

# Rationing healthcare

Ethical principles and legal practice

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## *Abstract*

As demand for healthcare continues to outstrip available public funding, healthcare rationing has become inevitable. Care rationing fundamentally is an ethical issue, which must respect moral principles to be publicly legitimate. In the face of a growing 'rights culture' within society, citizens are increasingly turning to the courts to claim care, invoking the right to health. Public law relating to healthcare rationing can prove valuable in achieving public legitimacy of allocative policy. Rationing in healthcare thus is in its core an ethical policy issue that could gain in legitimacy through public law adjudication. In this paper the underlying principles in ethics and European public law at the level of the UN, the Council of Europe and the EU on the subject of healthcare rationing are studied. Though much overlap between these principles exists, certain criteria for public legitimacy differ. As the judiciary serves an important role in providing the moral principle of *accountability*, the individual's access to justice is assessed. It is concluded that this must be expanded for European citizens from what is currently possible. More countries must allow the individual complaints procedure under the ICESCR Optional Protocol through ratification and the ECSR must expand its complaints procedures to include an option for the individual citizen.

## Table of Contents

### *Abbreviations*

<b>1. Introduction</b>	4
<b>2. Methods</b>	10
<b>3. The Problem of Rising Healthcare Costs</b>	11
<b>4. Healthcare Rationing</b>	13
4.1. What is Healthcare Rationing?	13
4.1.1. <i>Fair Treatment and Dividing Benefits and Burdens</i>	13
4.1.2. <i>Defining Healthcare Rationing</i>	14
4.2. Types of Healthcare Rationing	15
4.2.1. <i>Implicit Healthcare Rationing</i>	15
4.2.2. <i>Explicit Healthcare Rationing</i>	18
4.3. Criteria for Moral Acceptability	18
<b>5. The Right to Health</b>	23
5.1. The United Nations	23
5.2. The Council of Europe	27
5.3. The European Union	35
<b>6. Comparing Ethics Theory to Legal Practice</b>	46
6.1. Procedural Principles	46
6.1.1. <i>Transparent and Explicit</i>	46
6.1.2. <i>Accountable</i>	47
6.1.3. <i>Participatory</i>	48
6.1.4. <i>Open to Rationing Democratic Deliberation</i>	48
6.2. Substantive Principles	49
6.2.1. <i>Equity and Equality</i>	49
6.2.2. <i>Non-discrimination and Inclusiveness</i>	50
6.2.3. <i>Accessibility and Affordability</i>	51
6.2.4. <i>Acceptability</i>	51
6.2.5. <i>Quality of Care</i>	52
6.3. Discussion	53
<b>7. Adjudication of the Right to Health</b>	54
7.1. Risks of a Rights-Based Approach	54
7.2. Need of a Rights-Based Approach	56
7.3. Criteria to Assess Governmental Due Process	57
7.4. Citizen Access To Justice	61
<b>8. Conclusion</b>	64
<b>9. Bibliography</b>	66

## *Abbreviations*

AAAQ	Criteria under the CESCR's GC No. 14. <i>Availability, Accessibility, Acceptability and Quality of Health</i>
BCD	Baumol's Cost Disease
CESCR	Committee on Economic, Social and Cultural Rights
CFR	Charter of Fundamental Rights of the European Union
CJEU	Court of Justice of the European Union
ECHR	European Convention of Human Rights
ECSR	European Committee of Social Rights
ECtHR	European Court of Human Rights
EMA	European Medicines Agency
EO	European Ombudsman
ESC	European Social Charter
ESCRs	Economic, social and cultural rights
EU	European Union
EU-FRA	European Union Agency for Fundamental Rights
GC No. 14	CESCR General Comment No. 14 on art. 12 ICESCR
ICESCR	International Covenant on Economic, Social and Cultural Rights
OECD	Organization for Economic Co-operation and Development
OHCHR	Office of the United Nations High Commissioner for Human Rights
TFEU	Treaty on the Functioning of the European Union
UDHR	Universal Declaration of Human Rights
UN	United Nations
WHO	World Health Organization

## 1. Introduction

Public discussion on the reimbursement of extremely expensive drugs under the public insurance scheme has flared up frequently during the past decade in the Netherlands.<sup>1</sup> Understandably so, as new cures are being promised for previously incapacitating and often terminal diseases. The percentage of the national healthcare budget spent on these extremely expensive drugs has accordingly been growing at a steady pace over the past years.<sup>2</sup> The difficulty in determining the value for money of such treatments is twofold. Not only are such drugs often excessively expensive, prompting public and political debate on whether they should be reimbursed by the state, but doubts exist about their promised clinical effect.<sup>3</sup> A good example of such an expensive drug is *Spinraza*, marketed by Biogen Inc. to treat certain subtypes of the degenerative muscular disease *spinal muscular atrophy* (SMA). Following the report of promising clinical effects, and the drug's approval by the European Medicines Agency (EMA) in 2017, the Dutch Ministry of Health started its assessment as to whether the drug would be reimbursed under the country's universal health insurance scheme later that year.<sup>4</sup> The public debate surrounding the reimbursement of this drug intensified accordingly, as it had previously during the assessment of the drug *Orkambi* against cystic fibrosis. Parents of toddlers with SMA were invited onto a popular Dutch talk show, and interviewed in newspapers.<sup>5</sup>

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<sup>1</sup> See 'Middel tegen spierziekte SMA te duur voor basispakket.' *NOS* (2018). Retrieved from <https://nos.nl/nieuwsuur/artikel/2213843-middel-tegen-spierziekte-sma-te-duur-voor-basispakket.html>. Accessed 3/8/2018. At the end of 2017, the Dutch Minister of Health reached a price agreement with Vertex Pharmaceuticals to reimburse *Orkambi* under the public insurance scheme.

<sup>2</sup> Nederlandse Zorgautoriteit. Monitor Geneesmiddelen in de Medisch-Specialistische Zorg. *Rijksoverheid* (2017). p. 3-8. Retrieved from <https://www.rijksoverheid.nl/binaries/rijksoverheid/documenten/rapporten/2017/12/21/monitor-geneesmiddelen-in-de-medisch-specialistische-zorg/monitor-geneesmiddelen-in-de-medisch-specialistische-zorg.pdf>. Accessed 3/8/2018.

<sup>3</sup> See Peperdure medicijnen tegen zeldzame ziektes blijken vaak niet te werken. *Trouw* (2018). Retrieved from <https://www.trouw.nl/samenleving/peperdure-medicijnen-tegen-zeldzame-ziektes-blijken-vaak-niet-te-werken~a4081484/>. Accessed 3/8/2018. Yvonne Schuller of the Amsterdam UMC concludes in her PhD dissertation that many orphan drugs do not yield the clinical effects they promise due to insufficient and inadequate clinical testing.

<sup>4</sup> Acht jaar en een traplift: geen vergoeding voor medicijn spierziekte *NOS* (2017). Retrieved from <https://nos.nl/artikel/2204911-acht-jaar-en-een-traplift-geen-vergoeding-voor-medicijn-spierziekte.html>. Accessed 3/8/2018.

<sup>5</sup> See Dirkje (2) en Thijs (5) hebben een ernstige spierziekte. Het medicijn wordt in Nederland niet vergoed. *Pauw BNNVARA* (2017). Retrieved from <https://pauw.bnnvara.nl/nieuws/dirkje-2-en-thijs-5-hebben-een-ernstige-spierziekte-het-medicijn-wordt-in-nederland-niet-vergoed>. Accessed 3/8/2018. ; Two mothers were invited to *Pauw* for the November 14<sup>th</sup> 2017 edition to discuss their children's SMA. Luka krijgt medicijnen, zijn zieke zusje niet. *NRC Handelsblad* (2017). Retrieved from <https://www.nrc.nl/nieuws/2017/12/21/luka-krijgt-medicijnen-zijn-zieke-zusje-niet-a1585714>. Accessed 3/8/2018.

Whilst the Dutch independent advisory body to the government on healthcare (*Zorginstituut Nederland*) advised against the reimbursement of *Spinraza* citing insufficient clinical effect, the Ministry of Health announced on 12 July 2018 that the Minister of Health had managed to reach a price agreement with Biogen Inc. securing reimbursement for certain Dutch SMA patients after all.<sup>6</sup>

An example as this illustrates the profound difficulties surrounding reimbursement discussions, in which health needs must be balanced against limited budgetary room. Independent expert advice on the clinical benefit versus budgetary impact from the *Zorginstituut Nederland* to the Minister is countered by an emotional public and political response arguing that ‘the price of a drug may never be the reason not to prevent a child from dying.’<sup>7</sup> Such discussions lay bare to the public the difficulties surrounding priority-setting in the allocation of limited resources. The strong public reactions to governmental decisions not to cover certain expensive treatments however, suggest that ‘individualistic and community-based ethical perspectives on the distribution of scarce healthcare resources may ultimately be incommensurable.’<sup>8</sup> This of course is deeply troublesome for authorities pursuing policy to fairly and justly distribute limited healthcare resources in a way that has public legitimacy. Several scholars have pointed out that such questions will not be settled using more clinical data, economic equations or by invoking organizational theory.<sup>9</sup> Instead, scarce resource allocation, or rationing, in healthcare must be addressed as a moral issue, and based on justified and general ethical values.<sup>10</sup> Guiding principles following from such values thus must be shaped from ethical theory.

Returning to the public legitimacy sought after by policy-makers, policies must be accordingly acceptable to the public facing the consequences of such policy decisions.<sup>11</sup> As difficult and daunting as it appears, a balance must be found between the health needs and interests of individuals and those of the public at large. The law

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<sup>6</sup> See Minister Bruno Bruins bereikt akkoord over vergoeding Spinraza. *Rijksoverheid* (2018). Retrieved from <https://www.rijksoverheid.nl/actueel/nieuws/2018/07/12/minister-bruno-bruins-bereikt-akkoord-over-vergoeding-spinraza>. Accessed 3/8/2018. For approximately 80 Dutch children with SMA, *Spinraza* will be reimbursed under the universal health insurance scheme.

<sup>7</sup> Dutch MP Fleur Agema (PVV) on *Pauw* on May 31<sup>st</sup> 2017. See Fleur Agema: ‘Een kind mag niet doodgaan door de prijs van medicatie.’ *Pauw BNNVARA* (2017). Retrieved from <https://pauw.bnnvara.nl/nieuws/fleur-agema-een-kind-mag-niet-doodgaan-door-de-prijs-van-medicatie>. Accessed 3/8/2018.

<sup>8</sup> Syrett, K. (2007) *Law, Legitimacy, and the Rationing of Healthcare*. Cambridge: Cambridge University Press. p. 8.

<sup>9</sup> Buijsen, M. (2016). Schaarre middelen, rechtvaardige gezondheidszorg. In T. Wobbes & M. van den Muijsenbergh (eds.), *De euro in de spreekkamer: Geld speelt wel een rol* (Annalen van het Thijmgenootschap) (1st ed.). Nijmegen: Thijmgenootschap. p. 130-131. ; Fleck, L.M., Just Caring, Health Care Rationing and Democratic Deliberation, 2009, Oxford University Press. p. 400.

<sup>10</sup> Hirose, I. & Bognar, G. (2014). *The ethics of health care rationing*. London: Routledge. p. 153.

<sup>11</sup> Ibid.

has an equally and increasingly irrefutable role on the subject of care allocation.<sup>12</sup> Litigation relating to healthcare funding decisions has become steadily more common over the course of the last years.<sup>13</sup> Initially, it had been mostly frustrated patients who took the path to the courts seeking reimbursement for treatment that had been denied to them. More recently, such appeals to the judiciary have been increasing in number due to 'a more litigious citizenry and the rise of a 'rights culture', coupled with declining deference to the judgment of professionals and the greater availability of information.'<sup>14</sup>

It thus seems close to certain that the role of the law will take an increasingly central position in the debate surrounding the allocation of scarce healthcare resources. To be clear, this is not an insurmountable problem, as some commentators have made it seem.<sup>15</sup> It does mean, however, that the deliberative possibilities of public law surrounding this issue must be further and more thoroughly explored by those pursuing public legitimacy of priority-setting in healthcare.<sup>16</sup> This necessity is increasingly advocated in the literature.<sup>17</sup> Nonetheless, there remains a shortage of literature on public law relating to healthcare resource allocation and on its added value in achieving public legitimacy of allocative policy.<sup>18</sup> Literature seeking to clarify citizens' health rights in the European context is equally scarce, leaving a gap and a need for scholars to clarify these rights and improve their realization in practice.<sup>19</sup>

Luckily, much has been written in ethics about rationing in healthcare, and the principles necessary for it to be fair and just.<sup>20</sup> Though many politicians appear to view scarce resource allocation in healthcare as a political issue, it is in fact fundamentally ethical.<sup>21</sup> Priority setting in healthcare must thus be based on sound and justified moral principles for such policy to be publicly legitimate.<sup>22</sup>

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<sup>12</sup> Syrett, *Law, Legitimacy, and the Rationing of Healthcare*. p. 9.

<sup>13</sup> Syrett, K. (2017). Healthcare Rationing and the Law. In A. den Exter, *European Health Law* (1st ed.). Antwerpen, Apeldoorn, Portland: Maklu. p. 173.

<sup>14</sup> Ibidem.

<sup>15</sup> Syrett, *Law, Legitimacy, and the Rationing of Healthcare*. p. 231.

<sup>16</sup> Ibid. p. 230.

<sup>17</sup> Newdick, C. (2018). Can Judges Ration with Compassion? A Priority-Setting Rights Matrix. *Health And Human Rights Journal*, 20(1), p. 117-118.; Hunt, P. (2016). Interpreting the international right to health in a human rights-based approach to health. *Health and human rights*, 18(2). p. 109, 122.

<sup>18</sup> Syrett, *Law, Legitimacy, and the Rationing of Healthcare*. p. 232.

<sup>19</sup> Lougarre, C., (2015). What does the right to health mean? *Netherlands Quarterly of Human Rights*, Vol. 33/3). p. 326.

<sup>20</sup> Scheunemann, L. P., & White, D. B. (2011). The ethics and reality of rationing in medicine. *Chest*, 140(6), p. 1625. ; For further reading, see Emanuel, E., Schmidt, H., & Steinmetz, A. (Eds.). (2018). *Rationing and Resource Allocation in Healthcare: Essential Readings*. Oxford University Press.

<sup>21</sup> Fleck, L. M. (2011). Just Caring: Health Care Rationing, Terminal Illness, and the Medically Least Well Off. 39. *JL Med & Ethics*, 2, p. 158.

<sup>22</sup> Hirose, Bogнар. *The ethics of health care rationing*. p. 3.

It is therefore important to reconceptualize the judicial role in the process of policy making on rationing issues in healthcare. A better understanding of the *facilitative* potential of public law adjudication is advocated in the pursuit of legitimacy of such policies.<sup>23</sup> Rationing in healthcare thus is in its core an ethical policy issue that could gain in legitimacy through the involvement of public law adjudication. Bearing in mind the scarcity of legal literature on healthcare rationing in contrast to ethics literature on the subject, it proves useful to examine whether overlap exist between the ethical principles underlying legitimate healthcare rationing, and the values and principles of European public law on the right to health.<sup>24</sup> This becomes useful when studying individual citizens' access to justice and assessing whether the implications for these citizens in practice correspond to principles for moral acceptability as defined in ethics literature. In other words, is the legal practice for citizens on healthcare rationing policies morally legitimate? It is the purpose of this paper to study this question.

The central question of this thesis is:

*How are the moral values underlying healthcare rationing in ethical literature reflected in European jurisprudence on the matter of healthcare?*

In order to answer this comparative question it will be split into its two components: ethics and law. First, the concept of healthcare rationing is assessed in ethics literature (A), after which attention will be turned to European public law on the subject (B).

The two main sub-questions underlying the ethical analysis under (A) are:

*Sub – 1. What is healthcare rationing, and what is the difference between implicit and explicit rationing of healthcare?*

and

*Sub – 2. When is healthcare rationing considered to be morally acceptable?*

Due to many scholars' reluctance to use the term *healthcare rationing* and the subsequent varying understandings of the concept, it is crucial to formulate a working definition of healthcare rationing to be able to adequately assess the ethics component of the main question. This definition will be assessed under sub-question

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<sup>23</sup> Ibidem.

<sup>24</sup> Syrett, *Law, Legitimacy, and the Rationing of Healthcare*. p. 231.



1, as well as the main variations in healthcare rationing – implicit and explicit rationing. Subsequently, under sub-question 2, the recurring principles and criteria are discussed necessary for healthcare rationing to be morally acceptable and publicly legitimate.

After assessing the ethics component of the main question, legal scholarly literature and grey literature (B) is researched with regards to the subject of healthcare rationing. Here, the attention centers on the question:

*Sub – 3. What is the scope of the European jurisprudence on the subject of healthcare rationing and which institutions handle such cases?*

To gain a thorough understanding of the international institutions covering such subjects for Europeans, three principle institutions will be analyzed within the confines of this paper. At the level of the UN, the Committee for Economic, Social, and Cultural Rights and relevant covenants will be assessed. At the Council of Europe level, mainly the European Committee on Social Rights will be looked into, as well as the European Court of Human Rights. Finally, the EU and its health related policies will be discussed. National case law will therefore not be at the heart of this analysis.

To synthesize the findings following the first three sub-questions (Subs. 1-3), they will be compared along the lines of the following question:

*Sub – 4. What commonalities exist in European legal sources concerning healthcare rationing and do they correspond to ethical ideals on its moral acceptability?*

After the comparison of the principles and criteria in ethics literature and in the discussed legal sources, it will become clear how they relate to each other. Finally, to discuss the implications for society of the findings the following question will be covered:

*Sub – 5. What are the practical ramifications for society of possible mismatches between ethical theory and legal practice?*

Here, the justiciability of the right to health will be examined. By discussing the need for and the risks of adjudication, the practical ramifications for individual citizens will become clear.

In order to answer the five sub-questions, each will be assigned a separate chapter in this thesis. The remainder of this paper is structured as follows. Following the methods section, an overview of the main demographic, economic and medical

developments will be presented which render healthcare rationing inevitable (Ch. 3). Subsequently, the issue of healthcare rationing and the principles for its moral acceptability will be discussed (Ch. 4), thereby covering sub-questions 1 and 2. The three international institutions (UN, Council of Europe, EU) and their treaty texts on health and the right to health will be covered in the chapter following (Ch. 5), answering sub- question 3. After having discussed the ethics component (A) and the legal component (B) of this study, they will be compared as stated in sub-question 4 (Ch. 6). In the final chapter (Ch. 7) sub-question 5 will be answered by assessing the adjudication of the right to health and its correspondence to the moral principles underlying legitimate healthcare rationing for citizens. In conclusion, the main findings of this paper will be reviewed and recommendations will be made accordingly.

## 2. Methods

For this paper, a mixed-methods approach was followed. First, healthcare ethics literature concerning the allocation of scarce resources and services was analyzed. A systematic search was performed to identify healthcare ethics literature, specifically in the field of healthcare rationing. To obtain such literature, a general boolean search was performed using several keywords in different combinations (including: *healthcare rationing; healthcare (resource) allocation; just rationing in healthcare; justice in healthcare, fair innings, age rationing; legal healthcare rationing; scarce resources in healthcare*). Use of the Leiden University Library's online catalogue, of the Erasmus University Rotterdam Library's online catalogue, and of Google Scholar provided most of the ethics literature that was used for this paper. Additionally, specified searches were performed in the Journal of Legal Medicine, the Journal of Medical Ethics, and in the Journal of Law, Medicine and Ethics.

In order to obtain legal sources concerning healthcare rationing, a similarly systematic search was performed to identify international treaties, charters and conventions covering the right to health in the context of the UN, the Council of Europe, and the European Union. Relevant grey literature (official publications) was obtained by consulting the websites of relevant international institutions and bodies. Additional legal scholarly literature was sourced from the same online university catalogues used for the ethics literature search. Additionally, emails were sent to the Secretariat of the Committee on Economic, Social and Cultural Rights, to the Department of the European Social Charter of the Council of Europe's European Committee on Social Rights, to the European Union Agency for Fundamental Rights, and to the European Ombudsman in search of suggestions for relevant case law and rulings concerning the process and substance of scarce healthcare resource allocation.

By obtaining both ethics literature and legal (grey) literature, both fields could be thoroughly examined on the subject of healthcare rationing and scarce resource allocation. Subsequently, it was possible to deduct central moral principles and to compare them to relevant legal principles and criteria.

The regular framework of the MSc Health Economics, Policy, and Law thesis is mainly aimed at quantitative research in (social) science or health economics, and thereby facilitates a different type and method of study. Accordingly, in this thesis a more apt chapter layout is used, as discussed in the Introduction. The findings of the performed research will be discussed in chapters 3 – 7.

### 3. The Problem of Rising Healthcare Costs

Several factors can be identified as important contributors to the rise in costs of healthcare, of which three will be discussed. The first of the most commonly heard explanations is the growing number of elderly citizens within OECD countries.<sup>25</sup> By 2030, half of the Western European population is projected to be older than 50 years of age, with an average life expectancy of 90 years.<sup>26</sup> The challenges the progressive ageing of societies brings with it are twofold.<sup>27</sup> First, healthcare spending on the elderly (those older than age 65) is significantly higher than for younger age groups, due to the increased frequency of use, and the use of predominantly more expensive healthcare during the later years of life.<sup>28</sup> As preventable deaths decline due to improved health systems, those treated drive up healthcare expenditures due to the shift to long-term care. Where the sick would previously not have survived their illness, they now continue to live but with increased chronic diseases and disabilities as a result of illness.<sup>29</sup> The second challenge from ageing is the steady decline of countries' workforce relative to those who have retired.<sup>30</sup> Simply put, this leads to a decreasing number of citizens in the labor force to collectively supply the tax revenue to fund the universal health insurance schemes of an increasing number of retired citizens using long-term care.

A second driver of increasing healthcare expenditure growth is the development of new medical technology, drugs and treatments.<sup>31</sup> Technology may replace older models and treatments, improving efficiency and lowering costs.<sup>32</sup> For the most part however, new drugs and treatments exacerbate the disparity between the demand and supply of healthcare, leading to higher costs through improved diagnostics and treatments of previously untreatable conditions.<sup>33</sup> People living with chronic diseases are now able to stay alive using expensive care, in contrast to brief sickbeds

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<sup>25</sup> Fleck, L. (2012). Just caring: in defense of the role of rational democratic deliberation in health care rationing and priority-setting. *Rationing Health Care: Hard Choices and Unavoidable Trade-Offs*, Maklu Press, Antwerp, p. 25.

<sup>26</sup> Angelis, A., Tordrup, D., Kanavos, P. (2017). Is the Funding of Public National Health Systems Sustainable over the Long Term? Evidence from Eight OECD Countries. *Global Policy*, 8, p. 9.

<sup>27</sup> Anderson, G. and Hussey, P. (2000). Population Aging: A Comparison Among Industrialized Countries. *Health Affairs*, 19(3), p. 195

<sup>28</sup> Hirose, I., & Bognar, G. (2014). *The ethics of health care rationing: an introduction*. Routledge. p. 14.

<sup>29</sup> Angelis, Tordrup, Kanavos. Is the Funding of Public National Health Systems Sustainable. p. 10.

<sup>30</sup> Maltby, T., Vroom, B., Mirabile, M., Øverbye, E. (eds) (2004). *Ageing and the Transition to Retirement – A Comparative Analysis of European Welfare States* (1<sup>st</sup> ed.). p. 1.

<sup>31</sup> Libby, C. (2012). Review of "Taming the Beloved Beast: How Medical Technology Costs Are Destroying Our Health Care System" by Daniel Callahan (Princeton University Press, 2009). *The Journal of Religion, Media and Digital Culture*, 1(1), p. 1.

<sup>32</sup> Syrett, K. (2017). Healthcare Rationing and the Law. In A. den Exter, *European Health Law* (1st ed.). Antwerp, Apeldoorn, Portland: Maklu. p. 175.

<sup>33</sup> Hicks, L. (2011). Making Hard Choices. *Journal Of Legal Medicine*, 32(1), p. 35-36.

and short periods of palliative care in the past.<sup>34</sup> Improved technologies and drugs, often at increasing prices, lead to increased expectations of medical care, and to a more educated and consumerist patient population, which additionally drives up national healthcare expenses.<sup>35</sup>

The third driver of higher healthcare expenditures is known as ‘Baumol’s Cost Disease’ (BCD).<sup>36</sup> BCD occurs when increases in productivity in one industry or sector lead to higher wages, forcing wages to rise accordingly in sectors that have not experienced a similar increase in productivity. If wages would not rise accordingly, employees would leave their jobs for a position in a market with a higher compensation. Healthcare is one of those sectors in which productivity cannot increase quickly, nor do we want it to. As Atanda, Menclova and Reed reflected, Baumol described healthcare as a ‘non-progressive, labor-intensive sector whose demand continually increases without corresponding increases in output per man-hour. Because of sluggish productivity growth and little substitutability of capital for labor, real costs inexorably climb over time.’<sup>37</sup>

As a result of these collective challenges annual growth in national healthcare expenditures is outpacing countries’ economic growth, rendering it unsustainable.<sup>38</sup> The supply of healthcare resources and services is finite – both financially and physically – whilst the demand for healthcare is virtually limitless.<sup>39</sup> It is clear that in this light, choices must be made in healthcare and that such choices will lead to unequal outcomes. As was illustrated by the public debate in the Netherlands about the funding of extremely expensive drugs – medication for the Pompe and Fabry diseases in 2012, Orkambi against cystic fibrosis in 2017 and Spinrasa against SMA in 2018 – it is very difficult to weigh the advantages of such costly drugs for few patients against the health gains for many from a less expensive treatment from the same budget. Who receives the treatment, and who does not?

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<sup>34</sup> Hirose, Bognar. *The ethics of health care rationing*. p. 3.

<sup>35</sup> Manning J, Paterson R. ‘Prioritization’: Rationing Health Care in New Zealand. *The Journal of Law, Medicine & Ethics*. 2005;33(4). p. 681.

<sup>36</sup> Hartwig, J. (2008). What drives health care expenditure? – Baumol’s model of ‘unbalanced growth’ revisited. *Journal of Health Economics*, 27(3), 603-623.

<sup>37</sup> Atanda, A., Menclova, A., Reed, W. (2018). Is health care infected by Baumol’s cost disease? Test of a new model. *Health Economics*, 27(5) p. 833.

<sup>38</sup> Manning, Paterson. ‘Prioritization.’ p. 681.

<sup>39</sup> Syrett, K. (2007) *Law, Legitimacy, and the Rationing Of Healthcare* (p 27). Cambridge: Cambridge University Press.

## 4. Healthcare Rationing

### 4.1. What is Healthcare Rationing?

Questions have emerged about the financial sustainability of national healthcare systems in light of high-cost treatments for a growing number of patients.<sup>40</sup> These deliberations often culminate in discussions about the value of a human life, and about how much we as a society are willing to spend in the face of medical need. But as Buijsen points out, this is not relevant issue to debate.<sup>41</sup> The predictable discussion about the price societies are willing to pay for medical treatments per person from their finite financial resources, however understandable, does not correspond to the discussion about how we value a human life. The answer to this discussion should not be framed in economic terms, but in terms of distributive justice.<sup>42</sup> Some method is needed to cope with the unsustainable reality of demand outsizing supply whilst respecting human dignity. There will always be individuals whose need will remain unmet. This fact compels a fair and just manner of allocation of these scarce healthcare resources. As such, all individuals must be treated as equals and all benefits and burdens must be shared equally for the process to be in line with the moral principle of justice.<sup>43</sup>

#### 4.1.1. Fair Treatment and Dividing Benefits and Burdens

Many scholars agree that distributive healthcare policies should be geared towards the achievement of both efficiency and fairness in healthcare service and resource allocation.<sup>44</sup> As Fleck points out, no person is entitled to unlimited healthcare and no person has the right to claim care over the just (higher-priority) needs of others.<sup>45</sup> In other words, equal care must be provided to equal need, and unequal care to unequal need. Not all healthcare needs can be met. Choices must thus be made and priorities set among healthcare needs based on medically objective and evidence-based criteria. Broad agreement exists about the main criteria on which priority-setting for healthcare allocation is based:

1. 'The severity of disease, if untreated;

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<sup>40</sup> Hirose, Bognar. *The ethics of health care rationing*. p. 156.

<sup>41</sup> Buijsen, M. (2016). Schaarre middelen, rechtvaardige gezondheidszorg. In T. Wobbes & M. van den Muijsenbergh (eds.), *De euro in de spreekkamer: Geld speelt wel een rol* (Annalen van het Thijmgenootschap) (1st ed.). Nijmegen: Thijmgenootschap. p. 130.

<sup>42</sup> Ibid. p. 136-137.

<sup>43</sup> Fleck. Just caring: in defense of the role of rational democratic deliberation. p. 26.

<sup>44</sup> Cappelen A, Norheim O. Responsibility, fairness and rationing in health care. *Health Policy*. 2006;76(3). p. 314.

<sup>45</sup> Fleck, L. M. (2009). *Just caring: health care rationing and democratic deliberation*. Oxford University Press. p.401

2. The benefit from the intervention;
3. The cost-effectiveness of the intervention;
4. The quality of evidence on 1–3.<sup>46</sup>

For a system of healthcare to be morally just, it must prevent and eradicate any form of discrimination.<sup>47</sup> A system of resource allocation in healthcare in which vulnerable populations within society are not taken into account and protected will lead to a system in which they inequitably suffer.<sup>48</sup> It is unjust and morally wrong for individuals not to receive health care they are legally entitled to as a result of allocative unfairness or inefficiencies.

Resource scarcity and access to care are intertwined.<sup>49</sup> Though it is clear that basic health services and care must be equally accessible to every citizen, this does not entail universal access to every possible treatment or service. Limit-setting in healthcare expenditures is thus unavoidable, by which access to certain care will be restricted.<sup>50</sup> Some allocative process to distribute inherent scarce resources in healthcare is therefore an inevitability of scarcity. Such a mechanism is known as rationing.<sup>51</sup> The central question thereby becomes *how* we ought to ration, rather than *if* we should ration our healthcare resources.<sup>52</sup>

#### 4.1.2. Defining Healthcare Rationing

Much scholarly debate exists surrounding the definition of *healthcare rationing*.<sup>53</sup> From a means to ‘apportion or distribute some good through a method of allowance’, to ‘a process of allocating goods in the face of scarcity’, several definitions of the process of rationing have been formulated.<sup>54</sup> In her 2002 article, Barbara Russell attempts to construct a working definition that is all-encompassing. The process of rationing presupposes the notion of ‘less than enough’ resources being available, a ‘shared valuation’ of the scarce resources demanded, a controlling entity that determines allocation, and a process of deliberation leading to

<sup>46</sup> Cappelen, Norheim. Responsibility, fairness and rationing. p. 314.

<sup>47</sup> Wong, W. F., LaVeist, T. A., & Sharfstein, J. M. (2015). Achieving health equity by design. *Jama*, 313(14), p.1418.

<sup>48</sup> Yearby R. Racial Inequities in Mortality and Access to Health Care. *Journal of Legal Medicine*. 2011;32(1). p. 91.

<sup>49</sup> Hirose, Bogнар. *The ethics of health care rationing*. p. 16.

<sup>50</sup> Ibidem.

<sup>51</sup> Syrett, *Law, Legitimacy, and the Rationing of Healthcare*. p. 20.

<sup>52</sup> Hicks, L. (2011). Making Hard Choices. *Journal Of Legal Medicine*, 32(1), p. 28.

<sup>53</sup> See Ubel, P. A., & Goold, S. D. (1998). ‘Rationing’ Health Care: Not All Definitions Are Created Equal. *Archives of Internal Medicine*, 158(3), p. 209-214.

<sup>54</sup> Russell B. Health-Care Rationing: Critical Features, Ordinary Language, and Meaning. *The Journal of Law, Medicine & Ethics*. 2002;30(1). p. 83.

‘conscientious decision-making.’ Synthesized into a definition, Russell states that ‘rationing is someone or some institution’s deliberate decision to distribute a scarce good among competing persons.’<sup>55</sup> In the context of healthcare, it is thus the ‘controlled allocation of health care resources.’<sup>56</sup>

Many people are reluctant, uncomfortable or even vehemently opposed to the notion of healthcare rationing.<sup>57</sup> Syrett notes that in the light of challenges surrounding the public legitimacy of healthcare rationing, a process of public deliberation concerning the societal necessity of rationing is needed, along with clear criteria that underpin such allocative decisions.<sup>58</sup> States cannot simply offer the ‘highest attainable standard of care’ to each and every citizen without taking resource constraints into account. Equity and ethics thus are heeded to ensure a proper process of scarce resource allocation, which is rationing.<sup>59</sup> It is important to observe that such policy decisions in healthcare are not inappropriate or unjust by nature. Only by engaging in an open and public debate about them can we avoid the common misconceptions that this policy problem of scarce healthcare resources does not exist or that it can be easily resolved.

## 4.2. Types of Healthcare Rationing

### 4.2.1. *Implicit Healthcare Rationing*

Rationing decisions are either of implicit or explicit nature, meaning that they are shielded from the public, or that they are publicly visible. In an implicit rationing system, the criteria by which rationing decisions are made are less clear to the public, providers or patients. The inclusion and exclusion criteria are often non-transparent, making it difficult to see who made which decisions and which arguments the rationing policy was based upon.<sup>60</sup>

Lauridsen, Norup and Rossel identify four conditions veiled care rationing must fulfill for it to be considered *implicit* rationing:

1. ‘It sets limits to the range of choices that are available to patients among potentially beneficial treatments;

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<sup>55</sup> Russell. *Health-Care Rationing*. p. 85.

<sup>56</sup> Hirose, Bognar. *The ethics of health care rationing*. p. 151.

<sup>57</sup> Ibidem.

<sup>58</sup> Syrett, *Law, Legitimacy, and the Rationing of Healthcare*. p. 20.

<sup>59</sup> Dittrich, R., Cubillos, L., Gostin, L., Chalkidou, K., & Li, R. (2016). The International Right to Health: What Does It Mean in Legal Practice and How Can It Affect Priority-setting for Universal Health Coverage?. *Health Systems & Reform*, 2(1). p. 25.

<sup>60</sup> Syrett, K. (2014). The Legal Context of Bedside Rationing. In M. Danis, S. Hurst, L. Fleck, R. Førde & A. Slowther, *Fair resource allocation and rationing at the bedside* (1st ed.). Oxford: Oxford University Press. p. 131.



2. The aim of setting this limit is to reduce or contain expenses;
3. The decision to set limits is hidden from patients;
4. The rationale for the decision to set limits is hidden from patients<sup>61</sup>

Due to the fewer checks and balances involved, implicit rationing decisions are often easier to implement as there is less attention drawn to them. This creates the misconception that fewer resources are actually being withheld, fueling the public illusion that no rationing has effectively occurred. A frequently used argument defending implicit rationing is that resources are not actually being withheld. Instead eligibility criteria are in place in order to qualify for certain care through a specific program, and some patients simply do not meet them. Here, not the limited financial resources are presented as the reason for not receiving care, but other non-medical, not evidence-based criteria. This misleading characterization veils the implicit rationing taking place through restricted access. Supporters of implicit rationing also point to the strong and influential patient lobbying groups advocating that certain treatments be refunded in public health insurance schemes. They argue that physicians would not be able to withstand pressure of the lobby, nor would politicians be able to withstand the often-ensuing emotional public outcry. It is argued by making rationing implicit – effectively hiding it from politicians, the public and even physicians – there would be a better chance of reaching fair and unbiased outcomes it is argued.<sup>62</sup>

Though proponents argue implicit rationing protects policymakers from special interest group pressure, a veiled allocation system in fact makes it easier for conflicts of interest to occur and to go unnoticed and unaccounted for, thereby facilitating certain patient groups to gain unfair advantages in such a system. This is not mere speculation, as investigative reporting by a Dutch newspaper laid bare.<sup>63</sup> This veiled system impedes a mechanism to ensure public accountability.<sup>64</sup>

Implicit rationing often occurs at the micro-level. Healthcare providers find themselves, in their role as gatekeepers, in a *Catch-22* situation in which they must balance the interests of the patient in their office and those of society.<sup>65</sup> Providers thus are pushed into the role of double agents, providing for patients health needs whilst simultaneously trying to limit healthcare expenses for society as a whole

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<sup>61</sup> Lauridsen, S., Norup, M., & Rossel, P. (2007). The secret art of managing healthcare expenses: investigating implicit rationing and autonomy in public healthcare systems. *Journal of Medical Ethics*, 33(12), p. 704.

<sup>62</sup> Ibid. p. 706.

<sup>63</sup> See the investigation of the lobby for Vertex Pharmaceuticals' *Orkambi* drug: De keiharde lobby voor een extreem duur medicijn. (2017). Retrieved from <https://www.nrc.nl/nieuws/2017/11/17/de-keiharde-lobby-voor-een-extreem-duur-medicijn-14080132-a1581643>. Accessed 4/8/2018.

<sup>64</sup> Hicks. Making Hard Choices. p. 39.

<sup>65</sup> Hirose, Bogнар. *The ethics of health care rationing*. p. 15.

simultaneously. This situation is ethically indefensible.<sup>66</sup> It is not inconceivable then, that personal preferences and (unconscious) biases implicitly influence caretakers' decisions unrelated to patient health status or medical need, such as age, prior medical history, social standing, intelligence, and financial position, all of which have known to be of influence upon their decisions.<sup>67</sup> There is no guarantee that their choices would be rational or morally justifiable.<sup>68</sup> Additionally, a care seeker is more likely to be awarded care when one demands specific services or if one challenges the providers' decisions.<sup>69</sup> Patients who are less demanding and less knowledgeable are more likely to be denied care. Such implicit influencers at the micro level lead to decisions that cannot be challenged by individuals or by society, as they cannot be transparently and trustworthily reconstructed, and thus remain impervious to discussion, assessment, or public scrutiny. Physicians and healthcare professionals will more likely enforce a system of just care allocation when they act within a framework of a capped healthcare budget and freely agreed to prioritization by the public.<sup>70</sup>

Considering that implicit rationing obfuscate allocation decisions for patients and the public, Lauridsen, Norup, and Rossel appraised its compatibility with the ethical principle of autonomy.<sup>71</sup> The authors make a distinction between individual and political autonomy in the light of implicit rationing. At the individual level, patients must give their informed consent for a treatment, and their right to refuse a treatment must be respected, as must their right to engage in medical decision-making.

In addition to their status as patient, each patient is of course also a citizen enjoying universal inalienable rights of political liberty, participation and suffrage. As such, citizens 'possess a broader set of political rights, which enable political autonomy by entitling people to participate in the political decision-making process where citizens mutually regulate their shared life conditions.'<sup>72</sup> Political autonomy is also incompatible with implicit rationing systems, as it would inhibit citizens to be able to exercise their right to participate in public deliberation about public affairs in an informed manner. Citizens thus may not be restricted to a role of mere beneficiaries of healthcare, as they have a positive right to function as distributors of healthcare through democratic deliberation.<sup>73</sup>

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<sup>66</sup> Crowe, M. (2010). Allocation of Health Care Resources at the Point of Care. *Journal of Legal Medicine*, 31(4), p. 464.

<sup>67</sup> Ibid. p. 461.

<sup>68</sup> Hirose, Bogner. *The ethics of health care rationing*. p. 151.

<sup>69</sup> Crowe. Allocation of Health Care Resources. p. 464.

<sup>70</sup> Fleck. *Just caring: health care rationing*. p. 401.

<sup>71</sup> Lauridsen, Norup, Rossel. The secret art of managing healthcare expenses. p. 705.

<sup>72</sup> Ibidem.

<sup>73</sup> Ibid. p. 706.

Implicit rationing is thus at odds with the individual's right to information, right to engage in medical decision-making, and right to participate in public deliberation about public affairs (in an informed manner), and allows for systematic discrimination to occur against vulnerable individuals due to its lack of a system of public scrutiny.

#### 4.2.2. Explicit Healthcare Rationing

Over the past decades there has been a steady trend towards more transparency in the process of scarce resource allocation in healthcare.<sup>74</sup> The explicit system of rationing, by nature, is more direct and transparent, allowing for clear understanding of what and who will or will not be covered. For individuals seeking care, it thereby becomes visible on what grounds access to care was granted or denied. The decisions concerning resource allocation are taken at the macro-level, and thereby create less conflict for the providers at the micro-level. This goes along with a loss of discretion, however, as providers have fewer services that are now available to treat patients.<sup>75</sup> A good example of explicit rationing in practice is the Oregon Health Plan, for which a list of transparent priorities was composed as part of the Oregon Medicaid program.<sup>76</sup>

Greater visibility will undoubtedly lead to more anguish caused amongst patients who do not receive care due to rationing policies, but who know that treatment *could* have been possible if not for budget restrictions.<sup>77</sup> The risk of more disaffected individuals contesting such allocative policy would seem larger.<sup>78</sup> The alternative can be described as a 'merciful lie', in which the real reason to deny or restrict care to a patient is hidden (or disguised as a clinical argument), and thereby would be in violation of a patient's right to information.<sup>79</sup>

#### 4.3. Criteria for Moral Acceptability

In their paper, Slowther and Hope bring forth Daniels' and Sabin's appeal for a process of fair scarce resource allocation. In order for it to be fair, four conditions

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<sup>74</sup> Syrett. The Legal Context of Bedside Rationing. p. 134.

<sup>75</sup> Hicks. Making Hard Choices. p. 38.

<sup>76</sup> Ham, C., & Coulter, A. (2001). Explicit and implicit rationing: taking responsibility and avoiding blame for health care choices. *Journal of health services research & policy*, 6(3). p. 163.

<sup>77</sup> Syrett. The Legal Context of Bedside Rationing. p. 131.

<sup>78</sup> Mechanic, D. (1995). Dilemmas in rationing health care services: the case for implicit rationing. *BMJ*, 310(6995), p. 1658.

<sup>79</sup> Syrett. The Legal Context of Bedside Rationing. p. 131.

must be satisfied, collectively constituting ‘accountability for reasonableness’, namely *publicity*, *reasonableness*, *appeals*, and *enforcement*.

1. For *publicity*, decisions about scarce resource allocation and their underlying rationales must be made publicly accessible;
2. For *reasonableness*, the process of decision-making must aim to balance ‘value for money’ and the varied health needs of citizens in light of scarce resources;
3. For *appeals*, there must be a system in place allowing citizens to challenge and to dispute rationing decisions, which offers the chance for decisions to be overturned when confronted with new evidence or arguments;
4. For *enforcement*, a regulatory body must be in place, either of voluntary or public nature, to guarantee the first three conditions.<sup>80</sup>

In order for healthcare rationing decisions to be publicly accessible, they must be of explicit nature.<sup>81</sup> Their underlying rationales must adhere to evidence and principles deemed morally ‘fair’ and ‘just.’ There must be routes for the revision of decisions and policies, and finally, there must be a system of regulation in place to make sure that previous three conditions are respected and adhered to.<sup>82</sup> The applicability of this framework has been demonstrated in several studies about allocative policy-making in both the UK and the USA, implying that such a system as the ‘accountability for reasonableness’ framework is defensible irrespective of systematic differences in care funding and provision.<sup>83</sup> By this structure, care rationing can be ‘fair, accountable, and transparent’<sup>84</sup>, even if no agreement on the outcome is achieved.<sup>85</sup> It thus reinforces the importance of transparent and accountable decision-making.<sup>86</sup>

A rationing process that guarantees such procedural fairness and reasonableness in its decision-making, when confronted with individual applications for specific healthcare treatments or services, is a ‘principled and transparent process of priority-setting’ in which competing views of the rationing decision invite public discussion.<sup>87</sup> A system of rationing must balance equity and efficiency. ‘Equity

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<sup>80</sup> Slowther, Hope. Resource allocation decisions. p. 65.

<sup>81</sup> Landwehr, C. (2009). Deciding how to decide: the case of health care rationing. *Public Administration*, 87(3). p. 590.

<sup>82</sup> Ibidem.

<sup>83</sup> Ham, Coulter. Explicit and implicit rationing. p. 166.

<sup>84</sup> Hirose, Bogner. *The ethics of health care rationing*. p. 152.

<sup>85</sup> Ham, Coulter. Explicit and implicit rationing. p. 166.

<sup>86</sup> Ibidem.

<sup>87</sup> Flood, C., Gross, A. Litigating the Right to Health: What Can We Learn from a Comparative Law and Health Care Systems Approach? *Health and Human Rights*. 2014; 16(2). p. 69.

without efficiency is unaffordable; efficiency without equity is iniquitous.’<sup>88</sup> As Fleck reminds us, no person is entitled to unlimited healthcare and no person has the right to claim care over the just (higher-priority) needs of others.<sup>89</sup>

For allocative decision making to be fair and just, it must be the result of ‘comprehensive, systematic, rational deliberation.’<sup>90</sup> Only when rationing occurs in a transparent and explicit manner, can the inherent trade-offs between those who do and those who do not receive care resources be societally judged in a democratic manner. Rationing decisions made case-by-case and without a clear underlying policy, are likely to have unjust and arbitrary consequences, paving the road for discrimination. Forcing trade-offs to be made explicitly and rationally substantiated and for them to be freely accepted by those (possibly) affected, offers the strongest protection against minority interest groups jeopardizing societal fairness of such trade-offs. In that same vein, rationing policies that are transparent to the public and thus open to critical assessment are more likely to be morally just. Those policies lacking transparency are much less likely to allow for correction, and leave room for abuse and unjust discrimination. The essential aspect of any societally acceptable rationing decision is that it is freely self-imposed. Only when those who are to be affected by a certain measure are able to participate in the process of democratic deliberation can this be the case.

However, how motivated will policymakers actually be when it comes to the engagement of patients and the public? Is such public participation designed for cosmetic reasons and merely symbolic, or would they embrace and promote such potentially disruptive consequences? These are difficult questions to answer, all the more because no unambiguous understanding exists of what public involvement would entail.<sup>91</sup> Would it be patients who participate in policy shaping, potential users of care, or individuals as part of the citizenry? To date, academic evidence of its value and impact remains meager, and even less clear is the degree to which it would actually induce policy changes.<sup>92</sup> This necessitates further research.

Several characteristics of a morally acceptable process of healthcare rationing recur throughout the literature. The process must be explicit and of transparent nature. It must be participatory, allowing all citizens to participate in a process of democratic deliberation, thereby securing accountability. It must be freely self-imposed. All

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<sup>88</sup> Fleck. *Just caring: health care rationing*. p.401

<sup>89</sup> Ibidem.

<sup>90</sup> Ibid. p. 400.

<sup>91</sup> Hunter, D. J., Kieslich, K., Littlejohns, P., Staniszewska, S., Tumilty, E., Weale, A., & Williams, I. (2016). Public involvement in health priority setting: future challenges for policy, research and society. *Journal of health organization and management*, 30(5). p. 804.

<sup>92</sup> Ibid., 805.

individuals who will be affected by the rationing policy decision must be included in the aforementioned 'rational, democratic deliberation.'<sup>93</sup> A scrutinizing body must be in place, which critically assesses rationing policies for their adherence to the previously mentioned process criteria.

In addition to process requirements, certain points are identified about the substance of healthcare rationing. It must be non-discriminatory and it must be equitable, thereby guaranteeing affordability and accessibility of care, regardless of socio-economic status or ability to pay.<sup>94</sup>

Though ethicists have been pointing towards an explicit system of healthcare rationing for it to be morally acceptable for society for some time, political leaders seem to remain reluctant to impose such an approach to policy making. One of the rather disappointing explanations lies with their ubiquitous hesitation to accept their political responsibility in having to make unpopular decisions.<sup>95</sup> In healthcare policy-making, a clear tendency among lawmakers to avoid and duck such difficult issues, or to deflect responsibility onto others can be observed. This tendency to seek to avoid blame for publicly unpopular rationing policies resonates with research into politicians' motivations.<sup>96</sup> As a result, it remains obfuscated how rationing policy is developed, avoiding public participation and without accountability.<sup>97</sup>

The true challenge thus will not lie with the avoidance of the rationing debate at the macro-level, but rather with the question of 'how to develop an informed democratic consensus model in which through broad mechanisms of public deliberation there is debate about how limited healthcare resources can be distributed.'<sup>98</sup> Rationing fundamentally must thus be legitimate and thereby also morally acceptable to those individuals who pull the short straw, especially when they are excluded from care as a result. 'Fairness, accountability, and transparency' are all essential for rationing to be legitimate for each individual of the population.<sup>99</sup> This reflects why the ethics of healthcare rationing are so instrumental to the construction of a just and equitable system of resource allocation. Many citizens will risk being excluded from receiving medical care they are entitled to under their country's universal health insurance scheme when rationing occurs in an unfair and inefficient manner. This is morally indefensible.<sup>100</sup>

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<sup>93</sup> Fleck. *Just caring: health care rationing*. p.400.

<sup>94</sup> Hirose, Bognar. *The ethics of health care rationing*. p. 152.

<sup>95</sup> Syrett, *Law, Legitimacy, and the Rationing of Healthcare*. p. 243.

<sup>96</sup> Ham, Coulter. Explicit and implicit rationing. p. 163.

<sup>97</sup> See Buijsen, M. (2014). Ben ik soms te duur? Retrieved from <https://www.trouw.nl/home/ben-ik-soms-te-duur~a08e6334/>.

<sup>98</sup> Ham, Coulter. Explicit and implicit rationing. p. 168.

<sup>99</sup> Hirose, Bognar. *The ethics of health care rationing*. p. 153.

<sup>100</sup> Ibid. p. 14.

As discussed in this chapter, several criteria for moral acceptability of healthcare rationing policy are reflected in the ethics literature. Such policy must guarantee the provision of the following: *transparency and explicitness, accountability, equality and equity, non-discrimination and inclusiveness, openness to rational and democratic deliberation, and openness to participation.*

In the following chapter, the attention is turned to the right to health as covered by the UN, the Council of Europe and the EU.

## 5. The Right to Health

### 5.1. The United Nations

The World Health Organization was the first to articulate the right to health as a human right. The WHO's 1946 Constitution states that '*the enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition.*'<sup>101</sup> The World Health Organization defines health as '*a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.*' Subsequently the Universal Declaration of Human Rights (1948) recognized the right to health as a dimension of the right to an adequate standard of living (Art. 25). In 1966 the United Nations arrived at what has become the standard definition of the right to health. The International Covenant on Economic, Social and Cultural Rights recognizes '*the right of everyone to the enjoyment of the highest attainable standard of physical and mental health*' (Art. 12).

The UN Committee on Economic, Social and Cultural Rights (CESCR) has clarified the normative content of the right to health in its widely cited General Comment No. 14.<sup>102</sup> The Committee interprets the right to health as '*an inclusive right extending not only to timely and appropriate health care but also to the underlying determinants of health.*'<sup>103</sup>

The right to health includes several essential elements:

- a) *Availability* in sufficient quantity of functioning public health and health care facilities, goods, services, and programmes, including essential medicines as defined by the WHO Action Programme on Essential Drugs;
- b) *Accessibility* of health facilities, goods and services to everyone without discrimination. Accessibility has four overlapping dimensions: non-discrimination, physical accessibility, economic accessibility (affordability), and information accessibility;
- c) *Acceptability*: all health facilities, goods and services must be respectful of medical ethics and culturally appropriate;

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<sup>101</sup> World Health Organization. (2006). *Constitution of the World Health Organization (WHO)*. (45th ed.). Geneva: WHO. p.1. Retrieved from

[http://www.who.int/governance/eb/who\\_constitution\\_en.pdf](http://www.who.int/governance/eb/who_constitution_en.pdf). Accessed 8/8/2018

<sup>102</sup> Committee on Economic, Social and Cultural Rights (CESCR), General Comment No. 14 (2000), E/C.12/2000/4

<sup>103</sup> CESCR, General Comment No. 14, paragraph 11. The underlying determinants of health include access to safe and potable water and adequate sanitation, an adequate supply of safe food, nutrition and housing, healthy occupational and environmental conditions, and access to health-related education and information, including on sexual and reproductive health.



- d) *Quality*: health facilities, goods and services must be scientifically and medically appropriate and of good quality.<sup>104</sup>

States must guarantee *equality of access* to health care and health services. They have a special obligation to provide those who do not have sufficient means with the necessary health insurance and health care facilities.<sup>105</sup>

States parties must ensure the satisfaction of, at the very least, minimum essential levels of the rights enunciated in the Convention. According to the Committee, these '*core obligations*' include, inter alia, the provision of essential drugs, the equitable distribution of all health facilities, goods and services, and the implementation of a national health strategy on the basis of a participatory and transparent process. The Committee also identifies '*obligations of comparable priority*', including immunization against major infectious diseases, and the prevention, treatment, and control of epidemic and endemic diseases.<sup>106</sup>

While some of these obligations are substantive (such as the provision of essential medicines), others are of a procedural nature (such as participatory and transparent policy-making).

As the reference to 'the highest attainable standard' makes clear, the right to health is not absolute. Every state has a margin of discretion in deciding how to implement the Covenant.<sup>107</sup> In particular, the Covenant provides for progressive realization of economic, social and cultural rights.<sup>108</sup> In relation to the right to health, states are entitled to take account of the state's available resources, and of the individual's biological and socio-economic preconditions.<sup>109</sup> However, several obligations are of immediate effect, such as the guarantee of non-discrimination and the obligation to take 'deliberate, concrete and targeted' steps towards the full realization of the right to health.<sup>110</sup> State parties must move as expeditiously and effectively as possible towards the full realization of Article 12.<sup>111</sup>

The Committee is aware that states, as sovereign entities, are free to cut public expenditure, including in the field of public health. This poses a risk that such cuts

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<sup>104</sup> Ibid. para.12

<sup>105</sup> Ibid. para.19

<sup>106</sup> Ibid. paras. 43-44.

<sup>107</sup> Ibid. para. 53.

<sup>108</sup> Committee on Economic, Social and Cultural Rights (CESCR) (1966). *International Covenant on Economic, Social and Cultural Rights (ICESCR)*. Article 12(1). Retrieved from <https://www.ohchr.org/Documents/ProfessionalInterest/cescr.pdf>. Accessed 3/7/2018.

<sup>109</sup> Ibid. paras. 9 and 30.

<sup>110</sup> Ibid. para. 30.

<sup>111</sup> Ibid. para. 31.

could adversely affect public health standards. The Committee is therefore at pains to point out that, as with all other rights in the Covenant, there is a strong presumption that retrogressive measures in relation to the right to health are not permissible. *'If any deliberately retrogressive measures are taken, the State party has the burden of proving that they have been introduced after the most careful consideration of all alternatives and that they are duly justified by reference to the totality of the rights provided for in the Covenant in the context of the full use of the State party's maximum available resources.'*<sup>112</sup> States are reminded that, as a human right, the right to health must be *respected, protected, and fulfilled*.<sup>113</sup> As an example of a violation of the obligation to fulfill the Committee mentions *'insufficient expenditure or misallocation of public resources which results in the non-enjoyment of the right to health by individuals or groups, particularly the vulnerable or marginalized.'*<sup>114</sup> The Office of the UN High Commissioner for Human Rights concludes that states must guarantee the right to health to the maximum of their available resources, even if these are tight.<sup>115</sup>

The World Health Organization notes that economic accessibility does not mean that all health services must be provided by the government, or that citizens should be entitled to receive them free of charge. However, the principle of equity applies: the poorest and most vulnerable groups must not be disproportionately burdened with health expenses.<sup>116</sup> The WHO points out that this may require governments to subsidize some costs. Economic accessibility also requires governments to implement funding mechanisms that shift the financial burden from health care clients to taxpayers. This can be achieved by reducing out-of-pocket payments when a service is delivered and by expanding taxpayer funded health insurance schemes, premiums, or other pre-payment mechanisms.<sup>117</sup>

In a similar vein, the UN High Commissioner for Human Rights warns that privatization of health care must not be allowed to undermine the availability, accessibility, acceptability and quality of health care facilities, goods, and services. Should such negative effects occur, the state would be in violation of its obligation to protect the right to health.<sup>118</sup>

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<sup>112</sup> Ibid. para. 32.

<sup>113</sup> Ibid. para. 33.

<sup>114</sup> Ibid. para. 53.

<sup>115</sup> Office of the United Nations High Commissioner for Human Rights. (n.d.). *The Right to Health*, Fact Sheet No. 31. p. 5.

<sup>116</sup> World Health Organization (2017). *Advancing the right to health: the vital role of law*. Geneva: WHO. p. 19.

<sup>117</sup> Ibidem.

<sup>118</sup> Ibid. p. 26.

As of June 2018 there were 168 state parties to the International Covenant on Economic, Social and Cultural Rights. Four countries have signed but not ratified (including the USA); 24 have taken no action (including Saudi Arabia and Singapore).<sup>119</sup>

The Optional Protocol to the International Covenant on Economic, Social and Cultural Rights (ICESCR) provides for three mechanisms to address infringements of the rights guaranteed by the ICESCR: an individual complaints procedure, inter-state complaints procedure, and an inquiry procedure. Under the individual complaints procedure communications may be submitted by or on behalf of individuals or groups of individuals. Complainants must have exhausted all domestic remedies. The inter-state complaints procedure and the inquiry procedure only apply to states that, having ratified the protocol, and have opted in to these procedures. The Optional Protocol to the ICESCR entered into force in 2013. It has been ratified by only 23 states.<sup>120</sup> Although most UN member states have been content to sign up to the principle of progressive realization of economic, social and cultural rights, as embodied in the ICESCR, they have on the whole proven reluctant to submit themselves to external scrutiny.

Economic, Social and Cultural rights can be litigated at court, as is confirmed by the UN's Office of the High Commissioner on Human Rights (OHCHR).<sup>121</sup> However, the OHCHR points out, there are several reasons why the justiciability of economic, social and cultural rights (ESCRs) is often questioned or doubted. First of all, ESCRs are commonly considered to be worded too vaguely in order for judges to decide a case properly. Considering terms such as 'hunger', 'adequate' housing, or 'fair' wages, no common benchmark exists. Secondly, the realization of internationally agreed to ESCRs largely depends upon domestic policies in the respective area. A role for courts does exist, however, when reviewing whether policies shaped by governments are in line with their national constitutions. Thirdly, the monitoring of the progressive realization of ESCRs can occur through several mechanisms, including by the judiciary. One such a measure for courts to assess – as occurred in South Africa – is 'reasonableness.' The CESCR has stated that the means that states have at their discretion to progressively realize the ICESCR's provisions must be reviewed by the Committee.<sup>122</sup>

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<sup>119</sup> OHCHR Indicators. (2018). Retrieved from <http://indicators.ohchr.org/>. Accessed 23/6/2018

<sup>120</sup> Including 8 of the 28 EU Member States (Belgium, Finland, France, Italy, Luxembourg, Portugal, Slovakia, and Spain)

<sup>121</sup> OHCHR. (2018). *Can economic, social and cultural rights be litigated at courts?* Retrieved from <https://www.ohchr.org/EN/Issues/ESCR/Pages/CanESCRbelitigatedatcourts.aspx>. Accessed 23/6/2018

<sup>122</sup> Cerquiera, D., *Enforceability of ESCRs: historical backgrounds, legal basis and misleading assumptions*. O'Neill Institute, 2016 [<http://www.oneillinstituteblog.org/enforceability-of-economic->

It is imperative for human rights to be judicially enforced. Courts do not pose the sole route to enforcement. They do however hold an important role, as the OHCHR states, *‘in the development of our understanding of such rights, in affording remedies in cases of clear violations and in providing decisions on test cases which can lead to systematic institutional change to prevent violations of rights in the future.’*<sup>123</sup> Several mechanisms exist to enforce ESCRs. In terms of the protection and promotion of ESCRs, the CESCR composes one of the most important of these mechanisms. It is mandated to review and monitor the State parties’ fulfillment of their ICESCR obligations.<sup>124</sup>

## 5.2. The Council of Europe

All 47 member states of the Council of Europe have signed and ratified the European Convention of Human Rights (ECHR).<sup>125</sup> The Convention, which entered into force in 1953, aims to protect a number of fundamental rights and freedoms, as ‘the first steps for the collective enforcement’ of certain of the rights stated in the 1948 Universal Declaration of Human Rights (preamble) (UDHR).<sup>126</sup> The European Court of Human Rights was set up to rule on allegations of violations of the rights enshrined in the Convention. The Court’s rulings are binding on the contracting parties. The Council of Europe’s Committee of Ministers is tasked with supervising the execution of the Convention.

The European Social Charter (ESC), agreed by the Council of Europe in 1961 (revised 1996)<sup>127</sup> is a treaty that guarantees fundamental social and economic rights as a counterpart to the European Convention on Human Rights, which covers civil and

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social-and-cultural-rights-historical-background-legal-basis-and-misleading-assumptions/. Accessed 22/6/2018.

<sup>123</sup> Ibidem.

<sup>124</sup> Human Rights Enforcement Mechanisms of the United Nations. Retrieved from <https://www.escr-net.org/resources/human-rights-enforcement-mechanisms-united-nations> Accessed 22/6/2018.

<sup>125</sup> European Convention for the Protection of Human Rights and Fundamental Freedoms, as amended by Protocols Nos. 11 and 14. (1950). Retrieved from [https://www.echr.coe.int/Documents/Convention\\_ENG.pdf](https://www.echr.coe.int/Documents/Convention_ENG.pdf). Accessed 22/6/2018.

<sup>126</sup> The rights and freedoms secured by the Convention include the right to life, the right to a fair hearing, the right to respect for private and family life, freedom of expression, freedom of thought, conscience and religion and the protection of property. The Convention prohibits, in particular, torture and inhuman or degrading treatment or punishment, forced labour, arbitrary and unlawful detention, and discrimination in the enjoyment of the rights and freedoms secured by the Convention. See The ECHR in 50 Questions. Retrieved from [https://www.echr.coe.int/Documents/50Questions\\_ENG.pdf](https://www.echr.coe.int/Documents/50Questions_ENG.pdf). Accessed 22/6/2018.

<sup>127</sup> Council of Europe. (1996). *European Social Charter (Revised)*. Strasbourg: Council of Europe. Retrieved from <https://rm.coe.int/168007cf93>. Accessed 22/6/2018.

political rights. The Charter is seen as the Social Constitution of Europe.<sup>128</sup> Compliance with the European Social Charter is monitored by the European Committee of Social Rights (ECSR) through collective complaints lodged by the social partners and other non-governmental organisations, and through national reports drawn up by contracting parties. States must respect the Committee's decisions and conclusions. These are not directly enforceable, but can provide the basis for positive developments in social rights through legislation and case law at national level.<sup>129</sup>

The Governmental Committee of the European Social Charter considers conclusions of non-conformity adopted by the European Committee of Social Rights. It may propose that the Committee of Ministers address a *recommendation* to the State concerned to remedy the situation. Most member states of the Council of Europe are parties to the European Social Charter.<sup>130</sup> The collective complaints procedure, however, has been accepted by only 15 member states.<sup>131</sup>

Although the European Convention on Human Rights does not guarantee economic, social, or cultural rights, the European Court of Human Rights has found it necessary to consider such rights where they raise issues under one of the civil and political rights covered by the Convention. This has led the Court to develop a considerable body of case law in relation to health-related issues.

Health-related cases brought before the Court have most frequently been argued under Articles 2 (right to life), 3 (prohibition of torture), 8 (right to respect for personal and family life), and 14 (prohibition of discrimination) of the Convention.<sup>132</sup> The Court's judgments include cases related to medical negligence, health and bioethics, health of detainees, health and immigration, health and the environment, health and the workplace, and protection of medical data.

Though the Court has not dealt directly with cases of health care rationing, it did rule that states have positive obligations under Article 2 to protect the health of individuals. States must not only refrain from the intentional and unlawful taking of life, but must also take appropriate steps to safeguard the lives of those within their

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<sup>128</sup> Council of Europe (1996). *European Social Charter (Revised)*. ETS No. 163. Retrieved from <https://www.coe.int/en/web/turin-european-social-charter> Accessed 24/6/2018.

<sup>129</sup> European Committee of Social Rights. Retrieved from <https://www.coe.int/en/web/turin-european-social-charter/european-committee-of-social-rights>. Accessed 24/6/2018.

<sup>130</sup> Except Liechtenstein, Monaco, San Marino, and Switzerland

<sup>131</sup> Belgium, Bulgaria, Croatia, Cyprus, Czech Republic, Finland, France, Greece, Ireland, Italy, Netherlands, Norway, Portugal, Slovenia, Sweden

<sup>132</sup> European Court of Human Rights. (2015). *Thematic Report – Health-related issues in the case law of the European Court of Human Rights*. Strasbourg: Council of Europe/European Court of Human Rights. p. 5.

jurisdiction. Several judgments concern cases where the contracting state has put an individual's life at risk through the denial of health care, which the state made available to the population in general (*Cyprus v Turkey*, App No 25781/94, para. 219;<sup>133</sup> *Nitecki v Poland*, App No 65653/01, para. 2;<sup>134</sup> *Oyal v Turkey*, App No 4864/05).<sup>135</sup>

In *Cyprus v Turkey* (2001) and *Nitecki v Poland* (2002) the Court dismissed the claims that Article 2 had been violated. In *Oyal v Turkey* (2010) it ruled in favour of the claimant.

In *Oyal v Turkey* the Court considered that states are required to make regulations compelling hospitals, whether public or private, to adopt appropriate measures for the protection of their patients' lives. They must also set up an effective independent judicial system so that the cause of death of patients in the care of the medical profession, whether in the public or the private sector, can be determined and those responsible made accountable. Noting that the administrative court proceedings aimed at determining the liability of the Ministry of Health lasted nine years, four months and seventeen days, the Court concluded that the Turkish courts had failed to comply with the requirements of promptness and reasonable expedition, and that Article 2 of the Convention had been violated.

Another case about access to healthcare arose in *Panaïtescu v Romania*.<sup>136</sup> The Romanian Health Insurance fund had declined to carry out a domestic court order to provide the anti-cancer drug Avastin free of charge, which resulted in a patient's death. The Court found that the state had not adequately protected the patient's right to life under Article 2.<sup>137</sup>

In *Sentürk and Sentürk v Turkey* (2013) the Court was asked to consider the case of a heavily pregnant mother who had died after having been denied access to emergency care. This was considered a violation of the substantive limb of Article 2. The Court also noted that, after nine years of legal proceedings, the criminal cases against the defendants had been time-barred and discontinued, which failed completely to satisfy the requirement of a prompt examination of the case without unnecessary delays. The Court found that also the procedural limb of Article 2 had been violated.<sup>138</sup>

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<sup>133</sup> *Cyprus v Turkey*, App. No. 25781/94 (ECtHR, 10 May 2001)

<sup>134</sup> *Nitecki v Poland*, App. No. 65653/01 (ECtHR, 21 March 2002)

<sup>135</sup> *Oyal v Turkey*, App No. 8464/05 (ECtHR, 23 March 2010)

<sup>136</sup> *Panaïtescu v Romania* App. No. 30909/06 (ECtHR, 10 April 2012)

<sup>137</sup> For a more detailed discussion see den Exter, A. (2017). The Right to Healthcare under European Law. *Diametros*, (51), 190-192.

<sup>138</sup> *Sentürk and Sentürk v. Turkey*, App. No. 13423/09 (ECtHR, 9 July 2013)

As noted by Graham, it appears that the Court is beginning to recognise not only the right to access to healthcare but also a right to a certain quality of healthcare.<sup>139</sup> In *Asiye Genc v Turkey* (2015) the Court found that systemic inadequacies in the Turkish healthcare system, notably a lack of equipment and shortcoming in communications among medical staff, had resulted in the death of a child.<sup>140</sup> A similar case arose in *Aydoglu v Turkey* (2016).<sup>141</sup> In both cases the Court found that Article 2 of the ECHR had been infringed.

Even though the Court did not acknowledge a general right to healthcare, it did 'push the envelope' by concluding that a state's failure to create a regulatory framework to guarantee access to health care in emergency situations violates the right to life.<sup>142</sup> Obviously, such judicial reasoning is likely to have budgetary consequences for the states concerned. Could the ECtHR be at risk of imposing an excessive burden on governments? The Court has addressed this question in the *Aydogdu* case (paragraph 87), where it noted that the Turkish government had failed to prove that providing a legislative framework would have been an excessive burden in terms of allocation of resources. The burden of proof, it seems, is on the state.

The European Social Charter contains a direct reference to the right to health. Article 11 of the Charter grants everyone the right to benefit from any measures enabling him (sic) to enjoy the highest possible standard of health attainable.

*'With a view to ensuring the effective exercise of the right to protection of health, the Parties undertake, either directly or in cooperation with public or private organisations, to take appropriate measures designed inter alia:*

- 1. to remove as far as possible the causes of ill-health;*
- 2. to provide advisory and educational facilities for the promotion of health and the encouragement of individual responsibility in matters of health;*
- 3. to prevent as far as possible epidemic, endemic and other diseases, as well as accidents.'*<sup>143</sup>

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<sup>139</sup> Graham, L. (2017). 'The European Court of Human Rights and the Emerging Right to Health [Blog]. Retrieved from <http://ohrh.law.ox.ac.uk/the-european-court-of-human-rights-and-the-emerging-right-to-health>. Accessed 22/6/2018.

<sup>140</sup> *Asiye Genc v Turkey*, App. No. 24109/07 (ECtHR, 27 April 2015)

<sup>141</sup> *Aydogdu c Turquie*, Requête No. 40448/06 (CEDH, 30 août 2016)

<sup>142</sup> Aleydis Nissen, 'A right to access to emergency health care: the European Court of Human Rights pushes the envelope', *Medical Law Review*, Vol.0, No. 0, p. 1-10.

<sup>143</sup> In addition, Art. 3 ESC concerns health and safety at work; Articles 7 and 17 cover the health and well-being of children and young persons; Articles 8 and 17 concern the health of pregnant women; Art. 23 deals with the health of elderly persons.

All state parties except Armenia have accepted the three paragraphs of Article 11, which address the curative, promotional, and preventive obligations of states.

Over the years, the European Committee of Social Rights has developed an extensive catalogue of thematic standards and indicators to assess how states comply with Article 11. In an effort to combine a results-based approach with a quantitative analysis the Committee often asks governments to submit health-related data. It uses two monitoring tools not employed by any other human rights body: thematic health indicators and international (European) averages. This practice is unique in the world: Claire Lougarre observes that no other human rights body goes into such depth.<sup>144</sup>

Of the three paragraphs, paragraph 11(1) is most relevant to any issues that could arise as a result from measures to ration national healthcare. The Committee has developed five sets of indicators and standards to measure compliance with Article 11(1). Lougarre summarizes them as follows:

Indicator: none in particular. Standards: *States' performance* must improve, must not be significantly below the European average, and must not reflect strong disparities between urban and rural areas or between regions;

Indicator: *life expectancy and main causes of death*. Standards: Health systems must respond appropriately to avoidable health risks, and states must reach the best results possible, according to the knowledge available;

Indicator: *infant and maternal mortality*. Standard: states must undertake measures to bring maternal and infant deaths down to zero risk, especially countries with highly developed healthcare systems;

Indicator: *access to healthcare*. Standards: healthcare systems must be accessible to everyone, and potential restrictions on the application of Article 11 must not impede access to healthcare for disadvantaged groups. Costs of healthcare must be borne, at least in part, by the community. States must take steps to reduce healthcare costs for patients, especially the most disadvantaged ones, and guarantee that they do not become an excessive burden. Health services must be provided without unnecessary delays;

Indicator: *healthcare professionals and facilities*. Standards: The numbers of health staff and facilities must be sufficient<sup>145</sup>, the living conditions in psychiatric hospitals must be adequate and preserve human rights.<sup>146</sup>

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<sup>144</sup> Lougarre, C., (2015). What does the right to health mean? *Netherlands Quarterly of Human Rights*, Vol. 33/3). p. 338, 353.

<sup>145</sup> The criterion is 3 beds per thousand citizens. See Council of Europe. (2009). *The Right to Health and the European Social Charter*. p. 10. Retrieved from [https://www.ilga-europe.org/sites/default/files/right\\_to\\_health\\_and\\_esc.pdf](https://www.ilga-europe.org/sites/default/files/right_to_health_and_esc.pdf). Accessed 11/8/2018.

<sup>146</sup> Lougarre, op. cit., p. 332. (italics CdV)



To assess compliance with the right to health the Committee thus employs a range of substantive and procedural criteria, not unlike (but not identical to) the ones used by the UN Committee on Economic, Social and Cultural Rights. In contrast to the CESCR, the ECSR does not appear to assess whether states have systems of participatory and transparent decision-making.

The ECSR integrates the issue of resource availability as it evaluates states' performance in healthcare according to their level of income. It assesses the performance of a state with a low income by comparing it with the overall performance of states with similarly low incomes. For example, it found that the results achieved by Turkey were significantly worse than those in countries with a comparable income level. It also sets stricter standards for countries with more developed health systems, expecting them to progress faster to zero infant and mortality rates.<sup>147</sup>

Historically, the ECSR has been reluctant to reach a finding of non-conformity with Article 11, and particularly with states' express obligations. Lougarre finds that non-conformity findings are mostly based on a state's failure to fulfil the implied obligations to submit data, or a failure to perform comparably with European averages. Out of the 870 findings reached by the ECSR with respect to Article 11, only 79 correspond to a violation, and only 37 of these 79 violations are due to inadequate performances in the field of healthcare (4.2%). In recent years, however, the Committee seems more inclined to reach a conclusion of non-conformity, with numbers rising to 30 in 2009 and 29 in 2013.<sup>148</sup> In numerous cases the ECSR has stressed the need for states to expand healthcare facilities and services for older people, to provide affordable care, and, where necessary, to provide assistance in covering the costs.<sup>149</sup>

The trend identified by Lougarre is borne out in the most recent analysis of compliance with the right to health. In contrast with its reticence in earlier years, in 2017 the Committee found that only around 50% of national situations were in conformity with the Charter (Article 11, paragraphs 1-3). Among the 'significant challenges' that have not yet been addressed it singled out the persisting high infant and mortality rates in a number of states (e.g. in Georgia, the Republic of Moldova, Romania, the Russian Federation, and Turkey). In relation to access to healthcare it stated that under Article 11 'the cost of health care must not represent an excessively heavy burden for the individual and the out-of-pocket payments should not be the

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<sup>147</sup> Ibid. p. 345.

<sup>148</sup> Ibid. p. 352.

<sup>149</sup> Battaini-Dragoni, G. (2016). *Aging and Health: a challenge to public health and social cohesion – a strong need for common action*. Speech, Strasbourg.

main source of funding of the health system.’ In this regard, the Committee found that access was not ensured because of long waiting times (In Poland and Albania), low public healthcare expenditure (e.g. in Albania, Azerbaijan, Latvia and Ukraine), as well as the high proportion of out-of-pocket payments or informal payments (e.g. in Lithuania and Ukraine).<sup>150</sup>

The ECSR was notably critical of the situation in Greece. It noted that according to the OECD, between 2009 and 2013, public spending on health in Greece fell by €5.2bn (a 32% drop in real terms). The UN Independent Expert concluded that unprecedented cuts to the public health system have resulted in a critical understaffing in parts of the public health system, increase in co-payments, waiting lists and difficulties to provide effective and affordable access to the right to adequate health care for all. However, the Committee stopped short of concluding that Greece was in breach of Article 11. Instead Greece was asked to provide comprehensive information on access to health care, information on the expenditure on health and out-of-pocket costs paid by patients, information on average waiting times for health care (primary and specialist care as well as inpatient and outpatient care) and the trend in actual waiting times. Pending receipt of the information requested, the Committee decided to reserve its position.<sup>151</sup>

The latest Council of Europe convention which has a bearing on the access to healthcare is the Oviedo Convention. The Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine was signed in 1997 in Oviedo (Spain), and entered into force in 1999. As of August 2018, of the Council of Europe’s 47 member states it had only been signed by 35, of which six have yet to ratify it.<sup>152</sup> The preamble stipulates that the Oviedo Convention is in line with several UN and Council treaties, among which the Universal Declaration of Human Rights (UDHR), and the previously discussed ESC, and ICESCR.

The most relevant Convention article to this paper is article 3 concerning ‘equitable access to healthcare.’ It states that ‘*parties, taking into account health needs and*

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<sup>150</sup> European Committee of Social Rights. (2018). *Press Briefing Elements, Conclusions 2017* doc 736. Strasbourg: Council of Europe. p. 5.

<sup>151</sup> European Committee of Social Rights. (2018). *Conclusions XXI-2 (2017) - Greece*. Strasbourg: Council of Europe. p. 12.

<sup>152</sup> Germany, Russia, Belgium, the UK, Ireland and Austria, among others, have not signed the Oviedo Convention. The Netherlands, Sweden, Luxembourg, Italy, Poland, and the Ukraine have not ratified the Convention. See Full list (member states) Oviedo Convention. Retrieved from [https://www.coe.int/en/web/conventions/full-list/-/conventions/treaty/164/signatures?p\\_auth=jGE2zXJE](https://www.coe.int/en/web/conventions/full-list/-/conventions/treaty/164/signatures?p_auth=jGE2zXJE). Accessed 28/7/2018.

*available resources, shall take appropriate measure with a view to providing within their jurisdiction, equitable access to health care of appropriate quality.*<sup>153</sup>

The core of the Convention is the right to self-determination<sup>154</sup> and it rests upon four normative pillars:

1. 'The right of protection for human dignity and identity;
2. The right of respect for one's integrity;
3. The right to (equal access to) healthcare;
4. The prohibition of unjust discrimination'<sup>155</sup>

The Explanatory Report adds some important points of consideration with regards to the Conventions articles. It specifies that equitable access is not equivalent to absolute equality in access to care, and that discrimination is prohibited in all circumstances. States must do everything within their power and means to provide equitable access to healthcare, thereby reflecting the requirement of progressive realization.<sup>156</sup> Their aim must be to guarantee equitable access to healthcare to all, according to objective medical need.<sup>157</sup> The goal of this provision is to urge states parties to implement the requisite measures into their healthcare policies in the pursuit of ensured equitable access to healthcare, not to shape an individual right to care.<sup>158</sup>

Art. 5 stipulates that each patient has the right to informed consent, including the right to know of alternative treatments to the one proposed. This is in line with the right to information.<sup>159</sup>

States parties are encouraged to ensure and promote public awareness of the content of the Convention. Parties are free to organize those procedures deemed most suitable, among which the Convention suggests the involvement of ethics committees towards public discussion and consultations.<sup>160</sup> In art. 28 the need to

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<sup>153</sup> Art. 3, Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine (Oviedo). (2018).

<sup>154</sup> Dute, J. (2005). The Leading Principles of the Convention on Human Rights and Biomedicine. In: Gevers, J.K.M., Hondius, E.H., Hubben, J.H. (eds.), *Health Law, Human Rights and the Biomedicine Convention: Essays in Honour of Henriette Roscam Abbing*. Leiden; Boston: Martinus Nijhoff Publishers. p. 9.

<sup>155</sup> Ibidem.

<sup>156</sup> Art. 3 paras. 23-27, Explanatory Report to the Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine (Oviedo). (1997).

<sup>157</sup> Ibid. para. 24. 'diagnostic, preventive, therapeutic, and rehabilitative' healthcare must be 'of fitting standard in the light of scientific progress and be subject to a continuous quality assessment.'

<sup>158</sup> Ibid. para. 26.

<sup>159</sup> Ibid. art. 5, paras. 35, 37, and art. 10, para. 66.

<sup>160</sup> Ibid. art. 28, para. 163.

involve citizens is recognized in shaping policy about issues that may directly affect them. In fact, in 1994 the draft version was made public in order for states to initiate public debate.<sup>161</sup> It is necessary to find common ground amongst the many diverging opinions within a pluralistic society in which different views on life coexist. All voices must thus be heard in the public debate.<sup>162</sup>

Though the Convention does not define 'access' to healthcare, it does stipulate that healthcare must be non-discriminatory, equitable, and adequate, implying a 'satisfactory degree of care.'<sup>163</sup> Health needs must be judged in an objective manner, and care must be of good quality and evidence-based.<sup>164</sup>

As a legally binding international treaty, the ECtHR uses the Oviedo Convention to strengthen its legal reasoning in its process of applying and interpreting the ECHR.<sup>165</sup> Similarly, the ECSR is able to assess the common ground between the Oviedo Convention and the European Social Charter.

### 5.3. The European Union

Public health was granted an explicit legal base within the EU for the first time in the 1993 Maastricht Treaty.<sup>166</sup>

The European Union only has the competences that the member states have conferred upon it through Treaties.<sup>167</sup> Any other competence, of which there has been no conferral on the EU, continues to rest with the member states. The EU itself thus may only act within the confines of what has been conferred on to it.

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<sup>161</sup> Gadd, E. (2005). The Global Significance of the Convention on Human Rights and Biomedicine. In: Gevers, J.K.M., Hondius, E.H., Hubben, J.H. (eds.), *Health Law, Human Rights and the Biomedicine Convention: Essays in Honour of Henriette Roscam Abbing*. Leiden; Boston: Martinus Nijhoff Publishers. p. 39.

<sup>162</sup> Borst-Eilers, E. (2005). The Role of Public Debate and Politics in the Implementation of the Convention. In: Gevers, J.K.M., Hondius, E.H., Hubben, J.H. (eds.), *Health Law, Human Rights and the Biomedicine Convention: Essays in Honour of Henriette Roscam Abbing*. Leiden; Boston: Martinus Nijhoff Publishers. p. 248-249.

<sup>163</sup> de Groot, R. (2005). Right to Health Care and Scarcity of Resources. In: Gevers, J.K.M., Hondius, E.H., Hubben, J.H. (eds.), *Health Law, Human Rights and the Biomedicine Convention: Essays in Honour of Henriette Roscam Abbing*. Leiden; Boston: Martinus Nijhoff Publishers. p. 51.

<sup>164</sup> Ibid. p. 52.

<sup>165</sup> Racounas, E. (2005). The Biomedicine Convention in Relation to Other International Instruments. In: Gevers, J.K.M., Hondius, E.H., Hubben, J.H. (eds.), *Health Law, Human Rights and the Biomedicine Convention: Essays in Honour of Henriette Roscam Abbing*. Leiden; Boston: Martinus Nijhoff Publishers. p. 33.

<sup>166</sup> Byrne, D. (2001). Public health in the European Union: breaking down barriers. *EuroHealth-London*, 7(4), 2-4.

<sup>167</sup> Division of competences within the European Union. (n.d.). Retrieved from <https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=LEGISSUM:ai0020>. Accessed 25/6/2018.

Competence division between the member states and the EU has been delineated in the Treaty of Lisbon, which divides the competences in three main categories:

- Exclusive competences;
- Shared competences; and
- Supporting competences.

As specified in the Treaty on the Functioning of the European Union (TFEU), exclusive competences refer to policy areas in which, as a rule, only the EU is permitted to legislate. Areas that fall within this category include the customs union and monetary policy for the euro-countries. In areas of shared competence member states may only act if the EU has chosen not to. These include such areas as the internal market, social policy and environmental policy. Finally, supporting competences exist, where the EU is only allowed to intervene in order to support, coordinate or complement EU states' actions. Legally binding acts of the EU may not include the harmonization of domestic legislation or regulation in member states. As well as areas such as education or tourism, the protection and improvement of human health is one of the fields amongst the supporting competences.<sup>168</sup>

Article 168 TFEU pertaining to the supporting competence in health stipulates what role the EU may take. Action taken by the Union must complement national policies. It may not infringe on the autonomy and responsibilities of EU states, including the organization and management of health services and medical care, and the allocation of resources assigned to them (Art. 168 (7)). Member states therefore remain free to finance their national health policy as they wish. The EU is only allowed to legislate in three areas: (a) quality and safety of organs and substances of human origin, blood and blood derivatives, (b) public health measures in the veterinary and phytosanitary fields, and (c) quality and safety for medicinal products and devices for medical use (Art. 168 (4)). Finally, the European Union may encourage cooperation between member states, including through guidelines and indicators, exchange of best practices, monitoring and evaluation (Art. 168 (2)). The restricted possibilities for the EU to act based on this competence explain why it has been so challenging to pursue health objectives at the EU level.<sup>169</sup>

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<sup>168</sup> Ibid.

<sup>169</sup> Brooks, E. (2017). Tamara K. Hervey, Calum Alasdair Young, and Louise E. Bishop (eds), *Research Handbook on EU Health Law and Policy*, Edward Elgar, *Medical Law Review*, 2018, Vol. 26 (1), p. 167.

## *Evolution of EU health law and policy*

European action on issues concerning health has been developing over decades, but has especially gained speed during the last one. In 2006 the Council of Ministers adopted 'Conclusions on Common values and principles in European Union Health Systems.' The Council recalls 'the overarching values of universality, access to good quality care, equity and solidarity.'<sup>170</sup>

'Universality' means that no one is barred access to health care; solidarity is closely linked to the financial arrangement of the member states' national health systems and the need to ensure accessibility to all; equity relates to equal access according to need, regardless of ethnicity, gender, age, social status or ability to pay.<sup>171</sup>

The Council of Ministers also puts forward a set of common principles, shared by all EU states. These are quality of care, safety, care that is based on evidence and ethics, patient involvement, redress, and privacy and confidentiality. Additionally, the EU Council turned to the European Commission to request that these principles be leading in later drafts concerning health services. These Common values and principles thus are not legally binding, but as 'soft law' they do offer an important and influential source for the EU institutions, including the Court of Justice of the EU (CJEU).<sup>172</sup>

There is wide consensus for the necessity of making health systems fiscally sustainable for the future in a way that protects and ensures the common values recognized in 2006 by the Council of Ministers.<sup>173</sup>

Elusive as the harmonization of healthcare policies in the EU has seemed, 2011 marked a change. In that year the EU Patient's Rights Directive was adopted, summarizing the existing patients' rights, introducing new rights of accountability and transparency, and advancing cooperation among member states' domestic healthcare systems. The Directive is based on Article 114 TFEU, which concerns the functioning of the internal market. The introduction of this new Directive can be

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<sup>170</sup> Council of the European Union. (2006). *Council Conclusions on Common values and principles in European Union Health Systems*. 2006/C 146/01. Retrieved from <https://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=OJ:C:2006:146:0001:0003:EN:PDF>. Accessed 22/6/2018.

<sup>171</sup> Ibidem.

<sup>172</sup> Hervey, T. (2017). Telling stories about European Union Health Law: The emergence of a new field of law. *Comparative European Politics*, 15(3). p. 358.

<sup>173</sup> Council of the European Union. (2016). *Council Conclusions on the EPC - Commission Joint Report on health care and long-term care in the EU*. 14182/16. Retrieved from <http://data.consilium.europa.eu/doc/document/ST-14182-2016-INIT/en/pdf>. Accessed 22/6/2018.

considered to be a significant milestone in the EU's efforts towards involvement in the area of healthcare.<sup>174</sup>

In the years before the Directive there has been a surprising development of case law in the field of health. These cases concerned patients who had sought supposedly better or quicker medical care in other EU states, whilst filing for financial reimbursement under their domestic health plans. The European Court of Justice has sided with the claimants and hereby shown support for patient mobility, citing a 'patient centered, needs based approach.'<sup>175</sup> Following the lack of appropriate implementation of this case law in most EU states, this justified the codification in the new patients' rights Directive.

The basic assumption in the Directive is that member states remain responsible for determining what medical services are covered by their national social security regimes and for the actual provision of healthcare.<sup>176</sup> Member states have limited the financial impact of the Directive by including that they are only obliged to reimburse up to what the same type of healthcare would cost in their own country.<sup>177</sup> However, in Sauter's view the main innovation is that the Directive sets out common principles for healthcare that can be seen as a new set of patient rights. Member states must provide universality, access to high-quality care, equity and solidarity of treatment. They must ensure the right to the information necessary for an informed choice, the right to make complaints and guarantees of redress and remedies, to privacy, equal treatment, and non-discrimination.<sup>178</sup>

Bearing in mind the limited scope of EU competence in the field of health, the European Commission has been remarkably active in trying to develop a more common European approach. In 2007 it launched a White Paper: 'Together for Health – A Strategic Approach for the EU.'<sup>179</sup> This strategy is in line with broader EU action to combat health inequalities and underlying determinants such as poverty or social exclusion, as part of the Europe 2020 strategy.<sup>180</sup> The White Paper was

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<sup>174</sup> Sauter, W. (2011). Harmonisation in Healthcare: The EU Patients' Rights Directive. *SSRN Electronic Journal*.

<sup>175</sup> Ibid. p. 3

<sup>176</sup> Ibid. p. 10

<sup>177</sup> Vollaard, H., van de Bovenkamp, H., & Martinsen, D. (2015). The making of a European healthcare union: a federalist perspective. *Journal Of European Public Policy*, 23(2). p. 168

<sup>178</sup> Ibid. p. 19.

<sup>179</sup> Commission of the European Communities, WHITE PAPER Together for Health: A Strategic Approach for the EU 2008-2013 (2007), {SEC(2007) 1374} {SEC(2007) 1375} {SEC(2007) 1376}. Retrieved from [https://ec.europa.eu/health/ph\\_overview/Documents/strategy\\_wp\\_en.pdf](https://ec.europa.eu/health/ph_overview/Documents/strategy_wp_en.pdf). Accessed 22/6/2018.

<sup>180</sup> ICF Consulting Services Ltd, VulnerABLE: Pilot project related to the development of evidence based strategies to improve the health of isolated and vulnerable persons (2017). Brussels: European Commission. Retrieved from [https://ec.europa.eu/health/sites/health/files/social\\_determinants/docs/2017\\_vulnerable\\_literature\\_review\\_en.pdf](https://ec.europa.eu/health/sites/health/files/social_determinants/docs/2017_vulnerable_literature_review_en.pdf). Accessed 22/6/2018. p. 30.

followed by a Communication, two years later, which focused more in detail on health inequalities and access to healthcare: 'Solidarity in health: reducing health inequalities in the EU.'<sup>181</sup> In 2013 a Commission staff working document (Investing in Health) was published, suggesting combined investments in areas to promote sustainable health systems, and people's health, and to reduce health inequalities.<sup>182</sup> In 2014 the Commission adopted a Communication entitled 'On effective, accessible and resilient health systems.'<sup>183</sup>

In each of these publications the Commission called attention to the need to tackle health inequalities and promote universal access to healthcare. In its Communication 'Solidarity in health', for example, the Commission proposed to take a series of steps to aid member states' governments to tackle health inequalities through the regular collection of statistics, the regular reporting on the size of such inequalities throughout the Union, and with strategies designed to successfully reduce them. Additionally, the EU would analyze these policies' impact on the reduction of health inequalities, and provide improved information on paths to EU funding, available to assist member states in the realization of health inequality reduction. 'Over half of the EU member states do not place policy emphasis on reducing health inequalities and there is a lack of comprehensive inter-sectoral strategies. (...) The EU has a role to improve the coordination of policies and promote the sharing of best practices.'<sup>184</sup>

In the 2014 Communication the Commission proposes to measure access to healthcare by using four indicators: health insurance coverage (share of the population), basket of care (depth of coverage), affordability of care (co-payment, cost-sharing), and availability of care (distance, waiting times).

The Commission also paid for pilot projects to reduce health inequalities, such as *VulnerABLE*, a project to develop evidence based strategies to improve the health of isolated and vulnerable persons (2017). The researchers found that, when looking at health inequality, certain key elements exist concerning this concept in that it is

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<sup>181</sup> European Commission. (2009). *Solidarity in Health: Reducing Health Inequalities in the EU*. {SEC(2009) 1396} {SEC(2009) 1397}. Retrieved from <https://eur-lex.europa.eu/legal-content/EN/TXT/PDF/?uri=CELEX:52009DC0567&from=EN>. Accessed 22/6/2018.

<sup>182</sup> European Commission, *Investing in Health - Commission Staff Working Document Social Investment Package* (2013), COM(2014) 215. Retrieved from [https://ec.europa.eu/health/sites/health/files/policies/docs/swd\\_investing\\_in\\_health.pdf](https://ec.europa.eu/health/sites/health/files/policies/docs/swd_investing_in_health.pdf). Accessed 22/6/2018.

<sup>183</sup> European Commission, Communication from the Commission on effective, accessible and resilient health systems (2014). Retrieved from [https://ec.europa.eu/health/sites/health/files/healthcare/docs/com2014\\_215\\_final\\_en.pdf](https://ec.europa.eu/health/sites/health/files/healthcare/docs/com2014_215_final_en.pdf).

<sup>184</sup> European Commission. Communication Solidarity in Health – reducing health inequalities in the EU. 2009. Retrieved from [http://www.health-inequalities.eu/wp-content/uploads/2017/11/vulnerable\\_scientific-report\\_final\\_october2017-lowres-compressed.pdf](http://www.health-inequalities.eu/wp-content/uploads/2017/11/vulnerable_scientific-report_final_october2017-lowres-compressed.pdf). Accessed 22/6/2018.



‘unnecessary, avoidable, unfair, and unjust.’ Broadly spoken, health inequality is measured using parameters such as life expectancy, mortality or disease, and can generally be related to ‘avoidable differences in social, economic, and environmental variables.’<sup>185</sup> It is important to correctly distinguish between a) inequalities in health problems’ determinants and risks, b) health status, and c) access to health care, when discussing inequalities in health.<sup>186</sup>

Another strategy used by the Commission to encourage governments to improve access to healthcare is to commission research. In 2016 a panel of experts produced a detailed report in which it analyzed access to health services as a critical component of universal coverage.<sup>187</sup> The Panel used 8 principles to measure access to health services in the EU:

1. Financial resources are linked to health need;
2. Services are affordable for everyone;
3. Services are relevant, appropriate and cost-effective;
4. Facilities are within reach;
5. There are enough health workers, with the right skills, in the right place;
6. Quality medicines and medical devices are available at fair prices;
7. People can use services when they need them;
8. Services are acceptable to everyone.

Most of these efforts of the Commission are aimed at encouraging member states to compare national experiences and follow good practices. As ‘soft’ as policy recommendations are, the use of ‘carrots and sticks’ underlines the EU’s active position on the improvement of EU-wide health, and the realization of the right to health.<sup>188</sup>

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<sup>185</sup> Ibid. p. 2.

<sup>186</sup> ICF Consulting Services Ltd, *VulnerABLE: Pilot project related to the development of evidence based strategies to improve the health of isolated and vulnerable persons* (2017). Brussels: European Commission. Retrieved from [https://ec.europa.eu/health/sites/health/files/social\\_determinants/docs/2017\\_vulnerable\\_literature\\_review\\_en.pdf](https://ec.europa.eu/health/sites/health/files/social_determinants/docs/2017_vulnerable_literature_review_en.pdf). Accessed 22/6/2018.

<sup>187</sup> European Commission, *Expert Panel on effective ways of investing in Health (EXPH) - Report on Access to Health Services in the European Union* (2016). Retrieved from [https://ec.europa.eu/health/expert\\_panel/sites/expertpanel/files/015\\_access\\_healthservices\\_en.pdf](https://ec.europa.eu/health/expert_panel/sites/expertpanel/files/015_access_healthservices_en.pdf). Accessed 22/6/2018.

<sup>188</sup> For an example, see European Commission. (2018). *Factsheet: Protecting Health, Saving Lives*. Retrieved from [https://ec.europa.eu/health/sites/health/files/vaccination/docs/2018\\_factsheet\\_en.pdf](https://ec.europa.eu/health/sites/health/files/vaccination/docs/2018_factsheet_en.pdf). Accessed 25/6/2018; European Commission. (2018). *Vaccination: Commission calls for stronger EU cooperation against preventable diseases*. Retrieved from [http://europa.eu/rapid/press-release\\_IP-18-3457\\_en.htm](http://europa.eu/rapid/press-release_IP-18-3457_en.htm). Accessed 22/6/2018.

The European Commission has also used its monitoring powers of member states' national budgets to push some countries to reform their health policies. The European Semester provides a framework for the coordination of economic policies across the European Union. It allows EU countries to discuss their economic and budget plans and monitor progress.<sup>189</sup> Baeten and Vanhercke find that the Commission's recommendations are so generic that member states will not find it difficult to claim that they are complying.<sup>190</sup>

That said, it seems that the more support countries need from Brussels, the more weight the Commission's advice carries. This has certainly been the case with Greece, which needed several large financial support packages. In Greece, the Commission found that a lack of universal coverage led to a lack of access to health services. It therefore applied pressure on Greece to improve the system. Universal coverage was set as a priority structural reform. The Commission also made universal access to healthcare a priority for EU financial support. It is positive about the results:

'This led to the adoption of new legislation introducing universal coverage in Greece, which brought it into line with modern EU health care systems in terms of potential access. According to this new legislative framework, all Greek citizens are entitled to universal health care coverage. Uninsured Greeks, as well as other vulnerable categories, are entitled to receive public health care and medicines under the same conditions as insured citizens. The coverage includes clinical and diagnostic tests, hospital treatment, prenatal care, rehabilitation, transfer abroad for specialist treatment and the handling of medicines and other consumables.'<sup>191</sup>

### *Charter of Fundamental Rights*

The rights of all EU citizens' were brought together in a single document in 2000, in the form of the Charter of Fundamental Rights (CFR). With the entry into force of the

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<sup>189</sup> The European Semester: Why and How. (2018). Retrieved from [https://ec.europa.eu/info/business-economy-euro/economic-and-fiscal-policy-coordination/eu-economic-governance-monitoring-prevention-correction/european-semester/framework/european-semester-why-and-how\\_en](https://ec.europa.eu/info/business-economy-euro/economic-and-fiscal-policy-coordination/eu-economic-governance-monitoring-prevention-correction/european-semester/framework/european-semester-why-and-how_en). Accessed 25/6/2018.

<sup>190</sup> Baeten, R., & Vanhercke, B. (2017). Inside the black box: The EU's economic surveillance of national healthcare systems. *Comparative European Politics*, 15(3). p. 486

<sup>191</sup> European Commission. (2018) *Compliance Report ESM Stability Support Programme for Greece, Fourth Review*. p. 14. Retrieved from [https://ec.europa.eu/info/sites/info/files/economy-finance/compliance\\_report\\_4r\\_2018.06.20.docx.pdf](https://ec.europa.eu/info/sites/info/files/economy-finance/compliance_report_4r_2018.06.20.docx.pdf). Accessed 25/6/2018.

Lisbon Treaty in 2009, the Charter became legally binding.<sup>192</sup> It includes all personal, civic, political, economic and social rights enjoyed by EU member state nationals, and comprises a) all the rights that can be deduced from CJEU case law, b) the rights and freedoms which are made explicit in the ECHR, and c) remaining rights and principles which exist in the collective constitutional customs in EU states and in other universal instruments.<sup>193</sup> Article 35 of the CFR pertains to healthcare. It reads that *'everyone has the right of access to preventative health care and the right to benefit from medical treatment under the conditions established by national laws and practices. A high level of human health protection shall be ensured in the definition and implementation of all Union policies and activities.'*<sup>194</sup> The principles delineated here mirror article 168 of the TFEU and articles 11 and 13 of the European Social Charter.<sup>195</sup>

When assessing the applicability of the Charter of Fundamental Rights, it must be noted that its protection of fundamental rights exclusively concerns the EU, indicating that it applies to actions taken at the EU institution level and at the domestic level, in case EU states apply EU law. Though it is theoretically possible for citizens to lodge complaints with the CJEU directly in case a member state EU does not comply with the EU's CFR, several hurdles effectively obstruct this in practice. At the national member state level, the CFR applies when EU law is applied or implemented by a EU state. Only when such domestic courts are not certain about the applicability or jurisprudence of EU law will they refer to the CJEU.<sup>196</sup> Individuals can also lodge a complaint with the Commission, which has the power to start infringement proceedings against the member state. Non-judicial approaches to the CFR implementation exist too in the form of letters to the European Parliament and petitions to the European Ombudsman.<sup>197</sup>

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<sup>192</sup> European Union. (2012). *Charter of the Fundamental Rights of the European Union*. 2012/C 326/02. Retrieved from <https://eur-lex.europa.eu/legal-content/EN/TXT/PDF/?uri=CELEX:12012P/TXT&from=EN>. Accessed 25/6/2018.

<sup>193</sup> European Commission. *Why do we need the Charter? The Charter of Fundamental Rights, what it covers and how it relates to the European Convention on Human Rights*. Retrieved from [https://ec.europa.eu/info/aid-development-cooperation-fundamental-rights/your-rights-eu/eu-charter-fundamental-rights/why-do-we-need-charter\\_en#background](https://ec.europa.eu/info/aid-development-cooperation-fundamental-rights/your-rights-eu/eu-charter-fundamental-rights/why-do-we-need-charter_en#background). Accessed 26/6/2018.

<sup>194</sup> Bojarski, L. et al. (2014). *The Charter of Fundamental Rights as a Living Instrument. Manual*. CFREU. Retrieved from [http://bim.lbg.ac.at/sites/files/bim/attachments/cfreu\\_manual\\_0.pdf](http://bim.lbg.ac.at/sites/files/bim/attachments/cfreu_manual_0.pdf). Accessed 28/6/2018.

<sup>195</sup> UK Government. (2017). *Charter of Fundamental Rights of the EU – Right by Right Analysis*. p58. Retrieved from [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/664891/05122017\\_Charter\\_Analysis\\_FINAL\\_VERSION.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/664891/05122017_Charter_Analysis_FINAL_VERSION.pdf). Accessed 28/6/2018.

<sup>196</sup> Ibid. p. 82.

<sup>197</sup> Ibid. p. 99.

Accessibility of health systems is one of the principles included in the European Social Charter, which stresses the significance of clear and transparent criteria by which to assess access to healthcare treatment and States parties' obligation to provide a system of healthcare which is both adequate and inclusive and does not allow for any groups within the population to be prevented from using healthcare services. As is made explicit, measures of cost-containment aimed to encourage more rational use of care, should not unjustly impede access to high-quality healthcare. The Communication acknowledges the difficulties existing when attempting to measure member states' performances in providing 'access to healthcare', and the lack of a comprehensive system by which to monitor and promote best practice this access among member states. The Commission stresses the importance of the development of such steps in the ongoing combat against health inequalities.<sup>198</sup> Here the European Commission is stretching its competence to monitoring domestic health policy and to reviewing barriers to access to healthcare in Member States associated with costs.

Article 2 ECHR in combination with art. 35 of the Charter of Fundamental Rights in the past have been referred to in Court cases discussing denial of access to healthcare due to limited resources. This approach does appear to be hampered by the fact that art. 2 ECHR 'must be interpreted in a way which does not impose an impossible or disproportionate burden on the authorities.'<sup>199</sup>

### *European Pillar of Social Rights*

At the end of 2017, the European Parliament, Council and Commission proclaimed the European Pillar of Social Rights, conveying the common EU wide promise of a strengthened social Europe.<sup>200</sup> It aims at supporting fair and adequate labor and welfare systems through a number of central principles and rights. The Pillar is a political declaration; it is not legally binding. Bearing the legal position of the Pillar in mind, its principles and rights must be met with specific measures or legislation at the relevant level – national or Union level – in order to be enforceable legally. The Pillar does include suggestions for member states or social partners towards the

<sup>198</sup> European Commission. (2014). *Communication from the Commission on effective, accessible and resilient health systems*. p. 7-9. Retrieved from [https://ec.europa.eu/health/sites/health/files/healthcare/docs/com2014\\_215\\_final\\_en.pdf](https://ec.europa.eu/health/sites/health/files/healthcare/docs/com2014_215_final_en.pdf). Accessed 26/6/2018.

<sup>199</sup> McHale, J. (2010). Fundamental rights and health care. in E. Messalina et al. (eds.), *Health Systems Governance in Europe - The Role of European Union Law and Policy*. Cambridge: Cambridge University Press, p. 299. Retrieved from <http://www.euro.who.int/en/about-us/partners/observatory/publications/studies/health-systems-governance-in-europe-the-role-of-eu-law-and-policy-2010>. Accessed 28/6/2018.

<sup>200</sup> European Union. (2017). *European Pillar of Social Rights*. Retrieved from [https://ec.europa.eu/commission/publications/european-pillar-social-rights-booklet\\_en](https://ec.europa.eu/commission/publications/european-pillar-social-rights-booklet_en). Accessed 29/6/2018.

implementation of each principle or right. Also, in the Pillar it is put forward that a system of benchmarking will be introduced in order to stimulate member states to converge towards the levels of those performing best on a string of important determinants of health, such as minimum wages, early childhood education and care, employment protection laws, and access to social protection.<sup>201</sup>

The Pillar's principle 16 on health care states that *'everyone has the right to timely access to affordable, preventative, and curative health care of good quality.'*<sup>202</sup> Here, the Pillar goes beyond article 35 CFR by making explicit the right to timely healthcare access, as well as requiring this to be both affordable and of good quality. Timely is defined as care whenever the patient needs it, thereby stipulating that care facilities and personnel must be geographically balanced, and that waiting times must be minimized through adequate policy. Health care is considered to be affordable when people are not deterred from seeking care they need due to cost. Care is of good quality when it is 'timely, relevant, appropriate, safe and effective.' Finally, the right includes that to medical care and public health services, responsible for health promotion and prevention of disease.<sup>203</sup>

Though it falls within the EU's competence to promote and suggest certain policies, it falls squarely within Member States' margin of appreciation to shape the policy ensuring access to health care. For example, Council Recommendation 92/442/EEC called on member states to ensure access to necessary healthcare, but each member state remains free to determine the conditions under which access is ensured.<sup>204</sup>

An example of the practice of benchmarking and the subtle use of peer pressure is seen in the Commission staff document on the European Pillar of Social Rights, in which France is highlighted for good practice in low unmet medical care needs and low out-of-pocket expenditures, and praised for its work towards better geographically balanced access to care facilities and professionals.<sup>205</sup>

The most frequent barrier for access to healthcare stems from patients not being able or willing to pay for medical goods or services. A common indicator used to make such barriers to access visible is patient self-reported unmet needs, based on 'financial reasons', 'waiting list' or 'too far to travel.' This indicator has been made part of the social scoreboard of the Social Pillar, effectively giving the subtle effect of EU peer-pressure. EuroHealthNet suggests the addition of 'healthy life years' and 'out-of-pocket payments' to the Social Scoreboard to 'better reflect accessibility and

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<sup>201</sup> Ibid. p. 4.

<sup>202</sup> Ibid. p. 72.

<sup>203</sup> Ibid. p. 73-74.

<sup>204</sup> Ibid. p. 73.

<sup>205</sup> Ibid. p. 74.

affordability of health for different social groups, preventative measures and performance of health systems.’<sup>206</sup>

After having assessed ethics literature in the previous chapter (Ch. 4), legal sources of the UN, the Council of Europe and the EU were studied in the past three subchapters (subCh. 5.1., 5.2., 5.3.). In the following chapter the respective criteria for legitimacy will be compared.

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<sup>206</sup> EuroHealthNet. (2017). *The European Semester: a health inequalities perspective*. p. 10. Retrieved from <https://eurohealthnet.eu/sites/eurohealthnet.eu/files/publications/EuroHealthNet%20Analysis%20of%20European%20Semester%20November%202017.pdf>. Accessed 29/6/2018.

## 6. Comparing Ethics Theory to Legal Practice

In this chapter the overlap and differences between principles on care rationing in European legal sources and the theoretical ideals on its moral acceptability in ethics literature will be examined. The following principles will be assessed, as were identified in the chapter on ethics (Ch. 4), and in chapter on European right to health (Ch. 5): *transparency and explicitness, accountability, equality and equity, non-discrimination and inclusiveness, openness to rational and democratic deliberation, openness to participation, availability, accessibility, acceptability and the quality of healthcare.*

As has become clear in the previous chapters, certain principles can be found in both ethics literature and legal sources, whereas other values are mentioned only in one or the other, but not both. Here, the central procedural and substantive principles will be discussed and compared for moral and legal content.

### 6.1. Procedural principles

#### 6.1.1. *Transparency and explicitness*

Only when the process of healthcare rationing occurs transparently and explicitly is it possible for individuals to see and judge the trade-offs made to decide who does and who does not receive care.<sup>207</sup> Only those rationing decisions openly transparent to the public can be assessed critically by them, and subsequently are most likely to be just.<sup>208</sup> This is in line with the publicity condition of the ‘accountability for reasonableness’ framework.<sup>209</sup> Transparency is a precondition for public discussion<sup>210</sup> and therefore is essential for the process of rationing to be legitimate for each individual of society.<sup>211</sup>

Only one of the legal sources that were assessed for this paper expressly obligates healthcare systems or policy rationing healthcare to be of explicit nature, namely

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<sup>207</sup> Landwehr, C. (2009). Deciding how to decide: the case of health care rationing. *Public Administration*, 87(3), p. 588. ; Buijsen, M. (2014). *Verdeling van zorg: recht en onrecht*. Speech, Amsterdam (Johannes Wier Stichting Symposium Transitie in de zorg, transitie in het recht op gezondheid(szorg)). Retrieved from <http://docplayer.nl/8318190-Transitie-in-de-zorg-transitie-in-het-recht-op-gezondheid-szorg.html>. Accessed 20/07/2018.

<sup>208</sup> Fleck, L.M., *Just Caring, Health Care Rationing and Democratic Deliberation*, 2009, Oxford University Press. p. 400

<sup>209</sup> Slowther, A. and Hope, T. (2002). Resource allocation decisions in UK healthcare: do ethics committees have a role?. *HEC Forum*, 14(1), p. 65.

<sup>210</sup> Flood, C., Gross, A. Litigating the Right to Health: What Can We Learn from a Comparative Law and Health Care Systems Approach? *Health and Human Rights*. 2014; 16(2). p. 69-70.

<sup>211</sup> Hirose, I., & Bogner, G. (2014). *The ethics of health care rationing: an introduction*. Routledge. p. 152-153.

article 12(1) of the UN's ICESCR. It states that healthcare systems must have a transparent process of policy making. Several legal sources do focus on citizens' right to information, however. The UN's General Comment No. 14 requires 'information accessibility' under its AAAQ 'accessibility' criterion. At the level of the Council of Europe, European Social Charter art. 11 requires parties to provide both educative and advisory facilities on healthcare, thereby facilitating the right to information.

No sources were found at the level of the European Union requiring healthcare systems to be transparent, explicit, or even respective of the right to information.

### 6.1.2. Accountability

Two other important conditions in the 'accountability for reasonableness' framework are appeals and enforcement. For scarce resource allocation to be fair a system must exist for citizens to challenge and dispute policy decisions, and even to have them overturned if new evidence or arguments so require. Additionally, an appeals body must be incorporated to guarantee a fair process.<sup>212</sup> In other words, a system of rationing must provide accountability for it to be fair.<sup>213</sup>

The principle of healthcare system accountability is widely covered by legal documents, at UN level, Council of Europe level, and EU level.

With the express goal of improving accountability, the UN launched the 2013 Optional Protocol to give the ECSR a scrutinizing role of monitoring states parties' adherence to the progressive realization of the right to health. General Comment No. 14 explicitly requires healthcare systems to provide citizens with 'access to effective judicial or other appropriate remedies at both national and international levels.'<sup>214</sup> In monitoring whether healthcare systems are in line with national constitutions, courts may function as a route to the enforcement of the right to health.

At the Council of Europe level, the ECSR monitors states' compliance with art. 11 of the European Social Charter using two monitoring tools to assess their performance. To better achieve this, the ECSR has developed several indicators to monitor performance and to identify cases of non-conformity, thereby increasing states' accountability. Also the ECtHR has required a mechanism to ensure accountability following *Oyal v Turkey*.

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<sup>212</sup> Slowther, Hope. Resource allocation decisions. p. 65.

<sup>213</sup> Ham, C., & Coulter, A. (2001). Explicit and implicit rationing: taking responsibility and avoiding blame for health care choices. *Journal of health services research & policy*, 6(3), p. 166. ; Hirose, Boggar. *The ethics of health care rationing*. p. 152.

<sup>214</sup> EC/2000/4 General Comment No. 14, para. 59.



At the EU level, no express calls for system accountability were found. However, many instances were identified in which member states' performance monitoring was proposed.<sup>215</sup>

### *6.1.3. Participation*

In order for healthcare rationing to be morally legitimate, it has to be of participatory nature.<sup>216</sup> This in addition to the democratic right citizens have as citizens to assess policy.<sup>217</sup> The true moral challenge of health systems lays in the development a democratically deliberative consensus model in which citizens are able to participate in the shaping of decisions and broader policy, of which they have to live with the consequences.<sup>218</sup> A fair rationing process thus invites public discussion.<sup>219</sup>

Though not much could be found in the legal sources assessed, the principle of public participation was most clearly reflected by the UN. ICESCR art. 12(1) states that health systems must be of participatory procedural nature. General Comment No. 14 goes on to clarify that each state party has the procedural obligation to make their healthcare system participatory and transparent.<sup>220</sup>

Though neither the ECSR nor the ECtHR under the Council of Europe state anything about healthcare systems needing to be of participatory nature, the EU does make a short mention. In its 2006 Conclusions on the common values and principles in EU health systems, the Council of Ministers emphasizes the need for patient involvement in healthcare systems.

### *6.1.4. Openness to rational democratic deliberation*

For rationing decisions to be morally legitimate, they must be verifiable and open to democratic assessment and deliberation.<sup>221</sup> Only through a system open to

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<sup>215</sup> The 2009 Commission 'Solidarity in Health Communication' called for the collection of statistics and regular reporting among member states to aid governments to fight health inequality. The 2014 Commission Communication and the Commission's 2016 Experts' Panel proposed indicators by which to measure member states' health system performances and access to healthcare services. In 2017, the European Commission (EC) recommended an appropriate monitoring body for the Pillar of Social Rights.

<sup>216</sup> Fleck. *Just caring: health care rationing*. p. 400.

<sup>217</sup> Buijsen. *Schaarse middelen*. p. 142.

<sup>218</sup> Ham, Coulter. *Explicit and implicit rationing*. p. 163.

<sup>219</sup> Flood, Gross. *Litigating the Right to Health*. p. 69-70.

<sup>220</sup> EC/2000/4 General Comment No. 14 para. 43, under f.

<sup>221</sup> Buijsen. *Transitie in de zorg*. (Speech).

consensus seeking in a democratic fashion can we consider care rationing to be self-imposed.<sup>222</sup>

Though some of the legal sources assessed covered the principle of participation, none seem to require or even propose health systems to be open to rational, democratic deliberation. Only the CESCR's GC No. 14 stresses the right of individuals (and groups) to take part in the process of policy shaping, which may affect their own life.<sup>223</sup> This right clearly overlaps with the principle of (public) participation, whilst refraining from explicitly requiring a process of democratic deliberation.

## 6.2. Substantive principles

### 6.2.1. *Equity and equality*

Equal care should be allocated to equal need, just as unequal need should beget unequal care.<sup>224</sup> As such, general consensus has been reached about the importance of achieving both efficiency and fairness in priority-setting for healthcare allocation.<sup>225</sup> A system of healthcare rationing must balance efficiency with equity, in order to keep the system of allocation fair.<sup>226</sup>

The principles of equity and equality are identified and propagated in the legal literature consulted. The UN's ICESCR art. 12(1) states that all healthcare systems must make an equitable distribution of resources and services. General Comment No. 14 complements that healthcare must be equal for all, removing any impediments to the achievement of such equality.

The ECSR has identified 'equity' and 'inclusiveness' as indicators to monitor states parties' performances in complying to European Social Charter art. 11.

Several EU sources reflect a push towards equity and equality. Suggestions and strategies attempt to integrate these principles into member states' healthcare

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<sup>222</sup> Fleck. *Just caring: health care rationing*. p. 400.

<sup>223</sup> The UN's ICESCR art. 12(1) states that health systems must be of participatory nature. General Comment No. 14 para. 54 states that 'in particular, the right of individuals and groups to participate in decision-making processes, which may affect their development, must be an integral component of any policy, programme or strategy developed to discharge governmental obligations under article 12.

<sup>224</sup> Buijsen. *Schaarse middelen*. p. 137.

<sup>225</sup> Cappelen A, Norheim O. Responsibility, fairness and rationing in health care. *Health Policy*. 2006;76(3). p. 314.

<sup>226</sup> Fleck. *Just caring: health care rationing*. p. 401.

policy-making, and show the indicators formulated by which to monitor member states' performances towards to achievement of both equity and equality.<sup>227</sup>

### 6.2.2. Non-discrimination and inclusiveness

An inevitable risk of healthcare system in which vulnerable groups within society are not taken into account is that such groups will suffer inequitably.<sup>228</sup> By preventing case-by-case allocation decisions without comprehensive underlying policies, unjust and arbitrary consequences can be avoided which often lead to immoral discrimination.<sup>229</sup> Would rationing decisions be made based on criteria other than those based on comprehensive, systematic and rational deliberation, such as a physician's personal implicit biases<sup>230</sup>, this would lead to the negative affecting of human dignity which is discrimination.<sup>231</sup> A person not receiving healthcare to which they are procedurally and legally entitled is morally indefensible.<sup>232</sup>

The principle of non-discrimination and inclusiveness is also widely covered in the consulted legal sources. Both the UN's ICESCR art. 12(1) and General Comment No. 14 state that health systems must be non-discriminatory and that extra attention must be paid to those vulnerable and marginalized.

At the Council of Europe level, the ECSR uses non-discrimination as indicator to measure and monitor whether health systems are in line with art. 11 of the European Social Charter.

Similarly for the EU, the Council of Ministers has stated that member states' healthcare systems must be guaranteed to be non-discriminatory. This principle has been adopted in the Europe 2020 strategy.<sup>233</sup>

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<sup>227</sup> In its 2016 Conclusions the CoM states that healthcare systems must guarantee equity. The 2017 VulnerABLE document and the Europe 2020 strategy reflect this commitment towards the fighting of inequalities as part of the realization of equity and equality. The 2017 Pillar of Social Rights requires member states to geographically balance health facilities and professions to counter inequalities. In 2007 and in 2016 through its Experts' Panel the EC pushed for indicators to measure member states' performances, including in health system equity and equality and sets out to compare such data amongst them.

<sup>228</sup> Yearby R. Racial Inequities in Mortality and Access to Health Care. *Journal of Legal Medicine*. 2011;32(1) p. 91.

<sup>229</sup> Fleck. *Just caring: health care rationing*. p. 400.

<sup>230</sup> Crowe, M. (2010). Allocation of Health Care Resources at the Point of Care. *Journal of Legal Medicine*, 31(4). p. 461.

<sup>231</sup> Buijsen. Schaarse middelen. p. 138.

<sup>232</sup> Hirose, Bogнар. *The ethics of health care rationing*. p. 14.

<sup>233</sup> Both the 2017 VulnerABLE report as the Europe 2020 strategy have made 'non-discrimination' a priority.

### 6.2.3. Accessibility and Affordability

Though accessibility and affordability are two distinct and separate principles, they are often grouped together in assessed literature and sources. Accordingly, they will be treated similarly in this section, to prevent redundancy in source referencing.

The two principles were not expressly mentioned as moral criteria for a legitimate system of care rationing, even though some authors did state that the allocation of healthcare resources and services should be equal and equitable regardless of socio-economic status or ability to pay.<sup>234</sup>

The principles of affordability and accessibility are widely reflected in legal sources. Both principles are reflected in the often-referenced AAAQ principles of the CESCR's GC No. 14. Healthcare must be both physically accessible and economically accessible, or affordable in other words.

At the level of the Council of Europe, the ECtHR has required healthcare to be sufficiently accessible, following *Sentürk v Turkey*. The ECSR included 'accessibility of healthcare' and 'affordability of healthcare' to its indicators to measure states' compliance with the European Social Charter art. 11.

Similarly to the principles of healthcare equity and equality, the EU has embraced the principles of healthcare accessibility and affordability. Both in the proclaiming by the Council of Ministers in 2006 and by the European Commission, in the shaping of principles to measure member states' healthcare systems' performance in 2014 and 2016, healthcare accessibility and affordability were included.<sup>235</sup> Additionally, the 2017 Pillar of Social Rights emphasized every individual's right to 'timely access to affordable, preventive and curative health care of good quality.'<sup>236</sup>

### 6.2.4. Acceptability of healthcare

The principle of acceptability of healthcare was not discussed in the ethics literature assessed for this paper.

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<sup>234</sup> See p. 21 of this paper.

<sup>235</sup> The 2006 Council of Ministers' Conclusions stated solidarity as a central value, which includes healthcare accessibility for all. The Charter of Fundamental Rights art. 35 also states that everyone has the right to access to preventative healthcare. The EC's 2014 Communication and the EC's 2016 Experts' Panel both propagate criteria to measure access to healthcare services in the EU, among which 'accessibility and affordability.'

<sup>236</sup> European Union. (2017). *European Pillar of Social Rights*. Retrieved from [https://ec.europa.eu/commission/publications/european-pillar-social-rights-booklet\\_en](https://ec.europa.eu/commission/publications/european-pillar-social-rights-booklet_en). Accessed 29/7/2018.

Like accessibility, acceptability of healthcare is part of the AAAQ framework. Acceptability is elaborated on to mean that 'all health facilities, goods and services must be respectful of medical ethics and culturally appropriate (...) [and] designed to respect confidentiality and improve the health status of those concerned.'<sup>237</sup>

Somewhat in the same vein, the ECtHR has judgments that include cases related to the protection of medical data. Among the indicators the ECSR has identified to measure compliance with art. 11 of the European Social Charter are life expectancy and main causes of death, and infant and maternal mortality. This is in line with the requirement for healthcare systems to be designed to improve individuals' health status under acceptability.

One of the 2016 EC Expert Panel's criteria to monitor healthcare systems was the degree to which healthcare services are acceptable to everyone.<sup>238</sup>

#### *6.2.5. Quality of healthcare*

The principle of quality of healthcare was not discussed in the ethics literature assessed for this paper.

The last element of the General Comment No. 14 AAAQ framework is quality of care. In it, healthcare facilities, goods and services are required to be culturally, scientifically and medically appropriate and of high quality.<sup>239</sup>

At the Council of Europe, the ECtHR has started to recognize a right to a certain quality of care, following *Sentürk v Turkey*, *Asiye v Turkey*, and *Aydoglu v Turkey*. The ECSR's European Social Charter art. 11 imposes preventative, promotional and curative healthcare obligations on states parties.<sup>240</sup> The ECSR in turn helps to monitor compliance to this article by measuring states' performances, and the adequacy of healthcare professionals and facilities. This process of monitoring helps to preserve a certain quality of care.

At the EU, three instances were identified in which quality of health was propagated. In 2006, the CoM Conclusions stated that healthcare must be of good quality, and must be evidence based. The 2016 EC Experts' Panel's criteria address whether

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<sup>237</sup> EC/2000/4 General Comment No. 14 para.12 under c.

<sup>238</sup> See p. 41 of this paper, under criterion 8.

<sup>239</sup> EC/2000/4 General Comment No. 14 para. 12 under d. To achieve quality of care, 'skilled medical personnel, scientifically approved and unexpired drugs and hospital equipment, safe and potable water, and adequate sanitation' are required.

<sup>240</sup> Art. 11 ESC states that each state party is obligated to remove any cause of ill-health, to promote health, and to prevent any epidemic, endemic or other diseases as well as accidents.

healthcare services are appropriate and relevant, whether there are enough healthcare workers, and whether the quality of medical devices and medicine is available at fair prices. Art. 16 of the 2017 Pillar of Social Rights states that everyone has a right to preventative and curative care of good quality.

### 6.3. Discussion

Three categories of principles can be identified. First, there is agreement between the ethics literature and the legal sources that healthcare rationing policy should be *accountable, equal and equitable*, and *non-discriminatory and inclusive*. The second category consists of principles that were identified in the ethics literature, but only marginally in the legal sources: *open to participation*, and *open to rational, democratic*. In the third category, the *AAAQ framework* from the General Comment No. 14 on the ICESCR<sup>241</sup> was found in the legal sources, but is hardly reflected in the ethics literature that was studied.

It appears as if disagreements exist among the three international institutions about the principles underlying legitimate healthcare policy. For example, the EU's Council of Ministers put forward several common guidelines: *quality of care, safety, care that is based on evidence and ethics, patient involvement, redress, and privacy and confidentiality* (p. 37). The Council of Europe's ECSR, for its part, uses different indicators to judge compliance with art. 11 ESC: *States' performance compared to the European average, number of healthcare professionals and facilities, access to healthcare, infant and maternal mortality, and life expectancy and main causes of death* (p. 31). The EU uses another set of indicators to measure access to healthcare: *health insurance coverage, basket of care, affordability of care, and availability of care* (p. 40), which again are distinct from the ones used by the ECSR. The UN's CESCR monitors whether healthcare policy employs *participatory and transparent* decision-making, whereas the ECSR does not (p. 32).

Two conclusions follow. First, the practitioners of ethics and of law should work to harmonize their criteria for legitimacy. Second, for international institutions to be able to monitor whether the right to health is respected in national healthcare policies, it is important that they improve their communication amongst each other and arrive at a common approach.

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<sup>241</sup> This framework covers the *availability, accessibility, acceptability and the quality of healthcare*

## 7. The Adjudication of the Right to Health

Access to care is inextricably related to healthcare resource scarcity, the issue central to healthcare rationing policies.<sup>242</sup> The need to ration healthcare is steadily growing (Ch. 3), whilst citizens suspecting denial of access to care are decreasingly willing to defer decision-making about resource allocation.<sup>243</sup> Courts subsequently are increasingly likely to be appealed to by individuals whose ever-growing collective health needs vie for a limited number of resources and services.<sup>244</sup> This is a trend that is becoming more and more common internationally.<sup>245</sup> Litigants who consider themselves to have been morally wronged are likely argue their claims to treatment by appealing to the human rights safeguarded in national and international rights instruments.<sup>246</sup> The judiciary thus holds an important role as mechanism for *appeals* and for *enforcement*. In this chapter, the practical ramifications for citizens of the rights-based approach, and the individual access to justice will be discussed.

### 7.1. The Need for a Rights-Based Approach

In adjudicating the right to health, judges balance refraining from infringing upon governmental authority in policy making and taking their judicial responsibility in enforcing positive rights of the individual. Societies must respect and uphold positive individual economic and social rights, and protect the communal interests simultaneously.<sup>247</sup> Bearing in mind, as Newdick puts it, that ‘investment in one part of the system may require *disinvestment* from another’, the overarching goals must be to promote the interests of the collective citizenry, in a budgetary sustainable manner, not just those of litigating individuals.<sup>248</sup> As a social right, the right to health helps to structure distributive questions *amongst* individuals, but does not offer an absolute substantive right to health *for all* individuals.<sup>249</sup> Trying to meet every healthcare need of every individual could overwhelm a society’s financial capacity to

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<sup>242</sup> Hirose, I. & Bogner, G. (2014). *The ethics of health care rationing*. London: Routledge. p. 14, 16.

<sup>243</sup> Manning J, Paterson R. ‘Prioritization’: Rationing Health Care in New Zealand. *The Journal of Law, Medicine & Ethics*. 2005;33(4). p. 681.

<sup>244</sup> Newdick, C. (2018). Can Judges Ration with Compassion? A Priority-Setting Rights Matrix. *Health And Human Rights Journal*, 20(1), p. 108.

<sup>245</sup> Dittrich, R., Cubillos, L., Gostin, L., Chalkidou, K., & Li, R. (2016). The International Right to Health: What Does It Mean in Legal Practice and How Can It Affect Priority-setting for Universal Health Coverage?. *Health Systems & Reform*, 2(1), p. 27.

<sup>246</sup> Syrett. *Healthcare Rationing and the Law*. p. 173.

<sup>247</sup> Newdick, C. (2018). Can Judges Ration with Compassion? A Priority-Setting Rights Matrix. *Health And Human Rights Journal*, 20(1), p. 108.

<sup>248</sup> *Ibidem*.

<sup>249</sup> *Ibidem*.

provide for other social goods, such as infrastructure or education.<sup>250</sup> Such opportunity costs require attention when policymakers promote the right to health.

Citizens have lodged complaints at court after having been denied expensive care or treatments under their public health insurance systems, to argue their right to health.<sup>251</sup> Such denial of access appears to occur for two main reasons: access to care or treatment could have been denied purposefully as part of informed rationing policy; in other cases, the care or treatment they were denied should have been accessible to them under the universal insurance program, but was not due to system or government failure.<sup>252</sup> Here, a rights-based approach has clear potential to be of positive value. In cases where citizens are denied care to which they are entitled under a state's universal coverage package, being able to appeal to the judiciary to claim the right to health is of critical importance. In such instances, the courts prove their fundamental societal value in laying bare system of government failure at the root of this obstruction of access to healthcare to which citizens hold a legal right.<sup>253</sup> In such scenario's, policy may be politically motivated, inequitably developed or otherwise unjust, and thus necessitates critical judicial review.<sup>254</sup> When properly framed, the right to health should serve as a yardstick for courts to scrutinize policy decisions that are blatantly retrogressive, and serve to help advance the realization of accessible public healthcare through litigation<sup>255</sup>, especially for those in greatest need.

Courts are not to take on the role of policymakers shaping our health systems, but should instead serve as a scrutinizing body, overseeing adherence to human rights standards. Such judicial supervision can overturn policies that impede access to care for the poor through co-payments, or refusing (the renewal of) insurance for those most vulnerable, like refugees or migrants.<sup>256</sup> This role for the judiciary is in line with the appeals and the enforcement conditions under the Daniels and Sabin 'accountability for reasonableness' framework. A comprehensive rationing system must indeed provide a mechanism for individual patients who have plausible evidence that their specific situation deserves an exceptional response. Contrary to the individual-substantive approach discussed previously, this approach is of individual-procedural nature in which the procedural process is scrutinized for

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<sup>250</sup> Dittrich, et al. *The International Right to Health*. p. 26.

<sup>251</sup> *Ibid.* p.23

<sup>252</sup> *Ibidem.*

<sup>253</sup> *Ibid.* p24

<sup>254</sup> *Ibid.* p27.

<sup>255</sup> As GC No. 14 indicates, art. 12 ICESCR requires governments to actively pursue progressive realization of economic, social and cultural rights, including the right to health.

<sup>256</sup> Flood, C., & Gross, A. (2014). Litigating the Right to Health: What Can We Learn from a Comparative Law and Health Care Systems Approach. *Health And Human Rights Journal*, 16(2), p. 69-70.



violations. Indeed, the circumstances of the individual's predicament are assessed not because of that individual's specific illness, but based on the potential benefit of treatment in those extraordinary circumstances in a way that would not be visible in the assessment made within the community-procedural approach.<sup>257</sup> Following the *Botta v Italy* (1998) and *Sentges v Netherlands* (2003) cases, the ECtHR has imposed such an individual-procedural check, in which applicants are required to prove a 'direct and immediate link' between their desired treatment and their particular circumstances.<sup>258</sup> Though no access to treatment without regards of the costs can be guaranteed, this mechanism does offer individuals the assurance that their specific circumstances have been properly considered, which would not be possible through community-procedural approach alone.

## 7.2. The Risks of a Rights-Based Approach

The role of the judiciary in adjudicating the right to health is delicate. Courts serve a crucial function in protecting citizens from system failure, as described above. However, cases may also be brought to court which challenge allocation policies that are the result of 'explicit and ostensibly reasonable priority-setting decisions', not of government failure.<sup>259</sup> Such cases can lead to the overriding of such official and rationally substantiated government rationing policies, designed to guarantee universal equity and fairness in the allocation of scarce resources.<sup>260</sup>

By granting access to treatments that explicitly are not covered under public insurance schemes, precedence is set in which 'courts may give priority to those with the means and incentive' to turn to the judiciary, over the interests of the public.<sup>261</sup> By invoking the right to health to allow an individual to access a specific treatment without duly respecting the purposeful and legitimate governmental rationing decision, courts risk granting a single citizen access to a certain treatment, whilst it remains unaffordable to all others who would medically require it.<sup>262</sup> As a result, in such instances, the judiciary indeed threatens the wider public right to health. This is causing increased frictions between policymakers and the courts in the process of priority-setting in healthcare.<sup>263</sup> Citizens appealing to the courts to claim care initially

<sup>257</sup> Newdick. Can Judges Ration with Compassion? p. 113.

<sup>258</sup> Parker, C., & Clements, L. (2008). The UN Convention on the Rights of Persons with Disabilities: a new right to independent living? *European Human Rights Law Review*, 4, p. 518.

<sup>259</sup> Dittrich, et al. The International Right to Health. p. 24.

<sup>260</sup> Newdick. Can Judges Ration with Compassion? p. 108.

<sup>261</sup> Dittrich, et al. The International Right to Health. p. 23.

<sup>262</sup> Ibid. p. 25.

<sup>263</sup> Ibid. p. 24.

denied to them are increasingly often winning their cases.<sup>264</sup> The judicialization of the right to health thereby proves to be both crucial and problematic.

### 7.3. Criteria to Assess Governmental Due Process

When the judiciary is able to overturn informed rationing policy decisions, it jeopardizes a government's ability to enforce reasonable and equitable policy decisions. The question lingers whether this should be possible. The processes and principles of (international) public law on the right to health are not intended to be (ab)used by individuals as vehicle to challenge the legitimacy of informed and rationally substantiated governmental decision-making or for courts to curb authorities in their exercise of state power.<sup>265</sup> Instead, the adjudication of the right to health should serve as a method to scrutinize whether those government decisions are justifiably based on evidence-based processes of informed and rationally substantiated decision-making, designed to ensure that the most effective treatments, both in terms of cost and clinical impact are pursued, and in accordance with social value judgments.<sup>266</sup> Decision-makers ability to do so, however, will continue to be threatened as long as no clear strategies for the judicial assessment of the of such rationing decisions' purported rationality are absent.

Dittrich et al. advocate a three-stage process to achieve legitimacy and accountability: a) rational priority-setting, b) appeal, and c) judicial review, in line with Daniels' and Sabin's model for 'accountability for reasonableness.'<sup>267</sup> Though a societal consensus on the *substance* of fair resource rationing may be difficult to achieve, the model's principles do guide a fair *process* of rationing decision-making and public accountability. To assure that courts are comfortable in examining not the *decision* itself, but the *process* underlying its shaping, there must be assurance that '1) the appeals process fairly reviews the coverage decision, and 2) the initial assessment process [of policy shaping] rationally considers the social and scientific evidence.'<sup>268</sup> Such assessment processes can incorporate an appeals mechanism on the rationing decision operated by an external actor. A good example of such an independent body is the National Institute of Clinical Excellence (NICE) in the UK, where individuals have to opportunity to challenge a recommendation, seek independent review, or to request judicial review.

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<sup>264</sup> Ibidem.

<sup>265</sup> Syrett, K. (2007). *Law, legitimacy and the rationing of healthcare*. Cambridge: Cambridge University Press. p. 237.

<sup>266</sup> Dittrich, et al. *The International Right to Health*. p. 23

<sup>267</sup> Ibid. p. 29.

<sup>268</sup> Ibidem.

The fundamental importance of an appeals process is that it enables citizens to contest the validity of specific policy, and that it guarantees judicial review to establish whether the process of policy shaping occurred in a rational fashion.

Turning to the aspect of judicial review, Newdick describes several possible approaches by courts in their supervision of healthcare resource allocation. Arranged in a matrix, he distinguishes rights that pertain to the individual, and rights of the community respectively on one axis, and then both procedural, and substantive remedies on the other.<sup>269</sup> As described above, there will always be a degree of tension between the needs of the individual and the communal needs of society as a whole. In line with the goal of national healthcare systems to achieve the largest gains for the largest number of people, Newdick advocates an approach aimed at serving the public and protecting their procedural rights, whilst guaranteeing individuals the possibility to appeal based on their substantive rights in exceptional cases.<sup>270</sup> The central point of importance is finding compromise between the interests of the public and the interests of the individual. The risk of the 'individualist' substantive approach when adjudicating the right to health is that it would harm communal interests. Social and economic rights are certainly justiciable, but the true challenge lies with adequately responding to *all* individuals' needs equally and equitably, rather than to those of articulate plaintiffs in court.<sup>271</sup> Courts thus ought to conduct their assessment of policy decision-making in light of equity and equality when adjudicating health rights, in order to better realize the values intrinsic to human rights.<sup>272</sup> It becomes easier for courts to enforce the right to health through litigation when certain rights are enshrined in national constitutions, especially when constitutional provisions allow precedence of international treaties over domestic law, though this currently is not the case in every country with regards to the right to health.<sup>273</sup>

When referencing the internationally defined right to health in human rights law, general comments and rapporteurs' thematic and mission reports offer useful insight into its practical application. Hunt cites a 2009 article by Gruskin, Bogecheo and Ferguson in which they identify central elements of a rights-based approach, specifically in the context of health. In it, they identify eight essential principles required to operationalize a rights-based approach. They include the AAAQ

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<sup>269</sup> Newdick. Can Judges Ration with Compassion? p. 110.

<sup>270</sup> Newdick. Can Judges Ration with Compassion? p. 118.

<sup>271</sup> Flood, Gross. Litigating the Right to Health. p. 62.

<sup>272</sup> Hunt, P. (2016). Interpreting the international right to health in a human rights-based approach to health. *Health and human rights*, 18(2). p. 109.

<sup>273</sup> Hogerzeil, H., Samson, M., Casanovas, J., & Rahmani-Ocora, L. (2006). Is access to essential medicines as part of the fulfilment of the right to health enforceable through the courts?. *The Lancet*, 368(9532), p. 306, 308.

principles (availability, accessibility, acceptability and quality)<sup>274</sup> on the one hand, and participation, non-discrimination, transparency, and accountability on the other.<sup>275</sup>

The latter four principles are related to a range of human rights in general, though not unique to the right to health. The AAAQ criteria, which stem from the CESCR's GC No. 14, do directly relate to right to health. In addition to this list, Hunt identifies three more necessary elements for an operationalized rights-based approach: progressive realization of the right to health, maximum use of available resources, and international assistance and cooperation in realizing the right to health.<sup>276</sup>

In a similar vein, Dittrich et al. advocate methods to safeguard that governmental decision-making on healthcare rationing is rationally substantiated, and to supply the judiciary with the appropriate mechanisms to determine whether the decision-making process was adhered to accordingly.<sup>277</sup> Both equity and ethics must be central considerations when shaping and reviewing such policies.<sup>278</sup> Governments should pursue an 'explicit, transparent, evidence-based approach' when policy-shaping, and the judicial assessment must consider the 'social, economic, organizational, and ethical issues' inherent to a specific rationing policy in allocating scarce healthcare resources.<sup>279</sup>

Returning to Newdick's proposed matrix for legal approaches to such cases and synthesizing its four quarters, the individual-substantive approach and the communal-procedural approach reflect the delicate balance discussed above. When the individual-substantive approach becomes dominant, a limited supply of healthcare resources and services perpetually eroding in the face of high demand will increasingly jeopardize community interests.<sup>280</sup> The risk of a rights-based approach thus is that it can bolster individuals in their demands for expensive treatments, thereby aggravating the existing difficulties domestic governments already have in their pursuit of fair and efficient healthcare systems.<sup>281</sup> A good example is the 2005 'Nikolaus Beschluss' case judged by the German Constitutional Court (*Bundesverfassungsgericht*) in which the court ruled that an expensive treatment, though without clinically proven effect, was to be covered for a terminally sick patient with Duchenne's muscular dystrophy, after refunding had

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<sup>274</sup> See para. 12(a-d) of the CESCR's GC No. 14 E/C.12/2004/4 on art. 12 ICESCR.

<sup>275</sup> Hunt. Interpreting the international right to health. p. 115.

<sup>276</sup> Ibidem.

<sup>277</sup> Dittrich, et al. The International Right to Health. p. 25.

<sup>278</sup> Ibidem.

<sup>279</sup> Ibid. p. 28.

<sup>280</sup> Newdick. Can Judges Ration with Compassion? p. 117.

<sup>281</sup> Flood, Gross. Litigating the Right to Health. p. 69.

initially been rejected under the health insurance scheme.<sup>282</sup> When individual substantive health rights are allowed precedence over larger community concerns of equity and solidarity, these principles are at risk.<sup>283</sup>

In UK judicial review the notion of 'procedural rights' has been developed, which allows courts to distance themselves from the 'politics' of decision-making through allocative policies.<sup>284</sup> Such procedural rights must constitute more than a 'promise of good intentions.' Through procedural adjudication health systems can ensure that 'fair procedures have identified relevant matter and weighed and balanced them properly.'<sup>285</sup> Such procedural rights then help to scrutinize the 'reasonableness' of allocative decision-making. Latin American and European courts tend towards more substantive rulings, in contrast to the procedural preference of Anglo-Saxon courts.

The ECSR already looks at state parties' realization of the right to health as is defined in art. 11 ECS, in two manners: through its jurisprudence on art 11 and indirectly, through the methodology used to evaluate states' compliance with this provision.<sup>286</sup> This occurs through the collective complaints procedure and through state reports.<sup>287</sup> The second most commonly found case of non-conformity concerns 'access to healthcare.'<sup>288</sup> There is no other human rights body that goes into such depth in monitoring social rights as the ECSR goes in combining a results-based approach with a qualitative analysis.<sup>289</sup> The ECSR also uses states' failure to provide information on their performance in healthcare to find non-conformity to art. 11 ESC.

The ECSR not only defines, but also impacts the very substance of the right to health. Because it relies on a comprehensive but precise range of indicators and standards, the interpretation of the right to health by the ECSR represents a unique and ambitious development in human rights law.<sup>290</sup>

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<sup>282</sup> Dannecker G., Streng A.F. (2013). Die Bedeutung des „Nikolaus-Beschlusses“ für die Priorisierungsdebatte. In: Schmitz-Luhn B., Bohmeier A. (eds) *Priorisierung in der Medizin*. Kölner Schriften zum Medizinrecht, vol 11. Springer, Berlin, Heidelberg. p. 135. ; Further information and discussion can be on Ruhr-Universität Bochum website Nikolaus-beschluss. Retrieved from <http://www.nikolaus-beschluss.de/pages/nikolaus-beschluss>. Accessed 19/07/2018.

<sup>283</sup> Dittrich, et al. The International Right to Health. p. 26.

<sup>284</sup> Newdick, C. (2014). Health care rights and NHS rationing: Turning theory into practice. *Revista Portuguesa De Saúde Pública*, 32(2). p. 157.

<sup>285</sup> Newdick. Can Judges Ration with Compassion? p. 111.

<sup>286</sup> Lougarre, C. (2015). What Does the Right to Health Mean?. *Netherlands Quarterly Of Human Rights*, 33(3). p.328

<sup>287</sup> Lougarre. What Does the Right to Health Mean? p. 330.

<sup>288</sup> Ibid. p. 336.

<sup>289</sup> Ibid. p. 338.

<sup>290</sup> Ibid. p. 346.

The use of thematic health indicators has enabled the ECSR to develop a more comprehensive and transparent interpretation of the right to health through art. 11 ESC.<sup>291</sup>

Shaping and pursuing legitimate decision-making on healthcare rationing will necessitate both efforts by governments to guarantee a fair and just process, and by the judiciary in taking its crucial responsibility in reviewing this process of priority-setting, assessing its role in achieving maximized population health without disregarding those marginalized and vulnerable.<sup>292</sup> Achieving this will incorporate the best of the appeals and enforcement principles. Rationally substantiated government allocative policies can and should be in harmony with the judicialization of the right to health. It is thus imperative that the courts hold on to their crucial role in supervising citizens' procedural rights and ensuring the equitable and just allocation of rationed health services and resources to society at large.<sup>293</sup>

#### 7.4. Citizen Access to Justice

As discussed, for a healthcare system to be morally legitimate and democratically acceptable, it must include, *inter alia*, accountability through an appeals mechanism and an enforcement body. The importance of the justiciability of the right to health thus is evident. Less so is the route for individual citizens to claim this right at the relevant international courts.

In line with the order of discussion used earlier, first the route at the UN level will be assessed, then the Council of Europe level, followed by the EU level.

To address breaches of the rights guaranteed in the ICESCR, the Optional Protocol allows for the individual complaints procedure, an inter-state complaints procedure, and an inquiry procedure. The only procedure open to individuals under the Optional Protocol concerns individual complaints, and only after all domestic remedies have been exhausted. Under this procedure communications may only be submitted by or on behalf of individuals, or groups of individuals, after a perceived violation of one of the rights set out in the ICESCR.<sup>294</sup> However, considering that only 23 States, among which a mere 8 of the 28 EU member states have ratified the Optional Protocol, this option remains inaccessible for most citizens.

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<sup>291</sup> Ibid. p. 348.

<sup>292</sup> Dittrich, et al. The International Right to Health. p. 29.

<sup>293</sup> Ibidem.

<sup>294</sup> Committee on Economic, Social and Cultural Rights (CESCR), *Optional Protocol to the International Covenant on Economic, Social and Cultural Rights*. Retrieved from <https://www.ohchr.org/en/professionalinterest/pages/opcescr.aspx>. Accessed 22/07/2018.

At the level of the Council of Europe, individual complaints can be lodged with the ECtHR, provided that they concern a violation of the individual rights stipulated in the ECHR. As the ECtHR recognizes no direct right to health, a more relevant body to adjudicate such cases would be the ECSR. Complaints about perceived infringements of the rights under the European Social Charter can be made through the collective complaints procedure. Only social partners and other non-governmental organizations can submit such complaints, however, not individual citizens. Both the collective complaints procedure and the reporting procedure under the ECSR implement the collective extent of the right to health, but leave the individual without options to claim their entitled rights under the ESC.<sup>295</sup>

The European Charter of Fundamental Rights (CFR) pertains to EU institutions and only to member states' domestic authorities provided that they have adopted and implemented EU legislation. As policy-making in the field of health falls within member states' degree of national discretion, the EU only has a supporting competence here.<sup>296</sup> The 2017 Pillar of Social Rights is a political declaration, and thereby not legally binding.<sup>297</sup>

The European Union Fundamental Rights Agency (EU-FRA) is only authorized to comment on EU institutions and does not have the mandate to accept and deal with individual complaints. It is neither sanctioned to comment on human rights cases in individual member states. Following the author's request by email to the EU-FRA, the institution responded not to have covered issues on healthcare rationing under art. 35 of the CFR.<sup>298</sup> With regards to access to healthcare, the EU-FRA has only published a single factsheet.<sup>299</sup>

A second institution approached by email for this paper was the European Ombudsman (EO) who investigates and assesses complaints about maladministration in the EU's bodies and institutions. Though the EO did occasionally deal with EU staff issues concerning the fundamental right to health under art. 35 ESC<sup>300</sup>, the EO is not able to comment on member states' domestic

<sup>295</sup> Lougarre. What Does the Right to Health Mean? p. 351.

<sup>296</sup> Following the Treaty on the Functioning of the European Union art. 168, member states remain free to organize and finance their domestic systems of healthcare.

<sup>297</sup> The right to 'timely access to affordable, preventative, and curative health care of good quality' under art. 16 thus cannot be claimed at the European level by citizens.

<sup>298</sup> EU-FRA Information Team. (2018). Request finding ECJ case law on 'Healthcare Rationing' [Email, 4/7/2018, 11:14].

<sup>299</sup> See EU-FRA. (2013). *Factsheet Inequalities and multiple discrimination in access to and quality of healthcare*. Retrieved from <http://fra.europa.eu/en/publication/2013/inequalities-discrimination-healthcare>. Accessed 8/8/2018.

<sup>300</sup> See European Ombudsman. (2008). *The respect for and pursuit of fundamental rights (Thematic Paper)*. Retrieved from <https://www.ombudsman.europa.eu/en/cases/thematicpaper.faces/en/75072/html.bookmark>.

health policies due to its restricted mandate. By extension, the EO has therefore not commented on cases about national access to, or rationing of healthcare.<sup>301</sup>

From an individual citizen's standpoint, both the UN and the EU fail to provide individual access to justice concerning the right to health. With only 23 countries having ratified the Optional Protocol since its adoption in 2013, the individual's access to justice is severely restricted. Here, countries must be coached and lobbied into ratifying this important step towards full accountability via the ICESCR Optional Protocol. At the EU level, fewer options are available. As health and healthcare fall within member states' competence following art. 168 TFEU and due to national authorities' widespread reluctance to transfer national competences to 'Brussels', it seems unlikely that the EU will develop a role in guaranteeing EU citizens access to justice concerning cases about healthcare any time soon.

At the level of the ECSR however, important improvements are possible. As complaints may currently only be lodged by groups of individuals collectively, there is room to add an *individual* complaints procedure, in line with the UN's ICESCR Optional Protocol, thereby allowing citizens' individual access to justice. As an important component of accountability, an enforcement mechanism must be added to this appeals body. Here, important potential exists for the judiciary to provide enforceability.

Finally, citizens should also be provided with more and better information by authorities. The ECSR must reach out to these citizens to explain how they can claim their right to appeal, one of the ethical procedural criteria towards a morally acceptable and legitimate system of care rationing.

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Accessed 8/8/2018. 'The EO launches inquiries concerning staff issues, which have a human rights component.'

<sup>301</sup> European Ombudsman (Press Officer). (2018). Request finding Ombudsman rulings on 'Healthcare Rationing' [Email, 13/7/2018, 10:37].



## 8. Conclusion

It is clear that both ethics and international human rights law have an important role to play in healthcare policy making on healthcare rationing. Where the frontiers of medical technology and available treatments used to compose the limiting factor, this barrier is increasingly formed by our national healthcare budgets. The result is that demand will increasingly outstrip finite resources. There will therefore always be individuals whose demand for care will not be met. In the face of the inevitability of scarce resource allocation, the question becomes not *if* we must ration care, but *how*. For such rationing policy to be legitimate to society, it must be based on sound moral principles, and is thereby a fundamentally ethical issue.

Citizens are becoming more informed on health, showing increasing consumerist tendencies towards medicine, and are decreasingly willing to accept their physician's decision as being definitive. This is reflected in popular talk shows where patients are interviewed who could possibly benefit from new and expensive drugs. By framing the patients as victims of heartless government rationing policies, the emotional argument is fed to the viewers. This further erodes public support for rational and informed allocative policies. Concurrently, a growing number of people is turning to courts and is attempting to use the international right to health as a vehicle by which to claim care. In case of denial of healthcare due to system failure, the courts prove crucial to guarantee justice. When citizens contest rational and informed government policy, however, the 'individualist' approach poses a genuine threat to the health interests of the population as a whole.

As seen (Ch. 6), significant overlap exists in moral and legal principles underlying a system of fair and just rationing. To meet the criterion of *accountability* formulated in ethics literature, the role of the judiciary is crucial. Both ethics and law thus are necessary for healthcare rationing to be publicly legitimate.

The role of ethicists must be included more in the process of policy shaping about resource allocation. Too often, it remains unclear and obscure how resource allocation policy is developed, bypassing public participation and lacking accountability for citizens. Secondly, it is certain that the judiciary plays an important role in supervising good conduct in the shaping of rational and informed rationing policy, facilitating an appeals mechanism, and in judicial review. This protects the individual from flawed policy, and protects the general interest against unjustly litigating individuals.

In that regard, it is time for a more intensive dialogue to develop between the fields of ethics and law with regards to healthcare rationing policy. As described (Ch. 6),

certain moral principles such as *public participation* and *openness to democratic deliberation* are hardly reflected in international legal documents relating to healthcare policy shaping. On the other hand, the legal AAAQ principles made explicit in, *inter alia*, the CESCR's GC No. 14 are not reflected in the ethics literature on the topic. For role of the judiciary to realize its maximum potential in providing accountability to the public on the ethical issue of allocative policy shaping, both fields should strive to harmonize their criteria for legitimacy.

Though public participation is required for moral legitimacy, it remains unclear how this ought best to be realized. More research is necessary to determine how best ensure effective participation in practice.

Access to justice for European citizens must be expanded from what is currently possible. At this moment, individual complaints can only be lodged at the UN's CESCR through the Optional Protocol (OP). Of the 28 EU member states, just 8 have ratified the OP, allowing for this option. In order for this complaints procedure to have practical use for citizens, this number of ratifications must drastically increase. Similarly, more countries must ratify the ESC's collective complaints procedure, as only 15 of the Council of Europe's 47 member states have to date. At the level of the ECSR, only collective complaints can be made by groups of individuals, but not by individuals themselves. An individual complaints procedure at the ECSR should be created for citizens to secure accountability of governments responsible for priority-setting, as it at the UN level.

Governments often hesitate to allow citizens to contest their policy decisions. However, contestation is the only way for care rationing to be truly respected as an ethical issue. The involvement of public law adjudication to nurture a 'culture of justification' will push the public and political debate on healthcare rationing towards justice.<sup>302</sup> And to respect the human right to health, as recognized by all EU member states, governments must provide policy that is fair and just.

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<sup>302</sup> Syrett, K. (2007). *Law, legitimacy and the rationing of healthcare*. Cambridge: Cambridge University Press. p. 245.

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