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Increasing the Legitimacy of Tough Choices in Healthcare Reimbursement: Approach and Results of a Citizen Forum in The Netherlands

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ABSTRACT

Background: Some studies in the Netherlands have gauged public views on principles for health care priority setting, but they fall short of comprehensively explaining the public disapproval of several recent reimbursement decisions.

Objective: To obtain insight into citizens' preferences and identify the criteria they would propose for decisions pertaining to the benefits package of basic health insurance.

Methods: Twenty-four Dutch citizens were selected for participation in a Citizen Forum, which involved 3 weekends. Deliberations took place in small groups and in plenary, guided by 2 moderators, on the basis of 8 preselected case studies, which participants later compared and prioritized under the premise that not all treatments can or need to be reimbursed. Participants received opportunities to inform themselves through written brochures and live interactions with 3 experts.

Results: The Citizen Forum identified 16 criteria for inclusion or exclusion of treatments in the benefits package; they relate to the condition (2 criteria), treatment (11 criteria), and individual characteristics of those affected by the condition (3 criteria). In most case studies, it was a combination of criteria that determined whether or not participants favored inclusion of the treatment under consideration in the benefits package. Participants differed in their opinion about the relative importance of criteria, and they had difficulty in operationalizing and trading off criteria to provide a recommendation.

Conclusions: Informed citizens are prepared to make and, to a certain extent, capable of making reasoned choices about the reimbursement of health services. They realize that choices are both necessary and possible. Broad public support and understanding for making tough choices regarding the benefits package of basic health insurance is not automatic: it requires an investment.

Keywords: benefits package, citizen consultation, priority setting, public deliberation, reimbursement decisions, universal health insurance.

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Introduction

The government of The Netherlands, like its counterparts in most other countries that have some form of universal health insurance, faces challenges in obtaining public support for its choices regarding the composition of the benefits package. In the context of increasing pressure on a limited healthcare budget, decisions to not or no longer fund certain treatments regularly meet with opposition from healthcare providers, private-sector parties, politicians, patient interest groups, and the public in

general. Cost increases that arise from innovations that enter the market (new diagnostic tests, drugs, technologies), changing disease patterns (more chronic conditions, multimorbidity), and aging all feed this pressure. Confronted with opposition to negative decisions, policy makers and scholars caution against budget increases that cannot be fiscally sustained.

Some studies in The Netherlands have gauged public views on principles for healthcare priority setting,³⁻⁵ but they fall short of comprehensively explaining the public disapproval of several reimbursement decisions, such as in the case of eculizimab used to

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treat atypical hemolytic uremic syndrome [aHUS]; approval of reimbursement under strict conditions); lumacaftor/ivacaftor (Orkambi), Vertex Pharmaceuticals Inc, Boston, MA, to treat cystic fibrosis (negative decision, later reversed); and fampyra for treatment of multiple sclerosis (negative decision). The opinion of informed citizens about services that should be covered under basic health insurance and the arguments they use are largely unknown. Citizens who are given the opportunity to reflect and interact with each other do appear to become more modest and more sympathetic to the complex tasks of healthcare decision makers.⁶ Thus, a better insight into the criteria that informed citizens consider relevant and acceptable for making tough choices in healthcare could inform the process of national-level decision making and improve public support for its outcomes. More specifically, it would assist The Netherlands' Healthcare Institute (ZiNL) in strengthening the fulfilment of one of its mandates as the national health technology agency, which is to advise the Minister of Health on the composition of the benefits package of basic health insurance.

During 3 weekends in the fall of 2017, the Citizen Forum "Choices in Health Care" was held, with 24 participants discussing which kind of services they would like to see included in the benefits package or, in other words, which services they would be willing to pay for each other and for what reasons. The objective of this Citizen Forum was to obtain insight into citizens' preferences and identify the criteria they would propose for decisions pertaining to the composition of the basic health insurance benefits package. The project's overall aim was to inform decision making around public funding of health services based on societal values. Although surveys that do not allow respondents the time and opportunity for reflection and interaction with others may be of limited value, focus group discussions and citizen forums can offer a richer picture, with participants expressing their views and opinions with more nuance.^{6,7} The guidance provided by O'Doherty et al⁸ for implementing a public deliberative forum informed the design of the "Choices in Health Care" Citizen Forum. One of the underlying premises of this Citizen Forum was "health technology assessment as learning."9-11 As argued by Cohen and Sabel¹² and Degeling et al,¹³ deliberation is an essential democratic requirement for forming a reasoned opinion, enabling lay people to inform themselves and engage in priority setting.

Methods

The participants in the Citizen Forum were selected from an existing panel compiled by Motivaction, a research and consultancy agency that specializes in values, motives, lifestyle, and behavior. Panel members were matched to 1 of 8 mentality groups (ie, attitudes to life) that represent shared aspirations regarding work, leisure, and politics and show similar lifestyle and consumption patterns. The segmentation into mentality groups was based on value orientation (eg, traditional, modern, postmodern) and status seeking (ie, low, middle, high).¹⁴ For the Citizen Forum, 3 citizens were recruited from each of the 8 mentality groups, with equal overall distributions of sex, age, and residence (province). Rather than seeking a representative sample of Dutch society (which would not have been possible with only 24 participants), the attempt was to obtain a group as diverse as possible in terms of their value orientation vis-à-vis societal issues. Instead of overly pursuing the inclusion of "ordinary" citizens, which Lehoux et al¹⁵ considered misleading, the participants were seen as individuals who were given the opportunity to exercise their citizenship through a consultation process. The only characteristic participants had in common was that they had

registered in the past with Motivaction to participate in surveys or market polls. Before the Citizen Forum, the participants were informed in general terms about the nature and purpose of the Citizen Forum, so as not to exert any influence beforehand. They received a financial incentive (a flat fee), as well as free accommodation (2 nights in each of the 3 weekends) and free meals. All participants signed a letter of informed consent; none dropped out.

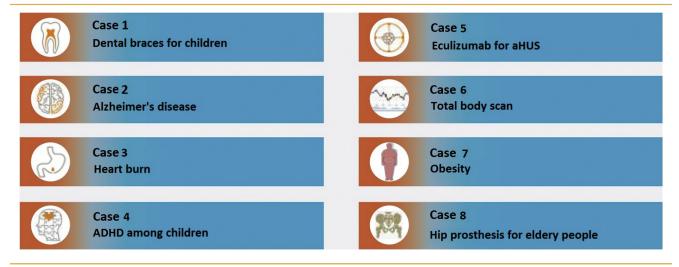
A constitutional framework, conceived in the initial stages of the project, comprises criteria and considerations that are commonly used for healthcare reimbursement decisions (see Appendix A in Supplemental Materials found at https://doi.org/1 0.1016/i.jval.2019.07.015). It informed the selection of 8 case studies that were subjected to deliberation in the Citizen Forum (listed in Fig. 1): dental (orthodontic) braces for youngsters, Alzheimer's disease, heart burn (pyrosis), attention-deficit hyperactivity disorder (ADHD) among children, aHUS, total body scan, obesity, and hip prosthesis for elderly people. These case studies had been carefully preselected so as to obtain the broadest possible spectrum of viewpoints, dilemmas, inclusion/exclusion criteria, and societal values. For each case study, participants were asked to answer the following questions: "Would you recommend that (all) medication/treatment for this particular condition be included in the basic health insurance benefits package?" and "What are your considerations?"

The program of the 3 weekends is listed in Appendix B (found at https://doi.org/10.1016/j.jval.2019.07.015). At the start of the Citizen Forum, participants received a succinct brochure, compiled by the project group, with some background information about the Dutch healthcare system. At the end of the second weekend, they received a more detailed brochure for individual use.¹⁶ For each of the case studies, discussed during the first 2 weekends, the participants first received a description of the clinical manifestations and treatment options. This information, validated by ZiNL experts, was presented in a neutral manner to minimize the chance of bias. The deliberations around each case study typically lasted 2 to 3 hours, culminating in a listing of arguments in favor and against inclusion of treatment for that patient group in the basic health insurance benefits package. Two moderators guided the deliberations, which took place in small groups and in plenary sessions, most of which were tape recorded. Three researchers participated as observers-cum-rapporteurs. They compiled summaries of the deliberations and fed these back to the participants in the morning of the next day for validation.

Participants further interacted in 3 separate sessions, each of which lasted $1^1/_2$ to 2 hours, with the following experts: an ethicist, a health economist, and a specialist in health technology appraisal. The latter was also a former member of ZiNL's appraisal committee that advises the Minister of Health about reimbursement decisions. These interactions, based on questions put forward by the participants themselves, served to share personal experiences and deepen their understanding of dilemmas.

In the third weekend, participants worked in small groups to prioritize the 8 case studies, under the premise that not all treatments can or need to reimbursed, and to justify why the treatments involved should or should not qualify for reimbursement. By assigning rankings to indicate the order of priority, the participants were forced to discuss and agree on tradeoffs between 2 or more criteria. In a subsequent session, participants worked individually, rating each of the criteria identified on a scale of 1 to 5, to indicate their importance. In a third session, they indicated the extent to which they agreed or disagreed with a list of 146 statements compiled by the researchers, based on arguments that participants had put forward in earlier deliberations. Participants were asked to color code each statement: green

Figure 1. Eight case studies discussed in the Citizen Forum.



meaning "I agree"; red, "I disagree"; and yellow, "I neither agree nor disagree." For the latter category of answers, participants were requested to write narrative explanations. In the analysis afterward, the level of agreement among participants per statement was calculated, resulting in 4 categories: no agreement (less than 25% who agreed with the statement), some agreement (between 25% and 49%), much agreement (between 50% and 74%), and near full consensus (75% or more who agreed). If a statement had been colored yellow by more than a quarter of the participants with contradicting or inconsistent comments, it was considered ambiguous (multi-interpretable) and therefore excluded from the analysis. This was the case for just 1 of the total of 146 statements.

The Citizen Forum resulted in a manifesto (in Dutch), which contained a summary of the results and some of the most poignant quotes from participants.¹⁸ An ad hoc sounding board, composed of 12 scientists, practitioners, and organization/management experts in the healthcare sector, advised the Citizen Forum project group.

Results

Identified Criteria

The Citizen Forum resulted in 16 inclusion/exclusion criteria that participants considered important (see Fig. 2). These criteria originate from underlying values, such as solidarity, equity, personal responsibility, and personal freedom. Here we highlight the 8 criteria that provoked the most discussion and best brought out opposing viewpoints as well as some of the principal arguments put forward by participants.

Participants considered medical necessity an important criterion: the more serious a condition, the more important that its treatment be covered by basic health insurance. Life-saving interventions would always need to be covered, as a matter of principle. Participants were sceptical about paying for treatments that alleviate discomfort that "belongs to human life," such as cosmetic surgery. They were also hesitant about conditions that have no clear medical cause.

Participants were of the opinion that treatments need to be *effective*, whereby effectiveness was interpreted broadly: improved health, better quality of life, and improved societal

functioning were all considered relevant. There should preferably be scientific evidence of effectiveness.

The cost of treatment was considered an inevitable criterion for reimbursement decisions. Participants would prefer not to "attach a price tag on someone's life" but argued that, ultimately, the cost of a treatment needs to be weighed against its benefits.

If there is no alternative treatment for a particular condition, this could be a reason for participants to accept coverage of the cost of treatment, even if it is expensive.

Participants did value prevention but were of the opinion that it should not be overemphasized: "life cannot be manufactured," they explained. Preventive diagnostics should be reimbursed, but random investigations, such as total body scans, should not, because they give people a "false sense of security," so the argument went. General prevention measures, such as health education, were perceived to lead not only to better health but also to important cost savings. Participants were of the opinion that these may therefore be financed from public resources as long as there is evidence that they are effective.

Participants almost unanimously rejected exclusion of patients for certain treatments above a certain age threshold. They considered it an unacceptable form of age discrimination.

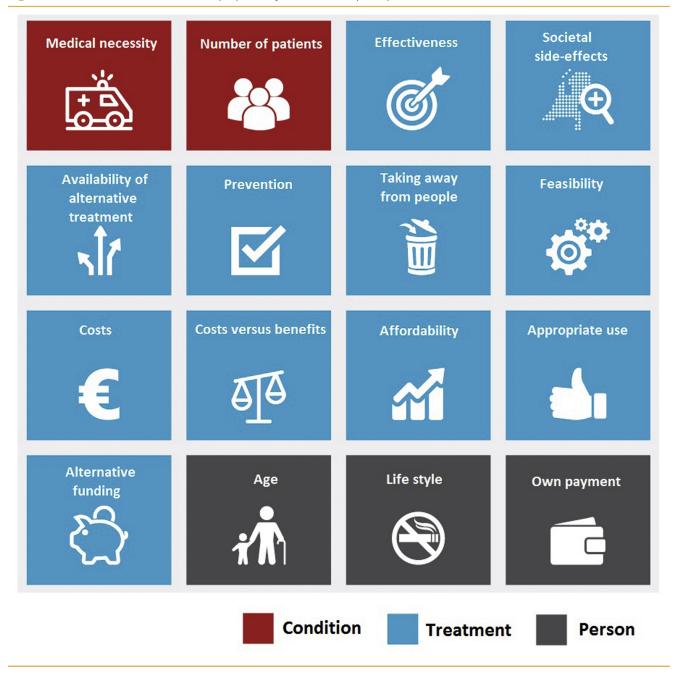
Most would not want to automatically reimburse interventions that address conditions related to lifestyle. Although they acknowledged that one cannot always be sure that a particular condition is caused by adverse behavior, they were of the opinion that certain patients need professional help, covered by health insurance, to change their lifestyle. They proposed to make it conditional: reimbursement should cease if the patient does not comply with the advice she or he receives.

Participants considered it fair that people are asked to pay for themselves if a treatment is relatively cheap. Nevertheless, they warned against accumulation of costs, especially for patients with chronic conditions and/or multiple morbidity, and against potential avoidance of care seeking.

Other criteria brought up by participants generated less controversy: the number of patients affected by the condition (the more patients are affected, the stronger the case for inclusion), the occurrence of societal side effects (positive side effects favor inclusion), the notion of people not wanting anything being taken away from them (a treatment once accepted should preferably not be removed from the package), feasibility of treatment (include

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Figure 2. Inclusion and exclusion criteria proposed by Citizen Forum participants.



only those that can actually be implemented), affordability (include only those that have a limited budget impact), and appropriate use (exclude treatments that may invoke inappropriate use).

The arguments from which the 16 criteria were derived are listed in the summaries of the deliberations around the 8 case studies, appended as annex B to the final report (in Dutch); the ratings assigned by the participants to the statements are appended as annex C.¹⁹

Applying the Criteria

Although many of the discussions focused on single criteria, in most case studies it was a combination of criteria that determined whether or not participants favored inclusion of the treatment under consideration in the basic insurance benefits package.

Individual participants sometimes had difficulty in trading off criteria in order to provide a recommendation (inclusion or exclusion), especially in case studies that scored high on one criterion but low on another. An example is bariatric surgery (stomach reduction) in people with obesity. Effectiveness of this type of treatment was forwarded as a reason for reimbursement, but several participants were uncertain whether that should outweigh the argument that it is someone's personal responsibility to change his/her lifestyle and lose body weight.

Participants differed in their opinion about the relative importance of criteria. This became particularly clear in the ADHD case study. Some argued that medication is potentially effective,

despite uncertainty about the medical cause of ADHD, but they drew different conclusions: one let the effectiveness argument prevail, whereas another attached more importance to the medical necessity of treatment. Such differences precluded unanimous recommendations.

In relation to the lifestyle criterion, participants had intense discussions about the role of one's personal responsibility as a social value; whether personal responsibility should be taken into account in reimbursement decisions, for instance in the case of lung cancer, obesity, or sports injuries; and how to weigh it against the social value of solidarity. Although most participants considered it appropriate to reimburse (preventive) services that support people in changing unhealthy lifestyles, they were less unanimous about the reimbursement of medical treatments of lifestyle-related conditions. Those who favored reimbursement pointed at the role of addiction and the fact that children sometimes grow up in unhealthy environments (unhealthy diets, parents who smoke, limited opportunities for physical exercise), for which they should not be punished.

In 2 case studies, participants generally agreed on the inclusion of particular health services in the benefits package: the provision of social support to people suffering from Alzheimer's disease and the treatment of aHUS with eculizumab. In the latter case, the argument that treatment offers the possibility of a partial recovery from a life-threatening condition overturned the counterarguments, including the high cost of treatment and large budget impact. Three forms of treatment (among the 8 case studies) were almost unanimously considered less eligible for coverage under the basic health insurance: total body scan, treatment of heart burn with antacids, and bariatric surgery for people with obesity.

Discussion

The Citizen Forum has demonstrated that (1) citizens are capable of articulating their viewpoints and preferences, (2) engagement of a heterogeneous group of citizens leads to a broad spectrum of considerations and opinions, and (3) informed citizens who challenge each other in a structured deliberation process do learn and develop their opinions, without necessarily reaching consensus.

The Citizen Forum has shown that informed citizens are prepared to make and, to a certain extent, capable of making reasoned choices about the reimbursement of health services. They come to realize that such choices are necessary because there is a limit to how much society wishes to spend on healthcare, which causes budget limitations. Initially, several participants rejected high cost as an argument to deny someone who is sick a treatment that is available—sometimes they did so in rather strong words. As the deliberations unfolded, participants became more aware that there are limits to the available resources in healthcare and that choices about what to fund and what not to fund are therefore inevitable. But even if there was enough money to reimburse all available treatments and services, so was the argument of some participants, it would still be appropriate not to include certain services in the basic health insurance benefits package.

Our study corroborates findings from a realist review performed by Kleinhout-Vliek et al²⁰ in The Netherlands, who found that the general public, along with patients and the media, use a broader type of argumentation and different justification schemes for health insurance coverage decisions than policy makers and insurance companies. Citizens also seem to differ in the weights that they attach to these criteria and how they make trade-offs. The societal debate around choices in healthcare is inseparably connected to citizens' preferences, norms, and values and the

trade-offs they would make if they were to choose. Nevertheless, it is the government that faces the challenge to actually make these choices. The legitimacy of such choices would be enhanced if the responsible government agencies managed to better align them with societal preferences.

Two parallel studies evaluated whether and to what extent participants had changed their opinions by taking part in the Citizen Forum. The results of these studies—one based on in-depth individual interviews before and after the Citizen Forum to unravel people's interpretative frames and the other using Q-methodology to investigate participants' views on priority setting, also using a before/after design—are reported separately (M. Jansen et al., unpublished data, 2019; V. Reckers-Droog et al., unpublished data, 2019). These studies demonstrate that over 3 weekends of deliberation, participants became more aware of the importance and complexity of making choices in healthcare, thereby transcending the views of the general public. They perceived the informed deliberation process as key to their newly acquired knowledge and insights. Many indicated it had also helped them to appreciate the reasonableness of other people's viewpoints, even if they differed considerably from their own.

In discussions around the prevention and treatment of lifestyle-related conditions, the Citizen Forum brought out the friction between personal responsibility and solidarity. Over time, participants appeared to look at such frictions with more nuance. Dolan et al⁶ in the United Kingdom reported on differences between people's views at the start of a first series of focus group discussions involving randomly chosen patients who attended their general practitioner, and at the end of a second series, after they had had an opportunity to deliberate with others. Respondents varied in their willingness to accept co-payments for medical treatments by smokers, heavy drinkers, and illegal drug users; after discussion, several of them had changed their opinion and looked differently at the issue of solidarity versus discrimination. Stronks et al²¹ explored the arguments underlying the choices of patients, the public, general practitioners, specialists, and health insurers regarding healthcare priorities. The various panels emphasized personal responsibility for healthy behavior and chose for co-payments. This shows that informed citizens across different studies imagine a role for one's personal responsibility in reimbursement decisions, especially in relation to the lifestyle criterion.

The United Kingdom's Citizens Council, which is a panel of 30 people who largely reflect the country's demographic characteristics, regularly provides the National Institute for Health and Clinical Evidence with a public perspective on overarching moral and ethical issues that the National Institute for Health and Clinical Evidence needs to take account of when producing guidance.²² The Council's recommendations include considerations such as patient safety, rule of rescue, and health inequalities, which are similar to the criteria identified by our Citizen Forum. Previous studies on citizen involvement in decisions around healthcare benefits packages have been reported in Belgium, ²³⁻²⁵ Canada,²⁶ Cyprus,²⁷ Greece,²⁸ and Switzerland.²⁹ They have shown that citizen consultation offers a feasible approach to involving the public in setting healthcare priorities and that participants to a certain extent change their views on complex matters if given the opportunity to acquire new insights as part of the consultation and deliberation process. Although the underlying values are similar across countries, the specific criteria that participants identify as important for healthcare priority setting vary from one country to another, partly because of different healthcare systems and cultural contexts.

The Citizen Forum had its limitations. Although we carefully selected participants, case studies, and experts—taking into

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account the findings from a systematic review of citizens' juries in health policy decision making³⁰—it is conceivable that different selections would have resulted in somewhat different lines of argumentation. Our Citizen Forum was a one-off event that would benefit from replication, so as to corroborate the findings. Clearly, because preferences and values are context specific, the results from this study cannot be transferred to other settings.

Further studies are required to shed light on the extent to which the depth of deliberation and the eventual results of a citizen panel depend on prior knowledge and experience of the panel members and how participation in a citizen forum actually induces changes in a participant's opinions and preferences. Relevant questions are, for example, how can such changes be achieved through other forms of informed deliberations? What are the essential ingredients of such processes? How can the above changes be achieved in the society at large?

Policy Implications: Scenarios for the Involvement of Citizens

This Citizen Forum has shown its potential for meaningful public accountability. Nevertheless, public support for choices in healthcare is not automatic. It requires an investment, which could take the form of 3 types of action.

(1) Take the 16 inclusion/exclusion criteria into account when taking health insurance benefits package decisions.

The Citizen Forum supports the standard set of 4 criteria that ZiNL uses in its assessment framework (necessity, efficacy, costeffectiveness, and feasibility).¹⁷ The 12 additional criteria, most of which are mentioned in that framework, would need to be taken into consideration more explicitly. They include lifestyle, age, prevention, and whether a particular condition can be seen as a normal part of life and the aging process. ZiNL could take them into account more systematically in developing its recommendations to the Minister of Health. In its future advice, ZiNL could show how the results of this Citizen Forum have been taken on board.

(2) Ensure high-quality deliberation and transparency in reporting.

The quality of deliberation is crucial for informed opinions and balanced decisions. Although the appraisal reports produced by ZiNL are available on the Internet and the advisory committee meetings are open to the public, ZiNL could further develop the quality of its consultations and deliberations as well as refine its reporting. Highlighting all the arguments considered and how they were weighed before arriving at final inclusion/exclusion advice would add nuance and may help increase the general public's understanding. In addition, ZiNL might want to embark on a broad public debate about the composition of the benefits package of basic health insurance, or—more generally—on choices in the Dutch healthcare system. Parliamentarians could take advantage of an informed and more nuanced debate that allows space for the entire spectrum of criteria and arguments before endorsing or rejecting reimbursement decisions.

(3) Involve citizens in health insurance benefits package decisions as a matter of routine.

Although this study suggests that citizen participation is of limited value for informing specific coverage decisions, it may be more meaningful to use it for periodically assessing whether the current practice of developing recommendations for the Minister, including the criteria considered in the process, is still appropriate or for gauging citizen views around specific thematic issues, for example, on the use of proportional shortfall as a criterion for determining the cost-effectiveness threshold in reimbursement decisions (as in the current guidelines).

Overall, this study has demonstrated the potential value of organizing public deliberation on priority setting in healthcare for the legitimacy of the overall process and its outcomes. Continued discussion and research are needed on how to integrate public preferences in reimbursement decisions.

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Supplemental Material

Supplementary data associated with this article can be found in the online version at https://doi.org/10.1016/j.jval.2019.07.015.

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