



BREVE 16

ETHICS OF HEALTH RESOURCE ALLOCATION IN THE BRAZILIAN PUBLICLY FINANCED HEALTH CARE SYSTEM

Based on a CRITERIA webinar presentation and thesis work by Dr. Fábio Ferri-de-Barros, November 30, 2015, and April 2013, respectively.

A series on policies and methods based on presentations for experts. Prepared by CRITERIA, a knowledge network on prioritization and health benefit plans from the Inter-American Development Bank.

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ACRONYMS

A4R	Accountability for Reasonableness
ANS	National Health Agency (<i>Agência Nacional de Saúde</i>)
BRL	Brazilian reais
CNS	National Health Conferences (<i>Conferências Nacionais de Saúde</i>)
CONASS	National Council of Health Secretaries (<i>Conselho Nacional de Secretários de Saúde</i>)
IDB	Inter-American Development Bank
LMIC	Low- and middle-income countries
SGEP	Secretary of strategic and participative management (<i>Secretaria de Gestão Estratégica e Participativa</i>)
SUS	Health care system (<i>Sistema Único de Saúde</i>)
WHO	World Health Organization

1. INTRODUCTION

This *Breve* is based on the original thesis work and on a webinar presented by Dr. Fábio Ferri-de-Barros¹ regarding the “Ethics of Health Resources Allocation in the Publicly Financed Health Care System in Brazil.”² The perspective offered in this *Breve* complements a previously published issue documenting the use of health technology evaluation in decision-making in Brazil’s health sector (IDB, 2015).

The *Breve* introduces the challenges of priority setting in the context of a large and decentralized national universal health care system, which confronts resource scarcity and substantial inequalities. It lays out the objectives and the methods of research carried out by Ferri-de-Barros regarding the ethics of health resource allocation in Brazil. Before discussing the results of this original research, the *Breve* offers an overview of Brazil’s publicly financed health care system (SUS) to provide the context in which priority setting is taking place. The *Breve* then focuses on Brazil’s

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² The presentation was delivered on November 30, 2015, to the members of CRITERIA, the Knowledge Network on Health Benefits Packages and Priority Setting in Health of the Inter-American Development Bank (www.redcriteria.org). The audio, PowerPoint presentation, and transcript can be accessed on CRITERIA’s website at: <http://www.redcriteria.org/webinar/los-etica-de-la-priorizacion-del-gasto-en-salud-de-brasil/>

National Health Conferences (CNS), which represent a key forum for social participation in decision-making regarding health resource allocation for SUS. The subsequent section highlights the key findings of the analysis provided in Ferri-de-Barros’s thesis research. Lastly, the *Breve* summarizes good practices as well as challenges related to health resource allocation in Brazil; it also provides related policy recommendations based on Ferri-de-Barros’s analysis.

2. RESOURCE SCARCITY AND PRIORITY SETTING IN BRAZIL

In low- and middle-income countries (LMIC) the ethics of priority setting is a very important topic, because health resources are scarce and decisions on the allocation of resources have far-reaching consequences on the health and wellbeing of the population (Glassman and Chalkidou, 2012). Allocation decisions often determine who lives and who dies. Brazil is no exception in that regard. Its publicly financed health care system is often considered underfunded and it struggles with significant regional disparities in terms of availability of

health resources, health indicators,³ and access to privately financed health care (Ferri-de-Barros, 2013 and 2015).

Dr. Ferri-de-Barros (2015) indicates that justice and fairness are absolutely critical to ensure that resources are allocated based on clear reasons that everyone can understand, and not based on who screams the loudest.

Not only policy makers, but also doctors are confronted with difficult decisions on a daily basis regarding allocation of scarce health resources to competing priorities. Especially in smaller hospitals, doctors and local health authorities have to decide, for example, if a severely injured patient can be transferred to a tertiary care center for limb reconstruction, where resources for limb reconstruction exist but are limited, or if the transfer cannot be done, usually due to overcrowding in tertiary care centers, and the limb has to be amputated instead, as a result of the lack of resources available for limb reconstruction in smaller hospitals.

Priority setting is a complex topic, which needs to be viewed in the context of allocating limited health resources to a given population with diverse health care needs. Just as health care systems in many other parts of the world, Brazil's health care system has to deal with scarcity of

resources as well as with increasing pressures on expenditures as new medical technologies and an increased burden of disease emerge. The epidemiologic profile is changing and the population is aging rapidly. At the same time, widespread and strong inequalities of opportunities for human development determined by immutable circumstances persist in Brazil. Most of the population (75%) depends on the publicly financed health care system and only a limited number of citizens can afford access to privately financed health care. Resource-allocation decisions in the publicly financed system therefore have a significant impact on the concept of opportunities for human development in Brazil. In addition, the population relying exclusively on SUS is not empowered to adequately participate in the decision-making processes for health resource allocation. As a result, the distribution of publicly financed health resources across the country is inequitable. According to Ferri-de-Barros, in Brazil, many decisions on how to allocate scarce health resources are based on undisclosed political interests. There is little transparency and limited information on the rationales behind resource allocation across health programs in different jurisdictions (Ferri-de-Barros, 2015).

All resource-allocation decisions have an opportunity cost. Ferri-de-Barros (2013) describes his personal experience with unmet needs for surgical care for children and young people in Brazil: When he was assigned the task of improving rehabilitation care in one of the regional jurisdictions in the State of São Paulo, Brazil, he was faced with a priority-setting

³ Geographical and social inequalities in morbidity and mortality rates persist across Brazil. For example, in 2006, the northeastern region had an infant mortality rate that was 2.24 times higher than that of the southern region, although this disparity has decreased. (Victora, et al., 2011a) Maternal and child health in Brazil: progress and challenges. The Lancet

dilemma, since disabled children had to compete for the limited surgical resources that were largely consumed by the epidemics of road traffic injuries. As Ferri-de-Barros (2015) put it:

“For any decision you make to allocate resources to expand one health care program, some other program will lose. Often [in Brazil] there is a lack of transparency in such a decision-making process and the winners and losers in that game and in that process are not disclosed.”

Motivated by this priority-setting dilemma, Dr. Ferri-de-Barros pursued extensive international training in pediatric orthopedic surgery in diverse health care systems in five different countries, as well as a graduate degree at the University of Toronto in health services research and bioethics. His thesis work was supervised by a world-class multidisciplinary research team equipped with diverse expertise in the areas of priority setting, epidemiology, and public health.

3. RESEARCH OBJECTIVE AND METHODS

Fábio Ferri-de-Barros’s research analyzes the ethics of rationing health care resources in Brazil. The main research objectives were to: 1) Describe priority setting for health resource allocation in Brazil, 2) evaluate priority setting according to an extended version of Norman Daniels’s Accountability for Reasonableness framework (A4R) (Daniels, 2000), including

an “empowerment condition,”⁴ and 3) provide recommendations for improving priority setting in Brazil based on the findings from objectives 1 and 2.

Ferri-de-Barros’s thesis reviews the Brazilian literature on the ethics of priority setting, maps and describes the key concepts on this issue using a scoping review.⁵ Based on the data collected with this systematic approach, the process of priority setting is analyzed using a modified version of A4R. The scoping review includes the documentation from Brazil’s three most recent CNS, as these are the main forums to propose guidelines for the formulation of health policy in Brazil. It also encompasses Brazilian studies on ethics of priority setting, and reports by the World Bank (La Forgia et al., 2007), *Conselho Nacional de Secretários de Saúde* (CONASS, 2009), and The Lancet Brazil working group (Victora et al., 2011b).

⁴ The empowerment condition has been suggested by Gibson et al. as a fifth condition. Gibson, J. L., Martin, D. K., and Singer, P. A. (2005). Priority setting in hospitals: Fairness, inclusiveness, and the problem of institutional power differences. *Social science and medicine*.

⁵ A scoping review approach differs from a systematic review approach in at least two ways: 1) A systematic review might typically focus on a well-defined question where appropriate study designs can be identified in advance, whilst a scoping study tends to address broader topics where many different study designs might be applicable. 2) The systematic review aims to provide answers to questions from a relatively narrow range of quality assessed studies, whilst a scoping study is less likely to seek to address very specific research questions nor, consequently, to assess the quality of included studies. Arksey and O’Malley (2005), p. 20

The inclusion criteria and the process for conducting the scoping review and the thematic analysis are clearly outlined in the methods chapter in Ferri-de-Barros's thesis (2013), which is publicly available online. The methods and analysis conformed to the high standards of scientific rigor applicable to this chosen line of inquiry, which is well aligned with this complex topic.

4. BRAZIL'S HEALTH CARE SYSTEM

The publicly financed health care system, the *Sistema Único de Saúde* (SUS),⁶ was implemented in Brazil in the late 80s. Its three core principles are universality (health care provided to all), integrality (complete package of service), and equity (care should be provided in an equitable manner).

The SUS is financed with taxes and social contributions from the municipal, state, and federal governments. Since its implementation there have been such substantial improvements in primary health care as universal vaccination coverage and the implementation of the family health program. However, due to the context of inequalities and the complexities of a large decentralized health care system, it is crucial to analyze how

decision-making processes regarding health resource allocation can be further improved, to achieve a fairer, more accountable, and more transparent distribution. Most of the population relies exclusively on the SUS for health coverage (see *Breve #5*). Health care services in the SUS are free of charge. Approximately 25% of the population has access to private health insurance. Private health care has developed fast over the past few years in Brazil; it covers the wealthiest strata of the population and it is more developed in wealthier states. This market-based approach to health care has contributed to inequities in the distribution of health resources to cover Brazil's diverse population. For example, 6.7% of Brazilian children and youth from the north and northeast have access to private health care, compared with 43.3% of adults and the elderly of São Paulo State (ANS, ND).

The CNS, which have an important impact on decisions regarding health resource allocation, constitute a fundamental pillar of the SUS. Their main function is to evaluate the health situation in the country and propose health policies (CONASS, 2009) (Ferrarezi and Carvahlo, 2011). The CNS guide the formulation of health policies at all jurisdictional levels, for each budget cycle (4 years) of the publicly financed health care system (Ferri-de-Barros, 2013). Therefore, the CNS constitute the main forums for priority setting within the SUS (Ibid). The following section describes the National Health Conferences, as well as some of their main topics, which have guided the formulation of recent health policies. These policies will be used as examples for discussing the fairness and legitimacy of priority setting in this context.

⁶ A wide range of literature is available on Brazil's SUS. Good reference material on how Brazil's health care system works is, for example: Victora, C. G., Barreto, M. L., Leal, M. C., Monteiro, C. A., et al. (2011b). Health conditions and health-policy innovations in Brazil: the way forward. *The Lancet*

5. NATIONAL HEALTH CONFERENCES AND CNS THEMES

The CNS are organized by three main levels: the municipal level, the state level, and the federal level. Box 1 displays an overview of the main aspects of the National Health Conferences. The conferences are meant to include participants from the general public (50%), elected representatives of health care providers (25%), and managers and decision-makers (25%). Health authorities in different jurisdictions elect the representatives. This process is usually organized by the Municipal Health Minister (*Secretário de Saúde*), with the oversight of the Municipal Health Council.

Box 1: National Health Conferences in a Nutshell

Participants:

- 50% members of the public
- 25% elected health professional representatives
- 25% elected manager and decision-maker representatives

Frequency: Every 4 years.

Organized at: Municipal, state, and national levels.

Decentralization and decision-making: Health policy reports made at each level are sent to a higher level (municipal reports are sent to the state level and state-level reports are sent to the national level). Health policies are voted on at the federal level.

Number of policies per set of CNS: More than 400 policies are voted on and approved per set of CNS; many are related to general priority setting for health services.

Example of an elected health policy related to priority setting: At the 14th CNS, dental health care was voted for as one of the priorities. The #11/guideline 7 approved policy states the following: *“Expand oral health coverage at all levels of care, [...] with universal and equitable access for all people, including access to urgent services.”*

Source: CONASS (2009) p. 31, Fábio Ferri-de-Barros (2013) p. 53

For each set of CNS, a central theme and several subthemes are defined. For example, at the 12th CNS held in 2003, the central theme was “Health as a legal right and a state duty; the health we have and the SUS we want.” The subthemes were: right to health, social security, and participatory management. Some recurrent themes of the CNS will be analyzed in more detail in this section.

Figure 1 identifies the main themes addressed in the past three National Health Conferences and what the Brazilian literature on the ethics of priority setting has discussed regarding these topics, based on the scoping review carried out by Ferri-de-Barros (2013).

Figure 1. Thematic Analysis: Examples Taken the CNS

CNS	<ul style="list-style-type: none"> • Societal participation 	<ul style="list-style-type: none"> • Integrality • Universality • Equity 	<ul style="list-style-type: none"> • Public / Private mix
Literature	<ul style="list-style-type: none"> • Power Imbalance • Council composition • Underrepresentation • Empowerment 	<ul style="list-style-type: none"> • Integrality challenged • Universality accepted • Equity endorsed / fairness • Explicit process 	<ul style="list-style-type: none"> • Inequities/ Inefficiencies • Lack of PS process for private sector

Source: Ferri-de-Barros (2015)

Theme 1: Societal Participation in Health Policy-Making

Public participation in health policy-making is an SUS legal requirement. It is planned by the health authorities and exercised by health council members at all jurisdictional levels of the system. Nevertheless, the scoping review evidenced a pronounced power imbalance and showed that the council's composition does not meet the requirements set forth by the legislation that guides the CNS. There is a strong underrepresentation of different stakeholder groups. Due to regional and age group differences in access to privately financed health care, the current distribution of voting participants underrepresents users from poorer regions, children, and youth, who depend exclusively on SUS.⁷

A study by Wendhausen (2006)⁸ showed that the numeric distribution of council members does not always meet the legal requirement. In the case analyzed by Wendhausen et al. there were 10% more government representatives and 8% fewer health care professionals assigned as council members, compared to what is prescribed by the legal requirement. In a qualitative analysis, Wendhausen et al. suggested that members not representing the government had fewer opportunities to participate during the debates on municipal health care issues, because members of the government controlled the discussions and imposed their ideas. Some authors also emphasize the inequity of education and of access to information among different health council members in Brazil, which impedes legitimate social participation (Martins et al., 2008).

⁷ This is something that was shown in a previous article by Ferri-de-Barros on inequitable distribution of health resources in Brazil, which was published in the 'Acta Bioethica 2009' journal.

⁸ Wendhausen studied decision-making processes for health resource allocation in a municipal health council of the State of Santa Catarina, Brazil. The author systematically analyzed legal documents and meeting reports, observed meetings, and conducted interviews to study the decision-making processes during health council meetings. (Wendhausen, Á., 2006).

Theme 2: Principles of Integrality, Universality, and Equity

The principles of integrality, universality, and equity are the main pillars of the SUS and they have been a recurring theme in the CNS.⁹ The literature on priority setting in Brazil supports the idea of the principles of universality and equity (Paim, et al., 2011), yet it looks critically at the principle of integrality¹⁰ and several authors argue that no health care system can offer everything to everybody (CONASS, 2009) (Ferri-de-Barros, 2013) (Fortes, 2009). Nevertheless, integrality was an important topic at the 14th—and most recent—CNS, and yet an extensive number of policies and guidelines focused on the expansion of health services (as opposed to rationing and setting priorities), such as the emphasis on strengthening primary health care (guideline 8), the expansion of oral health coverage at all levels of care (guideline 7), and the further extension of specialized urgent care and hospital-based care (guideline 10) (Ferri-de-Barros, 2013).

Theme 3: Public/Private Mix

Another recurring theme at the CNS has been the public/private mix. The literature on the ethics of priority setting in Brazil suggests that

the public/private mix generates inequities and inefficiencies. “Mixed public/private healthcare systems present additional challenges to decision-makers, because there are differences in governance, visions and missions, and accountability between the private and public systems. In addition, the two systems compete unfairly for limited health resources, especially human resources. The privately financed system offers salaries, infrastructure, and other incentives that are substantially more attractive to health care professionals compared with what the SUS offers; thus, the privately financed system draws human resources from the SUS and it reallocates them according to for-profit market needs, as opposed to allocating them to addressing population health care needs (SUS mandate)” (Ferri-de-Barros, Gibson, and Howard, 2012). Paim et al. (2011) state that “the continuous expansion of the private subsector is subsidized by the state, while the public subsector is often underfunded, which potentially compromises its ability to guarantee quality of and access to care.” At the 14th CNS financing conflicts caused by the public/private mix were also addressed explicitly in a guideline set forth in the final report (Ferri-de-Barros, 2013). As far as priority setting for resource allocation is concerned, the National Health Conferences guide this process for the SUS, yet there is no parallel process that directs resource allocation in the privately financed system (Ferri-de-Barros, Howard, and Martin, 2009).

⁹ At the most recent CNS, the 14th CNS, most policies approved refer to the principles of Universality, Integrality, and Equity.

¹⁰ A complete package of health services

Within the context of the public/private mix in Brazil, another challenge that emerged from the scoping review was that the people who could actually drive change, and actively participate in decision-making for health resource allocation in Brazil, are not affected by what is happening to the SUS. This is because the wealthiest strata receive health care services almost exclusively in the privately financed system. Martins et al. (2008) refer to this phenomenon as “self-exclusion.” That 25% of the population in Brazil who has access to private health care or who pays for services out of pocket does not have to struggle to have its health care needs met in the underfunded publicly financed system. This sector of the population typically includes empowered citizens who could hold decision-makers accountable (Ferri-de-Barros, 2013).

In addition to analyzing the CNS themes, Ferri-de-Barros used an expanded version of the Accountability for Reasonableness framework (Daniels, 2008) (Daniels and Sabin, 1997) to evaluate the processes of health resource allocation in Brazil. The following section provides an overview of his findings based on his scoping review.

6. ETHICS OF PRIORITY SETTING: A CRITICAL ANALYSIS BASED ON THE EXPANDED VERSION OF THE ACCOUNTABILITY FOR REASONABLENESS FRAMEWORK

As shown in the previous sections, priority setting is a complex topic and health resource allocation decisions have far reaching consequences to human health. Resource allocation decisions in health care involve multiple moral disagreements on what is most important, what should be financed, and for whom. A rigorous deliberative process is necessary to establish the legitimacy and fairness of such decisions (Daniels, 2008). Accountability for Reasonableness (A4R) (Daniels and Sabin, 1997) is a framework based on principles of justice and fairness. Developed by Norman Daniels and James Sabin, A4R has been applied empirically in diverse case studies in LMIC and it has been used by such major international organizations as the WHO to guide difficult priority-setting

decisions. A4R comprises four conditions that a decision-making process for allocating health resources must meet to ensure its legitimacy and fairness: Relevance, Publicity, Appeals, and Enforcement. A4R states that decisions must be based on relevant reasons and that these reasons should be publicly communicated to all stakeholders involved in, or affected by, allocation decisions. There must also be a mechanism to appeal or reverse decisions.

Gibson et al. have suggested adding empowerment (Gibson, Martin, and Singer, 2005) as a fifth condition to A4R. The empowerment condition entails that all decision-makers be empowered to participate in a similar manner. Together, the five conditions constitute an extended version of the A4R framework, which was utilized for the ethical analysis in this context. Ferri-de-Barros applied an evaluation checklist (Ibid), which is based on the extended A4R framework, to the data collected with the scoping review in order to analyze whether the decision-making process for health resource allocation in the three most recent CNS met all five conditions of the extended A4R framework.

1. Relevance: Are Priority-Setting Decisions at the CNS Based on Specific Reasons?

1.1 Criteria: One of the main questions in this context is whether CNS decisions were based

on relevant and substantiated criteria and reasons.

The CNS issue and vote on guidelines at the municipal and state level; policies are voted on and decided at the national level. The policies and guidelines selected are meant to provide information to guide allocation decisions. For example, at the 14th CNS, one of the approved guidelines (number 8) read: “Expand and strengthen the primary health network: all families, all people must be ensured the right to a family health team.” One of the policies approved at the national level based on this guideline was policy 25: “Increase resources [...] to prioritize implementation and continuation of primary care, building and renewing basic health care units, building capacity for electronic medical records, acquisition of motor vehicles and other necessary equipment [...]” (Ferri-de-Barros, 2013). Even though these guidelines and policies reflect the priorities voted for at the different levels, priority setting occurred rather implicitly because the policies were not clearly explained and justified (Ferri-de-Barros, Howard, and Martin, 2009) (Fortes, 2009). That is why the criteria and relevance condition was, at best, only partially met in this process.

Similarly, one of the approved policies at the national level was the allocation of 9 billion Brazilian reais (BRL) to expand oral health coverage. Despite the fact that this policy was voted for, it is not clear why the government or the Ministry of Health decided to expand

oral health coverage to that extent. Neither is there any information available regarding why a certain quantity was allocated to oral health coverage and not to pediatric surgery, for example. Ferri-de-Barros asks: *“Is it reasonable that the publicly financed system will pay for braces and dental implants while there are kids waiting for years to get time-sensitive reconstructive surgeries that could save their lives or prevent or mitigate significant disabilities and suffering?”* (Ferri-de-Barros, 2015)

1.2. Data: Another question that arises when thinking about relevance is related to data: Are decisions based on reasonable data?

One of the CNS guidelines¹¹ recommends improving evidence-based decision-making and decision-making based on the local population’s health situation. However, the representatives present at the CNS agreed that this has not yet been entirely achieved and there is still a need to further improve the capacity to base policy-making on data and solid evidence. It is therefore not likely that CNS decisions already meet the data condition.

This finding confirms what has been previously found by a robust analysis performed by the World Bank concerning the publicly financed system in Brazil (La Forgia, Couttolenc, and Matsudo, 2007). According to the authors, planning for

future resource allocation should be based on an assessment of the most important epidemiological issues and the effectiveness of government interventions in previous periods. However, the survey conducted by La Forgia, Couttolenc, and Matsudo suggests that the existing planning process in Brazil lacks information and an analytical basis. One of the study’s main findings was that the planning phase for the allocation of health resources in Brazil is conducted mainly as a formal exercise aimed at meeting legal requirements, rather than as a basis for resource allocation. This process implies that there is very little variation in the budget from one year to the next and no encouragement to plan well (Ibid). The previous year’s budget (adjusted for annual growth) is the main source of information used for subsequent planning for the annual health resource allocation and budgeting processes (Hsiao et al., 2013). Planning and budgeting often become a formalistic routine that varies little from one year to the next, and this does not encourage good planning or management of service delivery (La Forgia, Couttolenc, and Matsudo, 2007).

2. Publicity: Transparency, Aim, and Scope

The publicity aspect of A4R looks at the transparency of the rationales behind resource allocation decisions made during the CNS, as well as the way it is

¹¹ Policy number 7, guideline 2, of the 14th CNS document

communicated to the public. A positive aspect is that all guiding themes for the CNS and their final reports, including allocation plans for each budget cycle, are communicated to the public. However, the main flaw regarding transparency and communication is that the reasons behind allocation decisions are not communicated to the public (Ferri-de-Barros, 2013).

Ferri-de-Barros takes the earlier discussion regarding the expansion of dental health care versus reconstructive surgery for children as an example and asks: *“If the rationales related to the expansion of oral health, in the context of reconstructive surgical care for children as a competing priority, were clearly disclosed to the public, would most relevant stakeholders agree that funding more dental implants and braces is more important than expanding resources to save children’s limbs or lives?”* (Ferri-de-Barros, 2015)

3. Appeals: Revision of Decisions

After the policies are elected by a majority vote, there is no formal appeal mechanism to dispute allocation decisions (Ferri-de-Barros, Howard, and Martin, 2009). According to the A4R framework, if there are new reasons or new rationales for changing allocation decisions, there should be a mechanism through which decisions can be reviewed. In the above hypothetical scenario offered by Ferri-de-Barros regarding the policy for expansion of dental health coverage

versus increasing capacity for providing reconstructive surgeries for children, a fairer model would ensure that all stakeholders had access to the rationale behind the allocation decision to fund [or not fund] competing priorities. Based on alternative rationales, different stakeholders would then be empowered with a clear appeal mechanism to review allocation decisions. In this case, an advocacy group for children with unmet needs for surgical care would argue that expanding financing for reconstructive care for children should be a priority over expanding dental care, because reconstructive surgery for children provides more significant health benefits than dental implants. Perhaps if the rationales behind decisions were available to all stakeholders, if all stakeholders had a similar “voice” in the process, and if there were a clear mechanism to appeal decisions, expanding dental health coverage would not be voted as a priority over reconstructive surgical care for children in this context.

4. Enforcement: Leadership’s Commitment to Ensure that the Other Conditions of the A4R Are Met

To satisfy A4R’s enforcement condition, there must be either voluntary or public regulation of the process to ensure that the first three conditions are met (Daniels and Sabin, 1997).

The legal framework for leadership in Brazil's health sector is also crucial, since enforcement capacity is an important element for policy implementation. One of the main problems is the lack of enforcement of legislated principles and the commitment to apply the priority-setting framework consistently (CONASS, 2009).¹² Although legislation in Brazil supports broad public participation in health policy-making for the publicly financed health care system, it is not enforced properly (Ferri-de-Barros, 2013). For example, this was clearly shown in the study carried out by Wendhausen et al. (2006), which suggests that current practices in priority-setting processes are not democratic and refer to the authoritarian culture of our institutions. She calls for empowerment of the council members who represent users and elected representatives of health professionals.

5. Empowerment

The empowerment condition requires power differences to be mitigated in order to facilitate the effective participation of diverse members in the context of decision-

making regarding priority setting.¹³ Looking at the empowerment condition in the context of the CNS, power imbalance exists among different groups of participants who vote at the CNS, both in terms of their representation and their participation. This is a problem that is described in Wendhausen et al. (2006) and in a report prepared by CONASS (2009). In some cases, the numeric distribution of voting participants does not follow the rules established in the law. There is inequitable voting power by geographic regions. The number of participants in the CNS is determined according to the general population of each different region of Brazil and not to the population that relies on the SUS. For example in the northeast of Brazil most of the population relies on the publicly financed system, whereas in the southeast of Brazil there is a much larger proportion of people who have access to privately financed health care. However, voting members from the northeast of Brazil are outnumbered and outvoted by participants from the southeast, just because there are more participants from the southeast in the CNS. Within the current distribution of voting participants, users from poorer regions, children, and youth are underrepresented (Ferri-de-Barros, Howard, and Martin, 2009). Decisions based

¹² This is clearly demonstrated in: Wendhausen, Á. (2006). Power Relations and Democracy in Health Councils in Brazil: a Case Study

¹³ The "empowerment condition" was suggested by Gibson et al. as a fifth condition of the A4R framework. It suggests that power differences must be mitigated to facilitate effective participation of diverse members in the decision-making context for priority setting. Gibson, J. L., Martin, D. K., and Singer, P. A. (2005). Priority setting in hospitals: Fairness, inclusiveness, and the problem of institutional power differences. Social science and medicine.

on voting will always represent a challenge to the concept of equity due to the regional discrepancies of health indicators in the different regions of Brazil.

7. GOOD PRACTICES: WHAT HAS WORKED WELL IN BRAZIL?

Broad Social Participation

One of the aspects that has worked very well in Brazil is broad social participation in the publicly financed system. Public participation in health policy-making is a legal requirement of the SUS and it is exercised at all levels of the system. Community participation has also been included as a topic in the three most recent CNS.

Well-Defined Leadership for the CNS

Ferri-de-Barros identified the well-defined leadership of the CNS as one of the main factors to support his argument that the CNS are a fundamental starting point for developing ethical priority setting for health resource allocation in Brazil (Ferri-de-Barros, 2013). The process of decision-making regarding priority setting is clearly defined, since National Health Conferences are its main forums, and CNS are clearly legislated, occur regularly every four years, and involve diverse stakeholders.

Voting Process at All Levels

Health policy-making in Brazil is done based on voting. Voting processes take place at the municipal, state, and federal level. The number of voting participants per state in the CNS is proportional to the state's population. The SGEP (*Secretaria de Gestão Estratégica e Participativa*)¹⁴ plays an important role in this, since it is responsible for accelerating and perfecting strategic and participatory management practices for the SUS.

Priority setting for allocating health resources should be based on the policies and guidelines approved at the national level, which should reflect the values of the different interest groups represented at the CNS. Health council members at all levels should ensure that decision-making at their jurisdictional level reflects the approved policies and motions (CONASS, 2009). Nevertheless, some of Brazil's regions are underrepresented in the decision-making processes, and certain interest groups are not sufficiently empowered to contribute equally in the process (Ferri-de-Barros, Howard, and Martin, 2009) (Wendhausen et al., 2006). This will be analyzed in the following section on policy challenges and recommendations.

¹⁴ The SGEP was developed following the 12th CNS. It is the national agency that supports, monitors, hears, and audits participatory management for the SUS.

Policies Approved During the 14th CNS

A number of policies aimed at addressing some of the issues mentioned above, such as mitigating power imbalances in decision-making and improving the capacity for evidence-based policy-making, were approved during the most recent CNS. During the 14th National Health Conference in 2011, nearly 3,000 delegates discussed more than 15 guidelines and health policy proposals that were generated from 4,374 municipal and 27 state conferences. The working groups voted on and approved 343 policies, which were disseminated to the public in a final report published in 2012 (Ferri-de-Barros, 2015).

8. FUTURE POLICY CHALLENGES AND POLICY RECOMMENDATIONS

Several aspects of Brazil's health care system must be strengthened in order to improve fairness and legitimacy of priority setting for health resource allocation. This section summarizes some of the policy recommendations identified by Ferri-de-Barros (Ibid).

Enforcement of Legislation

Certain areas of the legislation, such as the principle of broad public participation, are not always enforced. There should be a clear process and leadership to ensure that the conditions and principles set out in the legislation are met at all times and across all health jurisdictions.

Planning Capacity/Rationality

The planning of allocation decisions should be based on strong rationales. The A4R framework suggests that priority-setting decisions should be based on rationales, including evidence, principles, values, and arguments. Stakeholders should agree that criteria and rationales are relevant to meet the needs of the population. As La Forgia, Couttolenc, and Matsuda (2007) state, planning for allocating health resources is often times done as a formal exercise to comply with the legal requirement rather than as an instrument to implement policy or as a basis to decide on resource allocation. Capacity building in the area of health services research would facilitate meaningful data collection and analysis for planning evidence-informed decisions and health policy-making. Identifying and measuring unmet health needs as well as supply and demand for core health services in different health jurisdictions is a basic, yet critical step towards developing rationales for legitimate and fair priority setting, which is currently deficient in the SUS.

Integrality

Another opportunity for improvement is to revise the principle of integrality, since it is not feasible and it is utopian for any publicly financed health care system to provide everything for everybody. In its 2009 publication, CONASS acknowledged the need to set priorities explicitly and more objectively in the publicly financed health care system in Brazil. The report stated that acknowledging priorities does not mean that other actions, which are constantly evolving, are considered unimportant. If the National Health Conferences are not capable of indicating what is most relevant, it is impossible to identify priority actions and consider them when planning government actions (CONASS, 2009).

Inequalities

Inequalities, not only regarding health care, are a broader problem in Brazil. Yet in the context of inequality, decisions regarding the ethics of resource allocation are even more challenging. Regional discrepancies of health indicators in the different regions of Brazil are significant. At the same time, people in poorer regions have less voting power in the priority-setting process within the public system, and less access to private insurance. The remarkable inequality regarding opportunities for human development may be a product of poor priority-setting processes and inequity in representation.

Transparency and Appeals Mechanisms

Although there is public participation in decision-making for health policy-making at all jurisdictional levels of the SUS, and elected health polices reflect the values of the elected representatives of all Brazilian citizens, the rationale behind the decisions made regarding the final allocation of funds is not publicly available. At the same time, due to this lack of transparency, it is not possible to determine how approved policies and motions guide allocation decisions. It is also challenging to appeal decisions if the rationale behind those decisions is not explicit to all stakeholders. To improve the legitimacy and fairness of the decision-making process for health resource allocation in Brazil, a clear appeal mechanism must be developed and enforced. The mechanism must ensure that rationales for the voted and approved health policies and allocation decisions are actively disseminated to the public and discussed at all jurisdictional levels, taking into account diverse health care priorities in different jurisdictions, prior to implementation.

Empowerment and Marked Power Imbalance

Another important challenge that must be addressed is the evident power imbalance that arises among different stakeholder groups when the extended A4R framework is applied to analyze priority setting in the context of SUS. Empowerment is an important factor to ensure that all stakeholders are equally considered

in the decision-making processes. Different participants should have an equal voice so their participation in the process can be leveled.

Further Research and Implementation of Recommendations

There is a lack of empirical studies regarding priority setting in Brazil. The literature is very scarce. Further research on this topic can contribute to calls for policy action. It is also crucial that the knowledge that is acquired from research is actually translated into policies. Due to political agendas and barriers to being explicit about the allocation of resources, it has been a challenge to engage stakeholders to consider recommended changes and to translate policy recommendations into reality. More research into the ethics of priority setting is likely to improve the process and fairness of health resource allocation in Brazil, if the critical mass of stakeholders is involved and aware of the issues regarding the current decision-making model. Further research is also clearly needed at the community level so that different interest groups and managers can show the reasons for the inequity of outcomes.

Self-Exclusion and Decision-Making for the Private System

Empowered citizens, who could arguably drive change and demand accountability in allocation decisions for the SUS are typically not directly affected by such decisions. Relying almost exclusively on the privately financed system for their health care needs, these citizens are typically self-excluded from the decision-making processes for allocating resources to the publicly financed system (Martins et al., 2008).

The privately financed system has no mechanism in place for broad deliberation and social participation in decision-making regarding its health resource allocation. The CNS structure that exists for deliberation and voting for health policy-making for the SUS does not exist for the privately financed system. As such, health resource allocation in the privately financed system, which accounts for 50% of health care expenditure in Brazil, is guided primarily according to undisclosed market needs (e.g., generation of financial profit as its main priority). The main profit-generation goal often conflicts with the main goal of addressing the population's health needs (e.g., prevention of disease and recuperation of good health). This represents a significant challenge to the notion of ethical priority setting in the current Brazilian health care context.

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