrealistic to expect that everyone will be served as he or she wishes. Priority setting is balancing between competing interests and values. It needs to be contextualized and prevailing cultural values have to be taken into account.

As in emergency situations, care must be distributed fairly, i.e. the various principles of distributive justice come into play. What immediately stands out is the fact that both reports emphasise the importance of transparency and the involvement of all relevant stakeholders, including the public. To start with the latter, both reports emphasize that the public engagement entails beforehand as during. Put differently, the power of damage control begins with preparation. This includes raising awareness among the public and other important stakeholders, involving them in the planning process, building confidence that policies are reasonable, responsible and non-discriminatory, explaining how and what is done with the input of the various stakeholders and why. After all, different stakeholders have different interests. Medical professionals, for example, are trained to act in an egalitarian manner, which is the basis of their professional ethics and for which they took the Hippocratic Oath.[62] Politicians tend to act according to their political ‘colour', and act more libertarian, egalitarian, etc. Individuals may be more selfish or altruistic in nature and wishing to allocate care accordingly. Furthermore, it is important to maintain the trust of all stakeholders involved and in specific the public. The WHO explicitly add that it is important 'to ensure the accountability of decision-makers both in the planning stage and during a plan’s implementation'.[63] The author of the essay wants to emphasize that accountability is important in all phases.[64] The importance of

[60] Raad voor Volksgezondheid en Zorg.
[61] World Health Organization, 'Ethical Considerations in Developing a Public Health Response to Pandemic Influenza', (World Health Organization, 2007).
[62] Ten Have, Ter Meulen, and Van Leeuwen, p. 50
[63] World Health Organization, p. 3.
[64] At the time of writing, the so-called 'allowance drama' is playing, exposing the 'failure' of the constitutional state, in particular of the Dutch tax authorities. Ulko Jonker, 'Toeslagdrama: De Rechtsstaat Faalde Faliekant En

transparency cannot be underestimated. Firstly, it is necessary in order to secure consensus. Secondly, it must guarantee the legitimacy of democracy. Thirdly, it makes people aware that there are limits to what is possible. In other words, the offer of healthcare is not inexhaustible and neither is the right to it. Last but not least, people are more demanding and higher educated. They have the right to be involved in setting priorities because it concerns their health.

Further Reflections

Apart from the above ethical deliberation, some other reflections are of importance. In the Netherlands, the 'community-based' approach, where health is defined as a social function, has been chosen as the starting point for priority setting. However, both this communitarian approach as the definition of health needs to be scrutinised.[65] To start with the latter, the connotation of health as defined by Machteld Huber and others has recently been gaining ground.[66] They advocate extending the current WHO-definition[67] and to formulate health as 'the ability to adapt and to self-manage, in the face of social, physical and emotional challenges'.[68] The first element of scrutiny is the community principle. In the Dutch highly individualised society, the question arises whether the aspects of freedom of choice and autonomy are not too underrated. It is unknown if and what implications both aspects could have with regard to the prioritisation debate.

Another reflection is the still limited experience with public participation in health care and the proposal by Mitton and others to therefore look at other policy areas.[69] One such practice is that of 'commoning',[70] often used in other fields such as housing or urban

Deed Ouders 'Ongekend Onrecht' Aan', *Het Financieele Dagblad,* 18 December 2020, pp. 2-3. Numerous articles have appeared about it, only one of which is mentioned here. The trust in the Dutch political system is under pressure, among other things because of this issue.

[65] Ten Have, Ter Meulen, and Van Leeuwen, p. 115. In chapter six a reference is made to Callahan's view on health and healthcare. P. 129. In chapter five the authors gave various existing views of the interpretation of health. One of these is the negative scientific definition as the absence of disease. The others, positive descriptions, are viewed from several domains such as the political definition: 'complete physical, mental and social well-being', or the social one: 'an individual's abilityto fulfill social roles and tasks'.

[66] Machteld Huber and others, 'How Should We Define Health?', *Bmj,* 343 (2011),1-3; Machteld Huber and others, 'Towards a 'Patient-Centered' Operationalisation of the New Dynamic Concept of Health: A Mixed Methods Study', *BMJ,* (2016), 1-11. Machteld Huber, Marja Van Vliet, and Inge Beers, 'Heroverweeg Uw Opvatting Van Het Begrip 'Gezondheid'', *Ned. Tijdschrift voor Geneeskunde,* 160 (2016), 1-5.

[67] WHO, 'Constitution of World Health Organization', (Geneve: WHO, 1948), p 1. The definition reads: 'Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity'.

[68] Huber and others, p.7. In their vision the physical, mental and social dimensions of health as described by the WHO should be expanded to include other dimensions such as the spiritual or existential dimension and a dimension of quality of life.

[69] Mitton and others.

[70] In 'The Tragedy of the Commons' Garrett Hardin describes a situation where people are exhausting their resources to such an extent that nothing is left over and all are deprived of the benefits of the resources. Garrett

planning, which are known for their scarcity problems.[71] Steven Woolf and Kurt Stange[72], signalling both financial and staffing shortages, suggest looking at the applicability of healthcare commons. However, it is unknown what the practical and ethical consequences are of applying practices that have proven their worth elsewhere.

A third consideration concerns technological developments. There is much to be said about this. For example, there is an increasing use of all kinds of tools such as apps and other digital resources that can support people in their care needs. Technological medical applications include operations on artificial hips and knees, as well as complex brain operations using neuronavigation; or the recent heart transplant with a heart from a deceased donor.[73] All very interesting developments. But there is also a downside. As a result of the increasing possibilities, also questionable practices emerge. For example, the donation of donor organs due to poverty or under pressure; types of medicine that raise some ambiguity, such as fast-growing transformative medicine or informative or predictive medicine.[74] Questions arise about (the limits of) the manipulability, the desirability, and/or the applicability of these new techniques.

The list of considerations, uncertainties and unknown facts is probably much longer than that presented in this essay. Only a few considerations are given here that may influence a debate on priority setting with all stakeholders.

Conclusion

Hardin, 'Tragedy of the Commons', *Science*, 162 (3859) (1968). Elinor Ostrom debunked Hardin's theory by asserting that this is not necessary to happen if people want to collaborate with each other and decide together how to use the resources to their full extent and benefit for all without depleting them. Her social theory is based on solidarity and engagement with other stakeholders. Elinor Ostrom, *Governing the Commons: The Evolution of Institutions for Collective Action*, (Cambridge, UK: Cambridge University Press, 1990).

[71] Sheila R. Foster and Christian Iaione, 'The City as a Commons', *Yale Law & Policy Review*, 34 (2016), 282-307.

[72] Steven H. Woolf and Kurt C. Stange, 'A Sense of Priorities for the Healthcare Commons', *American journal of preventive medicine*, 31 (2006), 99-102.

[73] Josselin Gordijn, 'Zelfs Artsen Verbazen Zich over Machine Die Hart Overleden Donor Buiten Lichaam Laat Kloppen: 'Verbazingwekkend'', *AD*, 6 Mei 2021. <https://www.ad.nl/utrecht/zelfs-artsen-verbazen-zich-over-machine-die-hart-overleden-donor-buiten-lichaam-laat-kloppen-verbazingwekkend~af6afe51/> [Accessed 7 May 2021].

[74] Ten Have, Ter Meulen, and Van Leeuwen, p.120.

Should the public be involved in the priority setting is the main question addressed in this essay. It concentrates on the priority setting at the macrolevel dealing, which concerns what should be included in the basic healthcare package. A question that is becoming more urgent by the day, as total healthcare expenditure is expected to increase to a level twice that of 2015. Therefore, the question arises as to who will decide on the pressing issue and how?

Since the early 1990s, there have been constant pleas to involve the public involvement in the priority setting debate. So far, however, there seems to be scarcely any public participation. Is that right? This essay does not want to fall into the trap of blaming anyone for the lack of public engagement. It focuses on the question of whether or not the public should be involved.

The signal 'Fair Selection in a Pandemic' shows that such an advice (or should it be called 'warning') should be taken seriously. Just like the previous pleas (or warnings) of all the authors of the various articles and reports about the necessity of the debate on prioritisation. A legitimate democracy as the Netherlands, with fundamental principles such as solidarity and equality, cannot afford to ignore the urgency of necessary reforms in the priority setting.

If the Dutch do not want to get into a financial pandemic, they ought to start a serious debate on how to transform the priority setting of their healthcare. They should do that with all relevant stakeholders and therefore the public should be engaged as well. No doubt about that, it is only ethical to involve the public in matters that so directly concern them.

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