

The Value of Health and the Rights of Patients

Cost-Effectiveness and the Right to be Treated as an Equal in a Public Health System

*Symposium at the Berlin-Brandenburg Academy of Sciences and Humanities,
Berlin, March 25/26, 2011*

Since 2007, Germany is in the process of implementing some form of cost-effectiveness analysis as a criterion for reimbursement decisions within its statutory health insurance. Neither utilitarian ethics nor health-maximizing economic approaches to health care evaluation developed in this tradition are, however, recognized as constituting as such an adequate basis for fair decisions. Notably, it is generally acknowledged that an acceptable method of evaluation must be compatible with legal non-discrimination rules or, generally, with the claim of every insured person “to be treated as an equal”.

A question that needs to be discussed in the process is just where and how the method, in order to be rights-compatible, must diverge from the standards developed by health economists. Will it be sufficient, if possible at all, to correct for any unlawful results after having performed economic health care evaluations in the conventional way? Or should the conventional method be redesigned as a value-maximizing task that follows two political goals, health maximization and fairness, instead of only one – and how much should fairness then count? Is it a viable and theoretically sound procedure to supplement the measurement of citizen’s preferences for health states, which is part of the conventional procedure, by the measurement of “fairness preferences”? Or will it perhaps prove impossible to fully account for rights to non-discrimination within any maximizing approach to resource allocation? Which role could in that case still be assigned to cost-effectiveness data by the law?

In order to inform future steps of an implementation of cost-effectiveness analysis in the German public health system, the conference brings together contributors to the international debate from the fields of ethics and health economics with national experts who share a concern for defining, and meeting in practice, basic legal demands that German health care politics should comply with.

March 25, 2011

- 9.00-9.30 **Weyma Lübke** (Philosophy, University of Regensburg)
Welcome and Introduction “Cost-effectiveness as a basis for reimbursement decisions in the statutory health insurance: Why has Germany chosen a non-standard approach?”
- 9.30-10.00 **Werner B. F. Brouwer** (Health Economics, Erasmus University Rotterdam)
“Equity weights for QALYs: Are they ad hoc-adjustments to reach intuitively acceptable results from cost-effectiveness analysis or do they have a sound theoretical basis?”
- 10.00-10.15 *Comment* **Friedrich Breyer** (Economics, University of Konstanz)

Equity weights are multiplication factors that are attached to QALYs in order to change the value, sometimes called social value, with which they contribute to the overall value of an outcome of resource allocation. The weights are said to depend on context factors like whether the QALY is an end-of-life QALY, a last hope from a usually poorly cost-effective treatment for patients with incurable diseases. However, redesigning a QALY-maximizing decision rule by such means is only a mathematical exercise unless it is informed by more than the decision maker's – or, as it were, the general public's – feelings about the normative adequacy of specific reimbursement decisions. The original idea of the QALY decision rule was to guide the decision-making process, not to represent intuitive notions of adequacy mathematically. If the exercise is intended to be informative, it must be explained why, e. g., an end-of-life QALY is rated higher, and the explanation cannot simply be that the decision maker or the people have been found to prefer that such treatments be reimbursed in spite of their poor cost-effectiveness. The explanation, to be sure, must be fully compatible with whatever elements the resulting decision rule keeps from the theoretical basis of the conventional QALY approach, among these the axiomatic basis of additive aggregation. What theoretical basis can be offered?

10.15-10.45 Discussion

Coffee Break

11.15-11.45 **Daniel M. Hausman** (Philosophy, University of Wisconsin-Madison)
“QALYs, Preferences, and Prioritizing Health Policies”

11.45-12.00 *Comment* **Hartmut Kliemt** (Philosophy, Frankfurt School of Finance & Management)

12.00-12.30 Discussion

Social preference studies ask people about their preferences concerning the allocation of scarce health care resources to different patient groups, while the traditional individual preference studies that form part of the conventional QALY approach ask people to rate the quality of life associated with different health states. Some social preference studies have been conducted or used in order to establish a basis for QALY weights. The idea, very basic indeed to economic thinking, is that people's preferences inform us about people's values. If producing certain QALYs is found to be preferred over producing certain other QALYs while the total amount is the same, these QALYs must be more valuable in the eyes of the people. But is this reasoning cogent? What if people's reasons for choosing in a certain way do simply not conform to the preconception that every choice is a value maximizing choice? Take a person who prefers that a patient group be given an equal chance to a costly life-saving treatment, say, double transplants, even though one could save twice the number of lives by directing all the resources to patients with single organ failure. It is probably nonsense to attribute to such a person the opinion that the lives of patients who need double transplants are twice as valuable. Rather, we should assume that she is not engaged in value-maximizing when judging on these matters. What theoretical and practical use can social preference studies have if people's reasons for their answers rest opaque? And how do more “delibera-

tive” methods designed to investigate selected subject’s reasoning behind their answers differ from conducting beginners courses in medical ethics?

Lunch Break

- 13.30-14.00 **Paul Anand** (Economics, The Open University, UK)
“Rights and the conceptual framework of social choice: Can non-discrimination rights be accounted for within a social choice approach to health resource allocation?”
- 14.00-14.15 *Comment* **Marlies Ahlert** (Economics, Martin Luther University Halle-Wittenberg)
- 14.15-14.45 Discussion

Social choice theory has long ago dropped the idea that central features of the utilitarian tradition in welfare economics like additive aggregation and welfarism – the idea that the only relevant informational input to a decision rule is some measure of the welfare of individuals – form the only defensible way of making social choices. The approach allows for all possible informational inputs and all possible forms of aggregation, including, e. g., aggregation under constraints (constraints exclude certain states from the set of feasible options, whatever their value in terms of aggregated benefits might be). Only the very formal idea – often called consequentialism – that the right choice is the one that produces the best state of affairs is maintained. The goodness of states, or so it is claimed, can be evaluated so as to account for all sorts of normative requirements, including requirements usually termed “deontological” like the keeping of contracts, the satisfaction of claims or the value of fair procedures. Claims (or rights), notably, could be modelled as constraints, or their satisfaction could be counted as a separate value in addition to the value of producing health. These two approaches, however, seem not viable for the accommodation of non-discrimination rights in health resource allocation. How can such rights be modelled as constraints on the set of feasible options since they do not require that a certain state be brought about, e. g., that a disabled patient end up in a certain minimally beneficial health condition, or that her health be equal to the health of other patients? And how can such rights be modelled as requirements whose satisfaction counts as valuable besides the value of producing health? Such rights oppose the idea that the greater sum of QALYs produced when, e. g., transplanting seeing patients as opposed to blind ones counts for something. They do not supplement this idea. Other approaches might, however, be imaginable. Which ones?

Coffee Break

- 15.15-15.45 **Dan W. Brock** (Medical Ethics, Harvard University, Boston)
“Can consequentialism make a plausible case for non-discrimination rights on the basis of the idea that rights are, in the end, a means to social welfare maximization?”
- 15.45-16.00 *Comment* **Thomas Schmidt** (Philosophy, Humboldt University Berlin)
- 16.00-16.30 Discussion

At its beginning, the utilitarian tradition had a theory of rights that was consistent with the conceptual and normative basis of the approach. Rights were not seen as something that has to be accounted for over and above the requirement of enhancing social welfare. They were conceived to be a means to welfare maximization in the long run, a useful institutional device that avoids the inefficiency of everybody's calculating best options for every decision anew. How much plausibility is left to this idea after some two hundred years of debate? Are there features of non-discrimination rights that definitively oppose this sort of theoretical account? And how can we make sure that such a theory is not just an ad hoc-defense of utilitarianism against intuitively unacceptable results? What situations of choice can be imagined for a public health care system where the difference between a foundational and a derivative role for non-discrimination rights would clearly come out? What intuitions seem to govern such choices, and which type of theory performs better in explaining them?

Break

Public Evening Lecture

18.00 *Welcome*

18.15-19.00 **Stefan Huster** (Law Faculty, University of Bochum)

“Priorisierung von Gesundheitsleistungen in einer alternden Gesellschaft: Ist die Sorge vor Alterdiskriminierung berechtigt? / Prioritizing health care in an ageing society: Must we fear ageism?” (German with translation into English)

19.00-19.30 *Discussion*

It has often been claimed that the conventional QALY approach discriminates against the Old, one reason being that a higher age correlates with a lower expected number of life years yet to be lived, another reason being that a higher age correlates with a lower quality of life on grounds of the increasing multimorbidity of the old. The claim, however, has not remained uncontested. One argument is that the QALY approach as such is blind to age. The relevant features are life-expectancy and quality of life, not age. Older patients are, of course, prioritized just as well as everybody when they score better under these measures, which can be the case, e. g., for children as opposed to babies. The approach, or so it is claimed, does therefore not amount to “ageism”, even if it will in many cases result in redirecting resources to the young. Another counter-argument says that the QALY approach, even if indirectly sensitive to age, is not discriminating because everybody who lives to an old age will already have had the benefits of a health system that prioritizes according to cost per QALYs gained, and can thus not claim to be disadvantaged by the system. What are we to make of these arguments? What, notably, is the state of the debate with respect to the question whether, and if so in what way, discrimination is to be judged from the distributional effects of an allocation rule or from the nature of the criterion that it explicitly mentions?

20.00 *Dinner*

March 26, 2011

- 9.00-9.30 **Erik Nord** (Health Economics, Norwegian Institute of Public Health)
“The positive value of healing a disabling condition and the equal worth of a disabled life: How can cost-value analysis consistently account for both?”
- 9.30-9.45 *Comment* **Weyma Lübbe** (Philosophy, University of Regensburg)
- 9.45-10.15 Discussion

According to all conventional measurements of quality of life, including measurements that ask patients who experience the disability they evaluate, a disabling condition lowers to some extent the quality of life – which explains the general opinion that healing a disabling condition is a benefit. The conventional QALY approach - indeed, any approach to health technology evaluation that counts quality of life as contributing to the value of outcomes - has to deal with the implication that treatment of a life-threatening condition is less QALY-productive when a patient or patient group is disabled. Cost-value analysis is a derivative of cost-effectiveness analysis that works with weighted QALYs and claims to maximize the “social value” of resource allocation. Weighting, however, as explained before (section on equity weights), needs a sound theoretical basis, and so does the idea of counting each disabled life year “as one” although it is generally acknowledged that it is a life year of lesser quality and thus scores less than one. Debates on this point feature the introduction of concepts like the equal “worth” of persons, or equal “claims”, which are said to be relevant in distributional contexts. The decision to heal a disabling condition is, however, also a decision in a distributional context when resources are scarce. The value of a non-disabled life, or so it seems, should count in distributional contexts. Is, perhaps, respect for the equal worth of persons an additional bearer of social value? Should it be counted besides the gain in social value that comes from more QALYs? Or does, perhaps, the equal worth of persons function as a constraint on social value maximization? The difficulties of these two lines of reasoning have been shortly highlighted above (section on social choice). What other proposal could account for non-discrimination in a way that keeps, or makes, cost-value analysis theoretically consistent?

Coffee Break

- 10.45-11.15 **Mario Martini** (Law Faculty, German University of Administrative Sciences Speyer)
“Legally acceptable applications of cost-effectiveness analysis: Under what conditions can patients who need but are denied high cost/low benefit-treatments said to be respected as equals within the statutory health insurance?”
- 11.15-11.30 *Comment* **Rainer Hess** (President of the Federal Joint Committee, Berlin)
- 11.30-12.15 Concluding Discussion

Using cost-effectiveness analysis as a basis for reimbursement decisions is not trivially legitimate. The reproach that the procedure is discriminating has to be answered. Proposals to revise the conventional approach in order to accommodate for fairness still lack a consistent theoretical basis. Juridical doctrines of institutionalized rights to non-discrimination might

help here. They should, however, be developed in more detail with respect to the present area of application. One might start by trying to characterize legitimate partial uses of cost-effectiveness data, uses under certain conditions that dissolve the reproach. A well-known line of reasoning is the idea, already mentioned above (lecture on age discrimination), that the denial of treatment on grounds of poor cost-effectiveness is not an illegitimate disadvantage if the patient can be said to have already benefited from the rule in the past (and often in the future, too) – including the benefit of having had chances to benefits. This line of reasoning can obviously not be applied in practice without empirical information on how risks for diseases with poorly cost-effective treatments are actually distributed among the insured. There is probably a thick veil of uncertainty for the onset of some diseases, no such veil for the onset of other diseases (congenital ones), and many diseases will lie in between. Another central issue is a careful reassessment of the idea that only trade-offs between health gains of different persons (interindividual trade-offs) are subject to distributional reservations while trade-offs between health gains in different states of a person's life (intraindividual trade-offs) are not. Medical and political practice in Germany, as well as public opinion and the law courts, seem deeply opposed to telling a dying patient that one will not reimburse a costly lengthening of her life for a couple of weeks because she has had the benefit of an efficient health system before. But after all, German politics is deeply opposed to explicitly acknowledging any sort of rationing. What remains to be explained is how, under this condition, the usage of cost-effectiveness data as a basis for reimbursement decisions might be justified to the public – and to the academic audience who knows about the problematic ethical status of such procedures.

12.30-13.30 Buffet lunch