



Societal views in the Netherlands on active disinvestment of publicly funded healthcare interventions

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ABSTRACT

Objectives: To obtain public support for the active disinvestment (i.e. policy decision to stop reimbursement) of healthcare interventions, it is important to have insight in what the public thinks about disinvestment and which considerations they find relevant in this context. Currently, evidence on relevant considerations in the disinvestment context is limited. Therefore, this study aimed to explore the societal views in the Netherlands on the active disinvestment of healthcare interventions and obtain insight into the considerations that are relevant for those holding the different views.

Methods: A Q-methodology study was conducted among a purposively selected sample of citizens (n = 43). Data were collected in June and July 2019. Participants individually ranked a set of 43 statements broadly covering the issues that participants could consider relevant in the disinvestment context, from 'least agree' to 'most agree'. Qualitative feedback on the statement ranking was collected from each participant using a questionnaire. Principal component analysis followed by oblimin rotation was used to identify clusters of participants with similar statement rankings. These clusters/factors were interpreted as distinct viewpoints using the factor arrays and qualitative questionnaire responses of participants.

Results: Four viewpoints were identified. People holding viewpoint I believe that reimbursement of necessary healthcare should be maintained, irrespective of its costs. People holding viewpoint II agree with viewpoint I, although they believe that necessity should be objectively determined. People holding viewpoint III think that unnecessary, ineffective and inefficient healthcare should be disinvested. People holding viewpoint IV, consider it most important that disinvestment decision-making processes are transparent and consistent.

Conclusion: Insight in the distinct viewpoints identified in this study contributes to a better understanding of why it has been considered difficult to obtain public support for disinvestment of healthcare interventions, and can help policymakers to change their approach to disinvestment to increase public support.

1. Introduction

The continuing rise in healthcare expenditure in OECD countries (Organisation for Economic Co-operation and Development, 2019), has put increasing pressure on public financing of healthcare (de la Maissonneuve and Martins, 2015; van der Horst et al., 2011). To curb the growth in healthcare expenditure, policymakers have increasingly been considering disinvestment of healthcare interventions as a policy option (Calabro et al., 2018; Daniels et al., 2018). Two types of disinvestment can be discerned: 1) passive disinvestment, which is not dependent on

any direct intervention by policymakers, but mainly results from changing practices of healthcare providers or withdrawal from the market by the manufacturer, and 2) active disinvestment, which is the full withdrawal, retraction, restriction or substitution of resources from certain existing healthcare interventions, as a result of policy decisions, affecting the accessibility of these interventions to patients (Daniels et al., 2013, 2018; Elshaug et al., 2007; Parkinson et al., 2015). There may be several reasons for the disinvestment of healthcare interventions, such as harm, limited effectiveness or not enough value for money (Elshaug et al., 2007). Disinvestment may be the outcome of

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Health Technology Reassessment (HTR), which is the structured, evidence-based assessment of healthcare interventions, currently being used in the healthcare system, based on their clinical, economic, social and ethical aspects (Leggett et al., 2012; MacKean et al., 2013).

The disinvestment of healthcare interventions has been described in the international literature as very difficult (MacKean et al., 2013; Makady et al., 2019; Robinson et al., 2011). Even in cases where there was strong evidence that the intervention was not (cost-)effective, withdrawal of this intervention was considered a delicate issue (MacKean et al., 2013). Unsurprisingly, a review of empirical evaluations of disinvestment initiatives from several different countries concluded that only a limited number of these initiatives was successful (Chambers et al., 2017). Support from healthcare professionals, politicians, and the general public has been described as essential for successful disinvestment (Daniels et al., 2013; Rotteveel et al., 2021). To obtain public support, it is important to have insight in how the public feels about disinvestment and which considerations they find relevant in this context. Furthermore, the engagement of public preferences in disinvestment decisions has been described to have a range of benefits: 1) instrumental benefits such as improving decision outcomes, 2) democratic benefits such as citizen engagement, and 3) educational benefits such as raising public awareness on the complexity of disinvestment decisions (Daniels et al., 2018).

However, the scientific literature on the considerations that citizens find relevant in the context of disinvestment is limited to two studies looking at disinvestment in the context of a specific intervention (i.e. cancer drugs and vitamin B12/folate pathology testing) and one study aiming to answer a specific question in the context of disinvestment (i.e. whether people would like to know if their care is rationed). These studies found that citizens consider it important that disinvestment decisions are transparent (Coast, 2001) and based on clear and consistent principles and real-world (cost)effectiveness data (Bentley et al., 2019). Furthermore, the latter study also found that citizens consider it important not to disrupt current treatments of patients (Costa et al., 2019). Finally, in the context of testing, Street et al. found it to be important to take costs, alternatives, disease severity, accuracy, potential to benefit and externalities into account in disinvestment decision-making (Street et al., 2015). Although these studies already provided some insight in the considerations that citizens find relevant in the context of disinvestment, it seems relevant to also investigate the relevant considerations for disinvestment in general, instead of in a specific context, to be able to improve disinvestment decision-making and increase public support for these decisions. Furthermore, it also seems relevant to assess whether views on which considerations are relevant differ between citizens. Therefore, in this study, we aimed to explore the societal views on the active disinvestment of healthcare interventions and to identify the considerations that people holding the different views consider important in this context. To this end, we have used Q-methodology, a method combining aspects of quantitative and qualitative research methods that enables the elicitation of rich, holistic viewpoints on a certain topic in a certain population (van Exel et al., 2015). In this study, we focus on the active disinvestment of healthcare interventions, with healthcare interventions indicating a broad range of curative care, including medicines, therapies, surgeries, medical devices, services and other types of curative care.

We have explored the societal views on active disinvestment and relevant considerations in the context of the Dutch social health insurance system. In the Netherlands, the coverage of the basic health insurance package is determined by the Minister of Health, Welfare and Sports based on advice from the Ministry of Health, Welfare and Sports and the National Healthcare Institute. In its advice, the National Healthcare Institute assesses healthcare interventions on four criteria: effectiveness, cost-effectiveness (i.e. health effects in relation to the costs of the intervention), necessity (i.e. do disease severity and the costs per patient justify coverage), and feasibility (i.e. is coverage feasible) (Zwaap, 2017). In policy documents, it is assumed that when a

healthcare intervention does not meet these four criteria anymore, it will no longer be delivered by healthcare providers (i.e. passively disinvested) (Couwenbergh et al., 2013). However, in the past, also several decisions have been taken to (partially) stop reimbursement (i.e. active disinvestment) (Rotteveel et al., 2021).

2. Methods

2.1. Approach

In this study, we used Q-methodology because this method fits the explorative nature of this study very well. Through the combination of qualitative and quantitative research methods, Q-methodology enabled us to obtain rich, holistic descriptions of the societal viewpoints on active disinvestment in a systematic way (van Exel et al., 2015).

In a Q-methodology study, participants are asked to rank a comprehensive set of statements on a grid, according to how they feel about these statements (e.g. agree/disagree, important/unimportant), and explain the motivation behind their rankings. By-person factor analysis is used to identify clusters of participants with highly correlated rankings of the statements. The interpretation of the factors is facilitated by the weighted average ranking of the statements for the participants statistically significantly and uniquely associated with each identified factor, together with the qualitative data obtained from these participants, when explaining their ranking of the statements (Baker et al., 2006; Watts and Stenner, 2012). Q-methodology has been widely applied in the context of health, healthcare, and healthcare priority setting (Honey et al., 2013; Patty et al., 2017; Stenner et al., 2003; Truijens and van Exel, 2019; van Exel et al., 2015).

2.2. Statement set development

We developed a statement set that was broadly representative for our topic of interest, i.e. the active disinvestment of publicly funded healthcare interventions, in three consecutive steps. In the first step, we aimed to derive a broad, comprehensive collection of considerations potentially relevant in the context of active disinvestment. To this end, we adopted the conceptual framework from a previous study in which stakeholders (i.e. policymakers, patients, healthcare providers and other stakeholders) were interviewed to obtain insight into active disinvestment processes and aspects determining their outcome. This conceptual framework consisted of the actors, considerations and structures that may play a role in the different stages of a disinvestment process (Rotteveel et al., 2021). Subsequently, the considerations from this framework were complemented by the considerations that are relevant for citizens as identified in three previous Dutch Q-methodology studies in the context of investment (Reckers-Droog et al., 2020; Wouters et al., 2017; van Exel et al., 2015), and in the three previously published studies in the context of disinvestment (Bentley et al., 2019; Coast, 2001; Costa et al., 2019; Street et al., 2015). This resulted in a broad framework containing 87 potentially relevant considerations (see Appendix A).

Secondly, in an iterative process, the augmented framework was critically reviewed by three researchers (AR, ML, JvE) to merge duplicate/comparable considerations and to discard considerations that were not relevant given the topic of interest. For each of the remaining considerations, a statement was formulated by AR and critically reviewed by ML and JvE to ensure that the statements were concise and clear. This process resulted in a set of 45 statements.

Thirdly, to test the comprehensiveness and clarity of the statement set (and the other study materials), a pilot test was conducted among a convenience sample ($n = 6$). As a result of the pilot test, the statement "If it is difficult to do research after the effect of the treatment, reimbursement may be stopped" was removed from the statements set, as participants did not understand why it may be difficult to do research, a problem we could not resolve with additional explanation or rephrasing

of the statement. The statement “It is important that all those involved should be consulted in decisions on stopping the reimbursement” was also removed as participants did not find this realistic. Based on the feedback provided by participants, we clarified the wording of six statements (i.e. statements 5, 10, 11, 12, 13, 18 and 34), the information letter, and instruction for participants. The final set of 43 statements and its embedding in the conceptual framework is presented in Appendix B. More details on statement set development (in Dutch) are available from the authors upon request.

2.3. Data collection

For efficiency reasons, data were collected in group sessions with, on average, seven participants each. In these sessions, held in June and July 2019, participants were instructed to conduct the tasks individually. Participants were recruited through a commercial panel company. This panel company approached a large sample for participation in this study by sending them the participant information letter. Participants who were willing to participate in this study, could subscribe to one of the scheduled group sessions. The panel company controlled the enrolment of subscribed participants in the group sessions to ensure that the sample was diverse with regards to age (≥ 18 years), education level, political affiliation, and geographical spread. We used these variables as sampling variables because we expected these to be predictive of people having different views on disinvestment, enabling us to include a purposive sample. Participants of the group sessions received a show-up fee of €42.50 to compensate them for their time and travel expenses. The group sessions were led by the same researcher (AR), alternately helped by one of the other authors.

Participants were recruited until data saturation was reached, that is when no new viewpoints emerged from the data (Saunders et al., 2018). Saturation was determined based on participants’ statement rankings and their written explanation of their ranking and their viewpoint on disinvestment. To ensure that we interpreted the written explanations right, these were checked with participants during the group sessions. In determining saturation, we focused on the most characterizing statements of the ranking (i.e. those ranked highest and lowest) in combination with the provided explanations. This combination allowed us to develop a general understanding of the viewpoints of participants, allowing us to determine saturation before formal analysis was started.

After obtaining written informed consent, participants received a short oral explanation of the task. Subsequently, participants were handed over a written instruction, the sorting grid (see Fig. 1), 43 randomly numbered cards containing the statements, and a glossary explaining terms that participants may consider difficult (i.e. basic benefits package and medical guidelines). The written instruction described the background of the task (see Appendix C), and asked participants to, first, read all statements and sort them into three piles (i.e. agree, disagree, neutral/don’t know), then, to rank the statements from each pile onto the sorting grid (starting with the agree pile, followed by the disagree pile and, lastly, the neutral/don’t know pile), and, finally, to check and confirm the overall ranking of the statements. After finishing the ranking exercise, participants completed a short questionnaire (see Appendix D) that asked them 1) to explain why they agreed most/least with the four statements placed in the outer columns of the sorting grid, 2) to phrase their opinion on the topic of interest in their own words, and 3) two questions about their current health (i.e. the EQ-5D-5L and the EQ-5D visual analogue scale (VAS) (Buchholz et al., 2018; The EuroQol Group, 1990)) because we hypothesized that participants’ health may affect their view on disinvestment.

2.4. Ethics

Ethical approval was obtained from the internal review board of the Erasmus School of Health Policy & Management (IRB 2019-03). Written informed consent was obtained from all participants at the start of the task. Participants were informed that participation was voluntary and anonymous, and that they had the possibility to retract their consent at any time without having to give a reason. The research team did not have access to participants’ contact information and handled the remaining participant information confidentially.

2.5. Data analysis and interpretation

A principal component analysis followed by oblimin rotation (a general form of oblique rotation (Jackson, 2005)) was conducted to identify clusters of participants with highly correlated statement rankings. We determined the best number of factors from all possible factor solutions based on the following criteria: 1) Eigen Value of each factor > 1.00 ; 2) a minimum of two non-confounded exemplars per factor (i.e.

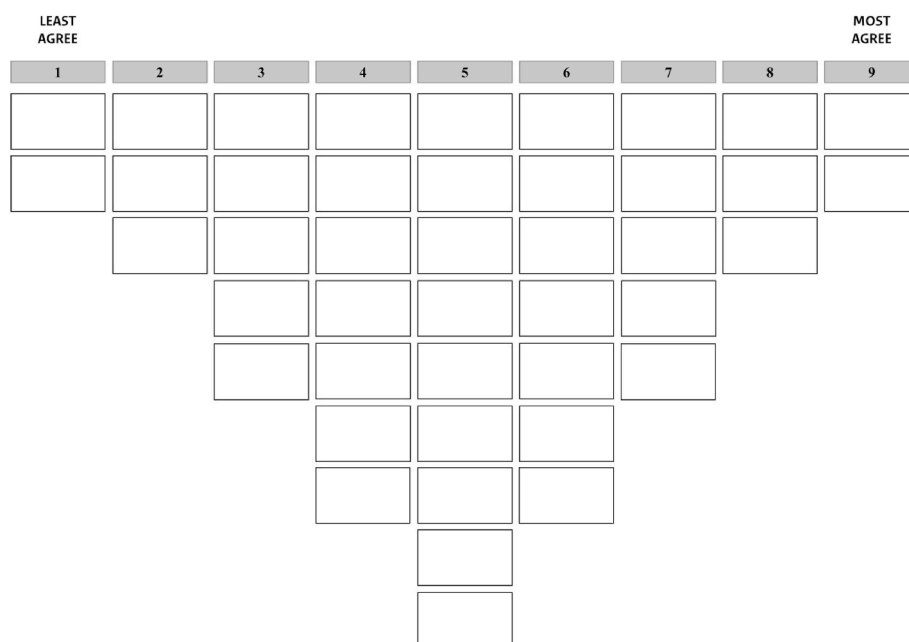


Fig. 1. Sorting grid used in this study.

participants whose statement ranking was statistically significantly (i.e. $p < 0.05$) and uniquely (i.e. square of factor loading $>$ sum of square of the loading on other factors) associated with the factor); 3) a low or moderate correlation between the factors in the solution (with <0.30 being low, between 0.30 and 0.50 being moderate, and >0.50 being high (Cohen, 2013)); and 4) coherence and distinctiveness of the interpretation of the factors as determined by the researchers (AR, VR and JvE).

For all factors, a factor array was computed. Factor arrays concern an average ranking of the statements by participants who are statistically significantly and uniquely associated with the respective factor, weighted by their factor loadings, and represent how a hypothetical person with a correlation of 1.00 with that factor would have ranked the statements. Factor interpretation was based on the factors arrays, with special attention for the characterizing and distinguishing statements, and the qualitative questionnaire responses obtained from participants. Characterizing statements are those statements that are ranked the highest and lowest in the factor array, i.e. the statements participants associated with the viewpoint agreed least or most with. Distinguishing statements are those that have a statistically significantly different position in the factor array as compared to all other factors (p -value < 0.05).

One participant placed 11 more statements on the 'agree side (column 6–9)' of the fixed sorting grid than was indicated. As the participant confirmed the statement ranking after having been pointed to the deviation from the intended form and the statement ranking was substantiated by the qualitative questionnaire responses, we decided to retain this participant in our analysis. To be able to include this ranking in our analysis, we analyzed the data as a non-forced distribution. A sensitivity analysis excluding this participant and analyzing the data as a forced distribution showed that the decision to retain this participant in our analysis had no significant effect on the outcome of the analysis.

The 'qmethod' package in Rstudio 1.2.1335 was used for the analyses (R Core Team, 2019; Zabala, 2014).

For the presentation of the study and our results in this manuscript, all statements, all presented quotes and the study material presented in the appendices were translated from Dutch to English by a professional translation company.

3. Results

Based on the statement rankings and the qualitative questionnaire responses, we found that saturation was reached after 43 participants. The mean (SD) age of the participants was 48.2 (16.4) years and the majority was male (56%, see Table 1). Participants were well distributed across education levels and well spread across the Dutch political spectrum. Geographical spread was ensured by the conduct of data collection on different locations across the Netherlands.

Based on the statistical criteria described in section 2.4, a maximum of four factors was supported by the data. After a first inspection, all four factors were retained as distinct viewpoints, as each of them had a coherent and clear interpretation and seemed to represent a distinct viewpoint on disinvestment. The factors were defined by 19, 4, 12 and 3 participants, respectively, and Eigen Values were between 2.8 and 9.1. Five participants were not statistically significantly associated with one of the factors, because they loaded on multiple factors. Together, the factors explained 48% of the data variance, with 6.5%–21.1% of explained variance per factor. Correlations between the four factors were low for factors 1 and 2 (0.27), for factors 1 and 3 (0.22), for factors 2 and 3 (0.21), and for factors 2 and 4 (0.21). Correlations were moderate for factors 1 and 4 (0.34), and for factors 3 and 4 (0.45). The factor loadings of participants are displayed in Appendix E.

Table 2 shows the factor arrays. The factor arrays display the weighted average ranking of the statements by all participants who are statistically significantly and uniquely associated with the factor: a score of +4 indicates that these participants would rank the statement in the most agree column of the sorting grid in Fig. 1 (column 9), a score of -4

Table 1
Descriptive statistics of the participants (N = 43).

| | | N (%) | Mean (SD ^a) | Median (quartiles) |
|---------------------------------|---|---------|-------------------------|--------------------|
| Sampling characteristics | | | | |
| Age | | | 48.2 (16.4) | 54.0 (35.0–59.0) |
| Gender | Males | 24 (56) | | |
| | Females | 19 (44) | | |
| Education level ^b | Low | 14 (33) | | |
| | Middle | 13 (30) | | |
| | High | 16 (37) | | |
| Political spectrum ^c | Left | 18 (42) | | |
| | Centre | 8 (19) | | |
| | Right | 14 (33) | | |
| | Missing | 1 (2) | | |
| Other characteristics | | | | |
| Quality of life | EQ-5D-5L utility value (0–1) ^d | | 0.84 (0.15) | 0.89 (0.82–0.92) |
| | EQ-5D-VAS (0–100) | | 79 (17) | 80 (70–90) |
| Living situation | Alone | 10 (23) | | |
| | Alone, but with children | 4 (9) | | |
| | Together with partner | 14 (33) | | |
| | Together with partner and children | 10 (23) | | |
| Children | With parents | 5 (12) | | |
| | No | 15 (35) | | |
| | Yes | 28 (65) | | |

^a SD = standard deviation.

^b Education levels correspond to the SOI 2016 and the ISCED 2011 classifications.

^c The parties participants would vote if there would be elections now were categorized by the commercial panel in left, centre and right. We adopted this categorization to report on this variable here, as the specific party participants would vote is not informative for international readers. However, when checking for spread across the political system, we looked at the specific parties the participants would vote, not the categorization as reported here.

^d Calculated from the EQ-5D-5L score using the Dutch tariff (Versteegh et al., 2016).

indicates that these participants would rank the statement in the least agree column of the sorting grid (column 1), a score of 0 indicates that these participants would rank the statement in the middle of the sorting grid (column 5). A superscript c displayed alongside the score indicates that the ranking of this statement is distinguishing between that factor and all other factors.

Below, the interpretation of the four factors as four distinct viewpoints on what people consider important in disinvestment decisions is presented. The viewpoints are described using the characterizing and distinguishing statements for that factor (where # represents the statement number, with the corresponding factor array score, and * indicates that the statement is distinguishing). Quotes selected from the qualitative questionnaire responses of participants statistically significantly and uniquely associated with the factor (with participant ID between brackets) are used for illustration. These quotes were selected based on how well they illustrated our findings.

Table 2

Factor arrays.

| # | Statement | F1 ^a | F2 ^a | F3 ^a | F4 ^a |
|----|---|-----------------|-----------------|-----------------|-----------------|
| 1 | If the treatment is effective, reimbursement should <u>not</u> be discontinued. | +2 ^c | +1 | 0 | +4 ^c |
| 2 | If the treatment leads to small health benefits, reimbursement may be discontinued. | -3 ^c | 0 | 0 | -1 ^c |
| 3 | If the quality of life of patients is still poor after treatment, reimbursement of this treatment may be discontinued. | -4 ^c | +2 ^c | +0 ^c | -2 ^c |
| 4 | If the quality of life of patients is good without the treatment, reimbursement of this treatment may be discontinued. | -1 | -1 | +2 | +1 |
| 5 | If there is a significant difference in the effect of the treatment between patients, reimbursement of the treatment should only be discontinued for patients in whom it has little effect. | -1 | -3 ^c | 0 | 0 |
| 6 | While it is not yet clear which patients will benefit from the treatment, this treatment should continue to be reimbursed for all patients. | 0 | 0 | -1 | 0 |
| 7 | If the chances of the treatment having an effect are small, the reimbursement may be discontinued. | -3 | -1 | 0 | 0 |
| 8 | If the effect of the treatment cannot be scientifically demonstrated, reimbursement for this treatment may be discontinued. | -1 | -1 | +2 ^c | 0 |
| 9 | While research into the effect of the treatment is still ongoing, the reimbursement should <u>not</u> be discontinued | +1 ^c | -4 ^c | -1 ^c | -2 ^c |
| 10 | If the treatment is included in the medical guideline, reimbursement for this treatment should <u>not</u> be discontinued. | +2 | +1 | 0 | 0 |
| 11 | If <u>doctors</u> believe that patients are benefiting from the treatment, reimbursement should <u>not</u> be discontinued. | +3 ^c | 0 | +2 | +1 |
| 12 | If <u>patients</u> feel they are <u>benefiting</u> from the treatment, reimbursement should <u>not</u> be discontinued. | 0 ^c | -1 | -3 ^c | -2 |
| 13 | If the treatment costs are high in relation to its effects, reimbursement may be discontinued. | -2 ^c | 0 | +1 ^c | 0 |
| 14 | If a cheaper alternative to the treatment is available (which works equally well), reimbursement of the treatment may be discontinued. | 0 | 0 | +3 | +2 |
| 15 | If the treatment is medically necessary, reimbursement may <u>not</u> be discontinued. | +4 | +4 ^c | +2 | +3 |
| 16 | If a serious illness is concerned, reimbursement for its treatment should <u>not</u> be discontinued. | +4 ^c | +1 | +1 | -1 |
| 17 | If a chronic illness is concerned, reimbursement for its treatment should <u>not</u> be discontinued. | +2 | +1 | +1 | +2 |
| 18 | If <u>patients</u> feel that the treatment is <u>necessary</u> , its reimbursement should <u>not</u> be discontinued. | 0 ^c | -3 | -4 ^c | -3 |
| 19 | If a particular complaint is part of normal life, reimbursement for its treatment may be discontinued. | -1 | 0 | +4 ^c | -4 ^c |
| 20 | If patients can pay for the treatment themselves, reimbursement for this treatment may be discontinued. | -2 ^c | +2 ^c | -1 ^c | -4 ^c |
| 21 | If the patient is personally responsible for developing a condition, reimbursement for its treatment may be discontinued. | -2 | -2 | 0 ^c | -2 |
| 22 | If the treatment is frequently used just because it is reimbursed, reimbursement may be discontinued. | -1 ^c | 0 | +4 ^c | +2 |
| 23 | If the treatment helps patients to maintain their dignity, reimbursement should <u>not</u> be discontinued. | 0 | -2 | -1 | 0 |
| 24 | If the treatment is the only treatment option for a condition, its reimbursement should <u>not</u> be discontinued. | +3 | +4 | +1 | +2 |
| 25 | If a small patient group is concerned, reimbursement for the treatment of this patient group should <u>not</u> be discontinued. | +1 | -2 | -2 | 0 |
| 26 | | -1 | -1 | -2 | -3 ^c |

Table 2 (continued)

| # | Statement | F1 ^a | F2 ^a | F3 ^a | F4 ^a |
|----|---|-----------------|-----------------|-----------------|-----------------|
| | If a condition is stressful for the patients' family, reimbursement for its treatment should <u>not</u> be discontinued. | | | | |
| 27 | If a contagious condition is concerned, reimbursement for its treatment should <u>not</u> be discontinued. | +1 | +2 | +3 | 0 |
| 28 | If the treatment improves patients' participation in society, its reimbursement should <u>not</u> be discontinued. | +1 ^c | +3 | 0 ^c | +3 |
| 29 | If the reimbursement of a treatment is discontinued, patients who are already being treated with this treatment should still have it reimbursed. | 0 ^b | +1 ^b | 0 ^b | +1 ^b |
| 30 | If there is no support in society for discontinuing reimbursement of the treatment, the reimbursement should <u>not</u> be discontinued. | 0 | +3 ^c | -1 | -2 ^c |
| 31 | If a disproportionately large part of the care budget is spent on the treatment, its reimbursement may be discontinued. | -3 ^c | -1 | -2 | +1 ^c |
| 32 | If the care is organized in such a way that the treatment cannot be offered safely, its reimbursement may be discontinued. | -1 | -2 | +1 | +1 |
| 33 | When deciding to discontinue reimbursement, the same criteria should always be applied in the same manner. | -2 | -2 | +1 ^c | +4 ^c |
| 34 | When deciding to discontinue reimbursement, it should always be made clear how and based on which criteria the decision was made. | 0 ^c | +2 | +1 | +3 ^c |
| 35 | If the discontinuation of the reimbursement of the treatment disproportionately affects a certain group of people in society, this reimbursement should <u>not</u> be discontinued. | +1 | +1 | -2 ^c | +1 |
| 36 | If the discontinuation of the reimbursement of the treatment concerns a vulnerable group in society, this reimbursement should <u>not</u> be discontinued. | +1 | +2 | -3 | -1 |
| 37 | When it comes to treatment of a life-threatening condition in young people, reimbursement should <u>not</u> be discontinued. | +3 | -1 ^c | +3 | +1 ^c |
| 38 | Because it is impossible to express a human life in terms of money, costs should not play a role in decisions about discontinuing reimbursement. | +1 ^c | +3 ^c | -3 | -3 |
| 39 | When it comes to care for patients who have a short time left to live, reimbursement of this care should <u>not</u> be discontinued | 0 | 0 | -1 | -1 |
| 40 | It is morally wrong to deny patients existing treatment. | +2 ^c | -4 ^c | -2 | -1 |
| 41 | If the treatment can prevent people from becoming ill, its reimbursement should <u>not</u> be discontinued. | +2 | +1 | +2 | +2 |
| 42 | If the costs of the treatment per patient are high, reimbursement may be discontinued | -4 ^c | 0 | -1 | -1 |
| 43 | If the healthcare provider has not yet recouped its investment in the treatment, its reimbursement should <u>not</u> be discontinued. | -2 | -3 | -4 ^c | -1 ^c |

^a The numbers displayed in these columns represent the factor score of each statement in each factor. This score indicates the column of the sorting grid (Fig. 1) where the statement would be placed if it would be sorted by a person with the particular view corresponding with the factor, with -4 indicating the most left column (least agree), 0 indicating the middle column and +4 indicating the most right column (most agree).

^b Consensus statement (no difference between factors at a p-value <0.05).

^c Distinguishing statement (p-value <0.05).

3.1. Viewpoint I

People holding this viewpoint consider it important that the reimbursement of necessary healthcare will be maintained. They believe healthcare is necessary if it concerns treatment for severely ill patients (#16, +4*; #37, +3), if a treatment is included in medical guidelines (#10, +2), if physicians think patients will benefit from the treatment (#11, +3*) and if the treatment is considered medically necessary (#15,

+4): “If there are medical reasons that have been determined by a doctor, this should always be reimbursed!” (ID-33). Such treatments should remain in the basic benefits package, even if these only result in small health gains (#2, -3*; #7, -3) or in a low quality of life after treatment (#3, -4*). People holding this viewpoint consider it morally wrong to deny patients an existing treatment (#40, +2*), in particular if no alternative treatment is available to patients (#24, +3), as is illustrated by the following quote: “As the text [statement] indicates. From a moral point of view, I do not think it is acceptable to deny existing treatment for any reason whatsoever (probably financial reasons).” (ID-01) People holding this viewpoint believe that the costs (#42, -4*), cost-effectiveness (#31, -3*) and budget-impact (#31, -3*) of treatments should not play any role in disinvestment decisions, as is illustrated by the following quotes: “That people get the care they need, no matter what it costs.” (ID-01); “Denying the right/necessary care should not be allowed. The country is prosperous enough to be able to offer this to every citizen.” (ID-20) For further reference, we will call this viewpoint “Maintain necessary healthcare, even if it is expensive or only results in small health gains”.

3.2. Viewpoint II

Similar to people holding viewpoint I, people holding this viewpoint believe that the reimbursement of necessary care (i.e. treatments that are medically necessary or are the only treatment option available) should be maintained (#24, +4; #15, +4*), irrespective of its costs (#38, +3*): “Care should be accessible to everyone, especially if it is medically necessary.” (ID-07) However, they believe necessity should be objectively determined and not, for example, based on insufficient scientific evidence (#9, -4*) or patient opinion (#18, -3): “Most important is if the treatment does not work after thorough study.” (ID-21) Furthermore, they believe that if quality of life remains low after treatment (#3, +2*), if providers have not earned back their investment (#43, -3), and if people can pay for their own treatment (#20, +2*) reimbursement may be stopped: “The costs of care are so high that the premium system should be changed. Wealthy people can then pay more and the socially disadvantaged can pay less.” (ID-21) Hence, they believe that in some situations, denying patients treatment is not morally wrong (40, -4*). Furthermore, what is distinguishing for this viewpoint, is the importance attached to public support for disinvestment decisions. If there is no public support for stopping the reimbursement of healthcare, reimbursement should be maintained (#30, +3*): “Everyone is entitled to care if there is no support [for stopping reimbursement].” (ID-10) Also distinguishing for this viewpoint is the importance attached to participation in society and protecting vulnerable groups in society: when treatment contributes to patients being able to participate in society (#28, +3), or if stopping treatment would affect a vulnerable group (#36, +2), reimbursement should be maintained. For further reference, we call this viewpoint “Maintain necessary healthcare, if objectively determined and if there is no support for disinvestment”.

3.3. Viewpoint III

People holding this viewpoint consider it important to spend the healthcare budget in a well-considered way. Therefore, they think that the reimbursement of healthcare that is not necessary or that does not have any effect can be stopped (#19, +4*; #22, +4*; #4, +2): “Everyone has aches and pains sometimes. The idea is not that you need immediate care for every little ache and pain (that is part of normal life). This is at the expense of the people who really need care.” (ID-04); “There can be all kinds of reasons to deny patients existing treatments. Maybe a specific treatment does not work in their case, or the improvement in health would not outweigh the suffering that this treatment entails. So it is not morally wrong, but there has to be a logical reason for denying a patient certain treatment.” (ID-36) Furthermore, the reimbursement of healthcare that is not effective (#8, +2*) or not cost-effective can be stopped as well (#14, +3; #38, -3*; #13, +1*): “From a business point of view, it is right to make a financial

consideration. If it can be done more cheaply with the same desired effect, then I think that’s right.” (ID-26) Whether disinvestment affects a vulnerable group or any other group in society disproportionately should not be taken into account in disinvestment decisions (#35, -2*; #36, -3). If a treatment would prevent other people from becoming ill (#41, +2), is targeted at contagious diseases (#27, +3) or concerns a life-threatening disease in younger people (#37, +3), than that would be a good use of the healthcare budget and, hence, reimbursement can be maintained. People holding this viewpoint think that the patients’ voice should not play a role in disinvestment decisions. Whether patients feel they benefit from treatment or consider the treatment necessary is not relevant (#18, -4*; #12, -3*): “I think the doctor or hospital should decide that, and not the patients themselves.” (ID-15) Furthermore, people holding this viewpoint disagreed most with the statement that treatment should remain reimbursed until healthcare providers earned back their investment (#43, -4*): “Nonsense, the composition of the basic health insurance package should never serve to balance the cash book of the pharmaceutical industry. This industry is already doing enough itself, with that argument to raise prices absurdly.” (ID-41) For further reference, we call this viewpoint “Disinvest unnecessary, ineffective and inefficient healthcare”.

3.4. Viewpoint IV

People holding this viewpoint consider it important that disinvestment decision-making (i.e. both the process and the considerations underlying the decision) is transparent and consistent. If reimbursement for a certain treatment is stopped, it should be clearly explained why (#34, +3*). Furthermore, disinvestment decisions should always be based on the same set of criteria (#33, +4*). Why transparency and consistency are considered important is explained in the following quotes: “Because everyone should receive the same treatment and opportunities.” (ID-29); “Then it’s easier to understand why the decision to discontinue it [reimbursement] has been taken.” (ID-29).

In this view, effectiveness (#1, +4*) and medical necessity (#15, +3) are important criteria for care to remain reimbursed, particularly if it helps people to better function in society (#28, +3). However, the sustainability of the healthcare system is also a matter of concern: “The sustainability of the care system is very important and this means that the right balance must be found between good healthcare and financial sustainability. One should not lose sight of the financial picture.” (ID-12) Therefore, the costs and budget-impact of a treatment should be considered as well (#31, +1*, #38, -3): “Discontinuation may be possible when costs are unnecessarily high and the same result is achieved with other cheaper means.” (ID-38).

If disinvestment decisions are made in a transparent and consistent way, (a lack of) public support (#30, -2*), patient preferences (#18, -3*), the burden of the disease on the patient (#16, -1) and the patient’s family (#26, -3*), or whether people can pay for the treatment themselves (#20, -4*) should not lead to exceptions to the rules. Also, whether a complaint is part of normal life should not play a role in disinvestment decision-making (#19, -4), because this cannot be determined in a clear-cut, consistent manner. For further reference, this viewpoint is described as “Transparent and consistent disinvestment decision-making processes”.

4. Discussion

The aim of this study was to explore the societal viewpoints in the Netherlands on the active disinvestment of healthcare interventions and to identify the considerations that people holding these viewpoints find relevant in this context. Four distinct viewpoints were identified, which can be shortly described as: 1) Maintain reimbursement of necessary healthcare, even if it is expensive or only results in small health gains; 2) Maintain reimbursement of necessary healthcare, if objectively determined or if there is no public support for disinvestment; 3) Disinvest

unnecessary, ineffective or inefficient healthcare; and 4) It is most important that disinvestment decision-making processes are transparent and consistent.

4.1. Comparison of our findings with the disinvestment literature

There are several similarities between the findings of the three previous studies on relevant considerations in the context of disinvestment and some of the viewpoints identified in our current study. For instance, in our current study, we found that people holding viewpoint 4 consider it important that disinvestment decision-making processes are transparent and consistent. This seems to confirm the finding of Bentley et al. that citizens consider it important that disinvestment decisions are based on clear and consistent principles (Bentley et al., 2019) and the finding of Coast et al. that people consider it important that disinvestment decisions are transparent (Coast, 2001). Furthermore, some of the relevant considerations identified by Street et al. (2015) are supported by some of the viewpoints identified in our study. For instance, taking costs and effectiveness into account in disinvestment decisions is supported by viewpoints 3 and 4. Moreover, taking the availability of alternative treatments into account is supported by viewpoints 1 and 2. However, it becomes clear from our current study that these considerations are not supported by all viewpoints, indicating that it is important to take heterogeneity in citizens' viewpoints into account.

Secondly, there are also some differences between the findings of previous studies and the findings of the current study. For instance, although Costa et al. found that citizens are reluctant to disrupt treatment of current patients (Costa et al., 2019), this is not supported by any of the viewpoints identified in our current study: Statement 29 on continuing reimbursement for current patients was ranked in the middle of the distribution for all viewpoints. Even though this does not necessarily mean that all participants sorted this statement in the middle of the sorting grid (i.e. agrees and disagrees among people holding the viewpoints may also cancel each other out for this statement), it does mean that in our current study we did not identify any viewpoint that found this consideration relatively important compared to the other considerations.

4.2. Comparison of our findings with the decision criteria currently used in Dutch policy

In the Netherlands, the National Healthcare Institute uses the four criteria effectiveness, cost-effectiveness, necessity and feasibility to advise the Ministry on the reimbursement of healthcare interventions. With regards to investment decisions, effectiveness is a 'knock-out' criterion (Zwaap, 2017). However, our study shows that support for effectiveness as a criterion for disinvestment decisions varies. People holding viewpoint 1 consider effectiveness relatively unimportant, while people holding viewpoint 2 rank these considerations in the middle of the sorting grid, and people holding viewpoints 3 or 4 consider effectiveness relatively important. A similar pattern can be observed for the cost-effectiveness criterion: people holding viewpoint 1 or 2 think cost-effectiveness should not play a role, while people holding viewpoint 3 or 4 consider this criterion important. However, there seems to be some consensus on the importance of the medical necessity criterion: statement 15 on medical necessity is located in the most agree tail of the distribution for all viewpoints (+4, +3, +2, +4). Nonetheless, there seem to be some differences between the viewpoints on the consequences this criterion should have: people with viewpoint 1 or 2 generally do not see a lack of medical necessity as a reason to disinvest an intervention or service, while people holding viewpoint 3 or 4 indicate that non-necessary care should be disinvested. Furthermore, from the factor arrays some differences with regards to the interpretation of medical necessity can be observed. For instance, people holding viewpoint 2, 3 or 4 generally do not agree with taking the patient's opinion on necessity into account (statement 18), while people holding

viewpoint 1 are more open to this. Moreover, while people holding viewpoint 3 think that treatments for illnesses that are part of normal life should be disinvested (statement 19), people holding viewpoint 4 do not agree with this (as this cannot be determined in a clear-cut way) and people holding viewpoint 1 or 2 are more neutral with regards to this statement. Finally, there is no consensus on the relative importance of the feasibility considerations budget-impact and public support, included in this study. Viewpoint 3 and 4 support the use of budget-impact as a criterion in disinvestment decisions, while viewpoint 1 does not support this and viewpoint 2 is neutral. Furthermore, viewpoint 2 considers public support very important, while viewpoint 1 does not seem to have a strong opinion on this and viewpoint 3 and 4 do not consider it to be important.

4.3. Methodological considerations

The use of Q-methodology in this study allowed us to obtain rich, holistic descriptions of the existing societal viewpoints on active disinvestment in the Netherlands (van Exel et al., 2015). Because of the combination of qualitative and quantitative research methods used in Q-methodology, it provided us with the opportunity to obtain in-depth insights in the existing viewpoints which are discerned in a systematic way.

However, Q-methodology also has three disadvantages compared to other research methods. Firstly, because of the structured way of data collection, by asking all participants to sort the same set of statements with the same instruction, it could be argued that Q-methodology is not able to obtain such rich insights as non-structured or semi-structured qualitative research methods can. However, the statement set used in this study was based on the findings of our previous study in which we obtained in-depth insight in the considerations that may be relevant in disinvestment decisions through a large number of semi-structured interviews (Rotteveel et al., 2021). Subsequently, the statement set was carefully developed and pilot-tested to ensure that the statements would cover the variety of aspects relevant in active disinvestment. After finishing statement sorting, participants had the opportunity to phrase their opinion. This process enabled us to evaluate whether any relevant aspect was missing. In this process no missing aspects were identified, indicating that all considerations relevant in the context of disinvestment were included in this study.

Secondly, because of the purposive sampling method, Q-methodology is not suited to examine how the different viewpoints are distributed across society and whether the viewpoints are statistically significantly associated with any socio-demographic characteristics (Baker et al., 2006; Mason et al., 2016). Survey approaches allowing a large number of probabilistically sampled participants to rate their agreement with aspects of the viewpoints (e.g. a selection of statements that discriminate best between viewpoints or short viewpoint descriptions) are more appropriate for this purpose (Baker et al., 2010; Mason et al., 2016).

Finally, Q-methodology is also not the appropriate method to measure the relative strength of the preferences for the different considerations in disinvestment decision-making. For this purpose, choice experiments would be more suitable. The characterizing and distinguishing statements identified in this study can serve as input for attribute development in future choice experiments.

4.4. Strengths and limitations

To our knowledge, this is the first Q-methodology study examining the societal views on the active disinvestment of healthcare interventions. We ensured reliability of statement set development and viewpoint interpretation by conducting the development of the set of statements as well as the interpretation of the viewpoints with three researchers (i.e. triangulation) (Mays and Pope, 1995). Furthermore, pilot testing of the study materials and the face-to-face approach to data collection ensured reliability of data collection (Watts and Stenner,

2012).

Despite these strengths, the current study also has some additional limitations to the ones described in section 4.3. Firstly, as for efficiency reasons the data were collected in groups, participants' explanations of statement sortings were collected using a questionnaire. This resulted in short, written explanations of participants' viewpoints. To ensure that the researchers would interpret these short explanations correctly, questionnaire responses were checked during the group sessions and any written clarification of the responses was requested if necessary. Despite this precaution, some nuances in viewpoint interpretation may have been overlooked due to the short, written viewpoint explanations provided by participants.

Secondly, this study has been conducted in a Dutch setting. As disinvestment processes are considered context-specific (MacKean et al., 2013), researchers and policymakers are recommended to take the context into account when considering the implications of the results of this study in their context. However, as a previous Q-methodology study assessing allocation preferences in the investment context in nine European countries (i.e. Denmark, France, Hungary, the Netherlands, Norway, Poland, Spain, Sweden and the UK) only found small differences in the views between these countries (van Exel et al., 2015), we believe that the views identified in this study are also broadly applicable to other (European) contexts.

4.5. Policy implications

Active disinvestment has been described as a delicate issue (MacKean et al., 2013), with public support being considered essential for its success (Daniels et al., 2013). Even though it is also part of a policymaker's job to make unpopular decisions, such as disinvestment decisions, public support may increase the success of such decisions. The results of this study show considerable heterogeneity between groups in society in their views on disinvestment and in the considerations they consider relevant in this context. This indicates that it will be very difficult, if not impossible, to design the disinvestment process and corresponding communication in such a way that the preferences of all people holding the different viewpoints will be met. Hence, it indicates that it is very difficult to obtain support for disinvestment from all groups in society.

However, despite the identified heterogeneity between the viewpoints, the results of this study also provide policymakers with guidance on how to increase public support for disinvestment. Firstly, our study shows that all four viewpoints support the use of medical necessity as a consideration in disinvestment decisions. Therefore, in selecting candidate interventions for disinvestment and in the communication on disinvestment decisions, we recommend policymakers to focus on medical necessity. However, the interpretation and consequences attached to this criterion differ between viewpoints, possibly explaining the broad support for this statement. Despite of this, people from all viewpoints seem to support necessity as has been determined by healthcare professionals as a way to determine what medical necessity is. Therefore, policymakers are recommended to focus on this interpretation of medical necessity. Although people holding viewpoint 1 and 2 support medical necessity as a criterion, they only seem to see medical necessity as a reason to reimburse treatments, not as a reason to disinvest treatments. Therefore, to also increase support among people holding viewpoint 1 or 2, policymakers are recommended to put emphasis on the fact that disinvestment of non-necessary healthcare will create scope for the reimbursement of necessary healthcare.

Secondly, our study shows that people holding viewpoint 4 consider a transparent disinvestment process very important. Although transparency is less important for those holding the other viewpoints, these people still place this statement on the most agree side of the sorting grid, indicating that, to some degree, they agree with this statement. Therefore, we recommend policymakers to improve the transparency of the disinvestment process and corresponding communication to

increase support from people holding viewpoint 4 and from people holding the other viewpoints as well.

5. Conclusion

In conclusion, this study shows that there are four distinct societal viewpoints on active disinvestment of publicly funded health technologies that highlight important considerations for decision-making in this context. Insight in these viewpoints can thus help policymakers to better understand why it has been considered difficult to obtain public support for disinvestment, and how this can perhaps be improved in the future.

CRedit author statement

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Declaration of competing interest

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Appendix A. Supplementary data

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